

9th ICEVI European Conference 2017



Empowered by dialogue

PROCEEDINGS

9th ICEVI European Conference
2 - 7 July 2017 - Bruges, Belgium



TABLE OF CONTENT

Parallel Session I

Early Childhood

- Evolution of visual impairment in children and adults born preterm
Katrien Keppens, Mieke Vandorpe, Myriam Callemeyn and Mieke De Pourcq 2
- Early intervention for visually impaired children: terms and stages of compensation of blindness in the first year of life
Ludmila Myasnikova and Vladimir Ruchin 4

School Age

- BRAITICO. A new braille literacy method of ONCE, using ICT
Elena Gastón López 6
- The development of online resources to support the effective assessment and teaching of literacy through braille
Rory Cobb and Steve McCall 8
- Audio description and students with visual impairments: what use for what benefits?
Nathalie Lewi-Dumont, Loraine Crépel and Laetitia Dumont-Lewi 10
- The assessment and development of digital literacy in students with vision impairment and additional learning needs: preliminary findings from a current PhD study
Emily H. White, Kerry Wood and Shiralee Poed 12

Young adults

- Non-verbal communication
Roselinde Strosse and Laurence Foulon 17

Adults

- Mindfulness-based treatment for persons with a visual impairment or visual-and-intellectual disabilities
Hannelies Hokke and Paula Sterkenburg 19
- A visual impairment is not just about seeing and watching. Get a view of the different aspects and dimensions of the emotional process
Heidi Deknudt 21
- Measuring the effect of functional rehabilitation on quality of life
Sophie Demoustier and Stéphanie Demartin 23

Various

- The role of "Gender", "Islam", and "Turkish Culture" on independence of individuals with visual impairments
Onder Islek 25

Museums and People with Visual Impairments: the case of the BaGMIVI project

- Current and future trends in museums regarding visitors with disabilities: the case of visitors with visual impairments
Vassilis Argyropoulos, Magda Nikolarazi, Charikleia Kanari and Sofia Chamonikolaou 32
- Interactions between a gallery, university and special school for visually impaired in providing access to ancient and contemporary art: the Bulgarian case
Mira Tzvetkova-Arsova, Vladimir Radoulov, Margarita Tomova, Rumiana Ioneva, Rositsa Chisheva and Emanuela Stoilova 34
- The cooperation of university, museum and special school for adapting the environment and creating new educational opportunities for children with visual impairment in museums: the Hungarian case
Krisztina Kovács, Beáta Prónay, Erzsébet Szűcs and Ágnes Somorjai 36
- Empowering people with visual impairments to visit museums by developing differentiated educational programs
Andrea Hathazi, Adrian Rosan, Tudor Salagean and Tekla Totszegi 38
- Bridging theory and practice in developing inclusive practices in museum: The Greek case
Vassilis Argyropoulos, Magda Nikolarazi, Charikleia Kanari, Sofia Chamonikolaou, Marina Plati, Eleni Markou and Betty Leotsakou 40

Workshop Session I

- Visual impairment and autism spectrum disorders: customised assessment and throughout the life course 42
 - Visual impairment and autism spectrum disorders: customised assessment and care throughout the life course
Peter Verstraten, Mathijs Vervloed, Joan Curran, Sinead Fitzpatrick, Kim de Verdier and Hans van den Heuvel 42
 - Assessment of autistic behavior in People with Multiple Disabilities
Mathijs Vervloed and Gitta de Vaan 44
- Apps for mobile devices: how to distinguish accessible apps from inaccessible apps
Jeroen Baldewijns and Eline De Ganck 47
- Social haptic communication
Veerle Vanthuyne, Vanhoutte Peter, Amerlynck Koen, Weemaels Jos, Verstraete Elke ... 49
- Up to an inclusive life after special education. An interactive session based on Testimony
Monique Van den Abbeel and Eva De Stecker 50

Parallel Session II

School Ages

- Stories: a different way to interact with blind or visually impaired children and adults with additional disabilities
Jeske D'haene, Annelies Meulemans and Wieteke Luppens 52
- Moving towards self-confidence
Ria Waele 54

• De Pit: an inclusion project for adolescents with visual impairment and multiple disabilities in the city of Tervuren <i>Veerle Coenraets, Susy Gijbels and Sonia Meys</i>	56
• Concept development of Blind Children - A General Introduction <i>Ans Withagen and Anneke Blok</i>	58
• Group meetings (1-4 days) for children or youngsters with visual impairment as a method to achieve individual goals <i>Emma Van Damme</i>	60
• Analyzing social interactions in a regular class: a pilot study with secondary students with a visual impairment <i>Mathieu Gaborit, Nathalie Lewi-Dumont, Kenza Berrada and Minna Puustinen</i>	63
• Screening characteristics of Autism Spectrum Disorders (ASD) in children with Cerebral Visual Impairment (CVI) <i>Griet Pattyn and Greet Vissenaekens</i>	65
• Using modern statistical mapping tools to identify social participation and wellbeing need in children with visual impairments <i>John Ravenscroft, Andrew Blakie and James Thom</i>	67
• Investigating risk perception and disaster management through perspectives of children with and without visual disability <i>Magda Nikolaraizi, Sofia Chamonikolaou, Vassilios Argyropoulos and Charikleia Kanari</i> ...	69
• The role of leisure time and sport activities for people with visual impairment in developing social participation <i>Andrea Hathazi</i>	71
• Art does not have to be visual <i>Anneli Embe</i>	74
• Making mathematics accessible. A study of how paraeducators work with adaptations <i>Ulrika Vanhoenacker</i>	76
• SensusAccess - Universal access to alternate media <i>Lars Ballieu Christensen, Tanja Stevns</i>	78
• Maximising Spatial Potential: Spatial thinking modification and universal design for students with VI <i>Mary Styliidi, Philippos Katsoulis, Maria Zeza</i>	81

Young Adults

• Professional training as a part of curriculum and its influence on employment <i>Jana Loudová</i>	83
• Expedition TOP: Experiences of adolescents with visual impairments, their parents and professionals in promoting success in job participation. <i>Judith Wijnen, Sabina Kef and Bella van Erp</i>	86
• Status of the specialist additional curriculum in the UK and outcomes for learners <i>Sue Keil, Rory Cobb, Rachel Hewett and Graeme Douglas</i>	87
• On the threshold of adulthood <i>Annica Winberg</i>	89

Adults

- Let me keep it safe!
Bert Veneberg, Leo Koopman, Mark Noorlander, Hans van Stam, Antoon van der Kamp, Serge Willemsteijn, Vincent Zijffers and Angelique Koelewijn 91
- My dog, my freedom: representations of the visually impaired and professionals
Angélique Mouton, Stéphanie Demartin and Sarah Velghe 92
- Employability of visually impaired persons: jobs tailored to the disability or 'the sky is the limit'?
Bart Verdickt 94
- The benefits of accessible theatre programmes on students with moderate and severe visual impairment
Judit Gombas, Erika Anita Baráth, Beáta Prónay, János Zalán and Cecília Tóth 98
- The DogSim lost his legs
Peter Lasaroms, Hans Damm and Anita Lasaroms 100

Workshop Session II

- Stimulating social contact between blind children and their sighted peers through playing together at regular kindergarten (age 5-6 year)
Tiene Vanreybrouck 101
- Sex and relationship education. "How to use the Sex Kit"
Emma Vandamme, Marlies Praet 103
- Creating universal accessible text documents
Pieter Brabant, Vincent Cassert 106
- Self concept and future concept and visual impairment
An Ooms, Tine Vanhauwaert 109
- Can smartphones and tablets replace dedicated assistive devices?
Jeroen Baldewijns, Steven Breughe, Eline De Ganck, Elin Galle 110
- Building mutual framework of quality educational services offering for individuals with MDVI and Deafblind in Europe/Eurasia region
Martina Celizic, Monika Tóth, Emanuela Stoilova, Andrea Hathazi 112
- Geocaching with and for visually impaired children and young adults
Marten van Doorn 117

Parallel Session III

Early Childhood

- Setback in development in young children with blindness? A systematic review and implications for practice
Ans van Eijden, Ellen van den Broek, Ans Withagen and Mathijs Vervloed..... 122
- The young blind child: developmental Assessment
Griet Pattyn and Katrien Perneel 124
- The Pearl - a preschool encouraging independence and participation
Agneta Westman and Lena Lindbom 126

School Age

- Tough talks: talking to children about sight loss
Sarah Holton, Robert Caswell, Rachel Pilling and Rachel Hewett 128
- "See?", psycho-education for visually impaired school aged children
Yvonne Kruthof 130

Adults

- Stimulating communication in individuals with deafblindness using an intersubjective developmental perspective
Saskia Damen 132
- Using my feet- A description of the use of guide lines by an adult women with congenital deafblindness inside her house
Marjo van Welbergen, Nathalie Lentink, Peter Peek and Mijkje Worm 134

School Age

- Individualised augmentative communication for individuals with autism, intellectual disability and visual impairment: Interpretation an implementation of the ComFor-V results
Petra Hagen-Geerts, Jarymke Maljaars, Kristien Hermans, Roger Verpoorten, Ina van Berckelaer-Onnes and Ilse Noens 136
- A model of national education system for multiply disabled, visually impaired children
Zeynep Nazan Baykan 138
- Behavioural change: inclusion or exclusion? A dilemma for educators
Elaine Gilmour 140
- Approaching the person through the disability
Albert Ruf 143
- Biblus - A digital library for alternate formats
Lars Ballieu Christensen and Tanja Stevns 150
- Improving access to external examinations for students with vision impairment in the United Kingdom
Rory Cobb and Sue Keil 152

Young Adults

- Direct braille printing of standard documents made easy
Niels van Weele and Björn Löfstedt 154
- A teaching framework for the teaching of a second/foreign language to learners with visual impairment
Aikaterini Athanasiadou 156

Adults

- Improving the quality of life for individuals with multiple disability and visual impairment by reaching out to other caretakers
An Verellen and Claudine Martens..... 158
- Prevalence of psychiatric and/or additional disorders in adults who are visually impaired
Marit van Buijsen, April Boessen, Uta Roentgen, Peter Verstraten and Luc de Witte..... 160

- What you can expect from the European Directive on accessible websites
Bart Simons 162
- Mental management: contribution to improving the quality of life in support of occupational therapy
Florence Terrier and Stéphanie Demartin 164

Parallel Session IV

Early Childhood

- Ipad applications for children with visual and multiply impairment - The family of EDA PLAY Apps
Alice Pexiederová, Martina Vaňkátová and Markéta Skalická 166
- The success of a new conference organization methodology
Elena Gastón López 169

School Age

- Spatial thinking and Visually Impaired students: an educational program of intervention
Maria Zeza, Philippos Katsoulis and Mary Styliidi 171
- The Spatial Representations Workshops: methods to develop skills and acquire autonomy
Mikhael Poznanski and Laurent Vincent 173
- How 3d printing can support and help children with VI in education
Ruben Brandsma and Eric Velleman 175
- Teaching mathematics and music to blind and partially sighted learners through knowledge and technology
Tanja Stevns and Lars Ballieu Christensen 177

School Age

- Children suspected of CVI: Structured way of observation children between 2,9 months and 12 years and the use of uniform observation lists, material and reporting templates
Nicole Scheirens 179
- Sensitization about Cerebral Visual Impairment. The Cerebral Visual Impairment awareness program
Lore De Deyne, Martine Dierckxsens and Emma Vandamme 181
- Empowering dialog in classrooms: Challenges and needs of teachers of students with visual impairments in Turkey
Mehmet Cihan and Kubra Akbayrak..... 183
- Visual ability in multiply impaired children with cerebral palsy
Ana Katusic, Snjezana Seitz, Tatjana Petrovic Sladetic and Sonja Alimovic 185
- The Visual data sheet, detailed information from visual disabilities and it's impact on daily life
Jessica Moens..... 188
- The effect of rehabilitation using Yoga elements on visual functioning in young adult with multiple disabilities and visual impairment , Case Study
Martina Sedlar 190

- Tactual Profile - The development of the MDVI version
Ans Withagen, Anneke Blok, Wieneke Huls, Ineke Jacobs, Marij de Lange, Nanouk Scheening¹ and Miranda Zwijgers 193

Young Adults

- Transition from adolescence to adult life
Riet Gyselbrecht, Arlette Vermeire and Kathleen Deweerdt 195
- Transition from youngster to early adulthood in different aspects of life
Eva De Stecker and Sharon Deprez 199
- The linkage between self-determination and psychosocial functioning of adolescents with a visual impairment
Eline Heppe, Sabina Kef and Carlo Schuengel 201

Adults

- Methodology of the training "Passeur de sens"©: accessibility in the cultural and touristic fields to improve quality of life
Stéphanie Demartinu and Sophie Hamaide 202
- Advising assistive technology in the era of Universal Design
Jeroen Baldewijns 204
- Non-verbal communication: Thoughts and experiences among persons with blindness
Tina Björk 206

School Age

- How do students use braille and synthetic speech while reading, comprehending and processing mathematical tasks?
Annemiek van Leendert, Michiel Doorman, Johan Pel, Paul Drijvers and Johannes van der Steen 208
- Who needs to know what? - A study to differentiate between the knowledge of TVI and mainstream school teachers in the inclusive education system
Marie-Luise Schütt 210

Workshop Session III

- Visual functioning of babies and young children with visual impairment or multiple disability and visual impairment: how to assess?
Myriam Callemeyn, Marlies Praet, Mieke De Pourcq, Mieke Vandorpe, Kim Maesele ... 213
- WerkWijzer A methodology for supporting people with visual impairment in combination with an autism spectrum disorder whether there is also another constraint such as intellectual disability
Anja Pouwels, Ellie Verstappen 215
- Reflections on how to foster better 'Quality of life' for the person with Congenital Deaf Blindness
Vanthuyne Veerle, Daelman Marlene 217
- Daisy player: The bigger picture
Tine Delporte, Piet Verstraete, Astrid Dekoe and Tina Mutschinski 219
- Independence through quality braille training
John Heilbrunn 222

Keynote lecture

- 30 years of care and rehabilitation of visually impaired adults and older people
Peter Verstraten 224

Posters Presentations

- Counseling children and adolescents with visual impairment and multiple problems: topics, methods, and adjustments
Karolien Bex 226
- Visually impaired people in Aruba: a shift in networks, identity and respect in everyday life in a small-scale community
Mieke de Droog 228
- Aetiologies of cerebral visual impairment in mainstream secondary education
Katrien Keppens, Rita Patteeuw, Anne-Leen Vandamme and Mieke De Pourcq 230
- Motor development and (early) intervention in blind babies, toddlers and children
Lieve Dewerchin and Katrien Keppens 232
- Problems in orientation and mobility in children with cerebral visual impairment
Emma Van Damme, Mieke De Pourcq and Katrien Keppens 235
- Rising prevalence of cerebral visual impairment in mainstream secondary education calls for a different approach
Mieke De Pourcq, Anne-Leen Vandamme, Emma Vandamme, Rita Patteeuw and Katrien Keppens 237
- Bookbox: a Story with 3D printed Tactile Plates
Griet Pattyn, Mieke Vandorpe and Sofie De Leener 239
- Families with a visual impaired child: integrating visual stimulation into daily life
Katrien Perneel, Mieke Vandorpe, Bastiaan Thijs and Patricia Delbeke 241
- Care binder for parents regarding (social) administration
Kim Maesele, Stefanie Maeghe and Myriam Callemeyn 243
- 'Regarding the future'. Inspirations for and by people with a visual impairment
Lorenzo Billiet, Debbie Claus, Eva De Stecker, Sarah De Ruyck, Heidi Deknudt, Sonia Meys and Marieke Weckhuyzen 245
- New techniques and methods in working with multidisabled visually impaired students at "Prof. Dr. Ivan Shishmanov" Special School for Visually Impaired Students
Yana Raeva and Julieta Petkova 247
- The benefits of specialized care for persons with congenital dual sensory loss
Wanda Frederiks and Caro Verlouw – Mooij 249
- CVI camp for children with cvi, from 8 to 12 years
Nicole Scheirens and Elke Spans 250
- Visual demands of augmentative and alternative communication
Friederike Hogrebe 251
- Dance therapy session as part of universal design for learning - "Body in Motion"
Ivan Macokatic 253
- Developing an online community of practice with professionals working with adults who are visually impaired and have psychiatric disorders
Lisanne Teunissen, Uta Roentgen, Marit van Buijsen, Peter Verstraten and Luc de Witte .. 255

• Realization of life habits in adults with visual impairment <i>Ksenija Stanimirov, Branka Jablan and Aleksandra Grbović</i>	257
• Lighting for people with low vision, our approach <i>Steven Breughe</i>	259
• The First Steps Project <i>Janja Hrastovšek, Sonja Furtomanova, Tatjana Medved</i>	262
• Creative occupation center for children with visual impairment <i>Menelaos Tsaoussis</i>	264
• Impact of ICT on social interactions in secondary mathematics classrooms: the case of students with a visual impairment <i>Mathieu Gaborit, Minna Puustinen, Dominique Archambault and Nathalie Lewi-Dumont</i>	266
• Experiences of parents and professionals of children suffering from Neuronal Ceroid Lipofuscinosis <i>Bert Veneberg, Erik Olsman , Claudia van Alfen and Dorothea Touwen</i>	268

9th ICEVI European Conference: Empowered by Dialogue
2-7 July, Bruges, Belgium

Evolution of visual impairment in children and adults born preterm

Katrien Keppens¹, Mieke Vandorpe², Myriam Callemeyn², Mieke De Pourcq^{1,2}

¹Centre of Expertise, De Kade, Spermalie,
Bruges, Belgium

{katrien.keppens, mieke.depourcq} @de-kade.be

²Mobile service Accent, De Kade, Spermalie,
Bruges, Belgium

{mieke.vandorpe, myriam.callemeyn} @de-kade.be

ABSTRACT

Preterm birth is known to be a risk factor for visual impairment.

A strict follow up for retinopathy of prematurity (ROP) is organised by ophthalmologists in neonatal care units. ROP is detected and treated in an early stage over the past 20 years. Oxygen is strictly limited to prevent ROP.

There is no screening for cerebral visual impairment (CVI) before discharge from neonatal care units. In Flanders specialised centres follow infants and children born preterm: the centres for developmental disorders (COS). They have knowledge on CVI. In neonatal care units visual enriched environment are not yet provided.

With this study, we want to investigate whether the current practise results in less visual impairment in children born preterm compared to the past.

The files of all individuals with a history of preterm birth asking for support from Spermalie were studied retrospectively from 2008 until 2015. Spermalie is a centre of expertise for visual and/or auditory impairment.

94 persons are included. 12 have only auditory impairment. They are excluded for further study.

48 have ROP (mean age 20 year). 33 have CVI (mean age 11 year).

21 of the persons with ROP are blind. 2 blind children with ROP are born abroad. They are 8 and 15 years of age.

6 persons with ROP are severely visual impaired and 21 are moderately visual impaired.

The characteristics of those groups are given in detail in this presentation.

Fazzi and Ricci are both working on an early screening program for CVI in neonatal care units.

Preterm birth is still a risk factor for visual impairment. ROP screening remains important. Good follow up of ROP children is important for the rest of their life to detect retinal detachment in an early stage.

Early visual stimulation is required in CVI. We believe early screening should be performed in all neonatal care units and early visual enrichment should be available and used in all units.

1. INTRODUCTION

Preterm birth is known to be a risk factor for visual impairment.

A strict follow up for retinopathy of prematurity (ROP) is organised by ophthalmologists in neonatal care units. ROP is detected and treated in an early stage over the past 20 years. Oxygen is strictly limited to prevent ROP.

There is no screening for cerebral visual impairment (CVI) before discharge from neonatal care units. In Flanders specialised centres follow infants and children born preterm: the centres for developmental disorders (COS). They have knowledge on CVI. In neonatal care units visual enriched environment are not yet provided.

With this study, we want to investigate whether the current practise results in less visual impairment in children born preterm compared to the past.

2. METHODS

The files of all individuals with a history of preterm birth asking for support from Spermalie were studied retrospectively from 2008 until 2015. Spermalie is a centre of expertise for visual and/or auditory impairment.

3. RESULTS

94 persons are included. 12 have only auditory impairment. They are excluded for further study. 48 have ROP. 33 have CVI. 21 of the persons with ROP are blind. 2 blind children with ROP are born abroad. They are 8 and 15 years of age. 6 persons with ROP are severely visual impaired and 21 are moderately visual impaired, visual acuity more than 0.1 (VA >0.1). 27 persons with ROP have a visual acuity less than 0.1 (VA <0.1), blind or severely visual impaired.

The mean age in the CVI group is 11 year, range from 2 years 3 months to 25 years. The mean age in the ROP group is 20 years, range from 2 years 8 months to 54 years. In the group ROP VA <0.1 the mean age is 24 years, range from 4 years to 54 years. In the group ROP VA >0.1 the mean age is 13 years, range from 4 years to 27 years.

The mean birthweight in the CVI group is 1426g, range from 550g to 2800g. The mean birthweight in the ROP group is 931g, range from 450g to 2500g. The adults with ROP had a mean birthweight of 1137g, range 450g to 2500g, but the small children (<10 years of age) had a mean birthweight of 801g, range from 600g to 1100g.

The mean gestational age at birth in the CVI group is 30 weeks, range from 26 weeks to 36 weeks. The

mean gestational age at birth in the ROP group is 27 weeks, range from 24 to 33 weeks.

4. DISCUSSION

Preterm delivery was a risk factor for visual impairment 50 years ago and it is still a risk factor for visual impairment today. The good screening and follow up for ROP in preterm born children has led to less severe visual impairment. At present studies with Ranibizumab are performed to prevent ROP.

For CVI no good screening is widely used in neonatal care units yet. Ricci and Rossi are both working on an early screening program for CVI in neonatal care units (1,2). Ricci has developed a structured test, which can be used from gestational age of 34 weeks on. An abnormal test gives a good prediction for developing CVI at later age.

The next step is to investigate whether structured visual stimulation of this subgroup with an abnormal screening test, can give better visual outcome. A controlled study in this group is not ethical. But results can be compared to historical data on CVI groups.

Another question to be answered is from which gestational age on you can safely stimulate babies without giving them too much stress. We didn't find any literature on this subject.

Another possibility is that you stimulate all preterm born babies from a save age on, detect which babies are at risk and keep on stimulating those in a more structured way. We believe this last option is the best one for all preterm born babies.

5. CONCLUSIONS

Preterm birth is still a risk factor for visual impairment. ROP screening remains important. Good follow up of ROP children is important for the rest of their life to detect retinal detachment in an early stage.

Early visual stimulation is required in CVI. We believe early screening should be performed in all neonatal care units and early visual enrichment should be available and used in all units.

REFERENCES

1. Ricci D, Romeo DM, et al. Early visual assessment in preterm infants with and without brain lesions: correlation with visual and neurodevelopmental outcome at 12 months. *Early Hum Dev.* 2011 Mar;87(3):177-82.
2. Rossi A, Gritti M, et al. Visual profile in healthy full-term newborns: use of the Neonatal Assessment Visual European Grid (NAVEG). In *Visual Impairments and Neurodevelopmental Disorders*, Editions John Libbey Eurotext, 2016, p133-141.

More information: katrien.keppens@de-kade.be

Copyright © 2017 Katrien Keppens

Early Intervention For Visually Impaired Children: Terms And Stages Of Compensation Of Blindness In The First Year Of Life

Ludmila Myasnikova¹, Vladimir Ruchin²

¹ National Research Saratov State University, Department of Psycho-Pedagogical
and Special Education, Saratov, Russia
myasnikovalv@gmail.com

² Yuri Gagarin State Technical University, Department of Sociology,
Social Anthropology and Social Work, Saratov, Russia
r-vl@yandex.ru

According to the World Health Organization (WHO), there is a steady trend of growth in the number of children with various forms of visual pathology. The Russian statistics registers about 10% of all newborns as premature which is about 125 thousand children total and eye disease is detected at 20% of these children.

Visual deprivation determines the formation of the child's personality, whose development differs qualitatively and structurally from regular children. Modern scientific researches have proved that the first years of life are decisive for the future as the most intense period of development. Correctional help during this period may contribute to substantial compensation of visual defect.

Children are born with the brain ready for learning and education. But a blind child is unable to do it without our help.

The formation of a human brain starts with the intrauterine development, the activity peak of this process is in the first year of a child's life, in other words, the first 12 months are crucial while brain develops.

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License 3.0 Unported, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited

There are some facts:

1. The weight of a brain increases twice during the first year of a child's life and weighs about 1 kg (the brain of an adult weighs 2 kg).
2. The weight of a brain is increased due to the formation of neural connections. A neural connection – synapse – is being formed when a child gets any experience. A blind child has few chances to get any experience at young age due to the parents' incompetence.

3. During the first years of a child's life there appear about 700 neural connections in his brain, but to keep the neural connection (and increase the brain weight on this neural connection) a child needs to live through the experience several times. Visually impaired children have insufficient volume and lack of visual information, lack of impressions lead to the lag of their psychomotor development.

4. The most active formation of neural connections is **within first six months**. It is the time which parents spend at the search of necessary treatment, sometimes in vain, not thinking about the need of special measures to develop a child.

5. Use it – or lose it! The neurons are either connected, forming the neural connections, or die. The brain of a newborn child has 150-200 billions of neurons, the brain of an adult - twice as less. It means that the fate of the majority of nerve cells of a baby is in his parents' hands. The smaller a baby is, the more special work should be done, but the blind children are deprived of it.

6. The strongest neural connections are the connections that arise in both hemispheres (an effective way to synchronize both hemispheres is to move toys from hand to hand, crawling, swimming, playing musical instruments). During physical exercises, new nerve cells are formed, chemical reactions are accelerated in the brain, including the anterior part of it responsible for the formation of cognitive skills. A small blind child moves little, his vestibular apparatus develops slowly, the development of active movements slows down, which affects the development of game, objective activity, which, in turn, slows the pace of cognitive development.

7. Priority of polysensory experience over monosensory. There are three stages of compensation for blindness at an early age. The first and partly the second stage refer to the first year of the child's life. The first stage is characteristic for the first half of the year and is associated with the

polysensory character of perception, with the child's reactions to complex stimuli, it is formed in communication with the adult on the basis of active stimulation and irritation of all the safe analyzers.

The second stage is connected with movement, space orientation.

Lack of special work with a blind child of early age has negative effect for his cognitive and motive development.

Practice shows, that the majority of parents of visually impaired young children are oriented at medical rehabilitation and tend to ignore the corrective work. Baby care and his physical health take the first place in the parents' mind which shows the unformed idea of the role of social and psychological factors in the public consciousness. As a rule, the appeal to professionals is registered at the age of three, when the time of effective impact on mental processes is lost.

Today, the society has a complicated situation, when parents do not understand the essence of problems, and the system of training and early intervention for children with visual impairment are at a low level. Moreover, the social position of the parents is passive, which leads to the "loss" of families from the area of professional attention, especially for low-income families. Thus the situation for a child can be fatal. Only partner relations of parents of blind babies with specialists can lead to the successful results in development children with significant visual pathology.

Taking into account research and practical experience, we suggest a number of complex measures to change the current situation.

It is necessary:

- 1) to create a unified data bank of children of early age, who has any visual pathology;
- 2) to organize the home visits of families with visually impaired children of early age;
- 3) to organize the training of methods of effective interaction between parents and their visually impaired children of early age;
- 4) to teach specialists to work with families with visually impaired children of early age, including distant technologies;
- 5) to attract volunteers from among students who study to become teachers of visually impaired children to work with such families; it has double benefit: correctional and pedagogical assistance to the family, acquisition by students of practical skills of working with a visually impaired child (development of individual educational routes, study of cognitive activity, emotional and volitional sphere of children, development of learning notes);
- 6) to organize public education on the need of early corrective care for young children with visual

impairments, to explain the consequences of late commencement of special work with such children;

7) to create a unified bank of methods and technologies for working with families with visually impaired children of early age, which are used in Europe.

Solving these problems will help to avoid the emergence of secondary deviations of children with visual pathology, will contribute to their development, solving their life problems, which, in the long run, will facilitate the successful integration of children in the social and educational environment.

BRATICO.

A new Braille literacy method of ONCE, using ICT

Elena Gastón

ONCE. National Organization of the Spanish Blind
Resource Center of Madrid

ABSTRACT

After decades of experience in the field of education and support to students with visual impairments, the Spanish Braille Commission (CBE) of the National Organization of the Spanish Blind (ONCE) has taken an important step with the development of a new methodology and didactics of Braille.

This new method consists in a theoretical manual and the practical activities and materials.

Born from the idea that learning Braille is not only learning a code, but a complete literacy process, the method is divided in four modules, from birth to the moment in which the student uses Braille with effectiveness.

Some of the main principles of this new glance towards Braille are based not only in the experience of many professionals and the researches and methods used up to now, but also in the new disciplines of neuroeducation and neurodidactics.

Finally, based on several investigations made by ONCE, we introduce technology in the learning process of Braille and also as a tool for the teachers to follow the program.

1. INTRODUCTION

Currently, almost all students with visual disabilities from Spain are enrolled in mainstream schools where literacy methodologies and didactics are increasingly visually attractive and technologically interactive. This is a challenge when it comes to teach Braille in an enjoyable way.

Besides this, in the last decades, many professionals in the field of visual impairment had been observing and were very concern about the decrease in the use of Braille, replacing it just with the voice of screen readers.

Another problem we were observing was that not only in the society in general, but even within teachers and professionals devoted to blind children, there is a social imaginary towards Braille as difficult, boring and a barrier between sighted and blind people. This is causing that Braille is the last resource offered to partially sighted children, after making them fail with print in many ways.

In this context, the Spanish Braille Commission (CBE) of the National Organization of the Spanish Blind (ONCE) created in 2012 a specific group to think and advance in Braille didactics, with different professionals working part time in it.

2. THE NEED OF A CHANGE

Our first step was to think about the background referred and decide if there were any changes to make.

We made many debates about his and made a first approach to many documents and professionals.

The results were clear. We needed to change the glance towards Braille for many reasons:

As it is established in the Convention on the Rights of Persons with Disabilities (UN, 2006) [1], students with blindness or severe visual impairment have the right to use Braille.

Children are included in mainstream schools, so their materials need to be more inclusive and attractive.

Neuroeducation and neurodidactics are offering new visions on how the brain works and how teaching affects to it in a positive or negative way depending on the way we teach.

Technology is present in live, and is a very important tool for blind people, so it must become an ally of Braille instead of its enemy.

3. BRAITICO

So the first step we took was a deeper research about literature and studies about Braille, neurodidactics, tactual and hearing perception, Braille methods, technology and some other items that we red and debated, giving a result of a theoretical manual, "Teaching Braille beyond the code. New perspectives on literacy for students with visual impairments", published in 2015 [2].

After writing the manual, we established the principles, objectives and methodology for the new method and now we are developing materials and a piece of software both for teachers and children.

3.1 Main principles

The main principles of our new method are the following:

- Braille is a complete literacy process. It starts from birth.
- As neurodidactics confirm, motivation is the main way to promote learning and there is a need to respect the child's rhythm and reduce their stress in order to let their brain process appropriately the contents.
- Oral communication, Phonological awareness is in the basis of any literacy process, the same in Braille.
- The more active and direct experiences the child has, the best he will understand what he reads and be efficient in his reading and writing.

- Technology is a wonderful way to learn Braille. This principle is based on some investigations made by ACCEDO Group of ONCE in the last decade. In all of them we proved that the use of ICT favors self-esteem, motivation and inclusion in learning Braille.

4. MODULES

In Braitico we have tried to make an inclusive approach, appealing to both blind and sighted students, promote motivation and self-esteem, enhance children capabilities and minimize their errors, combine traditional learning with technology, promote autonomy and cooperative learning, and encourage the expansion of interests and knowledge through reading and writing.

It is composed by four modules for different stages in the learning process of Braille:

4.1 Module 1: Little hands: previous abilities for Braille: 0-24

With the objective to awaken the desire, promote experiences and introduce oral communication in the child.

4.2 Module 2: On the point: pre-Braille skills

Thought to provide the child with enriching experiences that will favor their language and vocabulary; arise desire and motivation for literacy; interaction with others to promote language development.

4.3 Module 3: Brailleo: formal Braille

It is what is normally considered as learning the code, but it goes much further. It works with the learning of letters, words and phrases, but giving sense and connecting every lesson with a special interest or experience that motivates the child and their peers.

4.4 Module 4: Superbraille 4.0

The objective of this module is to achieve a complete competence in Braille, both reading and writing with effectiveness, to improve motivation, autonomy, decision and creativity and to forget the effort of reading and writing to be able to enjoy doing them and using Braille for their studies and ordinary life.

5. MATERIALS

Besides the theoretical book and the modules with their competences, objectives and activities, Braitico has different materials both for the students and teachers or parents who will teach or help them:

5.1 Technology:

Each module has software with all the information referred to it and some activities for the child.

The first module is made for adults, but has a part of songs and rhymes for the child. The rest have a part for teachers and increasingly, activities in the computer for the child, were they start from modulo 2 to use the Braille

display and the digital tablet with an embossed paper, adapted from what the sighted children see in the screen.



Figure 1. This photo shows a girl using the digital tablet.

5.2 Learning materials:

Besides the computer program, and in relation with it, there are other learning materials like story books, primers and workbooks and games.



Figure 3. This photo shows some materials of Braitico

5.3 Documents:

The method is completed with different documents for teachers and parents, like guidelines to use the Braille display at different ages, ideas to decorate the Perkins Braille, all the texts of the story books, etc.

All the documents created and the activities for paper, Braille display and digital tablet will be available to print.

6. CONCLUSIONS

After all this work, we conclude that a new glance towards Braille helps children enjoy learning, doing it in an interactive an inclusive environment, and awakes the desire both of them and others. Technology and attractive learning materials help in the way. Nevertheless, it is essential to respect to the child's rhythm, to create the need of Braille in the child and the family and lead them to love Braille as we do.

I want to thank to the Spanish Braille Commission for boosting this project, and to all my colleagues for their enthusiastic involvement in it.

7. REFERENCES

- [1] The United Nations. 2006. "Convention on the Rights of Persons with Disabilities"
- [2] Comisión Braille Española. "La didáctica del Braille más allá del código. Nuevas perspectivas en la alfabetización del alumnado con discapacidad visual. Madrid 2015.

The Development of Online Resources to Support the Effective Assessment and Teaching of Literacy through Braille

Rory Cobb¹ and Steve McCall²

¹ Royal National Institute for Blind People, United Kingdom
(rory.cobb@mib.org.uk)

² University of Birmingham, United Kingdom
(s.mccall@bham.ac.uk)

ABSTRACT

This paper provides an overview of two new online resources to support the development of effective braille literacy skills by children with severe vision impairment (VI). Both resources were developed to meet the needs of qualified teachers of children with vision impairment (QTVI) working with braille users in mainstream schools in the UK, in response to national concerns about the quality of the teaching of literacy through braille.

The first resource is an online training programme entitled 'The effective teaching of literacy through braille'. It comprises interactive study materials, video and online discussion activities, and requires around 80 hours of study over 6 months.

The second resource is an interactive version of the Learning Media Assessment tool, developed in conjunction with Cay Holbrook and Texas School for the Blind. The new online UK LMA has been adapted for the UK context to provide QTVIs and their colleagues with a structured framework to support decisions about the choice of learning and literacy media for pupils with VI.

The paper describes how the key elements of both resources were designed, developed and implemented.

1. INTRODUCTION

There are around 1000 children and young people who read braille in England and the majority of these are educated in mainstream schools, supported by QTVIs. Although learning the braille code itself is a required element of QTVI training, the breadth of content to be covered in the course means there is limited time to consider the teaching of literacy through braille in depth. In addition, many QTVI may have trained many years ago and their specific knowledge and skills in how to teach braille may have been largely forgotten through lack of use. The resulting pattern of expertise is therefore very patchy.

This difficulty was identified in a literature review into braille teaching in 2012 [1] which recommended the development of specialist second level training for QTVIs. The same report recommended the development of a robust assessment procedure to support decision making in whether children with severe vision impairment should learn through print or braille.

2. BRAILLE LITERACY COURSE

2.1 Course Development

In 2013 RNIB received government funding to develop an online course in teaching literacy through braille for QTVIs. Central to the new course would be the specialist nature of its content. We therefore recruited a team of four QTVIs who were known nationally as experts in teaching braille to write the individual units of the course. We also recruited an experienced instructional designer to advise on the structure of the online course and to build the final product.

In designing the course we had to make a number of key decisions. Firstly we decided that it should be a formal timetabled course with a high degree of prescribed content, not just an online resource which teachers could access as they wished. Although making it free might encourage more take up, we decided that payment was necessary to ensure the quality of the learning experience and to secure students' commitment to completing the course. We estimated the time commitment needed to study it to be around 80 hours. This would involve a significant commitment from QTVIs working full-time but we believed this was reasonable if it was spread over sufficient time. Finally, while external accreditation might make the course more attractive it would also make it more expensive. We decided therefore to simply award a certificate of completion to successful students.

2.2 Course Content

The course is arranged in six core units as follows, with self-study materials for each:

1. Fundamentals of braille literacy. This unit looks at braille as a literacy medium, key aspects of the code itself and how support for children learning braille is structured.
2. Pre-reading. This unit deals with the stage before formal reading and focuses on the early years prior to entering school.
3. Early reading part 1. This unit introduces reading strategies for children learning literacy through braille. The focus is on formal education in primary school and involving parents.
4. Early reading part 2. This unit looks at issues around the use of uncontracted/contracted braille and the use of reading schemes.

5. Fluent reading. This unit looks at the development of fluency in older braille users.
6. Implementing braille literacy. This unit covers a range of subjects that relate to braille literacy including assessment, using media, writing with braille, the role of teaching assistants and the use of technology.

Students also choose two out of seven supplementary units focusing on specialist aspects of braille teaching.

2.3 Course Assessment

Students' work is assessed in three ways:

- Contextual learning. Each unit includes a structured portfolio which students complete to demonstrate that they have understood the course material, applied it to their own context and reflected on its importance in their role.
- Collaborative learning. Each core unit contains structured online discussion topics to which students are expected to contribute in discussion groups of 6-7 students.
- Factual learning. Each unit includes a multiple choice quiz which students complete when they are confident that they knew and understood the self-study material.

2.4 Student Evaluation

Two cohorts of students have completed the course to date and a third has recently started, amounting to around 40 QTVIs in total. While these numbers are not high, the evaluations have been overwhelmingly positive, with the following ratings given by students:

- The study of these units will improve my working practice: 4.8 out of 5
- I feel more confident about teaching literacy through braille: 4.7 out of 5
- I would recommend this course to other QTVIs: 4.9 out of 5

Typical feedback comments include:

“Altogether I thought it was a great course, I have really enjoyed doing it and feel it has been very beneficial for my work and my confidence working with and promoting braille”.

3. UK LEARNING MEDIA ASSESSMENT

The UKLMA resource was created in response to the 2012 RNIB literature review [1] which found that many QTVIs struggled to judge whether and when a child should start to learn through braille as well as or instead of print. The original Learning Media Assessment (LMA) procedure was developed by Alan Koenig and Cay Holbrook in the USA and published by the Texas School for the Blind (TSBVI) in 1994. The original hard copy resource has been updated and adapted for the UK context to provide QTVIs and their colleagues with a

structured framework to record, evidence and justify decisions about the choice of learning and literacy media for pupils with severe vision impairment over time. It supports teachers in making, reviewing and justifying key decisions about learning and literacy media for children from early years through to school leaving age. Specifically it seeks to ensure that:

1. The initial decision about the pupil's initial literacy medium is based on best evidence and is transparent.
2. The pupil's current learning/literacy medium is consistent with the pupil's current needs and maximises their potential attainment.
3. Changes in the educational needs of pupils in relation to learning media are identified and addressed in good time.

The information in the UKLMA resource can be divided into the following categories:

- Background information about the UKLMA process.
- Video case studies that provide valuable examples of how UKLMA is used in real-life situations.
- Detailed information on how to implement the UKLMA for initial and ongoing assessment.
- Downloadable forms that can be used with individual pupils, along with completed examples.

The UKLMA has been available to QTVIs since autumn 2016 and we are planning an evaluation of its use in summer 2017. We have also shared it with Cay Holbrook and TSBVI so they can develop their own online version for use in Canada and the USA..

4. CONCLUSION

These two resources represent an important step forward in strengthening the entitlement of children with severe vision impairment in the UK to high quality assessment and teaching of literacy through braille. Recently both of them have been handed over to VIEW, the UK association for the Vision Impairment Education Workforce. RNIB and VIEW are keen to share our learning from developing these resources with teachers from other countries in order to raise standards of braille literacy internationally. Samples of both resources can be accessed via the VIEW website (www.viewweb.org.uk).

REFERENCES

- [1] McCall S, Douglas G, McLinden M. *A review of the literature into effective practice in teaching literacy through Braille*, London, RNIB, 2012

Audio description and students with visual impairments: what use for what benefits?

Nathalie Lewi-Dumont¹, Loraine Crépel², Laetitia Dumont-Lewi³

¹ EA 7287 Grhapes – INS HEA, UPL, Suresnes, France, nathalielewi@gmail.com

² Institut National des Jeunes Aveugles, Paris, France, lcrepel@inja.fr

³ Labex Arts-H2H, Université Paris Lumières, France, laetitia.montanina@gmail.com

ABSTRACT

In France, since the law of 11th February 2005 on equal rights and opportunities, participation and citizenship of people with disabilities, inclusion of students with disabilities in regular classes has increased and audio description has developed. We are studying the use that teachers make of audio description when they have a student with visual impairment in their class. We sent a questionnaire to teachers in order to analyse the benefits and limits of audio description, both in terms of learning and on a psycho-social level. Making pupils audio-describe short films could be a good learning tool in several subjects for both sighted and visually impaired students, and also a good way to promote the abilities of students with visual impairments in inclusive school settings. The study shows that audio description is used in secondary schools more than in elementary schools, and that its possible uses, in partnership with other professionals, is unequally known by specialist teachers who could make suggestions to their colleagues.

INTRODUCTION

The study of still or moving images is part of school curricula in France. Teachers are also encouraged to take their students to cultural venues. When they have a student with a visual impairment (VI) in their class, the issue of making visual elements accessible arises. In a context where inclusion is becoming more and more frequent, teachers need to find strategies for students to understand the role of images, for students with low vision and blindness to build a representation of images that surround them and which they have to study.

We will first quickly present the schooling of students with VI and an overview of audio description (AD) in France. Then we will study the use teachers make of audio description, by analysing a questionnaire sent to regular and specialist teachers in charge of students with visual impairments in order to analyse its benefits and limits, both in terms of learning and on a psycho-social level.

1. STUDENTS WITH VISUAL IMPAIRMENT AND AUDIO DESCRIPTION IN FRANCE

Since 2005, full accessibility has been required by the law of February 11th for people with disabilities (in

education, work, culture, leisure activities...). Integration for students with disabilities existed long before, particularly for students with VI, but they are more and more often included, even if they have additional disabilities. However, in theory, parents, at elementary and secondary levels, have the right to choose between a special school, inclusion in a regular school with a resource classroom for students VI and full inclusion in the school closest to home, with special support. The most common situation for students with VI is full inclusion [1].

Speaking of culture, France introduced audio description quite early, since French professionals were trained quite soon after it was invented in the United States and brought the process back home for movies. Then it was “applied” to live shows, museums and exhibits. In France, more and more cinemas have the right equipment, public theatres propose audio described plays and museums or cultural places propose audio headsets, together with models and raised lines drawings [2,3]. Television channels are required to broadcast a certain percentage of audiodescribed programs [4]. Audio description is now more and more studied in various European countries [4,5]

2. THE QUESTIONNAIRE

2.1 Presentation

During the academic year 2016-2017, a questionnaire was sent by email to our network of professionals working with VI students, mainly teachers for the visually impaired (TVI). People were free to forward the questionnaire to colleagues. The questionnaire consisted of five main parts: presentation of the respondents; experience and perception of the audio description (cinema, theatre, museums, etc.); use of AD with students in outings or in the classroom; suggestions for improvements.

We got 30 usable answers from all over France, mainly from elementary and secondary TVIs working either in special schools or in elementary or secondary schools with a resource room or as itinerant teachers at all levels. Among secondary teachers, 5 teach French, the others various subjects.

2.2 Answers

Although all people had heard about it, some had never tested audio description, and some did during their

training. Most of them, working in a resource room or itinerant, said they did not organize cultural outings themselves: teachers in the VI's regular classes are in charge of that. However, respondents said they found out and gave information about accessibility to regular teachers and parents.

The main use concerns movies. Few teachers take their pupils to live performances, even to exhibitions with audio description. They blame it on the difficulty to setup such activities: lack of information, difficulty as regards their students' level, the cost, the few choices in the offer. They find it very useful in museums. Sometimes they question the quality of AD.

For cultural venues using AD, they mention its great contribution, since the VI can follow the show like the other students. Some point out that partially sighted students have trouble accepting the headsets. One teacher would like to have extra headsets so that sighted students can experiment it. Several mention that AD helps students with learning disabilities.

Surprisingly, few questionnaires mention the use of DVDs with AD in the classroom, yet film analysis is part of the exam at the end of high school, and a special teacher working with adolescents with additional disabilities mentions an extensive use of those DVDs for studying various subjects (history, geography, literature, social sciences, biology...).

AD is specific to VI people, so TVI use it when they gather students who are included in their local schools. They also use it to make regular teachers, other students and parents aware of accessibility.

Using AD is a way to make cultural experiences fully accessible to students with VI, in addition to tactile drawings, models, etc. The respondents mentioned that without it, they have to do it themselves and they realize description is not so easy to achieve. Eventually, they believe that it is truly an inclusive experience in a world where images are so important, even when their students are in special schools.

3. AUDIO DESCRIPTION BY THE STUDENTS

3.1 A partnership experience

In partnership with an organization in the field of AD, in schools with a resource room and in special schools (in that case in partnership with a twin regular school), some teachers work on short films they have students audio describe [1, 6,7].

3.2 Objectives and organization

The objectives of these workshops are: sharing an artistic experience; making all students aware of the aesthetics of a piece of work (image and sound); deepening the meaning of works; using a specific writing style for each film; encouraging dialogue between students.

Students study the short film chosen and then write the AD. They have to be very careful about accuracy, to avoid redundancy between description and soundtrack.

This allows for fruitful interactions between sighted students and students with VI.

Depending on the age, pedagogical focus can be put on writing, vocabulary, reading aloud, understanding... With older students, as in the audiovisual high school [7], a very precise image analysis and study of director's intentions are required.

3.3. Contribution

All the partners highlight the contribution of that type of work, for the adults and all the students, in terms of learning and citizenship. The students with VI do not only validate the texts of their sighted peers, but they really take an active part, including in recording and participating in short film festivals (Angers, Clermont-Ferrand).

4. CONCLUSIONS

This inquiry shows that AD is worshipped by teachers who work with students with VI. Yet it is not used enough for several reasons, including inequality of shows and cultural offers in France, in spite of the law. Special teachers could be a driving force in informing their colleagues who have the student with VI in their inclusive classroom about this device, so they can choose pedagogical outings which allow full participation for this student and use audio description as a pedagogical tool to give all students a better understanding of image analysis and improve their culture.

REFERENCES

- [1] N. Lewi-Dumont, (éd.). *Enseigner à des élèves aveugles et malvoyants*. Lille : Canopé, 2016.
- [2] M. Simoneau, "Audio description", in *Voix*, n°38-39, pp. 30-35, 2011.
- [3] AFA (French Organization for Audio description), <https://audiodescriptionfrance.wordpress.com>
- [4] E. Perego (Ed.) *Emerging topics in translation: Audio description*. Trieste, 2012. <http://hdl.handle.net/10077/6356>
- [5] C. Taylor, *Audio description. Lifelong Access for the Blind*, Erasmus Project Final Report [online], 2014.
- [6] L. Crépel, "Si quelqu'un a des oreilles, qu'il voie. Si quelqu'un a des yeux, qu'il entende", mémoire 2CA SH option B, Suresnes: INS HEA, 2011.
- [7] <http://www.lefildesimages.fr/audiodescription-du-handicap-lanalyse-filmique/>

The assessment and development of digital literacy in students with vision impairment and additional learning needs: Preliminary findings from a current PhD study

Emily H. White¹, Kerry Woods¹, and Shiralee Poed¹

¹University of Melbourne, Melbourne Graduate School of Education
Melbourne, Australia
emilyw2@student.unimelb.edu.au
{k.woods, spoed} @unimelb.edu.au

ABSTRACT

Digital literacy is a 21st century skill [1] yet many teachers cite difficulty assessing and teaching it. This is problematic for students with disabilities as digital literacy enables technology use to access learning opportunities. For students with vision impairment (VI), for example, the ability to use a computer and the internet is associated with higher literacy test scores [2], and technology use supports improvements in learning maths [3].

This paper shares preliminary findings of a study of 1,413 students, which aims to support teachers' recognition of digital literacy in students with disabilities and with a focus on those with VI. Founded on prior work [4], the study applied partial credit item response modelling [5] to develop a progression of digital literacy for these students. The impacts of teacher and student background characteristics on their respective ability to assess and develop digital literacy are considered using evidence drawn from reliability indices, item and person fit statistics, and differential item functioning. The results may assist teachers to understand the digital literacy capability of students with disabilities, including VI, and what they are likely to be ready to learn next.

1. INTRODUCTION

Students with disabilities experience significant disadvantage in school [6, 7], due to the impact of their impairment/s meeting social [8], informational [9] and/or physical [10] barriers to learning. This includes students with VI, who may or may not have additional disabilities that further complicate their learning [11]. Skillful use of digital technologies can connect students with disabilities with opportunities for learning that they might be otherwise unable to access due to the impact of barriers on their impairments [12]. Learning to use digital technologies, and using them to learn, can be considered aspects of digital literacy. The combination of teaching students with disabilities [13] and teaching digital literacy [14, 15, 16] is difficult for many teachers, requiring provision of additional support.

This study aims to develop and validate measures to support the teaching and learning of digital literacy capability for students with disabilities. The study also investigates possible constraints on assessment of the digital literacy learning of such students due to student background

characteristics, including the presence of VI, and constraints on the use of the measure by teachers due to teacher background characteristics, such as experience teaching students with disabilities. The study further aims to develop instruments that can measure digital literacy capability for students with disabilities, as well as teaching advice for students working within different levels of digital literacy capability.

2. METHODOLOGY

The study used an established model for the definition of criterion-referenced frameworks [17, 18, 19]. Adhering to the procedures of related work to design and validate measures of communication and literacy [20], social processes [21], and emotional self-management and learning skills [22] for students with additional learning needs, the methodology included the following overlapping phases.

2.1 Construct Definition

A literature review was conducted which focused on the identification of evidence of development in digital literacy for students with disabilities as well as the definition of the construct of digital literacy for these students. A developmental taxonomy [23] was identified to underpin the design of the assessment. As a result of this initial phase, the construct of digital literacy was defined as being able to interpret and use the symbols, text/graphics, and tools of digital technologies and networks, and to do so in a culturally appropriate manner.

2.2 Draft Framework

Teachers with expertise in teaching students with a range of disability types, including VI, attended workshops to examine the results of the literature review. They helped to draft and review the *behavioural indicators*, the descriptions of evidence of learning for capabilities within digital literacy that were important for students with disabilities. They also drafted the *quality criteria*, the descriptions of what increases in ability looked like within each behavioural indicator, to create a draft developmental framework or set of rubrics. The quality criteria included examples of behaviours relevant to students with different disability types, including those with VI and additional learning needs. The intention was to build rubrics that could support

teachers' observations of their students and form the basis of a measure of digital literacy skills.

2.3 Judgement of Relative Difficulty

The expert teachers returned for a workshop to create a matrix, or draft *criterion-referenced framework* of the quality criteria, using pair-wise comparison [24] to judge the relative difficulty of each quality criterion. The draft assessment items and a demographic questionnaire were panelled and piloted before programming for online access. The purpose of this phase was to ensure that the framework underpinning the assessment was sufficiently comprehensive to meet its purpose of describing digital literacy skills for a broad and diverse population of students.

2.4 Trial

Initial data from 1,533 students were collected from teacher observers in 56 Australian schools who used the online program to assess their students. The program contained the behavioural indicators (items) as questions and the quality criteria (item-steps) as multiple choice options. Teachers were asked to select options closest to their student's observed abilities, and complete the demographic questionnaire to provide additional information about their students and their own experience with digital technologies and teaching students with disabilities. Each item also offered teachers an option of recording that the student had not yet demonstrated the easiest item-step described in a set. In total, there were 17 items trialled and these items included skills such as paying attention to familiar and unfamiliar digital technology, controlling one's use of digital technology, and finding information using digital technology.

2.5 Data Analysis

The data were cleaned to remove incomplete responses, resulting in 1,413 students in the trial. 142 students had VI, 98% of whom had one or more additional disabilities - primarily intellectual disability. 22% of students with VI used braille or a tactile symbol system with print or visual symbols and 4% used braille or a tactile symbol system exclusively. Data were calibrated using Rasch item response partial credit modelling [5]. The item-steps were plotted according to increasing difficulty and interpreted using data output. Reliability indices, item and person fit statistics, and differential item functioning were investigated to determine the quality of the measure.

2.6 Validation

Levels of progressive development in digital literacy were identified from the data to create a learning progression, and alignment between the levels and the original draft framework was checked as a first step towards a judgement of construct validity.

3. PRELIMINARY FINDINGS AND ARGUMENTS FOR VALIDITY

3.1 Reliability Indices

Reliability within the measure can support arguments for validity, as it can show that the measure is stable across use for different people as well as that the items measure different aspects of a skill, and therefore show good separation between them. The item separation reliability score of 0.99 indicated that the items each measured different characteristics. The WLE person separation reliability of 0.97 indicated that the items were able to discriminate well between different levels of person ability. The alpha reliability of 0.97 indicated very strong overall consistency of the items. As per advice [25], coefficients of 0.99, 0.97, and 0.97 reflect strong internal consistency.

3.2 Item and Person Fit

Use of the Rasch model to underpin the study required close attention to the goodness-of-fit to the model. Doing so can support arguments for the validity of the application of the results [26], as calibration and measurement within the model are founded on the fulfilment of the assumptions of the model by the data [27]. Determining fit to the model by items and persons can provide evidence that the model being used to analyze an instrument is suited for that purpose. Fit statistics express evidence for the accuracy of a measure [28].

3.2.1 Item Fit (*weighted MNSQ*)

Of the 17 items in the trial, two showed slight misfit to the model, at 1.46 (Item 3) and 0.71 (Item 11), as a fit score close to 1.00 is desirable [29]. Item 3 described a student's capacity to show interest in digital technology. Evidence of underfit for this item was attributed to the possibility that some students who were skilled in using digital technology might not be as skilled in maintaining interest in using it, or in other learning activities. However, a decision was taken to include the item as it added to the overall content or face validity of the measure. Item 11, which described a student's ability to apply digital technology terms, showed evidence of overfit or redundancy. However, upon further review, the degree of misfit was insufficient for item revision or removal. Overall, these item fit statistics revealed very high item technical quality.

3.2.2 Person Fit (*PFIT*)

A very low incidence of person misfit to the model was found, with 1.3% of students ($n=19$) having a PFIT score ≥ 3 . Of these students, 12 were excluded after individual review to determine plausibility of the response pattern. In each case, this was attributed to careless responding by teachers. Removing cases with implausible response patterns can strengthen the outputs, though the benefit to scale interpretation or measurement accuracy may be minimal [30]. The low incidence of person misfit indicated that

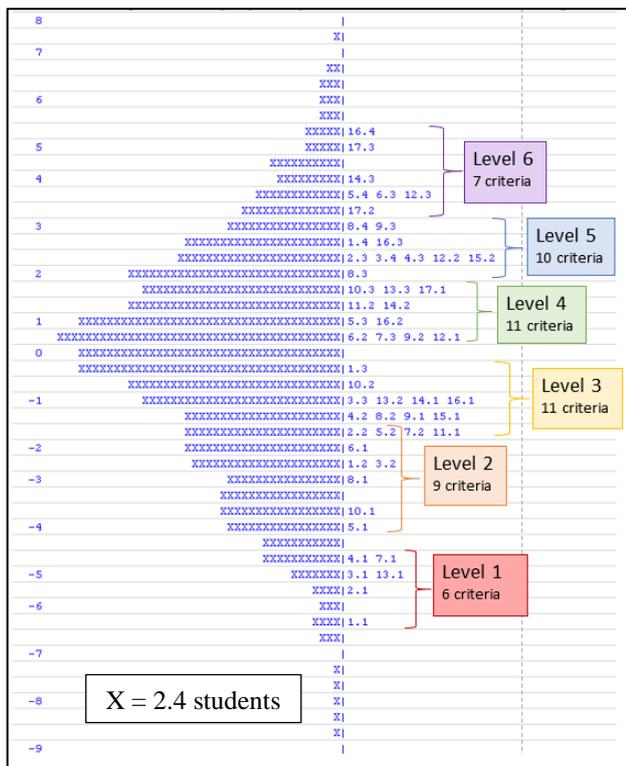


Figure 1. Variable map, with item-steps grouped into identified levels of digital literacy capability.

teacher and student background characteristics had a negligible impact on the teacher’s ability to assess a student using this measure, and a student’s assessed level of digital literacy learning. There were no systematic or interpretable relationships between student or teacher characteristics and probability of high person misfit.

3.3 Differential Item Functioning (DIF)

Differential item functioning (DIF) assesses whether an item worked differently for one student than another due to a characteristic such as disability type. DIF was investigated to determine the impact of student background characteristics on their digital literacy learning. Significant DIF based on student background characteristics, including disability type, was not detected. This means, for example, that a student with VI had the same pattern in their digital literacy learning progression, as assessed by the set of items trialled in the study, as a student without VI, and therefore the same likelihood of success on each item. This is an important step to ensure that items are not interpreted differently for students with different types of disability.

3.4 Variable Map with Levels

The variable map (see Figure 1) was one of the main statistical outputs used to determine the learning progression. The variable map orders the difficulty of the logits (shown as whole numbers on the figure’s left) of all of the item-steps, which served as the basis for developing the learning progression and the levels within it. A logit is the balance

between the difficulty of an item-step and how much ability a person needs to have a 50% chance of being able to demonstrate that item-step. Thus, the variable map shows the number of students who had a 50% chance of being able to ‘do’ each of the different item-steps, with an increased likelihood of being also able to do the easier ones beneath an item-step. In a partial credit analysis, this probability is cumulative. The six levels of digital literacy capability that were identified have been added to Figure 1 to show which item-steps correspond to each identified level of digital literacy capability, as each level is built from the content of the item-steps within it. The spread of ability within the students in the trial can be seen, as well as the spread of difficulty within the item-steps. The map shows a good match between item difficulty and the range of student abilities. To demonstrate the range of ability recognized in the levels, Level One described students who are learning to react and respond to digital technology and content, while Level Six described students who are learning to take control of digital technology through the use of guidelines and organisation.

4. DISCUSSION

Data analysis results indicated that the assessment had strong internal consistency, that the items were of a high technical quality, and that teachers could use the assessment consistently regardless of their background characteristics considered in the study. This included their own level of digital literacy, their feelings about, skill with, or experience with using digital or assistive technology for teaching and learning, the amount of support they receive to use it, their school location or type, or their experience in teaching students with disabilities. The assessment worked the same way for students regardless of their background characteristics considered in the study, including age, gender, school type or location, disability type – including VI, as well as their communication mode if they are Deaf/hard of hearing (sign language and/or spoken English), their literacy mode if they have a VI (braille/tactile symbol system and/or print/visual symbol system), their level of access to digital and/or assistive technology, or the background characteristics of their teachers. The assessment can thus be considered to be of a very high quality, with good evidence for several types of validity.

5. RECOMMENDATIONS FOR FURTHER RESEARCH

While this study identified six levels of digital literacy capability for students with disabilities based on evidence of the emergence of abilities from 1,413 students, not all students with disabilities will have their abilities recognized within these levels. Many students will be working at higher levels of ability than are currently described in the learning progression. While those working within higher levels of ability might be able to participate in more traditional forms of digital literacy assessment, some or all of these assessments may be inaccessible for some or all of these students. One recommendation is for research into

the emergence of abilities in digital literacy capability above those described in this study. This should include the development of an assessment and reporting system for teachers and teaching advice to support the understanding, teaching, and educational planning for students with disabilities in digital literacy within such levels. Additionally, research to determine the validity of the results of this current study for students without disabilities could serve to indicate whether there is a difference between the learning progression of digital literacy capability due to disability.

6. CONCLUSIONS

The aim of the research in this study is the design and validation of a judgement-based measure of performance in digital literacy capability to support teacher recognition of the ability of their students with disabilities, including those with VI who may have additional learning needs. The study used the expertise of specialist teachers to help provide other teachers with a framework for the monitoring of learning in an intersectional area of challenge for many teachers – teaching students with disabilities, and teaching digital literacy. This paper reported on the preliminary findings of the study, which indicated that the measure and its related outputs can have strong arguments made for their validity, due in part to the high quality of the instrument and the endorsement of expert specialist teachers.

As the study is still active, it is hoped that by continuing to draw on the wisdom of such teachers, as well as the research, to identify teaching strategies linked to each level of the learning progression, all teachers with students with disabilities, including students with VI who may have additional learning needs, can be helped to recognize and develop the digital literacy capability of their students.

Acknowledgments

This study is being undertaken at the Assessment Research Centre (ARC), located at the Melbourne Graduate School of Education. It is supported by University of Melbourne and the Australian Research Council through a Linkage Grant, with the Victorian Department of Education and Training (DET) as the Industry Partner in the Linkage Grant. The lead author expresses her gratitude to her supervisors Dr. Kerry Woods, Dr. Shiralee Poed, and Emeritus Professor Patrick Griffin, her colleagues at the ARC, the schools and teachers in the trial, and DET.

REFERENCES

- [1] P. Griffin, B. McGaw, & E. Care, *Assessment and Teaching of 21st Century Skills*. Springer, 2012.
- [2] Z. Li, N. Griffin-Shirley, P. Kelley, D. R. Banda, W. Y. Lan, A. T. Parker, & D. W. Smith, "The relationship between computer and internet use and performance on standardized tests by secondary school students with visual impairments," *J. Visual Impairment & Blindness*, vol. 106, no. 10, pp. 609-621, 2012.
- [3] E. C. Bouck, N. K. Meyer, G. S. Joshi, & D. Schleppebach, "Accessing algebra via MathSpeak™: Understanding the potential and pitfalls for students with visual impairments," *J. Special Education Technology*, vol. 28, no. 1, pp. 49-63, 2013.
- [4] K. Woods & P. Griffin, "Judgment-based performance measures of literacy for students with additional needs: Seeing students through the eyes of experienced special education teachers," *Assessment in Education: Principles, Policy & Practice*, vol. 20, no. 3, pp. 325-348, 2013.
- [5] G. Masters, "A Rasch model for partial credit scoring", *Psychometrica*, vol. 47, pp. 149-174, 1982.
- [6] Australian Education Union, *Submission to the Senate Inquiry into current levels of access and attainment for students with disability in the school system and the impact on students and families associated with inadequate levels of support*. <http://www.aeufederal.org.au/application/files/3614/4158/9165/DisabilityAccess2015.pdf>, 2015.
- [7] Victorian Equal Opportunity and Human Rights Commission, *Held back: The experiences of students with disabilities in Victorian schools*. <http://apo.org.au/research/held-back-experiences-students-disabilities-victorian-schools>, 2012.
- [8] S. McCoy & J. Banks, "Simply academic? Why children with special educational needs don't like school," *European J. Special Needs Education*, vol. 27, no. 1, pp.81-97, 2012.
- [9] V. S. M. Soman & K. G. P. Sudhier, "Information needs of hearing impaired students: A case study of government VHSS for Deaf, Thiruvananthapuram," *SRELS J. Information Management*, vol. 52, no. 2, pp. 111-117, 2015.
- [10] C. Kerr, B. McDowell, & S. McDonough, "The relationship between gross motor function and participation restriction in children with cerebral palsy: An exploratory analysis," *Child: Care, Health and Development*, vol. 33, no. 1, pp. 22-27, 2006.
- [11] K. de Verdier & U. Ek, "A longitudinal study of reading development, academic achievement, and support in Swedish inclusive education for students with blindness or severe visual impairment," *J. Visual Impairment & Blindness*, vol. 108, no. 6, pp. 461-472, 2014.
- [12] United Nations (UN), *Report on the United Nations expert meeting on building inclusive societies and development through promotion of accessible information and communication technologies (ICTs): Emerging issues and trends*. United Nations Information Center, 2012.

- [13] Australian Government Department of Education, Employment and Workplace Relations, *Report on the Review of Disability Standards for Education 2005*. http://foi.deewr.gov.au/system/files/doc/other/report_on_the_review_of_disability_standards_for_education_2005.pdf
- [14] P. A. Ertmer, A. T. Ottenbreit-Leftwich, O. Sadik, E. Sendurur, & P. Sendurur, "Teacher beliefs and technology integration practices: A critical relationship," *Computers & Education*, vol. 59, no. 2, pp. 423-435, 2012.
- [15] J. Janssen, S. Stoyanov, A. Ferrari, Y. Punie, K. Pannekeet, & P. Sloep, "Experts' views on digital competence: Commonalities and differences," *Computers & Education*, vol. 68, pp. 473-481, 2013.
- [16] S. Prestridge, "The beliefs behind the teacher that influences their ICT practices," *Computers & Education*, vol. 58, no. 1, pp. 449-458, 2013.
- [17] P. Griffin, "Profiling literacy development: Monitoring the accumulation of reading skills," *Australian J. Education*, vol. 43, no. 2, pp. 290-311, 1990.
- [18] P. Griffin, P. G. Smith, & L. Martin, *Profiles in English as a second language*. Robert Andersen & Associates, 2003.
- [19] P. Griffin, P. G. Smith, & N. Ridge, *The literacy profiles in practice: Toward authentic assessment*. Heinemann, 2001.
- [20] K. Woods, *The design and validation of measures of communication and literacy to support the instruction of students with learning disabilities*. (Doctoral Thesis). University of Melbourne, 2010.
- [21] B. Coles-Janess & P. Griffin, "Mapping transitions in interpersonal learning for students with additional needs," *Australasian J. Special Education*, vol. 33, no. 2, pp.141-150, 2009.
- [22] E. Roberts & P. Griffin, "Profiling transitions in emotional development for students with additional learning needs," *Australasian J. Special Education*, vol. 33, no. 2, pp.151-161, 2009.
- [23] S. E. Dreyfus, & H. L. Dreyfus, *A five-stage model of the mental activities involved in directed skill acquisition*. University of California – Berkeley, 1980.
- [24] L. L. Thurstone, "The method of paired comparisons for social values," *J. Abnormal and Social Psychology*, vol. 4, pp. 384-400, 1927.
- [25] T. Kubiszyn & G. Borich, *Educational testing and measurement*. Harper Collins, 1993.
- [26] J.-E. Gustafson, "Testing and obtaining fit of data to the Rasch model," *British J. Mathematical and Statistical Psychology*, vol. 33, no. 2, pp. 205-233, 1980.
- [27] B. D. Wright & M. H. Stone, *Best test design*. MESA Press, 1979.
- [28] B. D. Wright, "Which standard error? Item-specific or general? Ideal or real?," *Rasch Measurement Transactions*, vol. 9, no. 2, p. 436, 1995.
- [29] B. D. Wright, J. M. Linacre, J.-E. Gustafson, & P. Martin-Lof, "Reasonable mean-square fit values," *Rasch Measurement Transactions*, vol. 8, no. 3, p. 370, 1994.
- [30] J. M. Linacre, "When to stop removing items and persons in Rasch misfit analysis?," *Rasch Measurement Transactions*, vol. 23, no. 4, p. 1241, 2010.

Non-verbal communication

Roselinde Strosse and Laurence Foulon

Spermalie, vzw De Kade, school intervention team,
Bruges, Belgium
{laurence.foulon, roselinde.strosse}@de-kade.be

ABSTRACT

Visual information dominates our daily lives more and is having an increasing influence on our lives. The impact on the life of the blind and visually impaired is substantial.

We want to demonstrate the effect of this evolution on the non-verbal behaviour. This behaviour provides us with a lot of information about conversations and interactions. The blind and the visually impaired are not able to perceive (subtle) non-verbal communication. Being unable to see how others respond can have a great impact on understanding the effects of one's behaviour. This could result in social isolation, misconception and loneliness.

To demonstrate the impact on social life and the school environment, we'll make use of a testimony of a young adult. The difficulties she experiences during breaks at school or the challenge of having a (romantic) relationship are two examples that show the importance of non-verbal communication. The testimony will be alternated with a solution-orientated approach, by offering tips and tricks regarding social skills for the visual impaired. The environment can have a positive influence as well, for instance by being subtly supporting. We will also demonstrate this with "dos and don'ts", tips and tricks.

We'll give an oral presentation that allows us to emphasize the importance of awareness of the challenge of good communication.

1. INTRODUCTION

The impact of a visual impairment on communication is substantial, though not predominant. The personal identity has at least an equally important influence on social interactions.

Obviously little tips and tricks are essential and can make a world of difference. Therefore we would like to share our findings with young adults to coach them into fulfilling interpersonal communication.

2. WORKSHOP

First, we share some statistics about the different elements of communication. Next, we will discuss the role of identity on communication and the importance of self-esteem.

The confidence you have in your own abilities defines the way you communicate. It's important that the centre of the interaction lies in the inner self and not in the visual impairment.

Our intention is to give insight in the use of non-verbal communication as well as providing youngsters concrete tools to detect information given by non-verbal communication. Our goal is to let the adolescents reflect on their own communication skills, and to think proactively about how to compensate the loss of visual cues in daily communication.

2.1 Facts

Research indicates that 55% of communication is visual (body language), 38% vocal (how you say it) and 7% verbal (what you say).

Therefore, body language has the leading role.

Remarkable!

To prevent miscommunication, caution is recommended.

This emphasizes the importance of being aware of the non-verbal part of communication. So, for the visual impaired, some sort of education is indispensable. An example that demonstrates this value is when there's inconsistency between the non-verbal elements and the words you use. People are inclined to trust on body language!

2.2 Role of identity

Not only rational intelligence but also emotional intelligence is needed for interpreting non-verbal elements. Therefore, regarding non-verbal communication we must keep the whole identity in mind.

We differentiate several components in one's identity when we consider communicative interaction. The following parts of the visual impaired communicator play an important role: of course the visual impairment itself. Also, someone's body awareness (tension always reflects in communication), skills and personal challenges, emotional triggers (of very profound influence on communication), values and beliefs, context. Finally, there are the typical personal characteristics such as internal or external reference.



Figure 1. This figure demonstrates the different aspects which influence communication

2.3 Testimony

Inge is a self-conscious woman, driven by awareness for interpersonal communication. Her congenital blindness enables her to develop communication skills, which compensate the visual aspect. She's committed to share her vision and experience through workshops. In her testimony she shares her insights regarding limitations and possibilities according to communication.

2.4 Tips and tricks

We give tips and tricks from different perspectives. We focus on the visual impaired communicator equally as on the network around the visually impaired.

The social network plays an important role for the visually impaired. Giving them honest and sensitive feedback about their social skills enables them to have insights in their behaviour. Furthermore, they need to learn appropriate social skills, like turning their face to the speaker to maintain social interaction.

It's important that the visually impaired accepts and responds appropriately to suggestions and corrections from their social network. Additionally, they need to be prepared to answer questions about their disability and the consequences (like not being able to see facial expressions). In an interactive moment with the audience we reflect on a variety of non-verbal signals.

3. CONCLUSIONS

The main goal of our workshop is to enhance the concept of non-verbal communication and its impact for the visually impaired. Through testimonies and interactive moments, we have illustrated that although its role is substantial, non-verbal communication must be seen broader than that. One's identity plays an important role, try not to focus on the visual impairment but take a proactive

role in communication and realize that even sighted people do not have everything about non-verbal communication under control.

REFERENCES

- [1] Keppens, G., & Piotrowski, I. (2011). Syllabus vormingsdag presentatie en communicatie op de werkvloer.
- [2] Willings, C. (n.d.). Non-verbal communication. Retrieved from <http://www.teachingvisuallyimpaired.com/non-verbal-communication.html>
- [3] Vandamme, R. (2009). De Vork
- [4] Erickson, J. (2008). Communiceren zonder blokkeren.
- [5] Merlevede, E. & Vandamme, R. (1999). 7 lessen in emotionele intelligentie.

Mindfulness-based treatment for persons with a visual impairment or visual-and-intellectual disability

Hannelies Hokke¹, Paula Sterkenburg^{1&2}

¹Bartiméus, department of psychotherapy, Doorn, the Netherlands
hhokke@bartimeus.nl / psterkenburg@bartimeus.nl

²Vrije Universiteit Amsterdam, Clinical Child and Family Studies, Amsterdam, The Netherlands
p.s.sterkenburg@vu.nl

ABSTRACT

Recently there is more scientific support for the positive effect of mindfulness-based treatments. Mindfulness appears to be effective in the treatment of anxiety, stress and pain. In this presentation we will focus on mindfulness for persons with a visual impairment or visual-and-intellectual disability who experience high levels of stress. We will present best practices as well as results from our pilot study (N=2) on the effect of mindfulness for persons with visual-and-intellectual disabilities. The pilot study indicated that persons with visual-and-intellectual disabilities also benefit from mindfulness as it reduced stress and improved their well-being. The results showed that there is a decrease in aggression and anxiety. The effects of mindfulness training for the caregivers were also examined and indicated that the self-efficacy of the caregivers increased after the training.

1. INTRODUCTION

For some time now there is a growing interest for mindfulness. Scientific research indicates that mindfulness is an effective treatment for people with depression, anxiety and stress. In the past years there is also a growing interest in the effect of mindfulness for persons with an intellectual disability. At the department of psychotherapy of Bartiméus, an organization providing care for persons with a visual impairment or visual-and-intellectual disability, we examined the effectivity of mindfulness using a single case study design. We were interested whether mindfulness would improve the wellbeing of persons with visual-and-intellectual disabilities. Furthermore, we examined the self-efficacy of a client centered mindfulness training for their caregivers.

2. METHOD

The research design was a single case study (N=2) [1]. The participants were two persons with a visual impairment and a moderate intellectual disability. Both participants were 49 years of age and lived in a grouphome. Both participants had psychological and psychiatric problems, high levels of stress and they could not cope with stress (aggression / outbursts of anger and frustration). Mindfulness sessions were offered to the clients and their caregivers participated in a client-related mindfulness

training. The clients received individual one-hour mindfulness sessions every week over a period of 4 months. The caregivers received one two-hour group-session every month, over a period of 5 months. During these sessions information was given on mindfulness and on a basic mindfulness attitude when the client has outbursts of anger/frustration.

The sessions for clients as well as for caregivers were based on Mindfulness Based Stress Regulation (MBSR) developed by Kabat-Zinn [2]. Singh et al. [3] reported on mindfulness exercises for persons with intellectual disabilities, which were also included in the sessions.

The clients were taught through easy to understand and shortened exercises to learn the core elements of mindfulness (e.g. being in this moment in a friendly manner). At home they could do exercises with a CD made especially for them. Later on they learned with help of the caregiver to use mindfulness during moments of stress.

The training for the caregivers contained exercises of mindfulness to understand how the clients could use mindfulness and also to stay in tune (mindful) in their own work with all the clients. Furthermore, they learned to notice upcoming stress and learned to use mindfulness skills to help their client regulate their stress.

Research instruments were: the Clinical Outcomes in Routine Evaluation- Outcome Measure (CORE) [4], the Dutch General Self-efficacy Scale [5] and the Social Validity Scale [6].

3. RESULTS

In this single case study we found that the non-parametric Friedman Test for independent variables indicated a significant change ($X^2 = 11.15$, $p = .011$). The Reliable Change Index (RCI) indicated that the change is reliable ($z = 28.38$, $sd\text{-error}=1.014$; $RCI > 1.96$). It indicates a clinically relevant improvement. These results indicate an improvement over all the scales and that the wellbeing of the participants improved significantly. Feelings of anxiety as well as aggression diminished.

The Repeated Measure ANOVA for self-efficacy for the caregivers indicated a significant positive increase in self-efficacy ($F(2, 3) = 16.18$, $p = .025$). This indicates a significant improvement of the self-efficacy of the caregivers.

Both clients were very positive about the mindfulness session. They noted that they found it quite easy to do the

exercises and that they use the skills in practice. One client noted that he would advise others to participate.

Caregivers indicated that they were very positive about the training. They noted that they could recognize upcoming stress more easily. Although they found it difficult to use the mindfulness skills in practice, they indicated that it supports them in their daily caregiving (more self-efficacy). They are very positive about the use of mindfulness by their clients.

4. CONCLUSION

This single case study shows the positive effects of mindfulness for persons with a visual-and-intellectual disability. The mindfulness sessions contributed to a drop in anxiety and aggression and improvement in well-being. Caregivers felt more confident in their caregiving and support towards their clients (increased self-efficacy) as well as in their mindful attitude. As this study can be seen as a pilot study further research is needed to examine the effect of mindfulness for persons with a visual-and-intellectual disability and of the training given to their caregivers.

Acknowledgments

We thank the participants and caregivers for participating in this study. We want to acknowledge the work done by Pieterneel Lievense, MA in Developmental Psychology, for her contribution in collecting and analyzing the data.

5. REFERENCES

- [1] P. Lievense, H. Hokke, and P. Sterkenburg. "Pilotstudie naar de effecten van mindfulness voor mensen met een visuele en matige verstandelijke beperking en hun begeleiders". *Onderzoek en Praktijk*, 12(2), 7-18. 2014.
- [2] J. Kabat-Zinn. "*Full catastrophe living: using the wisdom of your body and mind to face stress, pain and illness*". New York: Delacorte. 1990.
- [3] N.N. Singh, G.E., Lancioni, B.T. Karazsia, A.S.W. Winton, R.E., Myers, A.N.A. Singh, A.D.A. Singh, and J. Singh. Mindfulness-Based Treatment of Aggression in Individuals with Mild Intellectual Disabilities: A Waiting List Control Study. *Mindfulness*. 1-10, 2012.
- [4] J. Conell, M. Barkham, W.B. Stiles, E. Twigg, N. Singleton O. Evans, and J.N.V. Miles. Distribution of CORE-OM scores in a general population, clinical cut-off points and comparison with the CIS-R. *British Journal of Psychiatry*, 190, 69-74, 2007.
- [5] B. Teeuw, R. Schwarzer and M. Jerusalem. *Dutch adaptation of the general perceived self-efficacy scale*. 1994. See: <http://userpage.fu-berlin.de/~health/dutch.htm>

- [6] D.M. Seys. *Kwaliteit van zorg: Zorg voor kwaliteit. Dissertation*. Nijmegen: Katholieke Universiteit Nijmegen. 1987.

A Visual Impairment Is Not Just About Seeing And Watching. Get A View On The Different Aspects And Dimensions Of The Emotional Process.

Heidi Deknudt

Blindenzorg Licht en Liefde
Gent, Belgium
h.deknudt@sintrafael.be

ABSTRACT

When you get a visual impairment, this requires an adjustment. One can consider this as a specific process of bereavement. In this presentation, I will explain different aspects of this emotional process:

- What is the impact of bereavement on the five different dimensions of life?
- A 'normal' process is an oscillation between two movements: a movement towards the processing of the loss (with the risk of depression when one gets stuck in this) and a movement towards recovery (with the risk of delayed bereavement when one gets stuck).
- Acceptance versus adaptation.
- The pattern of attachment and the influence this gives on maintaining relationships, on the acceptance of help, ...
- Risk of depression.
- Possibilities of and conditions for personal growth.

This workshop is meant for professionals who want to get a better view on the emotional aspect of the visual impairment and who want to get to learn about some possible angles to understand and guide (stranded) emotional processes. It is meant both for professionals and for psychotherapists.

Keywords:

Emotional process, adaptation and acceptance, depression, personal growth, attachment, psychotherapy.

1. INTRODUCTION

In this presentation there will be given information about the emotional adaptation process when one has to deal with a visual impairment.

Copyright: © 2017 Deknudt Heidi. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

This presentation is the result of a collaboration with the VU Amsterdam (The Netherlands) where Van Nispen R. set up a research about stepped care for visual impaired older (55+) patients with anxiety or depression. In this workshop I will give information about possible interventions in a gradual manner ('stepped care') and about the dynamics of such an emotional process. In the autumn of 2017 we will start in Flanders with a training with different workshops for people who have to deal with this, based on the information in this workshop.

In this model, there are four phases. After a period of watchful waiting (phase 0), which is mostly the waiting time between question for help and the first visit of the social worker, one can address the own resilience of the person. When there is no progress in the emotional process, there are gradually more intensive interventions the caregiver can do. In a last phase, when this doesn't help enough, the client is referred to a psychotherapist or to a doctor for medication, in the best case, there is a combination of these two.

During the first phase (addressing own resilience) it is very important that the client gets the chance to tell and retell his or her story. By telling, one can recuperate and see things in perspective. Often there is a spontaneous adaptation. Adaptation is the sum of assimilation (changing one's own opinions, thoughts,...) and accommodation (changing the environment). Important factors in this process are the (absence of a) social network, the capacities and coping mechanisms, a resilient way of coping,... Psycho-education about grief is very important, the process of losing your sight/your eyes affects your being in all aspects: bodily, emotional, behavioral, relational and on the domain of giving of meaning/belief/spirituality. Points of attention can be the regaining of control, of self-esteem and of perspectives for the future. Often the sense of fairness is damaged: 'Why does this happen to me?'

In the psycho-education, one can refer to the dynamics of a process, this can give some hope and perspective: there will come a moment when the pain is less and when there are other/new perspectives, next to the loss. There are different models to explain this. Former models are those of Kubler-Ross and Worden. These models give perspective for the client (there will be a period where I feel better), but acceptance is very difficult, it is better to speak in terms of adaptation of the loss. When it is a gradual loss of the sight (progressive eye disease), this gets more complicated of course. Another model that can

be explained is the dual process model of Stroebe and Schut. In a grief process there is a loss-orientation (the pain, the sadness, the feeling of dependency,...) and a restoration-orientation (life goes on, one has to learn again to cook, to use the bus, to ask for help,...). A 'normal' grief process exists in the oscillation between these two poles.

When the social worker/occupational therapist sees that the client doesn't make progress in the emotional process, there are specific points of attention for the caretaker. Involving the family members in the psycho-education can be very helpful, to normalize the feelings of the client, but also of the family members. For them too, it is an adaptation. By learning new skills (computer, mobility, ADL, Braille,...) the client gets hope and new perspectives. It also helps to maintaining or building up a social network, although this can be a difficult one if there was no network before. Relaxation exercises can help to learn how to stop depressive thoughts and anxiety. The caretaker can help the client to give attention to and dare to dream about positive things.

When one sees the process blocks, the caregiver can do specific interventions (phase 3). When referred to the dual process-model, one can see that a lack of oscillation between the two poles means a blockage. When the client gets stuck in the loss oriented pole, there is a risk of chronic grief, in the other case (restoration oriented) there is a risk of denied or delayed grief.

As a person with an impairment, you get more dependent from other people, this comes back to the attachment *strategy*. Someone with a secure attachment can ask for help, there is trust and reciprocity, however it is difficult. Someone with an anxious-preoccupied attachment wants to be completely emotionally intimate with others, they feel themselves dependent on others. Someone with a dismissive-avoidant style of attachment wants to be independent and prefers not to ask for help.

There can be extra attention given on the maintaining or building up of a social network. Besides of that, also the question of identity (who am I, who can I become, how can I be of worth for other people?) can be a theme in the process with the care-giver. This can also imply personal growth, choosing other priorities, valuing other things,...

When a client doesn't go on in the emotional process of adapting to the loss of vision, a referral to a psychotherapist and/or doctor (phase 4) can be important.

REFERENCES

Maes J., Modderman, H. (red.) (2014). *Handbouw Rouw. Rouwbegeleiding. Rouwtherapie*. Tiel: Witsand.

Stroebe, M. (2009). *Beyond the broken heart: mental and fysical health consequences of losing a loved one, oratie*. Utrecht: Universiteit Utrecht.

Neimeyer (ed.) (2002). *Meaning reconstruction and the experience of loss*. Washington: APA.

Measuring the effect of functional rehabilitation on quality of life

Sophie Demoustier, Stéphanie Demartin

Œuvre Fédérale Les Amis des Aveugles et Malvoyants, Ghlin, Belgique

s.demoustier@amisdesaveugles.org

s.demartin@amisdesaveugles.org

ABSTRACT

Visual loss irremediably affects the sensory integrity and leads to a loss of global autonomy as well as counts of consequences in the social and professional standing. Several studies demonstrate the presence of a depressive character related to the visual impairment which would increase proportionally with the change of quality of life when visual loss is perceived as a major source of interference in daily life.

In this context, functional rehabilitation aims to increase autonomy and quality of life by the implementation of adaptations and compensation mechanisms. It seems useful to analyze the question of the evaluation of the quality of life during this rehabilitation process in order to access to the way in which the person is experiencing his or her visual impairment and to measure the impact of Functional rehabilitation on quality of life, through the process of adjustment to the disability that the person will put in place.

The assessment, approaching the person in its real-life experience, its feelings and individuality and singularity, allows the professionals to get closer to patients by taking into account their physical and psychic state and their therapeutic wishes.

Nevertheless, few questionnaires are specific to the quality of life in ophthalmology or focus only on the objective side of its appreciation. Based on the criteria commonly attributed to these scales (physical, psychological, social, somatic), we have therefore intended to build a scale to meet the specific needs of a functional rehabilitation center. The purpose of this presentation is to present the assessment tool, its construction and the resulting observations.

1. INTRODUCTION

As part of its integrated service offering the federal association «Les Amis des Aveugles et Malvoyants» established, in 2003, a functional rehabilitation center proposing a multidisciplinary therapeutic support aiming at the improvement and the increase of the autonomy of the person in various fields.

For several years, a reflection has been conducted around the ways favoring the consideration of the person with visual impairment in its individuality and singularity. Several tools at our disposal,

among which the clinical examination in ophthalmology, initial assessment (interview led by an occupational therapist and a psychologist), the evaluation of the functional vision, etc. However, we raised the need of developing a tool which would allow us to better understand the person, on the functional and socio-psychological plans, in order to adjust as closely as possible to its needs in terms of Quality of life, our therapeutic actions.

2. GENERAL INFORMATION

Functional rehabilitation is a process oriented to the improvement of the quality of life of the person through the installation or the recovery of satisfactory functional capacities allowing an optimal adjustment to the handicap. Quality of life in the field of disability is a concept arousing the interest of many researchers. The concept is quite broad and there is a plethora of definitions so much there are parameters that can be included. However, we can commonly admit that it is about a concept approaching the notion of well-being and satisfaction in the areas of the physical, psychic and social life of the person. Furthermore, there is a consensus on certain characteristics: the multidimensionality, the complementarity of the objective and subjective side, the positive or negative valence (some scales are centered on the losses) and the intra- and inter-individual variability.

3. RESEARCH QUESTION AND OBJECTIVES

What is the impact of the functional rehabilitation on the improvement of the quality of life for people affected by visual impairment?

The aim of our research is the implementation of a quality of life questionnaire adapted to the specific situation of functional rehabilitation, the objective of which will be to reach a better understanding of the situation of visual impairment of the person, and by this way, to place it at the heart of the rehabilitation process. Indeed, thanks to this tool, we could individualize our accompaniment but also place the patient in relation to his rehabilitative approach.

4. ELABORATION OF THE TOOL

Quality of life model

In order to define the evaluation criteria of our scale, we based ourselves on existing references, in particular on the study of the Dr. N. Letzelter (LETZELTER, 2001), which presents a diagram highlighting the importance of the correlation between the objective (clinical field of action) and the subjective aspect (emotional and functional aspects) of the quality of life.

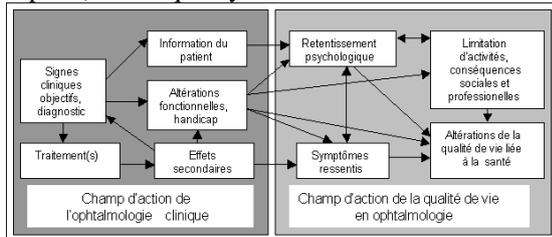


Figure1. Diagram of the relationship between clinical ophthalmology and quality of life.

The model of the Dr. R. Schalock also strongly inspired us; the measurement criteria appeared to us relevant to the field of application that concerns us. We also used existing questionnaires such as the Life Cycle Measurement Scale (MHAVIE 4.0), the National Eye Institute Visual Functioning Questionnaire-25 (VFQ-25), the SF36 generalist questionnaire, the inventory Beck Depression Abstract, Hamilton Anxiety Assessment Scale, Rosenberg Self-Esteem Scale, Tarragona Anxiety Scale.

Methodology

A review of the existing literature and tools led to the conclusion that most of the available questionnaires focus essentially on the objective dimension of quality of life measurement and that few of them are actually specific to the visual impairment and in the functional rehabilitation process. Thus, the ADA-SD2 quality of life questionnaire therefore considers these dimensions in its constitution. The criteria which we held to reach this goal are:

The daily functioning and the autonomy	Feeding in general, personal and health care management, housing management and adaptation, responsibilities, access to leisure activities
Mobility	Autonomy in mobility, control of the technical aids for the travels, anxiety linked to displacement
Access to information and communication	Access to reading, culture, administrative management, computing, ability to hold a conversation
The professional and educational sphere	Access to a professional activity, follow a training
Physical well-being	General health, general vision, pain
Psychological well-being	Psychic health and psychic health in relation to vision

Social integration and interpersonal relationships	Social life, family life, marital life, capacity to enter into relationship with others considering the vision
Learning and the integration of new concepts	Personal Skills and performance

The subcategories included aim to facilitate the data processing and to being able to target an individual quality of life profile based on the answers of the persons, but also a one level of satisfaction with regard to specific items.

5. RESULTS

The targeted population concerns adults presenting a visual, partial or total, acquired or congenital impairment, registered in a functional rehabilitation program.

The evaluation of the quality of life carried out at various moments of the program, at the beginning, during and at the end of the therapeutic course, allows measuring the effect of functional rehabilitation programs on the visually impaired person.

Globally, the obtained results demonstrate that the rehabilitation activities decrease the impact of visual impairment on the activities of daily living and increase the level of quality of life.

6. CONCLUSION

When severe visual impairment is established and clinical ophthalmology can no longer respond to it, the functional rehabilitation joins in a complementary way the medical approach. Its objective is to limit the functional consequences of visual impairment and thus to improve the autonomy and quality of life of the not and partially-sighted persons. Nevertheless, the effect of the interventions must be objectified in their ambition to favor adjustment to the disability, the autonomy and the quality of life.

The specific assessment grid in the quality of life within the therapeutic framework seems to be able to approach the objective and subjective aspects of quality of life in ophthalmology.

RÉFÉRENCES

- [1] Dr N. Letzelter, « Les Etudes de qualité de vie en ophtalmologie : intérêt et application concernant la cataracte, le glaucome chronique à angle ouvert et la dégénérescence maculaire liée à l'âge », *ill.*, 2000
- [2] R. Shalock, « La qualité de vie : conceptualisation, mesure et application », *Revue francophone de la déficience intellectuelle*, vol. 4, no. 2, pp. 137-151, 1993
- [3] R. Shalock, E. Faulker, « Validation croisée d'un modèle contextuel de la qualité de vie », *Revue Européenne du handicap mental*, vol. 4, no.14, pp. 18-28, 1997

The Role of “Gender”, “Islam”, and “Turkish Culture” on Independence of individuals with Visual Impairments

Onder Islek¹,

¹Aksaray University, Department of Special Education,
Aksaray, Turkey

ABSTRACT

Through my personal experiences as a person with visual impairment (VI) within the Turkish education system, as well as my further education studies and professional work in Turkey, the USA and England, I became interested in how the education system prepares students with VI for life after school. This related to the formal qualifications students may achieve, but also concerned broader outcomes related to employment, independence, inclusion in the community and general life fulfilment. Such a focus arguably cuts to the very essence of what an education system is for, and how schools should serve students with a VI. This interest guided me to develop an *exploratory study which is seeking to explore the perspectives of young adults with VI, and educators who are serving students with VI in order to determine:*

- the experienced balance of the curriculum content (Expanded Core Curriculum vs. academic curriculum)
- the direct and indirect consequences of this experienced curriculum balance on lives of individuals with VI
- the ideal curriculum balance should be available for students with VI
- the barriers to and enablers for the implementation of a balanced curriculum
- other factors influence the independence of individuals with VI (other than the ECC and associated teaching)

The exploratory study gathered evidence from twelve young adults with visual impairments and thirteen educators who are serving students with VI in Turkey via semi-structured interviews to answer the research questions.

This study revealed important issues regarding the existing Turkish education system especially in promoting independence of individuals with VI. Although these findings show similarity with main stream literature, there are unique findings. This paper will focus on these unique findings, especially will provide a summary of the key findings on the role of “gender”, “Islam” and “Turkish culture” on independence of individuals with VI which is anticipated to assist researchers and practitioners in developing a deeper understanding of unique needs and challenges faced by students with VI who are coming from Islamic background.

1. INTRODUCTION

This short paper is aiming to discuss the role of gender, religion and other cultural values on independence of females with visual impairment in Turkey. This paper is based on my PhD thesis which investigated the educational curriculum experienced by students with visual impairments in Turkey (see Islek, 2016). The study made a distinction between the traditional academic curriculum and the concept of an ‘Expanded Core Curriculum’ (ECC) which includes a range of disability-specific areas (e.g. Mobility, Braille), and aimed to determine the balance of the curriculum experienced by individuals with visual impairments in Turkey. The study specifically examined the barriers to, and enablers for, an appropriate curriculum balance which would develop individuals’ independence. The study made use of an exploratory inductive research approach implementing a cross-sectional research design. Mixed method measures were drawn upon to capture the views of twelve young adults with visual impairments and thirteen educators of children and young adults with visual impairments who had a wide range of schooling and teaching experiences across Turkey. The analysis revealed an emphasis on teaching the academic curriculum with relatively little attention given to ECC. As a consequence, it was found that individuals with visual impairments were not fully prepared to be independent and encountered a number of barriers including: remaining dependent on others; isolation; and psychological challenges in their everyday life. A number of barriers to the teaching of ECC were revealed, including: educational policy priorities in Turkey which give little or no remit to teaching a broader curriculum (teachers were fixed upon teaching the inflexible academic curriculum); little resource is given to specialist teaching support in mainstream schools; and specialist teacher training appears not to align to the educational context in which they work. Finally, the research identified other barriers to developing an individual’s independence which are beyond the teaching of ECC, including inaccessible environments and equipment, and inadequate accommodations and adjustments but this paper is especially focusing on role of gender, religion and cultural values on independence..

2. METHOD

The exploratory study gathered evidence from twelve young adults with visual impairments and thirteen educa-

tors who are serving students with VI in Turkey via semi-structured interviews to answer the research questions.

3. DISCUSSION

The analysis suggests that the existing services do not pay much attention to the ECC, and that an appropriate balance between the academic curriculum and ECC has not been achieved, even in schools for the blind. As a consequence of poor ECC training, individuals reported facing challenges in everyday life, including developmental delays, unpleasant schooling, becoming dependent on others, isolation, psychological and emotional challenges, low self-esteem, problems with health and safety, and lower academic attainment. Moreover, Female participants with total blindness presented the most distressing cases among the participants because they were the ones who were strictly prohibited from doing a variety of tasks in everyday life (e.g. leaving their homes).

In many Western cultures, there is a strong belief “in the inherent separateness of distinct persons” (Kitayama & Markus, 2000) and therefore, the imperative of this culture is to become independent from others and to discover and express one’s unique attributes (Kitayama & Markus 2000; Kitayama & Park, 2013; Markus & Kitayama, 2000; Miller, 1988). In contrast, in Asian culture instead of being “independent” being “interdependent” is more valued (Kitayama & Park, 2013). In Asian culture, “people are motivated to find a way to fit in with relevant others, to fulfil and create obligation, and in general to become part of various interpersonal relationships” (Kitayama & Markus, 2000, online). Even among the most rapidly modernising sections of the Asian population “there is a tendency for people to act primarily in accordance with the anticipated expectations of others and social norms rather than with internal wishes or personal attributes” (Markus, & Kitayama, 2000, online). Since the majority of Turks consider Asia as their motherland, I would expect them to place more value on interdependence rather than independence. Indeed, based on my personal experience whilst living in the USA, Turkey and England, I think this view of themselves and others is manifested in the everyday life of most Turks.

The exosystems layer sees life in a broader context and covers the wider community in which a person lives (Bronfenbrenner, 2005). As an important layer of the environment, society was one of the most important factors in influencing the independence of individuals with a visual impairment. Participants with a visual impairment found the “inappropriate reactions and interactions of society” to be one of the most frequent barriers to their independence. For instance, participants reported that when they go out others’ looks and questions bother them and discourage them from doing a variety of tasks which would identify them as being visually impaired, such as using a cane. Therefore, they reported that they avoided asking for help or using devices which may have revealed their visual impairment – even when they were needed badly. Similarly to participants with a visual impairment,

the educators stated that society’s lack of awareness and the negative approaches and reactions from the public hindered the development of independence by the individuals with visual impairments. This is supported by Yazıcı et al.’s (2015) findings: society is not very knowledgeable about people with visual impairments and people often make comments and ask questions which bother individuals with a visual impairment and their parents.

When I considered possible reasons for such negative attitudes towards people with disabilities, it seemed important to me to consider the dominant religion in Turkey. In Islam, “everything revolves around one powerful character called ‘Allah’ (God)” (Turmusani, 2008, p.76) and Allah is perfect in all aspects, including power and physical character (e.g. seeing, hearing, walking etc.); therefore, those who have difficulties with these aspects (i.e. are disabled) are not considered normal and are viewed as being less of a person and different (Turmusani, 2008, p.76). Turmusani (2008) examined the holy book, and he identified a number of references which portrayed people with impairments in negative ways, and often associated them “with evil-doers, unbelievers, and even beasts, and others” (p.77). Likewise, Turmusani (2008) claimed that Islamic enemies are frequently portrayed with physical disfigurements. For instance, those who will loot the holy place in Mecca are described as having short legs; likewise, Al-dajal (similar to the ‘Antichrist’ in Christianity) is also described as being a short man with one eye (p.77). Similarly, those with low intellectual abilities are described as being devious. “The time when deaf and dumb people become able to take part in public affairs” is given as a sign of the end of days (Turmusani, 2008, p.78). Naturally, Turmusani (2008, p.77) concludes that such representations have “served to perpetuate negative attitudes and discriminative practices towards people with a disability in their societies”. Therefore, some negative attitudes experienced by people with visual impairments can be linked to religious teaching and their interpretation of religion and other cultural values in Turkey.

On the other hand, Lutfu, a deputy head of a school for the blind, made an interesting point. Unlike in many western cultures, he argued that in Turkey people are willing to help people with disabilities without being prompted. This seemed to be linked to the Islamic belief regarding disability and people with disabilities. In addition to the negative views, it is widely accepted that people with a disability are subject to a faith test by Allah and if they pass this test they will be rewarded by Allah. In fact, several Qur’anic and Hadith narrations indicate that Allah promises both those who are in a disadvantaged situation, and those who take care of them, that they will be rewarded both in this life and in the hereafter for their patience (Al-Aoufi, et al. 2012). More specifically, Prophet Mohammed stated that whoever guides someone who is blind in both eyes for 40 steps will be rewarded with heaven (Özçelik, 2010). Indeed, this promise usually motivates people to support the disadvantaged, whether they are strangers or close relatives. Therefore, under these conditions it is not surprising that,

in Turkey, people with disabilities are offered help by strangers around them without first requesting it.

Nevertheless, although Lutfu considered this help to be an enabler rather than a barrier to their independence, individuals with a visual impairment sometimes complained about these attitudes. It is possible that Lutfu considered this support to be an enabler because he thinks some individuals might find travelling easier with it. Nevertheless, as Shakespeare (2006) pointed out, such charitable support can have unwanted consequences on the lives of people with disabilities since it causes dependence and inequality. Moreover, this support might devalue and discourage self-motivation amongst individuals with disabilities (Oliver & Barnes, 1998). Equally, society may think all individuals with a visual impairment need their help and cannot become independent. This view may contribute to developing further negative bias and devaluing due to perceiving them as incomplete people. Finally, such charitable support might contribute to seeing individuals with a visual impairment as an easy way to gain the positive attitude of Allah rather than helping them in a way that enhances their self-motivation and independence within society.

In addition to religious teachings, based on cultural attitudes and everyday interactions with people with a visual impairment, it seems that society has already developed an image of people with a visual impairment which is negative. Historically, individuals with a visual impairment were denied education and employment and are associated with unemployment or vocations which are undesirable (e.g. begging). This combination of societal attitudes, image and a lack of expectations has led to a lack of education and employment opportunities for people with a visual impairment. In turn this has led to barriers to achieving independence – despite such persons wanting to participate in society leading to further misconceptions about what people with a visual impairment can and cannot do.

Moreover, current practices seem to contribute further to the bias towards people with visual impairments. For instance, as a result of the mandatory disability quota (a progressive policy introduced to increase inclusion of disabled people in employment), many companies may have hired employees with a visual impairment to avoid paying fines, even if the person with a visual impairment did not have the necessary skills and qualifications. Since staff members with a visual impairment may end up incapable of doing the job due to a lack of skills (itself a lack of training) and poor accessibility of the work environment, then companies may have inadvertently assisted people in developing further negative attitudes towards people with a disability.

Another crucial factor that influences the everyday life of individuals with a visual impairment and has emerged consistently throughout the study is gender roles. Eleven educators and young adults with a visual impairment referred to gender differences and related issues directly and indirectly. Male participants with a visual impairment

reported that they were often not allowed to take part in any household duties by their parents because these duties are considered to be for females. Yet in contrast they are given more freedom to travel around. Similarly, female participants seemed much more protected and limited than males with regard to going out of their homes, whereas they were given more opportunities to learn and perform household roles. Overall, the general cultural view is that girls are more protected and limited in their freedom than boys and this is something that may be exacerbated when disability is involved. Even though this situation might immediately be associated with parental approaches, this is also intertwined with cultural values. Below, I discuss expectations of patriarchal Turkish society.

A serious issue in current Turkish society is gender inequality. The difference between males and females is not due just to their biological differences but it is rather due to their gender roles in a society which is constructed around a dominant male culture (Aslan & Şeker, 2013). Turkey is commonly described as a male dominant patriarchal society, in which women are restricted in many areas of life, including equal participation in economic and social life (Aslan & Şeker, 2013). This patriarchal society existed before the country converted to Islam, although it has been argued that there used to be a more acceptable gender equality (Ersoy, 2009; Mutlu, 2014). Turkish interactions with other cultures, especially Persian, Byzantine and Arabic cultures, influenced their understanding of gender and led to them becoming more patriarchal (Ersoy, 2009; Mutlu, 2014). The role of women has been shifted from being fully independent people who took part in wars, economical practices and administration to playing a role limited to being a good wife and carer (Ersoy, 2009; Mutlu, 2014). It seems that Islam, and the interaction with Arabic culture in particular, may have contributed to this change.

Turmusani (2008, p.76) states that, “In Islam, men are superior to women and women must accept men’s authority and obey their commands”. In the Hadith, women are viewed as spiritually lesser beings who are responsible for the downfall of humanity; they were created for the comfort of men and for procreation, and furthermore, they have not been allowed to take up official religious roles such as being an Imam (Turmusani, 2008, p.76-79). Turmusani (2008) adds that women are also disadvantaged with regards to pursuing economic and political activities in Islamic societies. For instance, women need two witnesses instead of one (as is the case with men) in business transactions. This could be interpreted as Islam contributing to creating a more patriarchal society and explicitly internalising male dominance. Consequently, arguably disabling practices against women with and without disabilities in Middle Eastern culture are witnessed in everyday life.

Nevertheless, attributing all gender inequality to Islam is unfair. Before Islam, and Prophet Mohammed, in Arabic cultures having a daughter was to be considered embarrassing as daughters were not seen as worthy of being

raised by their parents, especially since they would not contribute to the family's economic income. Therefore, girls were often killed (Guner, 2007; Sevgili, 2007). Although Çayır & Çetin (2011) illustrated with examples from the Qur'an that under some circumstances Islam allows violence toward females, they argue that the violence described in the Qur'an should be considered a revolution. This is because Islam brought about a revolution by giving more value to women and banning barbaric practises toward women by encouraging less problematic practises, e.g. beating instead of killing (Guner, 2007).

However, it is possible to anticipate that the violence encouraged by the Qur'an can be misinterpreted and still used to justify violence against women today. Although Islam and the Prophet Mohamed brought a significant positive change to the everyday life of women this momentum has not been maintained and many men still want to maintain rights and responsibilities over women in line with the standards set 1400 years ago. Indeed, Çayır & Çetin (2011) claim that Islam does not contain violence in its nature, yet some people manipulate the religion to make discrimination and violence seem acceptable in some circumstances so that they can have advantages over others. This seems valid, especially in male and female relationships. There are different versions of violence including physical, sexual, psychological and economic. In this section I would like to particularly focus upon "namus", a type of honour in Turkish and other Middle Eastern cultures, particularly drawing upon Sev'er & Yurdakul's (2001) feminist analysis.

According to Sev'er & Yurdakul (2001, p.971), "In the West, honour is often defined as moral integrity, the esteem accorded to virtue or talent", yet both the depth and the breadth of an eastern understanding of honour is very different to that of western culture, in that not only are one's own characteristic virtues viewed as a valued possession but so is the family name and integrity (Sev'er & Yurdakul, 2001). Regardless of one's conditions, no one is exempt from trying their best to maintain an honourable life and "to protect their own as well as the family name from insinuations or open charges of dishonour" (Sev'er & Yurdakul, 2001). A positive aspect of this kind of honour is that it enables the acquisition of a noble social standing within a culture regardless of one's economic status, however, the negative influence of this often admirable eastern tradition is when honour becomes an obsession which people exploit to judge others (Sev'er & Yurdakul, 2001; Yurdakul, 1999). Sev'er & Yurdakul (2001) indicate that in some extreme cases judgements over honour (especially, namus) can and do become deadly in the form of honour killings. Nevertheless, underlying these extreme cases may be traditions which are reflected in everyday life, and some of the findings from my research.

Namus is the honour connected to one's proper sexual conduct, especially with the consideration of one's community's expectations, and females in particular are usu-

ally expected to behave in certain ways (Sev'er & Yurdakul, 2001). Therefore, there is also an element of possible shame regarding women and their families, whereby they must protect their namus. Their reputation of namus even rubs off on their children and society makes judgements about their offspring based on this (Yurdakul, 1999).

After the mother, "the greatest dishonour of a man derives from the impurity of his wife" (Pitt-Rivers, 1974, p.52) or his sister and daughter. Hence, a female's sexuality in terms of her honour and namus is viewed as being her responsibility as well as the family males' responsibility, so the men in a family see it as their duty to sanction women who are deemed deviant (Goodwin, 1994; Sev'er & Yurdakul, 2001). Middle Eastern Islamic culture connects namus with women's bodies, whereby males are viewed as protectors of the family namus and female members' namus; a secular interpretation of this is the commodification of women (Sev'er & Yurdakul, 2001).

