

Report of the mapping exercise carried out by the commission of persons with
visual impairment and additional disabilities

Working period 2011 – 2015

June 2015

This is an internal EBU document

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Acknowledgments

We would very much like to express our most sincere thanks and gratitude to the member countries of the European Blind Union that took the time to complete the survey.

A heartfelt thank you also goes to the national representatives and other members of the International Council for the Education and Rehabilitation of Persons with Visual Impairments (ICEVI- Europe) that responded to our request to contribute to the survey.

Chapter One- Introduction

It is widely acknowledged that during the past three decades there has been a dramatic increase in the number of persons with visual impairments and additional disabilities within the general population of persons with visual impairments. In addition to reasons previously known to us for causing additional disabilities, such as illnesses, accidents etc., advances in medical technology, skills and knowledge have developed to such an extent that many children such as very premature babies or those suffering from traumatic illnesses can cling to life where previously this would have been impossible. Nowadays, in many countries, measures of the number of children and young people with visual impairment and additional disabilities vary between 30% and 70% within the population of persons with visual impairments.

The group of people with additional disabilities constitutes a distinct, diverse and heterogeneous one with a unique set of needs, mainly because the combination and severity of the disabilities in each individual varies. What is important to bear in mind, when talking about persons with additional disabilities, is to gain a perspective about the interactional factors in these additional disabilities. Each disability does not act in isolation, and should not be considered and managed in isolation.

Despite these growing numbers, there are limited case studies or projects available regarding this population, and the majority of them mainly refer to the educational needs and classroom interventions of this group. In addition, within organizations of the visually impaired, this population is not fairly represented – provisions are limited and the needs, problems and challenges faced by them are overlooked. This phenomenon is attributed to a number of reasons such as the fact that in some countries the majority of the persons with additional disabilities are classified under what is considered to be their primary disability. Within various organizations, the term “visual impairment and additional disabilities” is interpreted differently. Some organizations have a specific term for persons who have sensory impairments along with other significant disabilities, which allows for identification of both a sensory impairment and the presence of multiple disabilities. In other organizations some consider "multiple disabilities" to be a primary disability category, while yet others specify conditions as separate secondary disabilities. Frequently,

the vision of people with complex needs such as those with additional cognitive and developmental disabilities goes unassessed because of the lack of expertise that vision professionals have in the assessment of people who cannot respond conventionally.

The European Blind Union (EBU) is a non-governmental, non-profit making European organization that promotes the interests of blind people and people with low vision in Europe. It currently operates within a network of 44 national members including organizations from all 28 European Union member states, candidate nations and other major countries in geographical Europe. EBU, in its strategic plan for the working period 2011 – 15, having recognized the importance of the area of additional disabilities, decided that greater focus should be placed on people with visual impairments and additional disabilities. For this reason EBU established a commission to enable improved understanding and sharing of information about the population of persons with visual impairments and additional disabilities.

This report is the end result of a mapping exercise that was part of the work programme of this commission. The goal of the mapping exercise was to collect, analyze and assess information from EBU member countries in order to answer to the following research questions:

How is the term “visual impairment and additional disabilities” defined in each organization?

What statistical data is available for this group?

What provisions and services are available for this population?

What are the needs, problems and challenges faced by this group?

What best practice examples exist in various countries and regard this group?

The growing number of this population, the diverse and unique needs and challenges faced by the people with additional disabilities make the findings of this survey an important one. These findings can be shared not only by organizations representing people with visual impairments, but also by institutions, academics and policy makers across Europe. This mapping exercise is not an end in itself. It is a fundamental step in enabling the identification of challenges, the assessment of needs and better targeting of

interventions. These findings can set the basis for future programmes, projects and collaborations as well as define common policies all aiming for a best practice outcome for these people.

This report is divided into five chapters. Chapter Two gives a background to the topic of additional disabilities by providing a brief literature review. Chapter Three presents the methodology used to carry out this survey. Chapter Four presents the results of the survey. Chapter Five gives some recommendations based on these findings.