Sev'er & Yurdakul (2001) collate several extreme examples of honour killings which they argue are linked to the concept of namus. All these horrible examples illustrate how women were sometimes killed for little acts or suspicions such as going to the cinema without consent, coming home late, dating or having a song dedicated on a local radio. Simply, the masculine-centred quality of namus has led to potentially severe consequences for women who sexually deviate from the expected norms of their community, and this is especially true in rural parts of Turkey (Delaney, 1987; Farac, 1998); it continues to be one of the greatest causes of violence against women (Bilgili & Vural, 2011; Can & Edirne, 2011; Cindoglu, 1997; Cook & Dickens, 2009).

However, it is important to stress that these incidences are extreme, relatively uncommon, and do not reflect all Turkish culture (see Özyeğin, 2008). Moreover, it is also important to highlight that violence against women still is a serious issue in Turkey and it does not take place only because of namus or honour killings.

According to the report of "We will stop women murders platform" (KAD-MER, 2015), thankfully, no women were killed because of "honour killings"/namus during 2015 in Turkey. Although this is a good sign, in total, 303 women were killed by men during 2015. This highlights the existence of the patriarchal hierarchy in Turkish culture: 78% of these women were killed because they wanted to make their own decisions about their own lives e.g. they wanted a divorce, to end a relationship, to make economic decisions. Nevertheless, men's hegemony did not allow this and males who are very closed to these women punished them. Despite 46% of these women's murderers not being known, among the 54% known: 90 of were killed by their husbands; 40 by their boyfriends; 20 by their ex-husbands; 10 by their ex-boyfriends; 10 by their sons; and 8 by their fathers. These figures horribly illustrate the present level of violence against women in Turkey. Moreover, it shows how overall Turkish women

are restricted by their males in making decisions about their own life and living an independent life.

Returning to the actual discussion on gender issues and independence of people with visual impairment, as presented above, Turkish culture is quite different to western culture in many ways but especially in terms of given value on *namus* and females' virginity. Although I have little information about the background of the participants, e.g. if they come from a conservative or liberal family or if their parents were born in a rural or urban area, this discussion on *namus* and patriarchal views in Turkey assists understanding why some female participants might be more protected and restricted than male participants. Based on the discussion above, all members of society, regardless of whether they have a disability or not, are responsible for protecting their *namus* and the *namus* of others in their family; considering that females with a disability are seen as being more vulnerable to having their *namus* stained their parents, as well as other family members might feel more of a need to protect their *namus* by over-protecting and restricting their actions. Of course, this will lead to a situation whereby they will have fewer opportunities to go out of their homes independently and to participate in every part of modern life in comparison to males with visual impairments as well as women who come from more the liberal section of Turkish society. Indeed, this perspective may also be internalised by the female participants. For example, Fatma, a female participant, stressed her fear and her lack of trust in other people by stating others' worries, "what if people take her somewhere and do something wrong". This refers to her fear of facing any danger, and perhaps regarding staining her *namus* (see Islek, 2016).

Moreover, regardless of a disability, such practices to protect *namus* might have an influence on the gender gap across Turkish society. Existing research results highlight the wide gender divide in school access (MEB, 2015); access to employment (Arat, Icagasioğlu-Çoban & Polat, 2013; Sağlam & Bostancı, 2012); and many other aspects of life in Turkey. In addition, women, especially the ones with disabilities, have a significantly lower graduation rate from higher educational institutions than their male counterparts (TUIK, 2015). More specifically, Bengisu et al. (2008), Balta & Bengisu (2012) and Bengisu & Balta (2011) highlight the significantly lower access to employment by females with a visual impairment compared to males in the same situation. Although I have not encountered any author making such a connection, I do think that such practices protecting *namus* is likely to be a reason for this gender inequality in accessing education, employment and all domains of social life for women both with and without a visual impairment in Turkey.

Lutfu, a deputy head teacher at a school for the blind, indicated that more ECC training would be beneficial to students, although he suggested this training should be delivered based on students' genders and roles in society. This view could easily be linked to the traditional view regarding the role of females and males in the family. Since traditionally women are to be good wives, and girls

must behave well, and remain a virgin until marriage, Lutfu might be consciously or unconsciously over-protecting female students with visual impairments from any sort of danger by limiting their participation in everyday life, including educational activities. Maybe he considers everyday life activities as opportunities for females to meet someone who they could have an emotional relationship with – which might lead to their *namus* being stained.

It is not possible to explain the outlying understanding of Lutfu's thoughts with absolute certainty; nevertheless, when these cultural values are considered, it is possible that Lutfu prioritises the girls' *namus* over their independence. Consequently, he tailors a role for females which is just about completing household duties, and therefore, he felt that they should receive training on these areas of the ECC rather than all aspects – including the tasks which go beyond the home – and this is to make sure that their *namus* is protected until their marriage and even after marriage by restricting them to their house. However, Turkey has been influenced by other, specifically western, culture(s) in recent years and a huge modernisation process has been taking place since the 1920s (Arat, 2001; Combers, 2007; Ersoy, 2009; Mutlu, 2014). Based on this modernisation, the majority of modern Turkish young adults would not agree with such segregation and limited roles for females. Moreover, according to the Turkish constitution males and females are equal (1982), which would not allow any different instruction based on gender (as Lutfu wanted).

4. CONCLUSION

In summary, culture and society has been a major influence on the everyday life of individuals with a visual impairment as an enabler or barrier. Individuals with a visual impairment need to learn and perform all ECC skills regardless of their gender, yet the impact of the culture needs to be considered carefully. In addition to providing instruction on ECC, the environment should be designed to be accessible at all levels, including the cultural values and attitudes of society, so that individuals with a visual impairment can be prepared as independent individuals and fully integrated into their community. .

REFERENCES

- [1] Al-Aoufi, H., Al-Zyoud, N., & Shahminan, N. (2012). Islam and the cultural conceptualisation of disability. *International Journal of Adolescence and Youth*, 17(4), 205-219.
- [2] Arat, G., Icagasioğlu-Coban, A., & Polat, G. (2013). Social capital formation among Turkish women. *Cosmopolitan Civil Societies: An Interdisciplinary Journal*. 5(1). 97-108.
- [3] Aslan, M., & Şeker, Ö. G. S. (2013). Aile içi şiddetin bir boyutu olarak kadına yönelik şiddet toplumsal algıla ve tutumlar (Social perception and attitudes of violence against woman as extent of domes-

- tic violence). *Niřantaşı University Journal of Social Sciences*, 1 (1).
- [4] Balta, S., & Bengisu, M. (2012). Employment of the Disabled Workforce in the Hospitality Industry. *BEST Education Network Think Tank VIII: Sustaining Quality of Life through Tourism*.
- [5] Bengisu, M., Izbirak, G., & Mackieh, A. (2008). Work-related challenges for individuals who are visually impaired in Turkey. *Journal of Visual Impairment and Blindness*, 102(5), 284 – 294.
- [6] Bilgili, N., & Vural, G. (2011). Kadına yönelik řiddetin en ağır biçimi: Namus cinayetleri (The most extreme violence against woman: honour killings). *Journal of Anatolia Nursing and Health Sciences*, 14(1).
- [7] Can, M., & Edirne, T. (2011). Beliefs and attitudes of final-year nursing students on honour crimes: a cross-sectional study. *Journal of psychiatric and mental health nursing*, 18(8), 736-743.
- [8] Çayır, C., & Çetin, Ö. (2011) “Din ve řiddet Üzerine Psikolojik Bir Yaklaşım” (A psychological analysis on religion and violence), *Dicle Üniversitesi İlahiyat Fakültesi Dergisi*, 13(1), 23-35.
- [9] Cindoglu, D. (1997, April). Virginity tests and artificial virginity in modern Turkish medicine. *In Women's Studies International Forum*, 20(2), 253-261.
- [10] Combres, K., (2007) *Experiences of educated Turkish migrant women returning from Canada*. (Unpublished master's thesis), Middle East Technical University, Turkey.
- [11] Delaney, C. (1987). Seeds of honor, fields of shame. In D. D. Gilmore (Ed.), *Honor and shame and the unity of the Mediterranean* (pp. 35-48). Washington, DC: American Anthropological Association.
- [12] Erman, T., Kalayciođlu, S., & Rittersberger-Tılıç, H. (2002, August). Money-earning activities and empowerment experiences of rural migrant women in the city: The case of Turkey. *Women's Studies International Forum*, 25(4), 395-410. Pergamon.
- [13] Ersoy, E. (2009). Cinsiyet kültürü içerisinde kadın ve erkek kimliđi [The identity of women and men within a gendered culture]. *Fırat Üniversitesi Sosyal Bilimler Dergisi [The Journal of Social Studies, Fırat University]*, 19(2), 209–230.
- [14] Ghaly, M.M. (2008). Physical and spiritual treatment of disability in Islam: Perspectives of early and modern jurists. *Journal of Religion, Disability & Health*, 12(2), 105-143.
- [15] Güner, O. (2007). İslam Düşüncesinde Kadına Yönelik řiddet Söylemine Bir Bakış (A look into violence against woman in Islamic thoughts) . *On-dokuz Mayıs Üniversitesi İlahiyat Fakültesi Dergisi*, 23(23), 51-63.
- [16] Islek, O.,(2016). An investigation into the balance of the school curriculum content for pupils with a visual impairment in Turkey. University of Birmingham, unpublished PhD thesis.
- [17] KAD-MER (2015). “Kadın cinayetlerini durduracağız platformu“ 2015 yılı raporu (“We will stop women's murders platform”, report of 2015) Accessed: 17. 02. 2016 from: <https://kadin cinayetlerini durduracagiz.net/veriler/2551/kadin-cinayetlerini-durduracagiz-platformu-2015-yili-raporu>
- [18] Kitayama, S. & Park, J., (2013) CULTURE AND THE SELF: Implications for consumer behaviour. (eds Ruvio, A. A., & Belk, R. W. (2013). *The Routledge companion to identity and consumption*. Routledge.
- [19] Kitayama, S., & Markus, H. R. (2000). The pursuit of happiness and the realization of sympathy: Cultural patterns of self, social relations, and well-being. In E. Diener, & E. Suh (Eds.), *Subjective well-being across cultures*. Cambridge, Massachusetts: MIT Press.
- [20] Markus, H. R., & Kitayama, S. (2000). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological review*, 98(2), 224.(accessed online on 02/03/2016 : <http://chnm.gmu.edu/courses/honors130/culture.html>
- [21] Miles, M. (2008), Some Influences of Religions on Attitudes Towards Disabilities and People with Disabilities. *Journal of Religion, Disability & Health*. Published online: 10 Oct 2008
- [22] Ministry of National Education (MEB). (2015) National Education Statistics Formal Education 2014/15, Ministry of National Education Strategy Development Presidency. Retrieved June 2015, from: http://sgb.meb.gov.tr/istatistik/meb_istatistikleri_org_un_egitim_2014_2015.pdf [In Turkish]
- [23] Mutlu, S. Ö. (2014). 1923 Öncesi Dönemde Türk Kadını [The Turkish Woman Before 1923]. *Aydınlanma 1923 [Enlightenment 1923]*. 46(46). 59-66.
- [24] Özçelik, H. (2010). Hadislere göre günahların bağışlanma yolları (Ways of forgiveness of sins according to Hadiths). *Atatürk Üniversitesi İlahiyat Tetkikleri Dergisi (Atatürk University, journal of Religious Studies)* 34(1).
- [25] Özer, S. (2015) İslam ve diđer medeniyetlerin engelliye bakışı [Approaches toward disability in Islam and other civilisations]. *Bilimname*, 28(1). [In Turkish]
- [26] Ozyegin, G. (2009). Virginal facades sexual freedom and guilt among young Turkish women. *European Journal of Women's Studies*, 16(2), 103-123.
- [27] Sevrer, A., & Yurdakul, G. (2001). Culture of honor, culture of change a feminist analysis of honor killings in rural Turkey. *Violence against women*, 7(9), 964-998.
- [28] Sevgili, M.M. (2007) İslam Hukuku Açısından Töre Cinayetleri (from Islamic laws lence to honour killings), (Unpublished Master's thesis) Ankara University, Ankara, Turkey.
- [29] TÜİK (2015) Türkiye İstatistik Kurumu [Turkish Statistics Institute], “Main Statistics: Population and Demography”. Retrieved June 12, 2015, from <http://www.turkstat.gov.tr/UstMenu.do?metod=temel>
- [30] Shakespeare, T. (2008). Debating disability. *Journal of medical ethics*, 34(1), 11-14.
- [31] Turmusani, M. (2008). Disabled women in Islam: middle eastern perspective. *Journal of Religion*,

Disability & Health, 5(2-3), 73-85. (Published online: 13 Oct 2008)

- [32] Yurdakul, G. (1999). *Construction of honor: Reflections on women's status in Turkey*. Middle East Technical University, Ankara, Turkey.

Current and future trends in museums regarding visitors with disabilities: the case of visitors with visual impairments

Vassilis Argyropoulos¹, Magda Nikolaraizi¹, Charikleia Kanari¹, and Sofia Chamonikolaou¹

¹University of Thessaly, Department of Special Education,
Volos, Greece

{vassargi, mnikolar, chamonik}@uth.gr, kanarixarikleia@hotmail.com

ABSTRACT

It is stated that over the past decades museums have developed educational programs for individuals with disabilities, making adaptations according to the disability and the needs of each group. Nevertheless, people with visual impairments face many barriers regarding their access to museums. The present study highlights the contemporary role of the museums, the socio-anthropological paradigm for disability and the influence of many political and social movements of people with disabilities regarding access and cultural rights in general.

1. INTRODUCTION

Access to culture has been recognized as a right of people with disabilities in the Convention of the Rights of Persons with Disabilities [1]. It seems that access to culture encompasses multi-dimensional issues relevant to economic factors, societal norms and political movements.

This paper attempts to describe current and future trends in museums regarding visitors with disabilities giving an emphasis on visitors with visual impairments. Why the emphasis is placed on individuals with visual impairments? Because it is very likely that a person with visual impairment will end up with a disappointing museum experience, when he/she decides to visit a museum without any preliminary activities (i. e. inform the museum staff for his/her intention to visit the specific museum, etc.). On the other hand, museum professionals face this same challenge from a different point of view, having the difficult task of designing exhibits and programs with few universal guidelines for what the concept of cultural accessibility should look like for visitors with low vision or blindness [2].

2. CURRENT TRENDS

2.1 Policy makers and social model of disability

The adoption of the social model of disability in contrast to the individual or medical model of

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

disability had a significant impact on policies and practices towards disability, including those of museums [3].

All notions which were developed under the umbrella of anti-social models of disability model contributed to the perpetuation of various stereotypes and to the consideration of people with disabilities in terms of therapy or treatment ignoring the role of the society and the barriers that may affect and shape the experience of disability. The social model of disability stresses issues like the failure of the society to respond to the needs of people with disabilities, the barriers and the limitations of the society, which isolate and exclude people with disabilities from equal social participation. Such an example constitutes the interaction between museums and people with disability [4].

2.2 The educational and social role of the museums in the 21st century

Museums have recognized that audiences in general are not homogeneous groups but consists of different people with different and various needs, different ages, different social, educational, religious or ethnic backgrounds, different interests and expectations [5]. As a result, museums have developed a wide range of services, activities and practices such as educational programmes for schoolchildren with and without disabilities, workshops, educational material, outreach programmes, loan services, etc. In addition, it seems that the relationship between museums and schools is gaining ground and teachers contribute to meaningful learning experiences in museums and positive social experiences on behalf of their students [6]. This re-definition of the museums' role towards their educational and social impact is reflected on the museums' definition of the International Council of Museums (ICOM, 2007) as well as on the Convention of the Rights of Persons with Disabilities towards culture [1].

2.3 Issues of accessibility

Regarding access of people with disabilities to museums, it is true that constitutes one of the central topic of discussions in museums around the world. Speaking of individuals with visual impairments, the request for access to the exhibits of museums is in contrast with one of the most important objectives of many museums: to display artworks and museum objects and protect them at the same time [3].

Nevertheless, it is evident that museums are exploring ways in order to respond to the right of visitors who have visual impairment or blindness to have access to the content and context of cultural centres [7]. Examples of facilitating factors regarding access and accessibility may be the act of setting landmarks to enhance the location and the orientation of blind visitors, staff training, provision of tangible objects and tactile books, usage of assistive technology braille information, enlarged print, etc. [8]. On the other hand, there are examples of barriers such as: treat visitors with visual impairments as a homogeneous group, limited content of special museum educational programs, inappropriate museum staff's attitudes and behaviors towards people with blindness, and the "do not touch command" which prevails in most museums [9].

It seems that we are on the threshold of an age of universal design for learning which brings new perspectives and new social blueprints. Nevertheless, it seems that despite the intensive discussions about access to cultural goods for people with disabilities their cultural rights are for the time being poorly implemented [10].

3. FUTURE TRENDS

The trends that will shape the next museum steps seem to be dominated by an inclusive strategy and a network thinking. According to Coxall [11], an inclusive strategy may incorporate a variety of aspects such as "serving communities, consulting with audiences and communities, collecting and interpreting, collaborating with external bodies, working across disciplines, staffing and training and mainstreaming diversity awareness"(p139).

In addition, if museums want to occupy one of the main cultural and social epicenters, then they have to build up robust networks with schools, policy makers and universities. It seems that museums are heading to this direction because they are getting involved more and more in projects such as the BaGMIVI project and relevant activities [12].

4. CONCLUSIONS

The museum of the 21st century is aiming to be the "forum" of contemporary crossroads. Yet, there are many steps to go regarding theory and practice. Wapner [2] underscores the necessity of adopting an "inclusive spirit" and a "network thinking" by the following words "We must strive to cultivate an open, continuous, and lasting dialogue with experts from visually impaired audiences, and we must listen keenly for the suggestion of new best practices for museum inclusivity on the horizon".

Acknowledgments

This study constitutes part of the BaGMIVI project (No: 2014-1-EL01-KA200-001631) which is funded by the Erasmus+ programme of the European Union and co-ordinated by the State Scholarships Foundation (IKY).

REFERENCES

- [1] UN, *United Nations Conventions on the Rights of Persons with Disabilities*, retrieved by http://www.un.org/esa/socdev/enable/rights/convtext_e.htm#convtext, 2006.
- [2] J. Wapner, "Mission and Low Vision: A Visually Impaired Museologist's Perspective on Inclusivity", *Disability Studies Quarterly*, vol. 33, no. 3, <http://dsq-sds.org/article/view/3756/3290>, 2013.
- [3] V. Argyropoulos and C. Kanari, "Re-imagining the Museums through Touch: Reflections of Individuals with Visual Disability on their Experience of Museum-visiting in Greece," *ALTER, European Journal of Disability Research*, vol. 9, pp. 130-143, 2015.
- [4] T. Moussouri, "Implications of the Social Model of Disability for Visitor Research," *Visitors Studies*, vol. 10, no. 1, pp. 90-106, 2007.
- [5] G. Black, *The Engaging Museum. Developing Museums for Visitor Involvement*. Routledge, 2005.
- [6] V. Vemi, and H. Kanari, "School Teachers and Museum Education: A Key Factor in Expanding the Inclusive Character of Museums," *The International Journal of the Inclusive Museum*, vol. 1, pp. 1-8.
- [7] K. Hetherington, "Museums and the Visually Impaired: The Spatial Politics of Access," *The Sociological Review*, vol. 48, no. 3, pp. 444-463, 2000.
- [8] B. Ginley, "Museums: A Whole New World for Visually Impaired People," *Disability Studies Quarterly*, vol. 33, no. 3. <http://dsq-sds.org/article/view/3761/3276>.
- [9] M. Weisen, "How Accessible are Museums Today?," in H. J. Chatterjee (ed.) *Touch in Museums. Policy and Practice in Object Handling*, 2008, pp. 243-252.
- [10] EBU, *Access to Culture Survey 2012. Mapping Current Levels of Accessibility to Cultural Venues and Activities in Europe*, retrieved by <http://www.euroblind.org/working-areas/access-to-culture/nr/1315>, 2012.
- [11] H. Coxall, Open Minds: Inclusive Practices. In H. H. Genoways (ed.) *Museum Philosophy for the Twenty-first Century*, 2006, pp. 139-149.
- [12] V. Argyropoulos, M. Nikolarazi, S. Chamonikolaou, and C. Kanari, "Museums and people with visual disability: an exploration and implementation through an Erasmus+ project," in *Proc. Int. Conf. EDULEARN16*, Barcelona, 2016, pp. 4509-4516.

Interactions between a gallery, university and special school for visually impaired in providing access to ancient and contemporary art: the Bulgarian case

Mira Tzvetkova-Arsova¹, Vladimir Radoulov²

¹Sofia University “St. Kliment Ohridski”, Department of Special Education and Speech Therapy,
Sofia, Bulgaria
miratz@abv.bg

²Bulgarian Association for Education of Visually Impaired Children,
Sofia, Bulgaria
vlado.radoulov@gmail.com

ABSTRACT

In the past 20 years lots of efforts have been done in Bulgaria in order to provide more access for people with disabilities in general, and for Visually Impaired in particular, to museums, art galleries and other cultural places. Traditionally Visually Impaired people are not frequent visitors of museums and galleries due to the barriers put to them in these places and the lack of appropriate and accessible ways to perceive the exponents. The BaGMIVI project aims to help art institutions become more open, friendly and willing to accept more visitors with Visual Impairments. As Rakursi gallery is the only private gallery of smaller size within the project, it is an excellent example to show how a private art institution can be open to meet the specific needs of Visually Impaired visitors and to develop a friendly environment to them adapting its exponents or creating new ones.

1. INTRODUCTION

The review of the presentations and reports from the European and World conferences of ICEVI in the last 15 years show that only little attention has been given to the issues of art and the blind or access to art. However, some reports have focused on the education in music, dances and to some extent the tactile/relief materials.

The access to museums, galleries and other public places, where art forms are exposed, and thus the access to art for Visually Impaired in general, has been of interest to scientist, educators, parents and other specialists for years. There is no doubt that this topic is part of the integral policy of inclusion for people with visual impairments to all aspects of societal life. In the last decades, Bulgaria has worked hard and put lots of efforts a. in the process of setting the requirements for accessible environment for the whole population, including people with disabilities as well as increasing the access to traditional buildings, including the cultural ones (Decree № 4, and Regulation №

4 of the Ministry of Regional Development 2009 respectively), b. in ratifying the UN Convention on the Rights of Persons with Disabilities (national Law on 26.01.2012), c. in signing the Treaty of Marrakech of the World Organization of Intellectual Property to facilitate access to published works/materials for blind and visually impaired persons or for people with other visual disabilities to prevent them from reading printed publications (28.07.2013), and d. in accepting an official Concept with concrete proposals for improving the current legislation (Ministry of Culture in Bulgaria, November 2014).

Sofia University also implemented in its curriculum few subjects which deal with the access to art for Visually Impaired such as the subject Tactile creativity makes the university students familiar with different ways for making art accessible to Visually Impaired.

The special program on Activities of Daily Living (ADL) of 2014, approved by the Ministry of Education, also presents topics in regard to access to art. In turn, on 24 April 2017 the first movie for Visually Impaired people was shown in Sofia. The problem of access to art for Visually Impaired is important and significant. As Reeve (1991 states):

“It gives visually impaired people the opportunity to share in the cultural, social and spiritual life of our society and heritage” (p. 93). For this reason the traditional arts as music, dances, ceramics, pottery and drama in which Visually Impaired are typically trained are no longer enough and sufficient.

In the same time the access to art for Visually Impaired faces many obstacles: (a) the biggest amount of art is visual – oil paintings, graphics, watercolors, (b) many museums and galleries do not allow touching the exponents due to preservation and safety issues, which makes them inaccessible in a tactile form for the Visually Impaired, and (c) many museums and galleries place their exponents in glass cabinets.

Throughout time many scientists study also the issue of aesthetic appreciation in Visually Impaired and especially in Blind, in the attempt to find out similarities and differences between them and the sighted. Kilcoyne (1991) for instance describes the following case with Leonardo da

Vinci's painting "Last supper" made in 3D format and presented to Blind individuals for tactile exploration. The Blind people had the following understanding of it: "A table cloth, assorted foods and thirteen figures in passionate debate, with three windows at the back of the room" (p. 47). This example shows that it is simply not enough an art forms to be presented in 3D or 2D formats in order to be understood and appreciated by the Blind. They have to be presented with the meaning of the art piece, to be aware of its significance and should develop "touch literacy" in order to have the same or somehow similar aesthetic appreciations as the sighted people.

2. THE BAGMIVI PROJECT

In this regard the **BaGMIVI project** was designed to support on international level the issue of access to art, museums and galleries – physically and aesthetically of Visually Impaired children, students and adults. The main steps in the project from Bulgarian side were organized as follows:

STEP 1: Training of the museum and gallery staff by the universities in topics connected with the access to art for Visually Impaired students.



Photo 1. Learning basic Braille by the gallery staff

STEP 2: Preparation by the gallery staff of two appropriate exhibitions, especially designed for Visually Impaired students.

Step 2 started with some adaptations preparation of the gallery itself as for instance: new markings of the steps; guiding lines inside the gallery; contrast marking of the glass door; new LED lightening inside. Several consultations were carried out with the director of the school for blind in Sofia, with the teachers in history and tactile art and with the students in order to discover their interests. A serious preparation of the exhibitions was also done. It included research, preparation of braille and large print labels and development of tactile maps and materials.

STEP 3: Two visits by Visually Impaired students in the gallery and tours.

The first exhibition entitled "Touch the treasure" was organized by Rakursi gallery on 19 April 2016. Twenty Visually Impaired students from the special school for Blind in Sofia "Louis Braille" divided into two groups of ten, attended the exhibition and got the opportunity to explore tactually and the low vision students – visually, 10 replicas of artifacts belonging to the five biggest Thracian treasures found in Bulgaria. They explored artifacts such as: the mask of the first known Thracian king Terres of V century b.c., (part of the Rogozen treasure), rytons from the treasure of Panagyurishte, examples from the treasure in Vulchitran, which is the biggest gold treasure in our lands.

The second exhibition was organized on 7 June 2016. It was entitled "Look towards the modern art". Two new groups participated in the second exhibition. Different exponents were shown to them, among them few Bronze horses in different art styles – classic, abstract, cubic, expressionism etc.



Photo 2. First exhibition **Photo 3.** Second exhibition

STEP 4: Collecting information about the two visits through questionnaires (Reflection phase).

STEP 5: Multiplier event: national conference.

The national conference was held in Sofia on 26 and 27 January 2017. It gathered together more than 60 participants: university professors and students; museum and gallery representatives from all around the country, foreign professors and teachers, school teachers from the two special schools for Blind in Bulgaria etc.

3. CONCLUSIONS

BaGMIVI project gave the perfect opportunity for fruitful and active interactions between a gallery, university and special school for Visually Impaired in providing access to ancient and contemporary art. It proved that through a good cooperation the access to art for Visually Impaired can be guaranteed.

Acknowledgments

This presentation was feasible thanks to the BaGMIVI project, sponsored by the Erasmus+ program of the European Commission. Also many thanks to Margarita Tomova, Rumiana Yoneva, Rositsa Chusheva and Emanuela Stoilova for their participation in the project activities and for their ideas when writing this paper.

REFERENCES

- [1] J. Reeve, "Keeping in touch with cathedrals," *British Journal of Visual Impairment and Blindness*, vol. 9, no. 3, pp. 91-93, 1991.
- [2] A. Kilcoyne, "Common sense: making use of the sense of touch," *British Journal of Visual Impairment and Blindness*, vol. 9, no. 2, pp. 47-49, 1991.

The cooperation of university, museum and special school for adapting the environment and creating new educational opportunities for children with visual impairment in museums: the Hungarian case

Beáta Prónay¹, Krisztina Kovács², Erzsébet Szűcs³, Ágnes Somorjai⁴

¹ELTE University, Faculty of Special Needs Education, Institute for the Psychology of Special Needs, Budapest, Hungary
beata.pronay@barczy.elte.hu

²ELTE University, Disability Support Centre, Budapest, Hungary
kovacs.krisztina@kancellaria.elte.hu

³King Saint Stephan Museum, Székesfehérvár, Hungary
erzsebet.szuecs@gmail.com

⁴School for the Blind, Budapest, Hungary
somorjai@vakisk.hu

ABSTRACT

In the 1990s Hungarian museums opened their gates to provide accessible exhibitions for people with disability. However people, especially children with visual impairment still have to face obstacles when visiting museums. BaG-MIVI project gave us the opportunity to enhance museum access. We will report the work the three parties have done for enhancing museum access and experience for visitors with visual impairment in Hungary

1. INTRODUCTION

The Constitution of Hungary is declaring the rights of people with disabilities among which the fundamental right for equal access and participation in culture are underlined. Three further Acts: Built Environment and Conservation Act LXXVIII 1997, Rights and Equal Opportunities for People with Disabilities Act XXVI 1998 Equal Treatment and Promotion of Equal Opportunities CXXV Act 2003 cover directly or indirectly, participation in cultural life. The “Convention on the Rights of Persons with Disabilities” [1] was ratified and signed by Hungary in the first place among nations.

2. PREVIOUS GOOD PRACTICES IN HUNGARY

As early as in the late 70’s there were examples of sporadic attempts of conducting exhibitions for those with different disabilities in Hungary.

Pioneering exhibitions were for visitors with VI:

- in the Christian Museum in Esztergom in 1981 with copies of precious relics
- in the National Museum in 1982 by the copy of the Hungarian Crown and coronation jewelry.
- in the 1993 the Open Air (Ethnographic) Museum designed an exhibition directly for blind visitors “See with your hands” [2].

The exhibitions listed so far were more serving educational goals for students with visual impairment than artistic experience. The aim of the following exhibitions were artistic by offering palpable picture exhibitions of Victor Vasarely, Miro and Rembrandt.

Without complete listing we mention exhibition with dual purposes held in the Museum of Fine Arts in Budapest between 2005-2010 e.g. After Pharaohs – the treasures of Coptic Art from Egypt, Golden age of the Medicines, etc.

In 2008 an international conference was organized in the Károlyi Chateau in Fehérvárcsurgó (<https://karolyi-kastely.accenthotels.com/en>) with the participation of presenters from several famous museums from all over the world: Victoria and Albert Museum, MET, etc. This was the first event about museum access with the participation of representatives of museums who are responsible to organize exhibitions for those with visual impairment in Hungary. In the same year the book “Museums for all” was edited, which included universal design principles applied to a multi foci accessibility approach in exhibitions. [3] The Tangible Foundation, since its establishment in 2009, is arranging exhibitions for and of individuals with VI (<http://www.kezzelfoghato.hu/index.php?nyelv=eng>). The Foundation has recently published a book titled Tangible Art for All. This book is a nice summary of theories and good practice of palpable exhibitions [4]. Although we can declare that in Hungarian museums and others made efforts for accessible exhibitions there is still a lot to be done.

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

3. EFFECT OF THE BAGMIVI PROJECT

3.1 Partners of the BaGMIVI project

The BaGMIVI Project connected several organizations to work for accessibility for VI students to visiting exhibitions. The partner in this project were. *a) two units of ELTE University, b) two units of Saint Stephan Museum, Székesfehérvár, and c) the School for the Blind, Budapest, Hungary.* The Saint Stephan Museum has various exhibitions including a unique toy collection, sculptures and painting gallery. The School for the Blind serves different age groups on both daily and residential bases. ELTE University is offering special education teacher training and has a Center for Students with Disabilities.

3.2 Making acquaintances

The project started with study visits. The museum staff visited the school and the school teachers visited the museum.

3.3 Interviewing for the need assessment

In Hungary 26 special education teachers of students with VI and 15 students with visual impairments were interviewed, and 17 museum staff members filled in the questionnaire. In the interviews, participants expressed many interesting aspects and needs for access of VI in museum programs.

3.4 Training course for museum staff

Content of the training: Introduction to VI, definition, functional classification, effect on development and learning, visual, auditive and tactile senses, Braille; characters-size; Introduction and practice of O&M skills, sighted guide techniques, mental maps, etc. Accessibility of the environment (physical and info-communication), law, disability movements; universal design; heterogeneous needs (blindness; low vision; individual needs). Concrete examples: lightening; contrast; colours; glare; tactile marks; auditive signs indoor and outdoor. Theory and practice on designing tactile and auditive educational material. Audio description: training on giving useful verbal description of objects and pictures. Identification of tactile graphics and 3D objects. Making tactile graphics. Theory of organizing accessible museum programs. Practice: museum staff „visited” a small exhibition under blindfold.

4. RESULTS

4.1 Adapted museum program – 3 visits

Students groups were from different departments of the School for the Blind: 6 students studying in the vocational school (age: 15-20) with low vision and blindness; 7 pupils in lower elementary grades with blindness; 5 pupils with MDVI in upper grades with profound low vision.

4.2 Museum education program 1

Museum staff designed different programs for the different groups: for the vocational students: Deák Collection – offered palpable experience of 8 original masterpieces of 20th century statues in bronze and ceramics. During creative workshop students made their own statues from wax under music with the instruction of a museum educator and therapist.

4.3 Museum education program 2

Younger and MDVI students on the way to the museum visited the tactile model of the town and then visited the Moskovszky toy collection. They had experiences with tactile materials – copies of original toys in drawers under the exhibited interiors. They had a semi-directed play: building a doll house with dolls and furniture. They could design and, create a room –furniture and decoration– and telling a story of their self created doll house.

5. CONCLUSIONS

All three parties of the program had contributed to and profited from BaGMIVI project a great deal. However, the summary of the reflective logs was emphasizing the necessity of more knowledge and more cooperation –highlighted by Kovács [2].

Acknowledgements

The paper introduces the Hungarian results of the BaGMIVI project (No. 2014-1-EL01-KA200-001631) which was funded by the Erasmus + program of the European Union.

REFERENCES

- [1] Convention on the Rights of Persons with Disabilities UN, 2006.
- [2] K. Kovacs, “Palpable Outcomes of BaGMIVI Project in Hungary”, *presentation in Int. Conference: “Museums and Individuals with Visual Impairments: Bridging the Gap”*, University Thessaly, Volos, Greece, 2017.
- [3] B., Prónay Equal Access – palpable art In Móga E. (ed.) *Kézzelfogható Művészet Mindenkinek*. Kézzelfogható Alapítvány. Underground Kiadó Kft. Budapest, 2017.
- [4] S.E. Móga, Kézzelfogható Alapítvány a tapintható művészetért. In Móga E. (ed.) *Kézzelfogható Művészet Mindenkinek*. Kézzelfogható Alapítvány. Underground Kiadó Kft. Budapest 2017.

Empowering people with visual impairments to visit museums by developing differentiated educational programs

Andrea Hathazi¹, Adrian Rosan¹, Tudor Salagean², Tekla Totszegi²,

¹Babes-Bolyai University, Department of Special Education,
Cluj-Napoca, Romania
{andrea.hathazi, adrian.rosan}@ubbcluj.ro

²The Transylvanian Museum of Ethnography,
Cluj-Napoca, Romania
{t.al.salagean, tekla_totszegi}@yahoo.com

ABSTRACT

The relationship between museums and people with visual impairments must be realized in both directions, that is museums should be organized in such a way to encourage participation of people with visual impairments to access different exhibitions, but people with visual impairments must also present not only the willingness to visit the museums, but also the skills that support their independence. Opportunities are fewer whenever there are no organized activities, initiatives can be taken with difficulty, if the person with visual impairment considers that there are a lot of significant physical, informational, language and attitude barriers that there are difficult for him to overcome. The present project aims to support people with visual impairment to access museums as they find the visits relevant and accessible. The museum developed differentiated educational programs so that not only the experiences are positive, accessible, permanent, relevant, but also participation is encouraged. There were taken into consideration all the factors that could contribute to a holistic experience that include tactile experiences, conceptual development, access to knowledge and traditional materials, cultural values, traditions, stories, positive emotions.

1. INTRODUCTION

Major museums all over the world are in the process of addressing their services to people with disabilities with respect to their rights and diversity. Legislation on accessibility has been issued and implemented in order to support the core values and principles of equal access and participation. One of the main objectives of the Bagmivi project was to develop a network between institutions and people with visual impairments that would develop competences and programs. The accessibility of the common

resources of the community (facilities, services and products related to housing, health and rehabilitation, education and vocational training, culture, work, politics, sports) for the use of people with disabilities represents the essence of an open society. The scope is to sustain the increase of quality of life of people with disabilities in respect with independence, security, dignity, decision and personal responsibility.

2. ROMANIAN CONTEXT

One of the documents of major importance is the National Strategy of Social Inclusion for people with disabilities 2014-2020 developed by the Ministry of Labour, Family, Social Protection and Elderly issued in 2014 in Bucharest with the title "Social policies from the rehabilitation of the individual to the reform of the society" (available at http://www.mmuncii.ro/j33/images/Documente/proiectie_sociala/DPPD/2014-01-31_Strategie_DPPD-2014-2020.pdf).

According to the report, the society has the obligation to eliminate all the barriers that prevents or limits the inclusion and active participation of people with disabilities to social life. The accessibility of the common resources of the community (facilities, services and products related to housing, health and rehabilitation, education and vocational training, work, politics, sports) for the use of people with disabilities represents the essence of an open society. The scope of the strategy sustains the increase of quality of life of people with disabilities in respect with independence, security, dignity, decision and personal responsibility. The report states that accessibility is not just the first of the eight domains of reference of the European Strategy, but also a precondition of the other seven: Participation, Equality, Employment, Education and training, Social Protection, Health, External action. The National Strategy specifies under the Accessibility section specific objectives for Information and Communication, from which we select the following two:

16. the assurance from the public authorities of modalities of accessible information and communication for people with disabilities (sign-language interpreting, accessible

formats of public documents, public display, such as Braille, audio records, simplified versions, large characters, accessible web pages).

17. the assurance from the art and cultural institutions of accessible modalities of presentation for people with sensory disabilities or learning disabilities (tactile maps, audio/video materials).

3. IMPLEMENTATION OF BAGMIVI PROJECT

The major aim of the project is to facilitate access to culture and increase quality of life by encouraging participation to cultural and social life, but also to respect and assure the right of people with visual impairments to the cultural life of the community. The partnership with the Transylvanian Museum of Ethnography in Cluj- Napoca represented an opportunity to develop accessible educational programs for people with visual impairments. Museums are not only institutions for the collection, preservation and display of objects but audience-centred spaces with a wide educational and social role [1].

Van den Berg [2] supports the idea that the role of museums is educational, entertaining and emotional. In his view visiting museums can develop a feeling of entertainment, “being entertained feels good, you feel joy and fun”; of education, “understanding how things work, solving a puzzle, raises your self-esteem”; and of aesthetics, “the awe of seeing a great object of art, is uplifting, it stretches the imagination, it crosses a mental boundary”. Visiting museums have a direct effect also on academic achievements as a dynamic and bi-directional interaction between the social-emotional development and academic achievement in a way in which improving social emotional competences have a positive impact on interpersonal skills, not only on their knowledge and skills. To improve access to various environments and contexts, to facilitate access of children with visual impairments is achieved only with strengthening abilities, building up self-esteem, confidence, developed social and emotional competences.

The issues of accessibility and promotion of visiting museums were discussed in several meetings where different aspects of the universal design and accessibility of materials and environments were taken into consideration when planning the visits of the people with visual impairments to the Transylvanian Museum of Ethnography. The main benefits for people with visual impairments were identified, so that the visits would be not only educational, but also unique and authentic as experiences. Materials, resources, strategies and methods were proposed to facilitate access and understanding, enrich experiences, to create positive emotions with the objective of supporting a holistic approach. The discussions were based on the four aspects described by Handa, Dairoku and Toriyama [3] referring to priority needs for people with visual impairments when visiting museums. These were facilities for wayfinding, exhibitions and collections including objects that can be touched, heard or smelt, information in Braille,

audio and large print and finally assistance and interpretation by museum staff. Creating an inclusive museum was not only about Braille and audio transcription, but mainly creating a learning experience within workshops that included not only learning by touch or learning by doing, but creating the similar natural context.

4. CONCLUSIONS

With the achievement of the objectives, activities and the intellectual outcomes of the present project, a sustainable network was created, valuing the expertise of each partner and approaching holistically, not only the issue of accessibility and adaptation in the context of visual disability, but also the development of premises for the implementation of educational programs within the museums that can be experienced by people with visual impairment in the context of social participation and access to cultural values of the community.

Acknowledgments

The authors would like to acknowledge the support of European Commission through the Erasmus+ Programs for funding the BAGMIVI project (No: 2014-1-EL01-KA200-001631).

REFERENCES

- [1] V. Argyropoulos, and C. Kanari, “Re-Imagining the museum through touch: reflections of individuals with visual disability on their experience on museum visiting in Greece,” *ALTER, European Journal of Disability Research*, vol. 9, pp. 130–143, 2015.
- [2] K. Handa, H. Dairoku, and Y. Toriyama, “Investigation of priority needs in terms of museum service accessibility for visually impaired visitors,” *British Journal of Visual Impairment*, vol. 28, pp. 221-234, 2010.
- [3] D. van den Berg, *Why do people visit a museum?*, retrieved by <http://www.museummarketing.info/2008/09/why-do-people-visit-a-museum/>, 2008.

Bridging theory and practice in developing inclusive practice in museum: the Greek case

Vassilis Argyropoulos¹, Magda Nikolaraizi¹, Charikleia Kanari¹, Sofia Chamonikolaou¹, Marina Plati², Eleni Markou², and Betty Leotsakou^{† 3}

¹University of Thessaly, Department of Special Education,
Volos, Greece

{vassargi, mnikolar, chamonik}@uth.gr, kanarixarikleia@hotmail.com

²Nicholas and Dolly Goulandris, Foundation Museum of Cycladic Art,
Athens, Greece

{mplati, emarkou}@cycladic.gr

† ³ ICEVI-Europe, Netherlands

ABSTRACT

The development of inclusive practices in museums presupposes, among others, the conjunction between theory and practice, a well-established interdisciplinary approach and a well-organized collaboration between people with different specialties at different levels. The present paper refers to a European project entitled "Bridging the Gap between Museums and Individuals with Visual Impairments" (BaGMIVI) which aims to support museums to develop various practices in order to enhance the access and inclusion of people with visual disabilities into their spaces. In specific, the paper focuses on the Greek participating museum which is the well-known Museum of Cycladic Art (MCA). A multi-level of collaboration is highlighted which took place among University of Thessaly, MCA and the Greek special school of the blind in Athens. The presentation concludes with a. the outputs of the MCA, b. the differentiated museum educational programs, and c. blind students' reflections from their visits in MCA.

1. INTRODUCTION

A crucial factor for the enhancement of access to museums for individuals with disabilities is the training of museum staff. It is worth noting that museums' staff training in disability issues helps museums' staff to frame the knowledge that may already have [1] and also to update their knowledge not only in different practices of access - for example in new technologies - but also to contemporary issues in education such as the context and the practices of inclusive education and issues of differentiation [2].

The present work highlights a critical aspect of the BaGMIVI project which is related to museums' staff training in a. disability issues, b. visual disabilities, and c. accessibility and differentiation. In this context, training courses were organized for the staff in the MCA in order to update their knowledge and provide them hands-on experience

through workshops. The purpose of these training courses was to inspire and equip all members of the MCA with ideas and alternatives in order to develop their own accessible and differentiated museum educational programs and material.

2. MCA ACTIONS

2.1 Training courses

The training course was structured in the following thematic areas: a. Special Education and individuals with visual disabilities: haptic apprehension - communicative and educational perspectives, b. Individuals with visual disabilities and issues of accessibility in education and culture and c. Inclusion and differentiated programmes: Contemporary perspectives.

Many workshops were conducted in conjunction with lectures, which gave the MCA staff the opportunity to acquire hands-on experience and to work out ideas in the following areas: a. orientation and mobility: guiding and escorting a person who is blind, b. environmental adaptations, c. the use of the remaining senses, d. the construction of differentiated museum programmes for visitors with visual disabilities, e. the production of tactile diagrams; elaborating principles of designing tactile diagrams.

2.2. The differentiated museum educational programs

As the most popular collection of the MCA is the Cycladic one and especially the marble figurines, the members of the Education Department of the MCA in collaboration with external professionals decided to create a museum kit. This device would act as the basis for a series of multi-sensory activities and information about the Ancient Cycladic Civilization, 3rd millennium BC, in general and more specifically the marble figurines with direct and indirect references for the Cyclades and their history (see Figure 1).



Figure 1. The MCA museum kit

The contents of the museum kit were the following: a marble figurine of the folded arm type, an embroidered map of the Cyclades (Figure 2), a tactile water map of Cyclades (Figure 3), a puzzle consisting of broken parts of different figurines, which the children were invited to put together (Figure 4), a tactile book (Figure 5) and a tutorial video.



Figure 2. Embroidered map



Figure 3. Tactile water map



Figure 4. Puzzle



Figure 5. Tactile book and representative pages

3. SCHOOL VISITS

School visits were organized in the MCA and all students with visual impairment were invited to take part in a series of activities pertinent to the differentiated material as described above. A short description and a reflection of these visits are provided below:

All children enjoyed playing and learned about the islands, the origin of the name Cyclades (i.e. cycle, κύκλος), and the different minerals that were used by the people of the Cyclades through a tactile water map. The tactile water map is a round tin filled with water that depicts the geographical relief of the Cycladic Islands. In turn, they could palpate the seabed of the Cyclades and interact with the stone islands. Pebbles of different shapes and minerals such as obsidian, emery, pumice, cinnabar and of course marble played the role of identifying the different islands (see Figure 6).



Figure 6. Cyclades tactile water map

Also, the students were administered different parts of broken figurines to put them together to create a gigantic puzzle of a Cycladic figurine-doll. It was like the puzzle

with the broken statues and figurines that the archaeologists are faced with during the excavations (Figure 7). In addition, the students were invited to explore by touch an embroidered map of the Cyclades. The children touched the map, felt the different shapes of the islands and cited their names. With different threads, the children created sea routes, from island to island (Figure 8).



Figure 7. Gigantic puzzle



Figure 8. Embroidered map of the Cyclades

4. CONCLUSIONS

In total, all students during their visits in the MCA, touched, felt, played, improvised, and in the end learned through a differentiated set of materials. The development of collaborations and partnerships between museums and schools is considered to be crucial for the diffusion of good practices towards inclusion and the equal opportunities to cultural goods. For this, it may be argued that the underpinning of all effective types of intervention have to be based on the concept of differentiated instruction, according to which instruction is planned in such a way to meet the needs of all learners and maximizing their capacity [3].

Acknowledgments

This study constitutes part of the BaGMIVI project (No: 2014-1-EL01-KA200-001631) which is funded by the Erasmus+ programme of the European Union and co-ordinated by the State Scholarships Foundation (IKY).

REFERENCES

- [1] Z. Partington-Sollinger, and A. Morgan, *Shifting perspectives. Opening up museums and galleries to blind and partially sighted people. CultureLink*, retrieved from http://www.google.gr/url?sa=t&rct=j&q=&esrc=s&source=web&cd=4&cad=rja&uact=8&ved=0CDgQFjAD&url=http%3A%2F%2Fg3ict.org%2Fdownload%2Fp%2FfileId_854%2FproductId_175&ei=AcQSVfS1FcyBUbv6gFg&usq=AFQjCNE8neEla3ru5C1YeSM5khgyBINwog, 2011.
- [2] C. Tomlinson, "Grading and Differentiation: Paradox or Good Practice?" *Theory Into Practice*, vol. 44, no. 3, pp. 262-269, 2005.
- [3] D. Van Garderen, and C. Whittaker, "Planning differentiated, multicultural instruction for secondary inclusive classrooms", *Teaching Exceptional Children*, vol. 38, pp. 12-20, 2001

Visual impairment and Autistic Spectrum Disorder: customised care illustrated in case examples

Marit van Buijsen¹, Hans van den Heuvel¹ and Peter Verstraten¹

¹Robert Coppes Foundation, Expertise, Innovation and Knowledge (EIK),
Vught, the Netherlands
{mvbuijsen, hvdheuvel, pverstraten}@robertcoppes.nl

ABSTRACT

People with a visual impairment in combination with an autistic spectrum disorder (ASD), are faced with an exponential impact of their impairments in their daily life. These people need a customized care. This impact and customized care is illustrated in the description of the case examples of two women living in a residential care facility of the Robert Coppes Foundation. These case examples show the complexities of this people and their care givers are faced with every day.

1. INTRODUCTION

A small, not yet well known number of adults who are visually impaired have psychiatric disorders (people with VixPI). The Robert Coppes Foundation (RCS) is specialized in providing care to people with VixPI. Clinical experiences show that the impact of the combination of different impairments (i.c. PI and VI) is higher than the sum of its parts, as an exponential increase of impairments leads to an exponential decrease of possibilities to compensate. Adults who are faced with the combination of having a visual impairment and an autistic spectrum disorder (ASD) is one of the special groups within people with VixPI. Because of their ASD, these people have impairments in their social interaction, social communication and social imagination [1]. In combination with their visual impairment they experience an exponential impact of these impairments on their daily life [2] and are challenged every day in compensating for their combination of impairments. Therefore a customized care is needed. This is illustrated with the description of two cases.

2. CASE EXAMPLES

2.1 Case 1

This case is about a 40-year old woman who is living in one of the residential care facilities of the Robert Coppes Foundation. She has a visual impairment (left-sided hemianopsy), an atone bladder and brain damage as a result of a hydrocephalus at birth. She has to catheterize three

times a day. In her youth she has experienced a lot of hospitalizations for her physical problems and has been bullied at school. In 2014 she was diagnosed with an autistic spectrum disorder and a personality disorder not otherwise specified (PD). Because of the late diagnosis of the ASD and PD, she was mainly supported in her visual impairment and physical problems. For a long time she did not had the appropriate support for her cognitive and social emotional functioning. As a result she has developed a negative self image and is focused on satisfying others needs. She has developed an obsession for the local hospital. She sees this place as her safe haven, where the people understand her.

Incentives, thoughts and uncertainties in her life lead to agitations. She is not capable to regulate this agitation for herself and this leads to an overload in her information processing. Resulting in compelling, claiming and verbal and physical aggressive behavior.

The guidance of this woman is mainly aimed at preventing an overload in her information processing. Therefore the important triangle within the guidance for people with an ASD of providing structure in her day by giving clarity, safety and predictability [3] form the basics of her guidance. Because of her visual impairment in combination with her ASD and a low self esteem she has a great difficulty in estimating others intentions and trusting others. Therefore, building a confidence relationship is very important in her guidance. If she doesn't know what others intentions are, she will continuously be seeking for acceptance.

It's a challenge to hold on to the guidelines for her daily support and structure, because of her combination of impairments. Mostly people with ASD are given structure throughout the day by visualizations. However, this is restricted because of her visual impairment. Although she knows that holding on to her daily structure is the best for her, she tends to deviate from her daily structure. Because she believes that she needs to be treated as every other person and a daily structure does not belong to this (PD). For instance, she does not want to use her weekly planning board. If others come to visit her, she hides her board, because she is ashamed. Furthermore, she wants to have control over her own medicines. However, she is not able to keep the overview in this (planning and her visual impairment), so she forgets to take her medicine in time. Also, she keeps on helping others, although she is

Copyright: © 2017 Marit van Buijsen et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

already agitated. In consultation with her care givers she decides to cancel her work as volunteer, because she is already agitated. But is then helping a neighbor.

These examples are challenges for her caregivers and herself. Care givers need to be continuously creative to hold on to the guidelines set out for her.

2.2 Case 2

Case 2 is also represented by a 40-year old woman who is living in a residential care facility of the Robert Coppes Foundation. As a result of a retinoblastoma, her eyes were removed at 4 months and 2 years of age. She is completely blind. Furthermore, she has a mild intellectual disability, is diagnosed with ASD and her social-emotional functioning is equal to a child of 4 to 5 years. As a result of this combination of impairments she is not able to keep an overview, anticipate on changes, regulate her own emotions and process information. She has a limited stress reduction and builds up tension when situations are unclear or she is being agitated. An overload can lead to aggressive behavior and if she is continuously being overloaded, she can develop depressive symptoms. Therefore, she needs continuous proximity of a care giver.

As in case 1, the guidance is mainly aimed at preventing an overload in her information processing. Therefore the important triangle within the guidance for people with an ASD of providing structure in her day by giving clarity, safety and predictability [3] is the basis of her guidance. Furthermore, she is constantly supported in her communication with others. Communication with her is always concrete and unambiguous, and tactual and auditory supported.

As a result of this combination of impairments she has no possibilities to compensate. For instance, she is not able to walk outside her house independently. Her combination of impairments lead to an overload in her information processing in learning different routes and walk alone outside. Because of her blindness the situation is unclear for her. Furthermore, she is not able to get an overview of the situation and perform complex actions as a result of her ASD in combination with her mild intellectual impairment. And as a result of her low social emotional functioning she needs proximity from a familiar person.

Because of her blindness she is sensitive for misinterpretations in social situations and as a result of her ASD and low social emotional functioning she can link different information to each other. So, this leads to some convictions in her own head. She is unable to talk about this, but this can lead to agitations. For her care givers it is very important to be sensitive for these kinds of misinterpretations and help her in getting sense of the information.

These descriptions show how her different impairments tend to strengthen each other and have a high impact on her daily life.

3. CONCLUSION

These case examples show how having an autistic spectrum disorder combined with a visual impairment, will have an exponential impact on their daily life and leads to fewer possibilities to compensate. Guiding these people asks a lot of creativity of their care givers and therefore a customized care is needed.

REFERENCES

- [1] Wing, L., Gould, J., Gillberg, C. (2011). Autism spectrum disorders in the DSMV: better or worse than the DSM-IV? *Research in Developmental Disabilities*, 32,768-773.
- [2] Gense, M.H. and Gense, D.J. (2005) *Autism Spectrum Disorders and Visual Impairment: Meeting Students Learning Needs*. New York: AFB Press.
- [3] Speksnijder-Romijn, I (2008). Autisme in de dagelijkse praktijk. In: Didden, R. & Huskens B. (red.) *Begeleiding van kinderen en jongeren met autisme. Van onderzoek naar praktijk*. (pp13-50). Houten: Bohn Stafleu van Lochum

Assessment of Autistic Behavior in People with Multiple Disabilities

Mathijs Vervloed and Gitta de Vaan

Radboud University, Behavioural Science Institute, Nijmegen, Netherlands
m.vervloed@pwo.ru.nl

ABSTRACT

In people with sensory and intellectual disabilities behaviors that resemble Autism Spectrum Disorders (ASD) are often encountered. In a four year project we have tried to disentangle symptoms of ASD from behaviors resulting from sensory and intellectual impairments. As an introduction we first look at symptom overlap and differentiating characteristics of ASD and sensory impairments. Then we will present a critical review of current screening and diagnostic instruments for autism spectrum disorders in people with sensory impairments in addition to intellectual disabilities. Because current instruments do not suffice we designed a new assessment instrument, OASID, which we have been working on to assess ASD in people with combined intellectual and sensory impairments. In the last part we present our data on ASD, mental health problems, stress reactions and stereotyped behaviors in people with combined intellectual and sensory impairments.

1. INTRODUCTION

Several symptoms of ASD are not unique but also found in other groups of people with disabilities, such as people with hearing disabilities [1], visual impairments [2], intellectual disabilities [3] and combinations of these impairments, such as deafblindness [4]. As a result the prevalence of ASD seems to be much higher in people with one or more of these disabilities. In the entire population ASD is estimated to occur in at least between 0,1 and 0,6 percent [5, 6] and at most 2,64 percent [7]. In people with intellectual disabilities the prevalence is much higher, ranging from 4 up to 60 percent [8]. The prevalence of ASD and autistic features in people with sensory disabilities is reported to be much higher than in typically developing people [9-11] and almost 30 times more likely in blind children than sighted children [12].

It is an interesting question what causes this increase in prevalence when other impairments are involved. An obvious explanation could be a relationship between ASD and sensory or intellectual disabilities. An alternative explanation is an overlap of symptoms, but not of the underlying mechanisms, between autistic people without other disabilities and people with sensory and intellectual impairments. If the latter is the case, some people might be unfairly diagnosed as autistic when in fact they are not. False positive diagnoses then causes the increase in prevalence of ASD in sensory, intellectually and multiply impaired people.

When behaviors show overlap there is the risk that ASD is either missed or unjustly diagnosed. A wrong classification may lead to a wrong treatment plan, which is especially problematic if the treatment plan is counterproductive given the underlying cause. An example is the stopping of stereotyped movements. Whereas in the blind these are usually caused by sensory deprivation [13, 14], and are used to arouse the person, in people with ASD stereotyped movements help to cope with too much stimulation from the environment [15, 16].

2. SYMPTOM OVERLAP

A comprehensive overview of the overlapping symptoms between autistic and non-autistic people was published in 2013 [17]. This article describes the categories that the DSM-IV-TR distinguishes for ASD as well as on the overlap within these categories for autistic and non-autistic people.

3. ASD SCREENING AND DIAGNOSTIC INSTRUMENTS

Because of symptom overlap instruments that are used for diagnosing of, or screening for, Autism Spectrum Disorder (ASD) are mostly not applicable to people with sensory disabilities in addition to intellectual disabilities. Firstly, because they do not account for equifinality, the possibility that different conditions may lead to the same outcome. Secondly, because they do not have appropriate norms for this target population.

In our review we studied 20 instruments commonly used in the assessment of screening for and diagnosing ASD. With respect to the psychometric properties (norms, reliability and validity) most instruments indeed did not have norms for the target population and all instruments consisted of a quarter or more of invalid items. We warned against using these instruments for people with sensory in addition to intellectual disabilities [18] and started to design our own test.

4. NEW ASSESSMENT INSTRUMENT

To overcome the problems described above we designed Observation of Autism in people with Sensory and Intellectual Disabilities (OASID). OASID was designed to provide a more adaptive approach in diagnosing ASD in people with multiple disabilities. OASID is a semi-structured observational instrument.

After reviewing the literature and existing instruments, observations of the target population, conversations with caregivers and advice from experts in science and clinicians from the field, the differentiating characteristics for people with sensory and intellectual disabilities with and without ASD were selected. These findings were compared to the diagnostic criteria from the DSM-5. Transformation of these criteria into testable items was done by reviewing the literature and items of other instruments, especially of the O-ADB [19] and the ADOS [20]. Preliminary versions of OASID were reviewed by all authors, authors of the O-ADB and were discussed with caregivers and other researchers, before the final version was administered to participants. Table 1 shows an example item.

Task	Example question	Behaviour resulting in score of 0	Behaviour resulting in score of 1	Behaviour resulting in score of 2
The participant has played with their own toy or object, and after a while, the experimenter took away the object.	How does the person respond to the removal of their own object?	The person does not show anger, sadness or frustration as a response to the removal of their object.	The person shows some anger, sadness or frustration as a response to the removal of the object, or briefly clings to it, but gives the object away within three attempts of the experimenter.	The person shows anger, sadness or frustration as a response to the removal of their object, and he or she may cling to the object and refuses to give the object away even after three attempts of the experimenter.

Table 1. Example item from OASID

Sixty people with intellectual disabilities in addition to with visual impairments and/or deafblindness participated in a study on the psychometric properties of OASID. OASID was rated by three raters and cut-off scores for OASID were created using expert consensus. Cut-off scores were established based on the DSM-5. OASID showed good reliability and validity and is able to differentiate between four severity levels of ASD.

5. BEHAVIORAL PROFILES

5.1 Mental health problems

The persons we studied for the construction of OASID were also studied for mental health problems. We divided the sample in people with or without ASD based on OASID. We administered the List of disturbed attachment behaviors, the Anxiety Depression and Mood Scale (ADAMS), and the Stress Survey Schedule for Autism and Other Developmental Disabilities.

The persons with ASD showed more disturbed attachment behavior, manic and hyperactive behavior, and social avoidance, and less stress in reaction to unpleasant stimuli than persons without ASD.

5.2 Profiles of stereotyped behavior

All persons with ASD showed stereotyped behaviors. Since also 85% of the persons without ASD showed these behaviors stereotyped behaviors cannot be seen as discriminating features of ASD in the population.

5.3 Associations with stress

Multi-level analyses were performed to assess the effect of ASD on the cortisol response to the OASID administration. The control for individual differences cortisol levels were assessed on an ordinary control day. The cortisol measurements on the control day significantly predicted the cortisol response to the OASID. Higher cortisol concentrations on the control day predicted higher cortisol concentrations on the OASID test day. The predictors time and time quadratic were not significant, indicating that the OASID did not provoke a significant cortisol response for the whole group. Furthermore, the dummy indicating whether people are diagnosed with ASD or no ASD was not significant, indicating that the cortisol response levels of people with and without ASD were similar to the OASID, so with no significant cortisol responses.

6. CONCLUSIONS

The newly designed assessment instrument OASID was able to differentiate people with intellectual disabilities combined with sensory impairments, who clearly had or did not have signs of ASD. People with unclear signs of ASD scored in between those two groups with regard to their OASID scores. Overall the psychometric properties of OASID are promising. Single symptoms of ASD are hardly useful for differentiating people with and without ASD when these people have sensory and intellectual disabilities, since both groups showed stereotyped behaviors, social avoidance and symptoms of disturbed attachment.

Acknowledgments

This study was supported by a grant to the first author from ZONMW stichting inzicht, Royal Kentalis, and the Behavioural Science Institute of Radboud University.

REFERENCES

- [1] Knoors H, Vervloed MPJ. Educational programming for deaf children with multiple disabilities: Accommodating special needs. In: Marschark M, Spencer PE, editors. *The Oxford Handbook of Deaf Studies, Language and Education*. 2nd ed. New York: Oxford University Press: 2011. pp. 82-96.
- [2] Cass H. Visual Impairment and Autism. *Autism*, vol. 2, no. 2, pp. 117-38, 1998.
- [3] De Bildt A, Sytema S, Kraijer D, Minderaa R. Prevalence of pervasive developmental disorders in children and adolescents with mental retardation. *J Child Psychol Psyc*, vol. 6, no. 3, pp. 275-86, 2005.
- [4] Hoevenaars-van den Boom MAA, Antonissen ACFM, Knoors H, Vervloed MPJ. Differentiating characteristics of deafblindness and autism in people with congenital deafblindness and profound intellectual disability. *J Intell Disabil Res*, vol. 53, no. 6, pp. 548-58, 2009.

- [5] Fombonne E. The prevalence of autism. *J Am Med Assoc*, vol. 289, np. 1, pp. 87-9, 2003.
- [6] Fombonne E. Epidemiological Surveys of Autism and Other Pervasive Developmental Disorders: An Update. *J Autism Dev Disord*, vol. 33, no. 4, pp. 365-82, 2003.
- [7] Brown R, Hobson RP, Lee A, Stevenson J. Are There “Autistic-like” Features in Congenitally Blind Children? *J Child Psychol Psyc*, vol. 38, no. 6, pp. 693-703, 1997.
- [8] Hobson RP, Lee A, Brown R. Autism and Congenital Blindness. *J Autism Dev Disord*, vol. 29, no. 1, pp. 45-56, 1999.
- [9] Jure R, Rapin I, Tuchman RF. Hearing-impaired autistic children. *Dev Med Child Neurol*, vol. 33, no. 12, pp. 1062-72, 1991.
- [10] Matson JL, Shoemaker M. Intellectual disability and its relationship to autism spectrum disorders. *Res Dev Disabil*, Vol. 30, no. 6, pp. 1107-14, 2009.
- [11] Andrews R, Wyver S. Autistic tendencies: Are there different pathways for blindness and Autism Spectrum Disorder? *Brit J Vis Impair*, Vol. 23, no. 2, pp. 52-7, 2005.
- [12] Rubin J., Pogonza, R. & Rapin, I. Autism Spectrum Disorders (ASD) in Blind Children: Very High Prevalence, Potentially Better Outlook. *J Autism Dev Disord*. Vol. 46, pp. 749–759, 2016.
- [13] Frith U. *Autism: Explaining the enigma*. 2nd ed. Oxford, UK: Blackwell Publishing; 2003.
- [14] Wolters N, Knoors HET, Cillessen AHN, Verhoeven L. Predicting acceptance and popularity in early adolescence as a function of hearing status, gender, and educational setting. *Res Dev Disabil*, vol. 32, no. 6, pp. 2553-2565, 2011.
- [15] Wing L, Gould J. Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *J Autism Dev Disord*, vol. 9, no. 1, pp. 11-29, 1979.
- [16] Fraiberg S. *Insights from the blind*. New York, NY: Basic Books; 1977.
- [17] Gitta De Vaan, Mathijs P.J. Vervloed, Harry Knoors and Ludo Verhoeven. Autism Spectrum Disorders in People with Sensory and Intellectual Disabilities Symptom Overlap and Differentiating Characteristics, in *Recent Advances in Autism Spectrum Disorders - Volume I*, Michael Fitzgerald (Ed.), InTech, 2013, DOI: 10.5772/53714.
- [18] De Vaan, G., Vervloed, M.P.J. , Hoevenaars-van den Boom, M., Antonissen, A., Knoors, H., & Verhoeven, L. A Critical Review of Screening and Diagnostic Instruments for Autism Spectrum Disorders in People with Sensory Impairments combined with Intellectual Disabilities. *J Men Health Res Intellect Disabil*, vol. 9, no. 1-2, pp. 36-59, 2016. doi: 10.1080/19315864.2015.1119917.
- [19] Hoevenaars-van den Boom, M. A. A., Antonissen, A. C. F. M., Knoors, H., & Vervloed, M. P. J. Differentiating characteristics of deafblindness and autism in people with congenital deafblindness and profound intellectual disability. *J Intel Disabil Res*, vol. 53, no. 6, pp. 548-558, 2009. doi: 10.1111/j.1365-2788.2009.01175.x.
- [20] Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. *ADOS: Autism diagnostic observation schedule. Manual*. Los Angeles: WPS, 1999.

Apps for mobile devices: how to distinguish accessible apps from inaccessible apps

Jeroen Baldewijns

Blindenzorg Licht en Liefde,
Brussels, Belgium
baldewijns.jeroen@lichtenliefde.be

ABSTRACT

Apps can turn a smartphone or a tablet into an alternative for a dedicated assistive device. By using the right app, a visual impaired user can turn his iPhone, iPad or Android device into a daisy player, a colour detector, an OCR-scanner, a pocket CCTV-system, a braille note taker, ... But how to choose the right app for each of these purposes?

To be usable for visual impaired people, apps needs to be developed in line with the accessibility guidelines. The general principles behind these accessibility guidelines are equal to those of the web accessibility guidelines. And it is up to the app developer to meet these guidelines.

But how can you, as a professional therapist, judge about the accessibility of an app? In this workshop, we will demonstrate how to check if the app is accessible enough for your visual impaired client? We will show you how to determine the level of accessibility of an app. Furthermore, will learn you a few tricks how to find work-arounds for certain accessibility problems. We will show you how to create labels for badly labelled elements. And we will even show you how easy it is to translate apps that doesn't exist in your language.

1. INTRODUCTION

The Apple App Store contains 200.000 apps. Some of these apps are very interesting for people with visual disabilities. Some apps are specifically developed to replace traditional assistive devices, such as a daisy player or a color detector. Other apps are developed to replace frequently used apps such as the browser, the calendar or the address book by alternatives with big fonts, high contrasts or integrated speech facilities. Some apps are simply interesting because they offer an alternative for other inaccessible information sources, such as apps from train companies, TV program guides, waste collection calendars, ...

But do all these apps meet the criteria for accessibility? This is something you can judge yourself. This workshop will show you how.

2. ACCESSIBILITY OF APPS

An accessibility standard that is set up for the accessibility of apps doesn't exist. But the general principles for digital accessibility are similar for any kind of digital format. Thus, the WCAG (Web Content Accessibility Guidelines) offer a strong basis that can be used to judge the accessibility of apps for mobile platforms.

You can assume that apps, that are developed especially for people with disabilities, are fully compliant with the accessibility principles. Often this is not the case, and this is something to worry about.

During this workshop, we focus on the iOS platform and we assume some notions of the VoiceOver screen reader for the iPhone/iPad platform.

3. ACCESSIBILITY PRINCIPLES FOR APPS

Starting from the Web Content Accessibility Guidelines, we have derived 14 accessibility principles, that you can easily check if you know the basic principles of how to use the VoiceOver screen reader.

- Any object on the screen is reachable by the VoiceOver-cursor.
- Any object on the screen is been read by the VoiceOver screen reader.
- Graphics are provided with text alternatives.
- The complete information showed by complex graphics is available in an accessible way.
- The swipe-order is logic.
- When entering a new screen, the insertion point of the VoiceOver-cursor is logic.
- Popups and Lay-overs are accessible with the VoiceOver screen reader.
- Any operable object on the screen can be used with the VoiceOver screen reader.
- Headings are used where they facilitate the navigation.
- Hints are available for all operable objects on the screen.
- Text and images provide a good contrast.
- Well readable typefaces are used for displaying text.
- Color cannot be the only way to transfer information.
- Disturbing sounds can be switched off.

A selection from these guidelines will be explained in-depth and demonstrated by means of a good and a bad practice.

4. GOOD PRACTICES

Some apps contain very interesting user interface elements in terms of accessibility. We will show a few examples of such apps.

5. WORK AROUNDS FOR USERS

If an app isn't accessible for the full 100%, doesn't mean that this app is not accessible at all. Sometimes, these apps are still pretty usable for a VoiceOver user, except from a few functions.

What's interesting is that VoiceOver offers quite a lot of features you can use to overcome certain accessibility problems. If the VoiceOver user knows all these little ins and outs, he will be able to overcome quite a few accessibility problems. To conclude the workshop, we will give an overview of these interesting features.

Social Haptic Communication

Veerle Vanthuyne¹, Vanhoutte Peter¹, Weemaels Jose¹, Verstraete Elke², Amerlynck Koen²,

¹Border members v.z.w. Anna Timmerman Belgium
www.annatimmerman.be

²Assistants of deaf-blind Persons

SOCIAL HAPTIC COMMUNICATION

1. INTRODUCTION

Communication is more than language by producing words and making gestures. What about emotions, behavior, atmosphere, ... these items are important too. They can color what has been said but are extreme difficult to get accessible for those who are visually impaired: blind or deafblind.

2. SOCIAL HAPTICS

We offer you the solution: use the Social Haptics! Haptics are signs you produce on the body. Haptic describe what is happening how people are reacting, what you can see all around.

3. EXAMPLE

For example, people are laughing, the other is getting bored or angry, the audience is really interested, how is your food getting dressed up in your plate.

4. INFORMED

Social Haptics is giving the deaf blind person the occasion to get informed well about the situation and to get more involved. Third and Further Level Headings

5. MESSAGES

Another benefit is by using the Social Haptics you can give short messages. For example: it's high time! What do you want to drink? someone wants to shake hands, they're taking pictures, we have to queue....



6. WORKSHOP

In this workshop we will focus on describing the environment and facial expressions by haptic.

Copyright: © 2017 First autor et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Up to an inclusive life after special education

An interactive session based on a testimony

Monique Van den Abbeel

Experience expert

ABSTRACT

I'm convinced that everyone should have the possibility to give direction to his/her life. Having a visual impairment should not influence my dreams to take up different community roles. My knowledge and experiences gathered at school age will guide my adult life. On the way I learned to handle with both: support as prejudices.

Beside efforts to create independent living it was not easy to find meaningful daily activities such as a job, inspiring leisure or hobbies.

Later on, motherhood was consciously chosen.

I will share my experience of organizing daily life with a baby, a toddler, a child and an adolescent including my contacts with services, authorities, neighbours, parents at the school gate, etc.

If a paid job wasn't realistic, I'd had to look for a meaningful alternative.

Telling my story and writing it down opens the dialogue in society. It shows a way for both, sighted and visual impaired, to be partners in an inclusive society.

1. INTRODUCTION

From my fourth to nineteenth, I followed special education and care in Spermalie in Bruges. After the primary school I attended a training sales and office.

For the educator team self-reliance and independence were paramount. All registers were opened to allow you to function as independently as possible. But ... was this enough for me? What comes after your career in school and boarding school?

2. FLYING OUT

2.1 Step 1

At 18, I wanted to get rid of the protection I always had had and chose to be better prepared for real life. After many conversations and negotiations, my

dream came true. I had the possibility to live in small house near Spermalie.

An educator helped me to organizing my daily life, budgeting and time management. I enjoyed the independence and the opportunity to making my own choices and priorities.

2.2 A place called home

For almost sixteen years I only met my parents during weekends. The world I grew up in was a totally different from my parents' world. This made me decide not to go back home after leaving school but to start living independently.

To choose for yourself is not easy. My parents were struggling with it too. But, for me, this decision felt correct.

3. A JOB

Looking for a job was the beginning of an ambivalent process, full of questions as well for me and for my employers, to be answered. Was it really necessary to go for a job? To whom? For society? For me? Why make all these efforts? Should there be a result? Should I pick up a new study?

4. LOVE AND PREGNANCY

In the meantime I had met my prince charming. At least that was what I thought he was. At the age of twenty-four, I had to deal with an unexpected pregnancy and facing its consequences.

Many comments and prejudices appeared. I was deeply touched by the many negative comments, although I knew they were indicated by worry. People were anxious for the unknown situation. Nevertheless, after a lot of discussions with my family, my (ex)partner, my psychologist, I decided to keep the baby and to become a single mother.

5. MOTHERHOOD AND EDUCATION

When my little son had the age of 18 months I was asked to cooperate in a television program "Liefde is blind" ("Love is blind").

It was the start of more personal testimonies and participations to platforms discussing integration and inclusion. I was willing to participate provided that one had respect for my story. It was never my intention to put the spot on my own story but I hoped it would open doors for other persons with visual impairment.

We will look and discuss some fragments of this program while presenting this paper.

6. SUPPORT

Looking back at that period of trying to become more and more independent, it is my advice to look for the right attitude and ask for support when needed.

But, be aware. There is a great difference between being depending on the help of general services and managing my own personal assistance budget.

Assistance is expensive! The waiting lists for getting assistance are long! In the beginning, I managed with 6 hours of family help and 4 hours of cleaning help. Only after 13 years I received a budget with which I could buy assistance for about 24 hours a week.

7. DIFFERENT SOCIETY ROLES

7.1 Being a mother and an employee

I choose - not only for financial reasons, but also for social contact with colleagues – to find a job.

After graduating as a polyvalent employee, I worked as an interim clerk at the government.

I did an internship on diversity in the public broadcast corporation on a full time basis. In the morning and in the evening I had to arrange care for my son who was far too young to take care for himself.

I had to spend hours to commute between home and work and had to run to catch my train, tram or bus. Going to work, as a single, visually impaired mommy is not obvious at all. After a while, my

temporary job at the broadcasting service stopped and I became unemployed again.

7.2 Time for self-development

I then took time for self-development courses, followed yoga, and stayed active as an experience expert regarding visual impairment.

8. THE FUTURE – A DIFFERENT APPROACH

I put my testimony on paper and poured it into a book "Graag zien! Blinde mama, sterke vrouw" ("Like to see/love! Blind Mum, Strong Woman").

For the moment I give lectures to promote the ideas written down in my book, I give workshops ... through my own association, to create a full time job for myself!



REFERENCES

- [1] Television program "Liefde is blind" (Love is blind)
- [2] M. Van den Abbeel, Graag zien! Blinde mama, sterke vrouw. Van Halewyck, 04/02/2016
- [3] www.moniquevandenabeele.com

Stories: A Different Way To Interact With Blind Or Visually Impaired Children And Adults With Additional Disabilities

Jeske D'haene, Annelies Meulemans, Wieteke Luppens

Centrum Ganspoel,
Huldenberg, Belgium
{jeske.dhaene, annelies.meulemans, wieteke.luppens}@ganspoel.be

ABSTRACT

Stories over time have always been an important part of our lives, from early infancy to adulthood. This is no different for people with a visual (multiple) impairment. Stories can have different functions: pleasure, stimulation of interaction and transfer of knowledge. Through recognition and anticipation, early communicative functions are developed. Language development, social skills, and sensory development are also stimulated and self-expression can be developed. Reading aloud creates opportunities to improve the quality of interaction between children and their educators.

For people with a visual (multiple) impairment, stories are often inadequate and depending on the target group several adjustments are required. At Centrum Ganspoel, a Belgian centre for visually impaired and blind children and adults with additional disabilities, we make use of different types of stories, such as experience theatre, multi-sensory stories, newspaper articles, film and theatre.

While telling stories, we stimulate all senses by using stimuli related to the story. Various communication systems are used, such as personal movements, gestures, ... and various technological aids may be employed.

For years, these types of stories have been part of our work with people with a visual (multiple) impairment.

In this contribution, we want to present six different methods of storytelling.

1. EXPERIENCE THEATRE

In experience theatre, a story is told and experiencing the story is key. In other words, the content of the story is secondary to the experience. The story appeals to children and adults with severe multiple disabilities. The story tries to connect to their specific levels of experience and communication. The theatre is set in an attractive, yet low-stimulus area. We also provide a clear beginning and end to the activity. A song or some music can be helpful here.

The narrator moves amongst the audience. After each short text of about 1 to 2 sentences, he or she offers each listener individually related sensory stimuli. The narrator is assisted by other caretakers. The stimuli appeal to all the senses and are offered close to the body. Hearing as well as vision, smell, taste and touch are addressed. This allows the listeners to explore and increase their

perception of their environment. They are also given the opportunity to experiment with the materials themselves.

The story is told at a slow pace so that participants have sufficient time to take in the setting, to focus on the stimuli and to respond to them. We strive for a sense of basic security in the listeners. By repeating the story frequently, it becomes familiar and recognition occurs. This creates the opportunity for the participants to start anticipating the story. It is best for the group not to include too many people so that maximum individual attention can be provided. We aim for maximum 3 listeners per caretaker.

2. MULTI-SENSORY STORIES

The multi-sensory stories (PAMIS) that are being told are personalised stories. We start from the interests and close environment of the child or adult with severe multiple disabilities. These are real, concrete personal experiences he or she has gone through or will undergo. The story is created based on information obtained from parents or caretakers. All individual stories exist of 6 to 8 sentences or short paragraphs and use simple language. Each paragraph has a specific stimulus that illustrates what is being told. This object should draw the attention of the person and invite them to explore. For this, we make use of the different senses taking into account the particular sensitivities of the person. Moreover, the stimuli make the story more concrete, the words tangible.

Our intention is to standardise the way of telling the story regardless of the narrator. Therefore a clear instruction manual is provided with each story, which offers the text with the accompanying stimuli. It also includes a description of how the story should be introduced.

Although these stories were originally intended for one specific person, it is possible to tell a story to a small group, by working on a theme, e.g. the farm, or an activity, e.g. taking a bath. This story will take into account the interests and lives of the various listeners.

3. READING TIME

Reading time is a class activity which is carried out by the speech therapist and the teacher. The target group are pupils with a mild to moderate cognitive impairment. The big difference between this activity and both experience theatre and multi-sensory stories is the focus on content.

Within this activity, the emphasis is more on learning and less on experiencing.

The content of the story that is read reflects the theme of the moment. Themes are selected based on the life of the pupils (e.g. the house, the doctor, traffic, the farm) and the time of year (e.g. the seasons, holidays). Again, repetition is important to obtain recognition and understanding of the concepts.

Each part of the story is immediately made more concrete with materials and sounds. The children are each individually allowed to explore the materials with all their senses and experience their functions. In this way, we work on expanding their vocabulary. Especially with the blind, it is necessary to make the words more concrete to give them meaning and thus avoid empty concepts. In choosing the specific objects we take the possibilities and limitations of the children into account. It is for example sometimes desirable to use just a part of the entire object, e.g. horsehair instead of a toy horse, because it is a more concrete and tangible representation for them. It may also be useful for some children to associate pictures and/or photos to these objects in order to expand their visual database. Here we must take into account the visual possibilities.

Centrum Ganspoel has also developed a similar activity for adults with a mild cognitive impairment. It introduces a hand puppet that both tells and experiences the story.

4. NEWSPAPER ARTICLES

Working with stories should not be limited to fictional stories, but can also be based on today's news. At Centrum Ganspoel, this is done for different target groups with a mild to moderate cognitive impairment: primary school, secondary school and adults.

This is done by means of 'Kleine Wablieft', a Flemish newspaper that brings weekly news in simple language tailored to children, and 'Karrewiet', a news program for children and young people with a developmental age between 6 and 12 years old.

In this activity, we connect with the outside world to broaden the horizons of the children. We also pay attention to their own interests and give them the opportunity to provide input and express their opinions.

With adults, we use 'Wablieft', a newspaper aimed at young people and adults. The newspaper is read out loud and each resident has the opportunity to choose an article of their interest. These articles are further discussed in group. Afterwards, the selected articles are taken to the living unit or their homes. For residents who use a communication aid, the article is placed onto the tool so that they can independently tell us about the news later. It is also possible to draw up a communication sheet, which is then attached to the resident's wheelchair table. This promotes a topic of conversation and interaction with the environment. Using communication aids during this activity fosters the transfer to the living unit and their homes.

5. FILM

In addition to listening to stories, we want to offer children and adults the opportunity to tell stories themselves. Hence other skills are addressed and emphasis is placed on expression. Each individual takes part in the film in their own way, allowing for a wide range of target groups to participate. We try to maximally exploit and draw attention to their opportunities. Different communication aids are also used. The project of making a film is concluded with a presentation for residents and staff of Centrum Ganspoel as well as family members.

The participants work intensively on the creation of the film and they are involved in all preparations. Together we craft the decors and we promote the presentation. The different scenes are practiced both individually in therapy and in group. When the participants are familiar with the story and their role in it, the different scenes are recorded. In making the film, we also take into consideration the visual limitations of the actors and spectators. We do this by making sufficient use of sounds to support the visual story.

During the presentation, each individual is assigned a task according to their capabilities: welcoming the spectators (verbally or with their communication aid), managing the cash register, announcing the film, etc.

6. THEATRE SHOW

Children and adults can practice their expressive skills also through a theatre show. Yet in comparison to the film, the theatre show takes it one step further because the actors need to learn to cope with the tension and stress of the performance. The show can either start from an existing story or from a brainstorming session in which the participants themselves shape the story. It takes a lot of practicing for the actual performance: empathizing with your character, showing feelings on command, being silent when necessary, remembering text, and experiencing becoming someone else by dressing up.

As with the film, we try to fully exploit the supporting communication aids. This way we want to show how the residents use this tool to promote the integration of it.

In order to make the scenes accessible to persons with a visual impairment, we also pay attention to adding important auditory elements. Striking and clear accessories are used to visually support and accentuate a particular role.

Here too we attach importance to the recognisability of the story through repetition and the use of recurring sentences to delimit the different scenes in the story. This ensures that persons with a visual impairment can follow the story more easily.

Film and theatre shows are both ideal projects to put the capabilities of the child or adult in the spotlight. They stimulate self-confidence, self-development and promote cooperation and social relationships between participants.

All the stories are available in a digital format to all employees who wish to use them.

Moving towards self-confidence

Ria Waelen

Royal Visio Stationspark 2
4462 DZ Goes The Netherlands
Phone: 0031652679949
Email: riawaelen@visio.org

Abstract

In a changing world it is important to grow up to be a strong and independent individual. For visually impaired children it is harder to learn social behaviour by copying others. As a result, social interactions don't come as naturally.

How can we, professionals, teachers and parents, contribute to the socio-emotional development of the blind or visually impaired children? How can we help them to become happy, firm and socially independent individuals?

In Royal Dutch Visio, we stimulate socio-emotional development and social skills by physical exercises and practical assignments, in groups of visually impaired children of different ages (6-9 year, 10-12 year). We use a program called "moving towards self-confidence". The method is based on 7 themes: body-awareness, insight, emotions, communication, teamwork, resilience and autonomy. In "moving towards self-confidence" we combine existing methods such as "Sherborne", "Rock and Water" training and experiential learning. The presentation consists of video images of the training to illustrate its different themes and principles.

1. Introduction

In the method we focus on enhancing the child's personal factors by physical activity and optimize the environment (home and school) by parent courses.

The purpose is to increase the child's participation in society.

2. The problem

For visually impaired children it is harder to learn social behaviour by copying others. There is a lack of eye contact as well as body language.

The interaction between people with visual limitations and those without is problematic. As a result, social interactions don't come as naturally.

Body awareness is an important factor in developing body-language and social skills.

3. The program

We train the visually impaired children in groups of different ages. The frequency is 12 times a year. We stimulate socio-emotional development and social skills by physical exercises and practical assignments. During

the physical exercises, the child learns to be aware of his or her own body by questions for reflection. The child experiences stress or joy in his/her body and learns to recognise it. By getting in contact with other visually impaired children, a child recognizes problems and feels supported. We train these skills in the gym and the children practice them in their different environments. We give them assignments that are based on their personal goals. We combine existing methods such as "Sherborne", "Rock and Water" training and experiential learning.

The method "Moving towards self-confidence" is based on seven themes: Body-awareness, Insight, Emotions, Communication, Teamwork, Resilience and Autonomy.

The program includes: a questionnaire (child and parent), questions for reflection, physical exercises, practical assignments, homework activities and a parents course.

3.1 The questionnaire

A questionnaire is used as a basis for a conversation of the social worker with the parents. What problems do parents experience? On what aspects do they think their child needs support?

The questionnaire for the child tells us how the child feels, gives information about his/her self-esteem and it identifies problems the child experiences.

The questionnaire allows us to set smart and personal goals for the child.

3.2 Questions for reflection

We set up different activities and different questions for reflection. By thinking about these questions, the child becomes more aware of the signals in his/her body and their behaviour.

3.3 Physical activities

When the children play together during the course, all 7 themes are present within a game. By physical activities and questions for reflection, the children become aware of the relationship between emotion and the signals from their body.

3.4 Practical assignments.

Assertiveness and autonomy is particularly important during the practical assignments.

3.5 Homework activities

Every session is completed with a group conversation. The children then get a homework assignment that is in line with the practical activity during that particular session.

3.6 Parent group

Parallel to the children's course runs a course for parents. During each parents session the social worker starts a discussion. How can they best guide their child at home? How do they talk with their child about the visual impairment?

The parents exchange information and work on their goals in the next weeks.

By taking a sensitive and responsive attitude, parents can recognize the child's emotions and the child will feel supported.

Conclusion

Working on self-confidence of blind and visually impaired children requires special attention and takes time. We use physical activities and practical experiences to allow the children to learn social functioning. Our experience is that it is important for children to share experiences with other visually impaired children. Children can benefit from learning social skills in a safe environment. It is even more important to practice these skills in their own environment by working with parents and teachers. We can support parents to let their children experience themselves.

‘De Pit’: An Inclusion Project For Adolescents With Visual Impairment And Multiple Disabilities In The City Of Tervuren

Veerle Coenraets⁽¹⁾, Susy Gijbels⁽²⁾, Sonia Meys⁽³⁾

Centrum Ganspoel, Brussels, Belgium:

⁽¹⁾ Occupational Therapist

⁽²⁾ Care taker

⁽³⁾ Special Education Generalist

ABSTRACT

In 2014 Centrum Ganspoel v.z.w. opened a residence for young people, aged 12 to 21 years, in the city of Tervuren. The ten adolescents who live in this house all have multiple handicaps and are visually impaired or blind. The youngsters, as well as their parents, have the dream of becoming as independent as possible and make the best choices for their future.

We will discuss how a multidisciplinary team, consisting of teachers, therapists, and care-takers, manages to support these young people and how they develop a tutorial that shows how improving abilities such as mobility, self-reliance, and social skills can be achieved. The aim of this program is to have the pupils learn as much as possible, taking into account their capabilities, so that they can make realistic choices for the future including living, work, and leisure time.

We will demonstrate the importance of living in a city to enhance the learning process. It gives the youngsters the possibility to take public transportation, use commercial and public services, ... Moreover, they are able to take part in the social life of Tervuren.

1. ORIGIN OF THE CONCEPT ‘DE-CENTRAL LIVING’

Where did the idea come from? Why have we moved?
Origin of the name ‘De Pit’?

Coming from the support need of the children and youngsters themselves and their parents to reach as much as independence as possible in living, work and leisure, we started thinking on how to realize an inclusion concept.

Living in the street fits much more with the common life and offers a wide variety of opportunities to effectively participate in the social life.

The campus ‘Centrum Ganspoel’ is situated in a beautiful, however rural setting. Too distant to be able to easily participate in that social life.....

2. WHERE TO GO?

In a city... a municipality? Affordable and at the same time nearby Ganspoel. Quite a challenge! How did we proceed?

A bustling municipality at 7 km from the campus in Huldenberg seemed like the ideal location to us.

The choice was made for a new construction that we could fully adapt to the needs of people with a visual impairment. The accessibility for youngsters with a multiple motoric disability has been considered as well.



3. COLLABORATION WITH THE MUNICIPALITY OF TERVUREN

How did we organize the collaboration?

At first, we have established the necessary contacts with the infrastructure service and discussed a proposal for adaptations of the different trajectories with each other.

The municipality of Tervuren has shown a great willingness to adapt the surroundings, amongst others guiding lines and tactile paving at crossing points, rubber tiles to indicate the bus boarding points, ...

All of this has been implemented in a phased approach.

4. FOR WHOM?

How has the target group been composed?

We have considered following aspects to determine if youngsters were eligible:

Their age (as of the school year they turn on 12 years old), they have sufficient learning capabilities to reach the predetermined objectives, their intrinsic motivation, they have capabilities to develop their self-reliance, and they want to take steps to build their own identity and autonomy.

5. IMPORTANCE OF MULTIDISCIPLINARY COOPERATION

How did we concretize the integrated cooperation in the house?

The creation of a suitable program requires a close collaboration between the school, living group and therapists.

It took us two years of teamwork to acquire sufficient knowledge, create and elaborate a program and gather the required tools to give this project a chance to succeed. During this process, we took into account the dreams and wishes of the youngsters themselves and their parents. We regularly informed them, provided feedback and gathered input during consultative meetings.

Until today, we are still working to get the best possible answers to the current questions and needs of these young people.

6. THE OBJECTIVES FOR A CUSTOMIZED CARE

The offer is very differentiated because of the diversity of the impairments and ages.

The main objectives used are:

- Personal and household resilience
- Social Resilience
- Inclusion in living/internship/leisure
- Creation of a realistic image of their own possibilities to enable making the right choices “together” for their future.

As part of the customized care idea, we assume that every younger learns at his/her own pace, according to his/her own possibilities, needs and interests. This is made possible throughout a learning path (7 years) in which the growth is accompanied step by step. A learning path that start off from the individual support questions of the youngsters and that is being concretized in an offer to a group of young people with similar needs and possibilities.

7. ADDITIONAL CHANCES FOR THE YOUNGSTERS

Suddenly the youngsters get a whole new set of options for their leisure.

During the week evenings, they can follow judo lessons and Zumba classes in the local sports club, go to the swimming pool, go out to have a drink, go buy bread themselves, go for a walk in the nearby park... inclusion is held in high esteem!

In doing so, we like to make volunteers eager to participate to enable its realization.

Also, the Wednesday afternoon activities have gotten a very meaningful interpretation: amongst others visits to the museums, sports and games, going to the cinema, attend TV show recordings, go to the theatre, go out for dinner with the living group, ...

A meaningful way to broaden their living environment!

8. TESTIMONIALS OF A COUPLE OF YOUNGSTERS

Based on a number of testimonials, we would like to introduce to you the way the young people themselves experience their living in Tervuren.

And as a cherry on the cake, take a look at their life in ‘De Pit’, daily life as it is for them...!

Concept Development of blind children: a general introduction

Ans Withagen¹, Anneke Blok¹

¹ Royal Dutch Visio, centre for partially sighted and blind persons,
Huizen, The Netherlands

{answithagen, annekeblok}@visio.org

ABSTRACT

On the basis of what our senses tell us we build ‘concepts’. These help us understand the world. Conceptualization, as this process is called, does not take place in quite the same way in blind children as in sighted children. This is because their perception of many objects and other things in the extrapersonal and peripersonal space (or far and near space) is different.

During the day our senses provide us with all kinds of information. This is how we make sense of the world around us. Each sense has its role to play and together they form ‘a bridge to the world’. Blind children need extra support to learn about the world. Language can be a help but we have to bear in mind that concepts that are constructed from language alone can be misleading. Especially the so called ‘farther-away’ words are difficult to understand for blind children.

1. INTRODUCTION

There is a huge difference between the sense of touch and vision is the fact, that ‘touch’ is a so-called near sense and ‘sight’ is a far sense. For many of us, sight is the dominant sense and therefore the most important. It allows us to take in a situation at a glance and that is why we rely a lot on this sense. Blind children lack this ‘overview’ provided by the sense of sight and have to compensate by using other senses. In our guidance of blind children we can help them to discover the world and make efficient use of touch and other senses.

2. THE SENSE OF TOUCH

2.1 Forms of touch

Touch allows us to perceive in two ways [1]: cutaneously and proprioceptively. ‘Cutaneous touch’ refers to touch sensitivity, or the perception of stimuli through the skin. It’s this type of perception which plays a big part in the ability to distinguish the small raised Braille dots that make up Braille characters. ‘Proprioceptive touch’ is present in the joints, tendons and muscles and relays information about the position of the body and its movements. Blind children depend on this sense when they explore their environment. It enables them to feel the

difference in height between two towers they have been building, for instance. They also need it to experience distance, the spaces between objects, the (relative) position of objects and the position of the body.

Apart from proprioceptive and cutaneous touch, we also make a distinction based on function.

Tactual perception is made up of a ‘protective’ and a ‘discriminative’ system. The protective system tells us that we are being touched or are touching something ourselves. In order to keep us from harm, the system makes us withdraw. The discriminative system tells us about the nature of what it is we are touching by enabling us to distinguish between textures, like rough and smooth.

2.2 Characteristics of touch

Touch, compared to our other senses, covers the largest surface area of the body. Although we have nerve endings all over the body, not all areas of the body are equally sensitive. Some areas have more receptors than others and these will be the most touch sensitive. Our fingertips and mouth are exceptionally well-equipped to perceive detail. Babies and toddlers often use the forehead, cheeks and other sensitive parts of the body to acquaint themselves with objects.

Sequential perception

Our eyes give us detailed information and an overall impression at the same time. This is called ‘simultaneous perception’. Exploration by touch does not give us an instant ‘bigger picture’. It has to be explored bit by bit. This means that the information enters our brain in small pieces, one after the other. This process is called ‘sequential perception’. We then have to fit all the pieces together. Our sense of touch relies on our memory skills to a far greater extent than our sight: we can take in an object, like a new playground in the schoolyard, at a glance but blind children will have to explore and remember it bit by bit. Tactual perception not only taxes memory skills, it also requires concentration. If your concentration flags during the exploration process, part of the information will be lost and the final picture of the object will become distorted.

Three dimensional perception

Three dimensional perception and tactual perception go together. It means that objects that can be enclosed by both hands are 'looked at' both from the back and the front. This is not possible by visual means alone. A window at the back of a three dimensional toy house can be discovered immediately by manual exploration but in order to see it you have to turn it around.

3. WORDS AND CONCEPTS

There are many ways to categorize words. For blind children we have chosen the following categories [2]:

- 'nearby' words (for instance, sock, ball, book)
- 'farther-away' words (for instance horse, apartment, cloud)
- abstract words (for instance, time, idea, because)

The difference between one category and another is not always clearly defined. The word 'horse' can be a nearby word for a child living on a farm and a farther-way word for a child living in a town.

Take care not to take it for granted that the child has fully understood a word. Small misunderstandings can distort the child's image of the world quite a bit and cause it to draw the wrong conclusions. Formerly, children whose understanding of a word was incomplete were said to be using 'meaningless language' or 'verbalism'. These days we prefer to call it 'floating' language. It means that children know and recognise certain characteristics of an object but that some of the information is missing.

Farther-away words present a real challenge to blind children, mainly because the objects they refer to cannot be caught hold of or enclosed with the hands. The lack of concrete tactual experience makes it virtually impossible to develop a comprehensive image of such concepts.

When you explain this kind of concept it is important to make the connection with the knowledge your child already possesses.

4. FINALLY

During the presentation extra information will be given about the sense of touch; the different functions and characteristics of touch will be described. Furthermore, the influences will be discussed that affect the concept development of children with a severe visual impairment. Advices will be given to guide these children during the concept development.

REFERENCES

[1] Withagen, A., Heins, L., Blok, A., Betten, A., Buurmeijer, A., Mul, M., & Oosterlaak, L. (2013). *In touch, helping your blind child to discover the World*. Huizen, Netherlands: Royal Dutch Visio.

[2] Linders, C.M. (1998). *Zweeftaal en andere raadsels in het woordbegrip van blinde kinderen*. Huizen, Netherlands: Royal Dutch Visio.

Group Meetings (1 – 4 Days) For Children Or Youngsters With Visual Impairment As Method To Achieve Individual Goals

Emma Vandamme¹, co-workers Team Youngsters¹

¹Mobile Support Service Accent, Centre of Expertise Spermalie / De Kade,
Brugge, Belgium
Emma.vandamme@de-kade.be

ABSTRACT

During group meetings we work on individual goals of the children/youngsters by different activities: workshops, initiations of (challenging) leisure time activities, training mobility skills, training daily skills, practicing social skills, practicing skills in real life situations,...

We ask role models to give workshops and to be mentor during group meetings. The older participants can also be a role model for the younger participants. We choose positive role models to help children/youngsters feel confident. The interaction between children/youngsters and role models also enables an open and honest exchange of views and self-reflection.

The group meetings are an excellent opportunity to make contact with other partially sighted and blind peers and to build social networks. The children and youngsters experience support of their peers and are for once not an exception in the group of youngsters.

The group meetings give the space and opportunity to experiment with social behavior. Children/youngsters get a safe environment to practice social skills, make friends, start an intimate relationship, ...

The intensive support puts these goals into reach. Each tutor supports two (or three) children/youngsters during the meetings. This may seem a big investment in guidance, but in this way it is possible to give enough individual feedback and individual support, necessary for the children/youngsters to make real progress.

1. INTRODUCTION

Our mobile support service "Accent" offers individual mobile and ambulant psychological, social and educational support in consultation with blind or partially sighted children/youngsters and their families. We start from the questions that emerge in the families and their social environment. "Accent" was founded in 1977.

"Accent Actief" (Accent Active) offers activities to make children and youngsters stronger so that they feel up to participate in social life. The activities are a substantial part of the support we offer.

"Accent Actief" offers informative and interactive workshops (e.g. "On your way to secondary education", "On a bike in traffic"...), do-workshops (e.g. *shopping independently, urban exploration*), initiations (e.g. *acting, wall climbing, music...*), and since 2004 we organize

group meetings for children between 6 and 12 and between 12 and 21. The participants have all kinds of visual impairments.

During the shorter holidays we organize activities of one or half a day. During summer holidays, the **group meetings** are a multi-day activity with a variety of workshops and initiations: a four-day activity for children of 6 to 12 years old (with or without overnight stay) and a four-day activity (with overnight stay) for youngsters between 12 and 21.

2. THE SIGNIFICANCE OF GROUP MEETINGS FOR CHILDREN/YOUNGSTERS WITH VISUAL IMPAIRMENTS IN THIS INCLUSIVE SOCIETY

2.1 Important Social and Practical Skills Aren't Picked Up Incidentally Through Watching and Should Be Practiced Explicitly.

Studies are clear on this matter:

"Children with visual impairments often need more time, patience and perseverance to learn the same skills as good sighted peers." [1]

"Although numerous blind and visually impaired children and adolescents have been integrated into public school classrooms and are successful academically, both parents and professionals are deeply concerned that these children are not learning the social skills they need in order to interact adequately with their sighted peers. ... Research in the U.S.A. demonstrates that students in regular public schools lack the social skills to start and carry on conversations, play games effectively, and join and feel part of a group; are uncomfortable talking about their visual impairments; and, most important, they try to hide their visual impairments (Sacks, 1992). By concentrating more on interpersonal themes, the ideology of social integration should in the end lead to fewer relationship problems." [2]

"Students with visual impairments have the extra challenge of gaining information about visual aspects of social interaction, such as gestures and clothing; of being aware of standards of personal appearance, which is

based on limited or inaccessible visual information; and of developing self-esteem to oppose stereotypical attitudes about visual impairment.” [3]

Therefore social skills deserve all our attention during our group meetings, as well for the children of elementary school as for the adolescents.

Another problem is mobility. “International research (Sacks, 1992, , Sacks 2006, Kef, 1999, Kef, 2005 Sacks, 1998) demonstrates that youngsters with visual impairments feel quite dependent, but especially on the domain of mobility. Youngsters that experience a strong dependency, also have a lower self-esteem, more problems in accepting the impairment, more feelings of loneliness and a lower emotional well-being.” [4]

Therefore attention is given to training mobility skills during group meetings for children of elementary school as well as during group meetings for adolescents.

We pay more attention to practical skills in daily life activities, such as washing, clothing, eating properly,... in the group meetings for children of elementary school. During our group meetings for youngsters between 12 and 21 years old, special attention is given to three themes, also pointed out by Wolff (2006): “understanding how one looks in comparison to others and maintaining an attractive personal appearance, coping with the inability to drive and get around with transportation options available to non-drivers, and learning to flirt and date in hopes of developing positive intimate relationships.” [4]

2.2 Group Meetings as ‘Good Practices’

2.2.1 A Safe Environment

The group meetings give the space and opportunity to experiment with social behavior. Children/youngsters get a safe environment to try out practical skills, to practice social skills, to make friends or start an intimate relationship,...

Especially for visual impaired children and youngsters the threshold to experiment with mobility, with social skills, to try and make friends, to start a relationship... is big.

2.2.2 Practicing Skills in Real-Life Situations Instead of Practicing Skills During Individual Training in Artificial Settings.

“Many social skills can best be taught in the actual situations where they will be applied. This ensures that a student has both a need for the skill and an understanding of its context” [3].

The difference between applying these skills in everyday life and practicing them during our group meetings is that the youngsters can be observed and guided. With friendly, noncritical advice or small corrections, suggested by peers or tutors, in the safe environment of our meetings, they start to reflect on their actions and develop their skills.

2.2.3 Intensive and Competent Feedback and Support from Professional Tutors

J. Erin writes: “Sometimes people are reluctant to provide feedback to students about their appearance and physical movements, but it is important for visually impaired students to receive specific detail. This can be presented in a noncritical and informational manner.”[3]

During our group meetings the individual goals of the children and youngsters to learn practical and social skills can be achieved, thanks to the intensive support of professionals with specific knowledge about the impact of visual impairments. Each tutor supports two (or three) children/youngsters during the meetings. In this way it is possible to give continuous individual feedback, to explain, to model specific behavior,...

Wolffe, Thomas and Sacks raise our awareness of the following: “Professionals need to be aware of the unique problems and concerns of teenagers with visual impairment, to be able to offer helpful guidance and suggestions when appropriate, to lend support without being overprotective or intrusive.” [6]

This takes a difficult balance.

And finally: it is very important to pay a lot of attention to the choice of workshops and initiations. Entertaining activities are motivating.

There should be a varied offer of activities (sports, culture, nature, entertainment and challenging activities) in combination with the training of skills (such as mobility skills, social skills, skills in daily life activities, ...) and giving information about where to find tools and support. The activities should be sufficiently challenging, but of course also safe!

2.2.4 Role Models

We ask role models to give workshops or to be mentor during different activities. The older participants can also be a role model for the younger participants. We choose positive role models to help children/youngsters feel confident. The interaction between children/youngsters and role models also enables an honest exchange of views and self-reflection.

J. Erin: "Because visually impaired children in public schools may have little or no contact with others who are visually impaired, connection with a mentor who is visually impaired may provide opportunities to understand what experiences are common among people with visual impairments and how others have handled specific issues." [3]

2.2.5 Support of Peers with Visual Impairments

During group meetings the children and youngsters are for once not an exception to the other peers. Group meetings offer the opportunity to exchange experiences. Children and youngsters with visual impairments can extend their social networks with peers who can support them in a special way, because they often experience exactly the same obstacles in social integration.

3. BENEFITS OF GROUP MEETINGS AS INTEGRATED PART OF MOBILE SUPPORT SERVICE

Mobile support service Accent works with one central tutor per family. The same tutors guide the group meetings. It's an enormous advantage that our tutors know the children and youngsters so well: their families and backgrounds, their needs, their fears, their qualities and strengths. Vice versa the information from the meetings helps to give feedback and appropriate support to the children/youngsters and their parents during the family sessions of our Mobile Support.

In order to provide adequate support during the group meetings, it is important to have insight into the individual child or youngster, his/her environment and how he/she copes with the environment: the social and practical competences, social networks and emotional well-being. During group meetings it's possible to observe the child or youngster in many different situations. This information can be used to be discussed afterwards with parents or the broader context or with the children and youngsters themselves. The skills they started to develop can be trained more intensively afterwards during individual training, they can be discussed with parents or in the broader context of their social environment and follow up is possible.

4. CONCLUSION

Although we've come a long way in terms of inclusion, still group meetings for children and youngsters with visual impairments remain very significant. The individual goals which are so important for the target group can

be acquired through strategies applied in our group meetings.

Group meetings are a way of giving support to children with visual impairments, but it's not the only way. Support for children and youngsters with visual impairments should be flexible.

J. Erin, who wrote about pupils and students with visual impairment at school says: "Students are responsible for their own choices about socialization, but professionals can influence their experiences by modeling appropriate social behavior, encouraging students, and arranging opportunities for them to learn and practice their skills." [3]

We believe in our group meetings. They work. They are worthwhile.

REFERENCES

- [1] Gringhuis, D., Moonen, J., van Woudenberg, P. (red.) (1996). *Kinderen die slecht zien. Ontwikkeling, opvoeding, onderwijs*. Houten: Bohn Stafleu Van Loghum.
- [2] Kef, S. (1999), *Outlook on Relations. Personal Networks and Psychosocial Characteristics of Visually Impaired Adolescents*. Amsterdam: Thela Thesis.
- [3] Erin, J. (2006). Teaching Social Skills to Elementary and Middle School Students with Visual Impairments. In Z. Sacks & K. Wolffe (Eds.), *Teaching Social Skills to Students with Visual Impairments. From Theory to Practice* (pp. 364-404). New York: AFB Press, American Foundation for the Blind.
- [4] Sabina Kef (2009), Tussenmenselijke interacties en relaties bij slechtziende jongeren. In P.L. Looijestijn & G. van Delden, redactie (2010). *Handboek Visueel Profiel. – een ICF geïnspireerde werkwijze over visuele waarneming, slechtziendheid en visuele revalidatie*. Koninklijke Visio, Huizen. Publicatie op www.visueelprofiel.nl ISBN: 90-74641-10-5.
- [5] Wolffe, K. (2006). Teaching Social Skills to Adolescents and Young Adults with Visual Impairments. In Z. Sacks & K. Wolffe (Eds.), *Teaching Social Skills to Students with Visual Impairments. From Theory to Practice* (pp. 405-440). New York: AFB Press, American Foundation for the Blind.
- [6] Wolffe, K., Thomas, K., Sacks, Z. (2000). *Focused on Social Skills for Teens and Young Adults with Visual Impairments. Study Guide*. New York: AFB Press, American Foundation for the Blind.

Analyzing Social Interactions in a Regular Class: A Pilot Study With Secondary Students With a Visual Impairment

Mathieu Gaborit^{1,2}, Nathalie Lewi-Dumont², Kenza Berrada³ & Minna Puustinen²

¹ Paris Nanterre University, Nanterre, France

² EA 7287 Grhapes, INS HEA, UPL, Suresnes, France

³ Paris Descartes University, Boulogne-Billancourt, France

Abstract

Our previous questionnaire studies on help sought by secondary students with a visual impairment (VI) during mathematics lessons (Puustinen, Arneton, & Lewi-Dumont, 2017) and help provided to secondary students with VI by mathematics teachers (Lewi-Dumont, Arneton, & Puustinen, 2016) yielded contradictory results: teachers, but not students, considered that students with a VI should ask for more help in class (cf. Puustinen, Arneton, Lewi-Dumont, & Gaborit, 2015). These results might partly reflect the limits of the use of questionnaires in research on in-classroom interactions. Therefore, in the present pilot study, our aim was to test a new methodological paradigm for the analysis of technology-mediated and face-to-face interactions taking place between secondary students with VI and their teachers, teacher assistants, and peers in an inclusive setting. Three blind 9th-graders included in a regular mathematics classroom in Paris were filmed during two 1-hour mathematics courses. The students, their parents, mathematics teacher, and teacher assistant were also interviewed.

Background

The research we are conducting is based on our two previous questionnaire studies on mathematics-related help-seeking interactions in secondary students with a visual impairment (VI). The first one (Lewi-Dumont et al., 2016) focused on mathematics teachers' perspective on students with a VI included in their classroom. It underlined several specificities related to teaching mathematics to students with a VI.

The second study focused on the students' point of view, i.e., students with a VI self-reported on their help seeking in mathematics classroom.

These two studies revealed that teachers' and students' statements differ in that students consider they seek enough help in the classroom whereas teachers

consider that students should ask for help more often. Both studies endorse the necessity to collect data in natural in-classroom learning situations. In fact, Gaborit, Lewi-Dumont, Arneton, and Puustinen suggested that the discrepancy between students' and teachers' statements might be at least partly due to the reliability of the data collection method employed (i.e., questionnaire) and that other data collection methods should be tested in the future.

Objectives

In the present pilot study, our aim is to test a new data collection paradigm for studying in-classroom help interactions.

Method

Because of the lack of existing studies on in-classroom social interactions involving students with a VI, our research is based on previous studies involving students with other disabilities. For example, Koegel, Matos-Freden, Lang, and Koegel (2012), who conducted their research in the field of autism spectrum disorders (ASD) in inclusive school settings, considered that the omission of one of the following information sources is expected to lead to erroneous conclusions: (1) examination of the student's file, (2) interviews of the professionals who work with the student, (3) observation of the students in natural setting, (4) standardized testing of the student. In addition, Loyd (2015) considered that it is necessary to take into account the viewpoint of the students with ASD themselves.

Within this context, the data collection method used in the present pilot study was the following:

The first step consisted in the video recording of two 1-hour mathematics lessons in a 9th grade classroom in a mainstream lower secondary school in Paris. Four out of the 25 students have a severe visual impairment¹. Three of the students, whose parents signed a written consent, were included in our study. They all read and write in Braille and use a specific electronic Braille device in the classroom. Two of them cannot see images

Copyright: © 2017 Gaborit, M. et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

¹According to the International classification of diseases (updated and revised 10th version, 2006), severe visual impairment is the 3rd category out of four (4th is blindness).
<http://www.who.int/mediacentre/factsheets/fs282/en/>

(for geometrics or geography for example) and one of them, who also benefits from the help of a teaching assistant, can hardly see any geometric figures. The three students with a VI were all seated at the front of the classroom, close to the teacher. The teacher used an interactive whiteboard and a dynamic geometry software. The teacher, the teaching assistant, and the students with a VI were equipped with lapel microphones, and three video cameras were used to record the lessons. Two of them were directed towards the students with a VI, and the third one filmed the whole classroom.

After the video recordings, audio-recorded semi-structured interviews were conducted with the mathematics teacher, the teaching assistant, the three students with a VI, a sighted classmate seated next to the students with a VI and playing the role of a tutor, and the parents of the students with a VI.

Results

Data analysis is still ongoing.

Discussion

The present pilot study aimed at testing a new methodological paradigm for studying help interactions. The new paradigm will be discussed in the light of our need to observe in-classroom interactions in ecological settings.

Our analysis will be focussed on each individual's role in the learning process. Newman (1998) underlines the importance of the specific relationship between the help-seeker and help-provider. In parallel to this, we must pay special attention to the learning environment. It includes the classroom resources as well as the students' capacity to use them. Previous studies on student help-seeking behaviour stress the importance of an interaction-oriented learning environment (Van der Meij, 1988), specially in mathematics classrooms (Resnick & Nelson-Le Gall, 1987).

Acknowledgments

We are grateful to Jean-Éric Lhuissier from the unit of audiovisual production (UPAM) of INS HEA for his help with the video recordings.

References

- [1] Gaborit, M., Lewi-Dumont, N., Arneton, M., & Puustinen, M. (2015). *L'aide et la demande d'aide médiatisée et en présentiel: les spécificités du recueil de données chez les élèves déficients visuels*. Paper presented at EIAH 2015, Agadir, Morocco.
- [2] Koegel, L., Matos-Freden, R., Lang, R., & Koegel, R. (2012). Interventions for children with autism spectrum disorders in inclusive school settings. *Cognitive and Behavioral Practice, 19* (3), 401–412.
- [3] Lewi-Dumont, N., Arneton, M., & Puustinen, M. (2016). Comment des professeurs de mathématiques s'adaptent-ils aux besoins des élèves déficients visuels? *Carrefours de l'éducation, 42*, 119–132.
- [4] Loyd, D. (2015). Gaining views from pupils with autism about their participation in drama classes. *British Journal of Learning Disabilities, 43*(1), 8–15.
- [5] Newman, R. S. (1998). Adaptive help-seeking: A role of social interaction in self-regulated learning. In S. A. Karabenick (Ed.), *Strategic help seeking implications for learning and teaching* (pp. 13–37). Mahwah, NJ: Erlbaum.
- [6] Puustinen, M., Arneton, M., & Lewi-Dumont, N. (2017). *La demande d'aide chez des élèves du 2nd degré avec déficience visuelle: Quelles spécificités?* Manuscript submitted for publication.
- [7] Puustinen, M., Arneton, M., Lewi-Dumont, N., & Gaborit, M. (2015). *Help seeking in students with a visual impairment: Students' and teachers' perspective*. Paper presented at EARLI 2015, Limassol, Cyprus.
- [8] Resnick, L. B., & Nelson-Le Gall, S. (1987). Meaning construction in mathematical problem solving. (Vol. 3, pp. 215–221). Presented at the 11th Annual conference of the psychology of mathematics education, Montreal: Bergeron, Herscovics & Kieran.
- [9] Van der Meij, H. (1988). Constraints on question asking in classrooms. *Journal of Educational Psychology, 80* (3), 401–405.
<https://doi.org/10.1037/0022-0663.80.3.401>

Screening Characteristics of Autism Spectrum Disorders (ASD) in Children with Cerebral Visual Impairment (CVI)

Griet Pattyn¹ and Greet Vissenaekens²

¹Mobile Support Service Accent, Centre of Expertise Spermalie / De Kade, Brugge, Belgium
griet.pattyn@de-kade.be

²Mobile Support Service Ganspoel, Centre Ganspoel, Huldenberg, Belgium
greet.vissenaekens@ganspoel.be

ABSTRACT

Children with CVI often show behavior that can also be attributed to ASD. This may be confusing for professionals as well as parents and the children themselves. This was the reason for the development of a screening list. The purpose is to provide a more objective base for referring children with CVI for further diagnostic procedures concerning ASD and therefore the child can be given the appropriate support.

The screening list is meant for children with a developmental age of 5 till 12 years old. It assesses how a child usually behaves. We selected the characteristics of ASD that we don't expect in children with CVI. It is the degree in which a certain behavior is present that enables the differentiation.

The screening list is preferably completed by parents, assisted by a qualified professional.

So far we have done a limited research, using the screening list in our support of children with CVI. The actual version of the list is available for further exploration of its validity.

1. INTRODUCTION

As professionals who work with children with a Cerebral Visual Impairment we often hear the question if a child with CVI has the disorder ASD. The behavioral characteristics between CVI and ASD are nearly the same. Therefore it is often confusing for professionals, parents and the children themselves if a child has CVI and/or ASD.

A differential diagnostic is important for appropriate support.

Copyright: © 2017 Griet Pattyn et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

2. PROCES

Hearing this question of similarity between the behavior characteristics of CVI and those of ASD and therefore difficulty in correct diagnose, a few professionals who are active in the field of children with a visual impairment in Flanders, Belgium came together in a subteam of the CORV (commission for Development and Research about Visual Impairment).

The start was a study of literature and investigate existing questionnaires both from CVI as ASD.

We focused on the question to determine if a child with CVI whether or not show signals of ASD?

This led us to a first version of the list, that we proposed to different professionals who are active in the field of ASD. That gave us an interested discussion and support to optimize the screening list multiple times.

3. SCREENING LIST

The first part of this screening list consists of an introduction and 4 subparts.

- A. Short description of CVI
- B. Short description of ASD
- C. (categories of) Behavior that can be find both in children with CVI and in children with ASD (non differential behavior)
- D. Behavior that indicates an ASS problematic and ask for an extensive diagnostic process.

The second part (E.) is the actual questionnaire. It starts with some space with data concerning identification as name, birthday, age, developmental information and also diagnoses.

In this screening list they asked for typical ASD features that not occur in children with CVI.

The list is meant for children with a developmental age of 5 till 12 years old.

Not the presence or absence of a specific behavior enables the differentiation but the degree in terms of frequency and intensity.

That's why the possible answers are: often, sometimes, rarely.

When mostly the answer 'often' was given, this means that there is no indication for further diagnostic investigation concerning ASD. When mostly 'sometimes' or 'rarely' is answered, this means that further investigation concerning ASD is indicated.

The screening list is being built around the 2 clusters:

- (lack of) social-communicative reciprocity through a distorted perspective
- (lack of) flexibility in thinking and acting (rigidity vs deficits in inhibition and creative imagination) [1]

Parents of children with CVI where there is a supposition of ASD can fill in the list together with a professional who is familiar with the child and with the themes of CVI en ASD..

4. FIRST RESULTS

Till now we have some experience using the screening list in our guidance of children with CVI. We have obtained and discussed the results for about 25 children. The professionals are satisfied with these first results.

The list can also be very helpful to inform professionals on the one hand to understand more about the similarities of the behavior characteristics of ASD and CVI and on the other hand to know the differences (C and D of the list).

5. FUTURE

For now we are pleased with the first results but we're hoping to get send back more filled in screening lists so we – preferably in co-operation with members of a university – can prove more about the sensitivity, specificity and the validity of the list.

Acknowledgments

We'd like to thank everyone who contributed in any form to the making of the Screening list. This screening list is produced in cooperation of the Mobile Support Services and Centers of Expertise Spermalie and Ganspoel, Rehabilitation Center De Markgrave Antwerpen, Centers of Expertise Autism from Leuven and Brussel, Centers for the diagnosis of developmental disorders from Leuven, Gent and Brussel and Centre for Expertise Network.

REFERENCES

- [1] W. Peeters, "Classificatie van autismspectrumstoornissen: naar een klinische consensus?," *TOKK*, 35-2010, pp.66-91

Using Modern Statistical Mapping Tools to Identify Social Participation and Wellbeing Need in Children with Visual Impairment

John Ravenscroft¹, Andrew Blakie,² James Thom,³

¹University of Edinburgh, School of Education, Edinburgh, United Kingdom
{john.ravenscroft@ed.ac.uk}

²University of St Andrews, Global Health Implementation, School of Medicine, St Andrews, United Kingdom
{ab312@st-andrews.ac.uk}

³NHS Scotland, National Network Management Service NHS National Services, Scotland, United Kingdom
{jthom@nhs.net}

ABSTRACT

This paper will focus on the recent developments in economics, informatics, climatology and UK National Health Services in analysing big data. Using visual analytical tools that have been developed we can start to understand and identify the needs and profile of childhood visual impairment either within small defined geographical areas (communities), local education authorities (schools), health boards (hospital and general practitioner (GP) services), or even analysis that is countrywide. This paper will present visual maps, which are easier for multi-agency teams, working with children with visual impairment, to understand and identify need than by examining databases of information. By mapping data, we can expose hidden patterns and relationships that exist that previously may not have been identified. Using the Visual Impairment Scotland (VIS) data set, a 12-year incident notification study, as core data, these up to date software techniques will show that data can be defined as geographic boundary or location and used to overlay the population of children with visual impairment thus resulting in identify the profile, incidence and prevalence of children with visual impairment.

1. INTRODUCTION

A significant proportion of children with vision loss or blindness require an integrated multi-agency tailored service provision but in order to plan and develop such services, well-trained and competent professionals, first need accurate demographic profiles on the numbers of visually impaired children. Currently, many countries still do not know how many children and young adults there are who have a significant visual impairment, where they live and what their 'visual profile' is. One agency over another may have some data, which is not shared, analysed or even visualised. It is the case that policy-makers and planners of integrated service provision face the difficult task of delivering services based on information

that may not describe the full scale or spectrum of children needing support. Perhaps a simple analogy would help to express the concerns being issued here. By not having accurate details on the numbers (and potential numbers) of users of our services, such as education, health and social work, is surely like an architect planning a large public building, but not knowing how many people will go into it, or consequently what the internal and external requirements should be [1]. By visualising the data using such visual mapping programs as *Tableau* [2] we are able to see and identify clusters, and explore hypothesis that were previously unanswerable.

2. METHOD

Using the data collected from the Visual Impairment Scotland study, a 12-year longitudinal study, children were notified to a central datastore from Paediatric Ophthalmologists, (with parent consent) using the following criteria.

- A best corrected binocular visual acuity equal to or worse than 0.5 logMar (6/18 snellen) or
- Any form of visual field loss or
- An eye movement disorder which affects visual function or
- Any form of cognitive vision due to disorders of the parts of the brain subserving visual function

The data was then cleaned and checked for any anomalies by a Paediatric Ophthalmologist and by a data analyst. Once ready the data was imported to the visual mapping programme with Scottish mapping coordinates.

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

3. RESULTS

In total, over 1000 children were entered into tableau which were then geographically mapped highlighting the exact geographical area these children resided. This mapping allowed geographical division by postcode, health board, and by local authority. It also allows us, for the very first time in Scotland, to map children with visual impairment against their parents/carers index of multiple deprivation allowing us to understand, at a grassroots level some of the social, health and well being issues children with visual impairment are facing.

Figure 1 demonstrates an example of the ability to geo-map this data. It shows the geographical spread of 1000 children with visual impairment in Scotland by Scottish residential health boards.

Figure 2 shows how the mapping tool can be used for any primary diagnosis that is captured. In this example Rod-cone Dystrophy.

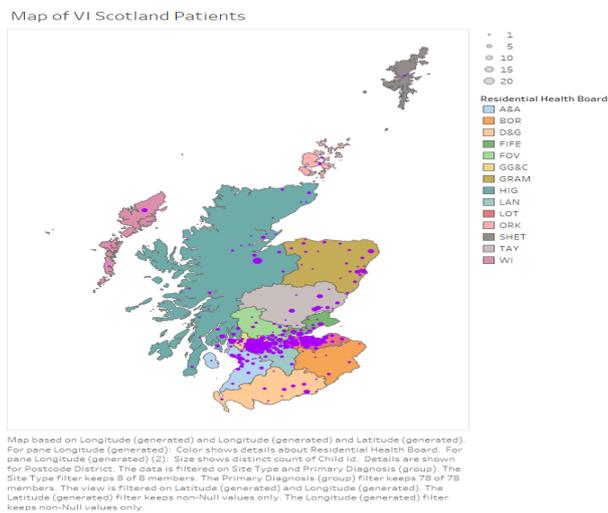


Figure 1. Mapping of Children with visual impairment in Scotland by residential health board

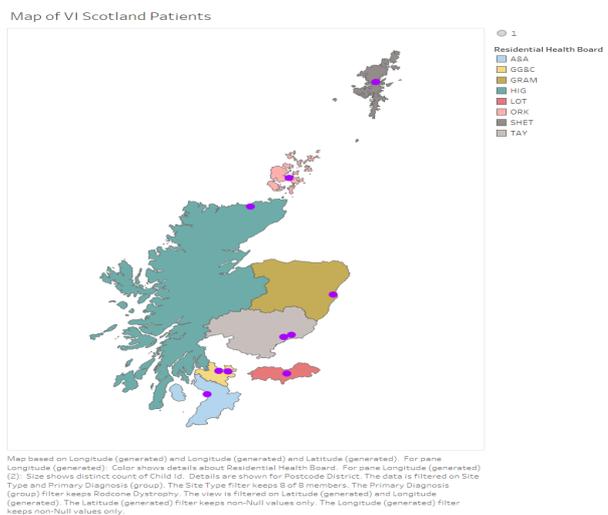


Figure 2: Mapping of children with Rodcone Dystrophy in Scotland by residential health board

4. DISCUSSION

This study supports the call that is often found in public health journals to use geomapped data to identify and support the work of professionals [3-5]. Knowing and understanding the profile of the children with visual impairment aids professionals, researchers, academics and parents and children through comprehensive geomapping with the necessary tool kit to enhance the service provision given to the children at the right time and at the right place. Geomapped data of childhood visual impairment should be used by all services that support children with visual impairment, health, education, and social services to aid planning, resources, transition, and standards. Being able to visually represent the profile of childhood visual impairment aids the development and enhancement of integrated services.

5. CONCLUSION

Geomapping data on childhood visual impairment can be a useful tool for enhancing and planning services for children with visual impairment.

Acknowledgments

We would like to acknowledge NHS Scotland, Dr Jennifer Skillen and Dr David Feeney for their help in data collection and analysis.

REFERENCES

1. Ravenscroft, J. (2016). Visual impairment and mainstream education: Beyond mere awareness raising. In L. Peer, & G. Reid (Eds.), *Special Educational Needs : A Guide for Inclusive Practice*. (2nd ed., pp. 232). [15] SAGE.
2. Chabot, C., Stolte, C., & Hanrahan, P. (2003). Tableau Software. *Tableau Software*.
3. Graham, S. R., Carlton, C., Gaede, D., & Jamison, B. (2011). The Benefits of Using Geographic Information Systems as a Community Assessment Tool. *Public Health Reports*, 126(2), 298–303.
4. Soares, N., Dewalle, J., & Marsh, B. (2017). Utilizing patient geographic information system data to plan telemedicine service locations. *Journal of the American Medical Informatics Association*
5. Hanna, N. K. (2017). *How Can Digital Technologies Improve Public Services and Governance?*. Business Expert Press.

Investigating risk perception and disaster management through perspectives of children with and without visual disability

Magda Nikolarazi¹, Sofia Chamonikolaou¹, Vassilios Argyropoulos¹,
and Charikleia Kanari¹

¹University of Thessaly, Department of Special Education, Volos, Greece
{mnikolar, chamonik, vassargi}@uth.gr, kanarixarikleia@gmail.com

ABSTRACT

Children, particularly those with disabilities, are often overlooked in disaster education programs and are rarely considered as important actors in disaster risk reduction (DRR). This paper describes a series of consultative workshops, the aim of which was to explore children's perspectives regarding risks and disaster management. Twenty children attending the first grade participated in the workshops; one of the twenty students had a visual disability. Action research was the method adopted throughout the workshops, and a wide range of accessible and child-led learning activities were implemented during the whole learning process. The results indicate the need for the development of disaster education programs that will address the multicultural needs of children and the accessibility barriers that children with diverse disabilities face in order to empower all children regarding their role in DRR.

1. INTRODUCTION

Children who receive hazard education seem to have more realistic perceptions of risk, reduced fears of hazards and increased knowledge of how to build preparedness [1]. Children can be educated to act independently as well as educate their parents by sharing their knowledge and experience with them [1,2,3]. However, children and especially children with disabilities are poorly considered in disaster education and disaster risk reduction (DRR) programs and also they are treated as social vulnerable groups who have little to contribute [4,5,6]. Often, disaster education programs for children including children with disabilities are synonymous with guidelines, emergency plans, and drills, while the methods and the whole learning process as well as the accessibility barriers that children with different disabilities face in formal or non-formal education receive less attention [7].

The aim of this paper was to explore and empower the role of the children, including a child with visual disability, in relation to DRR. A further aim was also to enable practitioners and policy makers to gain understanding and insight into children's needs and capacities in relation to DRR.

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

2. METHODOLOGY

2.1 Participants

A first grade class participated in the present study. This specific class consisted of twenty children and one of them had a visual disability (i. e. low vision), who was supported by a special education teacher.

2.2 Research Design

The workshops were planned and implemented by the Action Research Collaborative Team (ARCT), which consisted of three researchers, the general and the special education teacher. After planning each workshop, the ARCT observed the children's participation and reflected on the obtained data in order to carry on the plan of the next workshop. Seventeen workshops were implemented during three months, two days per week, for an hour each day. At the beginning, the workshops included discussions about various hazards and the focus of the workshops was placed on a specific hazard, namely fires, based on children's choice.

The Action Research Plan included two phases. The first phase was pertinent to the design and implementation of workshops, which took place in the students' classroom. The content of the workshops followed a social cognitive model of disaster preparedness [7]. All activities and educational tools during the whole learning process were accessible to the child with visual disability and enabled her to participate equally with the rest of her classmates. For example, tactile and audio material as well as enlarged printed educational material was designed. Also, the whole class was divided into small groups and worked on activities that the ARCT would suggest. The synthesis of the groups was changing and the student with visual disability had the chance to interact, collaborate, agree and disagree, in other words to build relationships based on dialogue and mutual support and respect with her classmates.

The second phase was focused on interactions with persons who had a chief role in education and risk management respectively. During this phase, all children with the ARCT's assistance developed questions and topics to discuss with important people-actors. Specifically, they arranged a meeting with the head of the school, they invited a rescuer and they visited a fire brigade. In all

cases, the children had the opportunity to ask questions and discuss issues in relation to fires.

3. RESULTS

During the workshops the children developed a more dynamic role in DRR. Most children have heard about a fire incident because fires are quite common in Greece but they did not personally experience a fire. Furthermore, due to the visual dimension of the fire, the child with visual disability had very vague perception of the meaning and the role of fire and she, as well as the rest of the children expressed their fear towards fire. Therefore, the members of the ARCT planned a workshop to emphasise the positive dimensions and benefits of the fire through the myth of Prometheus. Additionally, the children’s notions mostly concerned the phase of response to a fire. By following a social cognitive approach [7] all children were motivated to think about hazards and risks and in particular about fires and to explore how they could act and use resources to mitigate hazards effects. Furthermore, they were invited to develop a sense of belonging to a community, which according to the children’s notions in our study included mostly their family and their school (see Table 1).

Feelings about disasters	‘I am afraid’ ‘I do not feel anything’ ‘my eyes would burn’
Dangers regarding fires	‘the fire burns everything’ ‘can burn us’ ‘can destroy a forest’
Feelings about fire	‘fire is a bad thing’ ‘makes parents unhappy and children cry’
Benefits of fire	‘cook, bake, keep ourselves warm, light the darkness’
How to put out a fire	‘with water’ ‘sand’ ‘soil’
Self-management in fire situations at home	‘call 199’ ‘go outside our house carefully’

Table 1. Examples of children’s comments

Furthermore, in the second phase the head teachers, the fire-fighters and the rescuers who interacted with children were surprised because they did not expect from young children to have such focused questions about fires (see Table 2).

Fire Department	‘What clothes do you wear?’ ‘Did you have a fire today?’ ‘With what are we extinguishing the fire?’
Rescuers	‘How did you learn to put out a fire?’ ‘How many people have you saved?’
Headteacher	‘Do we have a fire alarm?’ ‘Are there any emergency exits?’

Table 2. Examples of children’s questions to key actors

4. CONCLUSIONS

All children in this study participated in child-led workshops that integrated a social cognitive approach of disaster preparedness. The whole learning process included activities and educational tools that made access and participation of the child with visual disability feasible. In this way, all children and in particular the child with low vision had the opportunity to express their own experiences and they were also empowered to understand their role in DRR.

Acknowledgments

 This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 653753

REFERENCES

- [1] V. Johnson, K. Ronan, D. Johnston, and R. Peace, “Evaluations of disaster education programs for children: A methodological review,” *International Journal of Disaster Risk Reduction*, vol. 9, 107-123, 2014.
- [2] H. Boon, L. Brown, K. Tsey, R. Speare, P. Pagliaro, K. Usher, and B. Clark, “School disaster planning for children with disabilities: a critical review of the literature,” *International Journal of Special Education*, vol. 26, pp.223-237, 2011
- [3] K.R. Ronan, “Progress made with school curricula, education material and relevant training in disaster risk reduction and recovery concepts and practices”, *Australian Journal of Emergency Management*, vol. 30, no. 1, pp. 8-9, 2015.
- [4] L. Peek, and L.M. Stough, “Children with Disabilities in the Context of Disasters: A Social Vulnerability Perspective,” *Child Development*, vol. 81, no. 4, pp. 1260-1270, 2010.
- [5] H.J. Boon, L.H. Brown, K. Tsey, R. Speare, R. Pagliano, K. Usher, and B. Clark, “School disaster planning for children with disabilities. A critical review of the literature,” *International Journal of Special Education*, vol. 26, no. 3, pp. 223-237, 2011.
- [6] S. Ronoh, J.C. Gaillard, and J. Marlowe, “Children with Disabilities and disaster Risk Reduction: A Review,” *International Journal of Disaster Risk Science*, vol. 6, no. 1, pp. 38-48, 2015.
- [7] M. Nikolarazi, V. Argyropoulos, and C. Kofidou, “Disaster education and sensory disabilities,” in *Proc. 1st Int. Conf. on Natural Disasters and Infrastructure*. Chania, 2016.
- [8] D. Paton, “Disaster preparedness: a social-cognitive perspective,” *Disaster Prevention and management: An International Journal*, vol. 12, no. 3, pp. 210-216, 2003.

The Role Of Leisure Time And Sport Activities For People With Visual Impairment In Developing Social Participation

Andrea Hathazi

¹Babes-Bolyai University, Special Education Department,
Cluj-Napoca, Romania
andrea.hathazi@ubbcluj.ro

ABSTRACT

The present paper will focus on the importance and characteristics of leisure time activities and sport activities for people with visual impairment and their role in the development of independence and social networking as a result of increased social participation, development of communication skills, but also increased self-esteem and identity. Leisure time activities and sport activities offer the possibility to develop social and emotional skills, increase the number of social partners and activities, opportunities for developing values and norms, but also self-determination and leadership and even development of innate abilities and talent in sports. The paper will present the results of a study which refers to people with visual impairment engaging in these types of activities, identifies factors that favor and encourage participation and describes factors that can make participation difficult.

1. INTRODUCTION

Inclusion, personal development, diversity, equality, support and participation are concepts that need to be approached in the context of new models of disability. Without the social and emotional support of significant persons, the cognitive, communication and social abilities of the individual with visual impairment will have a par-

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

ticular development. (Kef, 1999). The individual abilities and qualities that are considered essential for personal development include self-esteem, confidence, problem-solving skills, goal –orientated skills, participation in social and sport activities, independence, orientation and mobility skills, organizational strategies.

2. SOCIAL PARTICIPATION AND VISUAL IMPAIRMENT

In the context of visual impairment, reduced participation to activities can be influenced by lack of determination, lack of available choices, access only to organized activities and events, lack of access to transportation, location and inaccessible buildings, lack of equipment, but also lack of competent staff without positive expectations and information. There is no data of students with visual impairments who do sport at a professional level or who are members of a sport club, even though sport programs for people with visual impairment develop physical fitness and motor skills required by orientation and mobility and daily living skills, but also a more positive self-concept, self- efficacy and social inclusion (Huebner, 1986). There is also no data of services who offer on a permanent basis, accessible opportunities for recreation and sport facilities. It is known that children with disabilities are more physically unfit due to physical and psychosocial constraints (Stuart, Lieberman, Hand, 2006 apud Longmuir, Bar-Or, 2000).

To reduce the impact of visual impairment, support and educational activities need to be implemented from early age (Hutto & Hare, 1997; Sacks & Wolfe, 1998; Hodges & Keller, 1999; Rosenblum, 2000). Experiential learning allows children to develop a repertoire of social abilities need for social inclusion (Grusec & Abramovitch, 1982). Group identity represents a major factor that contributes to the success of the student in school. The lack of social acceptance can lead to a feeling of inferiority and non-acceptance (Huurre et al., 1999). Students with visual impairments can present difficulties in relating to peers and they tend to isolate, have few friends, spend their time alone in passive activities (Huurre et al., 1999; Wolfe & Sacks, 1997).

3. LEISURE TIME AND SPORT ACTIVITIES

Leisure time and sport activities offer the possibility to increase the number of social partners in organized or free play activities, opportunities for developing friendships, participation to social events developing thus a communication, social and emotional network. We must not forget the implications on the quality of life and opportunities for having fun, participation together with peers without disabilities, but also about how service – providers, especially in an institutionalized setting will take into consideration interests, specific abilities, hobbies, facilitating factors and barriers in the specific context of inclusive leisure activities.

Leisure time and extracurricular activities promote not only physical characteristics like posture, muscular tonus coordination, physical resistance, but also self-esteem, social skills and independence (Kekelis, 1992). One of the most significant effect of leisure time and sport activities in adolescents is the opportunity to explore identity, personal affirmation and transformation. It is about, in this period, to discover and assume strengths, capacities and abilities, hobbies and interests, goals and identity. In these activities, not only personal interests are pursued, but also the person is in a context that he or she can exert control on the environment, acts autonomously, assumes risks and play- roles (Coatsworth et al., 2005; Eccles, Barber, Stone, & Hunt, 2003).

4. BARRIERS TO PHYSICAL ACTIVITIES

In the development and implementation of sport activities, there is a lack of knowledge and competence regarding abilities of children with visual impairment in carrying out these activities, without strengthening the benefits of these on development. In a study realized by Jaarsma and al.(2014) the identified barriers to participation in sports activities are related to costs, difficulties in transport, lack of peers and the implications of visual impairment were mentioned as barriers to sport activities, but facilitating outcomes were mentioned such as health, fun, support from families and social contacts. Studies reported also as major factors the beliefs of professionals and parents regarding performances of children with visual impairment in sport activities, but also their own fears or lack of education and information with regard to their own ability in developing independent physical activities in children with visual impairments (Stuart, Lieberman, Hand, 2006). It is also about their fears related to the child's safety or on other set priorities in the child's education such as the academic performances.

5. RESULTS OF STUDY

The results of a study realized in 2016 with 20 people with visual impairments, between the age of 15-20, different aspects regarding participation to leisure time and sport activities were investigated. These aspects were: motivation to participate, opportunities and experiences within educational programs, expectations and support from teachers and parents. The answers at the interviews revealed that most of the times there was not enough support from teachers and parents in creating opportunities for the students to take part in leisure time activities or sport activities, that most of the time these were only structured activities, supervised by adults, with reduced possibilities for initiatives and spontaneity. There is also an evidence of fears of staff regarding the inclusion of students with visual impairments in different activities. Students who were in the sport teams reported greater number of friends and mentioned even lack of time to carry out all their activities. Students who were not members of team reported more frequently boredom and lack of activities.

6. CONCLUSIONS

The effects of participation in leisure time activities and sport activities must be approached within the context of visual impairment as there is an evidence of positive outcomes. Students with visual impairments need not only to develop academic skills and specific competences like Braille, orientation and mobility, use of assistive technology, but also leisure time skills and even developed physical skills in pursuing different sports . There is also the necessity to develop skills in teachers to develop and include students with visual impairments in this kind of activities.

REFERENCES

- [1] Kef, S., *Outlook on relations. Personal networks and psychosocial characteristics of visually impaired adolescents*. Amsterdam: Thela Thesis, 1999
- [2] Huebner, K.M., Social skills, in G,T, Scholl, *Foundations of education for blind and visually handicapped children and youth: Theory and practice*, New York: American Foundation for the Blind, pp. 342-362, 1986.
- [3] Hand, K., Lieberman, L. and Stuart, M., 2006. Beliefs about physical activity among children who are visually impaired and their parents. *Journal of Visual Impairment & Blindness (JVIB)*, (04).
- [4] Hutto, M. D. and Hare, D., Career advancement for young women with visual impairments. *Journal of*

Visual Impairment and Blindness, 91, pp. 280-295, 1997.

- [5] Sacks, S. Z. and Wolffe, K. E., Lifestyles of adolescents with visual impairments: An ethnographic analysis. *Journal of Visual Impairment and Blindness*, 92, 7-17, 1998.
- [6] Hodges, J. S. and Keller, M. J., Visually impaired students' perceptions of their social integration in college. *Journal of Visual Impairment and Blindness*, 93, 153-165, 1999
- [7] Rosenblum, P., Perceptions of the impact of visual impairment on the lives of adolescents. *Journal of Visual Impairment and Blindness*, 7, 434-445, 2000.
- [8] Grusec, J. E. and Abramovitch, R., Imitation of Peers and Adults in a Natural Setting: A Functional Analysis. *Child Development*, 53(3), 636, 1982.
- [9] Huurre, T. M., Komulainen, E. J., and Aro, H. M., Social support and self-esteem among adolescents with visual impairments. *Journal of Visual Impairment and Blindness*, 93, 26-37, 1999
- [10] Wolffe, K. and Sacks, S. Z., The lifestyles of blind, low vision, and sighted youths: A quantitative comparison. *Journal of Visual Impairment and Blindness*, 91, 245-257, 1997.
- [11] Kekelis, L., Peer interactions in childhood: The impact of visual impairment, in Zell Sacks, S. (Ed.), *The development of social skills by blind and visually impaired students*, American Foundation for the Blind, New York, 1992
- [12] Coatsworth, J. D., Sharp, E. H., Palen, L., Darling, N., Cumsille, P., and Marta, E., Exploring adolescent self-defining leisure activities and identity experiences across three countries. *International Journal of Behavioral Development*, 29, 361-370, 2005.
- [13] Eccles, J., Barber, B., Stone, M. and Hunt, J., Extracurricular activities and adolescent development. *Journal of Social Issues*, 59, 865-889, 2003.
- [14] Jaarsma, E.A., Dijkstra, P.U., Geertzen, J.H.B. and Dekker, R., Barriers to and facilitators of sports participation for people with physical disabilities: A systematic review. *Scandinavian journal of medicine & science in sports*, 24(6), pp.871-881, 2014.

“Art does not have to be visual”

- Students with visual impairment and their art teachers about motivation in art

Anneli Embe

Resource Center Vision, National Agency for Special Needs Education and Schools,
Stockholm, Sweden
anneli.embe@spsm.se

ABSTRACT

Inclusion in the art subject can be excluding for a student with blindness, as art traditionally focuses a lot on the visual sense. In this study some students and their teachers were interviewed about what can be motivating in inclusive art education when the student has blindness or severe visual impairment.

What basically motivated the students was creating together with sighted classmates, no matter how challenging the assignment was. In art education the differences between sighted and students with visual impairment became especially clear. Demands on teachers' planning and adapting are high. Students' tactile experiences constituted strong memories that stayed with them for many years.

To make art education meaningful for a student with visual impairment or blindness, lessons need to be planned, for the entire class, with focus on open tasks and with different solutions. Teachers can become aware of that focus on more senses than the visual may lead to all students getting inspiration and strong inner images in several school subjects.

1. INTRODUCTION

All of the students with visual impairment and no severe additional disabilities are included in mainstream education in Sweden since 1986. There is not very much research made on inclusive art education with students with blindness. For example what could be motivating for the students and what their teachers need to think about.

1.1 Aim of the study

The aim of this study was to shed light on what may be motivating in art studies in inclusive education for young people with visual impairment or blindness.

Questions for the study were: What are the students' experiences of art studies with focus on their motivation? What are the art teachers' ideas on lesson planning with focus on creating motivation in inclusive art education?

2. METHOD

This was a qualitative study and with semistructured interviews. The interviews were recorded and transcribed.

The transcribed material was analyzed with a phenomenological approach. This was a suitable method to examine the students' own experiences from art studies and to reach the perspective of the teachers in their planning of inclusive art teaching.

The participants in the study were four braille reading students with blindness or severe visual impairment in grades 7 to 9, and their art teachers. Two students were girls and two were boys. Three of the students had blindness with no light perception. Two of them had light perception up to school started. One of the students had a visual acuity of 10/200. All the students studied according to the elementary school curriculum. Two of the art teachers had attended the whole program for further teacher training at Resource Center Vision. One teacher had further training in teaching students with low vision. The fourth teacher had got no further training at all.

3. MAIN RESULTS

3.1 Strong memories

The students had several clear recollections from experiences in art studies. They had strong positive memories connected to multidisciplinary tasks and tasks dealing with complicated concepts. The use of molding material and exploration of objects or real places had also created positive memories. The students appreciated to be able to make individual choices, e.g. when choosing material and type of method. One student could recollect the feeling of awkwardness when nothing was suitably adapted.

3.2 Vague memories

Assignments that did not involve student's own creating were harder to recollect. One such example was to analyze an image that the assistant had described in words. One student noted that compiling facts about a painter was a meaningless assignment.

3.3 Opportunities and disadvantages

Inclusive art education could be inspiring to art teachers as well as most students in class. But some assignments were demanding for the teachers to adapt, and nor did the students with visual impairment perceive them as mean-

ingful. Such assignments could be about filmmaking, photographing, perspective drawing and colour theory.

3.4 Differential data

One of the students with blindness enjoyed painting. She liked to cover the whole surface with colours. She perceived that her colour painting had higher quality and would last. "Wikki stix usually fall off." Another student liked to draw depicting figures from his dreams.

4. DISCUSSION

4.1 Gaining new knowledge

Assignments where the students acquired knowledge about new concepts were motivating and left strong memories with them, especially knowledge that the students could benefit from in general, not just in art education. Gaining new knowledge that had not been made accessible earlier generated a feeling of inclusion. The Norwegian researcher Klingenberg [1] claimed that when the students reach knowledge about complex concepts in a specific subject, like mathematics, it facilitates for the students to involve themselves in discussions on the subject.

4.2 Exploring

Opportunities to explore objects and real places gave the students strong recollections. The students used their whole bodies and multiple senses, all at the same time, which might have contributed to their strong memories. Earlier when students with blindness attended the special school, the teachers found that students' own experiences and creativity was the best way to acquire knowledge, that would otherwise have seemed incomprehensible without vision [2]. Klingenberg observed that complicated mathematical concepts were easier to grasp when the students got to examine geometrical shapes with multiple senses, using both fine and gross motor skills [1].

4.3 Descriptions of images

The students in the current study found it hard to recall verbal descriptions of images. The reason could be that the images had been described only by visual qualities, which students with blindness do not have any experiences of. Tierney Kreuzer [3] noted that students with blindness use less descriptive words in their own stories than their sighted peers do, and the reason could be that our visual perspective is dominant in the language we use. In general, when images are used as inspiration for a writing assignment, the images are described on the basis of visual qualities [3].

4.4 Multiple senses

The students remembered well creating with clay, plaster and wax. These were memories from several years back. When modelling with clay a variety of receptors in the skin are activated. Even the linguistic area in the brain is activated, according to Eriksson [2], who refers to a re-

searcher named Heller. Also the haptic sense is used when exploring with the hands, which contributes to the perception [4].

4.5 Creating in common with others

Characteristic for the tasks that had left strong positive memories was joint creation. Joint creation meant to the students that they got the task at the same time as their peers. It did not necessarily mean creating together as a group. Their experiences from group work in art were actually not so good. However, to some of the participants group work had felt rewarding in cases where the visual sense had not been allowed to dominate, and further, one student thought he had learnt a lot from others during discussions.

5. IMPLICATIONS FOR PRACTICE

There will probably be consequences for the students' self-esteem and level of inclusion, when art teachers do not get further training as teachers for students with visual impairment. Teachers need to convert the contents in the syllabus to give knowledge not only through vision. Open tasks with different solutions are preferable. It could be recommended that all the students in the peer group use three dimensional elements in their creative work. Focus needs to be more on the qualities of other senses than vision, theoretically as well as practically. The students need opportunities to get mental images as often as possible, in as many school subjects as possible, and to work through exploring, creating and modelling.

6. REFERENCES

- [1] O. G. Klingenberg, "Matematikk og elever som bruker punktskrift i opplæringen: En kartlegging av elevgruppen i forhold til undervisningsnivå gjennom førti år, og en dybestudie av geometrilæringen med tre elever i grunnskolen", Doctoral thesis, fakultet for samfunnsvitenskap og teknologiledelse Pedagogisk institutt: NTNU. Norwegian University of Science and Technology, Department of education, Norway, 2013.
- [2] Y. Eriksson, "Tactile Pictures. Pictorial representations for the blind 1784 – 1940", Doctoral thesis, Gothenburg Studies in Art and Architecture 4. Göteborg: Acta Universitatis Gothoburgensis, Sweden, 1998.
- [3] D. Tierney Kreuzer, "An analysis of Writing Practices in 4th- and 5th Grade Students with Visual Impairments" Dissertation, San Francisco State University in Special Education. University of California, Berkeley with San Francisco State University, U. S. A., 2007.
- [4] G. Jansson, "Forskning och framsteg," *Data som känns*, vol. 44, no. 1, pp. 58–61, 2009.

Making Mathematics Accessible

A study of how paraeducators work with adaptations

Ulrika Vanhoenacker

National Agency of Special Needs Education and Schools
Stockholm, Sweden
ulrika.vanhoenacker@spsm.se

ABSTRACT

In Sweden all braille reading students are included in primary school and attend regular classes with a class teacher and a paraeducator.

The aim of the study was to highlight how paraeducators work with adaptations in mathematics for 7-9 year old braille reading students in primary school. It was a qualitative study and data were collected through video observations and stimulated recall interviews. Three paraeducators were observed and interviewed.

The paraeducators presented tactile material or whispered to the student while the class teacher was explaining mathematics to all students, including the student with blindness. The paraeducators' explanations to this phenomenon were poorly planned lessons, lack of time and the fact that the student wanted to know what the classmates were working with. Some of these simultaneous activities could easily have been avoided, if the class teacher had verbalized her teaching, rather than using expressions like "this" or "that". All three paraeducators stated good planning as a prerequisite for being able to adapt the teaching.

When teaching is optimally designed the student's adaptations are well prepared. Adaptations then lead to participation and independence for the student, as well as an increased level of learning and development.

1. INTRODUCTION

Students with blindness should achieve the requirements in mathematics, just like sighted classmates [1]. In order to achieve these requirements, the education need to be adapted to make it accessible for braille reading students.

Class teachers and paraeducators often bring up that they are unsure of how to adapt mathematics education to younger students.

2. INCLUSIVE EDUCATION

The Salamanca Statement describes how the inclusive education should be designed. The teaching shall be adapted based on the student's prerequisites, for example through specific methodology designed for the student [2].

In Sweden all students with blindness are included in mainstream education during primary school. In order to

meet the student's needs, there is a class teacher and a paraeducator in the peer group. The class teacher and the paraeducator attend further training to learn how to adapt the teaching. This training takes place at Resource Center Vision, which is a part of the National Agency for Special Needs Education and Schools.

As part of this training, the teachers and the paraeducators learn teaching methodologies for mathematics in the education of students with blindness.

The paraeducators have different educational backgrounds, but often they have some form of teacher training. In a longitudinal study, de Verdier and Ek stated that the majority of the paraeducators for the six participating students were primary teachers [3].

2.1 Mathematics and Braille Reading Students

Previous research shows that mathematics education is complex for students with blindness. When the student starts school, he or she has less experience of mathematical concepts compared to sighted students [4].

The class teacher needs to focus on verbalizing the teaching. The responsibility of the paraeducator is to adapt the teaching for the braille reading student. The class teacher and the paraeducator need time to plan the teaching together, which is a prerequisite for the paraeducator's work with adaptations [5]. The adaptations are necessary for the student to participate in the mathematics education. The functionality of the student's learning tools, such as the adapted computer, are absolutely essential for an accessible teaching [6].

3. THE AIM OF THE STUDY

The aim with this study was to highlight how paraeducators adapt mathematics education to the needs of 7-9-year old braille reading students in primary school.

4. METHODOLOGY

The paraeducators at the three schools had the responsibility for the adaptations in mathematics, and therefore focus was on them during observations and the interviews. The observations were video recorded and the interviews were then based on sequences from these recordings, a method called stimulated recall interviews.

5. RESULTS AND DISCUSSION

The results and discussion are presented thematically under the headings “Forward Planning”, “Simultaneous Activities” and “Prioritization”.

In the study, the schools were described as school 1, school 2 and school 3.

5.1 Forward Planning

All paraeducators highlighted the importance of forward planning. Two of the three paraeducators had difficulty finding time to plan lessons in advance together with the class teachers. This lack of planning became obvious during the observations. At school 3 the paraeducator and the class teacher had chosen to plan the teaching one hour before school started each morning. They both thought this system worked well, and they agreed that the time taken to plan their teaching in advance was absolutely indispensable.

5.2 Simultaneous Activities

During the lessons in the class, situations with simultaneous activities occurred. For example, when the paraeducator showed tactile materials to the student with blindness at the same time as the class teacher was addressing the entire class.

The reasons for the occurrences of simultaneous activities, differed in the three schools. At school 2 the student always wanted to know what the classmates were doing or talking about. At school 3, according to the paraeducator, lack of time was the reason for the simultaneous activities. The paraeducator considered that if she had waited to show the tactile material until after the class teacher’s lesson, there would not have been enough time to do it. The result was that the paraeducator and the student fell behind the class teacher’s lesson.

At school 3, the class teacher did not verbalize her teaching and the paraeducator had to whisper to the student, what the teacher was demonstrating on the whiteboard. The paraeducator and the student did not have a chance to keep up.

At school 2 the class teacher verbalized her teaching and she did not use expressions like “this” or “that”. As a result paraeducator 2 did not have to tell the student with blindness what the teacher was demonstrating. The student was fully included and could participate equally.

5.3 Prioritization

All three paraeducators mentioned lack of time in their students’ learning situations. They testified that the students with blindness had difficulty keeping up with their sighted peers. One way to facilitate for the students was to choose in advance which mathematical exercises the students needed to do. Paraeducator 3 assessed in advance which particular exercises the student was to undertake in the math book. Paraeducators 1 and 2 were very dependent on their study material and did not choose specific exercises for their students. Student 1 and 2 had

to accomplish the same quantity of exercises as their classmates.

When the paraeducator is a trained teacher he or she can make an assessment and determine whether the student can go ahead or not. When the paraeducator does not have, either teacher training or teaching experience, such assessments are difficult to make.

6. IMPLICATIONS FOR PRACTICE

In order to ensure that lessons are optimally designed for the students, the adaptations must first of all be well prepared in advance. Secondly, the adaptations should be presented to the student at the correct time. Such adaptations lead to participation and independence for the student. As a consequence, students with blindness can improve their learning and their educational development.

REFERENCES

- [1] Skolverket, *Läroplan för grundskolan, förskoleklassen och fritidshemmet 2011*. Skolverket, 2011.
- [2] Svenska Unescorådet, *Salamanca deklARATIONEN och Salamanca +10*. Svenska Unescorådet, 2006.
- [3] K. de Verdier, and U. Ek, “A Longitudinal Study of Reading Development, Academic Achievement, and Support in Swedish Inclusive Education for Students with Blindness or Severe Visual Impairment,” *Journal of Visual Impairment and Blindness*, vol. 108, no. 6, pp. 461-472, 2014.
- [4] O. G. Klingenberg, ”Matematik og elever som bruker punktskrift i opplæringen,” Doctorial thesis, Pedagogisk institutt, Norges teknisk-naturvitenskapelige universitet, Trondheim, Norway, 2013.
- [5] J. Sticken, and G. Kapperman, “Collaborative and Inclusive Strategies for Teaching Mathematics to Blind Children,” s. 1-13, 1998. [Online] Available: 2017-04-24, <http://files.eric.ed.gov/fulltext/ED421821.pdf>
- [6] A. C. Rule, G. P. Stefanich, R. M. Boody, and B. Peiffer, “Impact of Adaptive Materials on Teachers and their Students with Visual Impairments in Secondary Science and Mathematics Classes,” *International Journal of Science Education*, vol. 33, no. 6, pp. 865-887, 2011.

SensusAccess – Universal Access to Alternate Media

Lars Ballieu Christensen¹ and Tanja Stevns²

¹Sensus ApS,
Hillerød, Denmark
lbc@sensus.dk

²Synscenter Refsnæs,
Kalundborg, Denmark
tstv@regionsjaelland.dk

ABSTRACT

Catering for the needs of people with visual impairments included in mainstream education is challenging and timely provision of educational material in appropriate alternate formats (e.g., Braille, large-print, audio) is a frequently reported problem. SensusAccess is an adaptation of the award-winning RoboBraille service specifically targeting academic institutions. The adaptation was done in a collaborative project between the inventors of the RoboBraille service and Stanford University. The project added new user interfaces, customization possibilities, conversion options, reporting capabilities, best-practices guidelines and more. Today, SensusAccess is used as an official accommodation at a large number of academic institutions in the US, UK and elsewhere to support the alternate media needs of the blind, partially sighted and others with print impairments.

1. INTRODUCTION

Many people with visual impairments are unable to use printed material and therefore require alternate versions of the material in order to be able to complete an education, sustain a job or take part in society. Consequently, timely production of material in suitable alternate formats is a crucial aspect of providing an inclusive educational environment and fundamental to forming educational environments based on universal design principles as advocated by the UN Convention on the Rights of Persons with Disabilities [1]. Without access to the same material at the same time as their fellow mainstream students, students with disabilities are disadvantaged [2-3].

Alternate versions of educational material cover a wide range of different document formats and media types such as Braille, audio books, e-books and large-print. Converting material into these formats is time consuming, cumbersome and requires substantial skills and technical proficiency. In many cases, faculty needs to make lists of readings and other course material as well as actual handouts

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

and exercises available for conversion weeks or even months in advance if the material is to be available in suitable formats for students with disabilities, resulting in reduced flexibility. It may also be necessary for students with visual impairments to involve fellow students or staff members to have material converted, resulting in both delay and invasion of privacy. Because of the time and efforts needed for traditional alternate media conversion, catering for the needs of blind and partially sighted students is often being seen as an overly expensive burden by academic institutions.

2. THE CHALLENGE

A solution to the timely availability of educational material in suitable alternate formats could be a user-centric solution that enables the blind and partially sighted to convert their own documents. The tools and technologies used by alternate media professionals to convert material are well-known: OCR software, Office automation software, Text-to-speech synthesizers, Text-to-Braille transcription software, as well as DAISY and e-book converters. Most of these tools and technologies can be automated.

The above scenario was the foundation for the creation of the RoboBraille service in 2004. Incepted and developed by Sensus and backed by the national Danish Resource Centre for Blind and Partially Sighted Children and Youth, RoboBraille combines a selection of well-known document conversion technologies with a number of automated workflows and an easy-to-use user interface. RoboBraille was originally developed to support the needs for an inclusive environment for blind and severely partially sighted children and youth in the Danish educational system. However, it soon became apparent that the approach had the potential to solve a more universal problem of inclusive education [4-5].

RoboBraille was first introduced as an official accommodation in higher education in a collaborative project between Sensus and Stanford University in 2011. Rebranded SensusAccess, the project added a web interface, reporting capabilities and a range of important conversion options to the original service. The project also created the foundation for a sustainable financial model for the service and for a resource sharing scheme amongst subscribing institutions [6].

The SensusAccess was designed to support inclusion and universal access. As such, SensusAccess is not available

for individual, personal licensing but only offered to academic institutions for unlimited use by everyone associated with the institution. This approach serves several purposes:

Inclusive: By making the service available to everyone rather than just to people with disabilities, the aim is to avoid the stigma that may otherwise be associated with assistive technologies. Mainstream users include people with poor language and reading skills, flexible learners and language learners [7].

Long-term: Students with disabilities have exactly the same special needs when they graduate and go into further education or get a job. The service is therefore also available to alumni.

Open: Subject to a flat fee, institutions are granted unlimited rights of use.

3. THE RESULT

Today, numerous academic institutions across North America and Europe subscribe to SensusAccess and make the service available as an official accommodation to students with disabilities. SensusAccess is a self-service solution intended for students, faculty, staff, alumni and others with a need to convert material into alternate formats. Accessed through web and e-mail interfaces, the service is entirely automated. SensusAccess has support for a substantial number of languages for audio conversion and Braille transcription, including support for all the main European languages, many smaller European languages, American English, Latin American Spanish, Russian, Arabic and a number of Asian languages. Some target formats even support multilingual contents [8].

With SensusAccess, users can convert most popular document types into the following target formats:

- MP3 audio files. MP3 files are highly portable, play on a vast number of devices, and can be used in many situations. However, they may be difficult to navigate.
- Structured audio books in DAISY and EPUB format. Structured audio books are useful for textbooks and other material where it is important to be able to navigate and locate particular pages and chapters.
- E-books (digital large-print). E-books are reflowable, making it possible to scale up the text, substitute fonts, change colors, spacing, scrolling direction and more.
- Digital Braille books. The resulting digital Braille books are ready to emboss on a Braille embosser or display on a Braille display or Braille notetaker.
- In addition, SensusAccess can convert otherwise inaccessible or tricky formats into more accessible formats.

Based on interviews with staff providing student services, disability support and library services, academic institutions subscribe to the SensusAccess service for a variety of reasons:

- To promote and support independence and self-sufficiency.
- To ensure availability of material in suitable alternate formats.

- To preserve privacy amongst students with disabilities.
- To provide situation-dependent formats.
- To facilitate reuse of existing hardware and avoid costly, specialized equipment.
- To provide accessibility support in online education.

Although SensusAccess is mainly used as a user-driven document conversion service, academic institutions are increasingly exploring how the service can be exploited to improve the accessibility in other systems and services. As such, SensusAccess is being integrated with email-enabled photocopiers/scanners, as well as with learning management systems, digital library systems, learning portals and similar digital services.

4. DISCUSSION

The automated nature of the SensusAccess service constitutes a natural limitation as to what can be converted. These limitations are mainly caused by lack of mature technologies to adequately process, identify and describe structural and content elements in digital files. Examples of such limitations include the inability to recognize headings, heading levels and mathematical equations in image-type documents and the inability to automatically provide context-dependent descriptions of illustrations. Consequently, SensusAccess is primarily useful for converting documents that mainly contain text and documents that comply with the accessibility requirements [9]. In the latter case, documents may even include sophisticated contents such as math equations, charts and illustrations. SensusAccess is less suited for converting inaccessible documents such as scanned STEM-type material. An unpublished assessment suggests that as much as 60 per cent of all educational material can be correctly converted by SensusAccess [10].

As an alternate media conversion service, SensusAccess has two main capabilities: It can convert inaccessible and/or tricky documents – e.g., image-only PDF documents, pictures of text, Microsoft PowerPoint presentations – into more accessible formats and it can convert already accessible documents into sophisticated alternate formats such as DAISY Talking Books and e-books. Hence, SensusAccess is not the end solution to all alternate media conversion needs nor will it ensure accessibility compliance of all educational material.

At the current technology level, some documents – especially STEM-type material – will require human editing and value adding in order to ensure that the material can be made comprehensible for people with visual impairments. It may be required to recreate the semantic structure of documents, retype equations and provide image descriptions. It may also be necessary to produce tactile illustrations or 3D renditions of illustrations.

Likewise, compliance with accessibility requirements cannot (currently) be automated. To ensure compliance, documents must be authored and published using accessi-

ble practices and technologies. Authors need to be proficient in using their authoring tools, follow the accessibility guidelines and use accessible templates.

5. CONCLUSIONS

In the coming years, SensusAccess will continue to support and promote self-sufficiency, independence and inclusion amongst students with visual impairments. Improved capabilities and more conversion options will be added to cover a larger proportion of documents. However, improved authoring practices towards improved accessibility are also needed to ensure timely access to alternate versions of educational material.

The boundary between conversions that can be automated and conversions that need human intervention is not static. As existing technologies mature and new technologies emerge, major advances are expected over the coming years. Several technologies are being researched for adaptation in SensusAccess. These include the ability to recognize scanned math documents, recognition of the semantic structure of documents and automated/semi-automated provision of image descriptions and video captions. Emerging technologies are also expected make it possible to extend the capabilities of SensusAccess in several new areas such as language-to-language translation, speech recognition and text-to-sign language translation. Advancements in machine learning and crowd-sourcing are expected to dramatically impact such functionality over the course of the coming two to five years.

A significant challenge is the lack of skills amongst those producing digital material. Whereas traditional skilled workers are typically taught how to use tools and materials, so-called knowledge workers are frequently expected to know how to use word processors, presentation software, PDF converters and similar in a correct and accessible way without proper instruction. Furthermore, few are aware of the principles of digital accessibility and even fewer attempts to comply with these. The result is that the vast majority of all published material is inaccessible to readers with print disabilities. An unpublished survey (2014) by the Danish Ministry of Education of the practices at 13 educational institutions in Denmark revealed that almost all education material produced by the educational institutions failed basic accessibility criteria and that approx. 80 per cent of the errors were introduced by the authors themselves. To address this issue, instruction in the proper use of authoring technology such as word processors, presentation software, editors in content management systems and similar should be mandatory for faculty and staff creating or publishing educational material, ensuring that mainstream technology is used properly and that published documents comply with the basic principle of digital accessibility.

Acknowledgments

The European Union's Seventh Framework Program has contributed financially to the development of elements of the RoboBraille engine powering the SensusAccess service as part of the Prosperity for All project, grant agreement 610510. The European Union's Erasmus+ Program has contributed financially to the creation of learning material covering the RoboBraille engine as part of the IncluTech project, grant agreement KA201-205-012.

REFERENCES

- [1] United Nations: UN Convention on the Rights of Persons with Disabilities. 2006.
- [2] Christensen, L.B., & Stevns, T.: Universal Access to Alternate Media. M. Antona and C. Stephanidis (Eds.): UAHCI 2015, Part I, LNCS 9175, pp. 406–414, 2015.
- [3] Fullan, M: Change Theory: A force for school improvement. Centre for Strategic Education, Seminar Series Paper No 157. 2006.
- [4] Christensen, L.B.: RoboBraille – Automated Braille Translation by Means of an E-Mail Robot. K. Miesenberger et al. (Eds.): ICCHP 2006, LNCS 4061, pp. 1102-1109, 2006. Springer-Verlag Berlin Heidelberg 2006
- [5] Christensen, L.B.: RoboBraille – Braille Unlimited. The Educator, Volume XXI – Issue 2, ICEVI 2009, p. 32-37, 2009.
- [6] Christensen, L.B., Keegan, S. J., & Stevns, T: SCRIBE: A Model for Implementing RoboBraille in a Higher Education Institution, K. Miesenberger et al. (Eds.): ICCHP 2012, Part I, LNCS 7382, pp. 77–83, 2012. Springer-Verlag Berlin Heidelberg 2012.
- [7] Goldrick, M., Stevns, T. & Christensen, L.B.: The Use of Assistive Technologies as Learning Technologies to Facilitate Flexible Learning in Higher Education. K. Miesenberger et al. (Eds.): ICCHP 2014, Part II, LNCS 8548, pp. 340–349, 2014. Springer International Publishing Switzerland. 2014
- [8] SensusAccess Service Description: <http://www.sensusaccess.com/service-description>. Retrieved April 2017.
- [9] World Wide Web Consortium (2013): Guidance on Applying WCAG 2.0 to Non-Web Information and Communications Technologies
- [10] Johnson, J.: SensusAccess in Higher Education. Presentation at the First International RoboBraille Conference. Budapest. November 2012.

Maximising Spatial Potential: Spatial Thinking Modification and Universal Design for Students with VI

Mary Styli¹, Philippos Katsoulis¹, Maria Zeza²,

¹ Special Elementary School for the Blind in Athens, Greece
marystilidi@yahoo.gr , phikats@phs.uoa.gr

² Special Elementary School for Deaf- Blind in Athens, Greece
marialzeza@gmail.com

ABSTRACT

Complex spatial thinking phenomena are often described with visual imagery. Visual representations are motivating and critical in the communication of spatial thinking concepts for people with VI. Students with little or no vision face several difficulties in learning from the lack of these representations. The principle of ‘universal design’ suggests that holistic planning and design can yield spatial thinking education that is equally suitable to all students, pointing to educational modifications which may benefit large numbers of people, including students with VI. Tactile maps are an example of a spatial thinking education aid which may be useful for blind and sighted students alike. This paper explores the mental representations of spatial thinking concepts that students with VI build forming the role of passive and active spatial thinking processes. Also, it discusses the understanding that learning involves specific challenge in the area to be learned, eliminating unnecessary barriers without eliminating the necessary challenges. Thus, the UDL principles focus on access to all aspects of spatial thinking learning. Finally, this paper outlines the types of future research that are needed to more fully meet the challenge of providing high quality, accessible science instruction to students with VI. These types will become a part as implemented in VISTE project that aims to empower spatial thinking of primary and secondary school students with VI.

1. INTRODUCTION

The goal of education in the 21st century is not simply the mastery of content knowledge or use of new technologies, but that of the learning process. Education should help turn novice learners into *expert* learners—individuals who want to learn, who know how to learn strategically, and who, in their own highly individual and flexible ways, are well prepared for a lifetime of learning. Universal Design for Learning (UDL) helps educators meet this goal by providing a framework for understanding how to create curricula that meets the needs of all learners from the start [1].

Modern science phenomena are often imbedded in visual representations, such as textbooks, PowerPoint presentations and computer-based displays in multimedia materials that attempt to capture the complexity of structures, functions and processes. Yet very little is known about how students with VI learn without access to these representations. Parallel to the increase in the use of visualiza-

tions in science is a demand for students to have increased spatial thinking skills [2].

This paper explores how students with VI form sensorial mental representations of spatial thinking concepts using UDL principles.

1.1 About UDL

UDL is an approach to curriculum design that provides all individuals with equal opportunities to learn, designed to serve *all* learners, regardless of ability, disability, age, gender, or cultural and linguistic background. UDL provides a blueprint for designing goals, methods, materials, and assessments to reach *all* students including those with diverse needs. It can also help educators identify the barriers found in existing curricula [1].

The UDL framework encourages creating flexible designs from the start that have customizable options, which allow all learners to progress from where they are and not where we would have imagined them to be. The options for accomplishing this are varied and robust enough to provide effective instruction to all learners. UDL is an approach to learning that addresses and readdresses the primary barrier to learning: inflexible, one-size-fits-all curricula that raise unintentional barriers. Learners with disabilities are the most vulnerable to such barriers, but many students without disabilities also find that curricula are poorly designed to meet their learning needs. A universally designed curriculum is shaped from the outset to meet the needs of the greatest number of users, making costly, time consuming, and after-the-fact changes to the curriculum unnecessary.

1.2 About Spatial Thinking.

Whether blind, visually impaired, or sighted, quality of life is greatly dependent on a person's ability to make informed spatial decisions through the processing and synthesis of spatial information, within a variety of situations, at differing scales. Given this necessity, to varying extents, all people have a spatial awareness of their surroundings, deriving through senses as the person engages in direct perception of environments that are close enough to touch, taste, smell, hear, and see. These senses work at varying scales. For example, touch, taste, and smell tend to work within haptic, or body spaces. Sight and hearing help collect data from greater ranges. To collect spatial information relating to spaces that are not directly encountered, or to supplement direct encounters, there are a range of secondary sources available for con-

sultation, for example books, television, radio, newspapers, and maps [3].

Persons with VI may feel a shape and identify it with ease, though they are unable to see it. Because most people use spatial intelligence in conjunction with sight, its existence as an autonomous cognitive attribute may not seem readily apparent, but recent scientific advances do suggest that it is clearly an independently performing portion of the intellect. The special reasoning of the blind person allows them to translate tactile sensations into mental calculation of length and visualization of the form [4].

1.3 The VISTE Project

VISTE is an Erasmus+ KA2 project and its aim is to enhance visually impaired students' spatial thinking through an innovative methodological framework by taking into account the principles of Universal Design for Learning. The project's main target groups are primary/secondary education students, as well as teachers, teachers' trainers, and staff involved in their education.

1.4 Connecting UDL principles and Spatial Thinking Concepts for Students with VI

Three primary principles, which are based on neuroscience research, guide UDL and provide the underlying framework:

-Principle I: Provide Multiple Means of Representation (the "what" of learning). Students with VI differ in the ways that they perceive and comprehend spatial thinking information that is presented to them. Others may simply grasp information quicker or more efficiently through auditory means rather than Braille-printed text. Also learning, and transfer of learning, occurs when multiple spatial thinking representations are used, because it allows students with VI to make connections within, as well as between, concepts. In short, there is not one means of representation that will be optimal for all learners; providing options for spatial thinking representation is essential.

-Principle II: Provide Multiple Means of Action and Expression (the "how" of learning). Learners with VI differ in the ways that they can navigate a spatial thinking learning environment and express what they know. Some may be able to express themselves well in written text but not speech, and vice versa. It should also be recognized that spatial thinking action and expression require a great deal of strategy, practice, and organization, and this is another area in which learners with VI can differ. In reality, there is not one means of action and expression that will be optimal for all learners; providing options for spatial thinking action and expression is essential.

-Principle III: Provide Multiple Means of Engagement (the "why" of learning). Affect represents a crucial element to spatial thinking learning, and learners differ markedly in the ways in which they can be engaged or motivated to learn spatially. There are a variety of sources that can influence individual variation in affect including neurology, culture, personal relevance, subject-

tivity, background knowledge, as well as the amount of vision loss, along with a variety of other factors. Some learners with VI are highly engaged by spontaneity and novelty while others are disengaged, even frightened, by those aspects, preferring strict routine. Some learners with VI might like to work alone, while others prefer to work with their peers. In reality, there is not one means of engagement that will be optimal for all learners with VI in all contexts; providing multiple options for spatial thinking engagement is essential [1].

2. DISCUSSION

UDL and spatial thinking learning for students with VI draws from a variety of research including the fields of neuroscience, the learning sciences, and cognitive psychology. There is research on specific applications of UDL within spatial thinking learning environments for students with VI, including conditions necessary for implementation, common barriers, and lessons from the field. This new area of research is in its early stages but will take a more prominent place as full-scale curricular applications and system-wide implementations are developed. It should be noted that this is another area in which contributions from the research field are greatly encouraged.

3. CONCLUSIONS

There is an obvious risk that people who are visually impaired could be disadvantaged in an increasingly image-oriented society if they did not have the possibility of accessing visual information in alternative ways. Throughout this paper it is referred that spatial thinking skills for students with VI may be optimized when they are encountered by a holistic planning and design. UDL principles create the educational ground for resourceful, knowledgeable learners, with strategic and goal-directed tools through a purposeful and motivated learning.

4. ACKNOWLEDGMENTS

This paper is funded by the Erasmus+ Program of the European Union Pr. no 2016-1-EL01-KA201-023731.

REFERENCES

- [1] D. Rose and A. Meyer, *Teaching every student in the digital age: Universal design for learning*. Alexandria, VA: Association for Supervision and Curriculum Development, 2002.
- [2] S. Millar, "Theory, experiment and practical application in research on visual impairment", *European Journal of Psychology of Education*, vol.12, pp.415-430, 2007
- [3] R. Golledge, "Geography and the disabled: A survey with special reference to vision impaired and blind populations", *Transactions of the Institute of British Geographers*, vol.18, pp.63-85, 2003
- [4] H. Gardner, "Creators: Multiple Intelligences", in *The Origins of Creativity* by K.H. Pfenninger & V.R. Shubik (Editors), 2008, Oxford University Press: NY, USA

Professional Training as a Part of Curriculum and its Influence on Employment

Jana Loudová

Gymnázium pro zrakově postižené
a Střední odborná škola pro zrakově postižené,
Prague, Czech Republic
loudova@goa.brailnet.cz

ABSTRACT

Employment allows a person to get financial means needed for sustenance, living conditions and satisfying additional needs. Professional activity does not bring to one just a material security, but also meaningful activity, satisfaction and self-fulfillment. From the social aspect, workplace is the place, where people meet other people, make interacts and new friendships.

The employment is for a young person also a confirmation of his/her maturity. Young person becomes financially independent from parents and gets an opportunity to be self-reliant. However young people are one of the groups, which is more threatened by unemployment. They do not have professional skills and habits.

Another groups threatened by higher rate of unemployment are ethnical minorities, elderly people and people with disabilities.

People with severe visual impairment belong to the group which is the most threatened by unemployment. If we want to deal with a high rate of unemployment of people with visual impairment, we have to primarily start with preventive measures that consist in preparation for their future job, especially in education at secondary schools.

The goal of this article is to apprise readers with experience with preparation and organization professional training at secondary school for students with visual impairment, whose problems should be dealt with and how professional training can influence employment of graduates at labour market.

1. SPECIFICATION OF THE PROBLEM

Visual impairment affects people in many different ways. One of the problem is the unemployment. Currently there are no exact statistical data about the rate of unemployed people with visual impairment in the Czech Republic. But some older sources say that unemployment of people with visual impairment in productive age reaches up to 70%, and more than 90% of people who are blind are unemployed.

Problems with getting a job can be influenced by obstacles on the side of employers, but also on the side of the people with visual impairment. High rate of unemployed people with visual impairment can be caused by different aspects; from the low education of the people with congenital visual impairment or impairment

acquired in childhood, through longlasting and tedious process of rehabilitation of those who lost their sight during adulthood, to reluctance of employers to employ people with such handicap. The most of employers can't imagine what kind of job can the blind person do. [1] Moreover our current society is focused more on effectivity and performance.

Despite the fact that legislative measures should prevent unequal position of blind people in society, it should be noted that the direct impact of blindness is precisely in the field of employment, because the fact that a person can not use their sight limits the range of their adequate occupations. [2, p. 43]

Also the category of partially sighted people have a deficit reflected in possibilities of the employment. The situation may be even more complicated, as some cases are fated by the deterioration of sight. In this area of social interaction can problems sometimes arise due to one's feelings of low self-esteem. [2, p. 45]

2. EDUCATION OF PEOPLE WITH VISUAL IMPAIRMENT IN THE CZECH REPUBLIC

If we want to deal with a high rate of unemployment of people with visual impairment, we have to primarily start with preventive measures that consist of preparation for the future job, especially in education at secondary schools.

In the Czech Republic, education of pupils and students with visual impairment and with another kinds of disabilities (generally of pupils and students with special educational needs), is specified by Educational Act. According to the Educational Act, a pupil or a student with special educational needs is a person who needs special support to fullfill his/her educational possibilities and opportunities to reach the equal conditions as person without any disabilities.

Educational Act also says that for pupils and students with any disability (intellectual, physical, visual or hearing disabilities, with speech and language disorders, learning disabilities, multiple disabilities or autism) special schools, classes or educational groups can be established.

As a follow up from above, the pupils and students with visual impairment can be educated in mainstream schools or at schools established for pupils and students with visual impairment or, in special cases, in schools

established for pupils and students with another kind of disabilities. [3]

Education in mainstream secondary schools offers pupils and students with visual impairment possibility to choose different fields of study.

But individuals with visual impairment have limited opportunities of choosing the occupation because of health problems and some professions are even excluded by their visual impairment.

In the Czech Republic there are only four secondary schools established for students with visual impairment offering education in different fields of study. But this offer is not too wide. Additionally most of schools for students with visual impairment are situated in Prague. Although part of all special schools is dormitory, staying at dormitory is related with higher expenses and also with separation from family.

2.1 Introduction of High School for Visually Impaired in Prague

Gymnázium pro zrakově postižené a Střední odborná škola pro zrakově postižené, simply translated as High School for Visually Impaired in Prague, is a secondary school attended by students with visual impairment and with various disabilities like autism, general learning difficulties, reduced mobility, etc. This school offers education in four fields of study – Grammar School, Business Academy, Commercial skill school and Social Work.

The main aim of the secondary school is to prepare students for their future employment. According to the Czech Education Act, secondary education develops knowledge, capabilities, skills, attitudes and values important for personal development of students. Secondary education also creates preconditions for worthwhile personal and civic life, lifelong education, acquiring occupational habits and prepares students for particular professions. [4]

This article will be further focused mainly on field of Social Work study. The study of Social Work lasts for four years and is concluded by school leaving exam (equivalent to A-level exam). Graduates can be employed as workers in ambulatory or residential organizations which provide different kind of services for people in need. They have the knowledge and skills needed for provision of care and personal assistance, to support client's self-sufficiency and activation. They are able to provide social consulting, they have an overview about social legislation and knowledge about management of social services.

One of the premises of successful employment of students with visual impairment in labour market is also to be independent and handle daily living skills and orientation and mobility skills. Teachers of such school provide not only the education, but they also try to prepare students for independent and self-sufficient life.

As a part of curriculum professional training is also included. Professional training is partly organized at school, where the special classroom for this subject was formed and equipped, and partly in form of excursions in organizations, where students get the main information

about provided social services. Twice during their study spend students two weeks continuously as „employees“ of organizations according to their choice.

In the social services organizations students usually take care of clients (accompaniment, assistance, reading, interview), help with collective activities and carry out administrative or minor auxiliary works (preparing of refreshments, cleaning).

The main aim of professional training is to develop professional skills and habits. Within the framework of this subject students learn about social services of organizations designated to different kind of clients and get an overview of the possibilities on labour market and also in the field of social work. [5]

3. RESEARCH

This year the third class studying Social Work graduated. We decided to do research to verify successful integration of school graduates on labour market and to find out how professional training can influence their professional opportunities. The research was done by questionnaire method and it was divided into two parts.

The first part was focused on the graduates and its goal was to find out what the graduates of the school currently do, if they have some experience with looking for a job and if the professional training positively influenced their current situation.

Questionnaires were fulfilled in with 17 graduates with different kinds and grades of impairment. Specifically there were 6 individuals with visual impairment, 3 of those were ones with severe visual impairment, 8 individuals with MDVI (multiple disabilities and visual impairment), 2 individuals with autism and 1 person with a physical disability.

The research has emerged that 5 graduates decided to study similar field at universities or colleges. 1 of them decided to go in different direction of study. 4 graduates attend retraining or educational courses (language, computer) and so they develop other knowledge and skills.

Another 3 respondents work in social service organizations or as volunteers, 3 graduates work in the other field. Only 1 is unemployed.

Our research also shows, that the most of respondents would still want to work in field of social services. Remaining 5 respondents do not want to work in social services at all. The reasons are that they have found job in other field, they think that social work would be too psychical demanding for them or they are not interested in field of social work. However we can say that all graduates are satisfied with way how our school prepared them for future employment.

Those graduates, who has been looking for a job, have both, positive and negative experience with employers. The field practise had a positive impact on admission procedure to universities and colleges or in getting a job. Some respondents started to cooperate with social services organizations where they spend some time as a trainees during professional training, now they work there as an employees or as a volunteers.

The second part of the research was focused on social services organizations cooperating with our school in preparation of professional training. The goal of this part of research was to find out, how are they satisfied with work of students, if they employ people with disabilities and if they are willing to employ graduates of our school.

From the research done by a questionnaire method has emerged that most of social services organizations are satisfied with students' work. Simultaneously, most of organizations are aware realize of the fact that certain limitations of the visual impairment can negatively influence professional performance of students. The limits are mainly related with orientation and mobility.

Although some of cooperating organizations employ people with health disabilities, most of them are not willing to employ graduates of our school. Only organizations which provide care of people with visual impairment, would employ them. On the other hand most of such organizations are willing to employ our graduates as a volunteers.

4. RECAPITULATION

As it has been said at the beginning and the research has confirmed this fact, people with severe visual impairment have bigger problems with unemployment.

One of the people with visual impairment those addressed in the research, is unemployed. One school graduate with a milder form of visual impairment, works in the full-time job in social service organizations, two graduates work in the other field. Five graduates with visual impairment or MDVI decided to study similar field at universities or colleges, the other three further develop their knowledge and skills in various education and retraining courses.

Generally, we can say, that most of organizations realize that some limitations of the severe visual impairment can negatively influence professional performance of students. The limits are mainly connected with orientation and mobility. And therefore, some of cooperating organizations are not willing to employ graduates of our school. Only organizations providing care of people with visual impairment, would employ them.

The school also sometimes deals problems with preparation of the professional training, because some social services organizations do not want to accept students with severe disabilities, or only if they have personal assistance.

On the contrary, most organizations are willing to accept school graduates as volunteers. Two graduates have already started to cooperate with the social services organizations, where they were as a trainees, and now they work for them as volunteers.

Volunteering is a good alternative to job for people with disabilities. Although it does not provide financial means, it can be a meaningful activity and give person a feeling of satisfaction and self-fulfillment. A person in volunteer service can meet with other people who have different kinds of problems, establish contacts and new friendships. Volunteering also helps to acquire new

knowledge and skills and to develop one's professional habits.

In conclusion we can say that cooperation between school and social service organizations based on preparation and organization of professional training is beneficial for both parties; school can prepare students for their future occupation and the social service organizations educate and prepare a new capable employees.

REFERENCES, LITERATURE REVIEW

- [1] BUBENÍČKOVÁ, H. *About visual impairment and people with visual impairment* (own translation). Czech Eye Optics. 1/2007, p. 81, original available on <http://www.centrumpronevidome.cz/doc/opt5.pdf>
- [2] FINKOVÁ, D.; LUDÍKOVÁ, L.; RŮŽIČKOVÁ, V. *Special pedagogy of people with visual impairment* (own translation). Olomouc: University Palacky Olomouc, 2007. 158 p. ISBN 978-80-244-1857-5
- [3] Education Act (own translation)
- [4] Framework Educational Programme (own translation)
- [5] School Educational Programme (own translation)

Expedition ToP: Experiences of adolescents with visual impairments, their parents and professionals in promoting success in job participation.

Judith Wijnen¹, Sabina Kef² & Bella van Erp²

¹Royal Dutch Visio, Hettenheuvelweg 41-43, 1101 BM, Amsterdam, the Netherlands
Judithwijnen@visio.org

²Vrije Universiteit Amsterdam, Faculty of Behavioural and Movement Sciences, Clinical Child and Family Studies, Van der Boerchorststraat 1, 1081 BT Amsterdam, the Netherlands

s.kef@vu.nl; b.r.van.erp@vu.nl

ABSTRACT

Introduction: People with visual impairments (VI) are still facing problems in job participation (1,2,3). How could we focus more on success factors in (special) education? What are the experiences of adolescents themselves, parents and professionals?

Material and methods: In an innovative project of Visio and Vrije Universiteit Amsterdam, several data collections with multiple groups of participants will shed light on which factors are related to success in employment. Participants are: adolescents with VI (15-22 years), their parents, professionals of Visio, and successful employees with VI. Data are collected using questionnaires, interviews, assignments and focus groups.

Results: Preliminary results showed that professionals attributed the problems of employment for a large part (77%) on the VI. Professionals did believe in change, as was found on their score on the growth mindset index, but some have more fixed mindsets (4,5). Accordingly, also the adolescents themselves scored rather positive on the growth mindset index. Important success factors for employment in adolescents were attitude, self-efficacy and social skills. Important success factors for employment to be highlighted in education were insights in the possibilities (and not the impairments) of the adolescents and Visio's connections with companies in general. Interviews with successful employees with VI underscored the relevance of high self-efficacy and positive beliefs. Results of the focus groups with parents are to be expected in spring 2017.

Conclusions: If we know more on the success factors, we could shape the parenting and education more towards them. Using an integrative multi factorial approach, as in this project, seems the way to go.

Acknowledgments

This study is financially supported by Novum (grant number OI072027 and OI 0338). We want to thank all the different participants for their time and enthusiasm in this project.

REFERENCES

- [1] Goertz, Y.H.H., Van Lierop, B.A.G., Houkes, I., & Nijhuis, F.J.N. (2010). Factors related to employment of visually impaired persons: A systematic literature review. *Journal of Visual Impairment and Blindness*, 104(7), 404-418.
- [2] Heppe, E. C., Kef, S., & Schuengel, C. (2015). Testing the effectiveness of a mentoring intervention to improve social participation of adolescents with visual impairments: study protocol for a randomized controlled trial. *Trials*, 16(1), 506.
- [3] Van Leeuwen, L.M., Rainey, L., Kef, S., Van Rens, G.H.M.B & Van Nispen, R.M.A. (2015) Investigating rehabilitation needs of visually impaired young adults according to the International Classification of Functioning, Disability and Health *ACTA OPHTHALMOLOGICA* 93 (7), 642-650.
- [4] Meppelder, M., Hodes, M., Kef, S. & Schuengel, C. (2014) Expecting change: Mindset of staff supporting parents with mild intellectual disabilities, *Research in Development Disabilities*, 35, 3260-3268.
- [5] Levy, S. R., Stroessner, S. J., & Dweck, C. S. (1998). Stereotype formation and endorsement: The role of implicit theories. *Journal of Personality and Social Psychology*, 74, 1421-1436.

Status of the specialist additional curriculum in the UK and outcomes for learners

Sue Keil¹, Rory Cobb², Rachel Hewett³ and Graeme Douglas⁴

^{1,2}Royal National Institute of Blind People (RNIB)
Birmingham, UK
(Sue.keil, rory.cobb) @rnib.org.uk

^{3,4}VICTAR, University of Birmingham
Birmingham, UK
(r.g.hewett, g.g.a.douglas) @bham.ac.uk

ABSTRACT

In the UK there is a tension at national policy level between the academic outcome measures which schools are judged on, and the special educational needs (SEN) framework, which as well as academic attainment, prioritises the wider social and independence skills young people need if they are to achieve successful long term outcomes in adult life.

A challenge for specialist teachers is finding a way to achieve a balance between the academic curriculum and the additional skills (the UK additional curriculum) which children with vision impairment (VI) need to learn to become independent adults. How do they ensure that the additional curriculum is not overlooked in schools, when so much value is placed on academic attainment?

A new framework which expands the 5 categories in the UK additional curriculum to create 8 'learner outcome' categories, is used to present findings from recent research into the transitions of young people with VI. Participants' reflections on the specialist support they had received at school leads to the conclusion that the additional curriculum is important in enabling learners with VI to achieve both academic outcomes and to make a successful transition into independent adulthood. The new framework provides a way for schools and specialist teaching services to demonstrate their role in enabling pupils with VI to make progress towards the 8 learner outcome categories.

1. INTRODUCTION

Specialist educational provision for children and young people with vision impairment (VI) entails not only supporting them to access the core academic curriculum, but also teaching them a range of independent learning, mobility, everyday living and social skills. In the UK these skills are known as the 'additional curriculum' and in the US, the 'expanded core curriculum' (ECC). Teachers in the UK are faced with the challenge of fitting the additional curriculum, including mobility and everyday living skills, into the school day. Most young people with VI are educated in mainstream schools, which are judged on how well their pupils attain

academically. This risks provision being focused on short term benefits of ensuring that pupils have their learning materials in accessible formats, rather than taking a longer term perspective and teaching them the skills they need to become independent learners. This is what McLinden and colleagues [1] have referred to as 'access to learning' versus 'learning to access'.

A new 'Code of Practice' in England, places a statutory duty on schools and local authorities to consult with children and young people with special educational needs and disability (SEND) about their support and the outcomes that are important to them[2]. With the aim of developing an approach that could be used by specialist teachers to frame discussions with pupils with VI about their outcomes, the authors in partnership with Brent sensory service and Positive Eye, and funded through the National Sensory Impairment Partnership (NatSIP) expanded the UK additional curriculum to create the 'learner outcomes framework'[3].

2. LEARNER OUTCOMES FRAMEWORK

The Learner Outcomes framework was developed as part of a project to provide a structure and tools for talking to young people with VI about their experiences of school, and to check that the outcomes specialist teachers considered important were relevant to young people themselves. We compared the 5 outcomes from the UK additional curriculum with the 9 outcomes of the US Expanded Core Curriculum (ECC), and took into account the emphasis in the Code of Practice, on providing children and young people with SEND with support to help them achieve the best possible educational and other outcomes and prepare them effectively for adulthood. The result was 8 learner outcomes:

Outcome 1: Learning to access

- Teaching access skills such as use of LVAs versus provision of accessible material
- Sensory efficiency skills (visual efficiency, auditory learning, tactile learning, advanced tactile skills, organisation)

Outcome 2: Use of equipment

Teaching of skills in independent use of equipment:

- Assistive technology
- Standard equipment with accessibility options

- Low vision aids (LVAs)
- Able to choose which equipment to use and when

Outcome 3: Independence and negotiation skills

Teaching of skills to enable the child or young person to:

- Make a case for self if s/he wants something to change
- Explain own support needs
- Contribute to discussions with staff about own needs
- How to approach a task in a particular way
- Choose what to do when things don't go according to plan (strategies/solutions)
- Where to go to find out things
- Explain vision impairment to others

Outcome 4: Participation

- Being able to join in activities outside lessons when child wants to do so
- Social interaction skills that enable the child to feel confident when mixing with other children and to make and keep friends

Outcome 5: Meeting others

- Opportunities to meet with other children with VI
- Recreational and leisure skills

Outcome 6: Getting around

- Getting around familiar environments by his/herself
- Confidence in travelling alone
- Able to meet others outside of home
- Knows how to get help if stuck

Outcome 7: Looking after him/herself

- Age appropriate skills

Outcome 8: Life after school

- Knowing what support is available and how to apply for it

3. YOUNG PEOPLE'S REFLECTIONS ON THE SUPPORT THEY RECEIVED AT SCHOOL

In our presentation, we use the learner outcomes framework to consider how young people with VI aged 19-22 assessed, in retrospect, the support they had received at school and the extent to which it had prepared them for the transition to adult life. These were the young people with whom we consulted for the original learner outcomes project, and the participants in a longitudinal study into the transition of young people with VI [4].

Presenting the additional curriculum as 8 separate outcomes provides a useful framework for teachers to categorise and plan specialist support, although it is clear that the outcomes are inter-related. Participation, for example, is an outcome that requires good mobility and social interaction skills if young people are to avoid the risk of social isolation. We have seen that some young people resisted mobility education through fear of feeling 'different' but the opportunity to meet other children and young people with VI (outcome 5) provides them with a reference group and/or role models. Talking to young people who have left school about the benefits of mobility education may encourage a more positive

attitude to mobility training while at school. Similarly, finding out about how others use technology can move a young person from an expectation of dependency to that of becoming an independent learner (outcomes 1 and 2).

A common theme running through what young people have told us is that there are important benefits to acquiring independent learning, living and mobility skills from an early age. Skills learnt from an early age become embedded, younger children are perhaps less self-conscious than adolescents, and there are fewer demands from the academic curriculum.

While we have emphasised the importance of equipping children and young people with the range of skills described in the learner outcomes framework, we would not want to downplay the responsibility of institutions to provide an accessible learning and working environment. However, the transitions research has shown us that young people who lack these essential skills are less resilient, and less able to cope with the structural inadequacies of settings and systems

4. CONCLUSION

In conclusion, the additional curriculum is important in enabling young people with VI to achieve both academic outcomes and to make a successful transition to independent adulthood. The new framework, with 8 learner outcomes categories, provides a way for specialist teaching services and schools to demonstrate their role in enabling young people to become independent adults.

REFERENCES

- [1] Mc Linden M, Douglas G, Cobb R, et al. 'Access to learning' and 'learning to access': analysing the distinctive role of specialist teachers of children and young people with vision impairments in facilitating curriculum access through an ecological systems theory. *Br J Vis Impair* 2016;34:177-95.
- [2] DfE (2015) Special educational needs and disability Code of Practice: 0 to 25 years. Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities. January 2015. Department for Education and Department of Health.
- [3] NatSIP (2016) Learner outcomes framework for VI children and young people. A framework for support for young people with vision impairment provided by a VI education service. National Sensory Impairment Partnership (NatSIP) funded by Department for Education (DfE)
- [4] Hewett R, Douglas G and Keil S (2017) Reflections of Transition Experiences by Young People with Visual Impairments aged 19-22. Technical report of findings to April 2016. VICTAR, University of Birmingham report for the Thomas Pocklington Trust.

On the threshold of adulthood

How well are students with visual impairment prepared for adulthood after schooling within the general education system?

Annica Winberg

National Agency for Special Needs Education and Schools
Stockholm, Sweden

ABSTRACT

Young people with visual impairment may face severely limited opportunities for employment, independent living and social and community participation. This we know from many countries. The aim of this study is to try to create an image of the special challenges that young people with visual impairment may face and to reflect on the question if they get the right support in the process of transition within the inclusive education system. The paper is based on the results of a research project conducted in Sweden in year 2014 – 2015. Qualitative interviews were made with eight young adults, who were either attending university or equivalent educational settings or were on the threshold of entering the job market.

The results show that students with visual impairment face a more challenging situation than sighted students do. Throughout their school years they had suffered from a constant time problem in almost all learning situations. This situation caused a lot of stress and a feeling of low self-esteem.

When proceeding to higher education the visually impaired students also were facing a far more complex situation than sighted peers. When attending university they were expected to handle a lot of practical problems concerning their studies, such as make sure to get adapted material in time. This took a lot of time and energy and made it hard to focus academically.

The study also shows that many were quite unexperienced concerning the expectations and demands that comes with having a job or how to perform in a job interview. None of them had had the experience of having a paid job before leaving upper secondary school. Their own and other peoples' expectations on their possibilities to succeed in higher education or in the job market also had an impact on the actual outcome.

INTRODUCTION

In Sweden the absolute majority of Braille reading students attend mainstream settings. The regular classroom teacher is expected to meet the Braille reading students needs together with a support teacher or a teachers' assistant. But is this enough to support for Braille reading young students in the process of transition? From many countries we know that young people with a visual im-

pairment may face severely limited opportunities for employment, independent living and community participation. We need to find out what the reason is for this situation. What are the special challenges that these young people have to overcome and how can the support during the transition process be improved?

AIMS

The aims of this study is to enlighten conceivable pitfalls in the transition process for young people with visual impairment and also to enlighten factors has shown to promote a successful outcome.

METHODS

Eight young people who are either blind or have a severe visual impairment were interviewed. Seven of them were Braille readers and one used audio books in combination with magnified ink print. The interviews were conducted by using a semi-structured questionnaire. All interviews were recorded and the material was then processed and analyzed by using qualitative method for text analyze [1]

TARGET GROUP

The target group consists of eight young people who are blind or have a severe visual impairment, four are men and four are women. The ages vary from 22 to 28 years. Seven of them have Braille as reading medium in combination with auditory media, while one person uses audio books in combination with magnified ink. The respondents came from different places all over Sweden, some from cities and some from rural areas. At the time for the interview two respondents had full time employments. Two had part time employments. Two were full time students and one had recently graduated and was looking for an engagement.

MAIN RESULTS

The main results from the study show that the respondents at all levels in school had experiences a constant time problem in almost all learning situations. Braille is a more time-consuming reading medium than ink print [2]. To read and to understand tactile graphics also takes time

and energy. Furthermore the school day was influenced by the fact that the respondents had to spend a lot of time orienting from one section to the other in school, try to find their classmates in the schoolyard or in the lunch canteen. All of them also had experienced the problem of not getting adapted material in time quite frequently. The respondents expressed that this situation had caused a constant feeling of stress throughout the school years and that it also made them feel less competent than their schoolmates. They had often believed themselves that they were expected to perform at the same level as their sighted peers and felt less competent when this was not possible for them. The time problem made them also choose auditive media instead of Braille when they reached higher levels in school. When moving on to higher education students with visual impairment often face a more challenging situation. They still had to struggle with the problem of not getting adapted material in time. A totally new situation for many was that they also were expected to take on a major logistical responsibility to make their studies perform well. This took time and focus from the academic work. The study shows, in resemblance with other recent studies, [3,4] that young people with visual impairment not always get the best possibilities to prepare for higher education. Few of the respondents had been offered vocational guidance concerning the choice of university- or vocational training. Most of the guidance they had received concerning choice of university program or career often came from non-professionals like parents, teachers or friends. Furthermore almost none of the respondents had any experience of having a paid job before graduating from secondary education or university. The support from teachers and parents to find a summer job had been feeble or non-existent, since the general opinion was that school had been so demanding for them during semesters and that they needed to rest during the summer. Another result was that few had had any experience of how to write your CV or how to perform in a job interview. An important factor, mentioned by several respondents, was how important other peoples' expectations on their own possibilities to succeed in higher education or on the job market was for their own self confidence and own belief that this was going to happen.

DISCUSSION AND IMPLICATIONS FOR THE FUTURE

This study has shown that students with visual impairment often face a far more complex situation entering the transition process into adult life. They have to take on the same challenges as other young people in the same age but they also have their own barriers to overcome. In many ways it becomes clear that the transition process for young people who have a visual impairment sometimes fails in giving the extra support that would probably be needed. To create equal prerequisites as those for sighted

students the factor of time must be recognized and always been taken in consideration when planning the curriculum for the student who have a visual impairment. If this is not considered, this can cause a constant feeling of stress and feeling of not being as competent as sighted peers. This is something that almost all respondents have experienced throughout their school years. Vocational guidance regularly from upper secondary school would probably prepare these students better for the process of going on to higher education or entering the job market. To promote early experiences from the job market, efforts should be made to make it possible for students who have a visual impairment to get summer jobs or other possibilities of having a paid extra job. This could give experiences, self-confidence and important contacts for the future. To get the opportunity to practice how to perform in a job interview and how to write your CV could also be helpful. To get mentor or meet with young people who are visually impaired themselves and who have managed to enter the job market can give inspiration to younger students and work as important role models. In all inclusive education extra efforts must be made to strengthen the self-confidence of students who have a disability. Since you constantly compare your achievements with non-disabled students through the years in school, there is a great risk to feel less competent. In the long run this can result in a feeling of low self-esteem, based on the wrong prerequisites. This feeling can be very destructive for your own belief in what is possible to achieve in future life. Provided that you are given the right prerequisites, it is important to feel that people who are close to you really believe that you have the ability to live an adult and independent life in all aspects.

REFERENCES

- [1] A. Bryman. *Samhällsvetenskapliga metoder. (Research methods in social science). 1 uppl. Malmö: Liber ekonom.*
- [2] A. Rönnebeck, K. de Verdier, A. Winberg & S. Baraldi. *"Participation on equal terms"*. Specialpedagogiska skolmyndigheten, 2010.
- [3] S. Undhem. *"It is a very, very important transition – about what is important for young people with visual impairments in the transition process before entering higher education."* Masterthesis (<https://ub.uio.no/publisere/studenter>)
- [4] K. Wolffe & S.M. Kelly. *"Instruction in AreaS OF THE Expanded Core Curriculum linked to Transition Outcomes for Students with Visual Impairment."* Journal of Visual impairment & Blindness, June 2011, pp 104, 431 -443.

Let me keep it safe!

**Bert Veneberg¹, Leo Koopman¹, Mark Noorlander¹, Hans van Stam¹, Antoon van der Kamp¹,
Serge Willemsteijn²,
Vincent Zijffers¹, Angelique Koelewijn¹**

¹ Bartiméus
Doorn and Zeist, the Netherlands

² Transparant Training
Barendrecht, the Netherlands

ABSTRACT

Let me keep it safe!

1. INTRODUCTION

For the last 5 years Bartiméus (an health care organization that provides education, services and care to those that are at least visually impaired) is training all of her employees to keep them safe in their work with visually & mentally impaired clients. Most of the clients sometimes react in an aggressive manner to situations they don't understand or in which they are unable to cope with stress. They take their frustrations and pain out on their caregivers, themselves or the surroundings. Bartiméus wants to prevent these situations and the harm that comes from these escalations or incidents- for that reason a training is given to the caregivers each year.

2. QUESTIONS

Last year clients started asking; they asked what they could do to 'de-escalate' and be safe in harmful, aggressive situations. 'Is it wise to say something to a person that gets mad or should I get out of the room?' 'How do I recognize signs of agitation or stress?' 'Where do I sit best at the table, what is the safest place?' 'What do I say or do best in stressful situations?' These are all clients that live and work at Bartiméus. They are adults and they don't naturally learn these things. We teach their caregivers and help them what to do, but no one teaches them.

3. AWARENESS

But listening to the clients we learned that they wanted to know how to keep themselves safe! They wanted to be able to make safe and helping choices in stressful situations. They wanted to know the answers to the questions they asked us.

They no longer wanted to rely (only) on their caregivers, but they wanted to take responsibility and work on personal development by following this course.

4. RESULTS

So we sat with them and asked them exactly what they already knew and what they wanted to learn and together with them we developed a training/course. We worked together with them as we trained groups of clients to de-escalate and stay safe!

5. PRESENTATION

Together with our clients we would like to invite you to our presentation.

My dog, my freedom : representations of the visually impaired and professionals

Angélique Mouton, Stéphanie Demartin, Sarah Velghe

Ceuvre Fédérale Les Amis des Aveugles et Malvoyants, Vrienden der Blinden,
Belgium

a.mouton@amisdesaveugles.org
s.demartin@amisdesaveugles.org
vriendenderblinden@gmail.com

ABSTRACT

The guide dog is a medium for improving the quality of life of people with visual impairments. Providing autonomy and freedom, he contributes greatly to improving their inclusion in society, with a beneficial effect on self-confidence and the inclination to go to the other.

Demonstrating a dual role by greatly facilitating travel in terms of autonomy, security and fluidity and on the other hand being an undeniable catalyst for social connections, enabling their users to (re)create, to enrich their connection with society.

However a small percentage of Belgian visually impaired resorts to the guide dog. The analysis of the applications reveals that the motivation is sometimes dominated by aspect related to the travels, sometimes with social aspects.

Studies showing that erroneous representations were part of low demand, we wanted to analyze, on the basis of a specific questionnaire, the reasons for this low attractiveness of the target population in order to know the representations and potential prescribers, to identify the factors inducing demand to adapt the offer to the demand of the users..

Finally, we question the future of the guide dog at a time when technology occupies a preponderant place including in the daily life of the visually impaired.

1. INTRODUCTION

Since 1946, l'Oeuvre Fédérale Les Amis des Aveugles et Malvoyants trains guide dogs and gives them to visually impaired adults, through its Guiding Dog Training Centers in Ghlin and Koksijde. Both centers are members of the Belgian Assistance Dog Federation (BADF), which also has four other guide dog training centers as members. However, the total number of active binomials is small compared to the total population of Belgian visually impaired adults. This observation is identical in other countries and several studies have been carried out, notably in France [1,2] and in the United Kingdom [3], to explain this weak use of guide dogs and to identify possible solutions. This situation is all the more paradoxical while many studies have shown that assistance dogs,

whose dog guide, can greatly contribute to improve the quality of life [3].

The main objective of this research was to identify obstacles or, on the contrary, aspects facilitating the process leading to the granting of a guide dog. The motivations of the visually impaired underlying the request or the miss of request for a guide dog were analyzed, as well as guide dog representations of the Belgian visually impaired. Ophthalmologists and general practitioners were also interviewed to determine the extent to which they can be a lever to induce a guide dog request and / or support their patient when in questioning about the demand to get a guide dog. The secondary objective was to determine the extent to which, in the current context of incessant technical innovation in the field of mobility aids (electronic cane development, gps, augmented reality goggles, ...), the guide dog will be a major aid or will he disappear?

2. TERMINOLOGY

The Belgian Assistance Dog Federation defines assistance dog as follows: "assistance dog is the generic term used for dogs trained to help a person with a disability, regardless of disability, or a person suffering from certain diseases" [4]

Among the different categories of assistance dogs, we find the guide dog. He allows the visually impaired person to move in an autonomous, fluid, comfortable and relaxed way. Indeed, the guide dog can memorize several routes. He detects and indicates obstacles, dangers and disturbing elements for the handler, anticipates trajectories, responds to obedience and guidance commands, searches for specific objectives and can, if the safety of his handler is not guaranteed, disobey to a dangerous command. In contrast, the pet is a dog acquired for the essential purpose of being a companion with no ambition to make him carry out tasks similar to or near a job (hunting, guarding, rescue, ...)

Finally, "technical assistance" means: aids for reading, writing; all kinds of white cane; adapted material.

3. GUIDE DOG CONTRIBUTIONS

The visual impairment affects, in a global way, the autonomy of the visually impaired person. Loss is not lim-

ited to the visual sphere, since it leads to many functional limitations leading to a loss of independence in the various domains of everyday life (personal, social, professional, leisure, etc.). More specifically, mobility is strongly impacted and leads to a restriction of social opportunities; people with few opportunities to go out feel isolated or excluded. Faced with these difficulties, it is understandable that the level of depression is often higher in the visually impaired than in the overall population.

Guide dogs are mainly trained in order to ensure autonomous and safe travels for the visually impaired. Nevertheless, using a guide dog brings many other psychological and social benefits. It is also regularly observed that they increase self-confidence and play a significant role in the development of social relations. Ultimately, it is the quality of life of the person that is greatly improved.

An internal study carried out in 2012 comparing users of guide dogs and people deploying only with a white cane showed that, in comparison with other mobility aids (locomotion courses, white cane, Etc.), the guide dog significantly decreases the anxiety associated with displacements. Ultimately, the use of the guide dog is often seen as an indispensable element for the freedom of the person and it is the quality of life that is greatly improved.

4. METHODOLOGY

4.1 Recruitment of subjects

The subjects were recruited among visually impaired beneficiaries of BADF members, with or without guide dog. They had to be over 18 years old and had no intellectual disability or motor impairment. General practitioners and specialists in ophthalmology were selected from Les Amis des Aveugles et Malvoyants Social Service data base.

4.2 Survey

The survey for the visually impaired person included items relating to socio-demographic characteristics, representations of the guide dog, the motivations underlying a request for a guide dog or the absence of a request, the experience of the guide dog and the positioning in the face of new technologies related to mobility.

The survey addressed to general practitioners and ophthalmologists covered aspects relating to the professional characteristics, representations of the guide dog, the experience of the guide dog, support for visually impaired patients and positioning in the face of new technologies related to mobility.

Each subject was interviewed by telephone.

5. CONCLUSIONS

The primary goal of this study was to determine the factors hindering or facilitating the request for a guide dog to improve access to the guide dog. Depending on the profile of the visually impaired (severity of the visual pathology, evolutionary character of the disease, socio-

economic situation, professional integration, etc.), several specific variables have been analyzed to identify a number of obstacles and facilitators, both for the target population and for the various professionals interviewed. Among other aspects, we thought it important to reflect on how people using or not using a guide dog can imagine the different functions, advantages and disadvantages of various mobility aids (white cane, electronic cane, guide dog, etc.).

Finally, the second objective refers to the perennality of the guide dog as we know numerous technological innovations quick to appeal to more and more people within the visually impaired population.

The data analysis revealed a trend towards the future of the guide dog as a media for improving the quality of life of the visually impaired.

Acknowledgments

The authors would like to thank the BADF and its members, the visually impaired as well as the various professionals who have agreed to participate in this research and the many colleagues responsible for the interviews.

REFERENCES

- [1] F. Gaunet, J. Milliet, "Le rapport des personnes déficientes visuelles au chien guide. Comment l'usage du chien guide pourrait-il se développer en France" *ALTER, European Journal of Disability Research*, no.4, pp. 116-133, 2010.
- [2] Enquête FFAC OpionWay, "Les chiens guides et l'opinion des parties prenantes sur les questions d'accès à l'information et d'accompagnement", mai 2016.
- [3] L. Whitmarsh, "The benefits of guide dog ownership" *Visual Impairment Research* vol. 7, no. 1, pp. 27-42, 2005.
- [4] BADF website : www.badf.be

Employability of visually impaired persons: jobs tailored to the disability or the sky is the limit?

Bart Verdickt

Brailleliga vzw, GOB - Expertisecentrum Visus & Werk,
Brussels, Belgium

ABSTRACT

In our experience, focusing on a person's competences and making the match between jobseekers with visual impairment and the regular labor market, rather than trying to employ visually impaired persons as much as possible in jobs tailored to their disability, is the best way to maximize the employment opportunities for visually impaired persons.

In this paper, the Brailleliga's Expertise Center Visus & Werk¹ methodology is discussed.

We explain job-hunting, job matching, job carving and job coaching customized for visual impaired persons, but also the importance of assessment and differential diagnostics and the essence of a holistic approach of the person with visual impairment (the link between their home situation and employability).

In conclusion we suggest that such an approach not only promotes the inclusion of people with visual disabilities in the labor market and maximizes their employment opportunities but also promotes their inclusion in society. We point out that there is no contradiction between the wish to apply the UN Convention on Persons with Disabilities on the one hand, and specialized support for a certain period in order to reach inclusion on the other.

1. INTRODUCTION

People who are blind or visually impaired can perform almost any job you can imagine: lawyer, artist, accountant, secretary, customer service representative, food service worker, factory worker, financial analyst, teacher, medical transcriptionist, day care worker, counselor, computer programmer, cook, salesperson, clerk, and more. We cannot count the number of different jobs people who are blind or visually impaired are engaged in today or will be in the future. The possibilities are tremendous. [1]. This citation of the American Foundation for the Blind is completely in accordance with our experience in Flanders. However this needs to be placed in perspective. The sky is the limit, one might like to think

when taking a glance at the list of jobs above. Nevertheless not all jobs are currently accessible for visually impaired persons. For those jobs that are in principle accessible, a visually impaired job seeker may encounter a greater distance to the labor market for various reasons. Stigma attributed to the visual disability [2] and the stereotypes [3] that result from it can have a negative impact on the chance of being employed. It is clear that discrimination can be a consequence of such stigmatization. A study conducted in Flanders by Baert (2014) showed that, when a disabled person mentions his disability in his letter of application, the chance of being invited for a job interview lowered for about 52% [4]. The culture within an organization or company, HR processes and the workplace structure can also be inhibitory factors [5]. Also, visually impaired persons who are employed may at a certain moment in time experience difficulties in the workplace related to their disability. Many of the inhibitory factors for either job seekers with a visual impairment or for employees are also mentioned in the final report on the situation of persons with disabilities in Belgium with regard to their human rights and fundamental freedoms as guaranteed by the UN Convention on the Rights of Persons with Disabilities from 2013.[6] Clearly, not all visually impaired persons will need support, guidance when encountering difficulties such as these mentioned above. Nevertheless, it is our conviction that for those who need and seek support, an organization with expertise in visual disabilities offers the best possible approach. An efficient and adequate response to the request for help from a person with a visual impairment requires the intervention of a professional who has the expertise to correctly comprehend and evaluate the question and to respond accordingly. Furthermore, we deeply believe that the approach used should be a holistic one. In depth interviews with people with disabilities seem to confirm this believe [5, 6]. A holistic approach implies that we not only take the link between visual disability and work into consideration, but also the home situation, the social network, the state of health, the financial situation, mobility etc., boundary conditions that all may have an impact on employment.

In what follows we will explain what key activities in our experience seem useful: Assessment taking into account the functional vision, the impact of the disability on daily and hence professional activities, the visual handicap forecast and the known compensation techniques, the clarification of the (technical) supports needed, adapted lighting and customized work tasks, support including

¹ VDAB, the public employment service of Flanders, recognises both the assessment service and the vocational training and employment service (GOB) of the Brailleliga as a partner. Those two services form the Expertisecentrum Centrum Visus & Werk (Expertise Center Vision & Work).

‘work readiness’, competency enhancement, where necessary, including efficient use of tools (eg. high technology IT tools), orientation and mobility, braille, job hunting, job matching, job carving.

Job coaching for employees, including (if necessary) further training, retraining, mediation, job carving, awareness rising ...

2. ASSESSMENT

No two visually impaired people have the exact same level of functional vision or the same approach to executing work-related tasks. Some use their vision more than others; some may work more efficiently when they can use nonvisual techniques [1]. Therefore, clarifying the visual impairment and functional vision forms the basis of assessment by the Visus & Werk Expertise Center of the Brailleliga. All other data resulting from further assessment research will be viewed in the light of the outcome of this visual diagnosis/prognosis.