Chapter Two - Literature Review

This chapter presents a brief review about the population of persons with visual impairment and additional disabilities.

Statistics

The statistics offered by *The European Coalition for Vision* show that there are about **25 million people with visual impairment** (2,736,000 blind + 22,176,000 Low Vision) in all of Europe, but there are more than **70 million people** who have eye diseases that are in the early stages that, if untreated may lead to more severe impairments. Also, the rapid rise of diabetes and an aging population in Europe will put more people at risk of unavoidable blindness (<http://www.iapb.org/advocacy/european-coalition-vision>).

The World Health Organization estimates, in figures dating from 2010, that in Europe there are:

2,550,000 blind people and

23,800,000 people with low vision, giving a total of

26,350,000 visually impaired individuals.

This information and further data is available on [the WHO website](#).

The European Blind Union tends towards an estimate of **30,000,000 visually impaired individuals**. This higher figure takes into account the prevalence of sight-loss amongst an increasing population of elderly people in Europe which is extremely difficult to accurately quantify, and also the fact that there exists a number of people who suffer from varying degrees of sight loss but who either ignore this or decide for personal reasons not to declare their condition.

Persons with visual impairment and additional disabilities

The following goals in literature review could be followed: literature about those born with multiple disabilities and visual impairment (MDVI), those born with visual impairment (VI) and developing condition resulting in MDVI later in life, those born and developing typically but via illness or injury became VI and together with additional complications their condition is falling into the MDVI category. Namely, individuals who belong to the first two groups listed above can be originally premature infants with sensory and other disabilities, or those born with severe congenital impairments and those with cerebral injuries such

as cerebral palsy. In addition there is a considerable group of people with intellectual disabilities (ID) who during their life-span develop VI earlier than the general population. It happens because of the original injury to their nervous system or because suffering from chronic illnesses, which result in VI. When ageing they also may develop VI just as anyone else simply because of the eye diseases which are age related. Interestingly the majority of the articles in our findings concern research conducted among adults and the elderly with intellectual disabilities and visual impairments. These reports are very important and remarkable from our aspect.

Information regarding children

The demographics of the young school age visually impaired population is very important to be taken into consideration in the statistics of multiple disabilities with visual impairment as these children will become adults in a few years. Some of the literature is connected to these facts.

The increasing number of children with MDVI is known at least from the 80s. Literature concerning school age children with MDVI focuses basically on abilities and methods necessary for learning. Several resources referred to statistical data of the increasing population first in the USA. There is no doubt that the following European data published is no less significant. The increasing number of students with MDVI is challenging in educational approaches for professionals. Many authors dealt with this aspect.

Children with visual impairments or blindness combined with other disabilities represent a population that needs to be focused on and approached so as to identify and assess education and rehabilitation services. The multiple effects of combined sensory, neurological and/or psychological problems have to be understood and supported. This population is so diverse, so various in all psychological and physical dimensions that is only with attention to the individual child that we can discover how best to work with him or her (Rogow, 2005).

The literature review reveals few publications concerning visual impairment and additional disabilities, even though sixty-five percent of students with low vision have multiple disabilities, that is, at least one disability in addition to their visual impairment (Kirchner, Diamont, 1999). The terminology that is used is visual impairment, including those with multiple impairments or lately visual disabilities, including those with multiple disabilities, or when there is the

special case of dual sensory impairment, the term of deafblindness is most commonly used. One of the statistics that refer to the presence of at least one disability in addition to the visual impairment is of Kirchner and Diamont in 1999 who sustain that sixty-five percent of students with low vision have multiple disabilities (Kirchner, Diamont, 1999). Many of the individuals with multiple disabilities have cortical (cerebral) visual impairment that requires adequate services concerning assessment and intervention.