We clarify the medical situation. Not only will objective data regarding visual impairment be collected and studied but also relevant data about other physical and/or psychological complaints. Reading and writing skills will be clarified, taking into account assistive technology and other adjustments for visually impaired persons. Compensation techniques are clarified (to which extent the VI person compensates his vision loss in a correct way and which additional techniques might be useful? For example: tactile sense, knowledge of braille..). Differential diagnosis is the leitmotiv during the assessment process: Is the visual handicap the basis of the specific difficulties the client experiences or is there another underlying problem? Objectification is done on the basis of adapted test material/questionnaires and depending on the specific constraints experienced by the customer. The results of this assessment are translated into ICF terms. What do we assess? At this point it is important to note that we will not discuss each topic in detail, since this is not the subject of this paper. Cognitive skills are clarified (intelligence, attention and memory) as will the psychological functioning and the coping styles. We look at different labor skills, attitudes (motivation, degree of diligence, independence, self-reliance..). We also clarify which assistive technology may be useful and we draw up a lighting advise for which we can, when required make use of our light lab/light experience space.

3. SUPPORT OF JOBSEEKERS

3.1 Work readiness and competency enhancement

For some the distance to the labor market is still too big, and it is necessary to ensure that the person further develops some basic competencies, in order to be prepared to function in a job. We call this ‘work readiness’: together with the person, we work on a number of basic competencies, tailor made, to make him ready for the job mar-

ket. It is not a vocational training in the strict sense of the word that we offer. However, when needed, we work together with regular training centers and there are many opportunities for on-the-job training that we can offer.

3.1.1 ICT/computer skills

Before a client is ready to work, computer skills often need to be learned or optimized. In addition, it is necessary that at the same time the correct and efficient use of (appropriate) assistive technology is learned. This could be about magnification software, sometimes in combination with speech, about applying the correct contrast and color settings, using video magnifiers, scanners with speech, braille devices, etc. In some cases, it may be necessary to provide typing lessons first and/or braille lessons. Also, the use of tablets or smartphones, of course, with the appropriate customizations, may be included.

3.1.2 Language knowledge

In some cases extra attention needs to be paid to correct articulation, extra attention to intonation and speech speed (because attention of the listener through eye contact is not possible), vocabulary, spelling and grammar, reading in a fluent way etc. We offer these lessons -when needed- in Dutch, French and/or English.

3.1.3 Job application training

Not only do we offer training about (self-)evaluation of competences, about using the STAR-method, about creating a good cover letter and CV, about body language and presentation skills, as proposed in the Manual for inexperienced job seekers with visual impairment of the European Blind Union [7] but we also use Ofman’s Core Quadrants, we work on blindisms, on compensation techniques, clothing advice etc.

3.1.4 Mobility and orientation

Acquiring correct displacement techniques but also learning how to travel from home to work in a safe way, displacements at work, inside the building.

3.1.5 Braille

6-dot and/or 8-dot braille may need to be acquired. Besides, a study conducted by Bell and Mino (2015) on Employment outcomes for blind and visually impaired adults shows that the likelihood of being employed and receiving higher earnings was higher for individuals who read braille on a weekly basis. [8]

3.2 Job hunting, job matching, job carving

Job hunting consist of awareness rising and active propection of employers open to employing persons with

visual impairment. Job matching implies the search for the right match between job requirements and the competencies of the jobseeker, our job coach being the active link between the jobseeker and a potential employer. Alignment of the vacancy with the profile / competencies of the jobseeker. The following issues are mapped out: What competency requirements for the vacancy are absolutely necessary? Which competency requirements can be acquired before or during the employment? Can adjustments to the work organization, work environment, work material, and/or adjustments to the task package provide the right match? Job carving consists of making necessary adjustments in order to create the best possible tailor-made job.

3.3 Work post analysis, -advise and -adaptation

This implies, *inter alia*, the analysis of the accessibility of the workplace, but also the accessibility of the used IT system in the company and the compatibility of assistive technology software with the software used in the company. It is also important to ensure that the necessary assistive technology is available at the start of an employment, but also during an eventual internship, etc. In these we lend material, until the person's proper material is purchased. The workplace itself should also be analyzed and adapted to the needs of the person with the visual impairment. Advice on tools, necessary to perform the job adequately, advice on lighting as needed, all these aspects are taken in charge by our coaches.

3.4 Boundary conditions

As we stated in the introduction, we deeply believe that the approach used should be a holistic one: the home situation, the social network, the state of health, the financial situation, mobility and so on may intervene and impact the work situation and vice versa. In collaboration with other services and disciplines within the Brailleliga on the one hand, and with external partners on the other, these boundary conditions are addressed.

4. SUPPORT OF EMPLOYEES: JOB COACHING

Job coaching is the guidance and support of a (new) employee, in the aim of reaching sustainable employment (eg. at the start of a new employment, new team, change of tasks, deterioration of disability, ...). The expected outcome of job coaching consists of: (re-)integration of the (new) employee reinforcing the competencies of the (new) employee, learning to deal with the limitations (both for the employee as for the supervisor and/or colleagues), optimizing communication between the visually impaired employee, his colleagues and his supervisor, adjustments to the work organization, work environment, assistive technology, ergonomics, job carving, mediation with the purpose of job retention.

4.1 Competency enhancement: supplementary training

Supplementary training or retraining may be necessary for people who become visually impaired (eg. accident, illness), when deterioration of an existing visual disability appears, but also when new tasks need to be acquired (eg. during reorganization, with a new function within the company, after implementation of new software etc..). In most cases this supplementary training will relate to ICT/computer skills.

4.2 Job coaching, mediation, awareness rising, reorientation

Job coaching can take various forms and is always organized tailor-made, according to the employer and employee/jobseeker demands. It consists of the following elements: question clarification with the employer and the employee (mapping the different questions, analysis of competencies and limitations, ...). Workplace guidance through, among other things, coaching conversations and/or mediation conversations with the employee, his colleagues and his employer, developing methodology, schedules, procedures related to a task package, improve communication, increase employees self-reliance and self-management..

4.3 Work post analysis, -advise and -adaptation and boundary conditions

I refer to paragraph 3.3 and 3.4: The methods are the same for employees as for jobseekers

5. KEY RESOURCES

Not only do we offer our services from our headquarters in Brussels (building adapted to visual impairment, adapted classrooms with all necessary assistive technology, light lab/light experience space and a demo room for assistive technology can be used), but also from regional homes in each Flemish province (Leuven, Hasselt, Antwerp, Ghent, Kortrijk, Geel). In this way we are accessible in the whole Flemish region. The staff of the Expertise Center Visus & Werk consists of job coaches (divided by region), instructors (both in headquarters and on relocation), psychologists, special education generalist, social worker, occupational therapists/orthoptists, specialist light consultant. There is close collaboration with an ophthalmologist. Other Brailleliga services can offer support where necessary. We also have partnerships with specialized centers where rehabilitation ophthalmologists practice (Rehabilitation Center Horus - UVC Brugmann Brussels, Center for Visual Rehabilitation and Low Vision - UZ Ghent, Rehabilitation Center Eye Diseases - UZ Leuven), as with other partners working in the field of employment (both generalists and specialized partners).

6. CONCLUSIONS

Not every jobseeker with visual impairment, nor every visual impaired employee needs support or guidance in order to reach his professional goals. Nevertheless, for those who do estimate that they need support or guidance, the experience acquired during the past half century within the Brailleliga regarding visual impairment and employment shows that both the assessment of the capacity of a visual impaired person, and the guidance towards/during employment, is different than with persons without visual impairment. This suggests that the deployment of specifically trained staff is necessary to provide a sound response to the specific questions and needs of the visually impaired person.

In this paper, the methodology of the Expertise Center Visus & Werk of the Brailleliga was discussed. Well aware that this methodology may not be applicable in every country or region, among others depending on local law and the opportunities and constraints that these entail, we find that this way of working increases the chances of success in terms of employment for people with visual impairment and promotes their inclusion both professionally as in society as a whole.

One might think that, amongst others thanks to the evolution of assistive technology, legislative and societal changes, visually impaired people may perform many jobs that they never could have before. The sky is the limit. Nevertheless, a freshly (February 2017) published report from the Royal National Institute of Blind People (RNIB) about employment status and sight loss shows that in Britain only one in four registered blind or partially sighted people of working age is in employment. This figure is even worse for people who are completely blind. Only around one in 10 people with poor functional vision is in paid employment. [9] I have no knowledge of statistical data in Belgium, but it is clear that there is still work to be done. All the more because apparently there is a tendency in society to offer solutions to the problems of persons with a (visual) impairment as a "one size fits all" and no longer "tailor made". Mainstream where possible, specialized when required, it's a nice slogan, but only provided the mainstream answers are as adequate, efficient and relevant. Something to think about.

7. REFERENCES

- [1] American Foundation for the Blind, *Careers for Blind and Visually Impaired Individuals*. Consulted on April 24th 2017 via <http://www.afb.org/info/living-with-vision-loss/for-job-seekers/for-family-and-friends/careers-for-blind-and-visually-impaired-individuals/1235>
- [2] McLaughlin, M. E., Bell M. P., Stringer D. Y., Stigma and acceptance of persons with disabilities: Understudied aspects of workforce diversity, *Group and Organization Management*, Vol. 29, no.3, pp. 302-333, 2004
- [3] Stone, D. L., Colella, A., A model of factors affecting the treatment of disabled individuals in organizations. *Academy of Management Review*, Vol. 21, no. 2, pp. 352-401, 1996
- [4] Baert, S., Functiebeperking bij sollicitatie reveleren, kansen op jobgesprek liquideren?, *Tijdschrift van het Steunpunt Werk en Sociale Economie*, Vol. 24, no. 1, pp. 74-79, 2014
- [5] Dirx, E., Masterproef De loopbanen van personen met een fysieke of visuele handicap, scriptie ingediend tot het behalen van de graad van master in de toegepaste economische wetenschappen, UHasselt, 2016, consulted on april 24th 2017 via <http://hdl.handle.net/1942/22183>
- [6] Consortium KULeuven, ULB, UHasselt, UGent en UAntwerpen, Studie in opdracht van het Interfederaal Gelijkekansencentrum, De situatie van personen met een handicap in België met betrekking tot hun mensenrechten en fundamentele vrijheden zoals gewaarborgd door het VN-Verdrag inzake de rechten van personen met een handicap, Eindrapport, pp.167-202, 2014
- [7] Cascio, V., Ebels, J., Manual for inexperienced job seekers with a visual impairment, European Blind Union, 2016
- [8] Bell, E. C., Mino, N.M., Employment outcomes for blind and visually impaired adults, *Journal of Blindness Innovation and Research*, Vol. 5, no.2, 2015
- [9] Slade, J., Edwards, E., White, A., Employment status and sight loss, Research Report, RNIB, 2017

The Benefits of Accessible Theatre Programmes on Students with Moderate and Severe Visual Impairment

Judit Gombas¹, Erika Anita Baráth², Beáta Prónay¹, János Zalán³ and Cecília Tóth³

¹ELTE Bárczi Gusztáv Faculty of Special Education,
Budapest, Hungary
gombas.judit@barczy.elte.hu

²Primary and Residential School and Unified Methodological Centre for the Partially Sighted,
Budapest, Hungary

³Hungarian Theatre of Pest, Budapest, Hungary

ABSTRACT

The Hungarian Theatre of Pest (Budapest) is the first theatre in the country which provides patrons with VI (visual impairment) regular access to audiodescribed plays. Within a sustainable cooperation, for two school years the theatre has been providing students of the Primary and Residential School, Unified Methodological Centre of Special Pedagogy for the Partially Sighted (Budapest) highly discounted entry fees and, after each theatre visit, a theatre pedagogical event tailored to the students' special needs.

A 16-item questionnaire was put together in order to examine students' impressions on audiodescription and the accessible preparatory and follow-up programmes.

The questionnaire was filled in by 41, 9-15-year-old students with severe (N=7) or moderate (N=31) VI (4 students said they had no VI). All students needed to borrow smart phones from the theatre to listen to the audiodescription, they did not have their own devices. 7 respondents said they had never been to theatre before, 10 students said they had been there before with the school, not with their families, and only 3 out of the 41 students said they go to theatre with their family at least once a year. Even students with a moderate VI stated audiodescription helped them follow the plot more easily. 40 respondents would like to go to theatre again, which shows how important it is to widen the range of accessible performances all over the country.

Keywords: audiodescription, theatre, visual impairment

1. INTRODUCTION

Audio description or AD, a service tailored for ensuring access for individuals with VI to television, films and performing arts, has a history of around four decades in The United States where the methodological fundamentals of AD were set by Gregory Frazier in his masters thesis in 1975 (Snyder, 2007). It was soon introduced in Europe. However, the first training for audio describers, organized by a Hungarian non-governmental

organisation, 90 Decibel Project, with invited trainers from the British VocalEyes, took place no sooner than 2012. Until then audio described cultural events were rare and sporadic, available almost exceptionally in the capital city, Budapest.

The American Council of the Blind defines AD as follows: ' Audio Description involves the accessibility of the visual images of theater, television, movies, and other art forms for people who are blind, have low vision, or who are otherwise visually impaired. It is a narration service (provided at no additional charge to the patron) that attempts to describe what the sighted person takes for granted - those images that a person who is blind or visually impaired formerly could only experience through the whispered asides from a sighted companion.' (<http://www.acb.org/adp/ad.html#what>)

The Hungarian Theatre of Pest (Budapest) is the first theatre in the country which provides patrons with VI (visual impairment) regular access to audiodescribed plays. Within a sustainable cooperation, for two school years the theatre has been providing students of the Primary and Residential School, Unified Methodological Centre of Special Pedagogy for the Partially Sighted (Budapest) accessible visits with highly discounted entry fees and, after each theatre visit, a theatre pedagogical event tailored to the students' special needs. Our research aimed at examining what benefits audio description gave children and whether it had a positive influence on their overall experience.

The research was built on the following hypotheses:

1. Students with VI, independent of their visual capacity, enjoy audio description and profit from it;
2. Accessible theatre pedagogical programmes (such as stage and backstage tours with verbal and tactile input, and post-performance drama educational lessons) contribute to a better understanding of the play and make it more enjoyable for students with VI;
3. Theatre visits with their primary caretaker/family are not a characteristic free time activity for the majority of respondents;

4. The majority of students with VI do not have smart phones, which means they can get access to AD only thanks to the theatre's technological support.

2. METHOD AND SAMPLE

A 16-item questionnaire with both closed and open questions was put together in order to examine students' impressions on AD and the accessible preparatory and follow-up programmes.

The questionnaire was filled in by 41, 9-15-year-old students with severe (N=7) or moderate (N=31) VI (4 students said they had no VI).

3. RESULTS

Only 4 students with moderate VI said they did not use AD, while 29 respondents answered that although they saw everything (children were seated in the first and second front rows), they listened to the AD. When writing in detail about their experience of AD, several children underlined that verbal information helped them focus their visual attention, and the descriptions they heard in many cases completed otherwise incomplete scenes. Meeting actors before the play made the recognition of characters easier during the play. Concerning the tactile stage tour A respondent wrote: 'It was nice to do something exceptional that other visitors had no chance to do'. The opportunity to touch objects facilitated latter visual recognition, which meant 'less stress during the play', a respondent wrote.

7 respondents said they had never been to theatre before and 10 children stated they have been to theatre only with their school. Only 3 out of the 41 students said they go to theatre with their family at least once a year. None of the children had their own smart phone to listen to AD with, they all borrowed devices from the theatre.

4. CONCLUSIONS

'There is no reason why a person with a visual disability must also be culturally disadvantaged.' (Snyder, n.d.) This is the reason why sustaining the AD project is a priority for the Hungarian Theatre of Pest, where the first, and so far only, audio describer of Hungary is employed. The theatre makes every effort to have enough smart phones used by patrons with VI in order to provide access to everyone, independent of financial status.

The Non-Profit LTD for Individuals with Disabilities (FSZK), in line with the 'nothing about us without us' principle, has recently realised a course for individuals with VI to become expert advisors in future AD projects. FSZK also runs an updated database of its trained audio describers (<http://fszk.hu/szolgaltatasok/audio-narracio/>).

An NGO, For Accessible Culture (AKKU) serves patrons with VI in various theatres, thanks to a mobile device. The service is therefore increasingly available in the capital city, but further intensive infrastructural and

HR developments are necessary all around the country in order to make AD in theatres accessible for all in need.

REFERENCES

- [1] Joel Snyder, „The Visual Made Verbal”. Audio Description Associates, 2007.
Retrieved 04/04/2017 from <http://www.audiodescribe.com/links/AD-The%20Visual%20Made%20Verbal.pdf>
- [2] Joel Snyder, „The fundamentals of Audio Description”, Audio Description Associates, n.d.
Retrieved 04/04/2017 from http://www.audiodescribe.com/about/articles/fundamentals_of_ad.pdf

The DogSim lost his legs

Peter Lasaroms¹, Hans Damm², Anita Lasaroms¹

¹ P.C. Lasaroms, Dogs for Care
p.lasaroms@planet.nl

²Visioptronic
contact@visioptronic.fr

A new training aid, based on 'old' principles

1. INTRODUCTION

The DogSim has been an useful training-aid during the last decade in the preparation to the guide dog, but also in O&M training. But it also knew a number of disadvantages. In order to keep the positive qualities and lose the disadvantages, a new training aid is designed: the DogSim New Generation.



Figure 1. The DogSim

2. PURPOSE DOGSIM NG

The DogSim NG is an O&M training-aid. It can be used for the preparation of walking with a guide dog and for teaching skills in O&M for all ages, and of course to train the senses. Because the client walks in front it also improves his independence in taking decisions.



Figure 2. The DogSim being used

3. ADVANTAGES DOGSIM NG

3.1 Ergonomis aspects

The DogSim NG is small and light enough to put in a small backpack and take it with you. To use with the client both the bar for the client and the bar for the instructor is adjustable. The bar for the client as well for the instructor is adjustable in length. The grip for the client can be adjusted in anatomic position, for the right hand side and for the left hand side.

3.2 Use other senses

Because the client is in the front position he can get information all around him. The instructor is no obstacle in getting information

3.3 Appearance

The DogSim is not prominent present, the client feels less striking.

3.4 Price

In this case: more is less. You can buy 5 DogSim NG instead of one old type DogSim. The exact price you can obtain with Visioptronic.

4. TRAINING

To make sure you use all the benefits the DogSim NG can offer you, you can obtain training accessory.

5. CONCLUSIONS

The DogSim NG is a light cheap training-aid, which both client and instructor can benefit from. It is easy to take along, light, easy to hold, cheap, for righthand use as well as lefthand use, and is less prominent. But most of all it benefits the goals in O&M: optimal sensory information, keep the client in command, good preparation in walking with a cane or a guide dog.

Stimulating Social Contact Between Blind Children And Their Sighted Peers Through Playing Together At Regular Kindergarten (Age 5-6 Years)

Tiene Vanreybrouck - Early Intervention
Centre Ganspoel – Huldenberg
Belgium
(Tiene.Vanreybrouck@Ganspoel.be)

ABSTRACT

Based on personal experience and literature (A.. Ingsholt M. Dik et al ...) we observe that blind children and their sighted peers play in a different way. Blind children play longer functional play: they need more time to explore the world of objects and activities. Their sighted peers develop fantasy play more early on based on their visual imitation of the surrounding world.

How can they learn to play together?

Stimulating this playing together is teamwork: parents and early intervention, teacher and special teacher each have their own role.

We are working out a project bringing together all parties:

- in meetings we choose and align a limited number of activities.
- together, the early intervention worker, parents and their blind child are doing activities of daily living (e.g., shopping and kitchen activities).
- the school teacher and special teacher work in the classroom to develop social skills in both the blind and the sighted children, and guide fantasy play "shopping" and "cooking".
- this project will be illustrated with video recordings of the chosen activities
- experiences and recordings from this project will be used in the future with other families with a blind child, for information days for regular teachers who have a blind child in their class, to transfer knowledge to young colleagues, ...

PAPER

I was confronted with various problems around this subject: first of all from my job in early intervention with parents and their blind child and secondly from my collaboration with regular schools and the special teachers from our Centre.

The Children

Based on personal experience and literature (A.Ingsholt, M.Dik et al ...) we observe that blind children and their sighted peers play in a different way.

Blind children play longer functional play: they need more time to explore the world of objects and activities. They are in need of "scenario's" . They need adults to explain and help them.

Their sighted peers develop fantasy play more early on, based on their visual imitation of the surrounding world. They play on a higher level than their blind peers.

Keeping contact with each other for example using each other's names, answering each other, ... is not easy for both parties while playing.

Both sighted and blind children need help to learn to play together.

The School

Teachers in regular schools have no experience with a blind child.

The regular teacher has her own program for the group (with 20 or more children).

She wants the blind child to play independently when busy with other children.

The special teacher comes to the school two times a week for 3hours each.

She has a lot of work to do: sharing information, helping to adapt materials and learning activities, ... There is also the pressure of preparing the blind child for the start in primary school: preparation for learning braille etc.

So learning to play together is under pressure. It takes a lot of time to help the teacher and both the blind child and the sighted children.

The Families

There is less time in families with both parents working or having a lot of other problems.

They seem not to have time and space to think about blindness and the special needs of their child.

They expect their blind child to play alone.

This is why I started a project:

I wanted to bring parents, regular teacher, special teacher and early-intervention worker together and to work in a team. Because learning to play together is teamwork for the adults surrounding the blind child and their sighted peers.

- We sat together and made a plan that was achievable for all parties.
- We chose to work with two themes that children like to play in class: "playing shopping" and "playing kitchen".
- We plan to film the activities in order to have illustrations afterwards.
- We want to use our experiences and the video materials for our next meeting day for teachers in regular schools who have a blind child in their class, which we organise at our Centre.
- We want to look at the video at home with the parents to have new ideas together.
- And we also want to share it with new and young colleagues who start working with young blind children.

Each member of the team has his own role:

Parents and their child and Early Intervention worker at home:

We want to give the blind child "scenario's" by doing the real thing together. So we go shopping to a real shop.

Together we decide what we will prepare, we make a shopping list and we go shopping with time to explore and take all the different steps you need to take at a shop.

Back at home we make a simple "shop" with the real fruit/vegetables and play shopping, taking the opportunity to switch roles.

Afterwards we make fruit salad/soup, helping the blind child to do as much as possible. And of course we enjoy our meal together afterwards.

Mother and early intervention worker evaluate:

Did she and her child like the activity, what is achievable to repeat in the next weeks.

At school the teacher and special teacher work together to develop social skills with the blind child and his sighted peers:

learning to use each others name while addressing each other, answering each other when spoken to, how to have a conversation by taking turns, listen to each others ideas, taking initiative, ...

Teacher and special teacher evaluate the "play kitchen" and "play shop" in the classroom in order to adapt it to the needs of the blind child.

We decide together that we want to start to play in the shop with real things and not plastic miniature objects, so there is a connection with what the child did in the real shop and at home.

Teacher and special teacher learn how to guide the play. They have to learn how to guide more indirectly and put themselves in the background, to give limited intervention, ...

Purpose of this workshop

I want to illustrate this project with video fragments and I want to discuss the different aspects .

I want to exchange experiences with people from other countries on the subject of developing social contacts between blind and sighted children, about working together with all the people around the children etc. ...

Sex And Relationship Education.

“How To Use The Sex Kit.”

Emma Vandamme¹ and Marlies Praet¹

¹Mobile Support Service Accent, Centre of Expertise Spermalie / De Kade,
Brugge, Belgium
{emma.vandamme, marlies.praet}@de-kade.be

ABSTRACT

We teach young children to communicate, to ride a bike, to swim,... In the same way, as in these domains of personal development, we have to support children to become healthy, happy, balanced and responsible individuals who can enjoy their sexuality.

We want children to learn how to make friends and how to make up after a fight. They can learn which sexual behavior is accepted or when their behavior is exceeding boundaries. This is a real challenge.

Relationships, sexuality and safe sexual behavior is fun most of the time, but also very complex, especially for children and youngsters with a severe visual impairment.

Our team developed a sex kit with clear visual and tactile materials, game materials and guidelines, and of course vision texts as a background for parents and professionals.

In addition to the sex kit we also made a guidance on the use of the sex kit. It doesn't offer an elaborate method, but a survey of possible materials and procedures. The materials can be used during lessons, workshops or individual home support.

1. INTRODUCTION

While working with children, youngsters and young adults who are blind or have imperfect eyesight, we observed that there is very little accessible and suitable material with regard to the themes of relationship education and sexuality. Yet there's a great need for it, because children and youngsters with poor eyesight, don't have access to the great amount of visual information relating to sexuality.

Children and youngsters normally come into contact with this information at school or in their circle of friends. They spontaneously learn the difference between boys and girls, they read books or see pictures about relationships and sexuality, they see their brothers, sisters, mum or dad in their swimming-suit or naked in the bathroom, they see images of sexuality on television, on the internet, in magazines...

Children and youngsters with a severe visual impairment miss a lot of these spontaneous moments. As such they have a serious disadvantage in acquiring knowledge and developing attitudes and skills with regard to relationships and sexuality.

We also notice that our clients have a lot of practical questions. For instance: “How do you fasten a bra around mommy's belly?”, “When does a willy stop growing?”, “How does sex work?”, “How do you put on a condom?”.... To answer these questions in an adequate way, we needed visually clear and tactile material.

After deliberation with other welfare facilities and thanks to the financial support from the Fund Jeanne en Pierre Beeckman of the Foundation Koning Boudewijn we started to compose a sex kit.

2. THE SEX KIT

Our sex kit contains clear visual and tactile materials such as:

1. reading books and visually distinct picture books;
2. tactile materials such as contraceptives, underwear, life-like baby dolls, sanitary towels and tampons, shaving materials, life-like penis- and vagina models, anatomic models of a man and a woman, breast models;
3. game-materials and workshops;
4. guidelines, brochures and vision texts as background for parents and professionals.

3. THE MANUAL

In addition to our sex kit we also made a manual (see figure 1) on the use of the sex kit. This manual doesn't offer an elaborate method. It is a survey of materials and procedures.

For each material in our sex kit we made a card with a clear picture of the material, a short description, the reference where to find or to buy the material, a table with a survey of themes or objectives for which the material can be used, an enumeration of possible methods and adaptations and tips for combinations with other material from the kit.



Figure 1. Manual sex kit.

The materials can be used during lessons, workshops or individual home support.

3.1 What's the Same in our Approach to the Education of Relationships and Sexuality?

We didn't develop a new vision, since the relational and sexual development proceeds in the same way for blind or visually impaired children and youngsters and children and youngsters with good eyesight.

This manual is based on the vision of Sensoa [2,3], which says that sexual education is necessary for each child. It is as important as education in every other domain of personal development. "Sexual education aims to support youngsters in their development to become a person who respects himself and others, who is conscious of his own values, standards and possibilities and those of others and who can take well-founded decisions with regard to sexuality. A positive self-image, emotional openness and self-confidence are a precondition."

"From various studies it is clear that good relationship- and sexual education leads to more responsible sexual behavior, less sexual violence, less sexually transmitted disease (STD) and less unplanned pregnancies. In addition relationship- and sexual education makes that youngsters postpone the first sexual intercourse and it leads to a better use of condoms and contraceptives." [2].

We perceive the notion "sexuality", as in the vision of Sensoa [2], very broadly. Sexual education is not only about acquiring knowledge, but it also pays attention to learning attitudes and skills, dealing with emotions and giving information about where to find support.

These are indeed the objectives we work on with the help of the materials from the sex kit: acquiring knowledge, attitudes and skills, dealing with emotions and knowing where to find support when necessary.

The choice of themes we assimilate in our manual is based on "Raamwerk Seksualiteit en beleid" of Sensoa [3].

These themes are: body and puberty, self-care and self-image, friendship and relationships, sexuality and sex, communication, resilience and sexual cross-border behavior, gender and sexual orientation, sex and society, reproduction and birth-control, STD's and HIV.

All materials from the sex kit are numbered and a practical survey represents which material(s) you can use for each combination of theme and goal.

3.2 What's Different in our Approach?

Since the sex kit and the instruction manual are developed for a specific target group, we naturally make different accents or make use of different methods.

Because blind children and youngsters or children and young people with severe visual impairment don't have access to a variety of information about sexuality, we work mainly with tactile material. We explore this material together with the child or youngster and give oral information (describing details, explaining what the child is exploring,...). Exploring the material takes more time and energy for blind or visually impaired children and youngsters and it is therefore important that they can keep the materials for a longer period, so that they can revert to it if necessary.

We should be thoughtful to create a safe environment where children with visual impairment can experiment with behavior and social contact with other children and where they can explore freely. This is not always evident for children with poor eye-sight because they are more often followed, supervised and protected than children of the same age who can see well.

Because learning about social behavior by means of observation and imitation is very difficult for them, it is necessary to explain about social interaction and intimate contact in a more specific way. For instance: it is necessary to describe how flirting works. The interactive game material from the sex kit and the workshops, as described in this instruction manual, can meet this specific demand.

Often, because we emphasize the vulnerability of visually impaired and blind children and youngsters, we also tend to focus more on the risks and sexual cross-border behavior, instead of approaching sexuality in a positive way. With our sex kit and instruction manual we try to ensure that we can talk about the theme of sexuality in a more relaxed way.

With the adolescents we should also take extra time to dwell on the wish to have children and the heredity of visual impairment.

3.3 How do we use the Manual in our Mobile Support Service?

3.3.1 Demand-driven

With our team of the home-support we try to start from the concrete questions and concerns of the children, youngsters and their parents. There was for instance the boy who told us he couldn't see much from what was shown during the biology-lesson and how frustrated he was because, of course, it was inappropriate for him to watch the film with his nose against the screen to get the same information as his class-mates.

We also respond to situations that occur at home in relation to body experience, relationships and sexuality. For instance: it's an ideal moment to talk about the difference between boys and girls, or where babies come from, when a baby-brother or sister is born.

3.3.2 Proactive

By including the theme 'relationships and sexuality' in our support plans, we make sure that we don't lose sight of it and that we can talk about it during the individual home visits.

We also indicate to our clients that we find this theme as important as f.i. learning development, development of play and motorical development. Therefore the theme is also part of for instance group meetings for youngsters or multi-day summer camps...

Of course it is very important to be sensitive to the specificity and the place of the family: are they ready to talk about this theme and which topics are sensitive?

3.3.3 Scruple and shyness

We also have to take into account that we, as mentors, also may be shy to talk about certain themes. It's normal to be shy sometimes or have scruples. It should of course be possible to indicate boundaries, but we may not minimize sexuality.

A frame and vision about sexual education and regular deliberation with colleagues can help the mentor to overcome his or her shyness.

It's also important to have a good basic knowledge of relationships and sexuality in all its facets. There is a lot of background information about different themes in our sex kit which makes it easier to answer the questions.

4. CONCLUSIONS

Parents and other professionals experience a lot of questions and uncertainties with regard to relational and sexual education for blind children or children with severe visual impairment.

We, as a team of mobile support service, want to support children, youngsters, parents and professionals with this education task by offering accessible and concrete material. With our sex kit and manual we want to supply handles to interact about sexuality, to give sufficient answer to their questions, to enlarge their self-confidence and resilience and to make them become healthy, happy, balanced and responsible individuals who can enjoy their sexuality.

We hope that the materials in the Sex kit and the clear description of possible methods in the Manual will be fruitful!

Acknowledgments

We'd like to thank everyone who contributed in any form to the making of our sex kit and guideline.

We also want to thank the Fund Jeanne en Pierre Beeckman of the Foundation Koning Boudewijn and our other sympathizers for their financial support.

REFERENCES

- [1] Frans, E. & Klai, T. (2005). *Seksuele vorming. Raamwerk voor opvoeders, leerkrachten en voorlichters*. Antwerpen: Chris Lambrechts.
- [2] Sensoa (2013). *RSV-Wijzer, een Vlaamse visie op relationele en seksuele vorming*. Antwerpen: Sensoa.
- [3] Frans, E. & De Bruycker, A. (2012). *Raamwerk Seksualiteit en Beleid. Kwaliteit, preventie en reactie in jouw organisatie. Versie voor de jeugdsector, december 2012*. Antwerpen/Brussel: Sensoa en Child Focus.
- [4] Gringhuis, D. , Moonen, J. & van Woudenberg, P. (1996). *Kinderen die slecht zien. Ontwikkeling, opvoeding, hulpverlening en onderwijs*. Houten/Diegem: Bohn Stafleu van Loghum in samenwerking met Bartimeus.
- [5] Kef, S. (1999). *Outlook on Relations – Personal Networks and Psychosocial Characteristics of Visually Impaired Adolescents* [Academisch proefschrift ter verkrijging van de graad van doctor], Vrije Universiteit Amsterdam, Faculteit Psychologie en Pedagogiek.
- [6] Kinderrechtencommissariaat Dossier (2010), *Jongeren en seksualiteit. Het recht op seksuele gezondheid en ontwikkeling, Visie en aanbevelingen*.

Creating universal accessible text documents

Pieter Brabant and Vincent Cassert

Spermalie, vzw De Kade, school intervention team,
Bruges, Belgium
{pieter.brabant, vincent.cassert}@de-kade.be

ABSTRACT

Making information accessible to everyone, it's one of the main principles of Universal Design for Learning. Many public services as well as education in general need to tackle this problem in order to create platforms without restrictions to users.

This workshop addresses to those who create or lay-out textual content and who want to do this in an efficient and accessible manner so that students with a visual impairment can participate and contribute.

The domain text editing within a school setting (as well as in the business world) is often reverted to classical programs like MS Word and/or OpenOffice. In a practical way, we offer a demonstration of some simple rules and guidelines within the use of these programs to create accessible text documents. The use of styles, descriptions of images, avoidance of empty white space,... all contribute to a clearly recognizable and accessible document without having to compromise on design. Then we also demonstrate how such a document can be read by different users, with specific attention to the visually impaired.

1. INTRODUCTION

With the concept of Universal Design for Learning in mind, a lot of exploration in the field of accessible text documents has already been done by various organisations. A good reference point to start is the Accessible Digital Office Document (ADOD) Project [1]. It has been developed by the Inclusive Design Research Centre, OCAD University as part of an Enabling Change Partnership project with the Government of Ontario and UNESCO (United Nations Educational, Scientific and Cultural Organization) and gives an extensive overview of guidelines to create accessible office documents.

Our purpose is not to summarize all guidelines that can be found concerning this topic, but to give a clear overview of some best practices and their implementation.

2. UNIVERSAL DESIGN FOR LEARNING

Introduced by CAST [2], the concept of UDL is gaining more and more interest by public services as well as education. Its principles [3] can be summarized as creating curriculum with multiple means of representation, multi-

ple means of expression and multiple means of engagement to create a flexible learning environment that can accommodate individual learning differences [4]. When it comes to creating content by text documents, the purpose is undeniable to make them as accessible as can be for everyone. A consistent application of the following guidelines makes this possible.

3. TEXT EDITING GUIDELINES FOR ACCESSIBILITY

3.1 Use Accessible Templates

All office documents start with a template. These can be as simple as a blank standard-sized page or complex nearly-complete document with text, graphics and other content. Because templates provide the starting-point for so many documents, accessibility is critical. If you are unsure whether a template is accessible, you should check a sample document when the template is used (see 4. MS Word accessibility checker).

3.2 Specify Document Language

In order for assistive technologies (e.g. screen readers) to be able to present your document accurately, you must indicate the natural (human) language of the document. If a different natural language is used for a paragraph or selected text, this also needs to be clearly indicated.

3.3 Fonts and Colors

When formatting text, especially when the text is likely to be printed, try to:

- Use standard fonts with clear spacing and easily recognized upper and lower case characters. Sans serif fonts (e.g. Arial, Verdana) are typically easier to read than serif fonts (e.g. Times New Roman, Garamond).
- Use font sizes between 12 and 18 points for body text.
- Use fonts of normal weight, rather than bold or light weight fonts. If you do choose to use bold fonts for emphasis, use them sparingly.
- Avoid large amounts of text set all in caps, italic or underlined.
- Use normal or expanded character spacing, rather than condensed spacing.
- Avoid animated or scrolling text.

The visual presentation of text and images should have a contrast ration of at least 4.5:1. To help you determine the contrast, here are some examples on a white background:

Very good contrast (Foreground=black, Background=white, Ratio=21:1)

Acceptable contrast (Foreground=#767676, Background=white, Ratio=4.54:1)

Unacceptable contrast (Foreground=#AAAAAA, Background=white, Ratio=2.32:1)

Also, always use a single solid color for a text background rather than a pattern.

3.4 Use Headings and Styles

Any documents that are longer than a few paragraphs require structuring to make them easier for readers to understand. One of the simplest ways to do this is to use "True Headings". True headings are more than just bolded, enlarged, or centered text; they are structural elements that provide a meaningful sequence to users of assistive technologies.

3.5 Provide Text Alternatives for Images

When using images or other graphical objects, such as charts and graphs, it is important to ensure that the information you intend to convey by the image is also conveyed to people who cannot see the image. This is done by adding concise alternative text. If an image is too complicated to concisely describe in the alternative text alone (e.g. artwork, flowcharts, etc.), provide a short text alternative and a longer description as well.

3.6 Avoid 'Floating' Elements

When certain elements (e.g. images, objects, text boxes) are inserted into Word documents they default to being an "inline object". Inline objects keep their position on the page relative to a position in the text. This is beneficial for users of assistive technologies (e.g. screen readers), because the position of the object in the document order is clear, so the screen reader can read the object's alternative content (e.g. Description field) when the user moves keyboard focus to that position.

However, Word also provides the option to have these elements "float" outside of the text order, with text flowing around, under or over it. This is a problem because the position of the object in the document is no longer clear and the screen reader will often read the alternative text out of context, which can be confusing. These text flow options should be avoided.

Avoid placing drawing objects such as arrows, lines and shapes directly into the document (e.g. as borders, to create a diagram). Instead, create borders with page layout tools and insert complete graphical objects (e.g. pictures).

3.7 Keep it Simple with Tables

When using tables, it is important to ensure that they are clear and appropriately structured. This helps all users to

better understand the information in the table and allows assistive technologies (e.g. screen readers) to provide context so that the information within the table can be conveyed in a meaningful way.

Important tips for tables:

- Keep tables simple by avoiding merged cells and dividing complex data sets into separate smaller tables, where possible.
- Table cells should be marked as table headers when they serve as labels to help interpret the other cells in the table.
- If tables split across pages, set the header to show at the top of each page. Also set the table to break between rows instead of in the middle of rows.

3.8 Use Built-In Document Structuring Features

Creating an index or table of contents to outline office document content can provide a means of navigating the meaningful sequence of content.

Start a new page by inserting a page break instead of repeated hard returns.

Numbering the pages of your document helps those reading and editing your document effectively navigate and reference its content. For users of assistive technologies, it can provide a valuable point of reference within the document.

When you create lists, it is important to format them as "real lists". Otherwise, assistive technologies will interpret your list as a series of short separate paragraphs instead of a coherent list of related items.

4. MS WORD ACCESSIBILITY CHECKER

If you wish to check the accessibility of your document or template (see 3.1 Use Accessible Templates), Word offers an "Accessibility Checker" to review your document against a set of possible issues that users with disabilities may experience in your file.

Important Note: the accessibility checker cannot detect all types of accessibility issues. For example, it can tell if alternative text is missing, but it cannot tell if alternative text is actually correct. It also doesn't test for some issues, including colour contrast.

5. CONCLUSIONS

With a workshop of these guidelines and the use of a screen reader to demonstrate the accessibility, we like to make a clear example on how important it is to apply these instructions with every text document one creates.

It should be the baseline in the mindset of every author who's willing to spread a message as wide as possible. Because integrating these guidelines makes a difference if we want to honour the human right for everyone to have access to information!

Let's take our responsibility and make this happen!

REFERENCES

- [1] J. Treviranus, J. Richards, S. Ruplall, and V. Christanto, *Accessible Digital Office Documents (ADOD) Project* by Inclusive Design Research Centre (IDRC), from <http://adod.idrc.ocad.ca/>,
- [2] Rose, DH, & Meyer, A (2002) *Teaching Every Student in the Digital Age: Universal Design for Learning* Alexandria, VA: ASCD.
- [3] Orkwis, R, & McLane, K (1998). *A curriculum every student can use: Design principles for student access*. ERIC/OSEP Topical Brief No. ED423654. Reston, VA: ERIC/OSEP Special Project.
- [4] CAST (2008) *Universal design for learning guidelines* 1.0. Wakefield, MA: CAST. Retrieved July 1, 2008 from <http://www.cast.org/publications/UDLguidelines/version1.html>

Self Concept And Future Concept And Visual Impairment

Tine Vanhauwaert

vzw De Kade
Begeleidingscentrum Spermalie – Het Anker
Campus Spermalie
Snaggaardstraat 9
8000 Bruges
BELGIUM

1. INTRODUCTION

All (small) children have an idea, a dream of what they will become when they are grown up: a taxi-driver, a nurse, a teacher,... At this young age, parents and teachers go along with this dream, not yet thinking at the feasibility of the dream. They enjoy the desires of their children. Young blind children have the same dreams. Parents and teachers react the same way, but somewhere in their heads a bell is tinkling: “Will that be possible? Will I have to warn my child that maybe it will not be possible? That makes me sad ... or angry ...” Etc.

Young visual impaired adolescents also have dreams. Our experience shows several types of adolescents. A lot hold on to their unchanged dreams for a long time. Some hold an impossible dream, because it is impossible. Some adjust their dream during growing up and try to realize a part of it. And some change their dreams into feasible options.

2. WHY IS A FUTURE CONCEPT SO IMPORTANT?

Everyone develops a Self Concept that grows and gets steady during youth, but still can change along later life-stages. Everyone tries to establish an identity with which we feel comfortable, recognizable (for ourselves and for others) and significant in the world.

People with an impairment also establish this self-concept/identity. We see that our adolescents also struggle with this process and have to integrate/implement the impairment in their identity. The way in which they develop/give rise to their future concept often shows the balance of this integration. This process can be quite tough. Most adolescents want to share their sighted peer

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

group: they want to be “normal” and don’t like it to be confronted with the impairment. E.g. T wanted to become a professional photographer, Ti. ,who has also a motor disability, wants to be a cook of a restaurant, Th., who has also a mental impairment, wants to live alone and become a teacher, and L. wants to become a film director.

T. became an educator and still tries to make nice photographs, Ti. helps in the kitchen of a restaurant a few hours on Sunday when it’s not too busy. He learns a lot of other things there. Th. lives in a home for grown up visual impaired persons and assists twice a week in a nursery school. And L. finds his friends in a Cosplay: they gather with 100s of likeminded movie-fans and dress up in a theme of famous movies.

3. HOW CAN PARENTS, TEACHERS, EDUCATORS, ... SUPERVISE THIS PROCESS?

This is the toughest part: do we have to confront them with the impossible part of their dreams? Do we have to stimulate the dreaming even if we know that it will be impossible to fulfill it? Do we have to protect them against painful experiences?

Lots of factors will influence the process: the age, the mental capacities, the view of the parents/context, the presence of role-models, ...

At least all of them have the right to have a future vision and a significant role in the (small or broad) society they live in.

4. CONCLUSION

During this Workshop we’d like to present you 4 cases of adolescents who made/are making their own way to their future. We investigate the influences and the turning points and we try to find out what helped/helps them in their process. We’d like to share this with you and hope to learn from each other.

Can smartphones and tablets replace dedicated assistive devices?

Jeroen Baldewijns

Blindenzorg Licht en Liefde,
Brussels, Belgium
baldewijns.jeroen@lichtenliefde.be

Elin Galle,
Ghent, Belgium
galle.elin@lichtenliefde.be

Eline De Ganck,
Ghent, Belgium
deganck.eline@lichtenliefde.be

Jos Verhaegh,
Antwerp, Belgium
verhaegh.jos@lichtenliefde.be

ABSTRACT

Apps can turn a smartphone or a tablet into an alternative for a dedicated assistive device. An app can be an alternative for a braille note taker, for a pocket CCTV loupe, for a talking clock, for a colour detector, ...

But is an app the best solution for every one? What are the pros and cons of an app, compared to the dedicated assistive device that it wants to replace? Has the app the same functionality as the classic assistive device? What are strengths and the dangers of combining many functions into one single device? And what about power consumption of this one device?

In this workshop, we will demonstrate the app versus the classic assistive device in several functional domains. For each domain, we will discuss both the functional and practical differences, the aimed target groups and the advantages & disadvantages.

1. INTRODUCTION

The traditional market of assistive technology is changing rapidly. This includes both the way how developers think about creating new assistive devices and the way in which persons with a visual handicap are using assistive devices.

This is mainly caused by different evolutions that are going on in the ICT-sector: the Internet of Things, the popularity of cloud computing, the availability open source software, touch screens replacing the keyboard & mouse, the social network boom, online shopping became common, programs on a CD became apps in app stores, the miniaturization and growing popularity of mobile platforms, the birth of wearables, synthetic speech became a mainstream product, ...

These changes forced developers of assistive technology to think in different ways about creating new products. They will have to look for solutions for the usage of touch screens. They have to compete with open source tools for

impaired people, they have to consider how app stores can fit into their business models. They can take profit of the fact that synthetic speech became mainstream.

And they gave new possibilities to the users of assistive technology, but also new challenges. They will have to make the switch from traditional keyboards to touch screens. They will have to learn how to use cloud computing. But they will get new possibilities as well. Open Source products bring assistive technology within the reach of everyone. Apps on mobile devices, that are cheap (or even for free), can do very powerful tasks and even replace some classic assistive devices.

2. UNIVESAL DESIGN

But the major change is the awareness about Universal Design, which means that the provider of a product or a service makes reasonable efforts to assure that his product or service can be used independently by as many users as possible, including any persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability.

Apple took a leading role by adding accessibility features in their entire product line, Mac computers, the iPhone smartphones, the iPad tablets, the iPod music players, the Apple TV and the Apple Watch. They added accessibility features for vision (VoiceOver, synthetic speech, display accommodations, font adjustments, zoom, audio description, magnifier, speak screen, Siri, dictation), hearing (compatibility with hearing aids, software TTY, visible and vibrating alerts, closed captions), motor skills (switch control, AssistiveTouch, touch accommodations, keyboard shortcuts, predictive text) and learning disabilities (reading support, speech dictionary, Safari reader, Guided Access).

But Apple is not the only one to offer UD products. A nice example is the Flemish television broadcaster VRT. They make large efforts to make their products accessible

for disabled people. They offer audio description, subtitles and Flemish sign language for a significant part of their programs. They also do effort to make their websites and apps accessible and they are developing an accessible video player for their websites and apps. Another example is the bank PNB Paribas Fortis, that installed accessible cash machines.

Universal design will have a huge impact on the traditional market for assistive devices. Some dedicated devices will disappear from the market as UD devices will take over. Other, very specialized, assistive devices, such as braille displays, will become important, but will feel some pressure from the trend to the use of speech.

What we see now is that apps are taking over several functions of traditional assistive devices. Right now, we are on a turning point and the user must make the difficult choice between using an app or a dedicated assistive device to read books, take notes, watch television, recognize colors, ...

3. APPS VERSUS ASSISTIVE DEVICES

We are comparing several apps with their classic counterparts in order to get answers to these questions. We are listing all the possibilities and restrictions and we will judge every product by listing its pros and cons.

We are doing so for:

- Braille note takers versus text editing apps
- Color detectors versus color detection apps
- Handheld video magnifiers versus magnifier apps
- Scanning & reading devices versus OCR apps
- Daisy players versus daisy apps

The detailed results of this study (together with an overview of the market offer) will be presented during the lecture.

We will as well propose some ideas on how to make simple extra tools by yourself to make apps even more useful. We will also explain the many different ways in which the user can input text on a smartphone or tablet.

4. ANDROID VERSUS IOS APPS

The largest group of visually impaired people use the iOS platform as their mobile solution. But in term of accessibility, Android is catching up to iOS. As a consequence, a growing number of people is interested in the Android platform.

For this reason, we are comparing a few assistive apps that exist for both of these platforms. In doing so, we indeed have a special focus on accessibility.

We are doing so for:

- The ViaOpta Nav GPS app
- The KNFB Reader OCR app
- The Anderslezen daisy app

The detailed results of this study will be presented during the lecture.

Building Mutual Framework Of Quality Educational Services Offering For Individuals With Mdiv And Deafblind In Europe/Euroasia Region

Martina Celizic¹, Andrea Hathazi², Emanuela Stoilova³ and Monika Tóth⁴

¹Day care center „Mali dom-Zagreb“,
Zagreb, Croatia
martina@malidom.hr

²University of Babeş- Babeş-Bolyai, Department of Special Education,
Cluj-Napoca, Romania
andrea.hathazi@ubbcluj.ro

³Sofia University, Department of Special Education,
Sofia, Bulgaria
estoilova_spedu@abv.bg

⁴Budapest School for the Blind,
Budapest, Hungary
tothmoni@vakisk.hu

1. Perkins International in Europe/Euroasia region

Perkins International presents one of the global leaders in the education of children with visual impairment and multiple disabilities, including deafblindness. Perkins partners works with hundreds of local partners: schools, orphanages, daycare facilities, teacher training programs, government agencies, family advocacy groups and in more than 60 countries all over the world. Powered by their expert training and strategic support, their partners help in transformation of educational landscape in their regions.

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License 3.0 Unported, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Perkins International has worked in Europe and Eurasia since 1991.

Regional Partners in Europe & Eurasia come from 15 countries: Armenia, Bulgaria, Croatia, Czech Republic, Estonia, Greece, Hungary, Moldova, Poland, Romania, Russia, Serbia, Slovakia, Turkey and Ukraine.

This workshop aims at bringing together the expertise in providing educational services for children with visual impairment and multiple disabilities and deafblind in four of Perkins International partners in Europe/Euroasia region: Croatia, Romania Bulgaria and Hungary

„Mali dom-Zagreb“ (Croatia) is Day care center for rehabilitation of young and adults with multiple disabilities. The program started in late nineties as nongovernmental organization and one of the first services available to children with visual impairments and deafblind with additional disabilities in Croatia. In the year of 2009 the NGO transferred to city funded organization and transitioned to new facilities able to offer wide variety of services from early intervention, transdisciplinary assessment, day care program for students 0-21 years old and from 2015 as Educational center offering on site and in service trainings to professionals from Croatia and

abroad. There have been more than hundred children with multiple disabilities, including MDVI and deafblind, served through its programs.

The Special Education Department within Babeş-Bolyai University in Cluj-Napoca developed courses at undergraduate level, but also master level with the support of Perkins International. These courses brought valuable information and working skills and formed competencies for students, but also specialists in the field. Perkins International supported the organization of Summer Schools as an important component of the in-service training for teachers. These summer schools represented a huge opportunity to develop professional competencies, building networking and reach out with a competent approach to the education and rehabilitation of children with MDVI/deafblindness included. The other partner in Romania is the Resource and Educational Support Center Speranta in Timisoara. The center offers direct support for children and their families within the project Luminita for MDVI children, educational, therapeutic and inclusion support activities.

Perkins has been working with Bulgarian partners since 1991. The success of this collaboration is based on the good collaboration and communication within the programmes on which Perkins is working in Bulgaria along with Sofia University "St. Kliment Ohridski", School for Visually Impaired Students "Prof. dr. Ivan Shishmanov" in Varna and the School for Visually Impaired Students "Louis Braille" in Sofia. Both Schools provide services on different levels: early intervention, elementary school program, pre-vocational and vocational programs. All the programs support students with multiple disabilities and deafblindness from 3 to 21 years old. Currently there are 203 children with multiple disabilities in the two schools - 117 in Varna and 86 in Sofia. Every year, with Perkins's support, there are seminars and trainings for the teachers from the two schools during which they can consult with representatives of the University's professors and exchange experience, good practices, different needs of new generation of MDVI students and new challenges with their colleagues from the other school. All three Bulgarian programmes were supplied with Perkins Brailers. Various methodologies and handbooks from Perkins have been translated and they are now used to support the work of the teachers and to increase the knowledge of the university students for education

and rehabilitation of MDVI and deafblind children. Thanks to this collaboration in the past 25 years Bulgaria has had a working unified system for preparing teachers and for education, therapy and social inclusion of children with multiple disabilities.

The School for the Blind, in Budapest has had a good collaboration with Perkins International since 1992. It started with one of the teachers taking part in the Educational Leadership Program (ELP) at the Perkins School for the Blind. The School provide services on different levels: early intervention, kindergarten, elementary school program, vocational program, and also as a resource center for supporting children in the inclusive settings. All the programs support students with multiple disabilities and deafblindness. The total population within the school programs are 195 students and those receiving educational support through the Resource Center are 130. In the last five to seven years the students's profile has been changing very intensively. The majority of the population within its program are MDVI and population with profound multiple disabilities with very complex needs are increasing including the deafblind students. The professionals have been facing new challenges. All programs have been working on changing their pedagogical programs, curriculums and training the staff to meet these challenges.

The MDVI and DB Program at Budapest School for the Blind works cooperatively with the Hungarian Deafblind Association which is also supported by Perkins International. The Association has two major services: one for the acquired deafblind individuals. They support them with rehabilitation service, providing personal assistant help and communications assistants according their needs. The other major group is the congenital deafblind children. The Association support families, give early intervention support and counselling by home visits all over the country.

2. Educational practices in regional partner's countries

Persons with visual impairments and multiple disabilities (MDVI) and deafblind represents population that, although heterogenous due to combination and complexity of concomitant impairments, share some specific education needs that should be respected in the context of educational programs. The sensory impairments of this populations are often accompanied by other – intellectual, motor, communication, health impairments that require meeting their needs in the context of specialized educational and habilitation services not solely for one of the impairments. Because of it's low incidence among disability population this population is often included in programs for persons with multiple disabilities or profound and multiple learning disabilities (PMLD).

These needs are shown in the Table 1.

Predictability and consistency	Organized environment	Opportunities for generalization	Optimal level of support
Functional goals embedded in meaningful activities	Effective communication system	Meaningful outcomes	Meaningful topics
Enough time for learning	Skillful educator/ communication partner	Learning useful skills and concepts	Enjoyment

Table 1. Summary of educational needs of students with MDVI/Deafblind³

There has been huge shift in the way impairments are viewed and following that services improved in the last years. In contrast to medical perspective on disability, the International Classification of Functioning, Disability and Health, of the World Health Organization (ICF-WHO, 2007)¹ emphasize that disability needs to be seen in the context of levels of person's participation in his life context. Educational and habilitation services in our countries are changing in that direction too. The change is seen in developing educational programs for MDVI and Deafblind. In the cases where there exist a demand for following regular curriculum there exist discrepancy in the context of meeting state standards and participation in meaningful activities.

In Bulgaria, together with the Ministry of Education teachers from the two schools and professors from the university have developed

special curriculums for children with multiple disabilities which have been applied on the national level.

A Curriculum for deafblind/ multisensory impaired children was developed also in Romania, a curriculum that is part of the National Curriculum. The Curriculum is aimed for preschool children and school age children level 1-9.

In addition to what (the content), very important aspect in education of students with MDVI and deafblind is how the curriculum is delivered. The activity-based approaches takes everyday life situations as the context for learning.² Within this approach, developmental, learning and functional goals are embedded in naturally occurring activities helping children build a framework for their understanding of the surrounding world.³

There exist the need of blending traditional approaches (developmental or teaching academics in the context of general curriculum) with requirement of making learning as meaningful and for student relevant experience.

3. Quality indicators in education of persons with MDVI and Deafblind

There are several Quality indicators⁴ tools developed with the purpose of evaluation of programs serving students with visual impairments and additional disabilities and deafblind. These indicators are directed toward quality program development and process of self evaluation but also for outside supervisors as tool for measuring program capacities.

Based on the current perspectives on education for people with MDVI and deafblind the set of indicators was developed that can serve as a guide to professionals and the administrators in planning meaningful educational experiences. According to this framework the activity is in the center and services are developed around supporting the participation in those activities. These indicators are analyzing process factors which relate to activities that organization offer and the quality of planning. The Quality Indicators³ are developed through analysis of educational activities in program for children with visual impairments and multiple disabilities „Mali dom-Zagreb“. For the

purpose of this paper we are going to present just two sets of indicators. First set of indicators is related to selection of appropriate activities which contribute to supporting students become active and engaged in meaningful contexts. The slower processing in our students require enough time for activity which is reflected in the number of activities in our programs. Other important factors are also frequency of activity or understanding the result of an activity. These factors will be analyzed by showing examples of best practices in partner countries.

Second set of indicators are looking at student's engagement and participation in activities. Engagement is taken as a measure of quality of participation in activities within an environment. The goal of educational programs for children with PIMD must include an increase in the child's total amount of engagement as well as the level of engagement shown. This can be done by an analysis of the environment in which the activity is performed, defining the type and appropriate level of support, providing the structure for learning and meaningful outcomes, adapting complexity to level of understanding and ensuring effective communications system.

4. Strengthening teacher's competencies in the field

One of the Perkins International's most valuable impact in the region is organization and access to quality teachers trainings. It all started with opportunity for our teachers to be part of Educational Leadership Program, teachers training program at Perkins School for the Blind that many of our professionals successfully graduated from.

Since beginning Perkins International supported participation of professionals at national and international conferences that encouraged further networking.

Through collaboration with universities, courses on undergraduate and master level were developed. Universities also developed new curriculums with specialization in the field of visual impairments, MDVI and Deafblind. Student practice was improved where students got the chance to receive additional training on the curriculum for children with multiple disabilities in organizations.

There was number of professional trainings and seminars delivered on specific topics like communication, curriculum, functional vision assessment or orientation and mobility etc. Several regional trainings were given for teachers in Armenia, Serbia, Bulgaria and Romania. Study visits were encouraged to observe different programs within region.

The access to relevant resources and literature was also improved through translations of Perkins publications to national languages but also through own publications documenting best practices in various domains.

The partner organizations are developing into Educational and Resource centers with unique expertise accessible to population of persons with MDVI and deafblind, their families and professionals.

5. Conclusions

In the last thirty years since Perkins International works in our region there were significant improvements on different levels-professional, organizational, university, national levels. The programs serving students with MDVI and Deafblind went through huge transformations. The majority of this population is now supported by our services. The professional network in the region continues to grow. This workshop will also reflect onto some of future directions in providing quality services for MDVI and deafblind individuals and their families. Opportunity to connect and learn from each other.

Acknowledgments

Perkins International and Dennis Lolli, Europe/Euroasia regional coordinator for the encouragement and opportunity to connect and learn from each other.

Prof. Isabel Amaral, retired professor of the Polytechnics Institute of Setúbal, who through mentoring our program developed „Quality Indicators in the education of children with Profound Intellectual and Multiple Disabilities“. Through guidance in reflection on our own practice we got most valuable knowledge and skills and increased quality of our educational services.

REFERENCES

[1] World Health Organization. (2001) International Classification of Functioning, Disability, and Health. Geneva: WHO.

[2] Magne Tellevik, J., & Elmerskog, B. (2009). Activity-based intervention for multiple-disabled visually impaired people. *British Journal of Visual Impairment*, 27(3), 204-220.

[3] Amaral, I., & Celizic, M. (2015). Quality indicators in the education of children with Profound Intellectual and Multiple Disabilities. *Da Investigação às Práticas*, 5(2), 112-125.

[4] Perkins International (2010). Quality indicators for programs serving students who are blind and visually impaired with additional disabilities or deafblindness

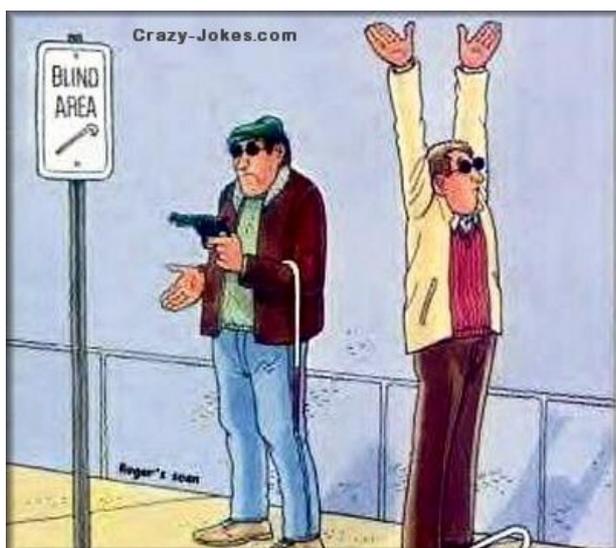
Geocaching with and for visually impaired children and young adults (as a means for orientation training)

Marten van Doorn

Bartiméus Education Centre, Zeist, The Netherlands
mvdoorn@bartimeus.nl

ABSTRACT

Orientation is knowing where you are. And to reach that place you need to navigate. That makes navigation one of the most important aspects of our training. Geocaching is a navigation game where you search with a GPS for treasures hidden by other players. A game based on orientation and mobility and therefore suitable for people with visual impairments. We developed a curriculum of 6 lessons and provided lessons for a period of 10 months. In this workshop we start with the consistency of orientation and navigation because you need to know how the effects on each other before starting with a GPS. We will describe the contents of the 6 lessons of which the curriculum Geocaching is. After the period of 10 months we evaluate the curriculum and came to some conclusions. This presentation will be followed by a practical workshop.



Copyright: © 2017 This is an open-access article distributed under the terms of the Creative Commons Attribution License 3.0 Unported, which permits unrestricted use, distribution and reproduction in any medium, provided the original author and source are credited.

ORIENTATION, MAINLY A MENTAL PROCES AND LESS A SKILL

I'm not telling anything new if I say that the basic for good mobility depends of good orientation and navigation abilities. Navigation is thinking how you're going to walk from point A to point B. And that is what most blind persons don't do or too late. They stand up and start walking immediately. As soon you want to go from A to B you have to be able to navigate. That means you have to make a navigation plan how to come from A to B. And if you want to follow that navigation plan orientation is very important. Over and over you must ask yourself the next questions. Where am I and in which direction must I go.

Orientation is the ability of a visually impaired client to determine his position in the surrounding environment. The key lies in the spatial relationship between the client and the surroundings. Is the exit left or right, how far away is the teacher, how far is it to the other side of the street and what is the shortest (bicycle) route to the store. These are all questions to do with the positioning in space. This spatial context is changing each time by changes in the environment and movement of the client. Only when the client knows where it is (A) and where want to go (B) he can decide how he gets there, along which route and by which means. You could use GPS for that purpose. But what if you don't understand these systems yet or you can't control them. And they don't work inside. These modern GPS systems doesn't help you how to cross a street or roundabout. Learning this skill, remembering certain knowledge and solving a problem depends also partly on the intellectual capacities of the client. When skills are mastered, it is important that the client can apply this in similar situations.

But also the ability to act in unexpected situations. The client can learn to walk a route or to do some shopping, but if he does not know what to do if problems arise, he will never be able to walk the route independently. One of the pillars on which orientation is based is the observation of the surrounding. During instruction is therefore important to find suitable environments to practice. By tapping the cane someone feels not only the surface but also hears his environment. The same applies to his footsteps. By linking the sound and the touch of the cane the possibility arises to anticipate what is coming. And particular this orientation to distance (the sound) makes him better able to anticipate things to come. Eventually he will remember that when a certain sound (landmark) is heard, he for example 4 meters later has to turn right. In orientation is often thought in advance. One must know where to go, where the destination is and they should have an idea how to get there. We realize maybe not so much that control where you come from - the basis is for your orientation. If your mind and your movement the position of the starting point can hold, you will not get lost easily. Stimulate therefore the visually impaired to remember where he came from and ask him to walk back. Ask him during walking back to mention the next landmark and what he have to do at that point. Use all available information and land-marks you can find, in particular the audible - often invisible - information.

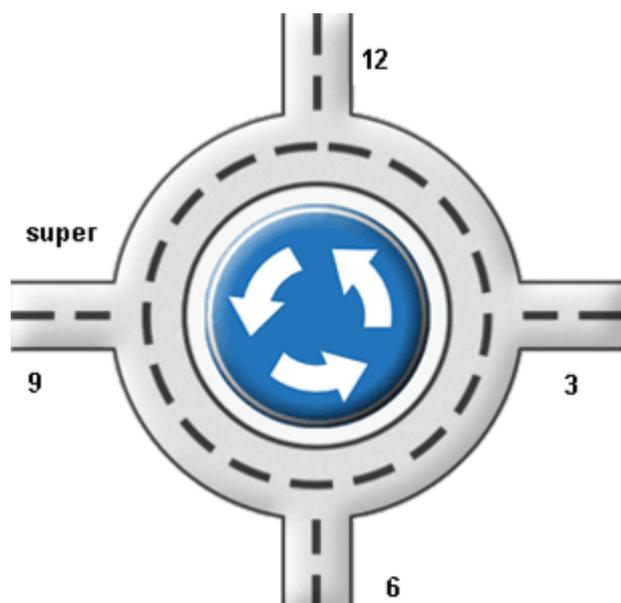
Children who have a bad memory and difficulty to remember, you must not learn a route but you have to learn them to navigate. In the school where I work we have a crossroad of corridors.

When a blind child comes from his class and he have to go to outside he passes that crossroad. On that point he has to go straight on. But often we all say when the child is doubting whether he has to go to the right or straight on: it's OK, go on instead asking him questions like "what do you hear? What is right or left from you. The child doesn't get the opportunity to think before acting. In this way it will take much longer before he knows his way to outside instead of that we let him discover his way by himself

without our support. The N of navigation (thinking) is for the child essential.



Orientation begins at this first step and requires continuous counseling, without giving concrete substance or information. Let see what a blind client has to do to be able to cross a roundabout. Purpose of this training is that the child builds a mental map of this roundabout. And learns to use the clock-method. As said, the map that the child is building with your confirmation is 10 times better as the map which you describe. Make a simple plan of the roundabout with the 4 streets. The four streets you can compare with the number on a clock. So you have street number 3, 6, 9 and 12. The street where we approach the roundabout we always call number 6. Most of the time your client will approach the roundabout from the same side.



Orientation begins at this first step and requires continuous guidance, without giving concrete substance or information. As Dan Kish says: every step under guidance is a missed step to learn. I want to nuance that. It is more important how you give that guidance. Give your client the opportunity the space and time to explore the world around him and give him the guidance he needs.

And Geocaching is a mean to fulfill all these needs.

Geocaching is a game where you search with a GPS for treasures hidden by other players. A game that takes you to places you probably would never come. A game based on orientation and mobility and therefore also suitable for people with visual impairments. Although there will have to be made some adjustments and sometimes a sighted guide is needed.



This package contains a number of lessons for our clients, the conclusion if this sport is suitable for our clients and which problems they have to face and which solutions may be.

GEOCACHING, WHAT IS IT?

These are 8 points that we are going through:

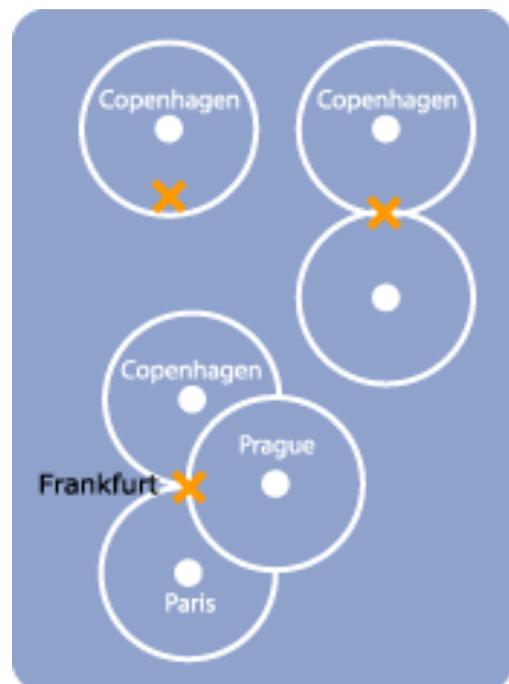
1. Geocaching the game.
2. Choosing a geocache.

3. Different types of geocaches.
4. The results explained.
5. The GPS coordinates.
6. Searching and finding a geocache.
7. What can you find in a geocache and what to do with it.
8. What is a Travel Bug

Imagine that you are completely lost. You wake up one morning in a strange hotel room and have no idea where you are. You go downstairs and ask the hotel receptionist, "Where am I?"

"No idea," he says, "but I can tell you that you are 955 kilometres from Copenhagen."

You now know that you are somewhere in a circle round Copenhagen with a radius of 955 kilometres. You walk into town and stop somewhere for coffee, the waitress tells you where you are. She says, "604 kilometres from Paris" and walks away. At that time you see the napkins on the table. And by pure coincidence here are perfect detailed maps of Europe! You take one, grab your handy compass and draw two circles. You now know that you are on one of the two points where the circles intersect. There are only two points that are both 955 kilometres from Copenhagen and 604 kilometres from Paris. Back on the street you will be called by an old man. He tells you that you are at 510 kilometres from Prague. You grab your napkin and compass and draw another circle. Now you know exactly where you are: Frankfurt!



WHAT ARE THE MAIN PROBLEMS FOR VI PERSONS AT GEOCACHING?

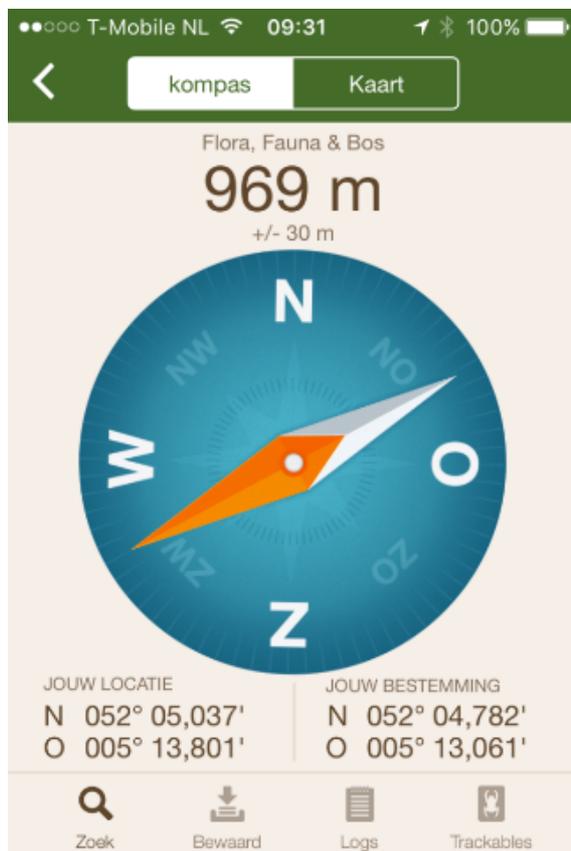
On the app geocaching coordinates are given in a format that it can't be read with the voice-over. When you are trying to read the coordinates of a cache on the app Geocaching it will be read split up and you can't use (or hardly) use it.

For example:
N. 052 05.518
E. 005 14.616
E 2.1 km

It will be read as:

N. E.
052 005 E
05.518 14.616 2.1 km
and it doesn't make sense for blind people.

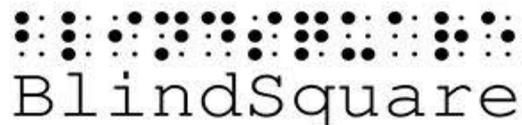
I wrote an email to Geocaching.com and presented this problem. Then got an answer that they want to customize the app for all people and that this is one of the action points. I'm at this moment in conversation with geocaching about changes at the app so that it can be used with Voice-over.



This issue is not on the computer with a braille or speech software. So it is possible to prepare at home caches in advance and convert them. But that's a lot of work and spontaneous geocaching during holidays is almost impossible.

For accuracy, the last 100 to 200 meters we use a different type of navigation. Blind Square or Heare.

- Since Heare and Blind Square over long distance does not accurately indicate the direction.
- Heareapp works with a sound left or right of you and so must use headphones
- Because Google maps, TomTom and Navigon do not work outside of roads and paths.



The app "Blind Square" uses decimal coordinates. When the coordinates of Geocaching can be converted to the coordinates of Blind Square the problem is solved. All of these navigation programs use different coordinates. A converter with copy and paste could be a solution.

At Bartiméus we have the department Accessibility. They are developing an app which can recalculate the coordinates and put them in the right app which you want to use to find a cache.

Accessible navigation programs like Google maps, TomTom and Navigon can be launched from the app Blind Square. A very popular free app like ViaOpta Nav not yet.



App Heare (www.heareapp.com)

The disadvantage is that that you can't make any routes / points when you are on your way. This must be done on a computer at home.

Another point in using Heare app may be that you need to use headphones because you will be redirected to the cache with a sound on your left ear, right ear or straight ahead (both ears). Heare uses the same coordinates that are also used by geocaching app.



We must still consider whether to use the cheaper App Ariadne to navigate along the last 200 to 500 meters. This app only costs 4 euros. Blindsquare costs almost 30 euros

In our lessons we used Apple iPhone. But most apps are also available in Android (exception Blind Square and Heare).

And maybe for the last few metres the blind geocacher can ask the help from a sighted person by making use of the apps Facetime and/or Be My Eyes.

IS GEOCACHING NOW SOMETHING FOR PEOPLE WITH A VISUAL IMPAIRMENT?

The answer is yes because:

- You can go until the last 3 to 5 meters independent.
- You often works in a team and thus learn to work together
- Good for the integration into a common sport.
- O & M promotes and you come in unfamiliar places
- A fun pastime is.

Conclusion must be that Geocaching certainly is suitable for people with impaired vision (partially sighted) and can be used as a rehabilitation tool, courses for pupils in mainstream and special education. And particularly suitable as a hobby.

The answer is no because:

- You for the last 3 to 5 meters still need a sighted person to find the cache
- You must be very precise set of starting points because you can easily get lost
- You are very dependent on how the cache and any hint described.

Blind persons must have a very good orientation, motivation and solving skills to do this all by themselves.

Nevertheless, the majority of my (blind) pupils are having fun in this sport which give them a good insight into the use of GPS and navigation in general.

OK Let's Geocache!!

Setback in Development in young Children with Blindness? A Systematic Review and Implications for Practice

Ans J.P.M. van Eijden¹, Ellen G.C. van de Broek¹,
Ans Withagen¹, Mathijs P.J. Vervloed²

¹Royal Dutch Visio, centre of expertise for blind and partially sighted people,
Amersfoortsestraatweg 180, 1272 RR, Huizen, The Netherlands
a.vaneijden@planet.nl, ellenvandenbroek@visio.org, answithagen@visio.org

²Radboud University, Behavioural Science Institute, Montessorilaan3, 6525 HR
Nijmegen, The Netherlands
m.vervloed@pwo.ru.nl

ABSTRACT

A presumed setback in development between 16 and 27 months of age in children with congenital blindness with no additional disabilities was studied by reviewing the literature on setback in development and longitudinal studies on children with blindness. The results showed that the period around the second year of life is a vulnerable period for children with blindness. The studies on developmental setback indicated that about 30 % of these children show a setback. Profound visual impairments, neurological abnormalities and social adversities seem to be important risk factors. Methodological issues complicate conclusive statements about the existence and the nature of this setback. Additional explanations for a developmental setback and the substantial overlap between behaviors often found in children with blindness and symptoms of Autism Spectrum Disorder are described and suggestions for future studies given. To be able to capture the phenomenon of developmental setback and to pinpoint moderating and mediating factors, children with congenital blindness need to be monitored prospectively in a longitudinal research design

1. INTRODUCTION

In retrospect of 25 years of work with blind children we got more and more concerned about a small group of children in our caseload that - with no apparent additional disabilities - seemed to show a setback in development and behavior starting at approximately 18 months of age after a period of seemingly normal development.

However, it is difficult to decide about the existence of a setback in development in children with blindness as their development often follows an atypical path. They also show, compared to sighted children, an

increased risk of developmental delay throughout the infancy and preschool years (Reynell, 1978; Hatton, Bailey, Burchinal, & Ferrell, 1997; Hatton, Schwietz, Boyer & Rychwalski, 2007). The high prevalence of additional disabilities in children with visual disabilities complicates the picture since it obscures whether, when a setback or delay is detected, this is the result of blindness, the other disabilities or both.

The results of a review by Dale and Salt (2008) were in line with our clinical impressions. They described 'developmental setback' in children with visual impairments in development starting between the ages of 16 to 27 months after a period of normal development. They retrospectively reviewed their database of 1300 children with visual impairments. Children with potential brain damage were excluded. About 33% of the children with Profound Visual Impairment (PVI, i.e. no form vision; comparable to the WHO definition of blindness) and only about 3% of the children with Severe Visual Impairment (SVI, i.e. form vision or better visual acuity) developed this setback.

The aim of our review was to look for further support of our own clinical impressions and of the findings of Dale and Salt. The main research question was whether there is empirical evidence for the existence of a developmental setback in children with congenital blindness.

2. METHODS

Two literature searches were carried out. The first search looked for empirical studies that specifically investigated a developmental setback in children who are blind. To compliment this search we looked for longitudinal studies in children who are blind, in the

second search. These longitudinal studies were not necessarily set out to describe a setback.

Articles were included when: 1) the participants were between 0 to 6 years, 2) were congenitally blind/had PVI, 3) a longitudinal design was used, 4) assessment instruments were named or described; 5) a setback, regression, stasis or delay was described; 6) they were published in journals and books after 1955, and 7) original empirical data were given.

3. RESULTS

The first search yielded 3 articles stemming from one group, the Developmental Vision Clinic in London. Based on retrospective research and using the same database, a developmental setback between 16 and 27 months was noted in 31 – 34% of the children with PVI. The retrospective developmental setback studies used the Reynell-Zinkin Scales to assess the children's development.

The second search yielded 25 general longitudinal studies of which 8 studies - all descriptive with detailed observations and video analyses of behavior - described regression both in development and behavior in the above mentioned age group.

Setback/regression was found both in development and behavior (disorganized and stereotyped behavior, and autistic like behavior). As risk factors were mentioned: visual status, neurological dysfunction, social adversities.

4. DISCUSSION

Methodological (problems with sampling, research design, sensitivity of the developmental scales used) force us to remain cautious in drawing firm conclusions. Additional explanations /risk factors for a setback / regression in development are described: 1) prematurity was insufficiently specified and/ or taken into account in most of the study samples. 2) incipient neurological problems that can go undiagnosed in infants with blindness, 3) delay and / or different processes in psychosocial development and social interaction.

The behavior of children that experience a setback / regression seem to have parallels with ASD. The question whether setback / regression is due to or a precursor of ASD however cannot be answered with the present available knowledge.

5. CONCLUSIONS

The period between the second and third year of age seems to be a vulnerable period for children with blindness.

As yet methodological issues complicate conclusive statements about the existence of a developmental setback or regression in children with blindness.

To help clinical practitioners further research into this phenomenon and its moderating and mediating factors is crucial. To capture this phenomenon adequately children with congenital blindness need to be monitored individually and prospectively from birth to 6 years of age in a longitudinal research design.

6. IMPLICATIONS FOR PRACTICE

Although as yet no firm statements can be made about the existence of and the contributing factors to a developmental setback, for the clinical practice some guidelines can already be taken from the reviewed literature. It is crucial to closely follow the development of infants and toddlers with blindness. Not only the cognitive and physical development, but also the psychosocial development needs close monitoring. Parents need professional help when disturbances in development and behavior occur.

Acknowledgments

We want to thank Anke de Jong and her colleagues of the library of Bartiméus for their help with the literature searches, and Naomi Dale and Michele O'Reilly for sharing their findings with us.

Funding:

This study is part a project by Royal Dutch Visio "Het jonge blinde kind" [The young blind child] and is funded by the Novum foundation, the Netherlands.

REFERENCES

- Dale, N.J., & Salt, A. (2008). Social identity, autism and visual impairment (VI) in Children with blindness. *British Journal of Visual Impairment, 26*, 135-146. doi: 10.1177/0264619607088282.
- Hatton, D.D., Bailey, D.B., Burchinal, M.R., & Ferrell, K.A. (1997). Developmental growth curves of preschool children with visual impairment. *Child Development, 68*, 788-806.
- Hatton, D., Schwietz, E., Boyer, B., & Rychwalski, P. (2007). Babies Count: The national registry for children with visual impairments, birth to three years. *Journal of American Association for Pediatric Ophthalmology and Strabismus, 11*, 351-355
- Reynell, J. (1978). Developmental patterns of visually handicapped children. *Child: Care Health and Development, 4*, 291-303.

The young blind Child: developmental Assessment

Griet Pattyn¹, Katrien Perneel¹

¹Mobile Support Service Accent, Centre of Expertise Spermalie / De Kade,
Brugge, Belgium
{griet.pattyn, Katrien.perneel}@de-kade.be

ABSTRACT

Every child develops at a different rate although you can generally predict when certain skills will appear. Vision loss can fundamentally change the way a baby learns and therefore it is harder to predict the course of development.

The modern idea of development is that it is the result of continuous interactions between the child and the environment.

In accordance with this view developmental information should be gathered combining different assessment methods, such as observation, parent interview, and standardized developmental assessment.

Standardized developmental assessment instruments play an important role in early intervention. However, when you want to test blind babies and toddlers, problems arise finding those standardized assessment.

This workshop is an interactive discussion about the assessment of the development for blind children, age 0-5 years.

1. INTRODUCTION

Home base counselling Accent assists the visually impaired. We offer support to the individual, their family and their social network. The early guidance team focuses on kids aged 0 to 6. One important aspect of our guidance, is to monitor and stimulate the development, especially for blind children.

2. ISSUE

Standardized developmental assessment instruments play an important role in early intervention. However, when you want to test blind babies and toddlers, problems arise finding those standardized assessment.

The number of young blind children that go through a normal development, is very small. Furthermore, the development of the very young blind child is not always a

harmonious process which makes it difficult to assess the general level of development. These two aspects make it impossible to compose enough age groups and to set up a standard that meets the common requirements.

There are different existing scales such as the Brambling scale, the Oregon scale, The Reynell-Zinkin-scales but these are either unfit for a differentiated assessment of the development, or they are dated and based upon a too small test group.

Parents do not have a reference framework as to the development of their blind child. During the early development guidance, we ask ourselves the same question as the parents. Is this kid doing well in terms of its development?

3. METHOD

This discussion is about mapping the development of the young blind child, aged 0 to 5. Due to the lack of standardized testing material, there is no uniformity and clarity. We wish to present you our modus operandi and by doing so we wish to open the possibility to discuss development research into young, blind children. How important is it? Who will be doing the examination? Etc...

During the early guidance, the development examination is done by an orthopedagogue. This examination is done at home, in familiar surroundings, accompanied by the parents and the home based worker.

During the development examination, we mainly focus on the social and emotional development, communication, the sensomotoric development, playing development, practical action and the development of mobility and self-reliance.

This development examination is part of a multidisciplinary research in which kids are also examined by a pediatric neurologist and a physiotherapist. If the child can still distinguish light, an ophthalmologist and orthoptist might also be consulted. These examinations are done in the care and counselling centre Spermalie, and take place in 1 morning session.

The report of these examinations is handed over to the parents and the results are discussed with the home based worker.

The aim of the development examination is to assess the development stadium the child is currently in, to map the development progress throughout the years, and to identify points of departure in order to facilitate further development.

We opt for qualitative research, which implies:

Interaction between the parent and child

Observation with a number of objects from the observer

Observation with toy/material the child is familiar with

Conversation with the parents

In order to draw up this qualitative examination, we went through existing literature and lists (among others the Brambring, Oregon and Reynell Zinkin). We do not base on these lists during the actual examination. We distinguish 3 age groups. We aim to reach a few development targets per age group. We have linked material to these targets.

-0-18 months

-18-36 months

-3-5 years

4. CONCLUSIONS

We have learnt that doing the development examination is not an easy task. We hereby wish to invite you to share your opinions about the way development research is done/should be done.

REFERENCES

- [1] Reynell, J., Manual for the Reynell-Zinkin Scales, Developmental Scales for Young Visually Handicapped Children- Part 1 Mental Development. NFER-Nelson Publishing Company, Windsor 1979.
- [2] L. Delaet, Ontwikkelingsonderzoek bij jonge blinde kinderen, intern document. 2016
- [3] Referenties brambring opzoeken
- [4] Referenties oregon opzoeken

The Pearl – a preschool encouraging independence and participation

Agneta Westman and Lena Lindbom

National Agency for Special Needs Education and Schools,
Resource centre vision
Stockholm, Sweden
{agneta.westman, lena.lindbom}@spsm.se

ABSTRACT

In Sweden there are no special preschools for children with blindness, these children attend mainstream preschools. Support to the preschools is provided by the National Agency for Special Needs Education and Schools, Resource Centre Vision.

A film has been produced to use in the further training of preschool staff. The aim of the film is to inspire the staff and give them competence to support the children in their development, and increase their independence and participation in the preschool activities.

Topics in the film are:

- The importance of creating an environment that encourages independence and participation for children with blindness.
- The importance of playing through all senses.
- The importance of an environment that stimulates “curious fingers”
- The importance for the future Braille reader to meet Braille in many different contexts in the environment.
- The importance of inspiring the staff to bring Braille into everyday activities together with the children.

1. BACKGROUND

In Sweden there are no special preschools for children with blindness, these children attend mainstream preschools together with sighted peers. At the National Agency for Special Needs Education and Schools, Resource Centre Vision, further training is arranged for preschool teachers who teach children with blindness. The aim of the training is to teach how to create an environment, that is stimulating for activity, independence and participation

We have produced a film to show good examples to our participants at the teacher training.

2. METHOD

The film “THE PEARL – a preschool encouraging play through all senses” has been recorded at a preschool, that used to be located in our premises at Resource Centre Vision.

Due to changes at our premises at the resource centre the preschool had to close down at short notice. We realized that this was a valuable environment, that needed to be documented. There was almost no time for planning and the recordings had to be made during one single day. The film team consisted of a camera man and the producer. The stars in the film are three children, 4 to 6 years old, with different degrees of visual impairment. Furthermore there are two special teachers cooperating with the children and acting as presenters. The film is 25 minutes long and at this conference a shortened version will be shown. The speech in the film is in Swedish with subtitles in English.

3. THE AIM OF THE FILM

The aim of the film is to be a supplement to other parts of our teacher training. The film is intended to - in a substantial way - give knowledge and inspiration to preschool staff in their own pedagogical work. Ultimately their competent work is supposed to contribute to the children’s independence, participation and favourable development.

4. CONTENTS

4.1 Participation

Participation is to permeate all day, and all days, in the preschool. In the film the environment is adapted to facilitate for a child with severe visual impairment or blindness to act independently and participate in all activities.

4.2 Independence

In the film there are several examples of environmental adaptations that enable the children to find their ways and to move independently from one room to another and between different activities.



Figure 1. Tactile schedule

There are also pedagogical methods that enable the children to act independently and participate in the preschool activities.



Figure 2. The text Room for games in braille and print. Below the text there is a dice on a string.

4.3 Tactile reading

Our experience is that preschool staff are insecure when working with tactile pictures and braille.

In the film we state the importance of braille in the environment, of access to tactile picture books and material to create tactile pictures. We hope that our examples will inspire the staff and give them confidence to provide the children with access to tactile experiences – text and pictures - in a natural and playful way.



Figure 3. A child reading a tactile picture book.

4.4 Toys and other material for play

Children with blindness need special support in their development, and the preschool need to choose material and toys that will stimulate the child's development in different ways. In our preschool, The Pearl, all material is chosen to stimulate the child's motor skills and concepts of body and space. Furthermore it promotes the child's tactual, auditory and language development.

The film shows material, toys and activities "encouraging play through all senses".



Figure 4. A big cardboard box, a little house, to stimulate the concept of space.

The children in the film play together. They play with toys and they play games, board games and digital games. All these activities stimulate and promote initiative, interaction and participation.

"THE PEARL – a preschool encouraging play through all senses" is available for watching at <https://www.spsm.se/funktionsnedsattningar/synnedsattning/>

Tough talks: talking to children about sight loss

1. Sarah Holton, 2. Robert Caswell, 3. Rachel Pilling, 4. Rachel Hewett.

1. Royal National Institute of Blind People, UK. Sarah.Holton@rnib.org.uk

2. York & Selby Child and Adolescent Mental Health Service (CAMHS), Tees, Esk and Wear Valleys NHS Foundation Trust, UK. robert.caswell@nhs.net

3. Department of Paediatric Ophthalmology, Bradford NHS Trust, Bradford, UK. Rachel.Pilling@bthft.nhs.uk

4. VICTAR, School of Education, University of Birmingham, Birmingham, UK R.G.Hewett@bham.ac.uk

ABSTRACT

This presentation gives an overview of guidance for parents and practitioners to enable them to have discussions with children and young people about the child/young person's vision impairment (VI). It will give an outline of the main guidance themes: 1) strategies for both parents and professionals, and 2) additional professional considerations regarding topics that can be sensitive to children and their families.

The guidance was developed by RNIB in response to requests from parents about how to talk to children about their VI, particularly if it is a condition where the child/young person's sight will deteriorate over time. The materials were informed by evidence from research in which young people with VI were asked about their experiences. [1] Many participants felt they had not had adequate or appropriate discussions with family members or professionals in order to understand their sight condition.

The 'Tough Talks' guidance has been written from three perspectives - family support, paediatric psychology and clinical ophthalmology. The guidance suggests the people, both within and outside a family, that can support the process of helping a child understand their sight condition and how it affects them. It also describes the approaches that can be used, gives advice on what to say and what not to say, and shares what young people say themselves would have been most helpful. The desired outcome is that parents feel enabled to use their own expertise and unique relationship in order to support their child in coming to terms with their condition.

Copyright: © 2017 S. Holton et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

1. INTRODUCTION – BACKGROUND

Recent research [1] into the experiences of young people in transition from childhood to adulthood shows that young people have different levels of understanding of their own eye condition, would often like to know more than they do, and have had varying levels of opportunity to talk to other people to find out.

The Royal National Institute of Blind People helpline receives a substantial number of queries from professionals and parents of children with vision impairment (VI) for advice about emotionally supporting their child, sharing information about their diagnosis and prognosis and enabling them to come to terms with their vision impairment.

These two factors, the research and the helpline records, gave a mandate to produce a guidance resource on this topic.

In producing the guidance, we incorporated three professional perspectives: family support, paediatric psychology and ophthalmology. This was to ensure that the guidance reflected current emotional and mental health professional practice and also that references to any clinical aspects of eye conditions, or clinical pathways were sound.

The guidance was reviewed in draft form by young people and parents of children of differing ages, for their comments and contribution. The final publication incorporates all of the changes, additions and amendments made by these people.

The full guidance is available online at www.rnib.org.uk/toughtalks and is also available in hard copy as a leaflet.

2. AIMS

Our aim in producing this guidance resource was to support and enable parents as they address this issue. The guidance is not prescriptive - we hope it will enable and encourage parents to have conversations with their children, as and when they arise. Our aim was to be sensitive to all of the individual differences that exist between

children, their parents, personal circumstances and experiences of VI. Piloting of the guidance suggested it would be of particular use for either a young person whose diagnosis indicates progressive loss of vision over time, or a child who was diagnosed as a baby or very young child, and then seeks to build their own understanding at a later time when they are older.

3. THE TOUGH TALKS GUIDANCE



Figure 1. This photo shows the front cover of the Tough talks leaflet. The image is of an adult male hand holding a child's hand.

The areas covered in the guidance are as follows:

Who is the right person?

- Getting help
- Planning ahead
- Connecting with other families

When is the right time?

- Changes right now?
- Allowing news to sink in
- Growing up
- Your child's time is the right time
- "Now" and "Later"

What should we say?

- Facing the future
- Clarifying assumptions
- Getting informed
- Coping with uncertainty
- Focus on the "can-do"

What shouldn't we say?

- Try not to blame anyone
- Avoid myths and false promises
- Consider your own feelings and their impact

Talking to siblings and other members of the family

What if they don't want to talk about it

- Encouraging acceptance and confidence

Additional needs and conditions

Getting further help and support.

Each section gives suggestions as to the considerations a parent might make in regard to their own child, and approaches and forms of words to address specific angles.

4. THE ROLE OF PROFESSIONALS

In producing this guidance we are aware that there are sensitivities regarding the role of professionals involved with supporting families of children with vision impairment, particular if the emotional needs of the child and the parents collide, or preclude each other from the right support. In many cases, understandably, a parent themselves finds it difficult to come to terms with the diagnosis of their child and therefore not only may find it difficult to support their child's emotional journey, but in some cases may become an unintentional barrier to their own child's acceptance and knowledge of their VI. Some young people report feeling less able to discuss and ask about their vision impairment because their parents found it distressing and upsetting. [1].

In professional workshops delivering this guidance we discuss the issues of parent consent, of situations where a parents' wishes and the needs of a child may not align, and of encouraging and engaging parents in supportive conversations. We also discuss the priorities and constraints which govern a professional's role in meeting the emotional needs of the children they support.

5. CONCLUSIONS

The guidance was first released in March 2017 and received 676 downloads and 340 print requests in the period to the end of April.

Positive feedback has driven us towards an extension of this work into 2017. We have identified a need for further guidance regarding the emotional support of children whose parents are facing sight loss and will seek to scope and develop such resources going forward.

REFERENCES

- [1] Hewett, Douglas & Keil. (2015 (d)). *Support and information received by young people with vision impairments: technical report of findings October 2014 to February 2015*. University of Birmingham: Visual Impairment Centre for Teaching and Research (VICTAR) www.rnib.org.uk/educationresearch

“See?”, psycho-education for visually impaired school aged children

Yvonne Kruithof¹, Pieterneel Lievense¹, Marian Doeve¹, Natasja Bronzewijker¹,

¹Bartiméus, Zeist/Doorn, The Netherlands
{YKruithof, PLievense, MDoeve, NBronzewijker}@Bartimeus.nl

ABSTRACT

“See?” is an intervention for visually impaired children of 6 to 7 years old in main stream education. The aim of the program is to help visually impaired children understand their visual disability, the impact of this impairment on their thoughts and actions and to teach these children behavioral alternatives in everyday situations. The intervention helps these children to develop a positive and realistic self-image which has a positive impact on their social and emotional development, social interaction and well-being. “See?” is a web based program. The program consists of 10 lessons, each lesson is based on a situation visually impaired children experience in main stream education. In January 2017 a scientific impact study has started to research the effect of this program. By means of an RCT study (a randomized, controlled-group trial, where subjects are randomly distributed between an experimental and control group) we are investigating whether “See?” is an ‘evidence-based’ intervention.

1. INTRODUCTION

Theory and counseling practice suggests that visually impaired children are more likely to have problems related to social interaction and in developing a positive self-image than their sighted peers. Research on this subject teaches us that visually impaired children in mean stream education have limited knowledge of and insight into their own visual impairment. There are existing methods for psycho-education, but children tell us they want a more modern and challenging method. There is need for an educational ‘tool’ to aid these children in having a better understanding of their visual impairment and to enhance self-image and problem solving skills related to their impairment. In answer to this need the program “See?” was developed.

2. THE PROGRAM

2.1 Goals

“See?” helps children to develop a positive and realistic self-image which has a positive impact on their social and emotional development, social interaction and well-being. To reach this goal children are given insight in their visual impairment and the impact this has on their thoughts and actions. An important part of the program is to teach them behavioural alternatives to cope with everyday situations. The expectation is that by following this program children

are better equipped to participate in social interaction in school, they have a better understanding of the influence of their visual impairment and show improved problem solving skills. It is also expected that these skills and knowledge will support social-emotional development.

2.2. ‘Helpful thoughts’

Research on the subject of social-emotional development teaches us that children with low self-esteem often have ‘negative thoughts’ about themselves and their abilities. In “See?” we use ‘G-denken’, a form of cognitive therapy, to analyze situations children encounter. This method helps children to understand situations and their role in it. The goal of this form of cognitive therapy is to reprogram irrational thoughts that lead to emotions that hinder us in daily life. We replace these negative thoughts by positive thoughts. When we change our thoughts about a situation, this leads to other emotions/feelings, which leads to other behaviour and another result/outcome. We aim to change negative thought patterns and replace these by what we call ‘helpful thoughts’. For example: “I can’t read the assignment because the letters are too small, I will never have this assignment ready in time, everybody will think I’m dumb, I quit” is changed into: “I can’t read the letters, but I can ask for an enlargement and then I will be ready in time”. For “See?” we collected helpful and non-helpful thoughts and linked them to situations children with a visual impairment encounter in daily life.

2.3 Content of the lessons

“See?” is a web based application, which has several advantages. Children find programs on the computer more attractive and challenging and it gives them the opportunity to work independently from teachers or other children. It also provides the opportunity to make visual adaptations for example in contrast and color. The program consists of 10 digital lessons. Each lesson is based on a situation visually impaired children experience in main stream education. There are five main characters to identify with. These main characters are all visually impaired. In each lesson the children are shown a short animation of a problem they encounter in school due to their visual impairment. There are situations in a classroom: making an assignment, working with visual aids. But there are also social situation outside the classroom: playground, physical education or social interaction in a classroom: working

together, playing together. The children analyze these situations by answering questions, choosing ‘helpful thoughts’ and giving alternative solutions to the presented problems. Each lesson consists of five parts: a short animation of the problem, a song about the specific situation and how it makes you feel, a game in which to select the helpful and non-helpful thoughts, a game to find matching emotions and every lesson ends with a helpful thought to solve the problem. This solution is shown in an animation.



Figure 1: The five main characters of the psycho-education program “See?”

2.4 Feedback

During the lessons the program keeps score of the results of the games. After each lesson the program sends an email to the teacher of the child with information about the choices the child made and the answers it gave. This feedback enables the teacher to discuss the problems with the child and help the transfer of the game to real live situations.

3. IMPACT STUDY

During the implementation of “See?” there were enthusiastic reactions from both children and teachers. Although the intervention is based on literature, scientific research and years of experience working with visually impaired children we want to scientifically prove that “See?” is an ‘evidence-based’ intervention. In January 2017 an scientific impact study started with 70 participants in main stream schools in the Netherland. A RCT (a randomized, controlled-group trial, where subjects are randomly distributed between an experimental and control group) with a pre-test, post-test and follow-up design is used. In this study we will measure self-perception, well-being and coping. The children are interviewed and the teachers are asked the same questions to compare the answers with

each other. The results will be available in September 2017.

4. CEREBRAL VISUAL IMPAIRMENT

During the development of “See?” we received a lot of requests from colleagues and parents to make a program for psycho-education specifically for children with a cerebral visual impairment (CVI). To research these requests further a questionnaire was developed and send to parents, teachers and colleagues. We also interviewed children with CVI at the school of Bartiméus. Based on the outcome of these questionnaires and interviews the development of a new psycho-education program for children with CVI started in May 2017.

REFERENCES

- [1] Glorieux, P., & Vanthome, J. (2010). *Zorgzame klas, psycho-educatie voor de basisschool*. Leuven: Acco.
- [2] Gringhuis, D., Moonen, J., & Woudenberg van, P. (1996). *Kinderen die slecht zien*. Houten/ Diegem: Bohn Stafleu Van Loghum.
- [3] Koppejan, J., & Kwast, M. (2009). *Emotie management voor kids*. Vlissingen: Bazalt.
- [4] Lievense, P., Sterkenburg, P., Bonnet, M. & Liber, J. (2015) ‘*Stop nu met pesten!*’: Een ‘serious game’-interventie voor ouders, leraren en begeleiders van kinderen met een beperking. *Tijdschrift voor Orthopedagogiek*, 54, 495-505
- [5] Lievense, P., Sterkenburg, P.S., Liber, J. & Bonnet, M. (in progress). *The effect of an intervention for caregivers and teachers: Stop bullying now!*

Stimulating communication in individuals with deafblindness using an intersubjective developmental perspective

Saskia Damen¹

¹University of Groningen, Department of Special Needs Education and Child Care, Groningen, The Netherlands

ABSTRACT

This study aimed to develop a social partner-oriented intervention based on Trevarthen's three layers of intersubjective development. Subsequently, this intervention was tested on interpersonal communication of people with congenital deafblindness (CDB) and their social partners. Multiple-case experiments were carried out involving 11 individuals with CDB and 34 communication partners. Each pair was observed repeatedly during baseline and intervention and follow-up phases. It appeared feasible to measure the three layers of intersubjective development in individuals with CDB. The enhancing effect of the HQC intervention on interpersonal communication could be detected and was replicable across participants. The study showed that the theory of intersubjective development is a valuable perspective for evaluating communication of individuals with CDB. The study also revealed the importance of investing in communication support for parents, teachers and professional caregivers of individuals with CDB.

1. INTRODUCTION

In literature, the communication of individuals with congenital deafblindness (CDB) is often described as delayed or limited. To explain this as a natural consequence of their dual sensory loss is not correct. Based on Trevarthen's theory of intersubjectivity [1], these problems can be understood as the result of problems within the interpersonal communication of these individuals and their communication partners that prevent these individuals to develop more complex forms of communication.

2. INTERSUBJECTIVITY

According to Trevarthen, intersubjectivity can be defined as 'the ability to share subjective states', an innate ability that can be observed already after birth during social interactions [1]. This ability becomes more complex as children grow older as a consequence of the child's experiences in

interpersonal communication. Communication partners play an important role in stimulating these experiences. On the basis of frame-by-frame analysis of videotaped interactions between typical children and their mothers, Trevarthen distinguished three layers of intersubjective development.

Sighted and hearing Infants of a few weeks old already show behaviors at the first layer of intersubjective development, which is characterized by awareness of the other. This awareness is shown by their active and responsive attitude towards their communication partners and engagement in turn taking activities. It is not until the infant is about nine months old however, that he or she starts to show mutual awareness, the characteristic feature of the second layer of intersubjective development. At this layer, the child is able to share attention with his social partner for objects and to negotiate and share communicative intentions. The main purpose for the communication at this layer is to get something or someone. Between ages two and six, typical children start to communicate more and more for the purpose of sharing their thoughts. The child now mainly uses symbolic forms of communication. These more complex communication behaviors reflect "a narrative and verbal self- and other awareness", which characterizes the third and highest layer of intersubjective development [1].

3. INTERVENTION

Our hypothesis was that individuals with CDB are born with the same innate ability to share subjective states as sighted and hearing individuals, but that they face difficulties to show and further develop this ability. We suspected that this is due to an interplay by the characteristics of the individual, such as his dependency on tactile experiences, and a lack of adaptations of communication strategies by their communication partners [2].

In order to support communication partners in their communication with individuals with CDB, the High Quality Communication intervention was developed [3]. This intervention is set up as a training for parents, caregivers and teachers provided by a coach. The coach supports the communication partners to stimulate intersubjectivity in a way that is adjusted to the needs of the individual with CDB [4]. The coach provides the support to the communication partners during two education sessions, five individual and three groupwise video-feedback sessions. In the first five weeks of the intervention the communication partners

learn how to attune their behaviors and emotions to those of the individual with CDB, for example by offering tactile initiatives and responses and providing sufficient time for the individual to respond. In the second 15 weeks of the intervention, communication partners are supported in meaning making. They for example learn how to encourage the individual with CDB to indicate if he or she feels understood, to give more information about the meaning of his or her utterances and to create a narrative of a past experience [4].

4. EFFECT-STUDY

The effect of the High Quality Communication intervention was tested with regard to seven intersubjective behaviors at three layers of intersubjective development in multiple case-experiments. Participants were 11 individuals with congenital deafblindness between six and 49 years old and their 34 communication partners (parents, teachers and caregivers) [5]. The interactions between the participants and partners were repeatedly observed during baseline, intervention and follow-up phases. These observations were coded by independent coders for occurrences of communicative behaviors at different levels of complexity, in line with the three layers of intersubjective development.

Comparisons of the baseline observations with the observations during and after the intervention revealed medium or large effects for all participants on communication at the first and second layer of intersubjective development. For the majority of participants, there were also medium or large effects on communication at the third layer of intersubjective development [5].

5. COMMUNICATION PATTERNS

To test the hypotheses that communication partners can stimulate higher complexity in intersubjective behaviors of individuals with CDB we analyzed the communication patterns in nine pairs, using sequential analysis [6]. This analysis revealed a strong association between the level and type of communicative behavior of the individuals with CDB and the preceding behavior of the communication partners, but only for those behaviors that were not fully mastered by the individual with CDB [6].

6. CONCLUSIONS

Trevarthen's theory of intersubjective development appeared a useful framework for the analysis of the interpersonal communication between participants with CDB and their communication partners and for the support of interpersonal communication. The study shows that the High Quality Communication intervention enhanced intersubjective behaviors for all participants with CDB. It also revealed that communication partners can elicit communicative behaviors in individuals with CDB.

Acknowledgments

This research project was funded by ZonMW/Inzicht, Bartiméus-Sonneheerdt foundation, Bartiméus, Royal Dutch Kentalis and was supervised by prof. Marleen Janssen, prof. Carlo Schuengel and prof. Wied Ruijsenaars.

REFERENCES

- [1] Bråten, S., & Trevarthen, C. (2007). Prologue: From infant intersubjectivity and participant movements to simulation and conversation in cultural common sense. In S. Bråten (Ed.), *On being moved: From mirror neurons to empathy* (pp. 21–34). Amsterdam, the Netherlands: John Benjamins.
- [2] Damen, S., Janssen, M. J., Ruijsenaars, W. M., & Schuengel, C. (2015). Communication between children with deafness, blindness and deafblindness and their social partners: An intersubjective developmental perspective. *International Journal of Disability, Development and Education*, 62(2), 215-243.
- [3] Damen, S., Janssen, M., Huisman, M, Ruijsenaars, A. J. J. M., & Schuengel, C. (2014). Stimulating intersubjective communication in an adult with deafblindness: A single-case experiment. *Journal of Deaf Studies and Deaf Education*, 19(3), 36684. doi: 10.1093/deafed/enu006
- [4] Damen, S, Janssen, M.J., Ruijsenaars, A.J.J.M. & Schuengel, C.(2015). Intersubjectivity Effects of the High Quality Communication Intervention in People with Deafblindness. *Journal of Deaf Studies and Deaf Education*, 20, (2), 191-201, DOI:10.1093/deafed/env001.
- [5] Damen, S. (2015). *A Matter of Meaning. The Effect of Partner Support on the Intersubjective Behaviors of Individuals with Congenital Deafblindness*. Dissertation. 's Hertogenbosch: BOXPress
- [6] Damen, S., Janssen, M. J., Ruijsenaars, W. A. J. J. M., & Schuengel, C. (2017). Scaffolding the communication of people with congenital deafblindness: An analysis of sequential interaction patterns. *American Annals of the Deaf*, 162(1).

USING MY FEET

A description of the use of in-home guidelines (tactile paving) by an adult women with congenital deafblindness

**Marjo van Welbergen,
Natalie Lentink, Peter Peek, Mijkje Worm.**

Bartimeus, Department of Research and Therapy,
Doorn, Netherlands
mvwelbergen@bartimeus.nl

ABSTRACT

An adult woman with complete deafblindness and an intellectual disability, we call her Nelly, moved to one of the houses for persons with congenital deafblindness of Bartiméus. Her access to information is fully allocated to the proximity senses touch and smell. However, she dislikes touching. She also dislikes to be touched by others on their initiative. At home she orients with her (bare) feet. Since the floor surface in her house feels the same everywhere, this is a difficult task, and she needs guidance in her orientation. Caregivers had questions about how to guide Nelly without having conflicts about touching and being touched. It was hypothesized that tactile paving could support Nelly in her orientation. A tactile guidance path could give her continuous tactile support in her wayfinding.

The tactile guidance path was applied between the living room and the bedroom. At the same time, caregivers received instruction on mobility training. Not only the route was taught, also guidance instruction was provided.

1. INTRODUCTION

For persons with deafblindness orientation and mobility requires specific attention. Because vision and hearing are limited, their world at an arm's length. Their environment doesn't provoke them to move or to leave their place. A person who is able to move on his own has more opportunities for activities and contacts. People with congenital deafblindness need others to let them experience the benefits of movements. And which devices are available [3].

If you want to learn a person with deafblindness a certain route, there are many limiting factors. The common ways of orientation are mainly visual and therefore barely available to them [4]. For example signs, maps and traffic lights. Touch is a very important sense for people with congenital deafblindness, also in orientation [1].

2. SENSE

Touch is a sense that can be embedded through the whole body. Therefore touch is the largest sense of human beings [6] Often we only think of touching by the hands, but we can touch with our whole body. For people with deafblindness touch is the main way to be in contact with reality [5]. Besides the hands, also the face, mainly by mouth, and the feet are used in touching (Van den Wildenberg, Van Welbergen & Van der Burg, 2002). Touch can never compensate vision and hearing. Using touch always gives fragmented information. One should combine the parts to form a whole [3,6]. Orientation by touch takes a lot of concentration. It is a challenge to create an environment to stimulate the person with deafblindness person to move by himself [7]. However, this is the best possibility to learn this person to orientate by herself.

3. THE PARTICIPANT

Nelly is a woman with complete deafblindness who moved to a new home. Her proximity senses and her smell are her main entrances to information. She has a strong tactile aversion. She doesn't like to be touched on the initiative of other people. She orientates herself with her bare feet. The floor area in the house is, however, everywhere the same. This makes it difficult for her to orientate. We hypothesised tactile paving could help her in her orientation ability.

A tactile guidance path gives her a continuous cue. It gives her the sign she is still on her way, and on the route. It shows her the way and is obstacle-free.

4. METHOD

We chose to start with one route. This was the route from the living room to the bathroom and back. She follows this route several times a day and it gave Nelly much confusion. The tactile paving is made of TACK plastic indoor (dimensions 285x12x3 mm). This material feels well on bare foot, is easy to clean and good to pass with a wheelchair. After video observation of the gait of Nelly, we chose to apply 4 lines next to each other.

The communication trainer and mobility trainer made an instruction video to teach the caregivers. In a team meeting this video is shown and discussed.

Content of the video:

- Indication of the route
- Which information is provided to Nelly before and during the route? (gestures, orientation points, tactile orientation board)
- Way to accompany (hands-under, inviting, position towards Nelly), also when she refuses to go.

We chose to introduce the tactile guidance path in phases. We didn't want to have much in-home tactile paving, before we knew what the effect would be. We also thought it would be easier for caregivers to focus on one route at the time.



Figure 1. This photo shows the tactile guidance path in the house

5. RESULTS

Analyses of video fragments showed Nelly touches the tactile guidance path with her feet. In the first fragment we saw Nelly search the caregiver with her left hand. She seemed to look for her caregiver to walk under her arm. She accepts a different way of guidance. In the first days Nelly preferred to walk next to the tactile guidance path, but after a few weeks we saw her using the path.

After 2 months Nelly followed the tactile guidance path well. She kept on searching contact with her caregiver with her left hand. We instructed the caregivers to bring her to the tactile paving and to stimulate her to follow the path on her own. This made Nelly, however, wander in the corridor. She seems to need the contact with her caregiver. Hereafter, the caregivers stay near her and assist her as much as needed.

In follow up video's we observe that Nelly moves along the tactile guidance path quickly and independently, if a caregiver touches her on her back. She still needs this physical contact. She the tactile guidance path with her feet and the bar on the wall and her caregiver with her hand. Sometimes she pauses, but continues her route after a while into the right direction.

6. CONCLUSIONS

The tactile guidance path gives Nelly more opportunities to express how and when she wants to be guided. The guidance in orientation has become more positive and the amount of conflicts between Nelly and her caregivers decreased. Furthermore, other residents of this house started using the tactile guidance path in their own orientation. Therefore, this case can be an example for future users of in-home tactile paving.

Acknowledgments

The autor wished to thank the Vereniging Bartiméus Sonneheerd for their financial contribution to this project.

REFERENCES

- [1] Anderson, K. & Rodbroe, I. (2006). *Identification of congenital deafblindness*. Aalborg, Denmark: The Resource Centre on Congenial Deafblindness.
- [2] Damen, S. & Van Nunen, T. (2011). *Longitudinal study of the behavioural development of persons with congenital rubella syndrome*. Paper 15th DBI World Conference. Sao Paulo, Brazil.
- [3] Damen, S. & Worm, M. (2013). *Congenital Deafblindness*. Doorn, Nederland: Bartiméus.
- [4] Den Brinker, Apituley, A. & Smeets, J. (2014). *Zicht op Ruimte. Handboek voor de visuele toegankelijkheid en bruikbaarheid van de gebouwde omgeving*. Amsterdam, Nederland: Stichting Silvur.
- [5] Werkgroep LVS. Meervoudig gehandicapten (1998). *Observatiegegevens tactiel functioneren*. Huizen, Nederland: Visio.
- [6] Withagen, A., Heins, L., Blok, A., Betten, A., Buurmeijer, A., Mul, M. & Oosterlaak, L. (2010). *FanTASTisch. Een inspiratiebron voor ouders van blinde kinderen*. Huizen, Nederland: Visio
- [7] Van den Wildenberg e.a., (2002). *Bewust Bouwen*, Doorn, Nederland: Bartiméus

Individualized augmentative communication for individuals with autism, intellectual disability and visual impairment: Interpretation and implementation of the ComFor-V results

Petra Hagen-Geerts¹, Jarymke Maljaars², Kristien Hermans², Roger Verpoorten¹,
Ina van Berckelaer-Onnes³ and Ilse Noens²

¹Koninklijke Kentalis, Sint-Michielsgestel, the Netherlands

²Katholieke Universiteit Leuven, Leuven Autism Research (LAuRes), Belgium

³Universiteit Leiden, Faculteit der Sociale Wetenschappen, Leiden, the Netherlands

ABSTRACT

Communication is indispensable for human beings. It enables them to initiate interactions, draw attention to their needs and desires, share experiences and emotions with others. Usually communication is taken for granted. Clinical practice, though, shows that it is not necessarily the case. Individuals with autism spectrum disorder (ASD), intellectual disability (ID) and co-occurring visual impairment (VI) form a particularly vulnerable group and often have severe communication difficulties. In clinical practice, individuals with ASD, ID, and VI are often confronted with symbol communication systems that they do not or not fully understand. Individualized augmentative communication is very important for communicative competence and independence in daily life.

The ComFor (Forerunners in Communication) [1] is an instrument to obtain a precise indication of augmentative communication, primarily developed for nonverbal or minimally verbal individuals with ASD and ID. Visual impairments were not taken into account in the development of the original ComFor. Recently, an adapted version of the ComFor - the ComFor-V - has been developed for individuals with co-occurring visual impairment (Figure 1). Based on the administration of the ComFor-V, an individualized strategy for augmentative communication can be developed. The instrument can be administered from both individuals with low vision and blindness [2].



Figure 1. The assessment tool: The ComFor-V

1. BACKGROUND

Most individuals with ASD take in information most readily through visual channels. Consequently, visualization forms the key to many educative programs and communication strategies for individuals with ASD. Such approaches are not evidently applicable to individuals with a visual impairment. When someone cannot sufficiently communicate by means of verbal language, other strategies need to be used. However, what does someone really understand of what he/she hears, sees and feels? Which adaptations are needed? The ComFor-V can help to determine how to set up communicative interventions, in particular how to tune augmentative communication to the individual needs. Augmentative communication refers to the totality of strategies and techniques to augment communication, in addition to natural gestures, vocalizations or speech of the individual. Individualized augmentative communication can offer clearness and predictability and enhance understanding and independence in daily life [3].

2. COMFOR-V

The ComFor-V addresses two core questions: (1) what is the most suitable form of augmentation? And (2) at which level of sense-making can the means chosen be offered? Concerning the form of augmentation, ComFor-V results indicate whether the form should be objects, (small) pictures, written language or Braille. With respect to the level of sense-making, three general indications are possible: sensation, presentation or representation (with further refinement).

The ComFor-V consists of several assembling and sorting tasks (Figure 2). There are specific items available for individuals with blindness versus low vision.

The ComFor-V was tested as a sample of 84 children and adults with visual impairment and a developmental level below 6 years. The ComFor-V turned out to be a reliable instrument and preliminary analyses suggest sufficient validity [4].

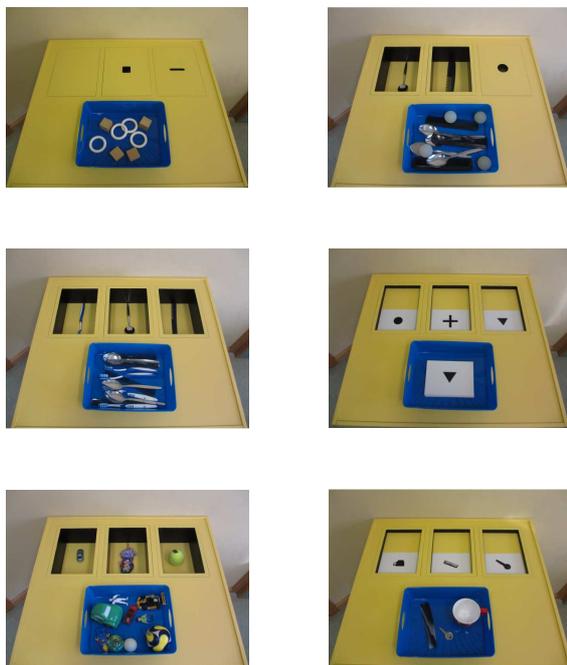


Figure 2. Examples presentation level: assembling objects (picture 1), assembling and matching identical objects (picture 2), matching identical objects (picture 3), matching identical swell pictures (picture 4). Examples representation level: sorting with the same form (picture 5), sorting between different forms (picture 6).

3. INTERVENTION

In order to be able to offer an individualized intervention plan for augmentative communication for individuals with ASD, ID and VI a multidisciplinary, integrated approach is necessary. Augmentative communication strategies for concept learning - a support model - helps to develop proper meaning by clarifying the concept in a structured and individual way [5, 6]. This way of supporting communication will enhance recognisability and predictability. The ComFor-V can be used to adapt both the form and level of communication to individual needs. Implementation of augmentative communication based on the ComFor-V results was investigated based on 10 case studies. Our intervention study demonstrated that individualized augmentative communication can lead to improvement in level of independence and/or mood [7].

Acknowledgments

Developers of the ComFor: Roger Verpoorten, Ina van Berckelaer-Onnes, Ilse Noens.

All residential services and schools in the Netherlands and Belgium which participated in this project: Koninklijke Kentalis, Koninklijke Visio, Bartiméus, Spermalie, Ganspoel.

All participants and their teachers / caregivers.

Funding: ZonMw/Stichting InZicht, Steunfonds Marguerite-Marie Delacroix and Leuven Universiteitsfonds.

REFERENCES

- [1] Verpoorten, R., Noens, I., & Van Berckelaer-Onnes, I. (Dutch version 2004/2007; English version 2008). *ComFor – Forerunners in communication. Manual*. Amsterdam, NL: Hogrefe.
- [2] Maljaars, J., Hagen-Geerts, P., Hermans, K., Verpoorten, R., van Berckelaer-Onnes, I., & Noens, I. (2014). *ComVoor-V: Voorlopers in communicatie met aanpassingen voor mensen met een visuele beperking [Handleiding]*. Leuven, BE: KU Leuven.
- [3] Hagen-Geerts, P., Maljaars, J., Denteneer-van der Pasch, W., Verpoorten, R., van Berckelaer-Onnes, I., & Noens, I. (2014). *Met ANDERE ogen: conceptondersteunende communicatie voor mensen met autisme en een visuele en verstandelijke beperking [dvd en brochure]*. 's-Hertogenbosch, NL: Tijdcode Producties.
- [4] Maljaars, J., Hermans, K., Verpoorten, R., Hagen-Geerts, P., Van Berckelaer-Onnes, I., & Noens, I. (2015). De ontwikkeling van de ComVoor-V: de ComVoor met aanpassingen voor personen met een visuele beperking. *Wetenschappelijk Tijdschrift Autisme*, 4, 124-133.
- [5] Brands., T., Denteneer-van der Pasch, W., van de Sande, K., & Versteegen, M. (2017). *Werken met Conceptondersteunende Communicatie bij mensen met autisme. Handleiding*. [iBook]. Sint-Michielsgestel, NL: Koninklijke Kentalis.
- [6] Verpoorten, R., & Denteneer-van der Pasch, W. (2015). *Conceptondersteunende communicatie voor mensen met een autismespectrumstoornis [poster]*. Sint-Michielsgestel, NL: Koninklijke Kentalis.
- [7] Maljaars, J., Hermans, K., Verpoorten, R., Denteneer-van der Pasch, W., van Berckelaer-Onnes, I., & Noens, I. (2015a). Conceptondersteunende communicatie voor slechtziende en blinde personen met een ASS en een verstandelijke beperking op basis van de ComVoor-V: een interventiestudie. *Wetenschappelijk Tijdschrift Autisme*, 4, 134-143.

A Model of National Education System for Multiply Disabled, Visually Impaired children

Baykan Z.Nazan 1, SERÇEV(Association for education and re/-habilitation of children with CP)²

1. Ayan vision center İstanbul /Turkey, nazanbaykan@hotmail.com,

2. Ankara /Turkey sercev@sercev.org.tr

ABSTRACT

In Turkey the quality of services for the re/-habilitation and education of disabled children have made great advancements within last years. These are mostly provided by legal regulations stating how educational services must be applied for each disability group. Even though inclusion and integration of disabled students into mainstream classes is a legal right, since support services, special educators for multiply disabled, visually impaired children are few in number only few classes are being opened for these children and most of them are not reached. SERÇEV (Association for education and re/-habilitation of cerebral palsied children) is a non-governmental organization, established by the parents of MDVİ children in Turkey in 2002. SERÇEV is the owner of the project named 'A Model of National Educational System for Multiply disabled, visually Impaired Children' which targeted MDVİ school children, . The purpose of the project is to increase the awareness of multiple disability within the community, develop new policies for inclusion/integration of these children, to increase the education level of MDVİ children up to typical growing age appropriate children, reach the unreached, stress the importance of multiple disciplinary assessment. The method of the project consisted analysis of the needs, arrangement of workshops at the beginning and end of the project, picture and composition competition within MDVİ school children under the topic 'The school I dream of', multidisciplinary Assessment of MDVİ students, preparation of printed materials and CDs for teachers, parents and school directors. preparation of community spots, closing distribution of these materials, evaluating the end results, preparation of the report. As a conclusion this project governed by SERÇEV has been a good proposal for the education system of MDVİ children in Turkey. It has caused an awareness within special teachers, class teachers families and school directors of how MDVİ students education must be, stressing the importance of biological, physiological and social rights and uniqueness of these children.

INTRODUCTION

In Turkey United Nations Convention on the rights of persons with disabilities was accepted in December 13 2006 and Turkey enacted it in December 18, 2008(1). This caused Turkey to establish new regulations, social services and posed new responsibilities for concerned ministries and non-governmental organizations. Since medical model excluded multiply disabled children from schooling with regard to their multiple disabilities, transition to social model and inclusion caused concerned disciplines to understand the importance of multiple assessments and t multiple needs with respect to children with single disability(2). Education programs and educational media assessments, with respect to personal needs of these children are not satisfactory yet. As parents, realizing the need for such a study SERÇEV made a project named 'A Model of National Educational System for Multiply disabled, visually Impaired Children' which targeted MDVİ school children,

THE PROJECT

The project named as 'A Model of National Educational System for Multiply disabled, visually Impaired Children' targeted MDVİ school children, their well being, having high standart living conditions, social inclusion, high quality education within their capacity, arranging environmental conditions with respect to their unique needs. The purpose of the project is to increase the awareness of multiple disability within the community, develop new policies for inclusion/integration of these children, to increase the education level of MDVİ children up to typical growing age appropriate children, reach the unreached, stress the importance of multiple disciplinary assessment. The method of the project consisted analysis of the needs, arrangement of an opening and closing workshop, target group study with 10 families, picture and composition competition within MDVİ school children under the topic 'The school I dream of', multidisciplinary Assessment of MDVİ students, preparation of printed materials, CDs for

teachers, parents and school directors. preparation of community spots, distribution of these materials, evaluating the end results, preparation of the report. The project is completed within 9 months. The printed material and CDs are published in the web pages of SERÇEV. The project has been a good study from different perspectives.

DISCUSSION

Multiply disabled students are educated in a variety of service delivery systems including special day classes in public and private schools, in inclusive education classes in public schools, sometimes at home and in special institutions in Turkey.(2). Mostly classes for multiply disabled children are opened in schools for the visually impaired. Assessments made with respect to their disabilities and educational needs do not suffice their educational needs to support them to reach their maximum capacity. Insufficient materials, lack of knowledge among teachers, often changing education policies, lack of support services can be some of the etiological factors of these insufficiencies .

From my point of view, I stressed the importance of functional vision assessment and cerebral/cortical vision impairment which is not much known even by ophthalmologists in Turkey. Teachers now know that visual acuity and visual field is not the only function of vision. This lack of knowledge, causes them to be labelled as autistic and most often mentally retarded . Inclusion and integration which is much written on paper but not well applied in reality in Turkey is now can be understood that such a system can only work and be possible by trans and interdisciplinary assessment of children by multiple disciplines. Individual education programs can be better prepared by taking into account different assessments of different disciplines not only that of special teacher.

CONCLUSION

As a conclusion this project governed by SERÇEV has been a good proposal for the education system of MDVI children in Turkey. It has caused an awareness with in the special teachers, class teachers families and school directors of how MDVI students education must be, stressing the importance of biological, physiological and social poperties and uniqness of these children.

REFERENCES

1.Orhan.S.,Genç K, Engellilere yönelik ülkemizdeki özel eğitim hizmet uygulamaları ve

örnek ülke karşılaştırması
file:///C:/Documents%20and%20Settings/pc/Belgelirim/Downloads/5000120930-5000355909-1-PB%20(1).pdf downloaded at 03.05.2017

2.Akçamete g.,Büyükkarakaya S.,Bayraklı H., ; Eğitim politikalarının yansımaları: Genel ve Özel Eğitim
http://www.ebuline.com/pdfs/22Sayi/EBU22_5.pdf
downloaded at 01.05. 2017

Behavioural Change: Inclusion or Exclusion? A Dilemma for Educators

Elaine S Gilmour

Blind and Low Vision Education Network New Zealand
Auckland, New Zealand

1. ABSTRACT

Stereotypic behaviour is at times considered a disordered behaviour because it is often regarded as inappropriate, resulting in social exclusion together with the concerns it may present, as a barrier to learning. This behaviour is characterised as repetitive sequences of fixed behaviours that are cyclical and rhythmic in nature. The behaviour is deemed to be self-stimulatory, exhibiting a lack of recognisable adaptive significance. It is considered to be pursued in an invariant manner and is also thought to demonstrate an invariant environmental influence. Stereotypic behaviour, in some of its many forms, is thought to occur with great frequency in children who are blind and in those with additional disabilities. The aetiological theories of stereotypic behavior offer insight into our understanding of the behaviours and to that of the high frequency of certain mannerisms in children who are blind. The possible impact of such behaviours in the domains detailed in Schalock's 'Quality of Life Framework' are highlighted as these are seen as significant for this group of children. This is especially so when discussing personal development, interpersonal relationships, social inclusion and human rights for an individual. As the drive for learners who are blind to be educated within inclusive settings, information about behavioural intervention to change what is considered inappropriate stereotypic behaviour to that which is considered culturally, socially acceptable, conflicts with the rights of the individual. This presents an interesting dilemma for vision educators.

2. INTRODUCTION

A considerable body of international literature discusses disordered behaviour in respect to the social environments in which it occurs. Research into the disordered behaviour of stereotypy emerged in the 1950s and continued until the mid-1970s. This focus has been far less prominent since the move internationally towards mainstreaming, integration and inclusion, driven by landmark legislation such as the 1975 Individuals with Disabilities Act (IDEA). The early research base, largely from the USA, was behavioural and somewhat quantitative in nature. Modern philosophies such as those of Skinner (1971), now question

the assumptions of behaviourism in that it is not necessarily considered permissible for others to change the behaviour of an individual. It is also important to note that the student population has changed, not only in the survival rates of children with a vision impairment but also for those with additional associated disabilities. These children are most likely to live at home and to be educated in their local community. Emphasis is placed on the integrity of the individual, respecting their ability to make decisions about their own life and behaviour.

3. WHAT ARE STEREOTYPES?

Stereotypic behaviour refers to repetitive body movements or the repetitive movements of objects by an individual. According to Barry, Baird, Lascelles, Bunton and Hedderly (2011), and Singer (2009), these motor responses are persistent and pervasive. They are excessive in rate, amplitude or frequency and are also pursued in an invariant manner (American Psychiatric Association, 2000; Schopler, 1995), as well as being cyclical and rhythmic in nature. They may involve vocal sequences together with fixed movement patterns (Berkson, 1983; Daversa, 2001). The behaviours include non-functional rituals and routines in respect to the observer, as well as behaviours that display a persistent preoccupation with stimuli (South, Ozonoff & McMahon, 2005). Barry et al., (2011) note that the behaviours are involuntary and rhythmic, with a predictable pattern, amplitude and location. The movements, according to Singer (2009) can last from seconds to minutes and they can appear multiple times a day.

Murdoch (2013) details the range of behaviours that may be considered when discussing stereotypy. These include; mouthing of objects, eye poking, light gazing, sniffing or smelling, screaming, crying or whimpering, teeth grinding, repetitive vocalisations, head movements, hair twisting or pulling, arm waving, clapping, hand flapping, hand or thumb or finger sucking, strobing light with the hand, complex hand or finger movements, throwing objects, repetitive manipulation of objects, body rocking, foot kicking, bouncing or jumping, twirling and fantasising. Some of the behaviours are more prevalent in children who are blind. These include oculodigital mannerisms (Brambring & Troster, 1992; Murdoch, 2013) and body rocking (McHugh & Lieberman, 2003; Molloy & Rowe, 2011).

4. AETIOLOGICAL THEORIES

Aetiological theories abound in respect to the cause of the emergence of the behaviours, to why the behaviours are maintained in a child's repertoire, and what conditions contribute to their development. Although Troster, Brambring and Beelmann's theoretical analysis was first published in 1991, their work embodies much of the current thinking. They list four stances:

1. The behavioural approach, where behaviours are maintained through contingent reinforcement
2. The developmental perspective, where behaviours are regarded as expressions of neuromuscular maturation processes that occur in transitional stages of development
3. The functional approach, where the behaviours are considered to be moderators of internal levels of arousal
4. The neurobiological approach, where behaviours are seen as expressions resulting from damaged neurobiological or biochemical processes.

Expanding on these stances, the behavioural approach is describing the behaviours as operant responses that are maintained by reinforcers. The developmental approach is describing the behaviours in reference to maturation in that they are an immature display of more complex movement patterns. The functional approach has a homeostatis interpretation in that it suggests an arousal-modulation hypothesis, while the neurobiological approach suggests the behaviours are the result of physiological damage to neural networks, neural transmitters and the like.

5. IMPACT OF VISION IMPAIRMENT

Vision is considered the most important modality for knowledge acquisition and the principal source of knowledge for children (Keefe, 2004). Without vision, a number of difficulties are apparent. For example exploration may be limited, there may be a lack of curiosity and the child may experience difficulty in using sensory information. Vision impairment may therefore compromise the quality of life of an individual and have a profound impact on how most knowledge is gained and how relationships progress. Concerns may emerge in communicating need, in progress through normal development stages and in managing environments.

Without vision, children do learn differently as they cannot use this sense to provide information (Ferrell, 2007). They ultimately gain information through their other senses. How that occurs, and the functionality of the behaviours they exhibit, is what is of interest. For some children who are blind, in the absence of appropriate culturally, socially acceptable behaviour, highly reinforcing behaviour excesses may be chosen. The reasons these behaviours emerge, persist and are preferred, are varied. The research confirms that lack of vision is a significant contributing factor.

6. IMPACT OF STEREOTYPIC BEHAVIOUR

How then are these stereotypic behaviours viewed by others? The literature suggests that such behaviours are perceived negatively and are a concern to others (Coots & Ringeon, 2007; Hartnett, 2013; Southwell & Hunt, 2011). Social interactions are reduced, effective reciprocal relationships are compromised, integration is limited, the child may become stigmatised, and social isolation becomes evident (Coots & Ringeon, 2007). The "quality of life", as detailed by Schalock is also likely to be significantly compromised. Without opportunities to grow and learn alongside their sighted peers, emotional wellbeing, interpersonal relationships and social inclusion are very real challenges. The likelihood of personal empowerment that offers choices in a welcoming educational environment is reduced.

7. IMPACT OF INCLUSIVE EDUCATIONAL PRACTICE

Inclusive practice has increased the need for culturally socially acceptable behaviour. Vision educators are consistently readying individuals for such settings. Programmes involve direct instruction in socialisation skills for the purpose of developing opportunities for successful interactions, for building self-confidence and for promoting risk taking (Wolffe, 2006). As microcosms of society, regular classrooms provide a social environment for students in which to learn and enhance these skills and to experience modelling of appropriate behaviours. For some learners who display challenging behaviours (such as stereotypy), exclusion from the classroom is the reality (Male, 2003).

8. THE DILEMMA OF INTERVENTION

If exclusion is in fact the reality, behavioural intervention is an option for educators. This involves Functional Behavioural Analysis in order to understand the purpose of the behaviour that is considered culturally socially unacceptable, and then interventions that reduce, replace or eliminate the behaviour. As vision educators, is this about the child who is blind fitting in to a sighted world, or is it about social acceptance and the rights of the child to behave in a way that provides both satisfaction and purpose to the individual (Wehmeyer & Schalock, 2001)?

9. QUALITY OF LIFE

How do we determine what is meant by the 'Quality of Life' for any individual? Schalock's multidimensional phenomenon has a number of core ideas and domains that vary in importance depending on what is relevant to the individual at any one time. 'Quality of life' is about fostering self-determination so that choices may be made. This is about feelings of well-being, positive social involvement and opportunities to achieve personal potential - it is very

much person referenced. What is appropriate for one student may be highly inappropriate for another. For those with a disordered behaviour such as stereotypy, is it about providing positive behaviour support that increases options? Are these options important? As a knowledgeable and reflective vision educator, this is your dilemma.

REFERENCES

- [1] Skinner, B. F. (1971). *Beyond freedom and dignity*. Indiana: Hackett.
- [2] Barry, S., Baird, G., Lascelles, K., Bunton, P., & Hedderly, T. (2011). Neurodevelopmental movement disorders – an update on childhood motor stereotypies. *Developmental Medicine and Child Neurology*, 53, 979-985.
- [3] Singer, H. S. (2009). Motor stereotypies. *Seminars in Paediatric Neurology*, 16, 77-81.
- [4] American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington DC: American Psychiatric Association
- [5] Schopler, E. (1995). *Parent survival manual*. New York: Plenum Press.
- [6] Berkson, G., (1983). Repetitive stereotyped behaviours. *American Journal of Mental Deficiency*, 88, 239-246.
- [7] Daversa, R. (2001). *Self-stimulatory and stereotyped behaviour in autism: A review of behaviour analytic perspectives*. Retrieved from www.ctfeat.org/selfstimdaversa.htm
- [8] South, M., Ozonoff, S., & McMahon, W. M. (2005). Repetitive behavior profiles in Asperger Syndrome and high-functioning Autism. *Journal of Autism and Developmental Disorders*, 35, 145-158.
- [9] Murdoch, H. (2013). *Repetitive behaviours in children with sensory impairments and multiple disabilities*. Retrieved from <http://deafblindinternational.org/review>
- [10] Brambring, M., & Troster, H. (1992). On the stability of stereotyped behaviours in blind infants and pre-schoolers. *Journal of Visual Impairment and Blindness*, 105-110.
- [11] McHugh, E., & Lieberman, L. (2003). The impact of developmental factors on stereotypic rocking of children with visual impairments. *Journal of Visual Impairment and Blindness*, 97(8), 453-474.
- [12] Molloy, A., & Rowe, F. J. (2011). Manneristic behaviors of visually impaired children. *Strabismus*, 19(3), 77-84.
- [13] Troster, H., Brambring, M., & Beelmann, A. (1991a). The age dependence of stereotyped behaviours in blind infants and preschoolers. *Child: Care, Health and Development*, 17, 137-157.
- [14] Keefe, J. (2004). Childhood vision impairment. *British Journal of Ophthalmology*, 88, 728- 729.
- [15] Ferrell, K. A. (2007). *Issues in the field of blindness and low vision*. Retrieved from www.unco.edu
- [16] Coots, M. N., & Ringeon, C. (2007). *Sensory play*. Retrieved from www.littlegiantsteps.com.
- [17] Hartnett, M. E. (2013). *Paediatric Retina*. Philadelphia: Lippincott, Williams & Wilkins. Southwell, C., & Hunt, D. (2011). Untitled work. *RNIB Insight Magazine*.
- [18] Wolffe, K. E. (2006). Teaching social skills to students with visual impairment. In S. Z. Sacks & K. E. Wolffe (2006), *Teaching social skills to students with visual impairment: From theory to practice*. Retrieved from www.afb.org/socialskills
- [19] Male, D. (2003). Challenging behaviour: The perception of teachers of children and young people with severe learning disabilities. *Journal of Research in Special Education Needs* 3(3), 162-171.
- [20] Wehmeyer, M. L. & Schalock, R. L. (2001). Self Determination and Quality of Life: Implications for Special Education Services and Supports. *Focus on Exceptional Children*, 33(8). Research Library

Approaching the Person through the Disability

Albert Ruf¹

¹Centre for Educational Resources for the Visually Impaired ONCE,
Barcelona, Spain
aruf@xtec.cat

ABSTRACT

The education of MultiHandicapped Visually Impaired (MHVI) children is not only a scientific or technical subject but also a philosophical, anthropological and ethical issue.

According to Andreas Fröhlich, the encounter between a MHVI children and his caregiver takes place at the essence of humanity. And this is why, ultimately, the educator has to hear and understand the children's desires as well as their necessities.

The use of scientific knowledge and methods will always be profoundly dependent on the relationship between two human beings. Thus, dignity, empathy and respect will be appended to any project involving a vulnerable person.

Very often, decisions that affect a child have to be made by others, and concern for their load of responsibilities cannot be avoided. Being so close to both MHVI children and their families' difficulties can make educators suffer from psychic pain.

Supervision is essential for professionals that take care of vulnerable people. Firstly, in order to assume the responsibility of doing one's best and to avoid burnout. And secondly, to honestly become aware of mistreatment whenever it takes place.

Having said that, we must accept that life is uncertain and we must try and act with prudence and respect.

1. INTRODUCTION

I know of a boy who, time and again, misses school. Adverse weather conditions, an unexpected delay, a bad breakfast, a dispute -the reasons for his inattentiveness, argued by his mother, can be manifold. This year, the boy has changed classrooms and now not only does he go to school regularly, but also has participated in the farm trip with the rest of the group for the first time in six years. His teachers wonder about the reasons behind this sudden shift and hypothesize that it is related to the fact that the boy has been set apart from a particular classmate, one with a very delicate health condition, vulnerable to infections and in need of a breathing apparatus.

Another child has been diagnosed a hypoxic-ischemic

Copyright: © 2017 A. Ruf. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

encephalopathy. He began his school years not that long ago so he still goes home at lunch time. His family comes from Latin America and it is usually the father who deals with the school when it comes to addressing the boy's issues. When the CRE (Spanish acronym for Centres for Educational Resources) services are offered to them, they always decline the suggestion and refuse to sign the requisite documentation. In its turn, the school presents this case as an ethical contention in which the child's right to receive a specialized treatment collides with the parents' right to say no.

Finally, I am acquainted with a boy who has already finished his school years and whose case needed an assessment so he could join a day centre and subsequently a home. Although the process had been premeditated and progressive, the shift from one institution to the other lead to a critical period for both himself and his family. He now lives in a home and seems to be adapted to the new environment. In order to be as close to their son as possible, the parents -who used to live only 16 kilometres away from the boy's new place of residence- moved to a residential area 500 meters away from him.

All these boys have one thing in common: they are blind.

Pau Casals once said:

'Each second that we live is a new and unique moment of the universe, a moment that will never be again. And what do we teach our children? We teach them that two and two make four, and that Paris is the capital of France. When will also teach them what they are? We should say to each of them: Do you know what you are? You are a marvel'.

2. A FEW PRELIMINARY IDEAS

Being able to share my experience with people with multiple disabilities is also an opportunity, for me, to evoke a commitment -intense and extensive, professional and personal- to which I have dedicated half of my life.

I see this educational event as a chance to share knowledge. Because by putting my ideas in order, by summarizing them and, more importantly, by passing them on, I have re-learned things that I know something about in a new fashion. Following Edgar Morin's [1] advice, I shall not allow my mistakes and illusions blind me with the belief that, what I know, I know with certainty. And so I shall keep up with the vital struggle for the kind of lucidity that does not rely entirely on wisdom.

There is an Indian fable about an elephant and a group of blind men. Each one of them touches a different part of the animal, willing to know it as a whole. Proud of their own revelation, they all go before the king, one by one, to illustrate their case. Let me be the last blind man. The others have already given their version of what the elephant looks like, based on the part of the animal they had touched -like a snake; like a plough; like a column. The last blind man can't help but chuckle. He recalls that, as a young man, he also believed that he could know about something by only grasping a part of it. He realises now how difficult it is to describe an elephant.

I don't mean to address the case of multiple disabilities just as a part of a much more complex entity, but even with our eyes open, I'm not sure we would all see the same. Each and every perception is unique and the result of our previous experiences. And so we must try to describe what we see and share it with others in order to find meeting points. And, in the best of cases, points of agreement. 'The only way that two people can coincide somewhere -or with some idea- is by coming from different places'. [2]

So when we talk about multiple disabilities, we need to include a multiplicity of experiences that we then must put in their own context within a global vision. The person comes before any of their particularities and this is how we should see it.

Also, we must take into account that knowledge, ideas, thoughts and beliefs can and do evolve, but that it takes time for that to happen. High-speed recipes might provide some relieve but knowledge demands the effort of personal involvement. Slowly but surely, we must carry on down the path we have chosen. In good company, if possible; taking cover, when necessary, under the shadow of a good tree. I have been fortunate in this sense.

'There is a secret bond between slowness and memory, between speed and forgetting,' says Milan Kundera [3] in his novel *Slowness*. 'Consider this utterly commonplace situation: a man is walking down the street. At a certain moment, he tries to recall something, but the recollection escapes him. Automatically, he slows down. Meanwhile, a person who wants to forget a disagreeable incident he has just lived through starts unconsciously to speed up his pace, as if he were trying to distance himself from a thing still too close to him in time. In existential mathematics that experience takes the form of two basic equations: the degree of slowness is directly proportional to the intensity of memory; the degree of speed is directly proportional to the intensity of forgetting'.

3. ANTHROPOLOGY

Being so close to kids with a myriad of difficulties, one realises that we must escape the simplistic stereotypes that mere diagnosis confer and that we must penetrate into more subtle, less specific realities that adjectives like joyful, calm, fun, weepy, fragile, small, anxious, sensitive, or kind can offer.

In our work field, doctors often find it hard to discern whether a case of fatigue or of sorrow are caused by physical or psychological reasons. In some primitive cultures, emotions are not regarded as intimate phenome-

na, but rather in social or physiological terms. Hunger, to give an example, is also a feeling, not just physical circumstance. Because it is connected to isolation and loneliness. Since food is the very first means of solidarity, hunger can't be detached from abandonment or solitude. [4] Etymologically, the word company (in Latin languages) means sharing the bread.

Let's talk about trust. How necessary is it? And how do we measure it? What is the ideal amount, or the minimum, to relate to someone? How do we get to know if we can trust a person? Trust means security, fearlessness to change; it means self-confidence and confidence towards the other. A man can't survive without trust. [5]

What about our sight? Our eyes. Is it just a coincidence that, in so many languages, the word 'pupil' also means 'small person'? We could find an explanation by getting really close to someone's eye. What we see is a person looking at us: ourselves. It is us looking at us looking - and feeling looked at.

In a broad sense, one could say that our job is commissioned by the parents, the Institution, and by society itself. But what does this job exactly entail? It consists of helping, collaborating, assisting -and that means staying close; it consists of walking the children with visual impairment and other disorders through his or her development and process of education. Through their lives. And 'to live is not [only] to live, but to realise'. [6]

'Although they often overlap, desires and needs are semantically different. I need to eat, but I may not have much desire for what is placed in front of me. While a need is urgent for bodily comfort or even survival, a desire exists at another level of experience. It may be sensible or irrational, healthy or dangerous, fleeting or obsessive, weak or strong, but it isn't essential to life and limb. [...] Desires are the fuel of life. The urgency that stimulates us to move forward'. [7] We want these children to move forward, too, and we need to capture their identity and to help its development so it can emerge to the surface. But, most of the times, these children depend on their parents and their care providers. So what are the parents' desires towards their child? What does this desire look like when they've had to face the end of the world, not just once, but twice? Fournier [8] writes about their children with a humorous approach ('just as Cyrano laughed about his own nose'). As a last resort, humour has always been useful -a means of decompression in difficult situations.

4. PHILOSOPHY

For our earliest thinkers, philosophy was a way of life: they thought life and they lived thoughts. This is where I have headed for, too, as a companion to giant figures such as Rafael Argullol, Nuccio Ordine, Hans-Georg Gadamer, Gaston Bachelard, Byung-Chul or Joan-Carles Mèlich. Along the way, I have come across a group of sociologists like Zygmunt Bauman and Richard Sennett; and linguists, like Tzvetan Todorov and George Steiner; art critics of the size of John Berger; architects like Juhani Pallasmaa and Ernst Neufert; writers like Primo Levi, Victor Frankl or Simon Wiesenthal; journalists such as Svetlana Alexievich; or playwrights, like William

Shakespeare or Neil Labute. One of the last findings in my persistent research on the subject of seeing was Josep Maria Esquirol.

Esquirol [9] says that you cannot respect the other unless you look at him or her attentively. The simplicity of the act of looking collides, paradoxically, with the arduousness of looking correctly. So, how do we learn to look and to do it right? With practice. We learn to look by looking. But to look correctly doesn't mean being stuck to someone. There has to be an approach, of course, but also a certain distance. But then again, what is the right distance? If it is too long a distance, we do not get to discern; too short can become invasive or even offensive. What we find in-between, an approach without manipulation, subordination or domination, is what increases our capacity to create an effect on the other person.

In his essay *Intimate Resistance*, Esquirol stands for a philosophy of proximity as a means to defend ourselves from eroding factors such as sickness, the process of aging, or absence -when nothingness means 'nothing to grasp with your own hands, no word to hear with your ears, no stare to contemplate, no smell, no ground to stand on your feet'. [10] In order to rebuild your own self again, you need another person and a bond. And that requires something: difference. No relationship is possible without difference. Each and every conversation can be new and unique. It only depends on what is said and what is listened.

Another inspiring idea is that 'the worst kind of misery is that of getting used to misery' [11] and so it is essential to learn how to coexist with adversities. Also, we have our sight and a healing way of looking, which not only serves the purpose of observing. It also transforms and transforms us.

Turning to those great minds has always been a nutritive source of provocation, controversy, creativity and argumentation in the comprehension of the human essence and conscience that no scientific discipline has been capable of explaining. And neither is philosophy, of course. Philosophy merely asks question after question in order to obtain new questions, given that 'Who are we?' and 'Where are we?' are inseparable. And yet, in many occasions it has become a lighthouse for disoriented sailors such as myself.

5. LITERATURE

Of course, literature has been another lighthouse for me. Isabel Allende depicted, both brutally and brilliantly, the spread of a serious neurological disease in the body of her daughter Paula. With great generosity, she shared with her readers the feelings and pain that her whole family went through. It was a life lesson that summarised in the moment when, having accepted the impossibility of a recovery, Allende [12] writes: 'the time of efficiency is up; we are now entering the time of love'. In that same book, her new couple's son, a boy decided to express his rejection to the newly arrived mother in law, says:

'I don't have an obligation to love you'.

To which she replies:

'Neither do I. So we can make an effort and *do* try to love each other, or we can simply be polite to each other. What do you prefer?'

'Let's try to love each other,' replies the boy.

Allende brings things to an end:

'Well, and if that doesn't go well, we will always have respect'.

In a similar fashion -let me please elaborate on this matter- Shakespeare's works are full of references to the human spirit and its conflicts. The example I would like to bring about is well known for most: *The Merchant of Venice*. [13] The main character owes some money to a Jewish man; an amount he cannot pay. Economic and legal issues are very tough matters in the Venice of the Eighteenth century and the failure to fulfil one's duty can be very damaging for the city's image. Threatened and vilified by Antonio's friends for willing to retrieve the pound of meat they had agreed upon, Shylock, the Jewish creditor, an archetype of the money-grubber, pronounces his famous monologue:

'...because I'm a Jew. Doesn't a Jew have eyes? Doesn't a Jew have hands, bodily organs, a human shape, five senses, feelings, and passions? Doesn't a Jew eat the same food, get hurt with the same weapons, get sick with the same diseases, get healed by the same medicine, and warm up in summer and cool off in winter just like a Christian? If you prick us with a pin, don't we bleed? If you tickle us, don't we laugh? If you poison us, don't we die? [...] If a Jew offends a Christian, what's the Christian's kind and gentle reaction? Revenge. If a Christian offends a Jew, what punishment will he come up with if he follows the Christian example? Of course, the same thing—revenge!'

The idea of *Summum ius summa iniuria* (rigorous law, rigorous injustice) can be, somehow, disturbing. Rule of law cannot prevail under each and every circumstance. Individual responsibility, that is, the obligation to respond to the events which we witness, must play a role, too, when it comes to facing difficult decisions.

6. NEUROSCIENCE

My initial humble incursions to the field of neuroscience soon became necessary and constant means of investigation. Novelties are exciting in the same proportion that repetition is boring. I remember with a smile those times when we agreed on the irreversible process of decay and death of our neurons. Now we know of its incredible capacity to regenerate throughout their lives and the development of stem cells foretells the possibility of exchange procedures. The medical records of those kids we assisted were full of new terms with straightforward translations that, nonetheless, were out of context not just for the families or ourselves but also for the medical staff. Gradually more and more specialised in their fields of research, they ignored adjoining parcels to which they were not devoted. The times of a GP who knows the case and the family and recommends a set of measures based on the personal circumstances of both the group and its entourage -those times are over. Now, in-depth studies on neurology are made by large multidisciplinary groups of expertise competing against other groups that also want

to seize success through scientific publications, industrial patents, excellence scholarships and world-ranked professional prestige.

In parallel, neuroscience became a popular subject and the results of their efforts appeared in newspapers as well as on TV. Books, too, allowed a rather global comprehension of certain biological mechanisms and, soon, both eyesight and the brain were on the spotlight of research and subsequent practice procedures. The so-called bionic eye hasn't stopped its improvements and finding candidates for the experimentation of new prosthesis and transplants has never been an obstacle. The Twenty-first century has been called the century of the brain, thus giving a scientific and economic stimulus to the possibility of deciphering the secrets of its operating mode, obtaining ways of both recovering from its injuries and avoiding its deterioration -a God-like agenda that would place life expectancy within parameters only imaginable, so far, in science-fiction literature.

Volumes like *To Each his own Brain*, by Ansermet and Magistretti, or *The Brain That Changes Itself*, by Norman Doidge, became prestigious studies on the functioning of the human body. The latter, with a well-measured writing process, included chapters with titles as eloquent as *Building herself a better brain*, *Midnight resurrections* or *Rejuvenation*, all preceded by a set of articles from journals such as *Science*, *Frontiers in Psychology* or *Journal of Visual Impairment & Blindness*, which for a period of time flooded my computer thanks to an alert system that I had in place.

Neurosciences shone with its own light. New data on the functioning of the visual neurological system and, by extension, the brain itself, helped us understand what injuries and dysfunctions compromised so we could begin to think of ways we could ease the process of re-learning how to look. However, scientifically, we couldn't apply those measures to each person we assisted, whose biology and biography were distant from a statistical average. 'Not everything that counts can be counted, and not everything that can be counted counts,' once said Albert Einstein.

We kept a watchful eye to the discovery of the so-called Jennifer Aniston brain cell, as well as to the fortuitous finding of the mirror neurons; to the exposure of the V1, V2, V3, V4 and V5 areas; to the enunciation of the Two-streams Hypothesis -the dorsal and the ventral; and to the chance of obtaining more and more information through the Visual Tracking. And yet, none of that helped us get a comprehensive view of what happened to each children with we were working with. In those circumstances, it was easy to come under the friendly orbit of Oliver Sacks.

7. OLIVER SACKS

Oliver Sacks was a British neurologist who described his patients as literary cases. To that endeavour, he put a lot of time and attention into learning, not just about the disease, but also about the person suffering from it. Thus, he could contextualize the loss of balance within a vital continuum that included a past, manifested in the present and headed to a new period towards the future. Today, we

call this technique a *case study*, which is in clear opposition to current pedagogical trends that advocate the formation of medicinal students who work with mannequins or even actors instead of real people with real medical conditions. [14] *Awakenings*, *The Man Who Mistook His Wife for a Hat*, *Seeing Voices*, *An Anthropologist on Mars*, *The Island of the Colorblind*, *Musicophilia*, *The Mind's Eyes* and, finally, *Gratitude*, published only a few weeks before his decease, alluded to personal stories.

Oliver Sacks was a confessed pupil of Alexander Luria. He discovered that complex functional systems can't be restricted to isolated areas of the brain. Instead, in order to achieve its purpose, they work as organized structures from distant areas. 'There is no such thing as individualised nodes, but a synchronized neuronal web that tie multiple functional areas together'. [15] Already in 1974, he dared to refer to the 'associative mental blindness in which the patient perceives the whole visual frame and yet is incapable of recognizing it to circumscribe its meaning'. [16] However, Luria held a twenty-year-long friendship with a patient with an exceptional memory. His expertise was requested by Salomon Shereshevsky, whose life had turned into a nightmare due to his boundless mnemonic capacity. Consultations became frequent and allowed the doctor to get to know the patient in multiple levels. It is all recorded in a book that I highly recommend called *The Mind of a Mnemonist: A Little Book About A Vast Memory*, which brings to memory Borges's *Funes the Memorious*. A new procedure was put in place that implied a new kind of bond between the physician and the patient. Subsequently, Sacks would state that 'the study of a disease demands a study of the patient's identity; a study of the inner worlds that they organize under the umbrella of the disease'. [17]

8. DISEASE AND HEALTH

And at any rate, not every child we have assisted is actually sick. It is true, unfortunately, that disabilities often start with a disease. But the two concepts are not exactly coincident. It is known that circumstances beyond the patient himself can be at the origin of a disability. The definition of 'health' that the World Health Organization proposes refers to a physical, mental and social well-being as well as to one's perception of being healthy. If I am locked in a pigpen doing a boring job with everyone else marginalizing me, I'll probably go through a kind of disenchantment that soon will turn into physical discomfort, distress or pathology, that is, real symptoms of a disease due to a bad functioning of the biological organism and its personal and social adaptation to the environment. Renata Walthes [18] sees multiple diseases, not as particularities of a person's life but in terms of relations within a particular social milieu. In other words, 'the categorization of what's normal and what's pathological is a social convention'. [19] 'Each society develops specific types of diseases, and the same happens with the ways they deal with them, so when health issues become a political subject, extraordinary amounts of resources are devoted to the identification of different necessities and solutions. Health issues are today disputed goods among

different social groups' [20] and decisions over a better or a longer life are totally pertinent.

9. PAIN AND DEATH

We have witnessed pain manifesting vividly and we have seen ourselves giving comfort, care and company. Because we don't need to be that sensitive to feel someone else's pain and we suffer with the suffering of others. In our search for initial descriptions of pain scales, we have located fine attempts to both identify and quantify severe and chronic pain, even in new-borns. At any rate, and siding with the idea that the experience of pain is personal and subjective, we can all agree, too, that pain is corrosive and rather incapacitating. It stems from the back, or the chest, or the hips and towards the rest of the body. It prevents you from doing anything, it turns you off and then on again, it makes you feel anxious, it gives you discomfort when people around you try to cut it out but find no way to do so. Also, we've come to ask ourselves, not just how much pain we can endure, but something more: how much pain do we need to do the right thing? Taking Emily Dickinson as an example -in one of her poems, she says 'water is taught by thirst'- we could say that compassion is taught by pain. Keeping in mind the medical motto 'Heal sometimes, ease often, keep company always' has been helpful along the way, because our job has a lot to do with healing in a very broad sense -with taking care of people. What an odd culture, our own, that has more words that serve to illustrate sadness than joy! 'Human beings suffer in numerous ways. And they have made up a large spectrum of words to describe them. Linguists know [...] that nearly every language is set to design negative feelings more precisely and rigorously than positive ones. [...] English language makes a distinction between *illness*, which is 'the experience of having a disease', and *disease*. A sharp observation that allows us to say that the same disease can be experienced as different illnesses'. [21]

Life itself has changed its own location. Right. It used to reside in the lungs. Those who didn't breathe were dead men. Breathing was a guarantee of being alive.

Then the burden of proof moved to the heart. A beating heart, a functioning pulse, was equivalent to existence.

Now life can be found in the brain. We can be connected to a respirator or carry an artificial heart. But as long as neurophysiologic activity is detected, as long as there is scientific evidence of an active encephalogram, no one can issue a death certificate -despite, for many people, existence vanishes before life itself does.

Four months after his son died, the writer Marius Serra [22] wrote the following: '*You can't die in peace in this country*'. Apparently, he still received phone calls asking about the last wishes of the deceased. Three years later, he wrote: '*They haven't forgotten you, Llullu*'. [23] Someone was calling to claim the recovery of amounts paid unduly after the passing of the boy.

10. DEPENDENCY STATUS

Individualist societies encourage autonomy and success as rising values. In more cooperative societies, there's the

belief that depending on others is a mutual and essential necessity. Nobody can do everything on their own. You're being helped today; you shall help others tomorrow. Relational learning systems like this allow mutual liabilities with our fellow citizens. The opposite of dependency isn't independence. It's isolation. [24] 'I need to be needed. I want to be sure that I have an impact on another person'. [25] By expressing our own vulnerability, we don't become more vulnerable. On the contrary, it is only then that we understand the human fragility and we get closer to each other in mutual defence. Also, in a more stable position we have the compromise of preventing the most vulnerable from being ill-treated.

11. ETHICS

Given that working with pain makes one suffer and that mankind has a natural tendency to avoid suffering, protection factors turn out to be very significant and necessary. Firstly, a certain mind-set is required to voluntarily enter a hostile territory in search of a kind of conflict that -we know- will arise also in our absence. Thus, in order to perform with acceptable levels of efficiency, it is essential that your mind and your heart are in the right place. Secondly, and I know this through my own experience, team work is always a guarantee of honesty. We have committed the sin of inexperience and allowed certain difficulties to become obstacles; we've argued fiercely over disagreements and made the same mistakes over and over again. And yet, we've tried to be sensitive to the demands of our fellow citizens and have pointed fingers at our own selves after a false step. We've had to struggle to preserve both respect and sincerity as inalienable values and every crisis and adversity has turned into an opportunity grow as a team. We've had to watch the watchers (*Quis custodiet ipsos custodes?*) because we've been witnesses of a few misdeeds. We also got paralyzed at certain stages; and speechless, and shocked, and outraged. And we've relied on our colleagues and external supervisors for an adequate reaction. And we still do, after so many years. We still ask ourselves that ethical question: what should I have done?

Our main focus has been the visual development of children with multiple disabilities. To direct questions like 'Do they see?', 'How do they see?' and 'What do they see?' we had to reply with provisional answers: 'What does *seeing* mean?' 'What does *looking* mean?' and 'What does *understanding* mean?' Cerebral visual impairment was probably the most provocative factor we employed to understand how an injured and an uninjured visual nervous system worked (also, in order to generate stimulating inputs for the brain and, more generally, the person). We are aware of the fact that other senses like the hearing or the touch required a more extensive research and we hope that forthcoming teams will take care of it.

12. THE VISUAL TASK

As for the visual nervous system, we learned that there are alternative routes to get to the same destination. We understood that it is possible to know *where* something is and, yet, ignore *what* this something is. Also, that an

object can be perceived when isolated and then turn invisible when surrounded by other objects. We observed with absolute astonishment that you can walk a distance without stumbling and yet ignore completely where you have passed by. We realised that, with a blind vision, one cannot *tell* directions, but can go to a place if directions are *told* to him. So he can't tell, but he can do! We also established that new-borns are genetically predisposed to reacting to the human face and that, instead, prosopagnosia prevents people from recognizing faces. We were confident that a baby would not fall into the visual precipice. We also verified that a complex stimulus can be subdivided into shape, colour, volume, movement and experience. However, a research study by Biederman and Vessel [26] showed us that one's natural need for information is widely proved by the evidence that the visual brain is strongly connected to one's pleasure through opioid receptors.

13. SUPERVISION

This task is both complex and gratifying. There's no doubt about it. But the emotional blow comes from working with those who have been expelled from their world and placed at the edge of every possible boundary. Honouring our commitment with them surpasses our professional responsibilities. Seeing the other is seeing yourself when it comes to pain, disease, vulnerability, or treatment received. It also means learning a life lesson -a lesson of self-improvement, of integrity, of hardness, of perseverance, of generosity. And all of this, just by going and see what they see! I don't know how things would have worked without a work team or the task of supervision. It wouldn't even be worth the try, I believe. Specialised literature is explicit in the necessity of healing those who heal so they can endure a situation of sustained pain and keep their individuality and personal character intact. We already know what happens when we depersonalize a human being -when we kick them out of their houses, or keep them apart from their families, or take away their belongings; when we degrade them and put them with a bunch of strangers, or shout at them, or shake them, or cut off their hair; when we put them in a uniform. At that point, he's no longer one of us, and any atrocity is then a possibility. Also, our conscience are clear... we just did what we were asked as hard-working public servants. Only the eyes of those who cannot shut stay open before the 'infinite boldness of the ignorant'. [27]

But our job cannot possibly leave us with a fully clear conscience. First of all, we must be self-critical and know that we are vulnerable, and that our intervention can be of importance but it always be limited. Of course, things can only change with a compromise with the other. Then, it is vital to maintain one's confidence pact with the rest of the team so any loss of hope can be dealt with adequately. It would be so easy to let certain aggressions disrupt our spirits into distress, violence or perversion, that it is essential to count on an external agent to remind us of the right direction. How cute is this girl with a paralysis! Can you hear the sounds of this boy? Look at this girl, she's staring at the sun! Perhaps beauty can be found in one's eyes, but we can only help them express it if we learn to

discern between the emotions that Paula, Carlos or Dunia project, and their personal competences, which are expressed through perception, movement, socialization and communication. Not communicating is not an option. Not learning is not an option. We can't just talk to someone in front of a child as if he or she wasn't there. Because they are. And so are their friends and the rest of the grownups. Whatever we do to a fellow man, we do to ourselves.

So here's a case of two parents who bring their four-year-old child to a psychologist. They're worried because the boy seems anxious and his school performance has worsen in the last few weeks. The psychologist starts by listening to the parents and then speaks with the boy. As she goes on, the parents, at the back, use body language to get the specialist's attention and then, in a low voice, tell her that the boy's grandfather died only a few days before. The psychologist then asks the child if something worries him, to which he answers: I *am* worried. My grandfather has died and my parents don't know about it.

14. EPILOGUE

After everything I have said, I must confess that I'm not completely convinced of any of it. I believe that uncertainty is also a fuel for those who are curious and always have questions -those who will have to face the pain of having to decide. [28] Tomorrow, I will see again a little boy or a girl who will smile and cry without anyone having taught them how to do either of those things. And I will have to respond to that smile and to that cry, too, without anyone having taught me how to do so. However, the moment that boy or girl smiles at me, a smile will be drawn on my face, too, even before I have time to realise. Through their eyes, I will see myself and that they like what they see. [29] And then, in front of the other specialists and parents staring at me the way you're doing it now, the stage fright will take over again. However, it will be a unique opportunity, a congregation of human beings that will dare to live like we just did here.

Acknowledgments

I would like to gratefully acknowledge the support of Victor Monreal, whose translation enriched this paper with a precise, accurate and collaborative work.

REFERENCES

- [1] E. Morin, *Seven complex lessons in education for the future*. Paris-UNESCO, 2001.
- [2] J. Fuster, *Aforismes*. Alzira-Bromera, 2002.
- [3] M. Kundera, *Slowness*. New York-HarperCollins, 1995.
- [4] J.A. Marina and M. López, *Diccionario de los sentimientos*. Barcelona-Anagrama, 1999.
- [5] J.A. Marina and M. López, *Diccionario de los sentimientos*. Barcelona-Anagrama, 1999.

- [6] J.M. Esquirol, *La resistència íntima. Assaig d'una filosofia de la proximitat*. Barcelona-Quaderns Crema, 2015.
- [7] S. Hustvedt, *Living, Thinking, Looking: Essays*. New York-Picador, 2012.
- [8] J-L. Fourier, *Where We Going Daddy? Life with Two Sons Unlike Any Other*. New York-Other Press, 2010.
- [9] J.M. Esquirol, *El respeto o la mirada atenta*. Barcelona-Gedisa, 2006.
- [10] J.M. Esquirol, *La resistència íntima. Assaig d'una filosofia de la proximitat*. Barcelona-Quaderns Crema, 2015.
- [11] J.M. Esquirol, *La resistència íntima. Assaig d'una filosofia de la proximitat*. Barcelona-Quaderns Crema, 2015.
- [12] I. Allende, *Paula*. New York-HarperCollins Publishers, 1994.
- [13] W. Shakespeare, *The Merchant of Venice*. Oxford-Oxford University Press, 1979.
- [14] J. Lobo, "Carta a un amigo nuevo" in J. Cardoso, *De profundis*. Barcelona-Libros del Asteroide, 2006.
- [15] J. Lobo, "Carta a un amigo nuevo" in J. Cardoso, *De profundis*. Barcelona-Libros del Asteroide, 2006.
- [16] A.R. Luria, *The Working Brain. An Introduction to Neuropsychology*. London-Penguin Books Ltd., 1973.
- [17] O. Sacks, *An Anthropologist On Mars. Seven Paradoxical Tales*. New York-Vintage Books, 1995.
- [18] R. Walthes, "Dialogues in Movement. Perception means making differences, that is essential differences." Germany-University of Dortmund, 2001.
- [19] C. Tobio et al, *La cura de les persones. Un repte per al segle XXI*. Barcelona-Obra Social la Caixa, nº 28, 2010.
- [20] C. Tobio et al, *La cura de les persones. Un repte per al segle XXI*. Barcelona-Obra Social la Caixa, nº 28, 2010.
- [21] J.A. Marina and M. López, *Diccionario de los sentimientos*. Barcelona-Anagrama, 1999.
- [22] M. Serra, "Aquí no hay quien muera" in *La Vanguardia*, (2009, Nov 24). Available: <http://hoteldilluns.blogspot.com.es/2009/11/aqui-no-hay-quien-muera.html>
- [23] M. Serra, "Et recorden, Llullu" in *La Vanguardia*, (2012, Jul 2). Available: <http://www.lavanguardia.com/encatala/20120702/54319468026/marius-serra-et-recorden-llullu.html>
- [24] C. Gilligan, "La resistencia a la injusticia: una ética feminista del cuidado" in *Cuadernos de la Fundació Víctor Grífols i Lucas*, nº 30, Barcelona, 2013.
- [25] J.A. Marina and M. López, *Diccionario de los sentimientos*. Barcelona-Anagrama, 1999.
- [26] I. Biederman and E.A. Vessel, "Perceptual Pleasure and the Brain" *American Scientist*, vol 94 (3), 2006, pp. 247-255. doi: 10.1511/2006.3.247
- [27] M. Serra, *Quiet*. Barcelona-Empúries, 2008.
- [28] A. Ruf, "Rethinking Uncertainty, or the Pain of Having to Decide," *Educació Social. Revista d'Intervenció Socioeducativa*, nº 60, 2015, pp. 28-43.

Biblus – A Digital Library for Alternate Media

Lars Ballieu Christensen¹ and Tanja Stevns²

¹Sensus ApS,
Hillerød, Denmark
lbc@sensus.dk

²Synscenter Refsnæs,
Kalundborg, Denmark
tstv@regionsjaelland.dk

ABSTRACT

Ensuring that blind and partially sighted children included in mainstream education have access to educational material in alternate formats alongside their sighted peers is a challenge. While it can be frustrating for visually impaired students not to have timely access to textbooks and other material, it also limits how well teachers and educators can establish an inclusive learning environment. Biblus is a digital library for educational material in alternate formats. Developed as a companion to the award-winning RoboBraille service to augment the availability of alternate media in mainstream education, the library contains digital copies of all the educational material used throughout the Danish primary and lower secondary educational system. Developed and operated by Sensus for Synscenter Refsnæs, in accordance with the Danish copyright legislation, the library allows teachers, relatives and the children themselves to retrieve digital copies of material as well as teaching instructions whenever the material is needed. Biblus even supports on-the-fly conversion of material through an integration with RoboBraille. The library is furthermore being used as collaborative platforms amongst special schools for the visually impaired and as in-house repositories at academic institutions to ensure access to material whilst protecting the copyrights.

1. INTRODUCTION

Since the 1980's, the education of the visually impaired in Denmark has been based on integration and inclusion. Of the approx. 2,000 blind and partially sighted pupils in the Danish primary and lower-secondary educational system, less than 100 pupils attend special school, bringing the integration ratio well above 98 per cent. In high school and beyond, the integration ratio is even higher.

A key barrier to the successful inclusion of visually impaired students is the availability of educational material in suitable formats. In accordance with section 17 of the

Danish Copyright Law, material can be produced in alternative formats for people who are incapable of using printed material. However, although almost all material is prepared and published electronically, Danish publishers seem somewhat reluctant to make these electronic copies available for alternative media production. As a consequence, printed books may need to be cut up, scanned and the formatting reapplied before they can be made available to the visually and reading impaired [1, 2].

Visually impaired pupils in the primary and lower-secondary educational system are supported by Synscenter Refsnæs, the National Competence Center for Blind and Partially Sighted Children and Youth, who operates an efficient alternate media production unit. Until 2012, its materials were not made available in searchable, digital formats, nor were teachers, pupils, VI professionals or relatives able to download such material. As no suitable digital library solutions were available, it was decided to develop Biblus and operate it as a national resource.

2. REQUIREMENTS

Consulting teachers, parents, VI professionals and alternative media professionals throughout Denmark as well as partners in selected European countries, a list of requirements to the system was developed. In brief, the solution needed to be able to manage users, titles, digital assets, access rights and various means of delivery mechanisms. Because the contents of the digital library system largely consist of copyrighted material, user management had to be based on those accommodated in the Danish copyright legislation. Consequently, all external access rights had to be linked to a primary user who satisfies the requirements in the copyright legislation with access rights granted to secondary users such as teachers, relatives and VI professionals. In addition to these groups, the system had to accommodate alternative media professionals and administrators.

To ensure accurateness and limit the resources required to register material, the digital library was to be integrated with library database, danbib [3]. In addition to copyrighted material, the digital library should be able to manage unpublished material such as lecture notes and PowerPoint presentations. Furthermore, the library should be able to contain one or more alternate versions of the printed material in suitable digital formats. As some alternative versions of titles – such as math books – consist of a combination of electronic files and tactile material, the

digital library should also be able to manage tangible assets.

The digital library would need to have suitable search capabilities. Once a media file has been found, it should be possible to download or otherwise acquire the file. It should furthermore be possible to perform on-the-fly conversions of media files into more suitable formats using the RoboBraille service [4, 5].

To ensure that the digital library was usable by all types of users and to accommodate a future decentralized upload model, the solution should be web-based, comply with the W3C web accessibility guidelines [6] and work across all major architectures, operating systems and browsers. It should furthermore be possible to localize the solution to other languages and to support different copyright regimes.

3. BIBLUS

Based on the requirements listed, the Biblus digital library was successfully implemented in 2011 (www.biblus.dk) in 2011 and became operational in 2012 [7].

The user interface adapts to the rights of authenticated users, making it usable for library consumers (primary users, professionals, relatives), as well as producers (alternative media professionals) and administrators. A primary user must exist in the digital library before associated VI professionals and relatives can be created. Similarly, once a primary user is deleted, the access privileges of associated users are revoked. Access to the digital library is typically granted for a period of one year, but access privileges can be revoked at any time in case of misuse of the system or other circumstances.

Users can search the digital library using simple as well as advanced search functions. Once a particular title has been located, the user can review available alternatives and order an electronic copy by email or download. The user may also use the download option in case of local limitations in his or her email system. Alternatively, the user can select to have documents delivered through RoboBraille, thus expanding the available formats beyond what is actually stored in the library. Biblus can furthermore manage tactile illustrations and other tangible assets, informing the system administrator in cases where the user requests copies of these to be sent by ordinary mail.

Alternative media producers and administrators can create new titles and upload media files with alternatives of these titles. Rather than typing substantial amounts of meta data, available meta data may be retrieved from the official Danish library database danbib. In addition to standard meta data, information such as Braille math in LaTeX and standard text with page markers for Braille can be added.

To prevent abuse and copyright infringement, all activities are logged and material is made available to users with strict stipulations on acceptable use. Finally, Biblus includes comprehensive reporting features.

4. CONCLUSIONS

Since 2012, Biblus has been offered as a free public service to mainstream schools with visually impaired pupils. It currently holds more than 4,800 unique titles and more than 15,000 media files. Biblus is being maintained on a regular basis and new features and functions are being added. Examples include full-text searching of media files, category-based and management of journals and journal papers.

The library has furthermore been translated into multiple languages (e.g., English, Spanish, Greenlandic, Romanian, Polish, Bulgarian), integrated with additional library meta databases and is being used in different settings in Europe and North America:

- Member library. Disability organizations and rehabilitation centers are using the library to serve members and clients.
- Collaborative platform. Special schools for the blind and partially sighted are using the library to share educational material in alternate formats.
- In-house repository. Mainstream academic institutions are using the library to manage their alternate media production.

Acknowledgments

The development of Biblus was partially funded by The Danish Agency for Culture.

REFERENCES

- [1] Christensen, Lars Ballieu: The Importance of Information Technology for Visually Impaired Children and Youngsters and the Expectations for Future Development, Proceedings of the ICEVI European Conference, 2000
- [2] Bengtsson, Steen, et al.: Blinde børn – Integration eller isolation. SFI, 2010
- [3] Larsen, Kirsten: Bibliotek.dk: opening the Danish union catalogue to the public. *Interlending & Document Supply*, Vol. 35 Iss: 4, pp.205 – 210, 2010
- [4] Christensen, Lars Ballieu: RoboBraille – Braille Unlimited. *The Educator*, Volume XXI – Issue 2, ICEVI 2009, p. 32-37
- [5] Christensen, L.B., Keegan, S. J., & Stevns, T: SCRIBE: A Model for Implementing RoboBraille in a Higher Education Institution, K. Miesenberger et al. (Eds.): ICCHP 2012, Part I, LNCS 7382, pp. 77–83, 2012. Springer-Verlag Berlin Heidelberg 2012.
- [6] Web Content Accessibility Guidelines 2.0, W3C, 2008
- [7] Christensen, L.B., & Stevns, T: Biblus - A digital library to support integration of visually impaired in mainstream education. K. Miesenberger et al. (Eds.): ICCHP 2012, Part I, LNCS 7382, pp. 36–42, 2012. Springer-Verlag Berlin Heidelberg 2012

Improving access to external examinations for students with vision impairment in the UK

Rory Cobb and Sue Keil

Royal National Institute for Blind People, United Kingdom
(rory.cobb, sue.keil) @rnib.org.uk

ABSTRACT

The UK operates a national exam system for 16 year old students and exam boards provide modified exam papers in braille and large print for students with vision impairment. This paper outlines the findings of recent research [1] carried out by RNIB in 2015 into the quality of exam papers in modified large print and braille provided in England and Wales. The research was carried out to address concerns expressed by many qualified teachers of children and young people with vision impairment (QTVI) about weaknesses in this crucial area of their students' education.

Key concerns from a survey of teachers included the poor availability of past papers for practice purposes, difficulties with ordering live papers, and the low quality of some diagrams, maps and graphs in modified papers. From a detailed quality assessment of around 100 papers in large print and braille, problems were also found in the modification, layout and production of many papers.

The paper sets out the recommendations arising from the research project and outlines new resources to help QTVIs and other education professionals prepare their blind and partially sighted students more effectively for taking external exams.

1. INTRODUCTION

Over many years RNIB has received anecdotal information from QTVIs about problems with the provision of exam papers in accessible formats for blind and partially sighted candidates. The situation is made more difficult because exam boards do not allow schools to make any changes to these papers locally. To get a better understanding of the scale and nature of the problem, in 2015, RNIB with the support of the exams regulator and the four exam boards carried out research on the accessibility of GCSE exam papers in braille and modified large print (MLP).

The project aimed to:

- Ascertain the frequency of problems in a large sample of braille and MLP GCSE Maths, Science and humanities exam papers.
- Identify the types of problem and whether they were more likely to arise as part of the modification or production process.

- Identify the types of papers within the subjects sampled in which the problems were most likely to occur (i.e. braille or MLP, particular subjects).
- Identify any other issues of concern for teachers relating to the provision of GCSE papers for candidates with vision impairment.
- Ascertain the extent to which QTVIs paid attention to the available exam formats when modifying curriculum materials for their pupils.

2. METHOD

The project comprised two stages: a survey of 94 educators and a quality assessment of 101 GCSE papers provided by four exam boards.

We designed a short written questionnaire which focused on the steps respondents take to prepare blind and partially sighted learners for GCSE examinations, and their views on the braille and MLP papers provided by exam boards. It was sent to local authority education VI services, and special schools and colleges for learners with VI, and was also available to download from the RNIB website.

The second part of the project was carried out in collaboration with the four main exam boards. Around 100 papers were randomly selected for inclusion. Biology, Chemistry, Physics, Combined Science, English Literature, English Language, Mathematics, History and Geography were all included. The papers were reviewed by three exam paper assessors, all of whom were QTVIs and subject specialists in science, mathematics and/or humanities. Their aim was to review the papers against the "Best practice guidance for the modification and production of examination papers for candidates with a visual impairment"[2]. This guidance is designed to ensure a consistent standard of provision between the exam boards and any variation from it would be considered a potential problem.

The assessors also rated each problem they found according to their perception of its likely impact on the candidate - either low, medium or high impact. Where the same problem recurred throughout a paper it was counted as only one problem in that paper's score. To provide an additional layer of scrutiny, an adult with a science degree who is an expert braille user offered a user's perspective on five of the braille papers.

3. KEY FINDINGS

The research project identified a number of difficulties with the exam system:

- 87 per cent of the QTVIs, teachers and teaching assistants (TA) surveyed had concerns about the provision of GCSE exam papers in accessible formats.
- Their concerns included the poor availability of practice papers, confusions in the ordering process for live papers, and the quality of diagrams, maps, and graphs in both braille and MLP.
- 75 per cent of those surveyed were aware of the 'Best practice guidance for the modification and production of examination papers for candidates with a visual impairment', nearly all of whom professed to follow it in the production of practice materials.
- The quality assessment of 101 papers indicated an average, per braille paper, of 2.3 problems which were likely to have a high impact on the candidate. The average per MLP paper was 1.75.
- Some of the individual papers assessed had a far higher incidence of problems than the averages reported here.
- Among the braille papers, science was of particular concern, with a high number of problems relating to layout and design.
- Among the MLP papers, mathematics was of particular concern, with layout and production problems predominating.
- The quality of tactile and MLP diagrams, maps and graphs were a particular cause for concern, with a lack of consistency across the AOs in how they were presented.

4. RECOMMENDATIONS

The report concluded with 10 recommendations for exam boards and educators to improve the current provision of accessible exam papers. These were discussed and agreed with the exam boards before the report was published.

1. The Best Practice Guidance should be reviewed and updated to ensure that it remains fit for purpose.
2. A proper system for recruiting and training modifiers should be established.
3. Producers should be required to demonstrate competence in producing MLP and braille papers in line with the Best Practice Guidance.
4. Producers should have effective systems in place for proof reading braille and MLP papers.
5. An independent quality assurance system should be established to check a sample of modified papers from all exam boards on an annual basis.
6. Options should be explored to achieve greater consistency in the way that graphics (and tactile diagrams in particular) are presented in modified papers.
7. Copies of past papers that have been modified should be made more readily available to schools and

colleges. This should include past braille papers available as electronic downloads.

8. QTVIs and TAs working with children and young people with vision impairment should receive more training in access arrangements to ensure they prepare their students appropriately.
9. Specific training should be provided for QTVIs and TAs in how to design and produce tactile diagrams.
10. There should be a review of the range of accessible formats which are available and consideration of how best to communicate information about these to educators.

RNIB has committed to leading on the implementation of the report's recommendations. Our plans include the following:

- Creating an online training resource for exam board staff, QTVIs and other educational professionals who are involved with modified exams. The intention is that this will operate at several levels, from a short self-study course for non-specialist educators through to a high level course which will be used to train exam modifiers and producers to apply the Best Practice Guidance to specific exam papers.
- Consulting with exam boards and educators on changes to the Best Practice Guidance which address specific areas of concern identified in the quality assessment of papers.
- Making a short YouTube film to promote better understanding of access arrangements and modified papers in schools. The completed film can be seen at www.rnib.org.uk/examaccess.
- Producing a new braille version of the science periodic table to test the idea of the exam boards sharing common resources in modified exams.

5. CONCLUSION

This research project has identified a number of areas of concern in exam provision in the UK which we are working to address. Exams play a vital role in education and any weaknesses may create unnecessary barriers to educational attainment. While exam systems in other countries may differ, we believe the central issue of ensuring that modified exam papers are produced to a consistently high standard is important to all educators of students with vision impairment.

REFERENCES

- [1] Flynn K, Keil S and Cobb R. *The quality of GCSE exam papers in braille and modified large print* RNIB 2016
- [2] Standing Committee for Examination Candidates with Special Requirements for Joint Council for Qualifications (JCQ) *General and vocational examinations best practice guidance for the modification and production of examination papers for candidates with a visual impairment*. JCQ 2012

Direct braille printing of standard documents made easy

Niels van Weele¹ and Björn Löfstedt²

¹INDEX Braille AB, International Sales Manager,
Gammelstad, Sweden
{nvw}@indexbraille.com

²INDEX Braille AB, Owner and CEO,
Gammelstad, Sweden
{bjorn}@indexbraille.com

ABSTRACT

Braille literacy is important for a successful development. A higher literacy rate will result in a higher number of successfully employed blind persons. [1]

We think that if braille printing is simplified, more printed braille documents can be made available, whenever and wherever this is needed. More materials available in braille and/or easier to print braille will also help to achieve a higher literacy rate among the blind and eventually lead to a higher number of successful blind persons at work, at school, and also in their private life. [2].

A few years ago, Index started an internal project called *Index-direct-Braille (idB)* to develop a built-in braille translator for its braille embossers. In the workshop, it will be shown how easy texts can be printed in braille from USB-stick, or from a tablet or mobile phone, even wirelessly. The development of *idB* has focused on user-friendliness, multi-platform support and web app functionality. It has been designed for easy handling of simple text documents and to any one; sighted, blind, braille knowledgeable, etc.

The workshop is meant for professionals but certainly also any other interested persons who want to know more about easy braille printing. We will present easy braille printing without difficulty and we hope to bring inspiration to show that more braille can be so easily implemented alongside of normal print.

1. INTRODUCTION

Literacy amongst blind persons is important for a successful development. It is necessary that blind persons need to be able to read braille to learn how to spell. Also, it is generally accepted that reading braille helps better memorizing of learning content. Reading braille from paper can give a better overview of learning content.

Copyright: © 2017 Niels van Weele et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

When printing braille, traditionally a software braille editor is used for translating texts from black print into braille. Whereas there still is a need for such braille editors for specialized texts, graphics, math, music notation, or multiple languages within one and the same document, there also is a great need for a simplified translator for simple text files that do not require lots of editing.

idB is a development from INDEX Braille AB that is simplifying such translation process, so texts can be converted into braille prints quickly and easily.

2. DETAILS OF PROJECT

The *idB* (Index-direct-Braille) is a standard and built-in feature inside INDEX V4 and current V5 embossers. Files with extensions doc, docx, rtf, txt and pdf are translated automatically into literary Grade 1 or Grade 2 braille inside the INDEX V5 embosser.

The text-to-braille translation process is using the embosser's own Linux computer in combination with LibLouis open source braille tables. Regular updates to the embossers make it possible to benefit from changes in certain braille tables or the addition of new languages. Momentarily over 140 languages are supported.

idB is free of charge. There is no software registration or license required.

3. BRAILLE PRINTING MADE EASY

3.1 Printing from USB-stick

Insert a USB-stick with stored standard Word-files into the braille embosser. If needed, verify print settings (e.g. paper size, language, single or double sided braille, etc.). Then the file to be printed must be selected (there is synthetic speech feedback as a guide for users).

The USB host port on the embosser is also used to perform embosser firmware updates or to back up and restore personalized embosser settings and layouts.

3.2 Printing wirelessly

All V5 embosser are equipped with dual band Wi-Fi support which follows standard communication protocols. This enables you to print wireless from your mainstream portable devices, such as smartphones, tablets, and of course laptops.



Figure 1. Circle with Wi-Fi and Bluetooth logo’s inside, and another circle with a picture of an Apple iPhone wirelessly connected to an INDEX braille embosser.

3.3 idB Web App

The wireless connection is supported by the *idB* Web App, which supports all major web browsers, including Chrome and FireFox. After connecting your mainstream mobile device with the same network, you can send documents from your mobile device directly to the braille embosser and monitor the braille embosser status remotely on your mobile device.

It is possible to preview a document on your mobile device before printing it.

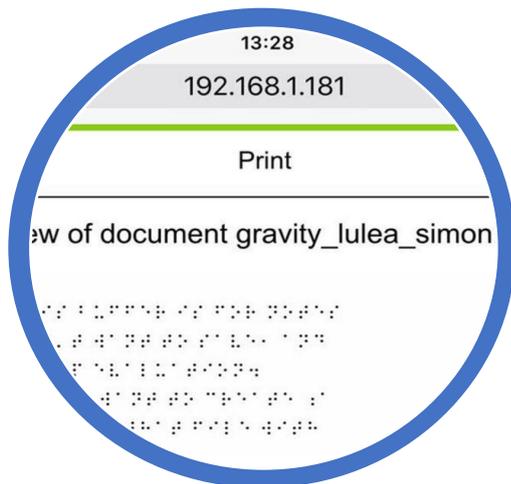


Figure 2. Circle with a view onto a mobile device that shows the *idB* Web App’s previewer.

The *idB* Web App is accessible with VoiceOver on Apple devices.

The built-in Wi-Fi capability also enables remote support to manufacturer or a local distributor, and downloading firmware updates for the braille embosser.

3.4 Future features

The *idB* project does not stop here, but will continue. From time to time, there will be available updates that can be downloaded and installed in the braille embosser.

After having realized the previewer inside the *idB* feature, it is planned to also offer some editing possibilities. Also, we are exploring our options regarding the Bluetooth capability of the braille embosser to let it connect with a number of other specific devices for the blind, in order to emboss documents from such devices in an easy way.



Figure 3. Picture of *idB* logo: a green square with letters idB.

4. CONCLUSIONS

idB makes it easier to print braille, allows even non-skilled sighted persons to print simple texts in braille, or even to print business cards with braille. It lowers the barrier for sighted persons, not necessarily having knowledge of braille, to print texts in braille. It helps professionals to quickly print braille materials on demand, without hassle. This will make the use of braille a little bit more acceptable.

During the workshop, it will also be shown that mainstream modern-day equipment such as tablets and smartphones can be used to generate prints in braille. Blind persons can use the accessible web app on e.g. Apple iPhone. The embosser has a text and braille labelled control panel and offer multi-lingual speech output when buttons are pressed.

Finally, for simple text files, there is no need any more to use a braille editor, which makes braille a little bit more affordable for both the blind and sighted persons.

REFERENCES

- [1] Ruby Ryles, PhD., M.Ed., USA “The Impact of Braille Reading Skills on Employment, Income, Education, and Reading Habits”, *Journal of Visual Impairment and Blindness*, 1996, AFB.
- [2] Björn Löfstedt, Owner and CEO, INDEX Braille AB, Sweden, 2016.

A teaching framework for the teaching of a second/foreign language (L2) to learners with visual impairment.

Aikaterini Athanasiadou,

Centre of Education and Rehabilitation for the Blind,
Department of Research, Scientific Studies and European Projects
Thessaloniki, Greece
hlios.relations@keat.gr
athkaterina@hotmail.com

ABSTRACT

The paper presents the fundamental difficulties met by teachers and visually impaired learners, while learning a second/foreign language.

The paper will examine issues pertaining to the conditions determining the L2 acquisition by BVI learners which they use non-visual means and are supported by hearing and touching, when they receive information in order to have access to learning.

The parameters to be taken in consideration by the teacher in order to reach a satisfactory result in the process of learning, will be presented, along with the foreign language motivation for BVI learners, the appropriate methodological approaches, the learning strategies involved, as well as the use of alternative techniques in L2 teaching.

Reference is to be made to the role of the teacher in the context of needs analysis for the specific target audience and the creation of appropriate guiding material.

Subsequently, ways of teaching the four L2 skills for the teaching of vocabulary, grammar and pronunciation are to be presented by providing concrete examples.

1. INTRODUCTION

In our days teaching a foreign language is included as a primary lesson in all National Curricula. Jespersen (1961) and Palmer (1926) have supported the opinion that we learn a language with the sense of hearing and not with our sight. Theoretically, foreign languages as a course may adapt in a way that corresponds to learners' needs and interests (Watkins 1995).

In practice, the content of lessons is greatly affected by the examination committees of the examination bodies or by the National Curricula and Syllabi. BVI persons present a strong inclination and talent in learning foreign languages due to their high hearing sensitivity and the exercise of their memory (Nicolíć, 1986).

2. PARAMETERS IN THE LEARNING PROCESS

2.1. Foreign Language Motivation

BVI persons learn a foreign language either because they wish to enhance their professional qualifications, to take part in examinations, to attend seminars/conferences abroad or for personal reasons, like their participation in exchanges and international meetings or/and travelling abroad.

Furthermore, the modern mode of foreign language teaching enhances the development of social skills and BVI learners' extroversion (Fawkes 1995a, Fowler 1989, Lee 1991).

2.2. Methodological approaches

Four factors define the success of BVI persons when they learn a foreign language and these pertain to enthusiasm, lack of timidity, excellent memory, dedication and good hearing (Worcester college, 1978).

These prerequisites are met with the application of the **communicative approach** which takes into consideration not only the structural aspects of language, but also the functional (Littlewood, 1971). As Nicolíć (1987) observes, BVI learners consider foreign language as an acquisition of the "unknown" that boosts their self-confidence.

In combination to the communicative approach the **Total Physical Response** (James Asher, 1977) seems to be appropriate. Its aim is to improve the oral speech of the learners and to develop their autonomy as foreign language speakers. At this point, emphasis is placed on grammar which is inductively taught and on the teaching of vocabulary by mobility activities.

2.3. The role of the teacher

The teacher shall know the particularities of his/her pupils, which are related to the time of manifestation of the visual impairment, the level of Braille reading and writing, the level of width and the degree of tactile texts comprehension.

Beyond that, he/she has to deal with the restricted relationships both with other pupils and the social context (Ramasut, 1989).

The difficulties, however, may be treated with the use of alternative techniques as the use of new technologies, while some others may be treated with the inventiveness of the teacher (Nikolic, 1987).

3. SKILLS IN L2 TEACHING

BVI learners need to be taught all four skills with the same weight (CEFR, Greek Edition, 2008).

3.1. Listening

According to Couper (1996) non-verbal methods of communication occupy a particularly important position in the teaching of meaning, while sight plays a prominent if not an exclusive role. It is estimated that the 80% of information pass through our sight (Best 1992).

It is important that BVI learners get to practice in the development of the skills of listening, namely in the development in their listening field of focus and in their listening ability to fill in the missing words or phrases that they have not fully heard (Mangold, 1982).

For the definition of objects it is required to be aware (sense of the existence of sound), to locate (determination of position) and to distinguish the sound, as well as to have an acute listening memory. The listening ability activities proposed by Bishop and Best (1992) may be helpful.

3.2. Speaking

The development of the sociolinguistic skill, namely the expression of the speaker with self-confidence and clarity, the comprehension of the communicative goal and the immediate reaction to the stimuli received by his/her interlocutors, is achieved to BVI learners with the teaching of the conventional speaking and discussing patterns, e.g. taking turns, looking at the person where speech is addressed, focusing on what is said and what is implied. Group work and dramatization encourage learners to reach this goal.

In a more advanced stage of speaking, the teacher needs to deal with the tendency to being superfluous, which is the greatest obstacle in learning a foreign language (Nicolíć, 1986).

3.3. Reading

In understanding written speech it is important to develop certain strategies a) learning, comprehension and practice in Braille in the foreign language and b) the prediction, the location of the general idea of the text and the activation of preexisting knowledge, within the aim of acquiring access to textual information, as well as the latter's integration in previous cognitive structures (Papadopoulos, 2005:18). For the achievement of these aims, both the extensive use of digitalized listening material and of Braille material is needed. The design of activities equally plays an important role: fill-in the gaps activities, web browsing and searching, prediction or comprehension questions, summary writing, multiple choice questions, questions of "true/false" etc.

3.4. Writing

In written speech the student is called to respond, with success, to a given communicative situation. This seems easy for BVI learners, but due to their restricted access to a great number of texts, they find it hard to acquire the required level of writing (Arter 1996).

Efficient writing activities, accordingly adapted, are the prepared speeches, the questionnaires, the role plays, dramatization, the narration of personal experiences, the report about or the review of a book, the description of an incident, the answer to a letter, or a job application etc.

4. CONCLUSIONS

Efficient foreign language learning from a BVI person requires a special methodological approach, as well as educational techniques, adapted educational material and, mainly, an inspired and sensitized teacher.

REFERENCES

- [1] Best, A. (1992). *Teaching children with visual impairments*, Open University Press,
- [2] Nikolic, T. (1986) *Teaching a foreign language in schools for blind and visually impaired children in school*, Language Teaching, p.218-213
- [3] Nikolic, T., *Teaching a foreign language in schools for blind and visually impaired children*, in Journal of Visually impairment and blindness, Febr. 1987, p. 62
- [4] Papadopoulos, K., (2005). *Blindness and Reading. Reading with touch. Thessaloniki, Ziti editions*
- [5] Council of Europe (2008). *The common European Framework of Reference for Languages*. Thessaloniki: Centre for the Greek Language
- [6] Harmer, J., *The practice of English language teaching*, (third edition), Longman, 2001
- [7] Mason, H. & McCall, S. (1997). *Children and Youngsters with visual problems, the access to education*. Greek Translation with the scientific supervision of A. Zoniou-Sideri, E. Deropoulou – Derou, Athens: Greek Letters (2005)

Improving The Quality Of Life For Individuals With Multiple Disability And Visual Impairment By Reaching Out To Other Caretakers

An Verellen and Claudine Martens

Centrum Ganspoel vzw, Ganspoel 2, 3040 Huldenberg, Belgium
claudine.martens@ganspoel.be

ABSTRACT

People with a multiple disability and visual impairment (MDVI), who are already, concerning their multiple disability, being supported by non specific organisations (such as schools for special education, day-care centres, institutions for persons with intellectual disabilities,...), are just like any other person entitled to receive specific support concerning their visual impairment. Centrum Ganspoel, based on an important legacy of care for this type of population, offers these non-specific caretakers specialized support and expertise.

The target group consists of children, youngsters and adults, all with multiple disabilities in combination with a visual impairment. Whether it's an ophthalmological problem or CVI, as well as whether it's a congenital or an acquired disability.

In the presentation we offer an overview of the different types of support related questions we receive and the issues we treat. The questions are very diverse. They are about various domains of life and always aim to improve the quality of life of the individual with MDVI. Different specialists reach out to advice locally other – non specific- caretakers or relatives : occupational therapists, speech therapists, pedagogues, educators,...

To finalize the presentation we make an overview of the benefits and the limitations of this approach of giving advice.

INTRODUCTION

Centrum Ganspoel is an institution located in Huldenberg, near Brussels. Ganspoel is an institution specialized in care and support for children, youngsters and adults with visual impairments and multiple disabilities. This care is carried out by multidisciplinary teams.

A specific service is called 'Outreach' and that is exactly what it is we do : reaching out to other caretakers when they need advice, counseling or guidelines concerning the support of people with MDVI.

TARGET GROUP AND ISSUES

Persons with MDVI often stay in a non specific institution for people with a disability. These institutions have little or no experience with the support of people with MDVI. As a consequence these caregivers have a lot of issues. These professionals need a lot of concrete guidelines about the best way to support persons with MDVI. And that is what 'Outreach' is all about. The outreaching specialists go out on location and observe the situation in order to give specific answers to all questions. By offering this outreach service our aim is to improve basically the quality of life of the individual with MDVI.

The issues people ask us to alleviate are very divers, and touch various domains of life. First there are general issues. Caretakers often wonder what it is like to live with low vision or blindness. We also offer a lot of general and very practical guidelines about the support of people with MDVI with some basic information such as how to make them find a free seat around a table, or how the offered assistance to a person with MDVI differs whether the needed help is about walking around inside the house or in the outside world.

A lot of issues concern the fields of mobility and orientation. When someone enters a new environment or when the visual impairment gets worse, caretakers notice fear and passivity in the behaviour of the persons with MDVI. Here specialized occupational therapists are the right people to give the best advice. Another group of questions relate to the use of low vision devices. Other professional care takers seek our advice about the design and possible adjustments of buildings and premises for people with MDVI. Also psychological questions arise. How to support people with MDVI in coping with anxiety, grief, and resistance when confronted with visual problems or when the visual impairment is getting worse.

BENEFITS AND LIMITATIONS

People with MDVI can go to school locally or stay in a setting closer to home. This has definitely advantages for a better social inclusion: they are closer to their own trusted network.

It is also positive that in the demanding institutions the local professional staff are provided with knowledge and skills so that they can support other clients who are visually impaired. Thus the group of professionals taking care of people with MDVI gets broader and this fact leads to better exchange of knowledge and good practice.

Of course, the 'outreach' program has limitations too. Because the outreach sessions are taking place at the location of the demanding caretakers, the available time to spend is limited.

Next to this, because most issues where help is needed, cover the life of just one individual specifically, the preparation of each session is quite time consuming for the outreaching professionals.

Another limitation is that it is not possible to demonstrate all possible devices on location.

As a further consequence of being out on location, there is less opportunity for sharing in depth knowledge.

CONCLUSION

Despite these limitations, the 'outreach' program can definitely perform as a rich service to finally improve the quality of life of people with MDVI, and this through the assistance of professional care takers, based on an in-depth knowledge experienced on –site support.

Prevalence of psychiatric and/or additional disorders in adults who are visually impaired

Marit van Buijsen¹, April Boessen¹, Uta Roentgen², Peter Verstraten¹ and Luc de Witte³

¹Robert Coppes Foundation, Expertise, Innovation and Knowledge (EIK),
Vught, the Netherlands
{mvbuijsen, aboessen, pverstraten}@robertcoppes.nl

²Zuyd University of Applied Sciences, Centre of Expertise for Innovative Care and Technology (EIZT),
Heerlen, the Netherlands
{uta.roentgen}@zuyd.nl

³University of Sheffield, Centre for Assistive Technology and Connected Healthcare (CATCH)
Sheffield, UK
{l.p.dewitte}@sheffield.ac.uk

ABSTRACT

In the Netherlands it is unknown how many adults face a combination of visual impairment with psychiatric and/or additional disorders (e.g. physical, cognitive and/or mild intellectual) (VIXPI), and if and where they receive care. A total of 18 different knowledge institutes, public authorities and related organizations were approached to collect data on numbers of people with VIXPI and in which health sectors they receive care. A survey on the prevalence of people with VIXPI was executed among all Dutch care organizations in question. Except for the Robert Coppes Foundation, none of the knowledge institutes, public authorities and related organizations could provide exact numbers about the prevalence of people with VIXPI. A total of 80,7% of the 93 organizations in the survey which responded, provided care to clients with a visual impairment, from these organizations, 86,7% reported that these clients also have additional disorders. The results of this study show that aggregated data on the target group is unavailable. Based on this study a careful estimate can be made that 2300 adults who are visually impaired have one or more additional disorder. The results show that people with VIXPI do not only receive care within facilities specialized in the care for people who are visually impaired.

1. INTRODUCTION

In the Netherlands approximately 300.000 or more people have a visual impairment. It is estimated that this number will increase to 354.000 people in 2020 [1]. For people aged 65 years and above this increase will even be exponential [2]. A small number of people who receive care from institutions for visually impaired people are adults who are visually impaired and have psychiatric and/or additional disorders (e.g. physical, cognitive and/or mild intellectual) (people with VIXPI). Clinical experience shows that these people usually need continuous specialist care, as the impact of the combination of different

impairments is higher than the sum of its parts, as an exponential increase of impairments leads to an exponential decrease of possibilities to compensate. However, it is unknown how many people face this combination of impairments and where they receive care. It is expected that a high number receive care in one of the three main care facilities for people with a visual impairment, Royal Dutch Visio, Bartiméus or the Robert Coppes Foundation. Another possibility is that they receive care in other care facilities specialized in psychiatric or other disorders, such as mental health facilities. To gain insight into the impact of the combination of impairments on daily live, it is important to ascertain the prevalence of this target group. Therefore, the following research questions were formulated: How many adults who are visually impaired also have psychiatric and/or additional disorders? Where do they receive care?

2. METHOD

A total of 18 different knowledge institutes, public authorities and related organizations were approached: Royal Dutch Visio, Bartiméus, Robert Coppes Foundation, Centre for indications (CIZ), Centre for Consultation and Expertise (CCE), Eye Association, Vektis, MEE, Association of Dutch Municipalities (VNG), Association for Disability Care in the Netherlands (VGN), National Institute for Public Health and the Environment, Dutch Health Insurers, Actiz, Statistics Netherlands (CBS), The Health Care Inspectorate (IGZ), Netherlands Institute for Health Services Research (NIVEL), Dutch Association of Mental Health and Addiction Care, Employee Insurance Agency (UWV). All were asked to provide data on the prevalence of people with VIXPI and the kind of care they receive.

Furthermore, a survey about the prevalence of people with VIXPI was executed among 621 organizations which are a member of the Dutch Association for Disability Care (VGN) (N=163), Dutch Association of Mental Health and Addiction Care (GGZ NL) (N=93) and Actiz (N=395). All organizations were approached by e-mail and asked to fill in an online survey within five weeks.

Copyright: © 2017 Marit van Buijsen et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

3. RESULTS

3.1 Knowledge Institutes, public authorities and related organizations

Except for the Robert Coppes Foundation, none of the knowledge institutes, public authorities and related organizations approached could provide exact numbers about the prevalence of people with VixPI. The Robert Coppes Foundation is an organization whose target group represents the one in this study. So all 256 clients (state October 1st, 2016) could be counted. Royal Dutch Visio and Bartiméus acknowledged that they provide care to people with VixPI, but could not provide exact numbers. The other knowledge institutes, public authorities and related organizations could not provide any information about the prevalence of people with VixPI in the Netherlands. Some organizations (such as RIVM, CBS) could provide information about the number of adults with a visual impairment or could refer to other organizations.

3.2 Survey

A total of 621 surveys were sent of which a 136 were completed. After eliminating duplicates and forms without a name, 93 surveys could be used to analyze the data, corresponding a response rate of 15%. In 75 of the 93 completed surveys (80,7%) organizations reported that they provide care to clients with a visual impairment.

In 65 of the 75 surveys of organizations that reported providing care to clients with a visual impairment they also reported that these clients had psychiatric and/or additional disorders (86,7%). Exact numbers were given by 10 organizations and ranged from 1 to 459 (894 in total), 18 organizations provided no estimate, 11 organizations reported 0 to 10 clients with a visual impairment and psychiatric and/or additional disorders, 7 organizations had 10 to 20 clients with VixPI, 6 organizations 20 to 40 clients, 6 organizations 60 to 80 clients, 1 organization 80 to 100 clients and 6 organizations 100 clients or more. By adding these numbers a careful approximation can be made that about 2124 to 2564 adults who are visually impaired have a psychiatric and/or additional disorders.

Five organizations reported that clients who are visually impaired did not have a psychiatric and/or additional disorder (n=5). Psychiatric disorders were reported by 33 organizations. Other additional disorder were also reported, such as physical (n=45), cognitive (n=40), or intellectual (n=28). Some organizations did not provide any information about additional disorders in the survey (n=5). A total of 51 organizations reported that the clients had multiple additional disorders and 11 organizations reported that the clients had one additional disorder.

4. DISCUSSION AND CONCLUSION

Some notifications need to be made about this study. The survey only addressed people receiving care at a care

organization and did not take into account people who are living at home independently. The latter could belong to the target group, but do not receive the care they need or do not need care. Therefore, the number of people with VixPI could be higher than ascertained in this study. Furthermore, 6 completed surveys were included despite missing information on the organization's name, which might have led to duplication. However, the disadvantage of missing information was weighted higher, so these forms were included. The survey mainly seems to be completed by organizations which provide care to people who are visually impaired. Some organizations responded that they had chosen not to complete the survey because they did not recognize this target group, they could not provide information about the target group or had no overview of it and gathering this information would take too much time. This means that the relative high percentage of clients with a visual impairment within the different care organizations is probably not representative for all Dutch care organizations in question. However, the additional information received through the survey shows how often people have psychiatric and/or additional disorders besides a visual impairment. This underlines the urge of more knowledge about the guidance of people with VixPI and possibilities to share it, because this target group is scattered among the different health sectors. An interesting subject for future research would be to conduct an inventory within the organizations which provide care to people with VixPI to verify if these people do belong to the target group and which differences or similarities can be described in the guidance and approach of these people.

The results of this study show that no aggregated data is available on the prevalence of people with VixPI. Based on this study a careful estimate can be made that approximately 2300 adults who are visually impaired have a psychiatric and/or additional disorder, but above notifications need to be taken into account for this number. The target group receives care in different health care sectors (disability care, mental health and nursing care), not only within care facilities specialized in the care for people with a visual impairment.

Acknowledgments

This study was financially supported by Bartiméus.

REFERENCES

- [1] Keunen, J.E.E., Verezen, C.A., Imhof, S.M., Van Rens, G.H.M.B., Asselbergs, M.B., & Limburg, J.J. (2011). Toename in de vraag naar oogzorg in Nederland 2010-2020. *Nederlands Tijdschrift voor Geneeskunde*; 155:A3461
- [2] Limburg, H. (2007). *Epidemiologie van visuele beperkingen en een demografische verkenning*. Grootebroek: Health Information Services.

What can you expect from the European Directive on accessible websites?

Bart Simons

AnySurfer
Brussels, Belgium
bart@anysurfer.be

ABSTRACT

Public sector bodies must make their websites and mobile applications accessible. We have been hoping to obtain this for many years but there was never a legal obligation. This changed on 22 December 2016 when the European directive on the accessibility of the websites and mobile applications of public sector bodies [1] entered into force.

As all legislations, this directive is a compromise. This paper clarifies what European citizens with a disability may expect from this directive, how they can help to implement it and what the possibilities are when accessibility issues still occur.

1. INTRODUCTION

People with disabilities need to be included in the digital society. While everybody agrees with this, government websites remained mostly inaccessible for people with disabilities. Many action plans were written and promises were made but year after year no real progress in web accessibility could be monitored. This is why the European Disability Forum and Blind Union insisted to have a legal basis. The European Blind Union undertook significant lobbying efforts to improve the initial proposal and after four years of political discussions, the European Parliament and the European Council published in December 2016 a directive [1] that requires public sector body websites to be accessible.

2. TRANSPOSITION

A European directive sets minimum rules that must be included in the national legislation of all member states. This transposition must be completed on 22 September 2018. Many member states already have some kind of obligation for public sector body websites to be accessible. They must verify that it is at least what the EU Directive asks. Other member states don't have any legislation yet so they must create one by this date.

What can you do? Find out who in your national government is responsible for the transposition and try to have your say in the process. Although the directive encourages member states to consult stakeholders, you might need to invite yourself to the table.

Why? The directive sets minimum requirements and contains a lot of exceptions. Try to encourage your government to extend the scope or drop certain exceptions.

3. RAISING AWARENESS

Member States should take the necessary measures to raise awareness about the accessibility of websites and mobile applications and promote web training programs for relevant stakeholders and in particular staff responsible for the accessibility of websites or mobile applications.

What can you do? Remind your government of this very important activity. The directive will only be effective if people making websites and apps start to be trained on accessibility as of today. E.g. on 22/09/2020 all websites should be accessible. This means that if a web page that you publish today will still exist on this date, it will have to be accessible. It makes more sense to do this today than hoping that magically someone will take care of everything in September 2020. The deadlines in the directive are realistic but not if people wait another three years. So spreading the word about this directive and accessibility training is key to the success of the implementation. We have to make sure that people can't use the excuse that they did not know that this obligation was under way.

4. MONITORING AND REPORTING

By 23 September 2018 member states have to designate a body to perform the monitoring and reporting functions that are described in the directive.

What can you do? Think about who could best take care of this in your country and communicate your suggestion to the people in charge.

5. ENFORCEMENT

The directive contains no sanctions for public sector bodies that do not comply. If a website or app does not fulfil the accessibility criteria, the only possibility is to send a complaint. Each website should have an accessibility statement where a way should be provided to send feedback. If no adequate response is received, there should be an enforcement procedure such as contacting an ombudsman. It will be essential that this is a strong procedure dealt with by well-informed people who have the power to take action.

What can you do? By 23 September 2018, Member States shall inform the Commission of the body responsible for the enforcement of this Directive. Think about who would be best placed in your country to deal with this and communicate this suggestion to the people in charge.

6. SPEAK ABOUT IT

The disability community has to be well-informed about this directive: the text is available in all official languages.

Inform your members about it and prepare them to send in complaints if websites fail to comply. This is the only way we can put pressure.

7. IN THE MEANTIME AT THE COMMISSION

The European Commission still has to establish:

- the technical specifications for the accessibility of mobile applications,
- a model accessibility statement
- a methodology for monitoring the conformity of websites and mobile applications with the accessibility requirements
- the arrangements for reporting by Member States to the Commission.

The deadline for those items is 22 December 2018. The Commission is assisted by a Web Accessibility Directive Expert Group, which is composed of member state representatives.

What can you do? Check who represents your country in this expert group [2], meet this person to find out whether their position is in line with what we need as a disability community.

8. CONCLUSION

The entering into force of this directive is an important step to ensure that in the future public sector body websites and apps are accessible for people with disabilities. However, we (individuals and organisations) have to use this tool effectively to obtain a real success.

REFERENCES

- [1] European directive on the accessibility of the websites and mobile applications, <http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32016L2102>
- [2] Membership list and meeting minutes of the Web Accessibility Directive Expert Group <http://ec.europa.eu/transparency/regexpert/index.cfm?do=groupDetail.groupDetail&groupID=3475>

Mental Management: Contribution To Improving The Quality Of Life In Support Of Occupational Therapy

Florence Terrier, Stephanie Demartin
Euvre Fédérale Les Amis des Aveugles et Malvoyants,
Ghlin, Belgium
f.terrier@amisdesaveugles.org
s.demartin@amisdesaveugles.org

ABSTRACT

As a rehabilitation therapy, the occupational therapy in low-vision aims to promote the autonomy of the visually impaired and to compensate the deficit by encouraging the participation of the person in activities that are important to him/her, thus improving the quality of life.

The possible rehabilitative approaches focus on personal factors (teaching cognitive strategies), modification of activity (the use of audio books rather than paper) or the adaptation of the environment (ergonomics, adaptation of lighting or use of an auxiliary means such as an optical help).

Whatever the approach, the effects of visual loss on sensory and cognitive spheres must be taken into account. So, occupational therapists have integrate the mental management in their specialized practices of accompanying the visually impaired people. Based on cognitive psychology, the tool explores, describes and studies the mental processes related to learning situations.

Through a educational dialogue, the purpose is to develop the metacognition of the person raising awareness on its mental habits and effective cognitive strategies in order to broaden his/her skills and then transfer them to other learning strategies. Thus, the discovery of mental processes helps to integrate new information and habits, and even to adapt cognitive functioning in order to compensate for the loss.

After a preliminary assessment of mental habits (how did I function in learning a device?), occupational therapists help the person to understand the evocations that they use in a privileged way (what can I rely on in my learning process), and suggest new perceptual modalities that enable him/her to access information (e.g. kinesthetic modality via tactile tools) and to evoke or represent the external world.

During our presentation, we will expose the key concepts of the tool and illustrate its use in specialized practices for the visually impaired.

1. INTRODUCTION

New materials, such as information and communication technology (ICT), promote the autonomy and quality of life of the visually impaired via smartphones or tablets, for example.

However, all these tools mainly make use of the visual modality, without tactile reference generally used in most devices specifically created for this audience (marking, relief ...)

How, then, facilitate the learning of this type of tool? Many practical fact sheets exist or have been created by specialized services. But we noted that the support provided on the basis of these documents was not always sufficient or was even ineffective. Why? How to reach the learner in his/her own functioning, help him/her to become aware of it? How can all these strategies be used to facilitate the learning process and transfer these skills to other learning abilities and areas?

Based on these findings and in the context of the evolution of our practice, occupational therapists have been trained in mental management. Specific sessions are then set up to discuss these educational concepts with the visually impaired, by fostering metacognition, and to highlight the paths for intervention.

Finally, the implementation of what has been deducted from these sessions allows us to optimize our care in various fields.

2. THEORETICAL CONTEXT AND CONCEPTUAL FRAMEWORK

2.1. Occupational Therapy : A Rehabilitation Therapy

2.1.1. Generality

According to the Belgian Federation of Occupational Therapy, "The occupational therapist is the paramedic who accompanies people with physical, psychological and / or social disorder to enable them to acquire, recover or maintain optimal functioning in their life, their professional activities or the sphere of their leisure, using concrete activities, relating to them and considering their potentialities and the constraints of their environment. "

Occupational therapy therefore consists of a person-oriented accompaniment, taking into account all the aspects specific to that person.

2.1.2. Readaptative approaches in low vision

The visually impaired must indeed learn again, to meet their practical needs to carry out their usual activities.

To do this, the occupational therapist will evaluate the skills specific to the tasks performed by the person. He then intervenes at different levels: advice on adapting the daily environment (lighting, contrasts, enlargements...); selection and adaptation of auxiliary means (optical and electronic magnifying glasses, reading devices, filters...); he will also teach him/her how to use the tools (technical aids, smartphones...) or compensatory

techniques in various activities of daily life (cooking, cleaning ...)

2.2. Mental management: a practice based on learning

2.2.1. General information

As the outcome of the work of Antoine de la Garanderie, mental management education has been established to provide each learner with the means to discover and use effectively his cognitive skills. Developed initially within a school learning framework, this practice can be transferred to other areas of intervention, including occupational therapy.

2.2.2. Theoretical notions

The Educational Dialogue (ED), a specific conversation about mental management, will allow the learner to discover his or her individual functioning through exercises involving different perceptions (auditory, visual, tactile and kinesthetic). This dialogue will focus on "how" rather than "why". It will enable the beneficiary to carry out a metacognition of his learning strategies.