In Foundations of Rehabilitation Counselling with persons who are blind or visually impaired, chapter VII, *People with Multiple disabilities*, the authors Sharon Zell Sacks, Stephen S. Barrett, and Michael D. Orlansky (1997), refer to persons with multiple disabilities, that is people who have physical, mental and emotional disabilities in addition to their visual impairment, and support the idea of the specificity of this category of disability, sustaining the need of specialised rehabilitation professionals. The authors consider a sizable percentage of people with visual impairment having additional disabilities that will lead to the need of developing and implementing adequate educational and rehabilitation services. Disabilities that frequently occur with visual impairments are: mental disabilities, emotional disabilities, autism, substance abuse, brain injuries and physical and motor disabilities. The authors revealed that 15.2 percent were reported as having a major secondary disability condition (Hill, 1989). Baird and Moore (1993) cited by Webster and Roe (2007) sustain that in the majority of epidemiological studies, children with severe visual impairments or blindness will have additional disabilities. The authors also brings up the issue of prematurity where the risk for developing retinopathy is rather high (Roe, 2007).

Scholl, G.T. (1986) mentions the following possible combinations of visual impairment with additional disabilities (p.137):

- Visual and auditory impairments
- Visual, auditory and motor impairments
- Visual and auditory impairments and cognitive delay
- Visual and motor impairments
- Visual, motor impairments and cognitive delay

- Visual impairment and cognitive delay
- Visual impairment and emotional disturbance
- Visual impairment and learning disability.

Pogrund and Fazzi (2010) state that there is a higher prevalence of children with visual impairment among children with multiple disabilities. So that children with cerebral palsy, developmental disabilities, down syndrome, fragile X syndrome, and hearing impairment have a higher frequency of severe visual impairment (p.9).

Also the increase of drug use by pregnant women determined the increase of number of infants being born with visual and other impairments. The drug-exposed babies can present neurological impairments including cortical visual impairment (CVI). Other studies indicate that prenatal cocaine exposure can impair visual attention, visual processing speed, and visual memory in infancy and throughout the first year of life (Jacobson et al., 1996, Singer et al, 1999, Minnes, S., Lang, A., Singer, L. 2011).

Education and intervention services for children with visual impairment and additional disabilities should refer to:

- The development of communication and literacy skills
- The development of functionality of residual sight
- The development of orientation and mobility
- The development of social- emotional skills
- The development of daily living skills and self-determination.

Erin, J. (1996) sustains that as many as 50 to 60 percent of children with visual impairments have other disabilities and most of the children who have visual impairment in combination with other disability have low vision, so functional vision can be used in learning, communication and education. Because of the combination of disabilities, each child with MDVI is unique, which makes prediction difficult on development and functionality as an adult. Erin, J. (1996) says that the most common conditions associated with visual impairments include mental disability, cerebral palsy, spina bifida, physical impairments

resulting from trauma, speech and communication disorders and hearing impairment. The author considers that the most important skills for children with multiple disabilities to learn are functional skills.

In the context of cerebral visual impairment (CVI) Zihl and Dutton (2015) mention that “children with CVI show combined impairments in vision, cognition, social-emotional and motor difficulties. The exact proportion of children with cerebral palsy who have CVI is unknown, but may be in the region of 60-80%” (Mervis et al. 2002; Venkateswaran and Shevell 2008; Barca et al. 2010) (p 117). They also mention the risk of additional cognitive impairments such as insufficient attention capacities and insufficient learning and memory capacities that need adequate intervention and support.

Van den Hout and collaborates (1998) state that the more brain structures affected, typically, the more severe the resulting disability, vision impairment included (Zihl, 2015 p. 117). Additional functional impairments may not only exaggerate the degree of visual disability but perhaps also impede spontaneous improvement (Bonnier et al. 2007; Tadic et al. 2009 cit. Zihl, 2015 p. 117).

Children with MDVI require an integrated and tailored service provision that involves attention to health, education and social interaction. Dependency on other individuals to structure their learning experiences is a common feature of children with multiple disabilities (McLinden and McCall, 2002).

Focusing on activities is particularly important since passivity and dependence on others are among the greatest life challenges of people with MDVI.