Different concepts, specific to the mental management, will be explored through this ED: perception; evocation; project implementation; mental gestures (attention, memorization, understanding, reflection and creative imagination).

3. METHODS AND MATERIALS

In order to realize the educational dialogue, which is the gateway to mental management, various exercises have been chosen for their adaptability to visual impairment (tactile puzzle or enlarged and contrasted, open questions...) while respecting the multimodality of perceptions. They allow us to highlight the evocative palette of the learner.

Our work was then oriented towards the visually impaired (blind or visual impaired people) who have also varying introspection capabilities. An interview based on the ED was carried out with the latter.

Following this, we have been able to highlight various data related to the learning of the people assessed (need of links with practical situations already experienced by the learner, difficulty in the appropriate mode of perception...) We also allowed these learners to become aware of several parameters related to their mental functioning

The second step was to transmit this data collection to the members of the multidisciplinary team, taking part in the care of the beneficiary, through coordination meetings. In addition to sharing the work already done with this person, work tracks are then given to refine the method used and optimize the work of each collaborator. We've discuss then how to transfer these findings to other fields of practice (activity of daily life, use of a new tool, mobility...)

The support for this learning has then been adapted if necessary, according to the results of the ED (see below for example).

4. RESULTS

In practice, we have determined, following the ED with a patient, a need to work in a linear manner, with frequent feedback, use of situations experienced and a need for tactile perceptions. These constraints are then applicable whatever the learning to be carried out: cooking classes, typing ... We will propose to him to split the session into more objectives than usually recommended, and to experiment the wrong action before letting him try the right way to execute the action.

For another beneficiary, the approach made possible to highlight a need for a multisensory perception: information given in a hearing (auditory by recording the sessions) and tactile (either by writing Braille instructions, or by using 3D representation of the screen of a smartphone thanks to magnetic material).

5. DISCUSSION AND OUTLOOK

Moreover, a modification in the way our dialogue is carried out seems indispensable to us (exercises not sufficiently adapted, difficulty to direct the dialogue, introspection towards the evocation, ...)

But we have no doubt about the relevance of using this approach to make learning as appropriate and sustainable as possible.

6. CONCLUSION

The work of the occupational therapist cannot be reduced to the establishment of compensations (material or environmental). We can also act as a learning facilitator to enable the visually impaired to become aware of their skills in order to learn in an appropriate manner and thus improve their quality of life.

REFERENCES

- [1] C. Evano, *La gestion mentale*. Nathan pédagogie, 1999.
- [2] A. de la Garanderie, *Réussir, ça s'apprend*. Bayard, 2013
- [3] V. Mattews, PP Delvaux, « Gestion mentale », Formation niveaux 1 et 2, If Belgique, 2006-2007.
- [4] A. Bianic-Rolland, « La pédagogie des gestes mentaux : un apport à notre pratique en ergothérapie », *ergothérapies*, n°55, pp 43-49, 2014.

IPAD Applications For Children With Visual And Multiple Impairment – The EDA PLAY Apps

Alice Pexiederová¹, Martina Vaňkátová², Markéta Skalická³

Early Intervention, EDA, Prague, Czech Republic

¹alice.pexiederova@eda.cz, ²martina.vankatova@eda.cz, ³marketa.skalicka@eda.cz

ABSTRACT

Since 2013 the Early Intervention Center EDA has developed four applications: EDA PLAY, EDA PLAY TOBY, EDA PLAY PAULI and EDA PLAY ELIS (<http://www.edaplay.com/>).

The applications are designed for vision training for children with visual disorders and visual impairment. All the pictures are rendered against a black background, in striking colours, and understandable shapes. Children can focus their attention on the picture and watch the change after touching the display.

The applications offer specific tasks, various levels of difficulty and choice from several options. Children control the application by a simple touch of the screen, following a trail with a finger etc., so children with multiple impairments are motivated to train their fine motor skills.

The applications contain a Skills section which records the activity of the child with the application. Thus, the parents and therapists can monitor the progress of the child's skill development over time.

After the successful introduction of the first application (EDA PLAY), the feedback and actual needs of our client families and their children led us to design applications for children with more severe impairments or apps with a storyline (EDA PLAY TOBY, EDA PLAY PAULI and EDA PLAY ELIS).

1. INTRODUCTION

Early Intervention Center EDA supports families of children with special needs to cope with difficult life situations. We provide services to families with young children (0 – 7 years) with visual and multiple impairments, mostly in their own home.

In recent years the EDA Center developed several new activities. Next to developing new tools – the EDA PLAY apps – the center initiated the first national crisis help line for families or carers of children with impairments.

Since the introduction in 2013 of the EDA PLAY application, that we presented at the ICEVI-Conference in Istanbul, Turkey that year, we developed three new applications: EDA PLAY PAULI (2016), EDA PLAY TOBY (2016) and EDA PLAY ELIS (2017); see Figure 1.



Copyright: © 2017 Alice Pexiederová et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Figure 1. The four EDA PLAY applications

1.1 Why are the EDA PLAY applications so special?

They were developed in cooperation with low vision and special needs experts from our organization EDA – a provider of early intervention in families caring for children with visual and multiple impairments. They were tailor-made for children with special needs, with visual impairment and motor skills disorders. They help children to improve their vision and fine motor skills, they also support their concentration and eye-hand coordination.

1.2 Why do children like the EDA PLAY applications?

Because they have the right kind of pictures and the right tasks: pictures are simple so that children easily understand what they see. They are big enough to be visible without making any extra effort. All pictures are in bright colours and make a perfect contrast on the black background.

The tasks come from everyday life, so children easily get their meaning. They are invited to play by another child, who explains the task in a very comprehensible way. And they are always rewarded by some funny sound after completing the task.

But parents like EDA PLAY too – they can easily customize the game so that it fits perfectly to their children – they can switch off the sounds children dislike or the tasks they don't want to play.

The applications contain a Skills section which records the activities of the child with the application. Thus, parents and therapists can monitor the progress of the child's skill development over time.

All applications include a simulator of the most common visual impairments: blurred vision, nystagmus, hemianopia, photophobia, diplopia, tunnel vision, scotomas, coloboma, so parents can try to see the world through the eyes of their visually impaired children.

2. EDA PLAY

The app EDA PLAY is designed for the training of vision and fine motor skills. Both the tasks and the visual levels go from very easy to rather complex.

To complete the task at the easiest level the child needs just to tap on any part of the display.

The second level brings more difficult tasks: colour and shape discrimination and recognition of concrete objects.

To complete the third level, children have to be more precise with their hand movements, e.g. to follow the path of an airplane or a train.

And in the most difficult task level they have to draw lines like curves and zig zag lines, add details (like wheels to a car) or connect objects with the same shape or colour.

Each level of EDA PLAY can be played with 4 levels of illustrations, as shown in Figure 2:

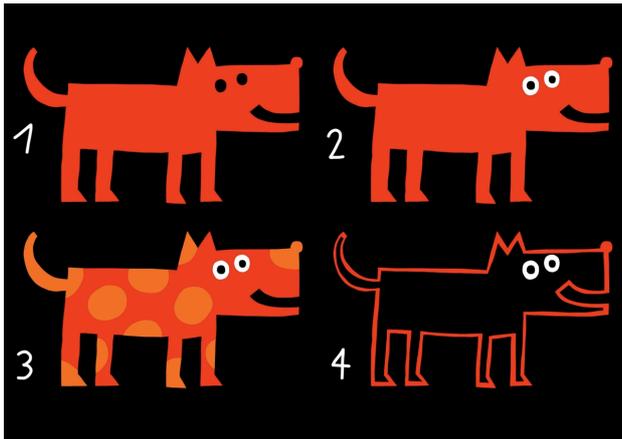


Figure 2. The four types of EDA PLAY illustrations

On the first level, you will always find the full shape of the pictures, with no details.

The second level shows full shapes with several details.

The third level contains pictures with an emphasis on several details, often in two or more colours.

And on the fourth level, the pictures are only visible in outline.

3. TOBY, PAULI AND ELIS

After the successful introduction of the first application (EDA PLAY), the feedback and actual needs of our client families and their children led us to design applications for children with more severe impairments or apps with a storyline (EDA PLAY TOBY, EDA PLAY PAULI and EDA PLAY ELIS). They are inspired by actual children with special needs.

As a fifteen-months old boy Toby was recommended to wear both an eye patch and spectacles, due to his complex visual disorder. Toby and his family are clients of our organization EDA. It was hard to catch his visual attention and offer him sufficient stimulation according to his developmental stage and visual skills.

Pauli is a seventeen-year old girl. The spasticity of her muscles doesn't allow her to fully control her movements. She was trying to complete the tasks in the first EDA PLAY with great excitement, but we understood that she would prefer some games that do not require precise touching of the display. The "British Blue" cat Lilly and the Grandma who has apple trees in her garden

that we meet in the game both come from Pauli's real life.



Figure 3: The real Elis

Elis is an eleven year old girl with central visual impairment (CVI); see Figure 3. Her eyes are in order, yet they fail to cooperate with the centre of vision. To help her understand what she's looking at, she needs to see and perceive the thing many times repetitively, with a sufficient explanation and a description of what she's looking at. Her brain doesn't cooperate with the body in the way that it should; this causes limitations to both her fine and gross motor skills.

3.1 EDA PLAY TOBY: watching the action, a simple touch on the screen

Training of visual attention: The application consists of two parts: the first stage "watch what's happening" is suitable for children even younger than six months. The second part, with touching tasks (see Figure 4), is suitable for children who are beginning to be interested in specific pictures, i.e. around one year old.



Figure 4. The real Toby playing EDA PLAY TOBY

Training of fine motor skills: The second stage of the game – "touch and make something happen" is suitable both for children with visual disorders and for children with severe fine and gross motor skills impairments. The children can touch the screen anywhere or just slap it – and they are rewarded by an interesting sound of a musical instrument or an animal. The game is very simple, designed to be handled by children at various levels of psychomotor development.

3.2 EDA PLAY PAULI: a story of a single day, a simple touch on the screen

In the game we experience a day in the life of a girl named Pauli (see Figure 5). The child progresses through the game with a simple touch on the screen. The plot of the game is so interesting that even children with severe hand mobility limitations try to engage in the game. The application can be played with by children at the stage when they start discovering the sequence of a plot and when they begin to understand simple stories.

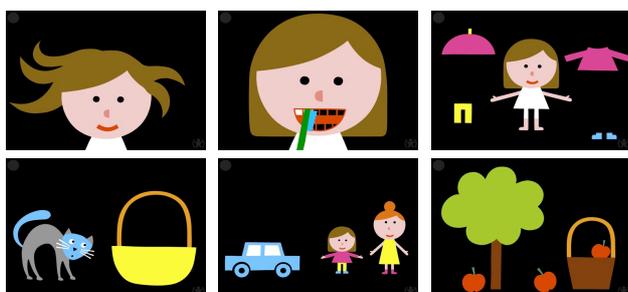


Figure 5. A day in the life of Pauli

Pauli – the real girl who inspired the development of this app – has only limited motor skills. But still she can be surprised by many things that happen when she touches the screen!

3.3 EDA PLAY ELIS: a surprise behind the door, a simple touch on the screen

A simple, but highly motivating game. Children with visual and multiple disorders can play the game, understand the tasks and enjoy the app.

By simply touching the screen, the children will find out what's hiding behind the door in the EDA PLAY ELIS app. An interesting sound when opening the door brings a moment of surprise which in combination with the animation on the screen, captivates the visual attention.

Each series of tasks begins with an invitation to open a door behind which something interesting is taking place. The repeated moment of surprise drives the motivation to follow the plot. Through repetition, children with CVI learn to recognize shown activities they know from daily life, such as doing the laundry or baking a cake.

4. SOME TIPS ON USING THE EDA PLAY APPS IN REAL LIFE

It is very important for children with visual impairment to grasp the meaning when looking at a 2D depiction of reality, thus developing their understanding of pictures. It is therefore important to work with real-life situations. We can take the app with us to the washing machine when we're doing the laundry and compare the real washing machine and coloured laundry items with its illustration. Or we can take a photo of the cake at a birthday party and then examine what the cake looks like,

what is identical and what is different – and what makes the cake distinctive. When blending the smoothie in the game, we can use our own blender and fruit and talk about what goes into the smoothie and what we feel like drinking (see Figure 6-7). We can continue with “real” toys inspired by pictures from the app.: „Put the cat into the basket!“ We can even turn it into a puppet show. There are many situations based on real-life in the apps. It would be a waste not to use them.



Figure 6. Children enjoying making a smoothie



Figure 7. Making a smoothie in EDA PLAY ELIS

Together with Elis, a girl in the app, we discover situations and people around us. One by one, we get to know her other family members and her friend through their typical features and activities. Her friend David wears glasses, Grandpa has a beard - we will later shave this off, but he will keep the wrinkles on his forehead and his white eyebrows and short hair. Mummy wears her hair at shoulder length and she smiles. This can be used to train children with CVI - central visual impairment - to learn the typical features of the various people around them.

5. CONCLUSION

Though the original EDA PLAY app was a big success, seeing it being used by children with visual and multiple impairments provided us with valuable feedback on how to improve on it. Taking individual cases as a starting point we succeeded in making the new applications more interesting and rewarding for children with various special problems like CVI or impaired motor skills. Our main goal in developing these applications is to use modern devices in a way that is not distracting children from reality, but is introducing them to common objects and life situations instead.

Important note – Until recently all our apps ran only on iPads, but since April 2017 EDA PLAY TOBY is available for Android devices too.

THE SUCCESS OF A NEW CONFERENCE ORGANIZATION METHODOLOGY

Elena Gastón

ONCE. National Organization of the Spanish Blind
Resource Center of Madrid

ABSTRACT

Last November 2016, the National Organization of the Spanish Blind (ONCE) organized a meeting of professionals of Early Intervention of children with visual impairments.

We want to share this experience, because it was organized with a different format to other Conferences and resulted very inspiring, dynamic and created a sense of belonging and network between professionals that was very positive.

We combined a round table with experts in innovative areas, coming outside from ONCE and the active participation of the participants in reflection groups and in a "6 minutes presentations" gave everyone the opportunity to express themselves and contribute with their experiences, materials, investigations and ideas.

The conclusions of the Conference were published and a monographic with all the contributions will soon be published too.

The participants valued very positively, both the exchange and reflection with their colleagues and the depth scientific knowledge and innovation proposed by the speakers.

We hope this paper will inspire other people to promote new meetings and participate in an active way.

1. INTRODUCTION

The National Organization for the Spanish Blind is the unique specific organization devoted to blind and partially sighted people and delivers services from birth to the third age, in coordination with public services when it comes to educational services.

Early intervention includes children from 0 to 6 years and their families. When children are at home, the attention is mainly delivered by professionals of ONCE. When the child is in a pre-school or a school, the service can be delivered by a professional from ONCE or from the public Administration, under the Specific Team of Educative Attention for the Visually Impaired in which both Institutions work together.

The training to professionals is given by ONCE. There are also five Workshops; each in one of the five Resource Centers that ONCE has within Spain. At least one professional of all the Specific Teams distributes all around the country attend these Seminars three times a year, were they work together with professionals of other provinces and share knowledge and experience with them.

However, there is no direct contact between the five Workshops.

In 2009, the Direction of Education, Employment and Cultural Promotion of ONCE created a Group of Dynamization of the Early Intervention, DATO Group, to promote, dynamize, coordinate and agglutinate all those issues, activities, initiatives or projects that refer to Early Intervention, as well as to collect and transmit, information on any issue that may be of interest to the professionals.

2. ORGANIZING THE CONFERENCE

2.1 The idea

After some actions, like writing a document setting the bases for Early Intervention to visually impaired children and their families, promoting a monographic in ONCE's journal, "Integración", printing, develop and distribute a booklet to promote early detection, and analyze the contents treated and the organization of all the five workshops, DATO group started with the idea of organizing a Conference for all the professionals working in Early Intervention.

2.2 The organization

In a first moment we wanted to organize a big Conference for all professionals working in Early Intervention for Blind and visually impaired children, but due to economical and organizational difficulties, we finally decided to organize it only for those professionals that attend the five Workshops already mentioned, more than one hundred between all of them.

2.3 The venue and dates

After debating about the dates and venue, we decided to do it in one and a half working days, replacing one of the three Workshops of the school year and the Conference was finally held in the Resource Centre of Sevilla, a wonderful city in the south of Spain, on the 16-17 November 2016, twenty years after the one made in 1996, in Madrid, recalling the importance of Early Intervention as a stage that must be prioritized, given the greater vulnerability of the population, in which the preventive approach is essential, as well as the need of care to the child and family.

3. ORGANIZING THE CONFERENCE

3.1 The objectives

Several objectives were set for this meeting: to facilitate the exchange of experiences and reflect on the current reality of Early Intervention in the field of visual disability. At the same time, it was important to know firsthand the needs of the visually impaired population at this stage, to encourage networking and coordination among professionals, as well as to stimulate actions related to Early Intervention. We also wanted to encourage innovative and creative thinking from a deep knowledge of the needs of visually impaired children and their families.

3.2 The program

To fulfill these objectives in such a short time we needed to design an exhaustive program, which consisted in:

- An institutional welcome offered by three managers of ONCE, who stressed the importance of this meeting, the need for prevention, detection and the transcendence of Early Intervention programs for the visually impaired population.
- A round table, moderated by a psychologist of ONCE. The aim of the round table was to analyze the current situation of Early Intervention from different perspectives: neuroeducation, neurodidactics, and psychiatrist and psychotherapist. It was very inspiring starting point, full of deep knowledge and a great sensitivity towards visually impaired children, their families and professionals.
- The rest of the first morning, after the round table, and the first part of the morning of the next day there were nine Reflection Groups simultaneously developed and moderated by 12 professionals from different centers and different profiles (teachers, psychologists, social workers or pedagogues) who had prepared them for several months. There was a variety of themes: the role of professionals, intervention with the family, intervention models, training and qualification of professionals, living the body, multiple disabilities, the importance of training in neurology or the affective bond mother/child.
- As every attendant would be in two of the Reflection Groups, some weeks before the Conference they had expressed their preferences, with punctuation from 1 to 9. The organizers analyzed all those preferences and everyone could attend to two of their four first choices. All these groups drew conclusions that were read the last day in a plenary session.
- In the afternoon of the first day we had an exhausted session of 24 "quick oral presentations" of no more than 6 minutes each, all of them at the Assembly Hall. It involved a lot of previous work for the organizers and a strict control of the time, but all professionals who wanted had the chance to take the floor and tell us about

their experiences, materials, good practices and personal reflections. It seems it could be tiring, but surprisingly no one went out of the room and everyone was absolutely attentive and active. A conscious planning of the session, combining theoretical and practical papers, and the previous technological effort to have all the presentations ready to change quickly from one to another made the session a complete success and participants were very glad to be heard. We need to highlight that those professionals who normally don't present papers due to fear to public speaking, motivated by the fact that they were very short presentations and feeling they were not the only ones to present papers, felt comfortable telling us about their experiences.

- Of course the social program consisting in a dinner in a nice restaurant on the river bank was a perfect end to the first day that allowed people to enjoy together, exchange their impressions about all the information and knowledge accumulated during the day and taste a nice dinner.
- On the second and last day, we started the morning with the second sessions of the Reflection Groups and ended the day and the Conference with the conclusions of all the groups, read and explained by the chair of each one, and the general conclusions, given by DATO Group.

4. CONCLUSIONS

The general feeling of the participants was not only of having attended to an interesting Conference, but the sense of belonging, a feeling that they were the protagonists of what had happened there and a great wish of networking.

All of them were very interested in advance and the link professionals between DATO group and them, one in each Resource Center, normally the coordinator of the Workshop, have been essential.

Important professionals from different fields who have confirmed us the importance of Early Intervention.

All participants wish to make more Conferences like this as a way of networking and exchange of experiences, and beside this, to take advantage of technological resources to promote networking and coordination of professionals.

The great quality of the papers and experiences lead us to make a new monographic about the Conference in "Integración".

Acknowledgments

Thanks to the Director of Education, Employment and Cultural Promotion and the managers of ONCE for boosting the project and for the support given.

Thanks to all the staff and managers of the Resource Center of Sevilla for their warm welcome and wonderful organization.

Thanks to all the participants, speakers and chairs, who have made the Conference a complete success.

And thanks to my colleagues in DATO Group for all the illusion demonstrated and the time spent.

Spatial thinking and VI students: an educational program of intervention

Maria Zeza¹, Philippos Katsoulis², Mary Stylidi²

¹ Special Elementary School for Deaf- Blind in Athens, Greece
marialzeza@gmail.com

² Special Elementary School for the Blind in Athens, Greece
phikats@phs.uoa.gr, marystylidi@yahoo.gr

ABSTRACT

The purpose of this study is to present an educational program of intervention for students with visual impairments and screened difficulties in spatial thinking. The study uses a qualitative research methodology and the case study methodology was followed. The program of educational intervention was planned and modified in order to meet students' difficulties and promote the spatial thinking in the allocentric frame of reference. Spatial thinking includes processes that support exploration and understanding, beginning with the ability to use space as a framework. Students with visual impairments usually tend to use an egocentric (referred to the body location) strategy to elaborate and encode on spatial information and may find it difficult to succeed in transition from that egocentric to the allocentric (externally organized space) frame of reference, based on their experiences. In the case of students with visual impairments spatiotemporal patterns are encoded through touch (text, tactile image, objects) and it is the coherent and sequential way of the representation which allows the extended spatiotemporal patterns to be emerged. The designed multisensory and concrete activities offer opportunities for spatial thinking based on experiential learning experiences. Through this educational program of intervention students with visual impairments promote their spatial thinking, become more independent and start to perceive and elaborate on curricular objectives insightfully.

1. INTRODUCTION

Trough the egocentric and allocentric spatial frame of reference, students may encode and represent the position of objects in space. [1,2]. Undoubtedly, vision has an important role in action and spatial memory and the absence of vision may influence the egocentric and allocentric relations and spatial thinking. [3,4, 5]. In the research presented here it is investigated the impact of blindness on the ability to process egocentric and allocentric spatial frames of reference. A program of intervention referred to the transition from the egocentric to the allocentric spatial thinking is implemented, through story telling. Drama and role playing may encourage the development and perception of spatial concepts, such as direction and position. Additionally, through role-playing the children are encouraged to express themselves, develop their imagination and the concept of body image while orienting themselves spatially and exploring their environment without the risk of failure. [6].

2. SPATIAL THINKING AND VI

The studies referred to the relation of the egocentric and the allocentric spatial thinking process with blindness point out the blind students' preference and reliance on egocentric frames. It has been observed that blind students may find it difficult to deal with allocentric spatial frames of reference. [7,8]. Additionally, when blind students are asked to make spatial judgment originated from an allocentric representation, they may confront with difficulties in spatial processing. It seems quite convincing from the research review that congenital blind students may have limitations in processing allocentric spatial information, rather than egocentric.[9,10].

3. METHODOLOGY

3.1 Method- Participants

The presented study aimed to present an educational program of intervention for blind students, assessed with difficulties in spatial thinking. Following the methodological approach of case study, through direct observation, it has been noticed that students could perceive spatial concepts, when referred to themselves and present difficulties in perceiving the spatial concepts in the allocentric way of reference. The sample comprised 1 congenital blind student and 3 MDVI students, all with assessed difficulties in processing allocentric spatial information.

3.2 Setting and Material- Program of Intervention

Prompted by students' active participation in storytelling and drama- role playing, we read a fairy tale well known to all students, "The three little pigs".

In the second phase we drew a tactile map showing the points of spatial reference and the routes that the three little pigs and the wolf were following in the story. More specifically the spatial concepts referred to the following spatial directions: in front, behind, left, right. The tactile map was presented to the students and they were asked to answer questions about the spatial points. In all phases of the program, the same questions were posed to the students, asking them to locate the spatial points of interest (the forest, the chaffy house, the wooden house, the bricked house, the lake) in reference to another spatial point (the forest, the chaffy house, the wooden house, the bricked house, the lake). The students were observed to have difficulties in encoding the spatial data and in

perceiving the spatial concepts while “reading” the tactile map.

Therefore, in the third phase, we relocated and transferred the action to the scene and role-played the story in the school theater. Three houses (chaffy, wooden, bricked) and a forest were placed in the theater scene in the same places as they were located on the tactile map. The students role- played all 4 roles. From students’ answers to the same questions posed in the previous phase it was observed that students seemed to understand and perceive the spatial location, since they were asked to think egocentrically and perceive the spatial thoughts referred to their bodies’ location. It was also observed, that students were helped by echolocation.

In the fourth phase we created a story box. By the time the students opened and unfolded the box, the whole story was in front of their hands: four wooden dolls, three houses and a forest, all placed in the same direction and location as in both the tactile map and on the theater scene. The students now were asked to activate the allocentrically way of spatial thinking and define where the spatial points of interest were located in. Through the answers they gave to the repeated spatial questions, it was noticed that only in some limited extent they could transfer their spatial thinking from the egocentric to the allocentric point of reference. Specifically, only the blind student succeeded in the transition to the allocentric spatial thinking. MDVI students could not easily perceive the spatial information when it was not based on self-centered data. [1]. In the last phase, the tactile map was presented again to the students and the same spatial questions were posed to them. It is observed that students could in some extent “read” the tactile map and spatially interpret the positions and the marked locations.

4. RESULTS

The purpose of this study was to investigate the process of spatial thinking from blind and mdvi students under the prism of the egocentric and allocentric frame of reference. Our observation confirmed the blind students’ difficulties in the transition from the egocentric to the allocentric information processing.[11,12]. By implementing the program of intervention and including the story-telling and role-playing in the process of spatial thinking it has been noticed that mdvi students were positively responding mainly to the egocentric spatial thinking, which represents their empower. Therefore, the extended period of role-playing could encourage the mental representation and the spatial concepts perception, since the transition to the allocentric spatial thinking is recorded as a conflicting area for mdvi students. Mainly blind and in some extent mdvi students, perceived the spatial concepts when presented in the story box, since the egocentric spatial thinking through the role playing has been preceded.

5. CONCLUSIONS

The means of intervention used in this research are referred to role-playing and story-telling. This program of intervention encouraged in some extent the transition

from the egocentric to the allocentric frame of spatial thinking mainly of blind and mdvi students, since the students participated actively and perceived the spatial concepts not only in the egocentric role-playing but also in the transition to the allocentric frame of reference using a tactile map and a story box.

Acknowledgments

This paper is funded by the Erasmus+ Program of the European Union Pr. no 2016-1-EL01-KA201-023731.

REFERENCES

- [1] E. Collucia, I. C. Mammarella and C. Cornoldi, “Centred egocentric, decentred egocentric, and allocentric spatial representations in the peripersonal space of congenital total blindness”, *Perception*, vol. 38, pp.679- 693, 2009.
- [2] G. Ruggiero, F. Ruotolo and T. Iachini, *The role of vision in egocentric and allocentric spatial frames of reference*. Marta Olivetti Belardinelli and Springer-Verlag 2009
- [3] T. Iachini, G. Ruggiero and F. Ruotolo, “Does blindness affect egocentric and allocentric frames of reference in small and large scale spaces?”, *Behavioural Brain Research*, vol. 273, pp. 73–81, 2014.
- [4] Z. Cattaneo, T. Vecchi, C. Cornoldi, I. Mammarella, D. Bonino, E. Ricciardi E, et al., “Imagery and spatial processes in blindness and visual impairment”, *NeurosciBiobehav Rev*, vol. 32, pp.1346–1360, 2008
- [5] A.Pasqualotto, M.J. Spiller, A.S. Jansari, M.J. Proulx, “Visual experience facilitates allocentric spatial representation”, *Behav Brain Res* , vol. 236, pp.175–179, 2013
- [6] P. Grimmens, *Drama Therapy and story making in special education*. London: Jessica King.Publ., 2006
- [7] E. Coluccia, I.C. Mammarella, R. De Beni, M. Ittyerah, C. Cornoldi, “Remembering object position in the absence of vision: Egocentric, allocentric, and egocentric decentred frames of reference”, *Perception*, vol.36, pp.850-864,2007
- [8] S. Schmidt, C. Tinti, M. Fantino, I.C. Mammarella, C. Cornoldi, “ Spatial representations in blind people: the role of strategies and mobility skills”, *Acta Psychol*, vol. 142, pp. 43–50, 2013
- [9] G. Ruggiero, F. Ruotolo, T. Iachini, “ Egocentric/allocentric and coordinate/categorical haptic encoding in blind people”, *Cogn Process*, vol.13, pp. 313–317, 2012
- [10] A.E. Bigelow, “Blind and sighted children’ spatial knowledge of their home environments”, *Int J Behav Dev* vol.19. pp.797–816, 1996
- [11] D.H. Warren, *Blindness and children. An individual differences approach*. Cambridge University Press, 1994
- [12] S. Millar, *Understanding and representing space: theory and evidence from studies with blind and sighted children*. Oxford: Clarendon Press; 1994

The Spatial Representations Workshops: Methods to Develop Skills and Acquire Autonomy

Mikhael Poznanski and Laurent Vincent

Institut national des Jeunes Aveugles,
Paris, France
{mpoznanski; lvincent}@inja.fr

ABSTRACT

At the “Spatial Representations Workshops” of the National Institute for Blind Youth (INJA) in Paris, visually impaired students develop tactile, haptic and cognitive capabilities. Five workshops were conceived and have been led for over four years by teachers, ADL and locomotion instructors, as well as psychomotor therapists. Each workshop comes with a booklet of competencies and an educational sheet for teachers. Our purpose is to improve their autonomy, increase their efficiency during their schooling and everyday life, and help them build a more accurate representation of reality. We seek to identify and develop core competencies essential for VI students, help them to skillfully use adapted tools, enhance their capacities to go from reality to abstraction and back, and finally teach them how to guide human assistance during their final exams. Extreme individualization of the learning process is essential for students to commit, and confront their limits. The competencies developed here need to be used on a regular basis.

INTRODUCTION

Visual impairment is not well understood in society, the imaginary representation of the blind man with his walking stick is predominant, when professionals of the VI people have a whole different understanding [1]. Therefore, our students face a challenge: they must understand their impairment, but also educate the people they meet to understand VI. As professionals guiding VI students, we need to address this issue.

The National Council for School System Evaluation in France (Cnesco) recently published a report indicating that students schooled in special institutes particularly appreciate the specialized pedagogical technics used there and nowhere else [2]. The “Spatial Representations Workshops” (Pôle de Représentations Spatiales – PRS) at the INJA in Paris are an example of what can be done.

It is an interdisciplinary program designed for VI middle and high-school students schooled in our Institute or in inclusion. The students develop tactile, haptic and cognitive capabilities by working in a workshop for one hour a week, while constantly verbalizing their practice. These workshops were conceived and are led by teachers of science, geography, mathematics and plastic art, ADL and locomotion instructors, as well as psychomotor therapists.

Competency-based learning is quite recent in the French educational system. It was first introduced in 2005 and reinforced in 2011, becoming more and more

effective in the last two years. Each workshop of the PRS comes with a booklet of competencies and with an educational sheet for teachers. The booklet allows the team to precisely assess each competence being worked on. The educational sheet details concrete activities that help students progress in each separate skill. This material (in French) can be obtained by writing to: prs@inja.fr.

IDENTIFY AND DEVELOP ESSENTIAL CORE COMPETENCIES

We first present the students with eight core competencies in every workshop: adopt a proper posture for tactile exploration; explore with flexibility; organize their workspace; using two-hand exploration; dare to touch without fear; persevere in every activity; be capable of self-evaluation in simple situations; follow simple instructions, in autonomy. We noticed that all these core competencies are very seldom present at the beginning.

Each student, as soon as they arrive at the INJA, generally starts with the first workshop: “Touch and Say”. It is often their very first approach to tactile grip and it aims to giving them the appropriate vocabulary related to the sense of touch. The first activity consists in listing words describing the objects and materials they touch in a box. Our first objective is to disinhibit the apprehension to touch for blind and low-vision students. Many students oppose being VI and being a sighted person. We, on the contrary, think that one should not renounce on being a sighted person to become an efficient blind [3].

Our second goal is to enrich their vocabulary and link it to their tactile experience. We then offer them several elements to exercise the different techniques of efficient tactile grip: rub, press, wrap, lift, follow the contours, etc. Like in all other workshops, the students are supposed to automatize the movements and repeat them in any other context. Here, verbalization is essential to make some of them realize that, although sight is what he would have selected naturally, touching can be more efficient, particularly for a VI person. Touching is far from being natural, for low-vision students, but also for some students born blind. It becomes then vital to teach them how to touch.

The second workshop, “Orientation”, uses the haptic dimension of spatial representations to develop skills in 2D supports and in space. Here, the goal is to enhance the students’ capacities to orientate themselves. We use the egocentric spatial processing to transpose it into allocentric one. In other words, we start by offering activities for which a student uses his own body to achieve a spatial representation in space, using the cardinal directions. In the process, we offer exercises of orientation on a 2D document, very often used in school.

For many students born blind, we observed that when the egocentric spatial processing is not established, we can't, as teachers, help them acquire these competencies after they reach a certain age. These learning processes, mainly linked to the first years of development, are slowly acquired with our medical staff. Then, we tend to teach them technical protocols, compensation technic, how to succeed in a task required by school, as we are unable to make them acquire new competencies.

For our other students, who became blind or are partially sighted, this workshop is particularly important in their daily learning and they can make significant progress.

A SKILFULL USE OF ADAPTED TOOLS

"Precise Drawing" gives the opportunity to enhance the accuracy of detailed gestures, and gain experience in the rigorous use of adapted tools.

Our purpose is to make our students acquire mathematical skills: drawing complex geometric figures, mastering the use of simple geometric tools like a graduated scale, a set square, a pen, a compass, etc. This workshop is particularly technical and each student is guided individually: How to measure as precisely as possible? How to stabilize ones tools? How to use a pen on a plastic embossing film? How to close properly a geometric figure, particularly the angles? But we also go against the common idea our students tend to share: VI people can draw.

Blind students encounter specific difficulties, like the impossibility to erase their drawing on a plastic embossing film, when sighted people can use a rubber. They must think about their strategy to figure what they seek to achieve and be extremely rigorous. Theoretically, a single mistake means they will have to start over the whole drawing. Since starting over and over can be discouraging, they must learn "to lose time in order to gain it". They must check before, during and after their gesture.

FROM ABSTRACTION TO REALITY AND BACK

"Projections and Representations" help students improve their skills to represent objects in 2D and 3D, significantly developing their capabilities for abstraction. We use orthographic projections of different elements and sectional views and templates of a large variety of objects.

Therefore, this workshop is very hard for our students, as it would be for sighted students. It requires very accurate spatial representations and high capacity of abstraction. For instance, they can be required to decide which sectional view is most useful to represent a certain object or draw as many templates of an object as possible.

Most of our students do not validate all the competencies of this workshop. But we offer them the opportunity to make as much progress as possible.

GUIDE A HUMAN ASSISTANCE TO PRODUCE DRAWINGS

"Complex Strategies" encourages them to use human assistance during exams and trains them both in reading and in producing tactile drawings for school use. This

workshop was designed especially for students in their last two years of high school, mainly those with scientific orientation, and the goal is focused on helping them for their graduation exams (Baccalauréat in French). Particularly in Biology, students are required to produce diagrams, and VI students must learn how to use a human assistance that will draw for them, following their directions. But producing diagrams is also a very effective tool to acquire disciplinary knowledge.

We give the students a large variety of documents: diverse types of charts or diagrams, tactile adaptations of an art work, but we ask them to ignore the meaning of the document and focus on its structure. Two mains strategies are used. Generally, sighted students are more efficient starting from the global perspective and adding details progressively. We noticed that some of our students are more efficient when they start with details.

OBSERVATIONS AND CONCLUSIONS

This program was not meant to be a research program; therefore, no tool was thought in advance for evaluating the results scientifically. However, we can try to draw several observations and conclusions from our four years of experience with hundreds of students:

- Extra-curricular workshops, though not always well accepted in the beginning, become quickly significant for our students in their daily life and learning process.
- The extreme individualization of the students learning process is a key factor of success. It ensures the student he does something made for him personally.
- As teachers, we are reluctant to put our students in a situation of failing, especially VI students. Sometimes, "learning by failing" can nevertheless be a strategy to make a low vision student understand that using specific tools is inevitable. This strategy can be used when trust is established between teacher and student.
- Our students acquire new competencies, but if these skills are not used on a regular basis, they must be worked on again. One of our current concerns is to link more efficiently the learning in the workshops to all the classes in our Institute. This issue is particularly complex when the students are in inclusion with teachers not specialized in VI.
- There is not one strategy to achieve results, but a unique way for each student. Nevertheless, eventually, we want them to acquire spatial and mental representations common to the sighted persons, an important condition for them to live in a world made for sighted people.

REFERENCES

- [1] A. Corn, and J. Erin., *Foundations of Low Vision: Clinical and Functional Perspectives*, AFB Press, 2010.
- [2] C. Coudronnière and D. Mellier, « Qualité de vie des enfants en situation de handicap. Revue de questions », *Rapport du CNESECO sur la qualité de vie à l'école*, 2017 (to be published).
- [3] M. A Heller and E. Gentaz, *Psychology of Touch and Blindness*, Psychology Press, 2013.

How 3D-printing can support and help children with Visual Impairments in education. An Example.

Ruben Brandsma¹, Eric Velleman¹

^{1,2}Accessibility Foundation,
Utrecht, The Netherlands
{r.brandsma, e.velleman}@accessibility.nl

ABSTRACT

Rich media is becoming more present in everyday education. Today, this includes interactive and multimodal 3d printed models that are finding their way into our classrooms. All this directly impacts the accessibility of education for persons with Visual Impairments (VI).

We have experienced that 3d printing can greatly benefit persons with VI and offer them new opportunities for multimodal exploration and learning that goes far beyond classic paper, webpages or other forms of digital learning and even beyond traditional 3D printed models. Today, creating rich 3d printed models and combining them with conventional modalities can create accessible educative experiences that have not been seen before and that can be easily produced at low cost by every school.

In this paper, we present the preliminary conclusions of our fieldwork study into 3d printing BRABO.

1. INTRODUCTION

We have five senses to choose from in daily life. Only a very small part of them are used in the educational context where we mostly focus on sight and hearing. When sight is taken away, the modalities students can choose from are very limited.

For persons with VI, touch and sound are senses that are often used to compensate, but what about in education? There are a lot of haptic materials available, but education is changing fast and in practice we see that haptic solutions are replaced more and more by text descriptions. But does text offer the same information and learning experience? The same question applies to tactile drawings that are 2.5D.

It is important to note that most VI read tactile drawings and 3d models sequentially, piecing information together to form a whole. Their strategy of exploring a model differs significantly from sighted people. Translating an image one on one to something haptic does not automatically make it accessible for the VI as it loses visual aspects like color, scale, perspective etc. without replacing them with tactile information or alternatives in other modalities.

With 3D we can create a haptic experience that represents reality. The problem is: 3D models in education are designed for sighted people. Most designs do not address haptic information and are difficult to adapt.

With the rise of 3D printing adapting and per-

sonalizing 3D models has become easy and cheap. 3D printing allows users to create physical models from digital models, combining the digital and the physical. There is no (expensive) production chain needed to create a 3D model. You only need a digital blueprint and a 3D printer. You are your own factory.

In this paper, we describe the making of a basic but not less necessary 3d printed tool: the BRABO, a mathematics device for blind students.

2. DUAL-CODING THEORY

3D models allow for the use of multiple senses. While a student uses the haptic model, a teacher adds context and information enriching the experience. The dual-coding theory [1] describes stimulating the non-verbal (3D model) and verbal (teacher) in the brain together, thus enhancing the educational experience. Our colleague Esther Rieken applied this to tactile drawings. Her research [2] shows improved results when tactile drawings are used in comparison to only plain text. Though Rieken's tactile drawings are only 2.5D it is the haptic information that allows for better results.

3. 3D PRINTING

3D printing is not difficult. It uses additive manufacturing, which actually means combining materials to create something new. 3D printing is one of the greatest examples of additive manufacturing that you can even do in the classroom. In our research we focused on Fused Deposition Modelling (FDM) that works by melting plastic and stacking this on top of each other in the shape of the model. FDM is the cheapest and most accessible method for 3D printing.

Based on a digital 3D model or a 3D scan it is easy to create and slice a 3D file. Slicing is adding physical properties to the print. This is translated to Gcode which holds the X, Y, Z coordinates for the print (among other things). Besides a basic knowledge of the above no other skills are needed to 3D print. This empowers everyone with access to a printer to create 3D models by simply downloading a model from the internet or making one yourself with simple and online 3d software.

4. DEVELOPMENT OF THE BRABO

BRABO stand for braille bow, a protractor for people with visual impairments. It allows users to not only measure angles but also draw them. It is not the most spectacular 3d model and there is no need for multimo-

dality but the demand by VI was high so we worked on it together. The existing BRABO was heavy and large, made out of 5mm Plexiglas with iron arms sized over 100 x 200 mm. It costs about 25 Euro and there is a long waiting list. We developed a 3D printable model and tested that with 2 end-users (blind students 12-16 years old actually using the BRABO in school). We went through four iterations in a period of 8 weeks applying the comments and findings into the final model.

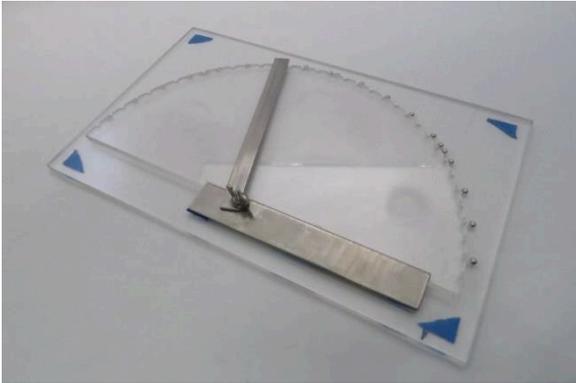


Figure 1. Older heavy version of the Braille Bow.

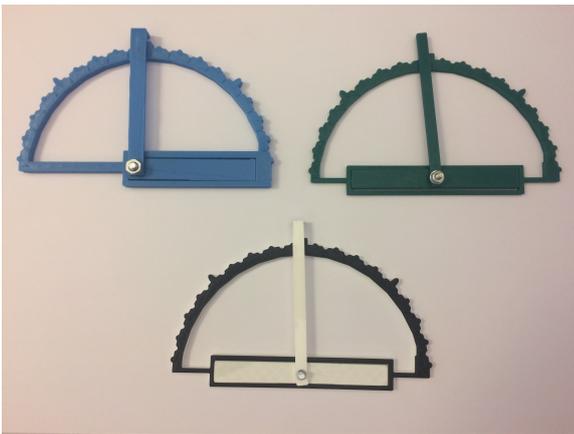


Figure 2. Interactions of the new 3D printed BRABO. Version 1 to the left and the final version below.

During the the iterations, we made it smaller and easier to use. We also limited the amount of material making it cheaper to print (about 1,80 Euro). And we changed the arms because students kept misplacing them the wrong way around. This in turn also helped the accuracy because the point of measurement remained more consistent with measuring angles below 45 degrees. We also added color as additional information for VI who can see color.

But most important, the BRABO 3d file can now be downloaded for free and printed. The latest version can even be ordered online if you do not yet have a 3D printer (Korneels hub prints them at 3Dhubs.com, an online printing service).

Over 50 BRABO's are currently used by persons with VI all over The Netherlands.

5. PRINTER SETTINGS

The physical properties of a 3D printed modal are assigned during slicing. These settings determine the

strength, printing time, amount of material and overall quality and feel of the model. FDM printing also allows for several materials to be used on the same machine.

To see what 'feels' best for VI people, we created a model that holds three shapes: angled, round and organic. All 3D models have at least one of these shapes. We printed 5 models in total at: 0,2, 0,1 and 0,05mm layer height and two more models that we treated after printing at 0,2 layer height: ABS treated with acetone and PLA with a XTC 3D coating. We tested with 5 VI students ranging from 15-17 in age, three being blind and two partially-sighted at Bartiméus in Zeist.

The results show a preference for the models that were treated after printing. It also showed that the shape and quality are connected. The angled models scored better on every model while the organic and round shapes scored lower on a smaller layer height.

The direction the model is touched also relates to the haptic experience. Feeling along the lines of printing made it hard to feel the difference while going against the printing lines gave a rougher experience on lower quality.

6. CONCLUSIONS

Based on our finding and experience with 3D printing for people with visual impairments, it can greatly impact education and not only increase the accessibility but also the learning results. There is still a need to empower educators to help them create 3D printed solutions or even just download them from the internet. 3D printing allows for personalization and adaptation at low cost.

While higher quality gives VI persons a better haptic experience, it also depends on the model itself. Printing time and materials influence the feel, but also the cost of a 3D printed model.

We're just at the start and a lot more research is needed to show the added benefits for persons with VI in education. Also more research is needed into multimodal interaction with 3d models adding sound, vibration etc. There is also a need to share more models that are specially designed for VI persons. And most of all, we need to empower educators to use, make and share 3D models.

We developed TEP, a method to connect 3D models to an accessible website that holds all the educational information. TEP uses NFC chips that can be put on any model with a link to the TEP website. This way every model can be made interactive and users can independently explore 3d printed models. TEP even plans to help them with tactile strategies. Further development and testing will start this summer.

REFERENCES

- [1] M. Gellevij, H. Van der Meij, T. De jong (2002) "Multimodal versus unimodal instruction in complex learning context," *Journal of Experimental education*, 70, 215-239.
- [2] E. Rieken, "Tastbaar resultaat: het effect van tactiele tekeningen op de leerresultaten van brailleleeringen in het primair onderwijs." *Unpublished 24-01-2013*.

Teaching Mathematics and Music to Blind and Partially Sighted Learners through Knowledge and Technology

Tanja Stevns¹ and Lars Ballieu Christensen²

¹Synscenter Refsnæs,
Kalundborg, Denmark
tstv@regionsjaelland.dk

²Sensus ApS,
Hillerød, Denmark
lbc@sensus.dk

ABSTRACT

While the move towards inclusive education for all is generally accepted as a major improvement of the rights and opportunities of the blind and partially sighted, it also exposes challenges. The transitioning of special schools into resource centres comes with a high risk of eroding basic teaching skills amongst those teaching the blind and partially sighted.

IncluTech is an EU Erasmus+ project (2015–2017) aimed at documenting good inclusion practices as well as how a variety of subjects are taught to blind and partially sighted learners. Bringing together partners from Bulgaria, Cyprus, Denmark, Hungary, Italy and Romania who are all at different stages of inclusion, the project has documented the combined experiences from special schools, resource centres, rehabilitation centres and academia into a catalogue of good inclusion practices and a series of educational guides covering first language learning, foreign languages, mathematics and music.

The presentation will present the results of the IncluTech project and discuss the importance of documenting core principles, methods and tools of teachers at special schools for the blind and partially sighted before these are forgotten.

1. INTRODUCTION

Throughout the EU, accommodation of the educational needs of the blind and partially sighted are at different stages of evolution. Some countries abandoned segregation more than 30 years ago and phased out special schools for the visually impaired and others with disabilities in favor of competence centers and mainstream integration. Other countries have retained the special schools, providing not only basic education but also high school education and vocational training. A third group of countries operate blended models with a combination of special schools, special classes in mainstream schools and full inclusion in mainstream classes. Fueled by demands from parents and economic pressure from legislators and administrators, and supported by disability organizations, the UN Convention the Rights of Persons with Disabilities [1] and the UNESCO Salamanca Statement on Principles, Policy and

Practice in Special Needs Education [2], the general trend is towards inclusive education for all at all levels.

Teaching blind and partially sighted children and youth requires significant skills. In addition to knowledge of Braille, tactile illustrations, audio books and assistive technology, teachers need to understand the basic pedagogical principles of teaching someone who lacks visual perception or is unable to form meaningful syllable, words and sentences out of sequences of symbols. Furthermore, teachers need to know - in practical terms - how best to teach various subjects such a first language, foreign languages, mathematics and music to blind and partially sighted learners. Finally, educational material in alternate formats such as Braille, large-print and audio must be available.

At special schools, employing teachers with the proper skills to teach learners with various disabilities is usually not a problem. With a steady supply of learners with disabilities, teachers get to practice and refine skills, pedagogical principles and methods that are known to work. In mainstream education, the situation is vastly different. Less than one percent of the European population is visually impaired, and for children and youth the prevalence is much lower. Hence, teaching someone with a visual impairment may occur once in a decade. To a large extent, mainstream teachers rely heavily on technology and the knowledge and skills of others. However, in countries that abandoned special schools for the visually impaired decades ago, teachers with working knowledge and skills are on the brink of becoming extinct because of retirement and old age.

Inclusion of learners with special disabilities into mainstream education is happening. In some cases, inclusion has been successfully supported by adequate infrastructures, competencies amongst mainstream teachers, competence centers and training courses. In other cases, lacking structures, competencies and support have resulted in poor integration of those with disabilities.

2. METHODOLOGY

Partners were chosen considering the following three aspects:

1. Partners representing different stages of inclusion to be able to document good practice covering all stages of inclusion.
2. Partners from both former Eastern Europe, Southern Europe and Scandinavia to ensure getting a diverse cultural angle.
3. Partners representing both special schools and mainstream education settings at all levels primary to tertiary to be able to describe core methodology and didactics for teaching learners that are blind and partially sighted.

Information on the fundamental principles practices, educational material and teaching aids used to teach various subjects to learners with disabilities are few and far between. In some cases, material have been prepared for internal use at the special schools or in other closed environments. In other cases, knowledge has been passed from teacher to teacher as part of workplace training. Few systematic material on pedagogical principles, practices, educational material and teaching aids for teaching first language teaching, foreign language teaching, mathematics and music for the blind and partially sighted exists.

The subjects first language, mathematics, music and foreign language were chosen as these areas are either main subjects across curriculum in Europe or difficult to teach in a proper quality. Furthermore, partners wanted to document good inclusion practise in order to support inclusion in mainstream education across Europe and to share the knowledge of those experienced with inclusive education with a strong focus on what universally works. Lastly, the project wanted to promote self-sufficiency and access to educational material in alternate formats using the RoboBraille service [3, 4].

Although the RoboBraille service is well-documented and educational material exist, using the service in mainstream education to create educational information in alternate formats has proved difficult because of lack of a basic understanding of digital accessibility and alternate media.

3. RESULTS

Project partners have authored 12 series of practical educational guides covering fundamental principles, practices, educational material and teaching aids covering first language teaching, foreign language teaching, mathematics and music for the blind, partially sighted and dyslexic (dyslexic not covered in this presentation).

Furthermore, partners have collated good inclusion practices in five select areas (teacher skills, alternate media, support structures, preparation for inclusion and teaching environments) in a catalogue of good practices.

Finally, the project has adapted a comprehensive set of educational materials on the RoboBraille service prepared in a previous Leonardo da Vinci project under the Life-Long Learning program of the European Commission. RoboBraille SMART project [5] into a complete e-learning course in 9 modules on how to use the RoboBraille service to convert documents into alternate formats.

4. CONCLUSIONS

Although the project has succeeded in documenting some fundamental aspects of teaching mathematics, music, first- and foreign language to learners that are blind or partially sighted, it is definitely not enough to secure that all important aspects are covered. It is mainly a starting point for a more comprehensive and detailed description that is needed if a high quality in teaching and learning these subjects is to exist in the future considering inclusive education of the blind and partially sighted in mainstream settings.

The good practice catalogue should be seen as a reflection of current practice more than best practice as these will differ in time and place and are likely to change as inclusion becomes more mature and better implemented in all EU countries.

The RoboBraille e-learning course is solving a current and ongoing problem: attending face-to-face training session to learn how to convert is time consuming, expensive and have not been available to all relevant users. The RoboBraille e-learning modules are unique and will enable all students and teachers at all educational levels and in all geographies to train themselves in alternate media conversion.

Acknowledgments

The IncluTech project was completed with funding from the European Commission under the Erasmus+ program, Grant Agreement KA201-2015-012.

REFERENCES

- [1] United Nations: UN Convention on the Rights of Persons with Disabilities. 2006.
- [2] The Salamanca Declaration and Framework for Action, 1994
- [3] Christensen, Lars Ballieu: RoboBraille – Braille Unlimited. The Educator, Volume XXI – Issue 2, ICEVI 2009, p. 32-37
- [4] Christensen, L.B., Keegan, S. J., & Stevns, T: SCRIBE: A Model for Implementing RoboBraille in a Higher Education Institution, K. Miesenberger et al. (Eds.): ICCHP 2012, Part I, LNCS 7382, pp. 77–83, 2012. Springer-Verlag Berlin Heidelberg 2012.
- [5] EU Life-Long Learning. Leonardo da Vinci: RoboBraille SMART Project, 2013-2015. Available at www.robobraille.org

Children suspected of CVI: Structured way of observation children between 2,9 months and 12 years and the use of uniform observation lists, tools and reporting templates.

Nicole Scheirens

¹Early support team Center Ganspoel, bachelor orthopedagogic sciences

ABSTRACT

This project deals with children who are supposed to suffer from CVI but who have not been diagnosed as such.

For this project Ganspoel Centre co-operates with the CVI – hospital in Leuven where CVI is researched and diagnosed with children between 2 years and 9 months till 12 years. There is always a group of children who have not (yet) been diagnosed with CVI. In case of doubt or uncertainty Ganspoel is asked by the CVI hospital to observe these children during one year in their daily life.

For some children, this standardised testing, at one moment, mostly using paper- or computer tasks, is not the best way to diagnose CVI or not.

Especially with children who are dealing with additional problems this is not easy to find out. This concerns children who could eventually be diagnosed with ASS/DCD, or children with limited verbal possibilities.

1. THERE IS A NEED FOR A MORE UNIFORM WAY OF OBSERVING.

On one hand there is a demand of the CVI hospital for a wider observation, on the other hand we have noticed that observing can be very wide and different.

The goal of the team we started was to create a more uniform way of observing and to create a manual with useful tools which could be used throughout an observation year.

The children who were assigned a CVI observation year were monitored by the following services: home supervision (ambulatory help at home), Integrated education (GON: help in schools), children in semi boarding within Ganspoel (children who stay in the center during the week).

In December 2012 we had our first meeting with people from different teams: early supervision teams for children aged 0-12, integrated education teams for nursery schools and primary schools and the Ganspoel GON therapy team.

2. OBSERVATIONLISTS

The first step was making a list of all the present observation lists inside and outside Ganspoel :the lists of homesupervision,ergotherapy, integrated education (GON) and ILO (international concertation between

Flemish and Dutch services), lists of doctors and the visual profile of P. Looijestijn.

In order to prevent duplicates we checked and compared all lists and eventually ended up with 16 lists we found useful for our target group and the functioning of our services.

3. TEMPLATE FOR REPORTING

Furthermore we also needed a more uniform way of reporting. The CVI hospital thought reporting to be clearer if reports were made in the same way. So arrangements were made with the hospital to make the reporting should be done in a fixed template. It should be given in time and before re-evaluation or re-testing. Our template is based on the visual profile of Looijestijn since this is the most complete guideline within the ICF frame.

4. TOOLBOX

In addition to the fixed observation lists and the template we decided to gather suggestions for useful tools. As a result we acquired toys and other tools that we can use during this observation year.

The toolbox contains: markers, duplobricks, coloured cards, contrastreducing images, memory, puzzles...

This way we want to provide an impetus to check a number of things we find in the visual profile and the template. We do not want to limit ourselves to these tools. They can be extended if we want to check or observe more profoundly. Within Ganspoel there are more toys present that can be quite useful but this set is meant to be a basis.

5. DIGITAL COLLECTION OF IMAGES

An observation kit of digital images was put together by the ergotherapy service in Ganspoel. This kit contains 27 powerpoints with each 25 carefully chosen images.

The kind of image is the first subdivision. A distinction is made between photos,pictures and drawings. Each category is subdivided into simple images, actions and situations.

The level of difficulty is a last subdivision.All images are arranged from easy to more difficult.

Templates have been added so the observer can quickly make notes when a certain image has been wrongly identified. He can also note eventual remarks.

It is equally important to pay attention to the way in which the tasks are being done: is the viewing distance being reduced, is there an overview of the screen, is there more focus on details, or is there a more general overview, is there weak search behaviour, is response time slow, are there any signs of frustration, is there auditory distractibility,...

This set has not been standardized / normalized but we know from experience which mistakes can be made and we are able to situate them within the suspicion of CVI. The level of the children is also taken into account. Young children get less difficult categories.

6. RESULTS AND FINDINGS

Since 2014 we have been consequently using lists and templates during a CVI observation year. Since 2015 we have started using the tools. All additional information has been reported and sent to the CVI hospital. These are our findings up to now:

The CVI hospital states that the more uniform way of reporting is a gain in processing the reports

Supervisors (or coaches) state that the template is a great support to start and work throughout an observation year

The digital observation kit with images is complete and very handy in use because a CD or memory stick can be easily taken to the families.

No remarks have been made about the tools yet.

REFERENCES

- [1] Visual profile , Paul Looijestijn
- [2] Practice paper Jolien Verdonck, collection of images used in center Ganspoel

Sensitization about Cerebral Visual Impairment

The Cerebral Visual Impairment awareness program

Lore De Deyne¹, Martine Dierckxsens², Emma Vandamme¹

¹Begeleidingscentrum campus Spermalie
Bruges, Belgium
{lore.dedeyne, emma.vandamme}@de-kade.be

²Secundaire school Spermalie
Bruges, Belgium
{martine.dierckxsens}@de-kade.be

1. INTRODUCTION

Since Cerebral Visual Impairment (CVI) has become one of the most important causes of visual impairment in children, the need for information about this condition increases. This was the motive to organize a systematic awareness program about CVI. This program is focused on referring authorities and on persons involved in the care of children with CVI.

The main aim of sensitization is to spread and increase the knowledge about CVI. For the referring authorities, we hope better knowledge increases early referral to a specialized team. We hope early referral leads to early stimulation. For people involved in the care children with CVI, we hope better knowledge helps them better understanding the visual impairment and better understanding the child. From understanding the characteristics of the impairment, the problems that can occur and the recommendations for approach & support, the support of the child can be optimized. This will increase the wellbeing of children with CVI.

Since CVI is difficult to comprehend, finding a good way to explain it and to let people experience it is challenging. Besides a theoretical explanation and discussing case studies, the use of practical exercises that make people experience some CVI-related difficulties have proven to be very clarifying and illustrative.

2. THE AWARENESS PROGRAM

2.1 BACKGROUND

Spermalie offers different forms of support to children with a visual impairment. The support can be offered by our diagnostic low vision team, the home support team, school support team, primary & secondary school and our center of expertise. A substantial part of the support is given to children with a Cerebral Visual Impairment. This impairment is often not well known and therefore it is important to sensitize about it. Over the past few years we

have created an awareness program that can be adapted to different target audiences.

2.2 TARGET AUDIENCES

2.2.1 Referring authorities

Referring authorities who can refer children for diagnostic purposes or for support include student guidance centers, pediatricians, ophthalmologists, rehabilitation centers, follow up centers for babies and centers for premature born babies. Since these authorities play an important and sometimes a first role in the care of children it is of great importance that they know how to identify the early signs of cerebral visual problems. Of course the same is true for other visual problems.

A good knowledge of the existence and characteristics of CVI, the at-risk-groups and the support options will be of great importance for referring authorities.

2.2.2 Caregivers

People involved in the care of children with Cerebral Visual Impairment are parents, educators, teachers who assist children with CVI in regular or special education, physiotherapists, occupational therapists, pedagogues,... They are responsible for the daily care of the child with CVI and know the child the best. These people are indispensable in encouraging and stimulating the early visual and general development of the child, from early childhood to adolescence. For the caregivers a good understanding of the visual problems and other domains at risk (e.g. communication, motor skills, language,...) will be important. During the different stages of development of the child (baby, toddler, preschool, grade school, teen) typical CVI-related problems often manifest. Caregivers need to be informed that CVI is not a stable impairment and changes can occur. They need specific recommendations for approach and support.

2.3 AIMS OF THE PROGRAM

- Spread and increase the knowledge about CVI.
- Induce a better understanding of the visual impairment.

- Increase early referral to diagnostic and support teams and clarify the importance of early referral.
- Stimulate the children as early as possible.
- Offer recommendations for approach & support.
- Optimize the support of children with CVI.
- Increase the wellbeing of children with CVI.

2.4 METHOD

To sensitize referring authorities about CVI we organize systematic courses for them. This can take different forms, such as an info night for medics or a one day course for employees of rehabilitation or student guidance centers, follow up centers for babies,... By these courses we try to reach and sensitize all the referring authorities in our region.

Likewise, the courses for caregivers also can take different forms. For parents and other family members we organize systematic info moments. Besides all the information about CVI people receive during such moments they are also grateful for the opportunity to share their experiences with others. For parents and the child with CVI the home support team is also an important partner who can provide them with information and advice at any other moment. For peers of children with CVI a lesson about CVI and a 'live in moment' is often organized to better let them understand what CVI means.

Teachers who have a child with CVI in their classroom generally request more information about the impairment. By the start of every schoolyear we organize a course for teachers and other caregivers of whom we know they assist children with CVI in regular or special education. Besides the explanation of CVI, this course mainly focuses on recommendations for approach and support of children with CVI in the class and other environments.

At last it is also of great importance that we provide essential information to our own employees such as educators, teachers or therapists at the moment when they start working with visually impaired children or at any later moment. Therefore we provide an annual training for all our new employees or any other employee who wishes a refreshment.

2.5 CONTENT

Depending on the target audiences the content of the info moments or courses can be adapted. The base from which we start is generally a theoretical explanation where we speak about the visual system, possible causes of CVI, characteristics of the impairment and general guidelines. The representation of the brain and the visual areas from Dr. Gordon Dutton (Dutton 2001, fig.1) is an important source of inspiration for our theoretical explanation of the visual system and CVI.

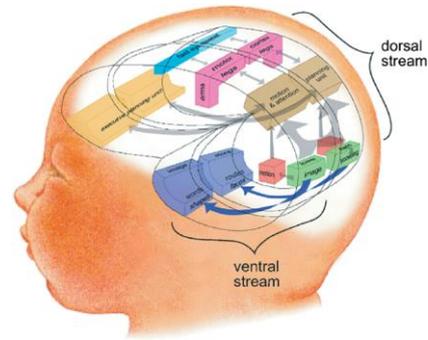


Figure 1 Schematic drawing of the brain from Dutton

To make the theory more vivid and understandable we often make use of case studies. When we use case studies we present visual profiles of children with CVI and say something about the different visual areas, such as the visual attention, visual recognition, orientation and visual guidance of movements. We give examples of problems that can occur on the level of the different areas. In that way we try to link the theory with examples from the daily life and make the information more comprehensible. While presenting possible problems that children with CVI can experience we also try to offer some 'live in exercises' to the audience. Besides helping them to understand the theoretical explanation, it also helps them to really experience some of the difficulties children with CVI are confronted with. It's challenging to find exercises that let people experience some of these difficulties. We use exercises from the CVI Experience (Pilon 2014, fig. 2) and some exercises we created our own.

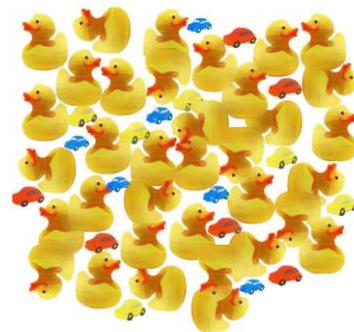


Figure 2 CVI Experience

As a result of these 'live in exercises' caregivers often better understand the functioning of the child and it makes them comprehend the need and importance of a good support for children with CVI. They get a better grip on the presented recommendations, which can change the support and the wellbeing of the children with CVI for the better.

REFERENCES

1. G. Dutton, *Cerebral visual impairment: working within and around the limitations of vision*, 2006 from: http://www.liv.ac.uk/~pcknox/Publications/trimble/CVI%20chapter%20for_hers-Dutton.pdf
2. F. Pilon, *CVI Experience*. Bartimeus, 2014

Empowering Dialog in Classrooms: Challenges and Needs of Teachers of Students with Visual Impairments in Turkey

Mehmet Akif Cihan¹, Kubra Akbayrak²

¹ Texas Tech University, College of Education,
Texas, USA
mehmet.cihan@ttu.edu

² University of Birmingham, School of Education,
Birmingham, UK
kxa307@bham.ac.uk

ABSTRACT

The aim of this study is to investigate challenges and needs of teachers of students with visual impairments (TVIs) working at schools for the visually impaired (SVIs) in Turkey in order to find out potential barriers for empowering dialog between teachers and students in classrooms. To achieve this, an online survey was designed and distributed to TVIs working in 17 SVIs across Turkey in the 2016-2017 school year. The participants were asked to rate their challenges and needs in relation to 'teaching and learning activities', 'collaboration', and 'professional development' with using 4-point and 5-point Likert type scales as well as to answer open ended questions. The preliminary results from 49 TVIs illustrate that TVIs have a range of challenges including having a lack of materials, too much paperwork, a lack of supports from parents and administrators, and ineffective pre-and in-service trainings. Consequently, needs for extra classroom materials, reduced paperwork, extra administrative supports for TVIs, and more qualified pre-and in-service trainings are recognized by participants.

1. INTRODUCTION

Over the past several decades, the roles and responsibilities of teachers of students with visual impairments (TVIs) have changed [1, 2]. In particular, the shift towards greater inclusive practice has resulted significant changes in educational support for children with VI [3]. Furthermore, teaching expanded core curriculum (ECC) skills to students with VI has become highly essential [4].

There are some studies conducted to determine TVIs' needs and challenges regarding their roles and responsibilities. One study from US with 510 participants found that TVIs have a 'complex' job with a range of responsibilities [2]. Another study from Australia also emphasized complexity of the roles of TVIs and TVIs' challenges regarding time and collaboration [5]. The literature says that there is no study investigated the roles and responsibilities of TVIs in Turkey. It is believed that an insight of the potential challenges and needs of TVIs regarding the complexity of their roles might remove potential barriers for empowering the dialog between students and teachers in classrooms. Therefore, this study aims to understand challenges and needs of TVIs working at schools for the blind

and visually impaired (SVIs) in Turkey by answering the following questions:

1. What challenges do TVIs face with regard to their roles and responsibilities in Turkey?
2. What needs do TVIs have to address those challenges?

2. METHODOLOGY

2.1 Method and Participants

Quantitative research design with the survey instrument was used in this study. To recruit participants, the purposive sampling method was utilized [6]. Following the ethical approval from the Turkish Ministry of Education (TME), the online surveys were e-mailed to TVIs working in 17 SVIs in the 2016-2017 school year ($n=183$). As of now, 49 participants were recruited (response rate 27%). Out of 49, 20 TVIs have less than 5 years teaching experience, and 19 TVIs hold a bachelor's degree in visual impairment education. Furthermore, 30 TVIs reported that they have at least one student with low vision and one student with multiple disabilities in their classrooms.

2.2 Data Collection and Analysis

The survey of the study consisted of two main sections: (1) personal information and (2) challenges and needs. The second section divided into three main subcategories: challenges and needs regarding (a) 'teaching and learning activities', (b) 'collaboration' and (c) 'professional development'. Participants were mainly asked to rate their challenges by using 5-point Likert scale (1=strongly disagree–5=strongly agree) and their needs by using 4-point Likert scale (0=no need–3=highly needed) as well as to answer open ended questions in each section of survey. The open-ended survey questions were content analysed whereas the quantitative data was descriptively analysed using the SPSS 20 program.

3. FINDINGS

The findings of the study are reported in three main categories: 'teaching and learning activities', 'collaboration', and 'professional development'.

3.1. Teaching and Learning Activities

The preliminary results indicate that 60% of TVIs think that they do not have adequate materials in classrooms ($n=29$). As parallel to these results, 75% of TVIs rated getting additional classroom materials as either moderately or highly needed ($n=35$). As another important point, 95% of TVIs ($n=47$) report that they have less than 10 students in their classrooms. However, most of TVIs, 75%, believe that their classrooms should be re-arranged based on age groups and types of impairment ($n=35$). Lastly, the results of the content analysis reveal that TVIs feel that they spend too much time on paperwork and believe that the volume of paperwork should be reduced in order to focus more on instruction.

3.2. Collaboration

Regarding TVIs' collaboration with parents, other professional, and administrators, 41% of TVIs ($n=20$) believe that there is a good collaboration between *stakeholders* whereas 33% of them ($n=16$) believe there is not. One of the TVIs also reports their challenges regarding collaboration: "Having lack of support from parents, and not getting positive feedback from students negatively affect us and causes fatigues." In addition, almost of half of TVIs ($n=25$) believe that they are not supported by administrators. As possible solutions for these issues, most of TVIs, ranging 80-90%, believe that additional activities to promote collaboration and supports for teachers should be provided as moderately or highly urgent.

3.3. Professional Development

The data shows that more than half of TVIs (64%) feel that their pre-service training was not adequate to meet students' needs ($n=31$), and 90% of them ($n=42$) believe that there should be more qualified and practice based education for pre-service teachers. As a specific example, one TVI says that "mostly, there is no in-service training provided about students with multiple disabilities. If there is, I believe it is going to be productive." As parallel to this, 70% of TVIs ($n=34$) report that they have limited professional development (PD) opportunities as in-service teachers. Consequently, 85% of TVIs ($n=40$) believe more PD opportunities for both new and experienced teachers should be provided as moderately or highly need.

4. DISCUSSION

The preliminary findings of this study provided an initial snapshot of challenges and needs of TVIs in classrooms in Turkey. It seems that most of TVIs lack classroom materials for different groups of students in their classrooms. Secondly, most of the caseloads are almost in a suggested ratio which is 1 teacher for 8 students with VI as opposite to results from US study [2, 7]. However, there is a similarity with the study regarding to time spent on paperwork.

The initial results also indicate that TVIs are not supported well by their administrators and parents which might lead to insufficient collaboration between those. In addition, most of TVIs are not satisfied with pre-service education they received and recommend teacher training

that offers more practice-based activities targeting diverse types of students. Lastly, there are a few PD opportunities provided to TVIs in different areas. Thus, both inexperienced and experienced teachers need more in-service trainings to improve quality of their instructions especially for students with multiple disabilities. The need for extra education in pre-and in-service trainings was also recognized by a study from US [2].

5. CONCLUSIONS

The preliminary results of this study provided a limited perspective for understanding challenges and needs that TVIs have in the classroom; however, some significant challenges and needs of TVIs have been highlighted for eliminating the communication barriers between TVIs and students with VI in the classroom in Turkey. Results of the study will be shared with the TME. So, it is researchers' hope that findings of the study will provide a guidance policy makers to recognize TVIs' challenges and needs and eventually address these issues to empower dialog in classrooms.

REFERENCES

- [1] H. Mason, "Competencies of Teachers of Children and Young People with a Visual Impairment", *Visual Impairment: Access to Education for Children and Young People*, London, 1997.
- [2] N. Griffin-Shirley, A. Koenig, C. Layton, R. Davidson, L. Siew, A. Edmonds and M. Robinson, "A survey of teachers of students with visual impairments: Responsibilities, satisfactions, and needs", *RE:view: Rehabilitation and Education for Blindness and Visual Impairment*, 2004.
- [3] M. McLinden and G. Douglas, "Education of children with sensory needs: Reducing barriers to learning for children with visual impairment", *Educational Psychology: An International Perspective*, 2014.
- [4] W. Sapp and P. Hatlen, "The expanded core curriculum: Where we have been, where we are going, and how we can get there", *Journal of Visual Impairment and Blindness*, 2010.
- [5] J. Brown and W. Beamish, "The changing role and practice of teachers of students with visual impairments: Practitioners' views from Australia", *Journal of Visual Impairment & Blindness*, 2012.
- [6] J. W. Creswell, *Qualitative inquiry and research design: Choosing among five approaches*, 2nd ed. Los Angeles: Sage Publications, 2007.
- [7] C. Mason and R. Davidson, "National plan for training personnel to serve children with blindness and low vision", *Council for Exceptional Children Publications*, 2000.

Visual ability in multiply challenged children with cerebral palsy

Ana Katusic¹, Snjezana Seitz¹, Tatjana Petrovic Sladetic¹, Sonja Alimovic²

¹Day-care Centre for Rehabilitation "Mali dom-Zagreb",
Zagreb, Croatia
ana@malidom.hr

²University of Zagreb, Faculty of Education and Rehabilitation Sciences, Department of Visual Impairments
Zagreb, Croatia

ABSTRACT

Background: Visual functioning is often impaired in cerebral palsy (CP). Tools are needed to describe this complex function, in order to aid resource planning and to provide effective support.

Aim: To describe visual ability in CP subtypes in relation to gross motor function, manual ability and neuroimaging findings in multiply challenged children with CP.

Methods: Fifty children with CP (32 males, 18 females) aged 6-14 years (median age 10 y 3 mo) participated in the study. The Visual Function Classification System (VFCS), Gross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS) levels and neuroimaging findings were recorded.

Results: The classification system provided information about daily visual performance. VFCS levels I-II were found in 65% of children with unilateral spastic CP, 40% in bilateral spastic CP and 16% in dyskinetic CP ($p = 0.03$). VFCS correlated with the GMFCS and MACS level ($p < 0.01$). Periventricular lesions and subcortical lesions were associated with the decreased visual ability.

Conclusion: Visual function profiles in CP can be derived from the VFCS, which correlates to gross and fine motor function. An early and accurate description of visual ability is critical in the context of neurorehabilitation of CP. It undoubtedly contributes to neuromotor and cognitive improvement.

Keywords: visual ability, multiply disabled, cerebral palsy, neuroimaging

1. INTRODUCTION

Children with cerebral palsy (CP) often have functional impairments and activity restrictions added to the motor impairment relating to cognition, communication, behaviour, and sensation.

CP is known to be associated with disorders of the visual system including refractive errors, poor visual acuity, accommodative dysfunction, oculo-motor disorders, and cerebral visual impairment [1]. The visual impairments and additional functional disorders lead to decreased visual functioning.

Copyright: © 2017 Katusic et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

The description of visual ability, that is, of usual visual performance in CP children present a complex challenge for the clinician. Thus, visual function classification system (VFCS) with focus on activity and participation levels was developed in order to classify visual functioning of children with CP in everyday life into five levels [2]. Visual functioning refers to how the child actively uses vision to see, direct gaze, recognize, interact with the environment and explore it. Accordingly, VFCS classifies the child's visual ability taking into account both sensory and motor elements of vision.

Many factors may affect visual abilities of a child with CP, among other main motor impairment, thus accordingly influencing VFCS level. The aim of this study was to describe visual function in multiply disabled children with CP and its relation to CP subtype, motor impairment and neuroimaging findings.

2. METHODS

2.1 Subjects

We evaluated 50 children with CP, ranging in age from 6 to 14 years (mean, 10,3 years; SD), who were included in rehabilitation and educational program in Day-care Centre for Rehabilitation Mali dom - Zagreb. This study followed the tenets of the Declaration of Helsinki. Informed consent was obtained from the parents of the children after the nature of the study was explained.

All participants had mild to profound motor and intellectual disability and an inability to communicate consistently through either verbal or assisted communication.

2.2 Procedure

The subtypes of CP were classified according to the Surveillance of Cerebral Palsy in Europe [3] into unilateral spastic, bilateral spastic, dyskinetic, or ataxic CP, by the dominating symptom. Diagnosis was made by the local paediatric neurologist.

The following classification systems were used: 1) GMFCS-E&R was used to classify the gross motor function of children [4]; 2) MACS was used to classify the manual ability of children. MACS classify children with CP according to how they use their hands when handling objects in various daily activities [5]; 3) VFCS was used

to classify the everyday visual performance of children with CP [2].

Neuroimaging findings from magnetic resonance imaging (MRI) were classified into five categories: brain maldevelopment, periventricular white-matter lesions, cortical and deep grey-matter lesions, other lesions, and normal, according to Krageloh-Mann [6]. The group with cortical and deep grey-matter lesions was subdivided into cortical/subcortical and basal ganglia lesions.

2.3. Statistics

Kappa was used to measure inter-rater agreement for the VFCS. Analysis included descriptive statistics and Fisher's test for comparisons of several groups.. Spearman's correlation coefficient was used to study correlations.

3. RESULTS

Results were obtained from 50 multiply disabled CP children. VFCS inter-rater reliability between two assessors was $k = 0.902$.

3.1. Distribution of VFCS levels

The classification system provided information about daily visual performance. Three (6%) children were found at VFCS level I (uses visual function successfully), 5 (10%) at level II (uses visual function successfully but needs self-initiated compensatory strategies). At level III, 15 (30%) children were classified (uses visual function but needs adaptations), while 19 (38%) were at level IV (uses visual function inconsistently) and 8 (16%) at level V (do not use visual function even in very adapted environments).

3.2. Visual ability by CP type

The children with unilateral spastic CP were at VFCS level I-II in 4 of 6 children (65%), while this was the case in 14 of 33 children (40%) with bilateral spastic CP. In the children with dyskinetic CP, two of 11 (16%) use visual ability successfully. The differences in visual ability, expressed as VFCS levels, between the CP types were significant, with dyskinetic CP being the CP type with least functional visual ability, Fisher's test $p = 0.02$.

3.3. Visual ability by gross motor function and manual ability

The level of visual ability correlated strongly with gross motor function expressed as GMFCS levels (Spearman's correlation coefficient 0.76, $p < 0.01$). All the children at GMFCS level II, were at VFCS level I-II. When the MACS was applied, the same pattern emerged (Spearman's correlation coefficient 0.82, $p < 0.01$).

3.4 Neuroimaging and visual ability

Neuroimaging results were available for 42 (84%) children. There was a difference between neuroimaging findings associated with the level of visual ability. In children

with decreased VFCS level, periventricular lesions and subcortical lesions were more prevalent.

4. DISCUSSION

The visual ability may be impaired in several ways for children with CP. In the present study, a new classification, the VFCS, was used to obtain an overview of visual ability in a group of multiply disabled children with different CP types and functional severity. The professional inter-rater reliability for VFCS classification was excellent.

Children were found on every VFCS level. Of the 46% children who use visual function in a consistent way, 13% were classified at VFCS level I, i.e. use visual function successfully. This may indicate the needs for environment adaptation for effective use of vision in everyday life of multiply disabled children with CP. The ability to use visual function successfully was associated with gross motor function and manual ability.

To investigate the neuroanatomical correlates for visual function, we included neuroimaging data. Children with periventricular white matter lesions and subcortical lesions had less effective use of visual function, of which subcortical nuclei lesions were more prevalent in most severe visually impaired children, what is in line with other reports suggesting a key role for the basal ganglia and thalami in the development of visual functions [8, 9].

One limitation of this study is the relatively small sample size, so these findings need to be confirmed in bigger studies. Furthermore, neuroimaging findings can be applied next to functional performance profiles constructed from CP type, gross motor function, manual and communication ability in order to predict future impairment of visual functioning in children with CP.

5. CONCLUSIONS

Describing visual abilities is crucial in considering how a child with CP functions in vision-related activities. Common tools such as the VFCS are needed to include communication in the comprehension of strengths and weaknesses that features multiply disabled children with CP.

Neuroimaging improves the understanding of the neuroanatomical basis for visual function in CP. Type and severity of motor impairment and manual ability is related to the visual functioning, supporting the pivotal role of vision in neuromotor development of multiply disabled children with CP.

Acknowledgments

We wish to thank the participating children and families.

REFERENCES

- [1] E. Fazzi, S.G. Signorini, R. La Piana, et al., "Neuro-ophthalmological disorders in cerebral palsy:

ophthalmological, oculomotor, and visual aspects,”
Dev Med Child Neurol vol. 54, pp. 730-736, 2012.

- [2] G. Baranello, P. Rosenbaum, B.D. Denver L. Haataja, “The Visual Function Classification System,” in *Book of Abstract of 28th Ann Meeting of the European Academy of Childhood Disability*, Stockholm, 2016.
- [3] Surveillance of Cerebral Palsy in Europe, “Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers,” *Dev Med Child Neurol* vol.42, pp. 816-824, 2000.
- [4] R.J. Palisano, P. Rosenbaum, D. Bartlett, et al., “Content validity of the expanded and revised Gross Motor Function Classification System,” *Dev Med Child Neurol*, vol. 50, pp. 744-750, 2008.
- [5] A.C. Eliasson, L. Kruminde-Sundholm, B Rosblad, et al., “The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability,” *Dev Med Child Neurol*, vol. 48, pp. 549-554, 2006.
- [6] A. Someone, B. Someone, and C. Someone, “The title of the conf paper,” in *Proc. Int. Conf. Sound and Music Computing*, Stockholm, 2013, pp.213-218.
- [7] I. Krageloh-Mann, “Imaging of early brain injury and cortical plasticity,” *Exp Neurol* vol. 190, pp. 84-90, 2004.
- [8] L.A. Ramenghi, D. Ricci, e. Mercuri, et al, “Visual performance and brain structures in the developing brain of preterm infants,” *Early Hum Dev*, vol. 86, pp. 73-75, 2010.
- [9] T. Pansell, K. Hellgren, L. Jacobson, R. Brautaset, K. Tedroff, “The accommodative process in children with cerebral palsy: different strategies to obtain clear vision at short distance,” *Dev Med Child Neurol*, vol. 56, pp. 171-177, 2014.

“The Visual data sheet: detailed information on visual disabilities and its impact on daily life.”

Jessica Moens

Centrum Ganspoel

Huldenberg, Belgium

E-mail : jessica.moens@ganspoel.be

ABSTRACT

For parents and supervisors of a person with visual and multiple disabilities it is not easy to have a concise and clear overview of the person's visual disabilities. Parents are often looking for how they can inform the visual performance of their child to a wider public. In order to gather detailed information from the visual disabilities and their impact on daily life we use the Visual Profile of Dr. Paul Looijestijn [1], in Centrum Ganspoel, Belgium. The visual data sheet is a customizable Word document with speech bubbles that are actualized according to the person's development. The file contains information about visual problems, the impact of visual impairment on the functioning of the multiple aspects of life such as reading and writing, managing computers and technology, ADL, leisure and physical activities. The involvement of the visually impaired person is important when filling in the data sheet. During the past two years, our occupational therapists composed this visual data sheet within our centre for a large number of children, adolescents and adults. The visual data sheets were presented to a team of counsellors and parents which were invited to use it as guide for the visual performance of their child.

1. INTRODUCTION

In this presentation, we want to introduce the visual data sheet and share our experiences. An example of a visual data sheet of a person with MDVI will be shown.

The multidisciplinary team (MDT) has a completed file about every person with visual and multiple disabilities. This file is not always accessible to everybody and is elaborated. The MDT saw the need of having a concise summary about every person's visual disability.

This summary can be presented to the family when it is completed, to sports organizations/leisure clubs which the person takes part of, to a new colleague, etc. Immediately one gets a clear view on the visual disability

and its impact on the person's daily life. The sheet is accessible to read and gives an immediate idea of the person's visual disabilities and how to make adjustments for the person and facilitate the tasks of his daily life.

2. TARGET GROUP

The visual data sheet can be drawn up for all persons with visual disabilities. At Centrum Ganspoel we use it for pre-school children, adolescents and adults as for elderly people with VI and MDVI.

3. COMPOSITION AND COMPLETION

The composition of the visual data sheet was created by occupational therapists at Centrum Ganspoel. The occupational therapist fills in and completes the data sheet with or without the target person. The visual data sheet is reviewed with persons who are capable to express themselves on their visual disability. The person's input is considered very important. Through observation information is gathered about people who are unable to communicate verbally anymore. Information is also assembled with a MDT consisting of the oculist, educators, etc.

The visual data sheet is presented and discussed during a multidisciplinary meeting with the target person when possible, the parents, all the therapists and educators. When necessary, the visual data sheet is adjusted annually. It is written from the first-person perspective because it is considered more accessible to read.

3.1 The Speech Bubbles

The visual data sheet consists of six speech bubbles shown and explained below. Within the visual data sheet there are two green speech bubbles where one can put a picture from the person's face and in the other speech bubble a picture of the eyes in order to get an understanding of how the person looks like. At the upper

side of the sheet one can fill in when the data were completed and by whom.

3.1.1 Speech bubble 1: Visual disability.

This speech bubble gives brief information on the visual problem of the person. The person gives up his name and date of birth. Information on eye position, eye movements, visual acuity, visual field, contrast and color is briefly described.

3.1.2 Speech bubbles 2 and 3: Impact of the visual disability on daily life.

The impact of the visual disability on the function of several aspects of learning and daily life such as recognizing objects, pictures and illustrations, reading and writing, the use of computer and technology, environmental adjustments, activities of daily life, orientation and mobility, leisure and physical activities is briefly described.

3.1.3 Speech bubble 4: Lighting

Persons with a visual disability often need a custom lighting in their surroundings such as their workplace. This speech bubble indicates how one can better adjust/adapt the lighting for the surroundings and for the person's workplace.

3.1.4 Speech bubble 5: Information on disability experience.

The person gives information how he/she experiences the visual disability. The person gives information on what you can do to help them.

3.1.5 Speech bubble 6: Reference to more information about visual data.

If somebody needs more detailed information on the visual disability of the person one can look into his/her files.

4. EVALUATION

The visual data sheets were filled in by several occupational therapists and other professionals. While filling in the sheets, some questions and remarks came up which will be described during the oral presentation.

5. CONCLUSIONS

The visual data sheet can be used directly and adjustments can be made during the process. In the meantime, every member of the MDT, the parents and other people who guide the person can get a clear and concise overview of the person's visual disability and contribute to a better guidance.

The visual data sheet is a prototype that is in constant development.

Acknowledgements

Special thanks go to the many professionals in Centrum Ganspoel for their help and testimonials on the visual data sheet.

REFERENCES

[1] Paul Looijestijn, *Het visueel profiel. Een onderzoek naar visuele perceptie, visuele activiteiten, participatie, probleemgedrag en opvoedingskenmerken bij kinderen en jongeren met oculaire slechtziendheid*, 2004.

The Effect of Rehabilitation Using Yoga Elements on Visual Functioning in Young Adult with Multiple Disabilities and Visual Impairment – Case Study

Martina Sedlar

Day Care Centre for Rehabilitation of Children and Young Adults “Mali dom – Zagreb”,
Zagreb, Croatia
martinas@malidom.hr

ABSTRACT

Using yoga positions and breathing exercises have shown to be effective in decreasing visual reaction time in children without disabilities. Objective of this study was to establish if rehabilitation through using yoga elements can influence visual functioning of multiply disabled visually impaired young adult.

Case study was conducted during 6 month period with the 15 year old student with MDVI in “Mali dom – Zagreb”.

The study was divided into three parts:

Baseline - initial assessment was done prior to intervention. During the assessment we measured visual functions (convergence, visual tracking, motility and contrast sensitivity) and visual-cognitive functioning.

Implementation of rehabilitation program created with yoga elements was conducted during period of 4 months 2 times a week. Sessions were 45 minutes long.

Every seventh session reassessment was conducted in order to monitor changes in visual and visual-cognitive functioning.

In order to measure the lasting effect of this kind of program on visual functioning, we did final assessment (follow up) one month after the last session was implemented.

Results have shown changes in pursuit eye movements: wider range of vertical and a narrower range of horizontal eye movements. Quality of vertical and horizontal eye movements dropped during the treatment.

Key words: rehabilitation using yoga elements, visual functioning, young adult with MDVI

1. INTRODUCTION

Yoga is an ancient practice whose aim is to tune up body, mind and soul. It uses different elements in reaching this goal and was shown to have developmental benefits for children with disabilities such as enhancement of motor coordination, increased body awareness and orientation, developed concentration, improved learning skills, creativity and imagination. [1]

Copyright: © 2017 Martina Sedlar. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Children and youth with multiple disabilities (MD) have a combination of two or more disabilities such as cognitive, sensory and motor, and all of these disabilities are in intercorrelation with each other. Children with MD often have difficulties in attention span, memory and visual functioning. One third of children with partial sight have developmental disabilities [2] which puts them in a category of children with MD. Using all elements of yoga has shown to facilitate development of concentration and attention when used as a complementary therapy for children and adolescents [3] and increase verbal and spatial memory [4]. This raises a question of what affect would rehabilitation using elements of yoga have on visual functioning of a multiply disabled visually impaired young adult.

2. METHOD

The study was conducted during the period of six months: from September to the end of December 2016 in Day Care Center for Rehabilitation of Children and Young Adults „Mali dom – Zagreb“.

In the first part of the study - baseline, there was a baseline made by impartial investigator. The investigator tested visual functioning (visual functions and visual-cognitive function) of the participant before the program of rehabilitation using yoga elements started. Then, during the second part of the study – implementation of the rehabilitation program, two sessions a week were held in duration of 45 minutes by the lead researcher. Program is divided in few steps which occur always in the same sequence, ensuring memorization of sequence and anticipation of the next step. Five yoga elements were used: chanting of the Mantras, breathing exercises, eye movements, yoga positions (Asanas), and relaxation. After approximately every sixth session (a period of one month) there was conducted a reassessment by the lead researcher. Every reassessment was videotaped, and the results were recorded by the same impartial investigator to ensure the objectivity. After the forth reassessment was made, the third part of the study, follow up, began. There were no sessions held during the one month period. After that, impartial investigator made another reassessment of the same visual functions and visual-cognitive function, which aim was to investigate potential changes in visual functioning since the last assessment.

All assessments of visual functioning were made in the same room with the same lighting conditions.

Visual functions assessed were: convergence, contrast sensitivity, motility and pursuit eye movements. Visual-cognitive function assessed was matching picture with corresponding object.

Convergence was tested by assessing the nearest point of convergence. At a distance of 30 cm a visually interesting object was shown. The participant was given verbal instruction to follow it with her eyes. Results were entered as “positive convergence” (3 points), “attempt to converge” (2 points), “negative convergence” (1 point).

Contrast sensitivity was assessed by using „Hiding Heidi“ Low Contrast Face Test for Communication. It was tested at a distance of 1.5 m. Participant had to confirm her answer three times. The results were recorded in the following order: 1.25% contrast detected (3 points), 2.5% contrast detected (2 points) and 5% contrast detected (1 point).

Motility was tested only horizontally, for each eye separately. It was tested by using red object diameter 5 cm, at approx. 40 cm away from the participant.

Pursuit eye movements were tested by using red object diameter 5 cm, at approx. 40 cm away from the participant. Vertical, horizontal and diagonal eye movements were assessed by moving the object from midline of participant’s vision to the point her eye movements reach the farthest position to the right. This procedure was repeated for movements of the target to the left and in two vertical and four oblique directions of gaze (up and down to the right and up and down to the left). We recorded quality of the movements (“smooth” – 3 points, “combination” – 2 points, “saccadic” – 1 point) and the range of motion (“full range” – 3 points, “over the center of visual field” – 2 points, “to the center of visual field” – 1 point). Also, it was noted if the participant compensated eye movements with head movements.

Matching picture with corresponding object was assessed by using “Bust test” (Form Perception Visual Acuity Test). In our assessment we used 4 pictures: SPOON, FORK, GLASSES AND SCISSORS, together with the matching objects. Three objects were put on a table in front of participant and two corresponding pictures were offered. The help was provided by positioning. The results were recorded as “confirmation of correct answer three times” – 3 points, “confirmation of correct answer two times” – 2 points and “correct answer given one time” – 1 point.

The results are obtained by visual analysis for single-case study.

3. PARTICIPANT

The participant was a fifteen year all girl with multiple disabilities and visual impairment. She shows communicative initiative by using pointing directed to the object of interest. As a support system in communication and system of presenting activities she is using pictograms and photos. She visually explores the environment, but has a short visual fixation on material or an object. She uses natural gestures (“yes”, “no”, “eat”, “drink”). She is at-

tending habilitation programs in Day Care Center “Mali dom – Zagreb” every week day from 2009.

Her functional vision is satisfactory and she uses it best while communicating. She has difficulties in visual-motor coordination because, when pointing her hand toward visual target, she looks away to the side. Her visual field seems constricted. She shows more accurate answers and longer visual attention when using materials in color.

4. RESULTS

The results have shown no changes in the following variables: convergence, contrast sensitivity, quality of diagonal eye movements, motility and matching picture with corresponding object.

The level of quality and range of horizontal eye movements (pursuit eye movements) have dropped during the implementation of the program and reached the same level which they had on the baseline assessment (Chart 1.). Same thing happened with quality of vertical eye movements. However, range of vertical eye movements expanded during the treatment and follow-up by two points (Chart 2.).

Variable “range of diagonal eye movements” varied throughout the implementation of the study in each reassessment, but ended up on the same level as is started during the first assessment (1 point).

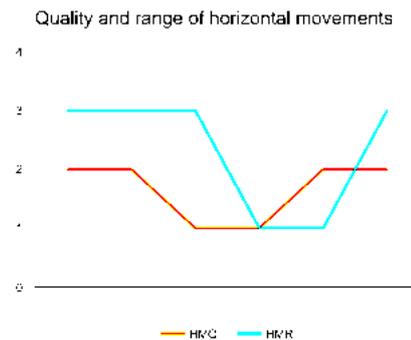


Chart 1. Quality and range of horizontal eye movements



Chart 2. Quality and range of vertical eye movements

5. DISCUSSION

There has been a lot of research made about the benefits of the use of yoga for rehabilitation in children with mental challenges by improving their mental ability, motor coordination and social skills and in children with visual impairment there has been a decrease in their anxiety levels, improvement of their sleep appetite and decrease in physiological arousal [5, 6]. One study has even found that Mukha Bhastrika yoga produced immediate decrease in visual reaction time in children with intellectual disabilities [7].

In this study there we found that convergence, contrast sensitivity, motility and quality of diagonal eye movements' variables remained stable before, during and after the implementation of rehabilitation program using yoga elements. Changes happened in participants pursuit eye movements. Environment factors like the noise in the hall, tiredness and the main diagnosis (cerebral palsy - CP) may contribute to the level of quality and range of horizontal and quality of her vertical eye movements. Children with CP often have difficulties with tracking an object without compensating with the head movements throughout the whole range of their visual field. Motility results showed no change during the study which suggests that oculomotor function is intact, so these results could also be contributed to difficulties with keeping her posture while tracking a visual target and with collaboration of eye muscles or their interrelation with the brain. These children can also easily get distracted by the lowest level of noise in the surrounding. However, all of these factors did not influence the range of her vertical eye movements. Although, people with CP often show better results in keeping the fixation on an object moving horizontally then vertically and this type of tracking is earlier developed during infancy, the participant showed wider range of these movements during the implementation of program and also at the last reassessment. I could not find a reason to explain this phenomenon, but the reason for the wider range of horizontal movements could lie in improvement of her body and head posture which we noticed after every yoga session.

It was also noticed that duration period of assessment shortened from first to the last assessment, which is an indicator of participants learning abilities and longer attention span when familiar tasks are being used. This study was conducted with only one participant, so the results cannot be generalized to population of youth with MDVI, but it gives important considerations for further research. It would be interesting to examine does this rehabilitation program have an influence on duration time of visual attention span, visuomotor coordination or visual reaction time in functional activities (functional vision) with a larger sample size. For example, near task activities require longer periods of focused visual attention, so maybe the use of yoga elements could lengthen this period and consequently affect the participant's performance.

To conclude, yoga therapy can be used as a complementary therapy with children and young adults with MDVI because it empowers individuals to progress toward improved health and well-being through application of its philosophy and practice. [3] To my knowledge there are no studies made yet to explore how yoga influences visual functioning of population with disabilities. A more systematic study is needed to investigate which areas of visual functioning and to what degree this kind of program can affect when used in population of children and young adults with MDVI.

Acknowledgments

I want to thank Ella and her family for accepting to participate in this study, to my colleague Ana Katušić for her time, knowledge and patience, Nikolina Mihalić Kocijan for participating and helping me conduct this study, Snježana Seitz for all her advice, Darija Udovičić Mahmuljin for being open for new ideas and all of my colleagues in Day Care Center "Mali dom- Zagreb" for their flexibility and support during the process of research.

REFERENCES

- [1] J.S. Chittoor, "Yoga for Children with Disabilities", *International Scientific Yoga Journal: Sense*, Vol. 1 (1), pp. 374-380, 2011.
- [2] N.M. Salleh, M.M. Ali, "Multiple Disabilities Among Students with Visual Impairments", *ICEVI publications*, found on the webpage: http://icevi.org/publications/icevi_wc2006/13_multi_disabilities_and_visual_impairment/Papers/ea_035_norshidah_mohd.%20ali%20and%20manisah%20mohd.ali.pdf
- [3] L.C. Kaley-Isley, J. Peterson, C. Fischer, E. Peterson, "Yoga as a Complementary Therapy for Children and Adolescents: A Guide for Clinicians", *Psychiatry*, Vol. 7 (8), pp. 20-32, 2010
- [4] K.V. Naveen, R. Nagarathna, H.R. Nagendra, S. Telles, "Yoga Breathing Through a Particular Nostril Increases Spatial Memory Scores Without Lateralized Effects", *Psychological Reports*, Vol. 81, pp. 555-561, 1997.
- [5] M.L. Galantino, R. Galbavy, L. Quinn, "Therapeutic Effects of Yoga for Children: A Systematic Review of the Literature", *Pediatric Physical Therapy*, Vol. 20, Issue 1, pp. 66-80, 2008.
- [6] S. Telles, KV Naveen, "Yoga for Rehabilitation: an overview", *Indian J Med Sci*, Vol. 51 (4), pp. 123-127, 1997.
- [7] AB Bhavanani, M. Ramanathan, Harichandrakumar KT, "Immediate Effect of Mukha Bhastrika (A Bellows Type Pranayama) on Reaction Time in Mentally Challenged Adolescents", *Indian J Physiol Pharmacol*, Vol. 56 (2), pp. 174-180, 2012

Tactual Profile: the development of the MDVI version

Ans Withagen¹, Anneke Blok¹, Wieneke Huls¹, Ineke Jacobs¹,
Marij de Lange¹, Nanouk Scheening¹ and Miranda Zwijgers¹

Royal Dutch Visio, centre for partially sighted and blind persons,
Huizen, The Netherlands

{answithagen, annekeblok, wienekehuls, inekelijacobs, marijdelange, nanoukscheening, mirandazwijgers}@visio.org

ABSTRACT

In 2014 we started at Royal Dutch Visio with a group of practitioners to develop an addition of Tactual Profile for MDVI persons. Tactual Profile is an instrument that provides a procedure to assess tactual functioning in children, with a severe visual impairment, from birth up to 16 years of age. The instrument has been outlined as a 'structured observation'. The items of the new instrument for MDVI were discussed with an expert group and several pilot studies carried out to come to the final item-set. Tactual Profile MDVI will be available in Dutch in the autumn of 2017 and translated in the near future into English and German.

INTRODUCTION

In the last years there was a strong request from persons who use Tactual Profile to develop a special version for multiple disabled visual impaired. Since Tactual Profile was not especially developed for this target group, we thought it was not the appropriate instrument to use for MDVI. The verbal instructions were too difficult to understand and the steps in development too big. We decided to develop a special MDVI version of Tactual Profile to observe the tactual skills of this target group. In 2014 we started with this project.

1. THE DEVELOPMENT

The project group consisted of a behavioural scientist PhD in special education, occupational therapists, teacher of MDVI children, rehabilitator in early intervention, MDVI specialists and a speech therapist. This group created the first item-set, which was based on Tactual Profile, experience and relevant literature [1,2,3,4,5,6].

An expertgroup of experienced psychologists and other professionals in the field of visual impairment and an expert form in this field from the Radboud University Nijmegen was set up to comment on the ideas of the projectgroup. In 2015 and 2016 there were several trial versions of Tactual Profile MDVI assessed in pilot studies. A pilot study has been carried out with a group of 12 persons with different levels of cognitive development and different age groups. The value of the instrument was proved in the pilot assessments. The results were evaluated with the expertgroup and the item set was adapted

after every trial. This results in the final version of Tactual Profile MDVI.

2. TACTUAL PROFILE MDVI

There are several differences between the regular Tactual Profile and the MDVI version.

The first is that prior to an assessment, an extended interview will take place with a person who knows the MDVI person well. This can be a parent, teacher or care taker in a setting for MDVI persons. The reason for this, is that the attention span for achieving an active assessment is less lower in MDVI persons.

General data will be gathered and the mental developmental level will determine the developmental phase of the instrument: A (0-2 years), B (2-4 years) or C (4-6 years). Next the Alerting Signals must be considered.

The Alerting Signals refer to hyper or hypo reaction to tactile stimuli, they can be taken in account when the items are offered to the person in the assessment.

2.1 Item-set

The main categories are the same as in the original Tactual Profile, which are:

- tactual sensory functioning; Noticing, Body awareness, Touch sensitivity, Proprioception
- tactual motor functioning; Manipulation, Two-handedness
- tactual-perceptual functioning; Recognition, Perception of detail, Part-whole relationships, Tactile-spatial perception, Figure-ground perception, Tactual language, Touch Strategy

The steps in an assessment are more refined than in Tactual Profile. The instruction is less verbal and when possible non-verbal. The persons are evoked more explicitly to show tactual responses to the items which are presented.

2.2 Survey of factors which influence tactual perception

Tactual Profile MDVI also offers an overview of Factors, which influence tactual perception and functioning. The survey provides a so-called tactual conceptual framework.

They were specially written with MDVI persons taken in account.

For example:

In **Client Variables:** Motor development, Alertness, Incentive regulation, Exploration style: taking initiative, preference for touch.

In **Stimulus Variables:** Living environment variables: how do persons in his environment approach the client, impact of atmosphere. Distractors: sound, smell, amount of sensory stimuli.

This survey can be used when evaluating the performance of a person on the assessment. The results of the observation in combination with the conclusions from the survey will be the starting point for stimulation and training of tactual functioning.

For the assessment a special set of material was composed, when the instrument will be available they will be included in the observation kit.

3. IN CONCLUSION

Tactual Profile MDVI can be used for assessments with MDVI persons, children as well as adults with a severe visual impairment and mental disability.

The outcome of an assessment with Tactual Profile MDVI will give an idea of the type of tasks which might be difficult for this person. For instance, is this person able to perform a combined task. Think of listening to a verbal instruction when tactile exploring is demanded.

But also how long will it take for a person to react to an offered task and what is the impact of cluttering stimuli.

A so called tactual crowding effect, where multiple objects or textures can be detected at the same time.

The results of the MDVI-Tactual Profile will be the starting point for stimulation and training of tactual functioning. The project group would like to write an addition for MDVI to Feel Free (activity book for Tactual Profile) to stimulate and train tactual functioning, after an assessment.

REFERENCES

[1] Withagen, A., Vervloed, M.P.J., Janssen, N.M., Knoors, H. & Verhoeven, L. (2009). The Tactual Profile: an assessment procedure for tactual functioning of children who are blind. *British Journal of Visual Impairment*, 27,3,221-238.

[2] Withagen, A., Vervloed, M.P.J., Janssen, N.M., Knoors, H. & Verhoeven, L. (2010). Tactile functioning in children with blindness: a clinical perspective. *Journal of Visual impairment and Blindness*, 104, 1, 43-54.

[3] Withagen, A.J., Baerwaldt, I., Blok, A.G., Ekkens, E., Hamelink, A. & Vervloed, M.P.J. (2005). Tactual Profile (Manual). Kortenhoef, Netherlands: Xsites BV.

[4] Hatwell, Y. (2003). Introduction: touch and cognition- In Y. Hatwell, A. Streri & E. Gentaz (Eds.), *Touching for knowing* (pp.1-17). Amsterdam: John Benjamins Publishing.

[5] Lederman, S.J., & Klatzky, R.L. (1987). Hand movements: a window into haptic object recognition. *Cognitive Psychology*, 19, 342-368.

[6] Millar, S. (2008). *Space and sense*. New York: Psychology Press.

Transition from Adolescence to Adult Life

Riet Gyselbrecht, Arlette Vermeire, Kathleen Deweerdt

Secundaire School Spermalie
B- 8000 Brugge - Belgium
buso-spermalie@de-kade.be

ABSTRACT

“What comes after school age?” This question is so often asked, when talking to our students and their parents. An urgent question for students whose perspective is to move to a day-care centre. To prepare students and their parents for this future step, we focus on this transition from early on in their school career. The school curriculum is therefore build around these 3 themes: ‘work’, ‘living skills’ and ‘free time’. One of the groups in our school, called ‘JOVO’ which is short for “Jong Volwassenen (Young Adults), is actively preparing the transition from adolescence to adult live. A key item in this program is ‘Social and Society Training’ (Sociaal Maatschappelijke Training - SMT). At the beginning of the school year the team of teachers consider and plan the individual activities for each student. Specific needs and talents of each student are the starting point for an individual program for each student and his/her network. The individual program is build step by step towards the main goal of the future adult life in a day-care centre or group home. At a certain time, the student and his/her teacher, parents and a family-counsellor will visit different day care centres and/or group homes for adults. They learn about different types of activities, organizations and support systems for adults. We want to show concrete examples of how a transition project can be realized in a pro-active collaboration of all partners concerned.

1. INTRODUCTION

Secundaire School Spermalie is one of 2 school for secondary education in Flanders that that provide special education for students with visual impairment. All of our students (aged 12-24) have multiple restrictions and complex needs, which is the reason for being oriented to our campus. The majority of our students have a learning disability, and will need continuous support in adult life. In this perspective we see the transition from childhood to adult life as our main responsibility in organising the school program. This paper will present “Mary”, aged 19. She is a vivid adolescent with visual impairment, CVI and a learning disorder, describing a brief overview of how we support her transition through an adapted school curriculum and in a rewarding collaboration of school and guidance

centre / centre of expertise of vzw De Kade (Bruges – Belgium) .

2. THE SCHOOL CURRICULUM

In Flanders, each school for special education whose students will have a future in one form or another of a ‘sheltered’ adult life, has to work within the legal framework of the developmental goals, set clear by the Department of Education (**Vlaamse overheid, 2016**). These goals are structured into 3 specific domains: Selfcare/Living Skills, (*productive*) Activities/Work and Leisure/Free Time. A 4th domain focusses on general competences (self-awareness, communication, ...). Each school for special education in Flanders has the responsibility to translate this general framework into a specific curriculum that meets the needs of the specific population of their own school.

Starting secondary education at the age of 12 of 13, our first focus of the curriculum is the exploration and broadening of talents and interests. Specific skills that are the core business of primary education (learning to read and write, counting, ...) are still major learning goals, but are progressively switching to functional goals (shopping list, price tags, menu’s, ...). In a range of thematic projects (for example: family relations, clothing, theatre, waste management, ...) specific learning goals are introduced. These projects not only introduce social and practical knowledge. They also aim at a set of general competences that strengthen the student in his or her personal life: making choices, setting their own goals, making compromises, recognising and communicating needs, etc.

Starting from the specific talents and interests of each individual student, that occur through these first 2 to 4 years of secondary education, the curriculum activities gradually move away from the school campus towards other locations that might suite as a possible place of adult support. The set of goals for each student shift focus from general and fit for (almost) all students towards very specific goals focussing on the personal plan of action for this student. At a certain point in this plan of action, we explicitly start with a ‘Transition Plan’. From that point on, the main focus of the individual curriculum of the student is on the

closure of the school career and starting adult life. This shift usually occurs around the age of 18 (19).

A key characteristic in our school is a very close collaboration between teachers and the support team of the guidance centre (centre of expertise) of our organisation. Each has a specific role in the process of exploring, DECIDING on and preparing each next step in the process. A “trajectory supervisor” has a broad perspective on the developmental history of the student. A family counsellor supports the family over the years, which makes it possible to build a stable relationship with parents. Group home counsellors and teachers match their developmental goals, ...

From the first year on, on Tuesday mornings the school program is organised in the form of “workshops”, offering a first experience with the way activities are organised in most day care centres. Students take turn in different workshops to become acquainted with new materials and develop new skills: woodwork, cooking, arts and crafts, ... Also from the very beginning, on Friday afternoon, the school program focusses on making a personal choice between the activities that are organised. Students have to make their own choice between a computer class, a language class, relaxation activities, ... For some students, this is a complex skill to develop in order to be able to make their own choice as an adult in the day care program.

Once students get older, more functional skills are introduced in their curriculum. This shows in the way different themes are introduced in the ‘GASV’- lessons where functional social and practical skills are developed and trained (using public transport, ordering a meal, paying groceries, ..

Depending on the skills and talents of the students, different ways of processing information are used: a report in writing, a recording of a spoken report, posters, etc.

3. “MARY”

3.1 First step in the Transition Plan

Mary approaches her 19th birthday. Her parents already discussed their concerns and ideas for adult life from the start in Secondary education 6 years ago. They were quite realistic about the amount of life long support their daughter would need. Through the years they were well aware of the need to have a specific focus on preparing for adult life. They were keen to shift from the ‘technical’ skills of reading (letters) and counting towards functional skills. The theme of ‘adulthood’ was constantly present, so the start of the transition plan and preparing SMT came as a logic step to take. Which is not always the case. Sometimes the school and support team need to create the awareness that school will not go on for ever. Parents want their son or daughter to keep on training the technical aspects of counting, reading, ... and have a hard time to accept the limits of time that is put into these exercises, in order to focus on

functional application... In other cases, it might be the student himself that asks to put his school career to an end. He might be interested by the experiences of a classmate, he might want to move closer to the place where his family lives, ... This being an illustration of the importance of ‘general’ competences of making own choices, communicating and expressing preferences, setting your own goals, ...

As a first step in the process, the trajectory supervisor and family counsellor support parents to explore all forms of adult support in their area. Flemish Government provides an overview (**Vlaamse overheid, 2017**) which might reveal unexpected possibilities that match the needs of Mary. They accompany parents on a first visit at selected organisations. Since Mary lives at quite a distance of the location of our school, some of the organisations on the list are new to our staff. This means that supporting a girl with visual impairment might be also a first tot this organisation, and there is more to explore and discuss concerning specific needs, that are taken for granted when the organisation is already familiar with persons with visual impairment: illumination of the room/ specific software (Guide, Supernova...) adapted surface on the desk / contrast / mobility training i.e. use of stairs / ...

3.2 School Program: SMT (Social and Society Training)

After parents and staff explored the possible adult support centres in their area, we plan the next step that is part of the school curriculum: “SMT”. SMT means that a student takes part in the activities of a group home or a day care centre. From the age of 18 on, SMT is part of the legal framework. Unless special motivation, this is limited to 30 days per school year.

SMT is part of the school curriculum, so at this point one of the teachers takes responsibility in contacting, preparing, introducing, ... all partners. She not only contacts the adult support organisation, but goes to visit the selected day care centre of group home to explore, discuss, ... all elements of the training, and make practical arrangements. If needed, she can ask an occupational therapist to advise the adult support organisation in the adaptations needed regarding the visual impairment of the student.

As noted, there can be 30 days of SMT in one school year. Depending on different parameters this can be 1 day a week for the whole of the school year, 2 times 2 weeks in a row, ... and can gradually build up from a short first experience to a more intense long-term training towards the end of the Transition Plan. This way, several possible forms of adult support can be tried and evaluated.

At the beginning of each school year, there is a teacher-parents meeting, to discuss the main goals for the coming year. This year in September, when Mary was almost 19, the first SMT-activities were announced and agreed on. Location (= one of the organisations parents previously visited in their neighbourhood), duration, time of the year, etc.... Teachers, group-counsellors and therapists agree

on the adaptations in the environment that are important for Mary to transfer to the day care centre: she has to take her walking rack with her, there is special attention needed when using stairs, etc.

In preparing SMT, Mary's teacher gathers all information about the day care centre, which she shares with Mary. Together they investigate what workshops are going to be part of her program. They discuss the schedule and select the workshops that match her skills, talents and interests. They discuss what are criteria to evaluate, how to use a communication book to inform parents and school,... A first visit to the day care centre makes all information more concrete, and on the other hand creates more questions to be answered: What about breaks? Can I drink my favourite soft drink? Do I need to wear special gear to participate in the gardening workshop? At what time do I have to leave home, etc.... Using the strategies of a GASV-report, all information is brought together. Her familiar therapist helps her in training the route from home to the day care centre.

Once the SMT starts, Mary's teacher stays in close contact with the responsible of the day care centre. She can assist in solving any problem that might occur. In a meeting at the end of the SMT-period there is a closing evaluation of the teacher and the responsible of the centre: what skills need to develop? What new experiences might be interesting to explore, ... At school all this is discussed with Mary, her parents and school staff. This information inspires further activities in the school curriculum for both Mary and in general.

At a certain point, after a number of training-periods, it becomes clear what the most suitable place for adult support can be for this specific student. This doesn't automatically mean that the transition from school to adult support can be made at that point. All students that have SMT in their curriculum and that are working on transition, are together in one class group 'JOVO'. This creates a common motivation to work on specific skills and focussing on adulthood. Certain competences that need attention are introduced to the individual school curriculum which continues to add to the personal development of each student.

3.3 Final transition to a Day Care Centre or Group Home

Unfortunately issues of capacity and lack of open places in the adult support system might cause delay. So even though it is clear where the next step leads, there is a period of time between this moment and the final step of finishing school and moving in. The context of JOVO makes it possible to organise an adapted program in a specific type of collaboration between school and guidance centre. Gradu-

ally this group takes the rhythm of the adult life as a guideline in the daily programme. Learning and living are part of one integrated, continuous unity.

A specific effect of the unpredictability of vacancies in the specific adult support organisation (day care centre or group home) is that students aged 21 or older are on waiting lists, and that the day of leaving school can be at any given moment in the school year. So this JOVO-group organises goodbye parties at any time. It is an essential part of the group dynamics of JOVO

Mary is not ready for leaving school yet. She only started her path to transition and has many steps to take. But for students that left school for day care or group home, again staff of the guidance centre has a new task: Specific support to get started consist of outreach, counselling, continuous family support until he or she is settled in. Intensity of this service depending on the specific experience of the adult support organisation in the field of visual impairment.

4. IMPACT VISUAL IMPAIREMENT

In exploring different services for adult support, we find some highly experienced services that have yearlong knowledge and expertise. At the other hand, the majority of organisations might often be unfamiliar with the specific needs of (young) adults with visual impairment. It takes quite some counselling and advise to adapt and adjust the environment, and to brief the staff about specific needs. This is an important part of the task of the teacher that organises SMT, which might be the first contact of staff and others, with a person with visual impairment. In this, the collaboration with the expertise centre is an important extra that adds value and quality to the training of students.

5. CONCLUSIONS

Thanks to the intense collaboration and cooperation between our school staff and guidance centre (therapists, family support, group home counsellors & trajectory supervisor) we can support this important transition from school age to adulthood more in detail than any average school. The fact that the school curriculum can match the very concrete needs of the student creates a maximum of productivity and result. Teachers are experienced in setting goals and evaluating these goals in a continuous 'PDCA' process. Group home counsellors have a specific focus on Daily Life Skills and talents, the family counsellor who knows the parents for years, can support them in making important choices, etc. All this is a common and well-tuned effort to create a maximum of Quality of Life

REFERENCES

- A) Vlaamse overheid. (2016, 04 26). *Curriculum Buitengewoon Onderwijs*. Retrieved from www.ond.vlaanderen.be:
<http://www.ond.vlaanderen.be/curriculum/buitengewoon-onderwijs/secundair-onderwijs/opleidingsvorm1-2/algemene-ontwikkelingsdoelen/Algemene-ontwikkelingsdoelen-OV1-2.pdf>
- B) Vlaamse overheid. (2017, 04 26). Retrieved from Overzicht van voorzieningen uit de welzijns- en gezondheidssector in de Vlaamse provincies en Brussel: <https://www.desocialekaart.be/>

Transition from youngster towards early adulthood in different aspects of life

Eva De Stecker¹, Sharon Deprez²,

¹vzw De Kade, Begeleidingscentrum Spermalie
Brugge, Belgium
Eva.Destecker@de-kade.be

²vzw De Kade, Begeleidingscentrum Spermalie,
Brugge, Belgium
Savi.horizon2@de-kade.be

ABSTRACT

This presentation is about how youngsters with a visual impairment can experience different challenges in becoming maximally independent people when leaving (boarding)school.

Within the working with the youngsters, we foresee different contexts which gradually lean more towards a sense of responsibility and daily knowledge. Step by step they prepare themselves in becoming young adults who can use different strengths to increase their quality of life. Through the concept of studio training and/ or a stay in 'het Reihuis' youngsters can reach a degree of independence that relates directly to a sense of self-confidence. They learn a range of activities of daily living, topics about health and healthcare, budgeting and interpersonal relations, in a coaching relationship with their caregivers.

1. INTRODUCTION

We endorse the principles of Prof. Dr. Bob Shalock, who claims that quality of life is important for every human being and that a person with a visual impairment has or should have the same opportunities as each other person to pursue his own goals.

We also try to think solution-oriented: What could the solutions be for problems that are experienced? What can I do (as a person with a limitation) and where can others help me? And also: What can I mean to others? The focus is on the strengths of the young people and not on their limitations (which does not mean that we do not take these restrictions into account. This also means that we leave from the wishes of the youngster because we believe that the best result is achieved if the young person is self-motivated.

The young people we work with are between the ages of 14 and 21 and all have visual impairment (visibility / blindness). Sometimes there is an additional limitation (mental impairment, ASS, ..) The adolescence as a period of change, in which its own identity is further developed and the younger ones have to make certain choices. This is often even more difficult for people with visual impairment.

Good support on different levels during this process is therefore crucial. We focus on the strengths of the young people, we create (safe) experiential space and respect the individualities and questions of each individual. In this way, we hope to contribute to a sense of self-esteem, self-confidence and confidence in the future.

The pillars that may be addressed include: speech and participation, planning, budgeting, network development and household tasks / knowledge of the services. Of course, throughout the entire course, attention is also always paid to social skills and the social-emotional well-being of the young people.

2. CARE GROUPS

Young people usually start in our care groups when they are 15 or 16 years old. The first year(s) they stay joint in group. However, within the operation of these groups, the first steps towards independence and self-reliance are set.

Every young person gets responsibilities in (small) household tasks: table setting and cleaning, preparing something, shopping, answering the phone. The leisure activities in a group on Wednesday afternoon are made by the young people themselves. Upon completion of this, assistance may be requested from the supervisors. The supervisors organize themes with a view to the future: budget / financial planning, social skills, what is the offer of social services, ... On a regular basis, there is a 'Trek-my-plan-afternoon', where the youngster chooses how to complete it. This can be done on an individual basis or in the company of other young people from the care group.

Every three months, the care group is evaluated in all its facets together with the youngsters and adjusted if necessary.

3. STUDIO

In a second phase, our young people can grow into a stay in the studio. This studio is located close to the living areas, in the same building. At the studio, only one or two persons can stay. The frequency of stay (the number of days per week) is determined in consultation with the youngster. During the training in studio, the youngsters try to do things on themselves. They eat in the studio, do their part in maintenance and spend their free time separately from the group. When the youngster leaves the studio or when a visit is made, the group attendants must be informed. With the help of fictitious money, purchases can be made in the care group, which makes the young person take further steps on the level of planning and budgeting. Individual goals are discussed together with the youngster, based on a practical guide designed for this purpose.

4. REIHUIS

We are fortunate to make use of a typical 'Bruges' cottage nearby the care groups. In this house, each school year up to 3 students can live together. There are 3 bedrooms available. Living space, kitchen, bathroom and terrace are used in common. Prior to the start of a school year, a number of criteria (age, presumably final year in Spermalie, motivation, a degree of self-reliance, open-mindedness for guidance, etc.) are considered. Based upon these criteria, the decision is made of who can live in the house the next school year.

The residence in the Reihuis takes place in a number of phases. At the start, the youngster gets the space to get to know the house and the housemates. There are no immediate goals yet. The task of the group supervisor is for this moment to observe. During 1 hour a week, common guidance is provided for all the youngsters: focusing on the mutual dynamics, division of tasks, ...

After about two weeks, a plan of action will be set up based on the practical guide (see "Studio"). This plan of action sets out the points the young person would like to work on during the stay at the Reihuis and also the requirements of the supervisor. Based on the action plan, individual guidance starts. Depending on the person's questions and care needs, the supervisor will visit one or two times a week at the Reihuis for about 1 hour. In case of urgent questions, the youngster can always seek for help in the care group or can call up. In addition to the on-site coaching conversations, mobile guides are also offered: mobility training, making certain purchases, making contacts for leisure activities, ...

In this whole process, of course, parents are also very important and involved. However, the youngster is central: where does he or she want to gain more independence? What does he or she like to achieve in the future? And how can we all work together to ensure that that unique young person is able to live a good life?

Thanks to the youngsters and supervisors of the 'Horizon' care group.

REFERENCES

General vision text 'Horizongroepen'

The linkage between self-determination and psychosocial functioning of adolescents with a visual impairment

Eline Heppe¹, Sabina Kef^{1,2} and Carlo Schuengel¹

¹Vrije Universiteit Amsterdam, Faculty of Behavioural and Movement Sciences, Clinical Child and Family Studies and the EMGO⁺ Institute for Health and Care Research, Van der Boechorststraat 1, 1081 BT Amsterdam, the Netherlands
e.c.m.heppe@vu.nl; s.kef@vu.nl; c.schuengel@vu.nl

²Bartimeus, Zeist, the Netherlands

ABSTRACT

Aim: Adolescence is a period characterized by transitions and transformations, across physical, psychological and social domains. Self-determination is as much an outcome as a process factor within these transformations, closely related to psychological functioning. Youth with a disability are often less stimulated in self-initiated and volitional behavior, manifesting itself in dependency and overprotective parenting. This study focuses on the linkage between psychosocial functioning and basic psychological needs according to the Self-Determination Theory (1) for autonomy, relatedness, and competence of adolescents with a visual impairment (VI).

Method: 77 adolescents (35 male, 15-22y) having a visual impairment participated. Reliable and well-known questionnaires for self-esteem, loneliness, well-being, and the three basic psychological needs were administered via computer assisted telephone interviews (2).

Results: The mean scores on the three basic psychological needs of autonomy, relatedness and competence are rather high. Furthermore, no significant differences for people without disabilities (3) emerge, except one: youth with VI score higher on autonomy than persons without VI ($p < .05$). Results show that satisfaction of the basic psychological needs is associated with well-being, loneliness, and self-esteem. Regression results point towards the importance of especially relatedness and competence on psychosocial characteristics (R^2 ranges from .20 to .56, $p < .003$).

Conclusion: This study provides evidence for the important role of satisfying the basic psychological needs for self-determination during adolescence. Our results suggest that compensating support systems must be established, especially for those adolescents who are at risk of not meeting their basic psychological needs.

Acknowledgments

This study is financially supported by two organizations: Vereniging Bartimeus Sonneheerdt and ZonMw, the Dutch organization for the Health Research and Development program InSight (grant number 94309005). We want to thank Dr. Deborah Gold (international consultant of this study) and Sanny van der Steen and Jan Jaap Slobbe for coordinating the recruitment of participants from Royal Dutch Visio and Bartimeus.

REFERENCES

- [1] Deci E.L. & Ryan R.M. (2000). The “what” and “why” of goal pursuits: human needs and the self-determination of behavior. *Psychological Inquiry*, 11(4):227–68.
- [2] Heppe, E. C., Kef, S., & Schuengel, C. (2015). Testing the effectiveness of a mentoring intervention to improve social participation of adolescents with visual impairments: study protocol for a randomized controlled trial. *Trials*, 16(1), 506.
- [3] Chen, B., Mouratidis, A., Ryan, R. M., Sheldon, K. M., Soenens, B., Petegem, S. van, Verstuyf, J., Vansteenkiste, M., Beyers, W., Boone, L., Deci, E. L., Kaap- Deeder, J. van der, Duriez, B., Lens, W., & Matos, L. (2014). Basic psychological need Satisfaction, need frustration, and need strength across four cultures. *Motivation and Emotion* 39(2), 216-236.

Websites:

<http://www.mentorsupport.nl>

<http://helios.psy.vu.nl/verderkijken/index.html>

<http://www.emgo.nl/research/mental-health/research-projects/1401/guides-to-social-participation/background/>

Copyright: © 2017 Heppe et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Methodology of the training “Passeur de sens”©: accessibility in the cultural and touristic fields to improve quality of life

Stéphanie Demartin, Sophie Hamaide
Œuvre Fédérale Les Amis des Aveugles et Malvoyants,
Ghlin, Belgium
s.demartin@amisdesaveugles.be
s.hamaide@amisdesaveugles.be

ABSTRACT

The Federal Works Les Amis des Aveugles et Malvoyants organizes training courses for professionals of diverse sectors aiming to maximize the accessibility for the visually impaired. In the field of culture and tourism, the "Passeur de sens ©" course integrates a specific methodology, including multisensoriality in the putting in accessibility to encourage the creation of mental representations that generate meaning and vector of emotion for the public with specific needs. Integrating the expertise of museums, the training joins double in a participative approach, since the visually impaired people also validate the adaptations carried out by the "Passeurs de sens".

1. INTRODUCTION

Initially induced by sensory impairment, disability is also defined by contextual and environmental factors and influences widely the social participation. While some aspects fall within the scope of the individual's ability to adjust to disability, others are of the corporate social responsibility in the sense that accessibility must be ensured for all, whatever are the possible specific needs. It is within this framework that our formative initiatives aim to maximize the accessibility of cultural, tourist and leisure sites (the accessibility constituting a major stake in social relationships, in autonomy, in inclusion in the society and therefore of the quality of life). In the field of the cultural, touristic practices and of the leisure activities, the challenge consists of the increase of the accessible offer, allowing autonomous access to activities that generate pleasure and self-fulfillment for all.

It is in this context that the training "Passeur de sens" joins and aims at endowing the professionals of the cultural and touristic sector with theoretical and practical skills around the welcome of the public not or partially-sighted. The objective consists in integrating multisensoriality into the putting in accessibility, in order to allow the creation of mental representations with meaning and emotions for the visually impaired people.

The content integrate at the same time both aspects related to visual impairment and its functional consequences, as well as aspects related to the accessibility and development of specific tools (audiodescriptions, multisensory adaptations, etc.). The methodology is global as far as the training involves museums and integrates their expertise but also solicits the participation of the visually impaired people who systematically validate the adaptations carried out by the "Passeurs de sens".

Through testimonies of people with visual impairments and illustrations of adaptations, we propose to illustrate in what the training of the professionals around accessibility constitutes a vector for improving the quality of life.

2. CONCEPTUAL FRAMEWORK

2.1 Accessibility

The structural problems bound to the accessibility are many while she establishes a major issue in social relationship, in autonomy, in inclusion within the society and, consequently, in quality of life in what she favorites the extension of the access to the citizenship – including cultural citizenship - for all.

Envisaged in a universalist perspective, the putting in accessibility represents a qualitative earnings for a widely spread public, since it exceeds the problem of the specific needs related to the disability. It allows to reduce the influence of the contextual and environmental factors in the definition of disability as far as it exercises a positive influence on activities and social participation. In particular, the accessibility in the tourist and cultural field exercises an action at the individual level, since the participation of individuals in adapted activities is increasing, but also at the societal level because the training of the professionals allows to increase the availability of accessible services.

2.2 Mental representations and multisensoriality

No perceptive modality equals vision in the quantity and quality of information provided. In the situation of visual impairment, the global space escapes the perception and that within reach of the compensatory sensoriality arrests in a circumscribed and sequential manner. The visual impairment impacts on the cognition and on the way in which individuals construct their mental representations, since they must be developed on the basis of other sensory perceptions, complementary or not to the visual residue (when it exists). The world being multimodal, the cognitive aspects resulting from the use of one or the other sensory modality and the influence of other factors, among which emotions, lead to the construction of mental representations presenting a subjective character.

This is particularly true in the cultural and artistic field which involves the subjectivity and the emotions of the public. In this domain, sensory perceptions and mental representations which result from it allow the access to the meaning but also to the esthetics and to the emotions. The transmission of cultural, artistic or architectural con-

tents is a complex exercise insofar as the mode of approach must be determined on a case-by-case basis, so as to favor rich mental representations and likely to perceive the sense and the esthetics. This approach establishes an exponential challenge because, in particular, art in essence promotes and authorizes multiple and contradictory interpretations for every person facing an art work.

3. METHODOLOGY

3.1 Objectives

The training "Passeurs de Sens" aims to promote the inclusion of visually impaired people by creating social and cultural opportunities in their intention. By a better apprehension of the situation of sensory deprivation, the professionals in charge of the mediation are trained in the practice of accompaniment, to identify needs and opportunities of putting in accessibility, to use tools to design adaptations for the target public and to evaluate the relevance of the adaptations carried out.

3.2 Contents

The "Passeurs de Sens" training, provided by professionals of the Amis des Aveugles et Malvoyants, experts in the visual impairment approach, gets organized over three days. Interactive and deductive, it is based on theoretical concepts, practical exercises, simulations and exchanges.

It aims at developing the knowledge of the mediators through a theoretical approach (demystification of the visual impairment, the forms of low vision, functional consequences of the visual impairment, the identification of the specific needs and the adaptation possibilities, mental representations, accessibility, etc.)

The skills of the mediators are pulled around the implementation of a specific accompaniment (attitudes to adopt face for a person with visual impairment, guide technique and displacement of the visually impaired person, etc.), of the discovery of tools intended to promote the accessibility for the visually impaired, of their appropriation and the learning in their use in the adaptation work (guided tours, tactile adaptations, olfactive adaptations and audiodescriptions, bi- or three-dimensional models, adaptations in Braille and in large characters, etc.). Finally, the mediators are invited to evaluate the proposed alternatives in order to increase accessibility.

3.3 Participative approach

The participative approach of the training "Passeurs de Sens" is embodied, on the one hand, in the contribution of long-established museum partners formed into the putting in accessibility. Thus, a part of the training takes place in a situation, in the infrastructures of the museums and from the art works which are exposed into it.

This formula offers the advantage of enabling the participants to identify the set of parameters to be considered within the context of a adapted visit to the not and partially-sighted persons. The real situation scenario encourages the awareness of important elements which may seem harmless (need to describe the places, longer welcome of

the public, travel time more consequent, etc.) and favors the authenticity of the situation scenarios.

On the other hand, a group of impaired people representing the target public provides assistance in the context of visits test. These are organized at the end of the training and before every new offer, on the site of the mediator. Their objective is to validate the integration of knowledge and skills - and therefore the quality of the putting in accessibility - by a pilot group compound of professionals of the visual impairment and visually impaired people. Putting the target public at the heart of the work of adaptation enables mediators to a better knowledge of this public, to encircle better its expectations, to refine the implementation of the adaptations of the contents and the possible infrastructure improvements. At the end of the visits test, the participants share their experiences, comments and proposals in order to optimize the adequacy of the arrangement to the expectations of the visually impaired people. This way of contextualizing the discovery as well as the representations and interpretations generally admitted for an art work also allow the sighted persons to apprehend the art work in an alternative way. Spaces of exchange can then be opened and be built.

4. CONCLUSIONS

Although multimodal, the world in which we evolve remains mainly visual. In the cultural and tourist field, one must note that the majority of works of art are addressed almost exclusively to the visual modality. How, then, make feel works to a public deprived of this sense? How to describe them without betraying their evocative power? How to favor the creation of mental images and to arouse emotion? This is all the challenge there which faces to the cultural and tourist mediators. How to share this vast and rich universe with people who are blind or visually impaired? How to envisage the multisensory approach in such a way as to arouse the creation of mental images allowing to approach the esthetics, but above all, the emotion?

The putting in accessibility of the cultural and tourist sites is vector of inclusion since the visually impaired people can reach these contents autonomously, in the same way as their sighted congeners. Moreover, the approach goes beyond the needs of this specific public and allows to create tools and contents useful to all publics. In this context, the training of professionals is a significant factor of success in the mediation because it contributes to the better understanding of the issues and the challenges for a better social participation of this public. Promoting the inclusion of the visually impaired public and its social participation undoubtedly contributes to the improvement of its quality of life.

Advising assistive technology in the era of Universal Design

Jeroen Baldewijns

Blindenzorg Licht en Liefde,
Brussels, Belgium
baldewijns.jeroen@lichtenliefde.be

ABSTRACT

Until some time ago, visual impaired people needed to use assistive devices to gain access to computers. These assistive devices were developed by highly specialized companies, who are very aware of the special needs of people with vision loss or no vision at all. Therefore, they developed magnifying software, screen readers, synthetic speech engines and braille displays ... And each time Microsoft came up with a new Windows version, they had to make their products compliant to this new situation.

Some years ago, Apple started producing Universal Design products: computers, smartphones, tablets, smart watches, set-top boxes. These products are accessible out-of-the-box, without having to install extra access products, such as magnification or screen reading software. Google followed this trend by making Android accessible and Microsoft began to join recently.

This evolution has a huge impact - both positive and negative - on the use of ICT-devices by visual impaired people. Issues such as financing or support have to be solved.

Organizations that provide independent advice in assistive technology, have to implement this Universal Design approach into their services, based on a correct assessment. This is not an easy exercise. How can a consultancy service cope with this?

During this lecture, we will explain how Blindenzorg Licht en Liefde reorganized its consultancy service on assistive devices in this era of Universal Design.

1. WHAT IS UNIVERSAL DESIGN?

Universal Design means that the provider of a product or a service makes reasonable efforts to assure that his product or service can be used independently by as many users as possible, including any persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability.

Within the ICT domain, Apple was an early adopter of UD by adding a large amount of facilities for handicapped users, such as: VoiceOver with speech and braille support, Zoom, magnifier, Speak screen, Inverted colors, Font adjustments, Audio description, Compatibility with hearing aids, Vibrating alerts, Closed captions, Switch control, Assistive touch, Text prediction, Speech dictionary, Guided access, Safari Reader, Dictation, Siri, ... Many of these facilities are available throughout the

complete product line-up: Mac computers, iPhone, iPad, iPod, Apple Watch and Apple TV.

But we tend to forget that there exist other good examples of Universal Design. A very nice Universal Design approach is applied in the products of the Flemish public television broadcaster, VRT. They make big efforts in order to make their TV-programs accessible by adding audio description for visual impaired watchers and Flemish sign language and subtitling for hearing impaired TV-watchers.

Another example is the BNP-Paribas-Fortis bank who offer adapted cash machines that can be used on a spoken basis by visual handicapped clients.

2. THE INTERNET OF THINGS

Another interesting topic is the 'Internet of Things' (IoT): the growing need to connect all kinds of devices (such as the microwave, the television, the heating system, the lighting system, ...) to the internet.

The awareness of making UD products combined with the IoT-revolution, going on simultaneously, can result in a nice marriage. Let's take a thermostat as an example. Developing a thermostat with built-in speech, would be complex and expensive. In contrast, building an accessible app for an IoT thermostat, can be perfectly realized, based on the fact that most smartphones and tablets are accessible as they are UD-devices.

3. OTHER GAME CHANGERS

Universal Design and the Internet of Things are two major evolutions that influence the accessibility of ICT platforms and electronic devices.

But there are a lot more game changers that explain the changes in how R&D departments develop new assistive technology and how visually handicapped people use assistive technology.

The availability of open source solutions, mobile devices that became as performant as desktop machines, the cloud computing trend, the social networks boom, touch screens that replaced the mouse and keyboard, software in boxes changed to apps in app stores, synthetic speech for the masses, wearables that let you use technology all day long, ...

All these new developments are changing the way assistive technology is being developed and is being used.

4. NEW ASSISTIVE TECHNOLOGY

During the past 25 years, it was easy and in a certain way logical to arrange assistive devices into categories such as computer access tools (screen reading software, screen magnifying software, speech synthesizers, braille displays, ...), writing tools (braille note takers, braille embossers, braille typewriters, ...), reading tools (CCT systems, OCR software, reading machines, daisy players, ...), time keeping tools (talking clocks, braille watches, ...), ...

Today, we experience that this kind of grouping no longer works because assistive devices become increasingly multifunctional. As a consequence, users are no longer in search of a product to make their computers accessible or to print their documents. They seek solutions to perform specific tasks, such as: planning my train journeys, watching television programs or reading a newspaper. And often there are different solutions for each of these problems.

5. CONSULTING ASSISTIVE TECHNOLOGY

Blindenzorg Licht en Liefde developed a consultancy methodology that addresses all these new trends.

The new methodology is developed, taking in mind three important aspects: the needs of our clients, the skills of our service provider employees and the previously described game changers.

The basics of our methodology relies on the interaction between 'width experts' and 'in-depth experts'. Our with experts offer the client the primary care every assistive device related topic. Our with experts are aware of every type of assistive device and know the basic skills of every one of these devices. They help our clients in their search for the most adequate device. They obtain the necessary skills, to insure a quality service to the clients, from the in-depth experts. These in-depth experts are responsible for expanding the in-depth expertise and keeping it up-to-date on a constant basis.

Or to put it in another way. The width expert is the first contact person and thrusted person for the client. The width expert helps the client with all his questions that are originated mainly in problems in performing all kinds of daily activities. The in-depth experts provide the width experts with knowledge and expertise that he needs to help the client. An in-depth expert can assist the width expert in its service to the client, whenever extra in-depth expertise is needed.

6. CONCLUSIONS

We did put this new methodology in place during the past one and a half years and we are still learning and improving the method. But for us it is clear that this is a good way to cope with the challenge of the ICT game changers and the challenge of social entrepreneurship.

Non-verbal Communication: Thoughts and Experiences among Persons with Blindness

Tina Björk

National Agency for Special Needs Education and Schools
Stockholm, Sweden
tina.bjork@spsm.se

ABSTRACT

The use of non-verbal expressions is challenging in the interaction between pupils with blindness and sighted peers. In this study, interviews were carried out to gain knowledge about blind adults' thoughts and experiences on non-verbal communication. Four in-depth interviews were conducted and analyzed.

How do blind adults acquire, use and interpret non-verbal communication? The results revealed that it is difficult to express a moderate and appropriate body language according to sighted standards. This appears to limit one's own body language. Participants emphasized the value of close relations to sighted persons, who demonstrate body language. Although body language is frequently reflected in the voice, it can be demanding to perceive mixed messages.

How do blind adults think their visual impairment affects interaction with sighted people? According to study results, sighted people's attitudes to visual impairment highly influence the communication. Misunderstandings mainly arise in dialogues with unknown individuals, and background noise substantially aggravate interaction with others.

Implications from this study can make educators aware of factors that promote communication between sighted persons and persons with blindness.

1. INTRODUCTION

The overall purpose of this survey was to acquire knowledge of blind adults' thoughts and experiences on non-verbal communication to be able to use this knowledge in practitioners' education of pupils.

1.1 Previous Research

Gestures often complement spoken language, and the relationship between gestures and spoken words in full communication is complex [1]. Even if the person with severe visual impairment knows of the gestures, he or she cannot perceive the effect on the sighted partner [2].

Magnusson [3] studied blind persons' non-verbal communication through interviews and video recordings. The study shows the importance for persons with blindness to put their body expressions in relation to sighted standards. Fear of expressing themselves incorrectly and differently may prevent them from using body expressions. Lack of feedback on what expressions are adequate may also make a person avoid certain expressions [3].

2. METHOD

To achieve the purpose of the study and answer the survey questions, a case study with qualitative interviews was conducted. Four adults with congenital blindness, two men and two women, participated in the study.

They were informed about the purpose of the study and the voluntary nature of participation, how to consent, the right to cancel participation, and that they would be given the utmost possible confidentiality [4].

3. RESULTS

3.1 Knowledge of Body Language

Participants give examples of ways to learn about body language. Many of them prefer to have a close relationship to the person who describes body language. All participants believe literature is an important source to knowledge of body language. A couple of them have positive experiences of dramatizing as a way to visualize situations and emotions.

3.2 One's Own Body Language

To face the person you talk to, to nod, shake your head and shrugging your shoulders are the most commonly used body expressions among interview participants.

To express with your body what you judge to be appropriate according to sighted standards is complex. Interview participants use a restrained body language to minimize the risk of making mistakes. Not being able to use eye contact is mentioned as a factor of influence.

Another challenge is to decide whether your placement in the room signals avoidance or a desire for contact.

3.3 To Interpret Non-Verbal Communication

Body language is often reflected in the voice, but mixed messages are demanding to perceive. There can be messages in intonation, silence, atmosphere, and in a person's footsteps.

According to study results a good sighted interpreter is a person with great sensitivity, who verbalizes just enough and dares to tell what is being shown.

3.4 Consequences of the Disability

The results reveal that verbal clarity is very important in communication, and background noise substantially aggravates interaction with others.

Misunderstandings mainly arise in dialogues with unknown individuals. For example in a store where you stand in line to buy food and the cashier says "Yes please, what can I do for you?". One interview participant argues that in such situations it can be difficult to know who the cashier addresses.

Sighted people's attitudes highly influence the communication. For example, one interview participant, Bjorn, notes that his mother accompanied him during the first day of High School. A few weeks later his new friends asked if he had brought a nurse. Bjorn argues that this indicates the attitude that a person with a disability is ill.

4. DISCUSSION

4.1 Acquisition

Literary descriptions quite often contain details of how to use our body language. Hence, it is not surprising that interview participants claim literature is an important source of knowledge. Reading books to children with visual impairment gives a possibility for parents to visualize body language in a natural way. When teachers at school read aloud, for example about an angry lady, he or she might say, "How do you look when you are angry? Yes, I can see your eyebrows are wrinkled. Your mouth is closed and the lips are tensed". Everyone in class try out the expressions together, and it provides important information to the pupil with blindness.

In school, pupils with blindness could also be given the opportunity to try out their expressions in drama exercises. This could increase the pupils' ability to make their own choice about using body language or not [5, 6].

4.2 How Blind Adults use Body Language

The results revealed that it is challenging to express moderate body language according to sighted standards. This appears to restrict one's own body language. One participant argues that it is hard to acquire a natural body language when using it to such a limited extent. This is consistent with research results showing the importance of putting body expressions in relation to sighted standards [3].

Nodding, shaking one's head and shrugging one's shoulders are expressions used by a number of interview participants. Research indicates that nodding is common among the congenitally blind. This type of expression has a quite straightforward and conventionally defined meaning, and therefore it can be observed and learned [3].

4.3 Interpreting Non-Verbal Communication

The perception of what constitutes a good verbal describer differ among participants. It seems to be related to personal opinions. To become accustomed to describe verbally in a natural way may take time. However, if teachers verbally describe what they observe in the teaching environment to the entire class, they will serve as models for peers' natural way of verbally describing what happens.

4.4 The Effect of Disability in Meetings with Sighted

Helen Keller once said "The chief handicap of the blind is not blindness, but the attitude of seeing people towards them." [7]. Bjorn's example from High School points at sighted peers' attitude, which could be explained by lack of knowledge.

Someone said "Noise is the fog of the blind".

Interview participants exemplify that distance is critical for communication in a noisy environment, where they are restricted to talking only to the persons next to them. Several participants believe that verbal clarity can compensate for some of the body language they could not otherwise take part of.

5. IMPLICATIONS FOR PRACTICE

Implications from this study can make educators aware of factors that promote communication between sighted persons and persons with blindness. This could further favorably affect the teaching of pupils with blindness, facilitate the interpretation of non-verbal expressions and encourage persons with visual impairment to use body language.

6. REFERENCES

- [1] J. Allwood, "Bodily communication-dimensions of expression and content," i *Multimodality in language and speech systems*, Dordrecht, Kluwer Academic Press, 2002, pp. 7-26.
- [2] M. Frame, "The relationship between visual impairment and gestures," *Journal of visual impairment and blindness*, vol. 94, nr 3, pp. 155-171, 2000.
- [3] A.-K. Magnusson, "Blinda personers icke-verbala kommunikation [Blind persons' non-verbal communication]," Doctorial thesis, Department of Education, Stockholm University, Stockholm, Sweden, 2003.
- [4] Vetenskapsrådet, [Swedish Research Council], "Forskningsetiska principer inom humanistisk-samhällsvetenskaplig forskning [Ethical principles for research in humanistic-sociology research]," Vetenskapsrådet, Stockholm, 2002.
- [5] T. Björk and A. Croneld, "Kroppsspråk för alla" [Body Language for Everyone], Stockholm: Specialpedagogiska skolmyndigheten [National Agency for Special Needs Education and Schools], 2010.
- [6] J. N. Erin, "Teaching social skills to elementary and middle school students with visual impairment," in *Teaching social skills to students with visual impairments: From theory to practice*, New York, AFB Press, 2006, pp. 364-404.
- [7] H. Keller, *Speech for the American Foundation for the Blind*. [Performance]. 1925.

How do Students use Braille and Synthetic Speech while Reading, Comprehending and Processing Mathematical Tasks?

Annemiek van Leendert^{1,2}, Michiel Doorman², Johan Pel³,
Paul Drijvers² and Johannes van der Steen³

¹Royal Visio, Rotterdam, the Netherlands
annemiekvanleendert@visio.org

²Utrecht University, Utrecht, the Netherlands
{a.j.m.vanleendert, m.doorman, p.drijvers}@uu.nl

³Erasmus University Medical Centre, Rotterdam, the Netherlands
{j.pel, j.vandersteen}@erasmusmc.nl

ABSTRACT

Students who use braille and text-to-synthetic speech encounter problems when reading and comprehending mathematical tasks. To better understand and examine these problems we conducted an explorative study in which three grade 11 students participated. We observed the students while they tried to solve mathematical tasks. Individual interviews were carried out to collect data about individuals' usage and views on braille and synthetic speech. The results showed that the vocabulary in synthetic speech, that the students used, were not appropriate for mathematics: “(-6 - 7)” was read in audio as “minus six seven”. According to the students, braille is preferable over speech when they have difficulties comprehending the mathematical structure of an expression or equation. The students also said that a key advantage of speech over braille is the speed of reading. They used the spelling in synthetic speech to check uncertainties in braille. The students were very interested in possibilities to enhance the use of braille and synthetic speech. We conclude that a more mathematical vocabulary in synthetic speech will help students to better understand mathematical expressions and equations.

1. INTRODUCTION

Students who use braille as their primary reading medium encounter difficulties when reading and comprehending mathematical tasks. Using braille in combination with text-to-synthetic speech (hereafter called synthetic speech) may provide some help, but even students who use both modalities have problems. To better understand these difficulties, we conducted an explorative study. The purpose of the study was to investigate how students use braille and synthetic speech, separately or in conjunction, and to investigate their individual practices and opinions on braille and synthetic speech.

2. THEORY

A student who is functionally blind or blind has to read in braille or in audio. Each modality has its strengths and

weaknesses. For example, an advantage of the presentation on the braille display is that it is static, and therefore allows for at least a spatial overview of the boundaries of an expression or equation ([1]). A disadvantage of braille reading is that it is very slow (e.g., [2]). Moreover, braille characters have a low redundancy which can lead to errors in reading ([2]). This will probably occur more in mathematical text than in regular text, because mathematical text is context-arm and condensed. An advantage of synthetic speech is the high rate of reading. A disadvantage of synthetic speech is that the student cannot browse the expression or equation ([3]). Ideally, the combination of braille and synthetic speech would combine their strengths and avoid the weaknesses of each of the two ([4]).

3. METHODS

Three grade 11 students participated in the pilot study. Two of them are “above average” students; the other one is an “average” student. All three developed blindness at a very young age and started reading braille at the age of 6. Normally, all three students use both braille and synthetic speech while reading and comprehending mathematical tasks.

The students started with an assignment. The expressions and equations in the assignment were typed in a linear notation, accessible for students using braille or synthetic speech. First, the students were asked to read and solve different context-based and context-free mathematical tasks. Some of the tasks were routine tasks, whereas others were more challenging. Students were allowed, at their own discretion, to use braille as well as synthetic speech. They were not allowed to wear earphones because we wanted to record the reading in audio. After completing the assignments, the students were interviewed about their usage, likes and dislikes of braille and synthetic speech. The interviews were semi-structured.

4. RESULTS

On each new task, all students started with synthetic speech. The next step depended on the task. If the students had difficulties with understanding the structure of

an expression or equation, they wanted to use braille. This did not always help them to solve the problem correctly. The students found it very hard to grasp the structure of expressions or equations involving nested brackets. For example: “Simplify the expression

- $(h + 2(h + 1))$ ”. All students made mistakes while expanding the brackets. If the expression or equation was very familiar or when the students had to read a lot of non-mathematical language, they chose to continue with synthetic speech. They checked uncertainties in braille with spelling in audio. A lot of symbols, like “^”, “(“and “)”, were not read in synthetic speech: “ $2(x^2 + 4)$ ” was read as “two x two plus four”. In contrast, all elements of an expression or equation were spelled in synthetic speech: “ $2(x^2 + 4)$ ” was spelled as “2 open bracket x caret two plus four closed bracket”.

According to the students, advantages of braille compared to audio are the sense of active reading, the sense of being able to retain the information better, the opportunity to see more structure and more detail. However, a significant advantage of audio over braille was the speed of reading. They did not mention the fact that a lot of elements were not read in synthetic speech. When the first author told them that it is quite easy to change this, they got very excited. The students thought that this might have a great potential for improvement of the use of braille in combination with synthetic speech, and, as a consequence, in developing reading and comprehending strategies for mathematical expressions and equations.

5. CONCLUSION AND DISCUSSION

The results showed that students started every new task with reading in audio. Then they continued in braille or synthetic speech, depending on (the phase in) the task. The students had strong feelings about advantages and disadvantages of both braille and synthetic speech. They did not mention the fact that a lot of elements of an expression or equation were not read in audio. They were, however, pleasantly surprised to hear that it is possible to change this. Overall, they were curious about possibilities to enhance the use of braille and synthetic speech.

Another finding was that the math teachers and the itinerant teachers did not know that so little was read in audio, because the students always wore earphones while reading in audio. The teachers could hardly believe it when they read the expressions and equations in audio themselves.

The results of the study may inform a better support for students while reading and comprehending mathematical text. The most important thing to be done seems to be to expand and change the vocabulary in synthetic speech. All elements that are needed to understand the expression or equation correctly have to be read in audio. Furthermore, we expect that a mathematical vocabulary in synthetic speech, which is very close to the vocabulary the math teacher uses in class, can help to link the explanation of the teacher with the text in the math book. For example, “ $f(x)$ ”, will be read in audio as “f of x”. This will also reduce the amount of parentheses in the pronunciation and may, therefore, help to better understand the structure of an expression or equation. The spelling in

audio will not be changed: “ $f(x)$ ” will be spelled as “f open bracket x closed bracket”. Our hypothesis is that synthetic speech with a mathematical vocabulary can be very helpful to get a first global overview over an expression or equation. Continuing to read in braille can help to get a deeper insight into the structure of the expression or equation. If needed, uncertainties in braille can be checked with local speech. We will test this hypothesis in the next study.

Acknowledgments

This work is part of the research program ‘Improving the mathematical abilities of Braille-dependent students’ (023004048), which is financed by the Netherlands Organization for Scientific Research (NWO). This study has been approved by the medical ethical committee of the Erasmus Medical Center (MEC-2012-097 and MEC-2012-524) and adhered to the tenets of the Declaration of Helsinki (2013) for research involving human subjects.

REFERENCES

- [1] Archambault, D., Stöger, B., Batusic, M., Fahrengruber, C., & Miesenberger, K. (2007). A software model to support collaborative mathematical work between braille and sighted users. In ACM Sigaccess (Eds.), *Assets 2007: Proceedings of the Ninth International ACM SIGACCESS Conference on Computers and Accessibility* (pp. 115–122). New York, NY: ACM.
- [2] Tobin, M. J., & Hill, E. W. (2015). Is literacy for blind people under threat? Does braille have a future? *British Journal of Visual Impairment*, 33(3), 239–250.
- [3] Freitas, D., & Kouroupetroglou, G. (2008). Speech technologies for blind and low vision persons. *Technology and Disability*, 20(2), 135–156.
- [4] Bernsen, N.O. (2008). Multimodality theory. In D. Tzovaras (Ed.), *Multimodal user interfaces. From signals to interaction, Signals and communication technology* (pp.5-29). Berlin: Springer.
- [5] Jackson, R. M. (2012). *Audio-supported reading for students who are blind or visually impaired*. Wakefield, MA: National Center on Accessible Instructional Materials.

Who needs to know what? – A study to differentiate between the knowledge of TVI and mainstream school teacher in the inclusive education system

Marie-Luise Schütt¹

¹University of Hamburg, Department of Education,
Hamburg, Germany
marie-luise.schuettt@uni-hamburg.de

ABSTRACT

In Germany, Inclusive Education – children with and without disabilities participate and learn together in the same classes – is one key aim of the educational policy. Concerning this matter, prospective teacher must be prepared to handle the diversity in the classroom. According to the approaches of Universal Design in educational fields, specific knowledge based on the approach of education accessibility for teachers must identified and integrated in the curriculum of teacher training. As part of changes, the Faculty of Education at the University of Hamburg implemented the service center “InkluSoB” (inclusive school without barriers). “InkluSoB” makes it possible to integrate the approaches of accessibility into teacher training at the university. “InkluSoB” focuses on two university dimensions, (a) student dimension and (b) academic dimension, for developing movements and actions within the inclusive educational system

1. INTRODUCTION

Through the ratification of the UN-Convention on the Rights of Persons with Disabilities in 2009, Germany committed itself to implement an inclusive education system at all levels [1]. Currently, the inclusive education of pupils with blindness and low vision is increasing. As a result, qualified mainstream and special education teachers (especially TVI: teacher of students with visual impairment) are needed who are able to design accessible learning settings.

2. THEORETICAL BACKGROUND

Based on the approach of Universal Design for Learning (UDL), specific competencies of future teachers will be identified and the teacher training at the University of Hamburg will be revised [2].

2.1. Universal Design for Learning

UDL is an approach that transfers the seven principles of Universal Design (UD) to the educational field. UDL provides “a framework for designing curricula that enable all individuals to gain knowledge, skills, and enthusiasm for learning” [3]. It means to design a learning environment that is accessible to all learners – not depending on the linguistic differences, cultural backgrounds or disabili-

ties. Modern ideas of neuroscience are starting points of UDL. According to that, every learner is equipped with three different types of networks (recognition networks, strategic networks and affective networks). These networks differ from learner to learner.

Recognition networks	Strategic networks	Affective networks
“what” of learning	“how” of learning	“why” of learning
Present information and content in different ways	Differentiate the ways that students can express what they know	Stimulate interest and motivation for learning
Principle 1 More way to provide Multiple Means of Representation	Principle 2 More ways to provide Multiple Means of Action and Expression	Principle 3 More ways to provide Multiple Means of Engagement

Table 1. Principles of UDL

Following the neuroscientific background, the development of learning environments has to consider the different types of learners. Therefore, UDL describes three principles to satisfy all learning styles in the classroom. The three main principles of UDL are: multiple means of engagement, multiple means of representation and multiple means of expression. Following the three principles, UDL removes barriers and increases accessibility.

2.2. Principle 1.: Multiple Means of Representation and conclusions of Teacher Education

Mainstream teachers and special education teachers (TVI) are reliant on the knowledge to design their learning environments more accessible. By using principle 1.; multiple means of representation, the existing differences between their knowledge will be illustrated. The first principle is about the “what” of learning (“Input”). It implies that the ability of the learner to perceive and understand information depends on the style of representing information. To pick up as many learners as possible, the information needs to be presented in multiple ways. In detail, it needs three kinds of representational options to support a variety of learners: (a) provide options for

comprehension (b) provide options for language, mathematical expressions, and symbols and (c) provide options for perception. These three guidelines of principle 1 are divided in a minimum of three checkpoints. For example, in the case of a pupil with blindness in an inclusive classroom, printed materials are not accessible. “Accessible information is understood as information provided in formats that allow every user and learner to access content’ on an equal basis with others” [4]. The use of digital materials becomes particularly important. In contrast to printed material, the display information of the accessible digital material can be varied: in the size of text, in the font etc. Although, learners with sensory disabilities can decide to read or listen the text. It is a precondition that teachers know what an accessible digital document is and ideally how to produce an accessible one.

Currently, in contrast to TVI’s who are prepared to provide accessible materials (DAISY, EPUB) for learners with visual impairment, mainstream teachers are not very familiar in using accessible documents (textbooks, copies...). In the future, mainstream teachers need the knowledge how to create an accessible Word document. If mainstream teachers know how to develop accessible documents, the learning process will be easier for all children in class. In addition, TVI’s can focus their activities on pupils with blindness. For example, TVIs can use accessible documents and align them with the individual requirements of learners (extra aid structure...).

3. RESEARCH PROJECT INKLUSOB

Following this theoretical background, a research project called “InkluSoB” (inclusive schools without barriers) takes place at the University of Hamburg. “InkluSoB” is located within the “Field of Action: Inclusion” that is one of the four pillars of the ProfaLe¹ project. The main goal of “InkluSoB” is to develop a service center for all kind of teachers for improving the knowledge about accessibility. In this sense, knowledge about the designing of accessible learning materials.

3.1. Empirical methods

As a first step, the needs of prospective teachers have been empirically determined in an ad hoc analysis (Online Survey). In October 2015, a series of seminars with a mix of prospective teachers (vocational teachers, special education teachers and mainstream teachers) were surveyed about their knowledge of developing and using accessible text materials and presentations. In order to visualize the situation in the seminars, the results of one group were presented (N= 31).

¹ The project ProfaLe (“Professional teaching to promote subject-based learning under changing societal conditions”) is supported by the Ministry of Education and Research in the frame of the Quality Initiative on Teacher Education.

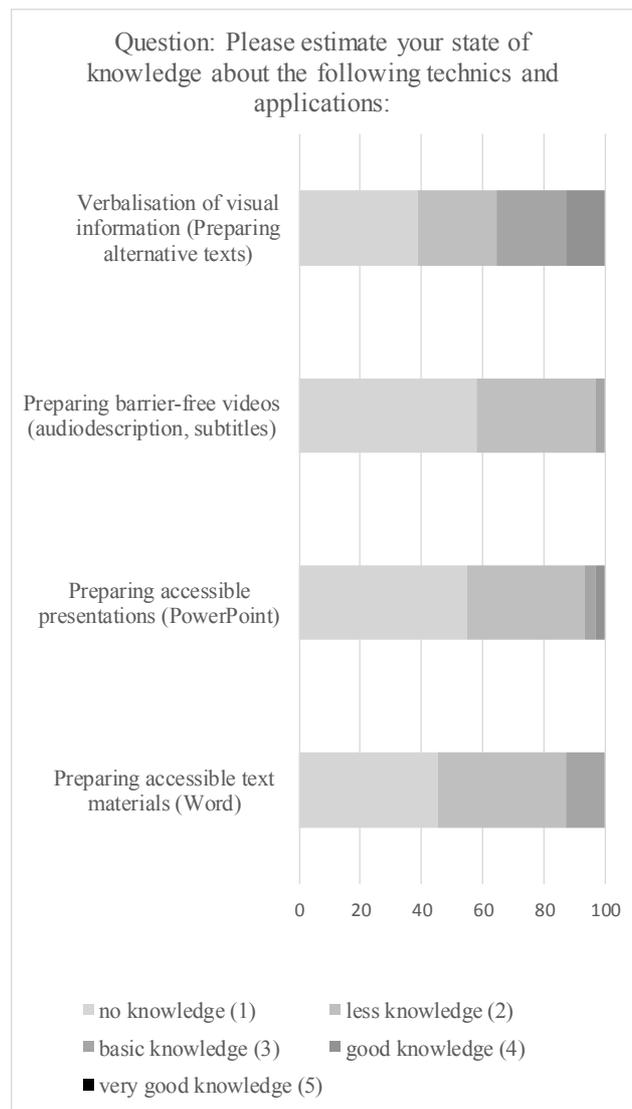


Figure 1. Knowledge about accessibility of learning materials

The majority of the respondents mentioned that they have no and less experiences about making accessible learning materials. This highlights the enormous need of action in the teacher training.

3.2. Measures: service offer InkluSoB

Following up this empirical background, the service center “InkluSoB” is active on two levels (since August 2016). The services are directed to students (‘prospective teachers’) and teaching staff at the university of Hamburg. “InkluSoB” offers three main types of service for both parties. First, workshops take place on a regular basis which focus on the development of skills, such as making accessible Word documents or PowerPoints and accessible videos with subtitles and audio description. Additional, the content of the workshops, will be made available as OER learning material (open educational resources). Second, “InkluSoB” cooperates with academics of different seminars to topics like accessibility at extracurricular places of learning (research workshop zoological museum). This allows prospective teachers and academics to make individual experiences with the

planning of accessible learning environments. Third, an individual consultation hour for academics and students is part of the service center. The media center at the Faculty of Education, the service center for students with disabilities and chronic diseases and HUL (Hamburger center for University Teaching and Learning) are important cooperation partners.

Actually, first applications as well as single evaluation of workshops, cooperation and consultation hours take place. In the future, a comprehensive evaluation process will be developed for the service center in order to optimize the offer at the University of Hamburg.

4. CONCLUSION

Accessibility is one important element of Inclusive Education. Accessible learning environments can increase the participation of learners with and without handicap. Therefore, mainstream teachers and TVI have to build up expertise in the field of accessibility. Of course, this article differentiates the expertise of both professionals only in a general manner and a more specific vision is required in future research. Without doubt, students (prospective teachers) and academics must be prepared simultaneously. In this way, students make the experience to be part of an inclusive learning system at the university. Otherwise, the development to an inclusive university will be not possible.

REFERENCES

- [1] United Nations (UN): *Convention on the Rights of Persons with Disabilities*, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>, 05.05.2017.
- [2] Universal Design for Learning: *The concept of UDL*, <http://www.udlcenter.org/aboutudl/whatisudl/conceptofudl>, 05.05.2017.
- [3] A. Meyer and D. Rose: *Universal design for learning: theory and practice*, Wakefield, MA, 2014.
- [4] European Agency for Special Needs and Inclusive Education: *Guidelines for Accessible Information. ICT for Information Accessibility in Learning (ICT4IAL)*, Mountain View, USA, 2013.

Visual Functioning of Babies and young Children with Visual Impairment or Multiple Disability and Visual Impairment: how to assess?

Myriam Callemeyn¹, Mieke De Pourcq¹, Kim Maesele¹, Marlies Praet¹ and Mieke Vandorpe¹

¹Mobile Support Service Accent, Centre of Expertise Spermalie / De Kade, Brugge, Belgium

{myriam.callemeyn, mieke.depourcq, kim.maesele, marlies.praet, mieke.vandorpe}@de-kade.be

ABSTRACT

Estimating the visual ability and assessing the visual function in babies and young children with Visual Impairment (VI) or Multiple Disability and Visual Impairment (MDVI) is a challenge.

By means of a workshop we will present and discuss the use of **Zieta!** and **Loeka!**.

Zieta! is a tool developed for professionals working with young infants or children with VI or MDVI which have a developmental age up to 6 to 8 months. This tool allows to observe and map out the different aspects of visual functions and primary visual processing like visual awareness, fixation, visual tracking, eye contact and initial eye-hand coordination (reaching - grabbing).

Loeka! is used to prepare toddlers and young children with VI or MDVI for optotype-testing (LeaTM, KayTM). It consists of 3D and 2D materials and a manual.

In addition, a leaflet useful as guide for **early detection** and recognition of distress signals of visual problems in babies and young toddlers (0 -2yrs) will be presented.

1. INTRODUCTION

“Mobile Support Service *Accent*” attends to blind and partially sighted persons and their families. Often there is more than one disability. We offer support to the person, their family and people in their social network.

The first months of one’s life are very important for the visus [1]. Therefore we recently published a leaflet which can help detecting visual dysfunction of young children at an early stage.

Copyright: © 2017 Myriam Callemeyn et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

We developed *Zieta!* [2] to map out the visual reactions of babies and children with severe visual impairment and a developmental age less than 6 to 8 months.

To prepare children or persons with a low developmental level to a consultation of the eye specialist, we developed *Loeka!*. It’s a step by step manual for the mentor.

2. OP TIJD ERBIJ! (START EARLY!)

The first months of one’s life are very important for the visus [1]. Therefore we recently published a leaflet which can help detecting visual dysfunction of young children at an early stage.

In the leaflet we describe the most important signals of visual problems of babies and toddlers who are 0 to 2 years old, meanwhile reviewing the different development domains.

We formulate first advice and tips when there’s presumption of a visual problem.

Finally we present our service and contact details.

3. ZIETA!

Zieta! is an observation instrument for professionals (see figure 1). The goal is to map out the basal visual functions and the primary visual processing. We focus on babies and children with severe (multiple) visual impairment with a developmental age lower than 6 to 8 months.

The observations are targeting the functions perception, fixation, following, face orientation and starting eye-hand coordination (reaching – grabbing). All these functions are explained.

We define the materials used for the test. They are presented in a standardized manner and the observed reactions of the child are noted on the form.

We also added a survey of the critical periods in the early visual development.



Figure 1. Brochure Zieta! Observation of the first phases of visual functioning.

REFERENCES

- [1] M. Dik, Baby's en peuters met visueel functieverlies, Robert Weijdert, Eemnes, 2005.
- [2] Team vroegtijdige thuisbegeleiding Accent, Zieta!, D. Provo NV, Gierle, 2013
- [3] Team vroegtijdige thuisbegeleiding Accent, Loeka!, 2017

4. LOEKA!

With the brochure “Loeka!” [3] we aim to prepare the consultation of an eye specialist in a playful manner. We target young children (or older persons with development retardation) who can use a little support for this kind of consultation.

Starting from concrete materials the children learn to recognize the images (Lea figures and Kay pictures) used by the oculist measuring the sharpness sight.

We developed a few games to get used to these pictures. In *Loeka!* We also give suggestions on how to prepare the child for the examinations of the eye specialist.

5. CONCLUSIONS

With the help of the leaflet “*Op tijd erbij!*” we hope young children will get appropriate assistance at the eye specialist or service in time.

With the brochure “*Zieta!*” we hope to meet the need of professionals to observe the visual behavior of babies or persons with multiple disability and with a developmental age up to 6 to 8 months.

With the brochure “*LOEKA!*” we meet the need of young children (or older persons with a young development level) to be well prepared for the consultation of the eye specialist.

With these publications we hope to have aided on the one hand to the early detection and follow-up of young children with (presumption of) visual impairment and on the other hand to the mapping out of visual behavior and functioning so that appropriate support can be organized as well as possible.

Acknowledgments

We'd like to thank everyone who contributed in any form to the making of our publications: *Op tijd erbij!*, *Zieta!* and *Loeka!*.

WerkWijzer,

A methodology for supporting people with visual impairment and an autism spectrum disorder (ASS) regardless of whether there is also another constraint such as intellectual disability.

Anja Pouwels¹, Ellie Verstappen¹,

¹Bartiméus Doorn, Zeist, Netherlands,
{apouwels, everstappen}@bartimeus.nl

WerkWijzer

A methodology for supporting people with visual impairment and an autism spectrum disorder (ASS) regardless of whether there is also another constraint such as intellectual disability.

Helping people with both visual impairments and ASS in developing life skills requires a different approach than the ones used for people with either visual impairments or ASS.

Someone with a visual impairment cannot (completely) trust the visual information she/he receives. Verbal clarification can alleviate this problem.

Someone with ASS on the other hand needs visual and clear information to comprehend what is going on in their environment. Verbal clarification is both volatile and abstract and the attribution of meaning is often difficult.

WerkWijzer is a methodology based on elaborate research aimed at completing the personal description. For example, sensory information processing, tactile functioning, cognitive possibilities, social-emotional aspects, level of sense-making and communication are taken into account.

To make the environment understandable and safe, it has to be structured and made 'clear', in a way that takes both limitations into account. Structuring comprises spatial surroundings, time, activities and approach/treatment.

By working this way somebody suffering from VIB-ASS can understand and tolerate the world. The methodology has been implemented successfully within Bartiméus. Quality of life has thereby been improved. The methodology is Evidence Based.

1. BACKGROUND

Bartiméus is confronted with an increase of children / young adults with a visual impairment and an autism spectrum disorder. This requires extra support from the teachers.

The fragmented perception of persons with a visual impairment and of someone who has ASS means that two

different approaches are expected that are not connected to each other.

A new method had been developed that takes into account both the visual impairment and the autism spectrum disorder: The WerkWijzer.

Originally, the WerkWijzer was written for Bartiméus school. But the method was also shown to add value for people with mental- / intellectual disabilities, or in an occupational situation. Currently, the WerkWijzer is being rewritten so that it is widely applicable.

The method is based on first mapping who somebody is. What are their possibilities and qualities besides their impossibilities and special behavior. A solid description that continually demands a supplement depending on the life phase of a person.

2. WERKWIJZER: METHOD

2.1 Imaging

First of all, the persons image is compiled. Intelligence, sensory integration enhancement, visual functionality, audit functionality, social emotional functioning and level of communication are established.

Based on these investigations, an 'image' report is compiled. This report will always be supplemented with new insights, obtained during the whole life of someone who has VIB-ASS.

2.2 Education

The system surrounding the person is educated about visual impairment and autism spectrum disorder (VIB-ASS). The education is based on theory and practice. The first (theoretical) part is about visual impairment, autism spectrum disorder and their influence on each other.

The second (practical) part consists of delineating which underlying communication system is required for this person to maintain as much personal control as possible. Aspects covered are adaptation of the environment, tools for communication and how to build up activities.

If possible, the person him/herself is involved in imaging and education. Otherwise, observation and appointments to the program are made.

During training, a lot of video material is used and experience moments (simulation glasses and the ABC circuit) are provided.

2.3 Implementation

A concrete goal (like being able to prepare food) is analyzed: how is this being done at the moment and how could somebody be doing it in the future?. The elaboration takes place in small steps in which the actions are always based on the established image or possible new insights.

2.4 New imaging

After the new skill is acquired, there is a moment of evaluation. New insights will be incorporated in the imaging profile, so that next time these will influence the program.

3. EVIDENCE BASED

In 2016, a short Evidence Based Research audit was done. The outcomes of the first applied interventions were investigated.

It was concluded that the desired results were indeed achieved. In addition, a positive change was observed in target behavior.

Key people in the environment of the person were satisfied with the results. In case where were the person him/herself could contribute to the evaluation it was remarked that this approach was a nice way of learning other skills.

4. WORKSHOP

The workshop during ICEVI will focus on:

Theory of visual impairment and autism spectrum disorder.

Imaging and possible research tools.

The roadmap: the application of the method.

There will be many examples of actual interactions. Special attention will be paid to mentally/intellectually disabled persons. Possible tools for supportive communication will be covered.

REFERENCES

- [1] M. Hamer-de Jong, Paul Lagerweij en Margreeth Strietman-te Roller *WerkWijzer*, , 2009.
- [2] Paul Lagerweij, Milou Westerink, Kennisgroep VIB-ASS, Bartiméus, *Effectiviteit van de WerkWijzer*, 2016..

Reflections on how to foster better 'Quality of life' for the person with Congenital Deaf blindness

Veerle Vanthuyne¹, Marlene Daelman^{1,2,3}

¹Care director/ remedial educationalist Spermalie, Brugge, Belgium

²Member of the Deafblind International Working group on communication

³ Guest lecturer at the International Master on Communication and (Congenital) Deaf blindness University of Groningen, the Netherlands

Reflections on how to foster better 'quality of life' for the person with Congenital Deaf blindness (CDB). Looking at communication development in persons with CDB. Discovering their personal voice influenced by dialogical versus monological third voices. °

1. INTRODUCTION

When it comes to language, the mainstream conception of what it is, does not apply to congenital deaf blindness, other than in exceptional cases.

Though thanks to increasingly better video- and computer technology in the last decades, new forms in which persons with CDB participate in communicative exchanges could be witnessed.

- the communicative processes are complex and rich.
- the tendency to engage in sense-making, meaning-making and language-making activity is expressed in a diversity of forms.
- the congenitally deafblind manner of being in the world is prominently embodied and dialogical.

Dialogicality (Linell, 2009) emphasizes on the other-directedness of the human mind.

2. MONOLOGICAL VOICES

30 to 40 years ago the *monological voices* that were leading our daily practices in education and teaching were reflecting the idea of normalization. We tried to teach and show the child with deaf blindness how to act and communicate, using an instructional pedagogy where input from one to the other is expected to re-occur as output by the other.

Copyright: © 2017 First author et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Using modern tools as a kind of magnifying glasses, we can micro-analyse video-interactions from 40 years ago and reveal tensions and imbalances between subjectivities. This creates awareness of third party influence on the structural desing of ongoing action (Nafstad, 2016)

Video-analysis I: influences of the monological third voice

3. DIALOGICAL THEORY

During the last decades the *dialogical theory* has more and more been influencing the implied pedagogy. Dialogical perspectives foster real and sustained communicative practices with the person with CDB as an active and co-creative social interactive and communicative partner.

Already 25 years ago we followed a track that looked into the aesthetic patterns of social and communicative interaction. We explored the efficiency of the strategy of immediate imitation (Nadel, 1993) with persons with CDB (Nafstad, e.a.1993). Immediate imitation from the sighted and hearing partner helped the person with CDB recognize the other as one like self and vice versa. Social directedness and reciprocity was boosted. We considered from then on the tendency to engage in spontaneous bodily-tactile gesturing as the first language of the congenitally deafblind. Declarative narrative types of dialogues could be sustained in spite of very little shared understanding regarding conversational topics. So we learned that intersubjectivity in a conversation was not primarily about successful decoding of messages, but should be understood in terms of engagement in meaning making (Nafstad, 2016). At that time, we were happy to collaborate with Saskia Damen who prepared her PhD research (Damen, 2015), based on the research of Marleen Janssen (2003). And starting from ongoing and reciprocal social interaction we found that students with CDB were showing growing possibilities in understanding cultural expressions in and out the daily context.

They also showed their engagement in languaging, even though they had very little language in the linguistic sense. In this we saw indications for a strong communicative agency.

Video examples will be used to exemplify this.

4. OVERHEARING

But still it was the question how to organize access to culture for those youngsters with CDB, who showed growing understanding of a cultural bodily-tactile vocabulary, and did not seem to know why communication is used for by hearing-seeing people.

When Eija Lundqvist wrote her master thesis on the procedure of tactile overhearing and multi-party interactions, this revealed to us the possibility that we were looking for (Lundqvist, E., 2012).

Video-analysis II: growing influences of the dialogical third voice Third and Further Level Headings

5. MULTY-PARTY INTERACTIONS

With illustrations of contemporary practice with tactile overhearing in multy-party interactions, influenced by dialogical theories and communication practices that take care of the YOU-perspective, understanding the initiative of the person with CDB as an utterance and engaging in negotiation towards ... co-created shared meaning (Nafstad & Rodbroe, 2015, p. 56). In this way lifting the communicative agency and the personal voice of the person with CDB (idem, p. 57).

REFERENCES

- [1] Damen, S. (2015). A matter of meaning. The effect of partner support on the intersubjective behaviors of individuals with congenital deaf blindness. Published by uitgeverij BoxPress, 's Hertogenbosch. The Netherlands.
- [2] Janssen, M. (2003) Contact: effects of an intervention program to foster harmonious interactions between deafblind children and their educators. *Journal of Visual Impairment and Blindness*, 97 (4), 215-229.
- [3] Lundqvist, E. (2012). Rethinking interactional practices in the tactile modality. A comparison between two-party and three-party interaction with persons with congenital deaf blindness. Groningen University, Groningen, The Netherlands.
- [4] Nadel, J & Camaioni, L. (1993). *New perspectives in early communicative development*. Routledge: London.
- [5] Nafstad A., Rodbroe, I., Daelman, M. (1993). The child with congenital deafblindness as an acitve partner. Lecture at the IAEDB-conference, Potsdam. Conference report.
- [6] Nafstad, A. & Daelman, M. (2016). Forthcoming.
- [7] (°) This workshop is largely inspired by the collaboration with Anne Nafstad, founding member of the DbIWGC and lector at the International MSc. Pedagogical Sciences on Communication and Deafblindness. In particular, whilst preparing the plenary lecture for the 10th-year anniversary of the Masters on Communication in the context of CDB.
- [8] Nafstad, A & Rodbroe, I. (2015). *Communicative Relations. Interventions that create communication with persons with congenital deafblindness*. Materialecentret. Aalborg, Danmark.

Daisy player: The bigger picture

Tine Delporte¹, Piet Verstraete¹, Astrid Dekoe¹ and Tina Mutschinski¹

¹Begeleidingscentrum Spermalie, Department of children with a visual impairment, Bruges, Belgium

{tine.delporte, piet.verstraete, tina.mutschinski@de-kade.be}

ABSTRACT

It's been known for a long time that a Daisy player can be very useful for visually impaired or blind people. Daisy books, music, digital magazines or complete courses are well known applications. We try to highlight the use of a Daisy player in an alternative way, to expand the traditional use of it.

Working in a pre- and elementary school (Spermalie) for blind and visually impaired children in Bruges, Belgium; we use Daisy players with young visual impaired children, some of them having multiple disabilities.

The possibilities of using a Daisy player are looked closer at, whilst making practical references to the usage in a child's daily life. Disadvantages we have experienced will be highlighted. It's a very fun and interactive way to trigger this target group!

1. WHAT

Daisy is the abbreviation for Digital Accessible Information System. This device is designed for a broader target group than visually impaired users. People with dyslexia or other disabilities that make it difficult to read printed language, can also profit from the functions of the Daisy – player.

During this workshop we focus on the group of visually impaired pre-schoolers and young children.

2. AREAS OF APPLICATION

The purpose of this workshop is to demonstrate on how one can use the Daisy player broader than the traditional way of

listening to Daisy books. We highlight the following practical applications that we have found to be stimulating and enjoyable for a child's development.

- leisure
- school and education
- language development
- ADL (activities of daily life)
- journal and logbook

At our school for the blind we stimulate children to use different technological technology tools at a young age. A Daisy player can introduce a child to the structure of files and folders of a computer. This is of great value for the future use of laptops, refreshable braille displays and other devices.

2.1 Leisure

The most obvious use of the Daisy player for people with print disabilities is in function of leisure and amusement. One can listen to Daisy books, music CDs, digital audio books, computerized text and periodicals. A computerized text Daisy book can be read using refreshable braille display or screen reading software, printed as braille book on paper. It can also be read in large printed texts on the computer. Possible there are Daisy – books available at your local library. Additionally, files on a USB stick or SD card can be inserted in the device. Taking into account the copyright terms of use, YouTube can be an interesting source to find great songs, sounds and books.

2.2 School and education

A Daisy player can be a valuable tool to use during school events. Important moments, songs, conversations or noises are recorded by the teacher or child itself. Afterwards records will be edited where necessary (cutting of minor moments of the recordings) and saved on a USB stick or SD card. That way a child is able to re-listen and relive field trips, excursions, classroom songs and activities or school plays, while focussing exclusively on the auditory stimuli, without having to combine different senses. In addition to processing school trips, we can use a Daisy player for step by step instructions to solve a task individually. Other fields of are: braille exercise, homework, and quiet time activities for kids. If a child is not able to read braille independently it can be a nice way of giving a child auditory instructions to work on assignments.

2.3 Language development

The Daisy player can be an important tool for speech therapists. It can stimulate language development in young children in a fun way.

- auditory terms of initial reading
- (nursery) rhymes, poems
- stories
- classroom activities

2.4 ADL

Young visually impaired children cannot refer to pictograms, mind maps or difficult step by step guides to achieve a goal. A Daisy player can help a child to dress or perform other ADL activities by using it as a mnemonic. Mnemonics can be used in an auditory form, such as short poems, or memorable phrases and songs. A child can also follow step by step instructions recorded by the therapist to perform a task independently.

2.5 Journal and logbook

Working with young children we often use journals and logbooks to communicate with parents and other involved care-givers. This is usually done on paper or crafting making it difficult for visually impaired children and/or parents to participate. By converting this written information into auditory records our children will be able to enjoy them as well.

3. USAGE AND ADJUSTMENTS

The Daisy player is a device with many possibilities and gradations. This way, young children or people with learning disabilities are able to use it independently, giving a boost to their self-esteem.

3.1 Bookshelf

The Daisy player recognizes various book types which are saved in separate folder structures called Bookshelves. On the SD or USB source each Bookshelf is stored within a folder name beginning with "\$VR". The understanding of the bookshelves is asking some guidance to the child.

Bookshelf \$VRDTB folder

- Book types: Daisy or NISO Books

In this bookshelf the current reading position and bookmarks are saved separately for each book.

Bookshelf \$VROtherBooks

- Book types: Non-Daisy or non-NISO recorded books

The files comprising each book should be saved in separate subfolders under this folder.

Bookshelf \$VRMusic folder

- Book types: Playlists and recorded files

A music book is either a playlist or the entire music structure (genre, artist, album, and tracks)

Bookshelf \$VRPodcasts

- Book types: Any of the Daisy player supported audio file types

A Podcast is an episodic series of digital audio files which a user can subscribe to so that new episodes are automatically downloaded.

Bookshelf \$VRText

- Book types: Text files (bra, brf, docx, html, rtf, ses3, txt, xml)

Reading position and bookmarks are saved separately for each book. Playback stops at the end of each book.

Bookshelf \$VRNotes

- book types: AMR-WB+ audio files recorded by the Stream

The \$VRNotes folder is created when you insert a non-write protected card.

3.2 Recordings

Recordings can be made with your smart phone or a digital voice recorder. It is not possible to directly record with the model of Daisy player we use. Other models we use with older children may have this function.

3.2.1 Audacity

We use the free digital audio editor Audacity. In addition to recording audio from multiple sources, Audacity can be used for post-processing and editing of all types of audio by adding effects such as normalization, trimming, and fading in and out. This process can be very time consuming and asks a big effort of the parents or professionals working with the child.

3.3 Variety of data storage devices

One way to adjust the use of the Daisy player to the needs of the child is to try out different memory devices. With most Daisy players one can use USB sticks, SD cards and CDs. If a child experiences difficulties in inserting a CD, we can easily transfer the data to an USB stick or

SD card. We can also make alterations on the device itself by attaching different key chains to the USB sticks or labelling them with braille.

3.2 Keypad cover

In some of the models you find an extra cover for the player. Working with the cover, the child will have less buttons to choose from. It is also possible to make extra holes in the cover to make individual adjustments.



4. CONCLUSIONS

The use of the Daisy player is definitely a great added value when working with young visually impaired children. At our school for the blind we have introduced the Daisy player during class room activities, therapy and leisure. Looking further than its traditional use as a talking book, one can make it a precious tool for children with multiple disabilities.

Independence through quality braille training

John Heilbrunn
Dansk Blindesamfund, Taastrup, DK
john.d.heilbrunn@blind.dk

Braille as the genuine font for blind persons is the prerequisite for communication, reading and writing and to ensure to become and remain literate. It is essential to acquire proficient skills at an early age and improve the ability to use braille in all practical, social and academic scenarios. Therefore, it is necessary that a blind child from the very early childhood and onwards is challenged by - and confronted with - well trained and skilled professionals and relevant materials in quality braille.

The Danish Association of the Blind runs the two-year-project, financed by EBU, in cooperation with ICEVI - Europe. The target group is persons under the age of 18 years, who do not have a severe additional disability apart from the visual impairment and the project therefore will focus on various proper solutions for children and young person's use of braille. The main focus is on screening and analyzing the use and availability of braille, the impact of modern technology, the best practices and materials in training braille and the availability of trained and skilled educators in braille. Phase one collects the information from the Nordic countries, and phase two will widespread the screening to other European countries. The result of the project will bring up the focal points of observations registered in the different countries.

The workshop offers a possibility to present the background of the project and the gathered results so far as well as a fruitful platform for discussions and exchange of views when promoting braille.

In our project, we wish to establish the following:

1. Use and availability of **braille**. **whether** the use and availability of braille in whatever format (paper or electronic) an for all crucial purposes (Education and/or leisure) is increasing or decreasing.
2. The impact of technology. Is modern technology (ICT) promoting a larger amount of braille and does that mean that persons who are blind or very severely partially sighted make use of this opportunity?
3. The potential impact of other formats and media on the usage of braille. How could the availability of text on computers (synthetic speech) and narrated text (humane voice) be seen as effecting the extent of use of acquired skills amongst blind children for writing and reading braille?

4. Availability of relevant braille material at the relevant time and of an equal contents. Are blind children from an early age (pre-school and in the initial grades - and later on) offered braille educational material and do these children get the same educational material and at the same point in time as their sighted classmates?

5. Educators and educational material both at initial and follow up training. Are children met by trained and skilled educators who can teach them braille competently and in an inspiring manner? Are educators using relevant training material?

6. Do children and young persons who are blind maintain their skills in using braille and do they continue to use it, and if yes, as a major or minor part of their handling of texts?

How can procedures / training courses etc. be put in place to ensure that children and young persons who are blind do not over time loose their competences in mastering braille?

The project, well halfway with research and recovery of data having been collected so far in all together 8 countries displays a variety of interesting trends. A few of these may be summarized as follows:

. In especially large countries, there seems to be a vast lack of coordination, a composit knowledge of the general situation and level of services for blind children and youth as no coordinating body exists.

. the level of knowledge, involvement and competencies regarding the braille system, and how to manage it, amongst teachers, especially in mainstream schools is worrying deteriorizing.

. As a result of this, the children - not getting the stimuli and receiving proper explanations and answers, tend to seek resort to text in spoken formats (recorded or from speech synthesizers driven by computers, smartphones etc).

There seems to be a very obvious trend that braille embossed on paper is something that is given decreasing priority vis-a-vis braille in electronic format. this means that braille readers - amongst other things - loos or never obtain the knowledge, understanding and feeling of the two-dimensional sensation of brailled text. Moreover, when braille is produced in paper format, producers tend to offer a

direct and unedited version of the text drawn from electronic formats without performing a proper formatting, editing and embossing of the text. This leads to books, e.g. cooking books etc. that are far from user-friendly and useful. And this, again, leads to a diminished sensation of relevance and advantage.

. Measuring of reading speed amongst children in lower grades is comparatively much lower than that of their sighted peers.

The above midterm observations are not fully consolidated, but they sadly confirm the assumptions that the steering group had and that has led to taking on this study.

30 years of care and rehabilitation of visually impaired adults and older people

Peter Verstraten

Robert Coppes Foundation, Department of Expertise, Innovation & Knowledge (EIK),
Vught, the Netherlands
pverstraten@robertcoppes.nl

ABSTRACT

From different perspectives - Dutch, European and global - an overview is presented of observed developments through the last three decades of rehabilitation services for visually impaired adults and mainly older people.

In the Dutch situation there is a focus on quality of life, working from a holistic viewpoint, including the use of the International Classification of Functioning, Disability and Health (ICF) and a history that shows different professional waves.

After a period of broadening the scope of service providers to include all possible visual impairment challenges, there is a recent focus on more complexity and multimorbidity as an important assignment for Dutch service providers.

On a European level differences are observed in financial opportunities for rehabilitation services development and accessibility, different demographic developments, different rules and regulations, yet a number of networks show how cooperation leads to increased participation of visually impaired adults and older people. One of the examples is the successful VISAL project.

The work of the World Blind Union network on visually impaired older people puts the European situation of ageing and sight loss in its own perspective.

1. DUTCH DEVELOPMENTS

Since the eighties regional centres for rehabilitation of visually impaired people living in their own homes have been developed. This has given an enormous boost to rehabilitation of adults and older people too. Before that time, most attention went to visually impaired children and young people. It also led to the development of a rehabilitation model that is supported by ICF-based tools. Since the beginning of the nineties the ICF^[1] (in those days ICIDH) was adapted for use with visually impaired people and in 1996 it was agreed that all Dutch VI service providers would work according to the ICF framework and terminology.

Through the years the multidisciplinary of rehabilitation teams grew and showed several professional waves. In the second half of the eighties in the outpatient rehabilitation there was still a strong focus on support by social

workers. Gradually occupational therapist came to light, followed by low vision assessment workers and therapists. Much attention was paid to low vision aids and all kinds of practical adaptations. Though psychologists had been present all along, the field of neuropsychology gained importance. And as a result of all technological opportunities for visually impaired people IT-trainers cannot be missed anymore and play an important role in visual impairment rehabilitation.

79% of all visually impaired people in the Netherlands is age 65 or older. 85% is over age 50^[2]. This majority calls for a clear focus on individual rehabilitation needs. Standard rehabilitation programmes are less applicable. And the visually impaired older people are more at risk for dual sensory loss and for loneliness and isolation. However, in adapting to sight loss social support is very important. Not surprisingly visually impaired older people are more at risk for developing depression.

In scientific research we have seen a development towards more attention for visually impaired older people, though nowadays attentions seems to be dropping somewhat.

2. EUROPEAN DEVELOPMENTS

Europe has a total population of about 850 million people, and it comprises an area covering 15 time zones and 54 countries. Europe has 19 of the world's 20 oldest countries in terms of population age and is predicted to see its populations continue to age to much higher levels over the next 25 years. Nearly 25 percent of people in the European Union in 2030 will be above age 65, up from about 17 percent in 2007. As much as 10 percent of Europe's population could be above age 80 by 2050.

It may be estimated that the prevalence of visual impairment (blindness + low vision) in Europe is 1.75% for the total population. Most of them are older people^[3].

Through cooperation of national partners together with the European Blind Union (EBU) the successful VISAL programme has been developed^[4]. Some of its objectives are to increase skills and competences of visually impaired older people, to value their experiences and to increase participation. Also worthwhile mentioning are the results and tools of the Intergen project (EBU) and the SensAge knowledge base (Enviver).

EBU also contributed to a project aiming at making European cities more age friendly.

Important recommendations are made in EBU's policy paper on rehabilitation of older people with acquired sight loss^[3]. Visually impaired older people need to be

included in the making of their own rehabilitation model. Awareness in society and amongst professionals and ophthalmologists as main referrers is of great importance. Because of comorbidity, visual impairment rehabilitation services should be part of a care chain of service provisions. Staff training and background in working with older people is needed.

There is still insufficient understanding about the policies, laws, type of services and circumstances regarding ageing people with visual impairment in the various European countries. Therefore, ICEVI Europe and the EBU had a desk research carried out on this topic^[5]. Services offered to visually impaired elderly persons could help improve their quality of life and will also enhance their social inclusion. Results showed that leisure activities (80%) and psychosocial support (79%) were most often available. The data suggest that the availability of services is almost equal to their reported accessibility. The data indicate that the government is the most important financier for all service categories.

3. GLOBAL DEVELOPMENTS

Serious sight loss is in the top 10 causes of disability, a disability which in older people can lead to a decrease in the quality of life, has an adverse impact on activities of daily living, causes falls and injuries and leads to social exclusion and depression. Whilst there is this clear moral case for action, there is also a clear economic case.

Vision 2020 and the organisations associated with the programme are working to prevent avoidable blindness. The World Blind Union^[6] concludes that we now need an action plan to reduce the impact or burden of sight loss, particularly on older people, achieved through the delivery of improved support.

Research is needed to understand the incidence, impact and specific needs of people who are blind or vision impaired over the age of 65 years.

Increased education and awareness of blindness and vision loss is necessary, even in developed countries. And it should include education of the general practitioner. The general practitioner has the most contact with people and refers for other services according to the care plan. Early identification of vision loss is needed. The earlier the assistance is provided where vision loss is first detected the better towards enabling the individual to optimise their remaining vision as soon as possible and mitigate further damage. This includes the need for a continuum of care from diagnosis to rehabilitation and support.

To assist in the development and delivery of services, there is a need to identify and promote 'best practice' services and interventions. This should also involve the formation of partnerships or alliances that will assist in the advancement of strategies and services to assist those who are blind or partially sighted.

4. CONCLUSIONS

As Europe is the forerunner in ageing, most 'best practices' can be collected in Europe. Though cultural differences have to be taken into account for transition of knowledge, European experiences and research can be of

use to other countries too. Cooperation and knowledge sharing are crucial in building expertise of knowledge providers for visually impaired older people. Dialogue is a necessary tool to promote self-determination of older people concerning their own rehabilitation.

REFERENCES

- [1] <http://www.who.int/classifications/icf/en/>
- [2] H. Limburg, J.E.E. Keunen, G. van Rens, "Visuele beperkingen bij ouderen in Nederland - risicogroepen en mogelijkheden tot interventie," *Tijdschrift voor Gerontologie en Geriatrie*, vol. 40, pp. 149-156, 2009.
- [3] A. Suttie, E. Howley, G. Dryden, H. Magnúsdóttir and P. Verstraten, *Rehabilitation and older people with acquired sight loss*. Paris: EBU position paper, 2014
- [4] <http://www.visal-project.eu/>
- [5] R. de Korte, *Services for Visually Impaired Elderly Persons in Europe*. Amsterdam: Vrije Universiteit, 2015.
- [6] A. Suttie, A. Daly, G. Good, K. Mambetkunov, A. Orr, J. Scott, P. Techavachara and P. Verstraten, *Ageing and Visual impairment - A report by the Elderly Working Group of the World Blind Union*. WBU, 2011.

Counseling children and adolescents with visual impairment and multiple problems: topics, methods and adjustments

Sonia Meys

Centrum Ganspoel vzw. Ganspoel 2 , 3040 Huldenberg, Belgium

ABSTRACT

People with multiple handicaps are particularly vulnerable for emotional and psychological problems. These problems are especially apparent in young children and adolescents who have to cope with several loss experiences due to their handicap(s). These experiences can have important effects on their self-esteem, the way they grow up, and the choices they have to make for their future.

We will discuss how we can support children and adolescents who have extra needs in their growth to adulthood. Furthermore, we will demonstrate how Centrum ganspoel tries to offer children, adolescents, and their families support aside from educational activities, therapy, and guidance in a residential group. within individual counseling, as part of a care plan, we offer children and adolescents extra guidance to discover their own strengths and determine which individuals are valuable within their network support group. this individual counseling method is based on principles such as holding, containment, mutual trust, and effective communication with others involved.

Finally, we propose that this individual counseling method can be integrated with commonly used methods such as creative means, role play, genogram, line of life, board games, and stories. more specifically, we believe the latter have to be adjusted, allowing children and adolescents with visual impairment and multiple problems to use the proposed means to help them express themselves.

1. INTRODUCTION

Centrum Ganspoel is an institution in the heart of Belgium, close to Brussels. In this institution, children, adolescents, and adults with visual impairments and multiple problems receive the care and support needed. This care is carried out by a multidisciplinary team of teachers, educators, and therapists who support the children both individually and in group settings. Sometimes children need extra individual support because of emotional problems. In this case, they can consult a counselor.

2. VULNERABILITY

2.1 Influence of a handicap on social-emotional development

Individuals with multiple handicaps are particularly vulnerable for the development of emotional and psychological problems. Individuals with a mental handicap often experience a discrepancy between being able to and manage to do something. The cognitive constraints influence the development of the self, the processing of experiences from the environment, and the relationship with others. As a counselor, it is important to search for ways to address how individuals manage these things [1] [2].

A visual handicap doesn't necessarily directly cause problems in social-emotional development. However, a visual handicap also entails a certain vulnerability: missing visual input makes it difficult to learn new skills, eye contact is important to foster relationships, etc.

2.2 Looking at the problems

Sometimes the child clearly indicates with his/her behavior that something is wrong. However, often parents and/or counselors sense that the child needs more attention than usual.

A first step in supporting the child is looking together at who this child is, what it can do, and what is difficult for the child. In Centrum Ganspoel, we evaluate the topics the child brings forward, how the child does this, and which relationships are important in this process.

2.3 Offering support and care

Often a warm home and a pleasant residential group and/or classroom are sufficient for the child. Good collaboration between the families and counselors is essential in this process. Life in a group can be very therapeutic for children as well, if basic needs of affection and safety, and stimulation and structure are met.

Moreover, each child needs an individual counselor who takes care of the material and physical needs of the individual child. Sometimes, however, this is not enough, and the child is in need of structured attention and support.

3. COUNSELING

3.1 Referral

Both the child as well as the parents and/or monitors can ask for counseling. The reasons for referral can be very diverse. Many children have to cope with several loss experiences due to their handicap. Others have difficulties coping with situations such as marital divorce, or bullying at school. And some children suffer from unhealthy attachment styles. All of this can have important effects on their self-esteem, the way they grow up, the relationships they have, and the choices they make for their future.

3.2 Goal

Within individual counseling, we offer children and adolescents extra guidance to discover their own strengths and determine which individuals are valuable within their network support group.

3.3 Basic principles

Counseling can only take place within a relationship that offers safety to the child. The counselor has to be reliably present and offer structure (holding). The counselor creates a psychological space in which each form of communication, no matter how confusing and painful, is possible for the child, and this space offers the child the opportunity to place it within their own experience (containment). This way, the child learns to deal with feelings without being overwhelmed by them.

Counseling is never detached from the concrete environment of the child such as the classroom, the living group, and the family. The counselor is part of the educational team. Mutual consultation is important and often necessary, and the privacy of the child is always respected.

At the start of the counseling process, important agreements are made (e.g., surrounding privacy) and a goal is formulated together. At the end of the process, the offer of restarting is presented.

To help a child with his/her problems, it is important to start from his/her strengths, from what the child is able to

do without problems. Hence, the methodology of 'strength-oriented conversations' lies at the base of counseling [3].

3.4 Methods

While counseling the child, we connect to the interests of the child. For children with a visual handicap, we try to avoid to get stuck within verbal therapy, and 'play' has to be introduced. We use all kind of toys, as well as role play and board games. We read books, tell stories or make stories together. We make a genogram and draw a line of life. We use all the commonly used methods and adjust them, allowing the children to express themselves.

In Ganspoel we have a play-therapy and a library that offers adjusted books and materials.

The use of duplo [4] and the children's psychodrama-puppets kit [5] offer a lot of opportunities because of their tactile nature.

3.5 External or internal counseling

Since a few years, children with a handicap can also consult external therapists. When appropriate, we refer children to these therapists. However, sometimes internal counseling offers advantages. The collaboration between counselors is smoother and easier, and the step to counseling is less big given that the counselor is part of the support team. The counselor has experience with working with people with a visual handicap, which can be considered a major advantage.

REFERENCES

- [1] A. Došen, "*Psychische stoornissen, gedragsproblemen en verstandelijk handicap. Een integratieve benadering bij kinderen en volwassenen.*", Gorcum B.V., 2005..
- [2] J. Heykoop, "*Vastgelopen. Anders kijken naar begeleiding van mensen met een verstandelijke handicap met ernstige gedragsproblemen.*", Boom/Nelissen, 1995.
- [3] J. Van De Putte, "*Krachtgerichte gesprekken-syllabus*", Vormingscentrum Ghuislain, Gent, 2015
- [4] N. De Greve, K. Neckebroeck, "*Basisopleiding duplo-syllabus*", v.z.w. Jongerenbegeleiding – Informant, Gent, 2017.
- [5] M. Verhofstadt, "*The Children's Psychodrama Puppets Kit – syllabus*", School of experiential-dialectical psychodrama, Gent, 2000.

Visually impaired people in Aruba: shifting networks, identity and respect in everyday life in a small-scale community

Mieke de Droog

University of Aruba, Department of Organization, Governance and Management,
Oranjestad, Aruba
mieke.de.droog@ua.aw

ABSTRACT

This interpretive study aims to elucidate the complexities of the condition of a visual impairment; it is layered and varies in dynamics per participant and situation. In total, 32 respondents aged fifteen years and older were interviewed in-depth. The focus was on their day-to-day constructions of reality, taking in account both their individual life stories and the specific cultural and historical context. Striking in this Aruban study are the shifting networks. They reflect a change in the balance between reciprocity and dependence, with consequences for the experienced identity, (self-) respect and their social participation. These networks also reflect the international mobility of participants for medical reasons, and some characteristic fluctuations involving practical and emotional support. On the long run, participants can be exposed to isolation and impoverished social standing. Important factors affecting their experiences are the quality of the relationship with others and agencies. Key incidents and ‘leverage figures’ play an important role. The study also highlights the ability of the participants themselves to learn to open up to others and/or new experiences. This appears to be essential to the experience of the fluxes in their network, these individuals’ identity and (self)-respect, with consequences for interpersonal relations and social inclusion.

Keywords: networks, identity, respect, key incidents, interpersonal relations, leverage figures, social inclusion.

1. INTRODUCTION

The aim of this study is to gain insight into the impact visual impairment has for those involved. It also aims to formulate a specific interpretation of what Carroll calls the complexity of “the whole multiple handicap” of blindness [1]. The goal is to offer visually impaired people leverage through which they can empower themselves, and through which significant persons and agencies can assist them more effectively. The central question is: What changes occur for visually impaired people in Aruba as a result of their condition with regards to their daily lives, their participation in society and their contact with significant persons and with agencies; how do they experience this and which opportunities do they have to continue to function, independently, or in collaboration with others and agencies? The setting of this study is the island of Aruba, located in the Caribbean Sea. This small-scale community must, like many other countries, use its limited resources in providing for the consequences of rapid population growth, an aging population

and an increase in people with chronic diseases and disabilities. In 2010, visual impairment was the most reported disability; 3% of the total population of Aruba [2].

2. METHODS

32 Aruban visually impaired persons were interviewed extensively. The choice was made to focus on their individual life stories [3] as they are linked to the specific local context. A “theoretical selection” was used for selecting respondents aged fifteen years and older through use of network method [4]. The fieldwork took place in the period of 2011 to 2013. Although “sensemaking” [5] is unique for each person, the analysis of the stories of the interviewees provided the researcher with a number of striking themes [4] which were reinforced making use of an eclectic range of “sensitizing concepts” [6] as identity and respect. The analysis also produced some “key incidents”, that can be assumed to highlight some striking patterns in everyday life [7]. This paper focuses on the most salient themes in this Aruban study.

3. RESULTS

3.1 Shifting networks

The data shows that during the different stages of life, different themes play a role in establishing or maintaining contacts [8]. With young people, it often involves the building of a circle of friends, and finding a suitable partner. With adults, it is more about maintaining contacts, especially with the loss of daily activities such as work, sports and other leisure activities. Moreover, it is remarkable that for most respondents the (for the small-scale community so characteristic and valuable) daily encounters outside the homes decrease. Older respondents experience many other losses at the same time, such as the death of a spouse, family members and friends. For several this leads to social isolation. All this occurs while the respondents are often becoming more and more dependent. People in their network who are available daily to help are of great value to them. The network is strikingly often addressed for needed transportation and guidance outside the home. Various respondents need to travel abroad for a second opinion or medical treatment. This has consequences for the help needed abroad, as well as at home for the family left behind. Since Aruba is an immigration country, family members and friends come and go and are not always available on site to help. Care providers, educational institutions and employers become especially important for several respondents. To keep in contact with these parties, most are dependent on assistance with transportation.

3.2 Identity transformation

The data also shows that the visual limitation certainly has an impact on the identity of the person involved [9]. It makes a difference thereby whether the visual impairment is visible to others, or not. For people with a congenital visual impairment, this is part of their identity since childhood. Those respondents, however, who acquired a visual impairment later in life, present themselves under influence of a “virtual social identity” and the associated “stigma” [10]. Nevertheless, there are big differences in this. Identity appears to be a dynamic process of defining yourself and being defined by others in various respects and throughout your entire life [11]. For several respondents, this involves an inner struggle. Not all respondents are able to see their visual impairment as a part of their identity yet [9]. Striking for Aruba is that the medical process frequently takes time, with consequences for the respondents’ experienced identity.

3.3 The mutual production of (self)-respect

Respect for differences between people [12] and the acceptance of one’s own situation appear to be closely interwoven in this study, especially in people with a non-congenital visual impairment. (Self)-respect is jeopardized when people see themselves as less. Several respondents deny their disability or feel ashamed of it. The reciprocity in relationships is often put under pressure, with significant consequences for the (self)-esteem and mutual granting of autonomy [12]. Visually impaired who contribute to the community earn (self)-respect.

3.4 Key incidents

In this context, much attention is paid to so-called “key incidents” [7] that seem to mark crucial developments for many visually impaired people. For example, the moment that it becomes clear what is (medically) wrong (‘I can’t do anything for you’); or the moment at which the extent of what the person is losing becomes quite obvious (‘That day, I stopped driving’); the moment that the person openly admits to being visually impaired (the white cane); or the moment he or she definitively tries to get a better grip on the situation (going to FAVI); the moment that the realization hits that a new path has been taken (or not); and an encounter with a so-called ‘leverage figure’. These incidents somehow mark their identity, (lack of) (self)-respect and autonomy as well.

3.4 Leverage Figures

Much depends in these on the quality of the interaction with various persons and agencies. For this reason, a great deal of value is placed on the empathy and respect with which such parties engage with the respondents. Special attention is paid to ‘leverage figures’; people who appear to have given those involved an ‘unsolicited’ essential nudge in a specific direction at ‘a particular moment’. These people can even be casual passersby. It is remarkable that these persons actively listen, speak and/or offer practical help, respectful of the own abilities

and choices of the person. As such, they support respondents with awareness of their disability, help seeking and/or learning new possibilities if they open themselves up for that.

4. CONCLUSIONS

The experiences and perceptions of those investigated are layered, complex, individually distinct and constantly changing [13], each person continuously gives his or her own meaning to everyday events and experiences, and acts accordingly [14]. What stands out for various visually impaired people on Aruba is the international aspect of the medically defined episode, with consequences for the time required for this and the needed support. Remarkable are also the international and diminishing networks, excluding structures, and a risk for isolation and impoverished social standing. Identity, respect and autonomy appear to be interwoven dynamic processes, taking place in the networks of the small-scale community. The data shows that visually impaired persons can increase their opportunities by opening up to others and new experiences. Furthermore, the quality of relations and encounters matters. From professionals to casual passersby who can serve as ‘leverage figures’ and in this way, significantly contribute to the social inclusion of visually impaired, if they are open to this. Through dialogs with all stakeholders the themes in this study can be further discussed in a creative quest for an inclusive society.

REFERENCES

- [1] T. J. Carroll, *Blindness. What it is, what it does, and how to live with it*. Library of Congress, 1961, p. 72.
- [2] CBS Aruba, *The prevalence of disability in Aruba*. CBS, 2013.
- [3] C. Brinkgreve, *Vertel. Over de kracht van verhalen*. Drukkerij Ten Brink, 2014.
- [4] H. ‘t Hart, H. Boeije and J. Hox, *Onderzoeksmethoden*, Boom Onderwijs, 2005, p. 270.
- [5] K.E. Weick, *Making sense of organization*. Blackwell, 2001, p. 199.
- [6] H. Blumer, What is wrong with social theory? *American Social Review*, 3-10, p. 7, 1954.
- [7] F. Erickson, Some approaches to inquiry in school-community ethnography. *Anthropology and Education Quarterly*, 8 (2), 58-69, p. 6, 1977.
- [8] J. Smart. *Disability across the developmental life span*. Springer Publisher Company, 2012.
- [9] S. Dale, *Songs at twilight*. Cambridge Scholars Publishing, 2011.
- [10] E. Goffman, *Stigma. Notes on the management of spoiled identity*. Penguin Group, 1990, p. 3, o.p 1963
- [11] H. Ghorashi, *Ways to survive, battles to win*. Novo Science Publishers, Inc. 2003.
- [12] R. Sennett. *Respect in a world of inequality*. W.W. Norton & Company, Inc, 2003
- [13] J. Law, *After method. Less in social research*. Routledge Taylor & Francis Group, 2004
- [14] K.E. Weick, *Sensemaking in organizations*. Sage Publications, Inc, 1995.

Aetiologies of CVI in Mainstream Secondary Education

Katrien Keppens¹, Rita Patteeuw², Anne-Leen Vandamme³, Mieke De Pourcq¹.

¹Centre of Expertise Spermalie, De Kade
Bruges, Belgium
{[katrien.keppens](mailto:katrien.keppens@de-kade.be), [mieke.depourcq](mailto:mieke.depourcq@de-kade.be)}@de-kade.be

²Secondary School for Special Education Spermalie, De Kade
Bruges, Belgium
{[rita.patteeuw](mailto:rita.patteeuw@de-kade.be)}@de-kade.be

³Primary School for Special Education Spermalie, De Kade
Bruges, Belgium
{[anneleen.vandamme](mailto:anneleen.vandamme@de-kade.be)}@de-kade.be

1. ABSTRACT

The aetiology of brain dysfunction in children with cerebral visual impairment (CVI) in mainstream secondary education is studied retrospectively. 25 Children are included, 9 male/16 female. Mean age is 15 years 7 months. The mean visual acuity of the best eye is 7,4/10. 28% had another ophthalmological diagnosis (7/25). IQ was good: total mean 90. 68% suffered from comorbidity.

64% have perinatal problems (16/25). 9 are born premature (36%). The lowest gestational age is 27/40, with a birth weight of 1000 g. In 4 term children problems during delivery are reported.

36% have no history of any perinatal problem (9/25). The aetiologies in these children are tumour, meningitis, head injury, hypoxia at later age, turner syndrome, an arterio-vascular malformation, cardiopathy with preoperative ischemic episode. We included two children with a genetic abnormality.

Children with CVI in mainstream education have less genetic abnormalities. Other aetiologies occur in the same percentage as in other studies. They have the same percentage of comorbidity, but less severe comorbidity. They have a better visual acuity. They might well compensate due to good IQ. In the future we will study the children with CVI who follow special education in order to compare whether they have different aetiologies than those in mainstream education.

2. OBJECTIVES

The aim of this study is to investigate the aetiology of the brain dysfunction in children with cerebral visual impairment in mainstream secondary education. In Flanders 450 000 children attend mainstream secondary education. 180 of them

(0.04%) get academic support by an expert for visually impaired. Among them, 38 (21%) have CVI, the main cause of visual impairment. This study focuses on these CVI patients. This percentage of CVI is very similar to findings of Boonstra et al. They report that CVI accounts for 27% of visually impaired children (1).

3. MATERIALS AND METHODS

A retrospective study in children with CVI in mainstream secondary education in Flanders is performed. 25 Children are included, 9 male/16 female. Mean age is 15 years 7 months, from 13 years to 18 years. The visual acuity of the best eye is 10/10 in 10 children, the lowest acuity measured is 1.6/10 and mean visual acuity is 7,4/10. 28% have another ophthalmological diagnosis (7/25), e.g. cataract, retinopathy of prematurity or optic atrophy. Intellectual capacity of these children is good. Their total IQ, measured with WISC-III, had a mean of 90, with a range from 64 to 127. 68% suffered from comorbidity (17/25), e.g. DCD and ASD.

Children with CVI, who attend special education are not included in this study.

4. RESULTS

64% have perinatal problems (16/25). 9 are born premature (36%). The lowest gestational age is 27 weeks, with a birth weight of 1000 g. In 4 term children problems during delivery are reported. Only very little is known about neonatal hypoglycaemia and CVI. In only 1 child neonatal hypoglycaemia is reported. In all the other children information on neonatal glycaemia is lacking. The periventricular leucomalacia on MRI images of children with neonatal hypoglycaemia is very similar to what can be seen in children with CVI.

36% have no history of any perinatal problem (9/25). The aetiologies in these children are tumour, meningitis, head injury, hypoxia at later age, Turner syndrome, an arterio-vascular malformation, cardiopathy with preoperative ischemic episodes and epilepsy.

We included two children with a genetic abnormality, a girl with Turner syndrome and a girl with Sturge Weber syndrome. The CVI is caused by an arterio-venous malformation in the parieto-occipital region in the latter child.

5. DISCUSSION

The percentage of premature born children is similar to other studies. Bosch et al report 32% (2), Khetpal et al 29% (3).

We included two children with a genetic abnormality (8%). Bosch et al find a genetic cause in 21% of children with CVI (3). This difference may be due to our inclusion criteria. All the reported children attend mainstream secondary education. We find the same difference in children with severe speech and language impairment (SLI). In children with severe SLI in mainstream education, a genetic abnormality is present in less than 1%. In children with severe SLI in special education, a genetic abnormality is present in 28%. These data are not published yet.

Other aetiologies are present in quite similar percentages than reported in other studies (4,5,6,7).

Comorbidity is present in a similar percentage of children in our study as reported in literature (1,2,3,4,6). The impact of comorbidity on functioning in general may be less severe in our study population, as they are still able to attend mainstream secondary education. A study focusing only on children who need special education is not yet available. Comparing which children remain in mainstream education and which children need special education is very difficult, because available support in mainstream education is not the same in all countries. In Flanders a system of more individual support is theoretically available from last year on. But the inclusion criteria to obtain educational support got stricter. At present there is a lot of uncertainty.

Visual acuity is good in the present study population, with only one child with a visual acuity of 1,6/10. Fazzi et al report reduced visual acuity in 87% (4). Bosch et al report severely reduced visual acuity in 20%(2). The difference may be due to the

fact that only children in mainstream education are included in this study.

6. CONCLUSION

The children with CVI in mainstream education have less genetic abnormalities. Other aetiologies occur in the same percentage as in other studies. They have the same percentage of comorbidity, but less severe comorbidity. They have a better visual acuity. They compensate due to good IQ. In the future we will study the children with CVI in special education in order to compare whether they have different aetiologies than those in mainstream education. It is interesting to look for more information on neonatal glycaemia to investigate whether there is a link between neonatal hypoglycaemia and CVI as the MRI abnormalities of both conditions look similar.

REFERENCES

1. Boonstra N, Limburg H, Tijmes N, van Genderen M, Schuil J, van Nispen R. Changes in causes of low vision between 1988 and 2009 in a Dutch population of children. *Acta Ophthalmol.* 2012;90(3):277–286.
2. Bosch D, Boonstra N, Willemsen M, Cremers F, de Vries B. Low vision due to cerebral visual impairment: differentiating between acquired and genetic causes. *BMC Ophthalmol.* 2014;14:59.
3. Khetpal V, Donahue SP. Cortical visual impairment: etiology, associated findings, and prognosis in a tertiary care setting. *J AAPOS.* 2007;11(3):235–239.
4. Fazzi E, Signorini SG, Bova SM, La PR, Ondei P, Bertone C, Misefari W, Bianchi PE. Spectrum of visual disorders in children with cerebral visual impairment. *J Child Neurol.* 2007;22(3):294–301.
5. Dutton GN, Jacobson LK. Cerebral visual impairment in children. *Semin Neonatol.* 2001;6(6):477-485.
6. Huo R, Burden SK, Hoyt CS, Good WV. Chronic cortical visual impairment in children: aetiology, prognosis, and associated neurological deficits. *Br J Ophthalmol.* 1999;83(6):670–675.
7. Afshari MA, Afshari NA, Fulton AB. Cortical visual impairment in infants and children. *Int Ophthalmol Clin.* 2001; 41(1):159-169.

More information: katrien.keppens@de-kade.be

Copyright © 2017 Katrien Keppens

Motor development and (early) intervention in blind and severely visually impaired babies, toddlers and children

Lieve Dewerchin, Katrien Keppens

Centre of Expertise Spermalie, De Kade
Bruges, Belgium
{lieve.dewerchin, katrien.keppens@de-kade.be}

ABSTRACT

Visual impairment interferes with gross and fine motor development in children: The motor development is at risk and delayed. On the other hand, a blind individual is in need of optimal motion possibilities in order to discover his/her world through moving and touching and to achieve a maximum of self-reliance and independence allowing participation in daily life.

Support and stimulation of blind children are provided by an early intervention team Accent. Targeted advice to these home caregivers is based on regular assessment of the child by our multidisciplinary team.