Recent EU projects on educational and transition needs of individuals with MDVI

ImPAct MDVI was developed as part of the Socrates Education and Culture programme of the European Union between 2003 and 2006. The project ImPAct MDVI was a Comenius 2.1 Action (training of school education staff). The project addressed the concerns of teachers of children and young adults with Multiple Disabilities and Visual Impairment (MDVI) as to how they were expected to integrate the diverse curriculum elements and particular skills they have been taught into a meaningful Individualised Educational Programme (IEP). A holistic approach centred on activities, participation and involvement in real life situation and based upon ICF / WHO Perspectives on Rehabilitation

and the Salamanca Statement was used. The objective of the ImPact MDVI project is to develop a holistic teaching approach for teachers working with children with Multiple Disabilities and a Visual Impairment (MDVI). The project has arisen out of a recognition that models of teacher preparation in the area of severe and profound special needs often lack an overall vision and strategy to achieve identified goals. This project responds to the needs and rights of children with MDVI which is to participate and be active within natural environments. Such needs should be central to the learning process and in the promotion of children's quality of life both in school and in the future (<http://www.mdvi-euronet.org/site/impact-mdvi.php>). ImPact MDVI project was including the countries of Portugal, Italy, Germany, the Czech Republic, Ireland, Scotland and Norway. Tellevik and Elmerskog (2009) also published their ideas about activity-based intervention for multiple-disabled visually impaired people based on social involvement in an article in BJVI (Tellevik and Elmerskog, 2009).

Over a European project sponsored by the Leonardo da Vinci Lifelong Learning Programme named **J.O.B.S. (Jobs and Opportunities that Benefit Society)** MDVI was given an overview by Mary Leonard (2013) from ChildVision, Dublin. Partners in the project were: Iceland, Italy, Finland, Hungary, The Netherlands, Germany, Romania, UK, Denmark, Ireland, UK.

The project was focused on the documented need to explore opportunities to identify issues related to the training of professionals of persons with MDVI. It also developed methodologies addressing lifelong learning and work related issues in regards to the development of this population during their transition stage towards work.

There was a strong need to better understand the barriers people with MDVI have in accessing the formal vocational training system and the traditional employment market. As a result the project acknowledges that professionals are in need of training methodologies and curricula to rehabilitate and educate the target group so that they can increase their capacity to acquire or update basic and general social competencies and work skills. To train staff to develop their skills and competencies in the following areas:

Job mediation (job coaching): the provision to people with MDVI mentors / job coaches in the work place, preparatory and ongoing work with employers to

help their approach and attitude, the identification of suitable, sustainable jobs and the establishment of appropriate support mechanisms.

Valued activities: the recognition of the need for professionals to be trained and enabled to offer valued activities which will contribute to the quality of life of people with MDVI and underpin their desire and capacity to seek work.

Social and personal skills: given the wide range of individuals with MDVI and the increasing spectrum of need, the project partnership has identified a fundamental need for individuals with MDVI to have training which understands etiology and presenting features in ways which increase and support the development of self-esteem, minimise challenging behaviours and, overall contribute to an increase in active citizenship.

Assistive technology: prefaced on the ever burgeoning increase in assistive technology, the ongoing training staff in this area is essential to their being able to offer the appropriate support to the individual with MDVI.”

There is a strong need for “advancing the agenda of people with MDVI’s right to meaningful work” (Leonard, 2013).

[Information regarding adults and elderly](#)

There are only a few research reports and researchers worldwide investigating MDVI in adulthood. In the territory of Europe we managed to find reports by Danish, other Scandinavian and Dutch research connected to our subject.

Evenhuis, Sjoukes, Koot and Kooijman (2009) revealed in their study on intellectual disability and visual impairment that, indeed, in old age independent living skills, communication and social skills are primarily determined by the severity of the intellectual disability. They also argue that visual impairment has an additional influence, and that the co-existence of the two disabilities will have a greater impact on daily living skills, linguistic skills and independent living skills. The authors also cite Splunder et al. (2006) who showed that 14% of the adult population with ID has a visual impairment and 5% is (socially) blind. The same authors consider that visual impairment and even blindness tend to remain invisible in the population, claiming that in 40% of Dutch adults with ID, visual impairment (or blindness) had not been identified. Splunder et al. (2006) in their study show that prevalence of visual impairment and blindness are higher in all subgroups with intellectual disabilities, including the young and mildly handicapped group and that the

diagnosis is often missed, making a very important statement that “all persons with severe or profound intellectual disabilities, and all older adults with Down's syndrome, should be considered visually impaired until proved otherwise”.

In this view the matter of identification and diagnosis of the occurrence of visual impairment in other categories of people with disabilities must be approached. The study carried out by Evenhuis, H.M., Sjoukes, L., Koot, H.M, and Kooijman, A.C. (2009) addressed the question of to what extent visual impairment leads to additional disability in adults with intellectual disabilities (ID). So it is again the issue of visual impairment (if identified and known) within the population of adults with intellectual disability. For the category of people with visual impairment as a primary disability (congenital or acquired), who would develop additional disabilities related to age, the literature is scarce and not approached. The main issue is to try to identify and support visual impairment that can occur in already other diagnosed disorders and conditions.

There is an alarming prevalence of visual impairment in adults with intellectual disabilities especially cataracts and keratoconus, with a focus on elderly residents in community or institutional settings who were not identified and supported for these specific needs, the prevalence of visual impairment increasing with the severity of intellectual disability and age (Warburg, 2001).

Van den Broek and his fellows found an unexpected 92% of clients with visual impairment in 76 people with severe and profound multiple disabilities when only 30% were previously known as having a visual impairment, in a study carried out in Denmark. These results must lead to discussions and decisions concerning screening, identification, possible corrections and environmental modifications.

Van Splunder, J., Stilma, J.S., Bernsen, R.M., and Evenhuis, H.M. (2004) in a study carried out in the Netherlands found that there are a series of ocular disorders with a higher prevalence in adults with intellectual disorders such as increased risk of severe myopia, strabismus, and lens opacities. Besides these, in participants diagnosed as visually impaired, cerebral visual impairment was the most common untreatable disorder (12.6%), followed by macular degeneration (5.4%).

Krinsky-McHale, S., Jenkins, E.C., Zigman, W.B., and Silverman, W. (2012) indicate a high prevalence of visual disorders such as nystagmus, strabismus, keratoconus, amblyopia, cataracts, and refractive errors in individuals with Down syndrome. The authors mention that these conditions may be supported in children and adolescents with Down syndrome, but the prevalence in adults has been less reported.

Swaminathan, M. (2011) states that, the prevalence of visual impairment in children with multiple disabilities is high and it has been found to be 10.5% in children with developmental disabilities. The author, citing numerous studies, shows that visual impairment reported in children with multiple disabilities may be secondary to ocular defects such as uncorrected refractive errors, cataract, nystagmus, retinopathy of prematurity (ROP), optic nerve atrophy, or oculomotor abnormalities, or on account of cerebral defects such as cortical visual impairment (CVI), delayed visual maturation (DVM), or nystagmus.

The book by Taub, Bartuccio and Maino (2012) makes a very detailed analysis of the importance of visual diagnosis and care in people with special needs, with a better understanding of the developmental and acquired disabilities that implies also that the presence of a visual impairment that is often not taken into consideration nor supported adequately. Visual impairment assessment and care is discussed within the following disorders and conditions: cerebral palsy, down syndrome, fragile X syndrome, intellectual disability, autism, rare neurodevelopmental disorder, ADHD, learning disabilities, acquired brain injury, psychiatric illness, brain damage, and neurodegenerative disease.