We provide an overview of the most important findings concerning the delayed achievement of the gross motor milestones in blind babies and toddlers, and the reduced general dynamic coordination in older blind children. We also list specific motor difficulties detected, for which special attention and stimulation is required by the caregiver through a specific yet varied motor education program

1. INTRODUCTION

When dealing with blind and severely visually impaired babies and children we face a paradox: The motor development is at risk, delayed and follows its own sequence in blind children.[1][2][3][4][5][6]. On the other hand a blind individual is highly in need of optimal motion possibilities in order to discover his/her world through moving and touching and to achieve a maximum of self-reliance and independence allowing participation to daily social life. Therefore offering support to the parents and developmental stimulation of blind children are necessary. This is provided by the early intervention team Accent. These specialized home caregivers can rely on specific and multidisciplinary assessment and follow-up of the (motor) development. The multidisciplinary research team consists of an ophthalmologist, a developmental psychologist, and

a physiotherapist. It is coordinated by a neuro paediatrician. The physiotherapist relies on neuro-developmental approaches, different (sensory-) motor scales (AIMS, Bailey, etc), literature on motor development in blind children and own experience.

2. OBJECTIVES

In this paper we give an overview of the most important findings and characteristics of the neuromotor development found in literature and acquired by own experience through dealing with blind and individuals: babies/ toddlers and (young) children. The most important guidelines to apply during the accompaniment of the children are stressed.

3. RESULTS

During the first 2 to 3 months no differences are observed in the neuromotor characteristics of blind babies, compared with babies with normal vision [1][3][4][5]. From 2 months onwards a delay of head control is seen, due to prolonged vestibular fine-tuning. Headlifting in prone position comes later till 6 months. In sitting and standing the head is bent 30° downwards. Until 7 months the head lays back when pulling to sit. Due to prolonged proprioceptive fine-tuning, 'jerky' fidgety movements are exaggerated until 8 to 10 months. Due to prolonged cerebellar fine-tuning postural instability with ataxic features in head and trunk are present until 12 to 14 months [1].

A typical trias of motor phenomena are seen as an early signal of visual impairment in neurologically normal blind babies [3]: more activity in lower limbs than in upper limbs, orienting ear towards sound and stopping motor activity when listening to sound (in older babies).

An important delay is also observed in the moment the blind baby brings his hands together on midline and plays with his feet (between 6 and 12 months).

All these factors explain the altered sequence and the delay in the motor milestones. The moment a blind baby starts to reach out and to grasp on sound is an important breakthrough for the further motor development [2].

Possible motor difficulties requiring special attention and stimulation are the fear of being moved and the fear to move, a preference to move only in the sagittal plan and the delay in gaining postural transitions. We see a lack of lateral and backwards supporting reactions of the upper limbs, difficulties with transferring the weight laterally, trunk rotation, often rocking for- and backwards. The postural transitions are delayed or not gained at all without stimulation: from supine to prone and back to supine, from lying to sitting, from sitting to creeping position, creeping and from sitting to standing.

Many blind babies have an increased sensibility of the hands, a decreased tactile exploration and a delay in constructive play up till 1,5 year.

When stimulating and handling the blind baby, focus should be on variation of movements and on transition of postures. It's important to give them time to integrate the tactile, proprioceptive, vestibular, auditory information.

In the older blind and severely visually impaired children some motor characteristics are typically different from children with normal vision. 30% have hypotonia, which causes a delay in motor development. They also have a typical standing posture and a typical gait pattern [3],[5],[6]: 30° anteflexion of the head, sometimes thoracic kyphosis and lumbar lordosis, sometimes elevation of the shoulders fixating the head, more flat feet, often more flexion in hips and knees (sometimes hyperextension), toeing out, a wider base of support reduced stride length, a slower walking speed, a prolonged duration of the double support phase, less trunk rotation, little reciprocal arm-sway, less heelstrike, more feet shuffling (echo-localization?), less fluency, diminished dynamic balance and general fitness.

The general dynamic coordination of 45 blind children and 61 visually impaired children was investigated in Zeist and Bruges from 1988 until 1998. Several groups, aged 5 to 14 years, were tested in *Bartimeus Institute* (Netherlands) and *Spermalie Institute* (Belgium). Results were pooled. The Körper Koordinations -test für Kinder (Shilling & Kiphard 1974) was adapted for visually impaired and blind children by A.M. Reimer in 1994. In the group of visually impaired children the Motor

Quotient (MQ) was situated between 60 and 75. In the group of blind children the average MQ was between 40 and 65. The MQ decreased with increasing chronological age. Individual variation was significant.

In older blind children specific motor stimulation, education and training on a daily basis is necessary, consisting varied gross motor exercises and activities with focus on: time for exploration of environment and materials, sufficient repetition, rest and attractiveness.

4. CONCLUSION

In the blind baby almost all motor milestones are delayed. We see an altered sequence. The delay increases with age. The different sensory neuro systems need more time for fine-tuning. The loss of vision however will never be fully compensated. Specialized support to the parents for handling their baby and motor stimulation of blind children requires multidisciplinary (early) intervention with focus on self-initiated mobility, transition of posture, locomotion and constructive play. Often individual physiotherapy is recommended.

The older child is faced with a distinct retardation on general motor coordination, strength and endurance. Varied and thorough motor exploration must be offered to older children to limit their delay towards sighted children and to enhance their general possibilities to independent living.

REFERENCES

- [1] H. Prechtel, G. Cioni, C. Einspieler, A. Bos, and F. Ferrari, "Role of vision on early development: Lessons from the blind," *Dev. Med. and Child Neurology*, no 43, pp.198-201, 2001.
- [2] E. Fazzi and P. E. Bianchi, *Visual Impairments and Neurodevelopmental Disorders. From diagnosis to rehabilitation*, John Libbey Eurotext, 2016.
- [3] P. Helders, "Aspecten van de motorische ontwikkeling bij blinde kinderen," *info VSVVO*, no 9, pp.21-28, 1992.
- [4] M. Dik, *Baby's en peuters met visueel functieverlies. Handboek voor ouders van jonge blinde en slechtziende kinderen*, Robert Weydert, , 2005.
- [5] S. Rosen, "Kinesiology and sensorimotor function,". *In: Foundations of Orientation and Mobility*, AFB Press, 1997, pp.170-199.

[6] R. Boter and P. Helders, “Motorische ontwikkeling,” In: *Kinderen die slecht zien*, Houten/Diegem, 1996, pp.74-85.

Copyright © 2017 Katrien Keppens

Problems in orientation and mobility in children with cerebral visual impairment (CVI)

Emma Van Damme, Mieke De Pourcq, Katrien Keppens

Mobile service Accent, De Kade, Spermalie,
Bruges, Belgium
{emma.vandamme, mieke.depourcq, katrien.keppens}@de-kade.be

ABSTRACT

Children with cerebral visual impairment (CVI) have difficulties in orientation and mobility. Better orientation and mobility helps those children to grow up more independently.

We look at different age groups, starting from babies unto adolescents. The difficulties these children report differ from age to age. For every problem, we look for an appropriate answer. They always have a major impact on the quality of life of these children.

This research focuses on children without major motor co-morbidity. Some children with CVI have cerebral palsy (CP). Children with CP are excluded, since their problems in mobility are linked to both, CP and CVI.

Babies fear unknown, busy environment. They tend to move less. Their motor development is delayed as seen in blind children (cfr poster ICEVI/043). Toddlers are afraid on the playground. In primary school, children have difficulties finding their way to the classroom. Going to secondary school gives most problems. The schools are larger, children have to switch from one classrooms to another more often. Social pressure of the peer group becomes harder.

We look for tips and tricks based on our experience and knowledge on mobility and orientation in blind and severely visually impaired children.

In this poster we give an overview of the typical problems in orientation and mobility in children with CVI and we look for an answer to these problems. Sometimes the answer is a compensation strategy, sometimes we teach these children to focus on special items, sometimes we try to translate the problem to a model, sometimes electronic devices are used for compensation.

1. OBJECTIVES

Children with CVI (Cerebral Visual Impairment) have difficulties in orientation and mobility. We will report which rehabilitation assistance can be offered. Better orientation and mobility will help those children to grow up more independently.

2. MATERIALS AND METHODS

A careful inventory was made regarding problems with orientation and mobility. ICF model is used to describe the difficulties and the current support and approach.

We describe the problems as they occur in different age groups, from infants to adolescents. Difficulties in orientation and mobility can have a major impact on daily life functioning.

This research focuses on children without major motor comorbidity. Children with CVI and severe motor disability, often due to cerebral palsy (CP), are excluded. Their mobility-problems often are linked to both, CP and CVI. A good knowledge of the problems in children with CVI and normal locomotion can lead to better understanding in CVI/CP children.

In this poster we present a clear case for each age category. CVI manifests itself differently in each child. A child is so much more than CVI. Many other aspects like mental capacities, coping strategies and surroundings also have an influence on functioning and participation. Specific patterns of problems are met in every age group. Because the problems vary for each child, the approach will have to be worked out individually. The ICF model is a good tool to get a clear view on specific difficulties.

3. DISCUSSION

Babies fear unknown, busy environment. They tend to move less. Their motor development is delayed as seen in other blind and severely visually impaired children. The motor development and early stimulation is described in a poster on this subject by our group.

In secondary school problems are very obvious. Secondary schools are larger, children have to switch classrooms more often. Social pressure of the peer group becomes harder.

Problems in orientation and mobility are more evident and more prominent in adolescents. They have greater impact on functioning and participation than in younger children. In infants these problems are more subtle. Their world is smaller. And yet... also in infants these problems often interfere with their functioning and participation. Moreover these problems may affect their later participation. One can hope that early intervention has a positive impact on participation in adolescence.

The approach as offered to blind and severely visually impaired children provides a good basis for developing a roadmap to address the problems with orientation and mobility in children with CVI. We look for a balance between stimulation, compensation, rehabilitation and dispensation. We strive for achieving maximum independence within safe limits.

It is important that children with CVI are supported by teams specialized in the care for visually impaired children. The problems they meet, are so similar to the problems visually impaired children with ocular pathology have. Obviously the approach should also be similar.

4. CONCLUSIONS

Specific age dependent problems in orientation and mobility are found in children with CVI. The answers are also individual and age dependent.

In this session we have given a practical overview of the typical patterns of problems in orientation and mobility in children with CVI and helpful approach. ICF model is used to get a clear picture of all the data. Support by a team for visually impaired children is strongly advised, as they have a lot of experience in mobility-training for children with ocular disorders.

We look forward to help you investigating orientation and mobility in your CVI patients and to help you looking for an answer to the problems they meet.

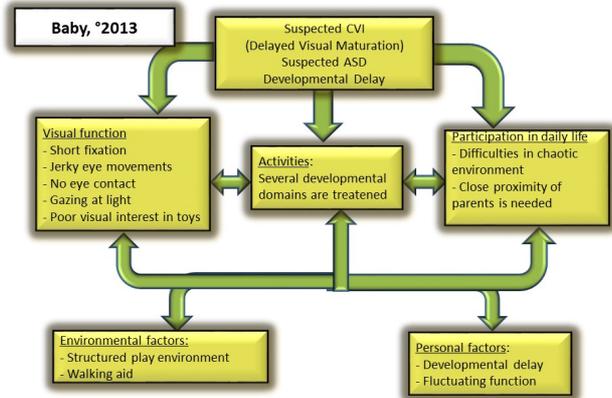


Figure 1. problems with orientation and mobility in a baby with delayed visual maturation.

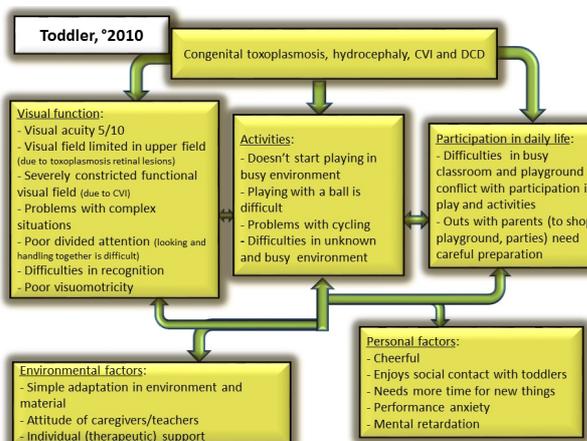


Figure 2. problems with orientation and mobility in a toddler with CVI.

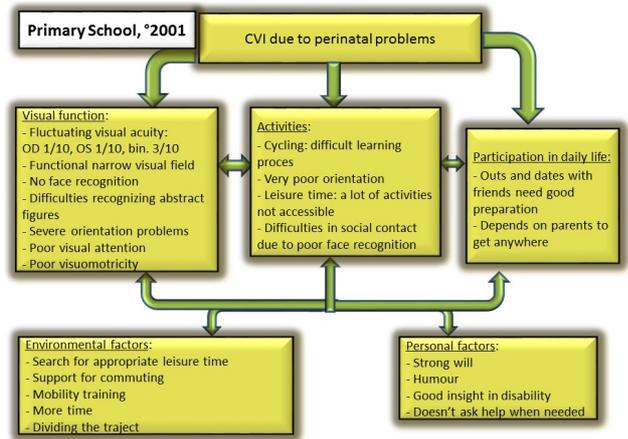


Figure 3. problems with orientation and mobility in primary school in a child with CVI.

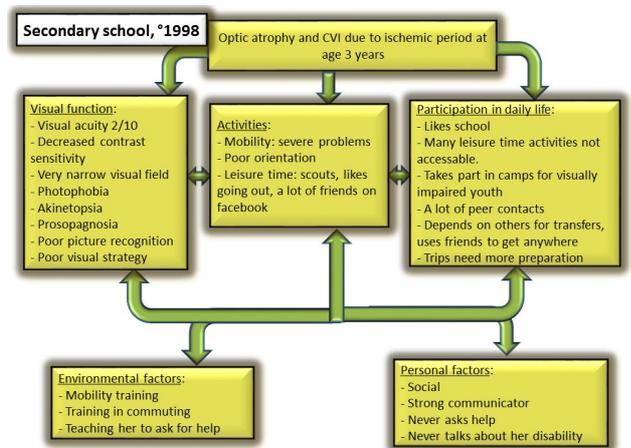


Figure 4. problems with orientation and mobility in secondary school in an adolescent with CVI.

More information: katrien.keppens@de-kade.be

Copyright © 2017 Katrien Keppens

Rising prevalence of students with cerebral visual impairment (CVI) in main stream (secondary) education calls for a different approach

Mieke De Pourcq¹, Anne-Leen Vandamme², Emma Vandamme¹, Rita Patteeuw³, Katrien Keppens¹.
De Kade, Spermalie, Bruges, Belgium

¹Centre of Expertise campus Spermalie
Bruges, Belgium
{mieke.depourcq, emma.vandamme, [katrien.keppens](mailto:katrien.keppens@de-kade.be)}@de-kade.be

²Special Primary School Spermalie
[anneleen.vandamme](mailto:anneleen.vandamme@de-kade.be)@de-kade.be

³Special Secondary School Spermalie
Bruges, Belgium
{rita.patteeuw}@de-kade.be

1. ABSTRACT

Prevalence data indicate that Cerebral Visual Impairment (CVI) is the leading cause of visual impairment in children.

Better ability of the school support teams in dealing with CVI-related problems ensure that more children remain in mainstream education. Whereas better general awareness for visual dysfunction leads to more referrals to CVI-clinics. Therefore we notice an increasing population of children with CVI in main stream education over the last ten years. The presence of students with CVI nearing or in secondary education calls for a customized, specific, often multidisciplinary approach.

The aim of this study is to create better support of CVI students in main stream secondary education.

For better understanding of the needs of CVI students, they are referred to our multidisciplinary team. The data of these investigations are collected in a retrospective study.

In 2006 only 2 students with CVI attended mainstream secondary education and were supported by home intervention team Accent and/or school intervention team Spermalie. In 2016 this amount increased to 25 students with CVI. We give a detailed overview of their needs and concerns and of the typical problems they are confronted with. We provide information about the current approach and support.

Students with CVI in main stream secondary schools need a different approach and support than children with CVI in primary schools.

2. INTRODUCTION

Better ability of the school support teams in dealing with CVI related problems ensure that more children remain in mainstream education. Whereas better general awareness for visual dysfunction leads to more referrals to CVI clinics and specialized multidisciplinary research teams.

3. METHODS

For better understanding of the needs of CVI students, they are referred to our multidisciplinary team. The data of these investigations are collected in a retrospective study. We provide information about the current approach and support.

4. RESULTS

4.1 DATA

In 2006 only 2 students with CVI attended mainstream secondary education and were supported by home intervention team Accent and/or school intervention team Spermalie. In 2016 this amount increased to 25 students with CVI.

4.2 TYPICAL VISUAL PROBLEMS OF CVI CHILDREN

They suffer from mild to severe vision loss. Their vision strongly varies, even from moment to moment. Visual processing takes a lot of effort. They have problems with visual search. In school surroundings a blackboard can be chaos to them. Some tasks are made very complex. They meet severe problems with orientation and mobility. A lot of them have tunnel-vision-like field of view

while in stress. Especially in unfamiliar environment, crowded rooms and in situations where their functioning is dependent on making sense of a lot of visual 'clutter'. Interpretation of drawings and depth perception is difficult for them. Recognition of faces and/or locating friends in a group is difficult for them.

4.3 NEW PROBLEMS FOR CVI STUDENTS IN SECONDARY SCHOOL

First of all learning pace is higher in secondary education. The teaching materials are less adapted. Different font styles and backgrounds are used in books. The data on the blackboard or the digital board are often unstructured. Maps, tables, graphs, pictures and drawings are widely used. Lots of visual materials are used, like videos, PowerPoint presentations and books.

More mobility is asked from the students. They have changing classrooms every hour. Secondary schools are bigger schools than primary schools.

The social interaction is more demanding in this age group. They have more teachers, changing class group. Peer pressure is higher at this age. Their self-esteem is under pressure. They can meet problems with the acceptance of the disability.

Critical moments are the start of the school year, exams, excursions, internship and career choice.

There is limited knowledge of CVI by laymen. Therefore the support team has difficulties in having adjustments accepted by teachers and other pupils. E.g. having trouble reading is accepted as a problem in people with dyslexia, but not in people with CVI.

4.4 CURRENT AIDS, SUPPORT AND/OR ADJUSTMENTS FOR CVI STUDENTS

Twelve have custom atlas, maps, drawings, graphs and images. Four students use magnifying copies, one a magnifying lamp and one conversions of textbooks in large print. Six students use digital textbooks, three digital files in Word and nine digital files in PDF. One student sits at a desk with adjustable inclination. Nine students use a laptop with digital files. Seven students have processing software or text to speech software.

For transfers three students use a white cane. And seven students get orientation and mobility training.

4.5 CURRENT ELIGIBILITY FOR HELP AND SUPPORT

CVI is recently accepted as condition for granting visual aids and adjustments. Processing software is only granted with a diagnosis of dyslexia. There is no funding for laptops and/or scanners. With the diagnosis "mild visual impairment" school support can be provided for 2 hours a week for 2 years in secondary school. With the diagnosis "severe visual impairment" school support can be provided for 4 hours a week each year.

4.6 NEEDS AND CONCERNS

Assistance and support should be based on individual visual function disorders. This should be described using the ICF model. Co morbidity should be taken into account, as it is very common in CVI. More details on this subject in our poster on aetiologies of CVI in mainstream secondary education. Multidisciplinary support should be considered.

4.7 SUGGESTIONS FOR BETTER SUPPORT OF THE CVI STUDENTS

For students with "mild visual impairment" yearly, but less intensive, school support should be provided.

Extensive mobility training should be given to all students with CVI in secondary education.

There should be assertivity training and training of the social skills. A buddy system can have advantage for a lot of the CVI students.

Internship should get special support, e.g. with temporary adaptation of the workplace. A hiring system for sporadically needed aids should be available. E.g. tandem bicycle at the day of an excursion.

All schoolbooks should be obtainable in accessible software.

Appropriate education and coaching for teachers and co-students should be started.

5. CONCLUSION

Students with CVI in main stream secondary schools demand a different approach and support compared to children with CVI in primary schools.

More and better support in secondary education offers an entrance gate to higher education, employment and independence.

More information: katrien.keppens@de-kade.be

Copyright © 2017 Katrien Keppens

Bookbox: a Story with 3D printed Tactile Plates

Griet Pattyn¹, Mieke Vandorpe¹ and Sofie De Leener²

¹Mobile Support Service Accent, Centre of Expertise Spermalie / De Kade,
Brugge, Belgium
{griet.pattyn, mieke.vandorpe}@de-kade.be

²Research and Design Oostende, Belgium
contact@sofiedeleener.be

ABSTRACT

Bookbox offers visually impaired children the chance to learn more about their local environment in a relaxing way. The story contains elements that the children know from their daily life. It is an opportunity for children to touch and feel the story which is enhanced through tactile input. The 3D printed plates give the opportunity to feel elements of the story that are hard to represent on any other tactile way, like for example the 3D version of the fly.

The box contains 5 plates with the story in a bookform. The plates can be placed in the cover of the box to create a steady base. The child can also listen to an audio file on the accessory USB stick or the Daisy-cd with the story in 5 chapters. It makes the story a valuable activity to do independently.

The bookbox is the result of a cooperation between Sofie De Leener and Mobile Support Service Accent.

1. INTRODUCTION

Parents who read together with their child create a cozy moment, a nice togetherness.

Not only is it entertaining but it is also a good and positive way to stimulate language development of babies and toddlers. Different studies indicate the positive effects of reading on oral language development^{1,2}.

Not only speech benefits from the reading and looking at the pictures. It also has a positive effect on imagination, emotional development and so on. A two-decade-long research study has shown that an early childhood surrounded by books and educational toys will have a positive impact on a person's brain well into their late teens³.

2. THE BOOKBOX

But what about children who are sever visual impaired? They can not look at the pictures or can not be triggered by colourful drawings. Even the language in books can be too

Copyright: © 2017 Griet Pattyn et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

visual to understand, making the concept of words too difficult.

The bookbox overcomes those issues and offers the child a simple but interesting story with five 3D printed plates who add tactile information for the child.



Figure 1: the bookbox in general

The bookbox reaches the target group of visual impaired children, age 4 to 8 years.

3. THE STORY

The story "Saartje and the little fly" is about a girl, Saartje, who meets a little fly at her room at home. It is a simple story containing every day elements. The simplicity makes it understandable for the child, relying on its immediate living environment.

The story is available in three forms:

- a folder: caregivers can read the text
- USB-stick with audio file
- Daisy CD with audio file

4. THE PLATES

The story is illustrated with 5 tactile plates. The plates are 3D printed in powder resin and measure 12 x 12cm.

The first plate illustrates a street with houses and an apartment building. The concept 'apartment' is in normal circumstances very hard to explain to young blind or severe visual impaired children. The 3D-printed plates make it possible to understand abstract concepts.



Figure 2: the first plate

The second plate illustrates the blocks where Saartje is playing with. There is the possibility to move the blocks back and forth. For young children it creates a fun little active moment during the effort of listening.

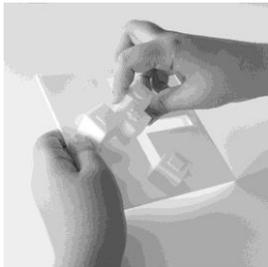


Figure 3: the second plate

The third plate illustrates a big and a small fly. The small fly has been printed in actual size, while the big fly gives the child the possibility to feel all the segments of the fly. A real animal is in normal circumstances a difficult thing to touch, especially insects. The 3D printed fly gives a good and realistic template for the child.



Figure 4: the third plate

The fourth plate enables the child to let the fly fly by making circular movements.



Figure 5: the fourth plate

In the story the fly flies away through the window. At the fifth and last plate the child can pretend to let the fly fly through a window.

5. THE BOX

To create a stable and clear surface for the child, the box of the plates can be used as a standard. The child can put the plates in the base. On that way it structured the work-field of the child and the child can keep its orientation well.

6. CONCLUSIONS

Bookbox offers blind and visually impaired children the chance to learn in a relaxed way about their direct living environment. The story contains elements that children know from everyday life. The supplied touching plates help them to make a correct presentation of the concepts⁴.

Acknowledgments

We'd like to thank everyone who contributed in any form to the making of the bookbox, with special thanks to De Makers and ISO800.

REFERENCES

- [1] <http://www.kindengezin.be/ontwikkeling/taal-en-communicatie/taalstimulering/voorlezen/>, consulted at 22 april 2017.
- [2] H. Raikes, B.A. Pan, G. Luze, C.S. Tamis-Lemonda, J. Brooks-Gunn, J. Constantine, L.B. Tarullo, H.A. Raikes, and E.T. Rodriguez, "Mother-Child Bookreading in Low-Income Families: Correlates and Outcomes During the First Three Years of Life," in *Child Development*, vol. 77, no 4, pp. 924-953, 2006.
- [3] J. Alok, "Childhood stimulation key to brain development, study finds" at <https://www.theguardian.com/science/2012/oct/14/childhood-stimulation-key-brain-development>, 2012, consulted at 22 april 2017.
- [4] F. Van Cauwelaert, "Bookbox, verhalen voor slechtziende kinderen in 3D" at <http://www.zeronaut.be/blog/2015/10/1/bookbox-verhalen-voor-slechtziende-kinderen-in-3d>, 2015, consulted at 22 april 2017.

Families with a visual impaired child: integrating visual stimulation into daily life.

Katrien Perneel¹, Mieke Vandorpe¹, Bastiaan Thijs¹, Patricia Delbeke¹

¹Mobile Support Service Accent, Centre of Expertise Spermalie / De Kade,
Brugge, Belgium

In cooperation with

University of Antwerp, department product development
Antwerp, Belgium

And

Dr Delbeke

{mieke.vandorpe – katrien.perneel}@de-kade.be

ABSTRACT

It is important to make children with a delayed visual maturation and children with severe/multiple problems aware of the visual world around them. In case the visual process doesn't get started, intense visual stimulation is an important stage in supporting and helping children and their families at home.

The black box (BOPL-box) is a primary method for visual stimulation. Fluorescent visual stimuli, powered by blacklight, can be showed in isolation. In this way, there is no interruption of other visual effects in the surroundings of the person.

The main goal is to make parents integrate visual stimulation into the daily life of their child. So, we need a portable system that can be easily used by families. Originally, the black box was developed by Paul Looijenstein and Ben Vanoverbeek, our colleagues of Holland in the late 80's. Ever since, the product has not been renewed. In order to integrate the black box into everyday life, adapting it to a modern, contemporary, accessible and attractive version was our number one condition.

This project was created through a collaboration between Mobile Support Service Accent and the University of Antwerp, department Product Development.

INTRODUCTION

Mobile support service Accent offers support to blind and partially sighted children, youngsters and adults and their families and social network. The early guidance team focuses on kids aged 0 to 6.

Copyright: © 2017 Katrien Perneel et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

The first months of a newborn child's life are crucial for the development of the visual system. Intense visual stimulation is indispensable to make children aware of the visual world around them. Visual stimulation can be provided in various ways and must always be customized.

1. BLACK BOX

The black box (BOPL-box) is a primary method for visual stimulation. It stimulates the basic visual functions such as perception/awareness, fixation, following with the eye and hand-eye coordination (reaching and grabbing). Furthermore, it can also be used for children that are struggling with selective attention. Fluorescent visual stimuli, powered by blacklight, can be shown in isolation. In this way, there is no interruption of other visual effects in the surroundings of the person.



Figure 1. Black box in daily light

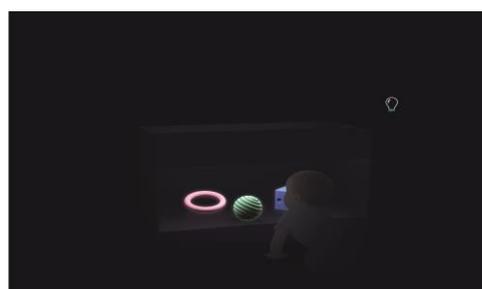


Figure 2. Black box in dimmed light

The concept of the black box is excellent, but it has some limitations in its present form.

The design is large, heavy and therefore hard to move. Moreover, it occupies a lot of space and does not look very child-friendly or attractive. The main goal in our guidance is to make parents integrate visual stimulation into the daily life of their child. This is why we must strive for a design which is not seen as a practical disability-specific tool, and is very inviting to provide visual stimulation. It is important for parents to be able to integrate this as a moment of play within their daily routine.

2. METHOD

We have entered a collaboration with the University, of Antwerp, department of Product Development, where a 5th grade student is currently developing our concept as part of his Master's thesis. He is being assisted by dr Delbeke, a child-ophthalmologist with whom we work close together and ourselves.

The use and the functions of the black box have been thoroughly decomposed, and parents were questioned and observed while using the black box with their child. Several aspects were essential while developing the new product, such as:

- The box must be easy to transport and handle
- The box must be usable at the table, while sitting, while lying on your side and while lying on your back
- External visual stimulation needs to be eliminated
- Hygiene
- Nice looking

...



Figure 3. Prototypse of the reworked Black box

The preliminary design is ready and has been tested on 2 severely partially-sighted children. The eventual product is expected to be ready by June.

3. CONCLUSIONS

Visual stimulation is an essential part in our support. It is important for parents to integrate this visual stimulation into their child's daily life. We want to offer parents all the opportunities to optimally address their child's development opportunities. This is much easier when the material

is easy to handle and inviting to play/stimulate. It is important to evolve along with the needs of young families and to adjust our material according to their needs.

Acknowledgments

We'd like to thank Paul Looijenstein and Ben Vanoverbeek to entrust us with the renewal of the concept 'Black Box'.

Care Binder for Parents regarding (Social) Administration.

Kim Maesele¹, Stefanie Maeghe¹ and Myriam Callemeyn¹

¹ Mobile Support Service Accent, Center of Expertise Spermalie / de Kade, Bruges, Belgium
{kim.maesele, stefanie.maeghe, myriam.callemeyn}@de-kade.be

ABSTRACT

Often we hear parents complaining regarding the stack of documents they collect over the years when they have a child with a visual or multiple impairment: medical records, social administration... And the number of different services that they have to deal with. Some parents don't know what they need to keep up or can throw away, can't understand the text, are poorly organized and can't find the right document when they need it.

We want to support parents make their way through the different (social) services, but also help to clear the paperwork for their child so they don't lose important documents. This will save a lot of time for the parents and (social) caregivers.

Therefore we propose parents a care binder, an organizing tool with formats with the name and symbol of the various services they get to deal with. This should enable them to keep track of important information about their child's health and care in a central place. They can also find a folder with an overview of the benefits where their child may be entitled to receive and the social services that can help giving further information of social allowances.

1. INTRODUCTION

Mobile Support Service Accent supports families with a child and youngster with a visual and/or multiple impairment.

Often we hear parents complaining regarding the paper mountain and information from many sources associated with their child's special needs and care. Some parents don't know what they need to keep up or can throw away, are poorly organized and can't find the right document when they need it, or can't read and understand the written language... They have a risk to lose important information and possible social benefits, to feel lost or lonely in the amount of different (social) services... This causes additional stress.

Copyright: © 2017 Kim Maesele et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

2. HAVING A CHILD WITH A VISUAL AND/OR MULTIPLE IMPAIRMENT

2.1 How to combine work, life and 'care'?

Many parent have already a very busy agenda where it's often difficult to keep balance between work and life. But when a child is born with an impairment it becomes for parents a real challenge to find a good balance between work, life and 'care'.

Research indicates that taking care of a child with an impairment is even more stressful then taking care of children with a normal development. The parental stress can have a negative impact on the family functioning. [1]

2.2 How to cope with...?

Parents of a child with an impairment have to find problem solving coping strategies to deal with the challenge of handicap related problems to reduce stress.

Effective strategies for parents are concentrating on the next step, active problem handling, creating positive meaning out of life, searching social support and information. [2]

3. SPECIAL NEEDS, SPECIAL CARE

3.1 Find your way through the papers...



Figure 1. This photo shows a personal family organizing system where all possible documents were well sorted.

Some parents develop spontaneously their own system to organize the paperwork, see Figure 1. Often families who are already well organized in their daily life.

Whereas other parents keep struggling with all those papers. Often parents who are less organized in their daily life have another mother tongue, can't read... They don't know what they need to keep up or can throw away, they can't find the right document when they need it, they lose reports, they can't understand the content...

3.2 Find your way through the services, benefits...

Parents can be overwhelmed by the number of different services that they have to deal with. Or get lost in the amount and procedures for social benefits.

3.3 Find your way with a little help...

Research shows that professionals can help parents to reinforce the family strength by giving them abilities, attitudes and resources. [3]

As professionals we try to empower parents to make their way through the different (social) services, but also help to clear the paperwork for their child so they don't lose important documents. This will save time and reduce stress for parents and for professionals too.

4. CARE BINDER

4.1 Professional, help to organize.¹

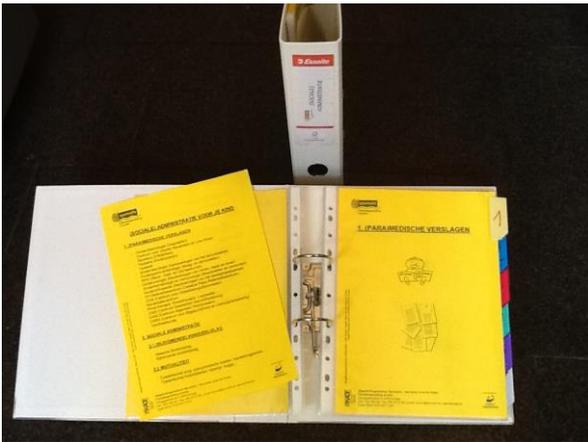


Figure 2. This photo shows the self-made care binder designed by mobile support service Accent.

Mobile support service Accent has designed a care binder, an organizing tool to support parents of a child with a visual (multiple)impairment to cope with the amount of papers and (social) services, see Figure 2.

¹ We prefer a large binder instead of scanning everything on computer. The benefit of a computer is that parents will have all documents they'll need, but they will either have to take their computer with them to all

4.2 Organize the paperwork!

We propose parents a care binder, an organizing tool with formats with the name and symbol of the various services they get to deal with. This should enable them to keep track of important information about their child's health and care in a central place.

4.3 An overview of benefits and social services!

Parents can also find in our care binder a folder with an overview of the benefits where their child may be entitled to receive and the social services that can help giving further information of social allowances.

5. CONCLUSIONS

Mobile support service Accent has designed a care binder to empower some parents of a child with a visual (multiple) impairment to cope with the amount of papers and (social) services. This enables them to keep track of important information about their child's health and care in a central place. Being more organized helps parents to reduce stress inherent in handicap related problems.

REFERENCES

- [1] D. Peeters and C. Saenen, i.s.m. N. Segers and Prof.Dr. B.Maes (promotor), *Ervaringsonderzoek naar de zorg-werk-leven balans van ouders met een kind met een handicap en aanzet tot evaluatie van een vormingspakket voor deze doelgroep*. Masterproef PPW Katholieke Universiteit Leuven, 2012-2013.
- [2] Idem
- [3] Idem

appointments, or try to anticipate what they will need and print and bring that documentation with them. And, not every parent has a laptop or tablet at home.

‘Regarding the future’. Inspirations for and by people with a visual impairment.

Lorenzo Billiet (1), Debbie Claus (2), Eva De Stecker (3), Sarah De Ruyck (1), Heidi Deknudt (4), Sonia Meys (5), Marieke Weckhuyzen (6)

(1) Center of Expertise Blindenzorg Licht en Liefde, Varsenare, Belgium

Billiet.Lorenzo@lichtenliefde.be

DeRuyck.Sarah@lichtenliefde.be

(2) Mobile Support Service Accent-Center of Expertise Spermalie/ de Kade, Brugge, Belgium

Debbie.Claus@de-kade.be

(3) Center of Expertise Spermalie/ de Kade, Brugge, Belgium

Eva.DeStecker@de-kade.be

(4) School for Adults, Sint Rafaël, Blindenzorg Licht en Liefde, Gent, Belgium

h.deknudt@sintrafael.be

(5) Center Ganspoel, Huldenberg, Belgium

sonia.meys@ganspoel.be

(6) Rehabilitation Center De Markgrave, Antwerpen, Belgium

marieke.weckhuyzen@demarkgrave.be

(7) Royal Institute Woluwe, Belgium

ABSTRACT

We want to present our book ‘Regarding the Future. Inspirations for and by people with a visual impairment’. This book is the result of interviewing 15 people with a visual impairment, mostly young adults. We asked them how they made the transition from youngster with a visual impairment to adult, on the domains of studies, work and free time. How did they make their choices? Every one of these interviewed people had obstacles on their way to build the life they want and had to be very creative to search for opportunities and chances. The stories in the book can be a great inspiration for children and youngsters with a visual impairment who are trying to make their way in life. This book hopes to show them that they have a lot of qualities and strengths and that they often can follow their dreams.

1. INTRODUCTION

The book ‘*Regarding the future. Inspirations for and by people with a visual impairment*’, is the brainchild of CORV, or the Commissie voor Ontwikkeling en Research ivm. Visuele Handicap (Committee for Development and Research regarding people with Visual impairments).

The members of CORV are, to date, the Center of Expertise Blindenzorg Licht en Liefde, the Mobile Support Service Accent-Center of Expertise Spermalie/de Kade, the Center of Expertise Spermalie/ de Kade, the School for Adults Sint Rafaël, partner to Blindenzorg Licht en Liefde, Center Ganspoel, Rehabilitation Center De Markgrave, and the Royal Institute Woluwe. The goal is to share knowledge, take joint initiatives and develop projects.

Each of these organisations works with either minors or adults who are confronted with visual (or multiple) impairments. Among those with visual impairments, we have noticed a longing to give meaning to their lives, to participate, achieve their goals and aspirations and become and remain contributing members of society.

They have a multitude of questions, which often have no easy answer, such as: “I have completed my education, how will I find a job?”, “I’ve lost the job I love because my sight has diminished, how do I go on?”, “I want to live on my own, is that possible?”, or even, “I’m looking for leisure activities that take my visual impairment into account – is there anything available for me?”

All too often, these people and their network receive the message that something is impossible, because of their disability. Barriers are put in their way, their hopes and aspirations are cut off at the knee, and it becomes increasingly difficult to envision ways to realise their dreams.

The book, ‘*Regarding the future. Inspirations for and by people with a visual impairment*’, aims to inspire people with visual impairments and their network.

2. THE BOOK

2.1 Objectives

People with visual impairment often do not have the chance to create a life that is of maximum importance to them and to others. The book aims to offer realistic and hopeful stories, told by people who themselves have visual impairments. These experiences can be a powerful incentive to think as a society about the importance of positive self-worth and to look for what is needed to enable full participation by people with visual impairment.

The book also aims to increase the visibility and recognisability of people with visual impairments. Non stereotypical portraits, as well as the myriad of positive qualities all people carry within them, quite apart from their disabilities, are put in the spotlight.

The intention behind the making of this book is to provide powerful stimulus through realistic, hopeful stories, to think together about what is important in life, in order to creatively search for less obvious, surprising ways to achieve our dreams.

2.2 Target audience

This book is intended for a wide range of audiences, such as:

- young adults with visual impairments, who are nearing the end of their educational path, and their parents.
- adults who are faced with a (progressive) visual disability.
- teachers, Centers for student counselling, mental health workers and coaches.

Through the stories of people who have faced the same questions, aspirations, obstacles and doubts, we aim to provide a realistic, yet hopeful vision for the future of the readers.

The stories in this book highlight a variety of paths which may be chosen, as well as the roads not taken. The contributors reflect on their decisions in life and their long-term effect on their well-being. They speak frankly about creating your own opportunities and roadblocks, as well as those that are thrown at you by life, and the people around you.

2.3 Content

'Regarding the future'. Inspirations for and by people with a visual impairment, is a collection of 15 interviews of "extraordinary" people, with "ordinary" dreams, wishes and desires. It pays homage to the strength of the individuals who share their stories, to the road they have chosen to take in their development and self-actualization, with an eye for both the opportunities and the obstacles that came their way.

Among these stories, some lead the reader away from the beaten track. For example, our society attaches great importance to paid employment, but this is not possible for everyone, nor may it be the best choice for everyone. Some contributors are employed or aspire to be, yet others speak openly about their choice to build a life that gratifies in other ways.

The book does not fail to provide an overview of the support nodes that enable equal opportunities for people with visual impairments. It offers the reader and interested parties an outline of the existing organizations and

structures which aim to facilitate the full participation of people with visual impairments to society.

2.4 Contributors

The people who share their personal stories within this book hail from a variety of different regions of Flanders. They are of all ages and backgrounds, and display a wide range of educational achievements, personal goals and needs. Within the limits of the medium, the book attempts to offer a cross-section of contemporary society.

2.5 Design

We have opted for a printed book, with an accompanying audiobook. The font and spacing [1] were chosen specifically to make the text easier to read for people with visual impairment. The layout and design are neutral, monochrome and straightforward, to make the text accessible for a broad audience, including those who may use low vision optical devices in order to read printed text.

3. FINAL NOTES

The term 'visual impairment', conjures up images of problems and impossibilities. *'Regarding the future'. Inspirations for and by people with a visual impairment*, aims to demonstrate that there many opportunities available, thanks to the often unique talents and skills of visually impaired people. Talents and skills that can only be expressed in as much as society offers the necessary incentives and support.

We hope to positively influence the way society as a whole, and people with visual impairment in particular, regard this disability.

Acknowledgments

The book *'Regarding the future'. Inspirations for and by people with a visual impairment*, is the tangible result of the collaboration between the various organizations that work for CORV.

To get from the first thoughts of combining the stories of several people with visual impairment to the publication of a book with an accompanying audiobook, we could rely on the unwavering support from our organisations, volunteers and sponsors. They helped us make this dream a reality.

The book is for sale with all the organisations who contributed to its realization. The contact details of these expertise centres can be found in the heading of this paper.

REFERENCES

- [1] www.dyslexiefont.com

New Techniques And Methods In Working With Multidisabled Visually Impaired Students At “Prof. Dr. Ivan Shishmanov” Special School For Visually Impaired Students

Yana Raeva, Julieta Petkova

“Prof. Dr. Ivan Shishmanov” Special School for Visually Impaired Students, Varna, Bulgaria

iana_r@abv.bg, julieta_petkova@abv.bg

At “Prof. Dr. Ivan Shishmanov” Special School for Visually Impaired Students in Varna, Bulgaria, 151 visually impaired students from the whole country receive educational services. The launched in 1989 Program for multi disabled visually impaired students, now enrolls 124 students whose training is carried out according to the requirements of the Ministry of Education and Science in three educational levels: Primary, Pre-secondary and Secondary. A team of different specialists carries out the initial assessment and individual program for each child, intermediate assessment and final assessment.

Five years ago was created a parents group for mutual psychological assistance and support, aiming to create opportunity for sharing personal experience, to find solutions for particular problems and to get real help.

MDVI students have the opportunity to participate in adaptive sports like New Age Kurling and Boccia.

Vocational therapy in the Ceramics and Knitting workshops involves students, including the ones with physical problems, and develops skills introducing different techniques.

This year a sand therapy was initiated.

Annually organize seminars for parents, teachers and teachers exchange with colleagues from other countries. Our teachers participate in European and world conferences to exchange innovative methods and techniques in education of visually impaired students.

Prof. Dr. Ivan Shishmanov Special School for Visually Impaired Students in Varna, Bulgaria, the oldest of its kind on the Balkan Peninsula, established in 1905, has at its disposal contemporary facilities, special equipment and a team of specialists. It enrolls 151 visually impaired students from all over the country on two levels:

- blind and low vision students with normal intellect, who are trained according the regular curricula of the regular schools. Graduates, who have successfully completed their secondary education, continue in higher educational institutions.
- multi disabled visually impaired students, including deaf blind, who are trained according individual school programs, designed by a team of different specialists. They do not receive a certificate for completed level, but they receive a certificate for completed class.

Since 1998 up to now the number of the multi disabled visually impaired students has grown up to 124, assigned in 20 classes. Their training is carried out according the requirements of the Ministry of Education and Science. The school team makes the initial assessment and designs special program for each child, as well as interim evaluation and final assessment of the achievements at the end of the school year.

Parental groups of mutual assistance and support

During 2011/2012 school year, the parental group for mutual assistance and support was started under the guidance of the school psychologist. A survey was conducted beforehand to study the opinion and desire of the parents. The basic principle in the organization and holding of such groups is the voluntary attendance. Parental meetings are held twice a month with duration of about 90 minutes, in a small group of up to 12 people.

Some parents visit the group regularly; others for various reasons stop visiting. At the beginning of each school year, new members - parents of newly enrolled students - are usually included. There are one-time visits as well.

The goals of the parent group are to create the opportunity for contacts and communication of people with identical problems and difficulties (in this case the parents of children with multiple disabilities); sharing information and personal experience; searching for solutions to specific problems and difficulties encountered; sharing emotions and experiences; support.

Each meeting follows a certain scheme and has its own rules that include the principle of confidentiality, the right to personal opinion, respect for other people's opinion, etc. The beginning is related to the process of getting to know each other, introducing and setting up group members for the upcoming interactive process. The leader of the group is a psychologist.

Sports activities

During the last four years, MDVI students are actively involved in sports activities in two sports - Boccia and New Age Kurling.

The selection of the children is at the discretion of the physiotherapist, according to the requirements and individual qualities. Leading role "plays" the ability of participants to be successful in games. The training process is tailored to the individual characteristics of the contestants, respecting the principle of consistency and graduation in upgrading the rules. The formation of the

final teams is a long process - from individual to group activities and formation of teams. Annually, a spring and autumn tournament is organized at the school, and the winners receive prizes for their achievements. The participation of children in adapted sports brings them many emotional experiences, confidence and socialization.

Modified tools and customized aids for students working in ceramics and knitting workshops

Over the past two years, the school has been using innovative methods in creating and using modified tools and customized aids for students in ceramics and knitting workshops.

In ceramics workshops students from 14 to 20 years of age are trained in vocational skills. Students work in groups up to six children. Training starts with clay kneading, ball shaping and packing for storage. Students develop skills for rolling, shaping and modeling. The older students work with gypsum molds, they mold and cast the liquid clay. They make decorative wall panels and candlesticks. Painting and varnishing of fired items are the last steps learned to varying degrees by students depending on their abilities

In the knitting workshop, students learn the basics of making baskets; master the technique of knitting a hat and a scarf. They develop skills for making necklaces, stringing in composition, varnishing finished products, using different tools according to their individual needs and abilities, engaging in family life and coping alone with different life situations. They master ideas and form skills for realizing personally significant, emotionally-practical norms of social activity for post-school life - which ideally includes work.

The activities planned in the knitting workshop aim to develop motor coordination, concentration and fine motor skills by training various techniques in applied knitting. We introduce students to two ways of knitting without needles – finger knitting and using adapted round knitting loom.

In the last school year, we also introduced working with wool or making non-woven cloth by wool felting, and by two felting techniques such as wet felt and needle-felt for the production of beautiful and spectacular martenitsas and small bases for different decorative panels that are sold at the traditional bazaar for our school in March.

Students with multiple disabilities can master crafts - knitting and ceramics, of course, according to their individual abilities.

Mastering the craft skills of multi disabled visually impaired students, although very limited, opens up various possibilities for realization. It should be done mainly by integrating them into small groups, in suitable premises - offering a working atmosphere and mastering of professional tasks.

During current school year, a new therapy was introduced - sand therapy. By means of voluntary work, a box of changing colors for painting on sand was made. Thanks to the sand therapy, students create interesting pictures reflecting their inner soul world. It helps children

to cope with different behavior problems, to improve communication and interaction with other children and adults, it affects their mental development. Sand therapy in school is used not so much to change the children, but to give them the opportunity to express themselves. By painting on sand, children can learn letters, figures, and study concepts such as "left", "right", day and night, seasons. It favors the development of visual thinking, improves perceptions and memory, tactile sensations and fine motor skills.

Sand therapy can be practiced in groups or individually by both the psychologist and the special teacher.

Conclusions

In conclusion, we have to say that of significant importance for increasing teachers' professionalism is the freedom given to them to receive upgrading training in leading educational institutions in Europe and the USA by exchanging foreground experiences and sharing innovative methods and techniques in working with multi disabled visually impaired students.

The Benefits Of Group Homes For Persons With Congenital Sensory Loss

A description of a successful movement by an adult woman with congenital deafblindness from a residential care to at specific care at Bartiméus

Wanda Frederiks, Caro Verlouw - Mooij

Bartiméus, Expertisecenter Deafblindness,
Doorn, the Netherlands
{wfrederiks, cmooij}@bartimeus.nl

ABSTRACT

As a consultant, my daily job is to visit organizations for persons with intellectual disabilities and give advices on care, related to visual functioning. One of the persons I met was Nance: a deaf, middle-aged woman with a severe intellectual disability. Nance experienced lots of difficulties and her caregivers worried about her well-being. Through our consultancy, a vision loss was diagnosed: something that has not been noticed before. When her life-story was studied, it became apparent that Nance's mother had been infected with Rubella during pregnancy. The congenital rubella syndrome explained the experienced challenges in care, and it was decided to move Nance to a group home for persons with congenital deafblindness at Bartiméus. These houses offer optimal care settings due to specialized education and knowledge of the caregivers. These skills bring excellent opportunities for interaction and communication, and also create houses that have good facilities at the level of acoustics, lightning and orientation support.

The poster presentation will describe Nance's move and the opportunities it gave her. Nance was always known as a person who did not like to be touched, but now she requests proximity. She also was very passive in her former house, while she now likes to watch the activities of the caregivers. She changed from a person who hardly smiled to a happy woman. The goal of this poster is to point to the possible benefits of houses for persons with sensory disabilities, using Nance's story as a illustrative base.

Copyright: © 2017 Frederiks et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Summertime for children with CVI

Nicole Scheirens¹, Elke Spans²

¹ Early support team Center Ganspoel, Bachelor orthopedagogic sciences

² Early support team Center Ganspoel, Master pedagogic and orthopedagogic sciences

ABSTRACT

By this poster we want to present the cvi camp organized in Center Ganspoel for children with cvi, from 8 to 12 years.

Children with CVI can come to school in our center Ganspoel and stay in boarding school during the week. Lots of parents prefer to keep their child at home and choose a school closer to their home, but less adapted to the visual problems of their child. Our ambulatory services support families and schools from this children regarding their visual problems.

Working with the families of school-aged children with CVI, a special need, urged: the need for adapted care during school holidays. Schoolmates can participate easily to all kinds of youthcamps and sportactivities. For children with CVI these camps and activities are too crowded, too difficult, too tiring because the visual problems are not taken into account. Above that, parents of these children, have a big job to take care of their child every day and may need 'a break' as a 'caregiver of a child with CVI'.

For the children who come to our camp, it is also a unique opportunity to meet other children with CVI. Above that, the campactivities like meals, washing- and dressingmoments, campexcursions are used to learn them how to be more independent (Eg example how to find your way in a supermarket).

The adjustments for this camp are all important for children with CVI and we will show examples on the poster with pictures by following statements :

1. WHY?

We organize a summertime for children with CVI because often they don't find their way in the regular recreation facilities (for example a camp of a youth movement).

2. WHO?

For children with the diagnosis CVI between 8 and 12 years old and possible additional disabilities.

3. WHERE?

In the Center Ganspoel (different locations). We choose for this location because the spaces and materials are mostly adapted for the children with CVI (and other disabilities). If needed, we do extra adaptations. Some activities are outdoors.

4. WHEN?

The camp is organized during the summer vacation (July-August) and lasts 4 days (3 nights). A longer periode is often more difficult and less approachable for parents and their children. For some it is their first camp experience.

5. ACCOMPANIMENT?

The camp is supervised by people who work at the Center Ganspoel and are experienced with these children.

6. ACTIVITIES?

Activities are for example to cook, to organise a shop visit, a ride with bus or train, games, sports, dance, visiting a playground, a parc or zoo, a creative workshop, riding bicycles...

Visual demands of augmentative and alternative communication

Friederike Hogrebe

TU Dortmund University, Faculty of Rehabilitation Sciences, ProVisIoN Project
friederike.hogrebe@tu-dortmund.de

ABSTRACT

Augmentative and alternative communication (AAC) allows people with limited possibilities of common communication modes (e.g. oral language) to express their needs, wishes and feeling and participate in interpersonal interactions [1]. AAC modes can be diverse, however, there is a strong emphasis on visual-based graphic systems via symbols and photographs. This study aims to analyse which visual demands the AAC devices present. For the purpose of analysis, a systematic literature review was conducted. The review analyses studies that examine different features of graphic design (colour, form, complexity, size, number, location etc.). This systematic analysis leads to the development of insights concerning the design of devices for AAC. The implications derived from the analysis of literature are compared with the design of existing devices.

The results of the analysis may help to indicate which visual demands presented by AAC devices must be considered during the process of choosing an appropriate AAC device.

1. INTRODUCTION

People with complex communication needs can be supported in their expression via other than oral modes using modes and methods of augmentative and alternative communication (AAC). These modes can be diverse (communication computers, sign languages, etc.), but the main emphasis is on visual-based graphic systems which contain symbols and photographs.

Besides cognitive requirements such as decoding and the identification of meaning, the users of AAC are faced with visual demands when using symbols and photographs for communication. In most cases, neither the demands nor the visual capacities of the users are taken into account during the process of choosing an appropriate device [2, 3].

Several authors have identified the need for further research, which takes the visual aspects of AAC into account. Consequently, this is an area for exploration to gain further knowledge about the visual demands of specific

graphic elements. This information could be applied in the design of AAC devices [4] to increase the users' successful communication by creating appropriate conditions [5]. Furthermore, research could focus on visual capacities of the users to understand the challenges of visual processing in people with complex communication needs [2] and to gain a better understanding how people interact with pictures as representatives for messages [6].

Although there is a broad range of scientific knowledge about different visual characteristics of graphic elements (colour, size, form, number, location etc.) from different scientific fields such as psychology, human-computer interaction etc., an integration of this knowledge into the field of AAC is still necessary.

2. METHODS

The aim of the study is:

1. To analyse which visual demands people who use AAC devices are faced with.
2. To analyse if and how visual capacities of users and potential users of AAC are taken into consideration in manuals and protocols for assessment in the AAC field.

Based on theory, elements for a criterion-guided analysis are developed. Relevant publications from different disciplines (psychology, human-computer interaction, education etc.) are compiled in a research synthesis about the AAC devices' different features of the graphic design. This systematic analysis provides a basis for the development of insights concerning the design of devices for augmentative and alternative communication. The insights derived from the analysis will be compared with the design of existing devices in order to gain knowledge about the actual demands users are faced with.

The second element of the research will be an analysis of manuals and protocols for assessment in the field of augmentative and alternative communication. The aim of this approach is to find out in which amount and if at all the visual capacities, which are essential to successfully respond to the actual demands of the AAC devices, are taken into consideration.

Copyright: © 2017 Hogrebe- This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

3. RESULTS

The study is currently in progress, so final results are not yet available. Preliminary results indicate a huge variety of different studies in different scientific areas, which can be compiled in the research synthesis.

4. CONCLUSION

The results of the analysis may help to indicate which visual demands are presented by AAC devices.

An active use of AAC devices for users with complex communication needs is a primary goal in education and therapy to overcome social and communicative isolation. Matching the device with the needs of the user is a step in reaching this goal. Considering visual aspects of AAC is an essential part of identifying appropriate devices and planning educational interventions. Erroneous allocations in cases of failure concerning the cognitive abilities could be reduced if a broader range of potential factors involved is covered during decision-making.

Acknowledgments

The first author is supported by a scholarship of the “Waldtraut und Sieglinde Hildebrandt-Stiftung”.

REFERENCES

References

- [1] D. R. Beukelman and P. Mirenda, *Augmentative and Alternative Communication: Supporting children and adults with complex communication needs*, 4th ed. Baltimore, Md.: Paul H. Brookes, 2013.
- [2] J. C. Light and D. McNaughton, “From Basic to Applied Research to Improve Outcomes for Individuals Who Require Augmentative and Alternative Communication: Potential Contributions of Eye Tracking Research Methods,” *AAC: Augmentative and Alternative Communication*, vol. 30, no. 2, pp. 99–105, <http://www.tandfonline.com/doi/pdf/10.3109/07434618.2014.906498>, 2014.
- [3] J. Brown, A. Thiessen, D. Beukelman, and K. Hux, “Noun representation in AAC grid displays: visual attention patterns of people with traumatic brain injury,” *Augment Altern Commun*, vol. 31, no. 1, pp. 15–26, 2015.
- [4] K. Gillespie-Smith and S. Fletcher-Watson, “Designing AAC systems for children with autism: evidence from eye tracking research,” *Augmentative and Alternative Communication*, vol. 30, no. 2, pp. 160–171, 2014.
- [5] K. M. Wilkinson, N.A. Dennis, C.E. Webb, M. Therrien, M. Stradtman, J. Farmer, R. Leach, M. Warrenfeltz, C. Zeuner, “Neural Activity Associated with Visual Search for Line Drawings on AAC Displays: An Exploration of the Use of fMRI:

AAC: Augmentative and Alternative Communication,” *Augmentative and Alternative Communication*, vol. 31, no. 4, pp. 310–324, 2015.

- [6] A. Thiessen, D. Beukelman, C. Ullman, and M. Longenecker, “Measurement of the visual attention patterns of people with aphasia: a preliminary investigation of two types of human engagement in photographic images,” *Augmentative and Alternative Communication*, vol. 30, no. 2, pp. 120–129, 2014.

Dance Therapy Session As Part Of The Universal Design For Learning “Body In Motion”

Ivana Macokatić

Day Care Center Mali Dom – Zagreb, Croatia

ivanam@malidom.hr

1. INTRODUCTION

“Body in Motion” is a set of sessions that gathers arts therapies focusing on movement. The main topic of the sessions is “The Four Elements: Fire, Water, Earth and Air” that were chosen because of their polarities of abstraction and simplicity. The abstraction is important because it can go into free movement expression as someone's authentic experience, through for example breathing, sounds, rhythm of walking, running and the like, and simplicity is something that is present and used every day, which can be tangible as well; it gives direct experience. For example, Earth is something stable that keeps us grounded and balanced, but we can also plant it or walk on it. Those two components are very important in the presentation of the content, as it has to be meaningful to the receiver and give them an opportunity to react to it.

2. METHODS

The work was carried out with 6 MDVI children aged from 4 to 10 years. The program was carried out by special education teachers, specialized in specific art therapy fields, in cooperation with the teachers and children of the Dance School. The Universal Design for Learning (UDL) is chosen as a method of teaching and presenting content, to emphasize the importance of flexible learning and point to the fact that every person is able to learn and follow the principles of UDL. In the movement area, Laban/Bartenieff principles and somatic studies are chosen as bodily based experimental knowledge and practice.

Objectives: To create a safe space in order to encourage self-expression concerning the given content, while also learning to handle artistic elements, movement and movement modes of expression. Improving communication through content, raising awareness of the body and space around it.

3. SESSION

3.1 Air – Earth

The activity starts with an essential body movement, such as breathing. It creates closeness and also a safe space for the children. The breathing movement is something that everyone can feel. It can be supported with touch or sounds which follow the breath.

Position in Space – Vertical: up and down, exploring the space up in the air and coming back down to the Earth.

Qualities: Exploration of movement from something that is light and free as "Air" to the stable component that the "Earth" is.

Sounds are something that every child can create by himself; something that he gives as his reflection of the given subject. The presented models are connecting vowels or the sound of wind with air, and the drums with Earth. The movement can be initiated with different props which can ease the way of understanding the present content, for example, some big fabric can be moved up and down so children can follow the movement either by holding it, following it with their gaze or by inhaling while the fabric is going up and exhaling while it is going down.

The activity is photographed and the children take home their book with photographs or materials that were presented at the session. Their parents are familiar with the content and they talk to their children about the session, based on the materials that they were given. That is how we also track their memory of the experience and build up communication.

Learning content – taking turns, listening and responding, learning the space positions, different textures, learning about who is present in the class, language expression in the form of vowels, sign language, the expansion of voice - loud and quiet.

4. CONCLUSION

The results of the session were visible through the body memory; embodiment of postures, gestures and movement sequences, which went through

communication and sharing experiences. A story book with all the presented materials adjusted to each individual's needs is a constantly re-evoked experience which influences memory, understanding and building up of the content. The stored experience broadens the vocabulary and above all self-concept and emotional well-being.

REFERENCES

- [1] C. Fernandes (Author), R. Miranda (Foreword), J. Mota (Contributor), J. Hand (Contributor), M. Scialom (Contributor), S. Schlicher (Contributor), R. Grassmann (Contributor) *The Moving Researcher: Laban/Bartenieff Movement Analysis in Performing Arts Education and Creative Arts Therapies*, Jessica Kingsley Publishers, 2015.
- [2] CAST, *About Universal Design for Learning*, <http://www.cast.org/our-work/about-udl.html#.WQITs9Lyjcs>

Developing an online community of practice with professionals working with adults who are visually impaired and have psychiatric disorders

Lisanne Teunissen¹, Uta Roentgen², Marit van Buijsen¹, Peter Verstraten¹ and Luc de Witte³

¹Robert Coppes Foundation, Expertise, Innovation and Knowledge (EIK),
Vught, the Netherlands
{lteunissen, mvbuijsen, pverstraten}@robertcoppes.nl

²Zuyd University of Applied Sciences, Centre of Expertise for Innovative Care and Technology (EIZT),
Heerlen, the Netherlands
{uta.roentgen}@zuyd.nl

³University of Sheffield, Centre for Assistive Technology and Connected Healthcare (CATCH)
Sheffield, UK
{l.p.dewitte}@sheffield.ac.uk

ABSTRACT

Professionals providing care and treatment to adults who are visually impaired and have psychiatric (and additional) disorders (persons with VIXPI) use a lot of practical, often tacit, knowledge to support their clients. Established methods and protocols for this target group are lacking. An online Community of Practice (CoP) is a powerful mean to make tacit knowledge explicit and to share it, and was therefore developed in co-creation with professionals. Subsequent to an inventory of relevant themes two consecutive rounds of focus group interviews, the second facilitated by a video conferencing tool, were conducted with a multidisciplinary group of professionals. The professionals reached consensus on the primary aim, the structure and listed the required functionalities of the platform. As this would contribute to frequent use a preferred structure was set up and it organizes the platform as a library, a consultation forum, an overview of collaborating institutions, interesting events and a comprehensive search function. Based on the results the online CoP is developed in an iterative process and will be filled bit by bit with relevant content.

1. INTRODUCTION

Professionals supporting adults, who are visually impaired and have psychiatric (and additional) disorders (persons with VIXPI), use a lot of practical knowledge and expertise in the care they provide to their clients. Their knowledge exists in their heads, hands and hearts and enables them to deal with unique and complex support questions which are common for this target group. Established methods and protocols for the guidance of

this target group are lacking [1].

An online Community of Practice can be used as a powerful mean to make this knowledge more explicit. Communities of practice are ‘groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly’ [2]. By connecting professionals through an online CoP, an online environment will be created for professionals to communicate with each other about their practical expertise in working with this target group, to help other professionals by sharing their practical knowledge and to put these insights into practice to improve the quality of life of their clients.

2. METHOD

An iterative process, including two rounds of (online) focus group meetings with a multidisciplinary group of professionals and several individual interviews with professionals, have been used to collect the required information for developing the online CoP.

During the first round, in total 26 professionals have been consulted during four focus group meetings and seven individual (online) interviews. Three main themes regarding the online CoP have been discussed; 1) defining the user group, 2) the content and functionalities, and 3) the purpose, benefits and advantages and disadvantages of the online CoP.

The second round consisted of three multidisciplinary focus group meetings using an online videoconferencing tool in which in total 12 professionals have been consulted regarding the required functionalities and the desired structure of the online CoP.

All focus group meetings and interviews have been recorded and summarized. They have been verified using a member check and are analyzed using directed content analysis [3]. The results of the first round were used to prepare the interview guide of the second round.

Copyright: © 2017 Lisanne Teunissen et al. This is an open-access article distributed under the terms of the [Creative Commons Attribution License 3.0 Unported](https://creativecommons.org/licenses/by/3.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

3. RESULTS

The following main themes have been discussed during the focus group meetings and interviews:

3.1 Goal

The purpose of the online CoP is to share knowledge and experiences, in order to improve the care and support for people who are visually impaired and have psychiatric disorders.

3.2 User group

Participants recommended only including professionals working with the target group in the Netherlands at the beginning. At a later stage it will be explored whether it is valuable to include clients, family, carers, experts by experience and professionals living in other countries, to the online CoP.

3.3 Structure of the platform

Two different examples of a possible structure for the online CoP have been presented and discussed during the online videoconference meetings. The preferred structure organizes the platform in a library, a consultation forum, an overview of collaborating institutions, interesting events and a comprehensive search function with main topics and tags.

3.4 Content

All information regarding the care and support of people who are visually impaired and have psychiatric disorders can be shared in the online CoP. Professionals suggested a broad range of themes they would like to discuss in the online CoP, for example: participation, communication towards the client, family and others involved, diagnostics, experiences in collaboration with other healthcare organizations and problem areas like conversion, Charles Bonnet Syndrom, addictions and personality disorders.

3.5 Functionalities

Organizing the online CoP by themes will never be exhaustive and therefore consensus was reached to not divide the consultation forum in different themes but to use tags to label the published information. A comprehensive search function is therefore required to easily find the necessary information. A list of tags will be developed to ensure unambiguous use of search terms. Professionals had different opinions about categorizing the library's content by different themes. Most professionals prefer organizing the library in themes but it was difficult to reach consensus about the themes that could serve as categories. This will need further exploration.

Prioritization of the functionalities led to the following required functionalities: individual profile, uploading documents, posting messages, most recent information on top, receiving notifications and a notification function to report an unqualified message. Other possible 'desired' functionalities are: messaging functionality, video conferencing tool, possibility to tag other users and a possi-

bility to rank the published information. A general requirement of the online CoP is that it needs to be accessible for people who are visually impaired.

3.6 Security

The online CoP will be a secured online environment and professionals can request their access to the online CoP through an online registration form. The administrator will receive this online registration form and can provide access (username and password) to professionals after verifying the information they provided.

3.7 Advantages and disadvantages

A disadvantage of the online CoP is that it is a new additional task professionals should include in their work. Time is always limited and discovering and using the online CoP will take time. On the other hand the online CoP can be an interesting way to exchange knowledge, to gain valuable information, to consult other professionals in specific cases and save time and work when the required information is easily accessible.

4. CONCLUSIONS

Formerly tacit knowledge and expertise can be collected and shared via this online CoP. This target group mostly has complex support questions and this requires a lot of expertise and knowledge from professionals. The online CoP will be developed to make this knowledge more explicit. Participating professionals see potential in a manageable online platform in which they can easily consult other professionals with specific difficult cases regarding this target group. The online CoP will be developed according to professionals' input. After developing the online CoP, participating professionals are going to test the online CoP during a defined period of time to provide feedback so that desired adjustments can be made. It is expected that the online CoP will be available online for other professionals around September/October 2017.

Acknowledgments

The authors would like to thank all participating professionals in this research project. This work was financially supported by a grant from "Programmaraad Visuele Sector".

REFERENCES

- [1] Boessen, A., van Buijsen, M., & Roentgen, U. (2016). Eindrapportage Vooronderzoek 'Verborgene Schatten'. Vught: Robert Coppes Stichting.
- [2] Wenger, E., & Wenger-Tayner, B. (2015). Communities of practice a brief introduction
- [3] Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative health research, 15*(9), 1277-1288.

Realization of Life Habits in Adults with Visual Impairment

Ksenija Stanimirov¹, Branka Jablan¹, Aleksandra Grbović¹

¹University of Belgrade, Faculty of Special Education and Rehabilitation,
Belgrade, Serbia
{ksenijastanimirov}@fasper.bg.ac.rs

ABSTRACT

The objective of this paper is to show the degree of realization of life habits of adults with visual impairment in Serbia in relation to the level of their visual impairment, gender and age. The sample consisted of 92 respondents, both genders, aged 19 to 65 years ($M=35.10$, $SD=10.78$). Life habits were examined with the short form of The Assessment of Life Habits – LIFE-H.

The results showed that, compared to blind respondents, people with low vision realize greater number of life habits with less difficulty, without the help of others and without the need for the adjustments. We did not find statistically significant differences in relation to age or gender in our sample.

Main goal of special education and rehabilitation is a full social participation of people with disabilities. In that sense, realization of life habits and removing existing barriers will enable adequate rehabilitation process.

1. INTRODUCTION

According to the International Classification of Functioning – ICF [1], the ability of realizing activities of daily living is a component of social participation. In the above mentioned classification, social participation is operationalized through the life habits concept. Life habits are understood as “everyday activities and social roles which enables the individual to live and develop himself in the society” [2, pp. 347]. The result of the inability of realization of life habits is social participation limitation in specific life domain. Difficulties which are often seen in people with visual impairments and which can have negative influence on realization of life habits relate to difficulties in the physical area functioning, difficulties with the orientation and mobility, with gaining experiences and learning social behavior, low degree of social participation, less social interactions etc. All of the mentioned difficulties can have an impact on the occurrence of the need for the support by other [3].

2. METHOD

Two groups of respondents were questioned: blind people ($N=46$, $M=34.09$, $SD=12.36$) and people with low vision ($N=46$, $M=36.11$, $SD=8.95$). Based on age, there were also two groups of respondents – young adults aged 19 to 34 ($N=47$) and older grownups from 35 to 65 years of

life. ($N=45$). As for the gender, there were 40 males and 52 females questioned.

Short form of The Assessment of Life Habits Scale – LIFE-H [4] was used. This scale consists of 12 categories of life habits that relate to regular activities (nutrition, fitness, personal care, communication, housing, mobility) and to social roles (responsibilities, interpersonal relationships, community life, education, employment, recreation). Short form of the instrument consists of 69 items and it enables the assessment of the level of difficulties during the life habits realization (no difficulty, with difficulty, accomplished by a proxy, not accomplished, not applicable) and also the assessment of the help type that person needs (assistive technology, adaptation, human assistance). Higher scores obtained mean better achievements, i.e. respondent successfully realizing larger number of life habits. If a person does not accomplish specific life habit because he made such a decision or that kind of activity is not realizing in the distinct environment, than the answer should be: not applicable.

Statistical analysis was done with the package for statistical data analysis for social sciences (SPSS for Windows, version 19.0). For analyzing the differences between respondents analysis of variance was used.

3. RESULTS

Results of the respondents on the Assessment of Life Habits Scale are presented in the Table 1.

Scale	Subjects	M	SD	SE
LIFE-H	Blind	444.67	61.61	9.08
	Low vision	526.78	39.33	5.80
	Male	495.75	69.96	11.06
	Female	478.02	62.23	8.63
	Younger adults	488.45	69.59	10.15
	Older adults	482.89	62.53	9.32

Table 1. Achievements of the respondents on the Assessment of Life Habits Scale

Obtained results show that respondents with low vision achieve higher scores on the Scale in whole. Additional analysis confirmed that there are statistically significant differences ($F=58.05$, $df=1$, $p<0.000$) in favor of respondents with low vision, i.e. that group of respondents realize higher number of life habits with less difficulties,

without help of other people and without different adaptations or adjustments.

On the Scale as a whole, males have slightly better results compared to female respondents, but those differences are not statistically significant ($F=1.647$, $df=1$, $p=0.203$).

In relation to age, younger respondents have slightly higher results on the Assessment of Life Habits Scale compared to older ones. However, in our study, there were no statistically significant differences based on age ($F=0.162$, $df=1$, $p=0.688$).

4. DISCUSSION AND CONCLUSIONS

Results of this research indicate that the degree of life habits realizations is related with the degree of the visual impairment. More precisely, because of the visual residues, respondents with low vision from our sample were obtaining statistically significant higher results ($p \leq 0.000$) compared to blind respondents, for whom is showed that the lack of this sensory channel have a disabling effect in relation to realization of everyday life activities and social roles. On the other side, in our study there weren't statistically significant differences in realization of life habits in relation to gender and age of respondents ($p > 0.05$).

Regardless of the fact that the presence of visual impairment can cause difficulties, the connection between this sensory impairment and a problem in the realization of life habits may not necessarily exist. Some persons with visual impairment can keep their independence, which was the case with the respondents from our sample, while others will depended on the help of other people. Internal, i.e. individual differences in a way or in a degree of accomplishment of different life habits can be explained with some other factors, like psychological or social ones [5].

Study realized by Clark et al. [6] showed that level of participation in different life situations among people with visual impairment varies depending of the environment characteristics, which authors consider to be: poor road conditions, heavy traffic, unavailability of public transportation, architectural barriers, weather conditions, noise, etc. All of the above can be a social participation barrier for visually impaired people and therefore can serve as additional explanation for detected differences in certain aspect of participation. Currently, actual paradigm of disability of ICF is emphasizing interaction between the individual and the environment: not only the person and its characteristics are important, but also the environment in which the individual lives is important, because it determines the level of participation [6, 7].

Main goal of special education and rehabilitation is full social participation of people with disabilities. In order to accomplish that goal, it is necessary to identify existing barriers, and then work on their removal, and also provide an adequate rehabilitation program to persons with

developmental disabilities. Realization of this study enabled us to highlight personal and environmental aspects (which were also part of this research, but weren't theme of this paper) which made harder to respondents to realize life habits and accomplish satisfactory quality of life. And at the end, it is possible to make a plan of individually based interventions based on that assessment.

Acknowledgments

This paper is a result of the project "Social Participation of Persons with Intellectual Disability", which was financed by the Ministry of Education, Science and Technological Development of the Republic of Serbia [No. 179017].

REFERENCES

- [1] World Health Organization, *International classification of functioning, disability and health: ICF*. Geneva, 2001.
- [2] L. Noreau, J. Desrosiers, L. Robichaud, P. Fougeryrollas, A. Rochette and C. Viscogliosi, "Measuring social participation: Reliability of the LIFE-H in older adults with disabilities", *Disabil Rehabil*, vol. 26, no. 6, pp. 346-352, 2004.
- [3] A. Dijkhuizen, T. I. Hilgenkamp, W. P. Krijnen, C. P. van der Schans and A. Waninge, "The impact of visual impairment on the ability to perform activities of daily living for persons with severe/profound intellectual disability", *Res Dev Disabil*, no. 48, 35-42, 2016.
- [4] P. Fougeryrollas and L. Noreau, *Life Habits Measure-General Short Form LIFE-H 3.1*. Lac St-Charles, Québec, Canada: INDCP, 2003.
- [5] M. A. Alma, *Participation of the visually impaired elderly: determinants and intervention*. Doctoral dissertation, University of Groningen, 2012. Retrieved November 3rd 2016 from: http://www.rug.nl/research/portal/files/14565617/the_sis.pdf.
- [6] P. J. Clarke, J. A. Ailshire, E. R. Nieuwenhuijsen and M. W. de Kleijn-de Vrankrijker, "Participation among adults with disability: The role of the urban environment", *Soc Sci Med*, vol. 72, no. 10, pp. 1674-1684, 2011.
- [7] M. Brown, "Participation: The insider's perspective", *Arch Phys Med and Rehabil*, vol. 91, no. 9, pp. S34-S37, 2010.

Lighting for people with low vision, our approach

Steven Breughe

Blindenzorg Licht en Liefde, Vlaamssoogpunt Kortrijk, Belgium

breughe.steven@lichtenliefde.be

ABSTRACT

Advising our visually impaired clients on how to adapt the lighting in their living space started out in 2015. Our goal is to optimize the illumination levels for orientation and/or day-to-day activities. Research has shown that for many visually impaired people individually adapted illumination is important but it is difficult to provide standardized optimal levels.[1]

We offer customized advice. The methods used depending on multiple factors such as the level of nuisances caused by inadequate lighting in day-to-day life, the need for adaptations benefiting their orientation and/or need to adapt task lighting, the adaptability of their current living situation and their available budget.

Depending on these factors we decided which clients would benefit from a full diagnostic in our light lab in Antwerp and which clients would only get a basic diagnostic on site or anything in between. This resulted in different kinds of advice ranging from general advice, glare-protection, relamping, refixturing to a complete light plan all with or without calculations using specialist software.

Follow-up shows that most clients benefited from the proposed adaptations resulting in a higher level of independence and quality of life. On a further notice on-site measurements have taught us that most people's living space is inadequately illuminated compared to non-enforced standards [2] and almost all clients did not use task-lights adapted for their needs. Many did not realize that adapting illumination would be a large part of the solution, we had to make them experience the changes in illumination levels to convince them.

Visually impaired people should all be made aware of the influence lighting has on their quality of life, their independence and even their personal safety by reducing the risk of falling or sharp or hot object related accidents.

Professionals should always consider illumination when dealing with a client's requests for help.

All should be aware of the difficulties encountered when searching for the right solution in a setting lacking any specialized dealers for the client's illumination needs.

1. INTRODUCTION

Two and a half years of providing advice on adapting illumination has learned us a lot. We have changed our approach in many ways. We have informed all members of

our organization that they should make their clients aware of the possible influences adapted illumination could have on their everyday life. We have educated a team of occupational therapists and/or orthoptists so they are able to advise our clients on adequate illumination. We have installed a light lab for diagnostics. We have created and are expanding a database with easy available task lights by testing them out by our team, noting down important specifications such as lux levels and light spread for ease of advising stand-alone solutions (desk lamps). We have reached out to commercial dealers to facilitate the process of finding practical solutions for our clients.

Still we encounter difficulties slowing down the process of finding a suitable solution for the client's specific needs.

2. METHOD

We use a fixed method when giving advice. Depending on the specific situation some steps in this process can be skipped. The result always is a written advice on illumination for the client.

First we analyse the current situation, then we determine the suitable light levels for the client's needs and finally we translate this in advice with specifications allowing the client to find suitable solutions.

2.1 Analysis

First we make an in-depth analysis of the client. Who is the client, what does he or she want to do, where does he or she want to do it and why. Creating a complete picture facilitates the search for suitable solutions.

Factors such as age, the nature of the visual and other pathologies, the impairments caused by those pathologies, current visual acuity, peripheral vision, contrast sensitivity, personal experiences with different aspects of illumination, the use of low vision aids, social network and co-habitants determine who your client is.

Determining during which day-to-day activities the client experiences hindrance by illumination is of the greatest importance. Finding out how this affects their daily life gives us an idea on how removing these obstacles can increase their independence and thereby quality of life. Does the client only need specific task lighting or does the general lighting need to be adapted to create a safe living space as well?

The location also has an influence on the client analysis. The function of each room is of influence, how does the client walk through the room, which objects are placed

where in each room, how good are the contrasts, are certain surfaces highly reflective, how much light is absorbed by the walls and floor,.... Measuring illumination levels in areas can be useful to create an image of the current state. The level of adequacy of existing luminaires and light sources, how the light is spread in the room, are all factors to consider when evaluating the current situation.

Ownership of their living space can make a difference later on, home owners have more liberty to make changes to their living space than renters.

Moreover, timing is an important factor as well. Ideally clients get their advice at the stage when they contact an architect with their plans. The further down the path the more we are confronted with harder to adapt situations. Most clients asking for advice are already living in the building and are not looking for a complete overhaul of the electrical wirings.

2.2 Determination of light levels

Determining the levels of illumination which are needed to fulfil the client's needs can be done in various ways.

First of all inviting the client for a complete test to a light lab setting where we control the levels of illumination is the most complete way of finding the adequate level for the individual client. Special attention should also go out to trying out filter glasses to reduce glare. This setting allows us to determine the level of illumination needed at 20 cm above floor level as a guideline for general lighting and the levels needed for specific tasks as reading, cooking activities, hobby activities ,lip reading, reading sign language...

In some cases a full exam in a light lab is not possible or necessary. When a client already has a room where the light level is adequate, simply taking a measure of the light levels in that room can be sufficient. When looking for a solution for a specific near-vision task, an on-site quick test with a portable task light to determine the needed level of illumination can suffice.

2.3 Advice

Combining the analysis of the current situation with the determination of the level of illumination needed can result in many kinds of advice.

We aim to keep it as simple as possible, if adequate illumination levels can be achieved by making small changes to the current situation we start out with these cheap solutions. This can include but is not limited to: relamping, retrofit, refixturing, cleaning the current light sources, adapting the distance between the light source and the surface, changing the direction of the light source, adding a floor lamp, changing contrast and colours of objects, walls, floors and ceilings, using shades or filter glasses. We include a suggestion for the lumen output of the to be replaced light sources and general advice on light sources and fixtures. This ensures the ease of finding the correct

lighting solutions at common DIY stores and helps the non-expert understanding our advice.

When the client is still in the stage of planning his future living space we can extend the advice by adding suggested illumination levels expressed in lux for the walking areas and each task surface in their living space and broader advice on reducing glare. This advice is not easy to interpret by non-specialists mostly resulting in the client contacting a specialist dealer. Our team then provides assistance when needed for the dealer to understand the client's specific situation and facilitate the process of finding an adequate solution.

3. DEALING WITH DIFFICULTIES

We have encountered many difficulties during the process of giving advice. We discuss them and propose possible solutions for these difficulties.

3.1 Awareness

Clients are not fully aware of the influence illumination could have on their day-to-day life. This results in many clients not asking for this specialist advice. Follow-up has shown that many clients asking for low vision reading aids were not aware adequate lighting would be so important, in some cases adapting light levels resulted in the client being able to read again. Unawareness also results in clients not putting the budget needed aside when making plans.

Most client's homes are not sufficiently lighted compared to the non-enforced standards [2], in some cases their situation only had to be brought to those levels to solve the issues but in most cases clients benefited from even higher levels of illumination as long as the luminaires prevented glare. Some clients make the comment that lack of knowing better is what had kept them literally in the dark.

Many clients have bad experiences with simply increasing the levels of illumination in their home. A common pitfall is replacing the current light bulb with a light bulb with higher lumen output within an ill-suited luminaire resulting in higher levels of illumination but also unacceptable levels of glare. There's a lack of knowledge of how to illuminate a room or task surface amongst clients and professionals. Special attention should go to glare prevention.

Educating health workers, ophthalmologists and other professionals on the influence of illumination could change this unawareness. When clients ask for reading aids or aids for near tasks, a quick test to determine the possible influence of adapting illumination should be done. Reaching out to architects can also help create more awareness.

3.2 Lack of try-out possibilities

Most clients like to try out the effects of adapted lighting before they decide on making the investments. Commercial dealers do not offer a living experience in their show

rooms, most are packed with plenty of fittings and fixtures all lined up, not giving a correct impression. These displays can even cause glare. Trying out different solutions is not possible because almost no dealer will lend a client the desired solutions for a small period of try-out.

Equipping our team with a few samples of lighting solutions for clients to demonstrate in their own living space can provide this try-out experience. A kit with some retrofit LED bulbs of various lumen outputs and colour temperature, a portable floor lamp, a few common fixtures with standard electrical cords should suffice for small demonstrations. Creating a living room experience in the light lab can also be a good way of letting the client experience other illumination levels.

3.3 Lack of specialized commercial dealers

Many commercial dealers have no experience in dealing with visually impaired clients. Many do not understand the client's problems and specific needs. A lot of dealers also lack the knowledge of giving lighting advice with illumination levels in their mind. Many dealers only sell lighting solutions and cannot interpret our advice.

As long as no commercial dealer puts in the effort and becomes a specialist in advising visually impaired clients we should counsel our clients when they contact the dealer and we should provide feedback on the solutions proposed by the dealer. Experience has shown that most dealers are more than willing to take our expertise into account when looking for the perfect lighting solutions for the client.

As long as no manufacturer develops a specialist line of products for visually impaired people all experts advising clients can only search for solutions in the current market, a market flooded with LED solutions making it very hard to find the right device for the client. Maybe universal design aspects with adaptable lumen outputs, glare protection and other specifications will become more common in lighting solutions, so bypassing the need for lighting solutions specifically designed for the visually impaired.

3.4 Budget

Many clients have not anticipated the necessary budget for adapting their home lighting. In most cases when a client needs higher levels of illumination, this results in a higher cost for acquiring and installing these solutions. Contrary to many other low vision aids and home-adaptations, lighting solutions are not included in the basic healthcare and insurance plan and support system provided by the government for people with visual impairments. Many clients decide on not fully adapting the advice because of budgetary reasons.

Inciting our clients to apply for budgets at the government agencies or health insurance services might create an awareness of the support those clients need. This should result in a more standardized way of acquiring support via those agencies.

Using our expertise to find out what the most adequate lighting solution could be for each budget can facilitate the most economical use of the available budget.

4. CONCLUSIONS

We conclude that despite the difficulties, all persons suffering from low vision should get advice on adapting illumination levels and glare reduction. The execution of the advice can get hindered by many factors but in the end the client will have a better adapted living space to suit his or her needs even if the advice is only partially executed. Raising general awareness regarding the effect of adapted illumination via visually impaired people, healthcare professionals, commercial lighting advisors, architects, government agencies, manufacturers and more should result in a higher level of independence and more inclusive life for the visually impaired.

REFERENCES

- [1] F.W. Cornelissen, Annetje Bootsma and A.C. Kooijman, "Object Perception by Visually Impaired People at Different Light Levels," *Vision Res.*, vol. 35, no. 1, pp. 161-168, 1995.
- [2] A. Deneyer, P. D'Herdt, B. Deroisy, B. Roison, M. Bodart en J. Deltour, "Praktische en technische gids voor de verlichting van woningen". Groen Licht Vlaanderen, 2011, pp. 38-39.

The First Steps Project

Janja Hrastovšek¹, Sonja Furtomanova², Tatjana Medved³

¹ Center for Education, Rehabilitation, Inclusion and Counselling for the Blind and Partially Sighted, Ljubljana, Slovenia

²School for Blind and Visually Impaired Skopje, Skopje, Macedonia

³School for Visually Impaired Pupils „Veljko Ramadanović“, Belgrade, Serbia

Early intervention (EI) for blind and visually impaired people is identified as an important factor for development of the child. In Balkan countries (Slovenia, Macedonia, Montenegro, Kosovo and Serbia) was no well-organized system of early intervention until the year of 2012 when First steps project began.

Project coordinator is Royal Dutch Visio and the participants of the project are:

Center for Education, Rehabilitation, Inclusion and Counseling for the Blind and Partially Sighted, Ljubljana, Slovenia; School for Visually Impaired Pupils „Veljko Ramadanovic“, Belgrade, Serbia; School „Milan Petrovic“, Novi Sad, Serbia; School for Blind and Visually Impaired „Dimitar Vlahov“, Skopje, Macedonia;

Blind school-Resource center „Xheladin Deda“, Peja, Kosovo; Resource center, Podgorica, Montenegro.

The project objectivities for each organization are:

(1) to have trained teachers in EI; (2) to have trained psychologist; (3) to have trained teachers who assess functional vision.

Presentation of the project

The First steps project began in the year of 2012 and finished in year of 2017. The whole project was organized, managed and financed by the Royal Dutch Visio. Two times per a year we had training with experts in early intervention from Royal Dutch Visio. Trainings consisted of theory part and practicing with children and their family. In addition of teacher training also directors of institutions had working meetings with the head of the project from Visio. They discussed and evaluated progress and search for solutions to improve conditions for workers and services which are carried out.

We achieved results which are foundation for well-organized services for visually impaired (VI) and

multiply disabled visually impaired (MDVI) children age 0-6 in our countries.

Results of the project

(1) Each organization have 2-3 well trained early interventionist, 1 well trained psychologist and 1-2 well trained teachers who assess functional vision. Early interventionist got trainings in different topics and they practiced their assistance with parents and children during the project. Some of the trainings topics were: development of VI children; International classifications of functions (ICF); Cortical visual impairment (CVI); Multiple disabled visually impaired children and communication with MDVI children; Play development of VI children and Play development scale; VIG; and many more.

(2) There is clear structure of early intervention program. Each child has an individual plan (individual family support plan).

(3) Protocols and work instructions are made for all early interventionist. The participants made one curriculum for the Balkan. The questionnaire for parents are made to assess the needs of each family of the VI/MDVI child.

(4) Each organization has rooms and needed equipment for early intervention. Each organization also have assessment materials for early intervention and functional vision assessment.

(5) There were constant increasing number of children in each country each year (approximately 10% more children in EI program each year).

(6) The parent's organizations were founded in each country.

(7) Different models of early intervention were analyzed and each participant chose which one is the best for their organization.

(8) Teachers who assess functional vision are trained to make quality assessment and to prepare recommendation for efficient use of vision and adaptation of the environment. In the involved

institutions we arranged rooms for executing the assessment. The aim is to assess each individual VI/MDVI child in involving countries.

The project meetings/workshops were held in the institutions involved in the project and moreover we learn from the experts from Visio, we all got chance to learn more about the host organization and about the institutional support for VI /MDVI persons in each involved country. And one of the results of the First steps project is good cooperation among teachers in EI and between the organizations participating in it.

Conclusion

The results of the project was presented in May 2017 in the final conference in Ljubljana which was attended by representatives of the authorities and media from each participating country to promote the early intervention into the wider community. We had an opportunity to show the fact that during the project the knowledge of all participants increased and that we are educated to ensure good support to the child, to his family and to the wider community. One of the main aim of the topics in the conference was to emphasize importance of services to make it being authorized by law to provide services quality and assessable to everyone. We are looking forward to have organized system of early intervention of the blind and visually impaired children in every country.

Creative Occupation Center for Children with Visual Impairment

Menelaos Tsaoussis

Center for Education and Rehabilitation for the Blind
Greece

Creative Occupation Center for Children with Visual Impairment

The Creative Occupation Center for Children with Visual Impairment provides several creativity classes for visual impaired children and teenagers of pre-school, primary and secondary education. The activities take place after school, and involve self-expression, entertainment and speaking practice, along with the development of individual and social skills. More specifically, the programmes which are offered are: a) school coaching to students of secondary education, b) orientation - mobility and daily living skills, c) foreign languages, d) physiotherapy, e) speech therapy, f) occupational therapy, g) therapeutic gymnastics h) psychomotor treatment, i) handicraft, j) theatrical play, k) computer science l) music. In addition, children and teenagers with visual impairment can attend courses of pre-vocational education, mentoring, and training. What is more important is the presence of supportive services for the children, and the teenagers, as well as their families and / or their closely related environment. The programs are implemented by specialist and experienced scientific staff, in the building premises of the Center for Education and rehabilitation for the Blind. Our sites are fully-equipped, with all resources in compliance with the relevant technical specifications.

The services provided by the Center are the following:

Adapted Physical Education and Sports

The Adapted Physical Education (APE) class is a specially designed or modified program of developmental activities, perceptual and physical abilities training, games and sports (Goalball, Athletics, Football, Judo), suited to the interests, capabilities, and needs of the students with visual impairments. The program can be provided one-on-one, in a small group, or within the general physical education setting. Its goal is to give the visually impaired students the skills and dexterities necessary for a lifetime of rich leisure, recreation, and sport experiences in order to enhance physical fitness and wellness.

Psychomotor Learning Class

Psychomotor learning is the relationship between cognitive functions and physical movement and it is demon-

strated through physical skills (movement, coordination, manipulation, dexterity, grace, strength).

Foreign languages (English, French, German)

Teaching foreign languages to people with visual impairment results in:

- Broadening students' cognitive horizons
- Integrated scientific training (use of foreign Bibliography)
- The possibility to study abroad
- Assistance in a professional career.

Moreover, through the comparison, a deeper knowledge of the native language is achieved, a better use of the Internet is achieved and a better communication is ensured while travelling abroad is facilitated.

Computer Science

Computer Science classes are provided where visually impaired students can be trained, in a computer room fully equipped with the latest information technology, according to the necessary requirements (scanners, CCTV magnifiers, Braille displays, Braille printer, OCR (Optical Character Recognition) programs and screen magnification programs, screen readers etc.).

Music

A student can undeniably benefit by music in many ways. It contributes to the mental activity and to the mental health, it reduces stress and relieves pain, it enhances creativity, it has a positive effect on memory, it creates a sense of success and it's entertaining.

Theatrical play

The objective of the theatrical play is to give students the opportunity to discover what the theatre has to offer. Through the play, children can explore and discover the world around them, but also, they can find their own place within it. It allows the child to express himself (something extremely important for introverted individuals), to release energy in a creative way, to increase his/her awareness, to communicate and most important, to be happy.

Occupational therapy

It enables people of all ages to engage in life through appropriate intervention so that the individual is functional and autonomous, making the most of his potential. Occupational therapy belongs to a wider range of therapeutic approaches, mainly guided by each individual and his/her needs. The game is the primary objective of Occupational therapy, as well as the main means it uses to reach goals. Through the game, children can understand the world around them and develop emotional maturity, social, perceptual, cognitive and sensory skills, so that they can explore new environments and new experiences.

Speech therapy

Speech therapy is the science that studies and investigates disorders of speech (spoken and written), disorders of voice - vocal and disorders of chewing - swallowing as well as non - verbal communication. It is a paramedical science that aims to diagnose, prevent and restore the disorders mentioned above. It's objective is to practice, correct and restore language disorders at all levels of the language: phonological, phonetic, semantic.

Physiotherapy

Physiotherapeutic intervention consists in applying therapeutic actions by physical means (heat, cold, water, massage, movement) as well as by therapeutic techniques and methods. The goal of Physiotherapy is to develop, restore and maintain the individual's functional independence and motor skills. Each visually impaired child is examined and evaluated with great detail and accuracy, while a therapeutic program is designed and adapted to his/her needs.

Social Service

It investigates and evaluates the specific problems of individuals or groups, provides advisory, supportive services, uses and develops voluntary services, deals with or tries to prevent the individual's or the family's social-economic problems, provides interconnection and referral to services (local authorities, primary care health services, children's Medical Centers, bodies and services supporting the disabled).

Psychological support

The Center's psychologist evaluates students and participates in the interdisciplinary team in order to monitor students' integration. He/she provides a supportive, counseling or therapeutic procedure, to the child or his/her family and collaborates with others (the educational staff, school counselors, medical services, schools, bodies which provide medical, psychological and social services).



Figure 1: This photo shows a student during a speech therapy session.



Figure 2: This photo shows a student during a session of adapted physical education.

Impact of ICT on Social Interactions in Secondary Mathematics Classrooms: The Case of Students With a Visual Impairment

Mathieu Gaborit^{1,2}, Minna Puustinen²,
Dominique Archambault³, Nathalie Lewi-Dumont²

¹ Paris Nanterre University, Nanterre, France

² EA 7287 Grhapes, INS HEA, UPL, Suresnes, France

³ EA 4004 CHArt/THIM, University of Paris 8 Vincennes-Saint-Denis, Saint-Denis, France

Abstract

Information and communication technologies (ICT) aim at improving the learning process. We are conducting a research project on the impact of ICT on social interactions in the context of schooling of secondary students with a visual impairment (VI) in inclusive mathematics classrooms. Secondary students with a VI frequently use ICT-AT (Assistive Technologies). At the same time, learning in the classroom typically occurs through some form of social interaction, and recent research has shown that technology-mediated learning situations present some characteristics that may have an impact on the nature and unfolding of social interactions (Karabenick & Puustinen, 2013). However, very few studies have focused on the impact that ICT-AT may have on the dynamics of in-classroom social interactions. Our aim is to fill this gap. A pilot study, aimed at testing the research methodology, has been recently conducted with three 9th-graders with a VI. The results of this research project should contribute to enriching knowledge on in-classroom learning and teaching processes for students with a VI. In addition to this, we expect to enhance teaching techniques for secondary students with a VI.

Background

Learning in the classroom typically occurs through some form of social interaction (e.g., teacher-student interaction, student-student interaction, teaching assistant-student interaction). At the same time, however, research has shown that a visual impairment (VI) may modify the dynamics of a social interaction. For instance, children with a VI have been reported to have difficulties in establishing joint attention (Hatwell, 2003).

The use of ICT within classrooms is continuously evolving since a couple of decades. Research has shown that ICT-mediated learning situations share some specific characteristics that may have an impact on the nature and proceeding of social interactions

(Karabenick & Puustinen, 2013). For example, ICT-enriched learning environments provide students with feedback which can contribute to making them more conscious of their need for help as compared to students who do not benefit from such learning environments. At the same time, however, help provided by a help system is not as personalized as human help.

In addition, previous research has shown mathematics to be among the disciplines that trigger the most help seeking at school (Nelson-Le Gall & Glor-Scheib, 1985). At the same time, it is well known that a VI has an impact on the learning on mathematics. In fact, a VI modifies the mental representation of the space (Hatwell, 2003) as well as the treatment of figures, schemes, and tables, for example (Lewi-Dumont, Arneton, & Puustinen, 2016).

Within this context, it seemed legitimate to ask whether the use of ICT – and, more specifically, assistive technologies, ICT-AT – by students with a VI has an impact on the dynamics of social interactions taking place in mainstream mathematics classrooms. We are particularly interested in secondary students with a VI because they frequently use ICT-AT in the classroom.

Objectives

Our aim is to analyse the impact of the use of assistive technologies (ICT-AT) by secondary students with a VI on the dynamics of social interactions taking place in mainstream mathematics classrooms. We are interested in social interactions between students with a VI and their teachers, teacher assistants, and other students. More precisely, we are interested in the eventual impact of the use of ICT-AT on social interactions aimed at providing students with a VI with help (i.e., help interactions).

Based on the limits of our previous questionnaire studies on in-classroom help interactions in secondary students with a VI (Lewi-Dumont, Arneton, & Puustinen, 2016; Puustinen, Arneton, & Lewi-Dumont, 2017), we decided to opt for a new data collection protocol.

Method

The participants will be about 24 students with a VI schooled in a mainstream lower secondary school in France as well as their mathematics teacher, teaching

assistant (if any), classmates, and parents.

Because of the absence of previous observation studies on in-classroom social interactions in students with a VI, we based our research protocol on existing research on students with other disabilities. In the domain of autism spectrum disorders, for example, Koegel, Matos-Freden, Lang, and Koegel, (2012) consider that the omission of one or several of the following information sources may increase the risk of erroneous conclusions: (1) examination of the student files, (2) interviews of the professionals who work with the student, (3) observation of the student in natural setting, (4) standardized testing of the student.

Within this context, the protocol of data collection will be the following: (1) three one-hour mathematics lessons will be video-recorded; (2) semi-structured interviews will be conducted with the students with a VI, their mathematics teacher, teaching assistant (if any), and classmates; (3) the parents of the students with a VI will be interviewed in order to collect data on the visual impairment (e.g., the WHO classification) and on the level of academic achievement of their child. The parental interviews will also allow us to evaluate the necessity to proceed to standardize testing of the students in the domains of their school performance or ICT literacy, for example. A pilot study (Gaborit, Lewi-Dumont, Berrada, & Puustinen, 2017), has been conducted to test the data collection protocol.

Results

Data collection will be realized during the 2017-2018 school year. The observation grids and interview guides are being constructed, inspired by research conducted by other members of the Grhapes research unit of INS HEA (e.g., Zorn & Puustinen, 2017).

Discussion

The aim of the present research project is to analyse the impact of the use of assistive technologies (ICT-AT) by secondary students with a VI on the dynamics of social interactions and, more specifically, on help interactions taking place in mainstream mathematics classrooms.

The data collection methodology, including both in-classroom video recordings and semi-structured interviews of the students but also their teachers, teacher assistants, and classmates, should allow us to seize the real nature of the help interactions taking place in the lower secondary mathematics classrooms, and the eventual impact of ICT-AT on them. In sum, we expect our study to enhance existing knowledge on the learning processes of students with a VI from both the teachers' and the students' viewpoint:

- mathematics teachers will gain better knowledge on the needs of students with a VI, and
- students with a VI will gain understanding on the impact of their VI on their own learning processes.

Such results should contribute to optimizing the learning of students with a VI, by developing their autonomy in inclusive learning settings and, thereby, in social and professional situations.

References

- [1] Gaborit, M., Lewi-Dumont, N., Berrada, K., & Puustinen, M. (2017). *Analyzing social interactions in a regular class: A pilot study with secondary students with a visual impairment*. Paper presented at ICEVI 2017, Bruges, Belgium.
- [2] Hatwell, Y. (2003). *Psychologie cognitive de la cécité précoce*. Paris: Dunod.
- [3] Karabenick, S. A., & Puustinen, M. (2013). *Advances in help-seeking research and applications: the role of emerging technologies*. Charlotte, NC: Information Age Publishing.
- [4] Koegel, L., Matos-Freden, R., Lang, R., & Koegel, R. (2012). Interventions for children with autism spectrum disorders in inclusive school settings. *Cognitive and Behavioral Practice, 19*(3), 401–412.
- [5] Lewi-Dumont, N., Arneton, M., & Puustinen, M. (2016). Comment des professeurs de mathématiques s'adaptent-ils aux besoins des élèves déficients visuels? *Carrefours de l'éducation, 42*, 119–132.
- [6] Nelson-Le Gall, S., & Glor-Scheib, S. (1985). Help seeking in elementary classrooms: An observational study. *Contemporary Educational Psychology, 10*(1), 58–71. [https://doi.org/10.1016/0361-476X\(85\)90006-2](https://doi.org/10.1016/0361-476X(85)90006-2)
- [7] Puustinen, M., Arneton, M., & Lewi-Dumont, N. (2017). *La demande d'aide chez des élèves du 2nd degré avec déficience visuelle: Quelles spécificités?* Manuscript submitted for publication.
- [8] Zorn, S., & Puustinen, M. (2017). *L'aide aux apprentissages: le cas des collégiens avec un trouble du spectre de l'autisme et de leurs enseignants*. Manuscript submitted for publication.

Experiences of Parents and Professionals of Children Suffering from Juvenile Neuronal Ceroid Lipofuscinosis (CLN3). An empirical-ethical study

Bert Veneberg MSc RN¹, Erik Olsman PhD MA^{2,3,4},
Claudia van Alfen MD¹ and Dorothea Touwen PhD MA³

¹Bartiméus NCL Expertise Centre, Doorn, the Netherlands

²University of Amsterdam, Department of General Practice, Section of Medical Ethics, Amsterdam, the Netherlands

³Leiden University Medical Centre, Section Ethics and Law, Leiden, the Netherlands

⁴Hospice Bardo, Department of Spiritual Care, Hoofddorp, the Netherlands

ABSTRACT

Background: Children with Neuronal Ceroid Lipofuscinosis face neurodegenerative decline that leads to death during young adulthood. Their parents and professionals have to deal with the disease of these children as well. **Objective:** To describe the experiences of parents and professionals caring for children with CLN3.

Method: Semi-structured interviews were conducted with 16 parents and 10 professionals, among whom physicians, teachers/social workers, and nurses. Purposive sampling aimed to obtain variation in *experiences* with stage of the disease, which meant parents and professionals of children in different stages of the disease. Interviews were analyzed within a research team, using thematic analysis and metaphor analysis. **Results:** Caring for children with CLN3 parents and professionals experience a tendency between continuity and discontinuity. On the one hand they strive for order and constancy, for example by repeating stories, rituals, and actions, which is required because of children's neurodegenerative decline. On the other hand they try to transcend this order and challenge children to do new things and add new experiences to their existing ones, which reflects the idea that children are still developing. **Conclusion:** The results offer insight into experiences of parents and professionals caring for children suffering from CLN3. These findings will be useful for parents and professionals who hardly meet others who care for these children in order to find recognition and find new ways of approaching them.

1. INTRODUCTION

CLN3 (Batten) is a rare neurodegenerative disease that starts with visual decline and leads to death at an early age. It includes motor regression, epilepsy, cognitive problems, communication difficulties and psychiatric problems.

Of course, this disease not only affects patients, but also their caregivers. However, the moral experiences of parents and professional caregivers have not been explored. The objective of this study is to explore the

moral experiences of parents and health care professionals of children with CLN3.

2. METHOD

2.1. Parents

Semi-structured interviews with 16 parents (mean age 50.1; 8 females). Sampling aimed at variation in gender and stage of their child's disease. The interviews were audiotaped and transcribed.

Transcripts were thematically analyzed and metaphors were analyzed. Two researchers independently analyzed the interviews, wrote memos, and discussed about their analyses until they reached consensus. The results of the metaphor analysis were compared to the results of the thematic analyses, which triangulated the findings.

The researchers worked in a research team with health care professionals and researchers with various professional backgrounds. They wrote memos during the data collection process and during the analyses.

2.2. Professionals (preliminary)

Semi-structured interviews with 10 health care professionals were conducted. At present, some additional interviews are conducted in order to reach saturation.

Variation was obtained by interviewing professionals with various professional backgrounds. Some had experience with working with patients at an early stage of their disease trajectory, whereas others had mainly experience with patients in later stages of their patient's disease trajectory.

The interviews were audiotaped, transcribed and the transcribed interviews were thematically analyzed. One researcher analyzed all interviews, whereas a second researcher independently analyzed half of the interviews.

The researchers discussed about their analyses with each other and within a research team with researchers with different professional backgrounds until they reached consensus.

3. RESULTS

3.1. Parents: grasping versus letting go

Participating parents referred to a central metaphorical dialectic: grasping versus letting go.

3.1.1 Their child's experiences.

When being confronted with neurodegeneration and the necessity of 'letting go' of functions, their child 'held' onto structures and rituals. For example, some children became obsessed with hobbies or stereotypical behavior.

When their children further deteriorated, some children 'grabbed' their parent's attention, which hindered the parent's freedom. One of them, for example, explained how he sometimes felt a 'slave' to his own child because his child constantly 'grabbed' his attention.

3.1.2 Participant's experiences

Almost all participants 'grasped' the present moments with their child because they were aware that they had to 'let go' their child at a young age. Participating parents, for example, 'squeezed the most out of' everyday life.

They also wanted 'to hold onto' caring for their child as long as possible and not 'let it go', sharing it with professional caregivers. This could complicate discussions with health care professionals on sharing the care.

3.2. Professionals: protecting versus confronting (preliminary)

Participating health care professionals wanted to protect children with CLN3 and their parents, on the one hand, while confronting parents with realism, on the other. For example, during the diagnostic phase, professionals wanted to be clear about the diagnosis, which would eventually lead to death at a young age. But they also wanted to give hope to parents because it could help parents cope with their situation.

4. DISCUSSION

The findings of this study, including the preliminary ones, suggest that grasping versus letting go (parents) and protecting versus confronting (professionals) are central dialectics in the care for children with CLN3. This study helps to understand what is at stake in this caring process and it acknowledges the complexities caregivers face when caring for a child with CLN3, which is important because of the rarity of the disease.

The findings also help parents and professional caregivers to acknowledge that there are at least two sides of the caregiving process. For example, health care professionals should not only focus on supporting the 'grasping' of their patients with CLN3, like reinforcing memories and the utilization of tools, but also support children when they feel sad because they have to 'let go' of functions, like visual decline or deterioration of motor functions.

In conclusion, this study provides insight into the moral experiences of parents and health care

professionals of children with CLN3. Their experiences have, to our best knowledge, not been explored. We hope that the results described in this study will support good care for persons with CLN3, their family members and health care professionals.

5. ACKNOWLEDGEMENTS

Parts of this Abstract were published as: Olsman E., Veneberg B., van Alfen C. & Touwen D.; The value of metaphorical reasoning in bioethics: An empirical-ethical study. *Nursing Ethics* 2017. Parts will be presented as Poster Presentation at the European Association of Palliative Care Congress 2017 (Madrid) and an Oral Presentation at the International Conference by the International Society for Low Vision Research and Rehabilitation: Vision 2017 (the Hague).

Funding: the Neuronal Ceroid Lipofuscinoses (NCL) Expertise Center, Bartiméus, Doorn, the Netherlands.