Another issue regarding visual impairment in the old age is the prevalence within age-related visual impairment of the critical mental health consequences (Boerner, 2004). Studies show a relationship between age-related visual impairment and implications such as lower morale, social isolation problems, affective disorders, and reduced feelings of self worth (e.g., Bazargan, Hamm-Baugh, 1995, Wall, Oswald, 2000). In a report of Alliance International (2011) it is stated that the prevalence of older adults living with chronic diseases including visual impairment and blindness will climb sharply (AMD Alliance International, 2011).

In terms of the services needed for adults with vision loss, Sandra Rosen and Janis S. Crawford (2010) mention the physical disabilities that frequently accompany vision loss. The authors mention the following three possibilities:

- Conditions that occur independent of visual impairment and they occur also in the general population.
- Conditions that may occur as a direct or indirect result of vision loss or are secondary to vision loss.
- Conditions that have vision loss as an associate impairment. (Rosen, Crawford, 2010)

Michelle Capella-McDonnall (2007) underlines the implications in the context of visual impairment of the lack of physical activity, restricted participation, implying becoming overweight and obesity with all the possible co-morbidities and need for prevention and care.

Chapter Three - Methodology

This mapping exercise is to collect, analyse and assess information from EBU member countries in order to answer to the following research questions:

How is the term “visual impairment and additional disabilities” defined in each country.

What statistical data is available for this group?

What provisions and services are available in each country?

What are the needs, problems and challenges faced by this group?

What best practice examples exists in various countries and regard this group

The survey was designed by the authors of this report based on their expertise on the area of additional disabilities and a review of the relevant literature. The content of the survey was drafted based on an intensive discussion on what information should be collected during a mapping exercise. It was agreed at the very beginning that the survey was not to deal with persons with dual sensory impairments, as this is the work of the DeafBlind Committee of EBU. Therefore, organizations were asked not to include any statistical information about persons with deafblindness.

The survey was divided into seven small sections. The first and last sections collected some demographic information regarding the country, organization and personal details of the person completing the survey. The rest of the sections contained tables for completion and open-ended questions that asked for information such as:

- Definition of the term “visual impairment and additional disabilities”,
- Statistical information of this group,
- Provisions
- Needs, problems, challenges,
- Best practice examples.

A copy of the survey can be found in Appendix A at the end of this report.

The survey was sent by email. A cover letter stating the purpose of the survey as well as timeframes for its completion accompanied the survey.

The survey was originally sent in October 2013 to all national member organizations of the European Blind Union in 44 European countries. Due to the poor amount of responses received by the end of January 2014, it was decided that an extension should be given and that the new deadline for submission was the end of May 2014. In addition, it was decided that as part of the agreed collaboration between EBU and the International Council for the Education and Rehabilitation of Persons with Visual Impairment (ICEVI), the survey was to be sent out to every contact person of ICEVI Europe via the relevant mailing list.

By the end of May 2014 a total of 19 completed surveys were collected from 17 countries. This included:

The Netherlands	Eye Association Netherlands
Slovenia	Zveza društev slepih in slabovidnih Slovenije (ZDSSS) Union of the Blind and Partially Sighted of Slovenia (UBPS)
Poland	Polish Association of the Blind
Austria	Austrian Federation of the Blind and Partially Sighted
Austria	Odilien-Institut
Estonia	Estonian Federation of the Blind
Czech Republic	Tyfloservis, o.p.s.
Greece	Panhellenic Association of the Blind
Lithuania	Lithuanian Association of the Blind and Visually Handicapped
Italy	Italian Union of the Blind and Partially Sighted
United Kingdom	ICEVI
Scotland	Scottish Sensory Centre
Hungary	School for the Blind, Budapest
Switzerland	Centre Pédagogique pour élèves Handicapés de la Vue - CPHV
Serbia	School for Visually Impaired Pupils "Veljko Ramadanovic"

Finland	Onerva Mäki Centre for learning and consulting / Onerva Mäki School
Belgium Flanders (Flemish spoken part of Belgium)	BC Spermalie/ De Kade
Greece	AMYMONI
Cyprus	Pancyprian Organization of the Blind

A more detailed list of the countries, the organizations and the individuals who completed the surveys is given in Appendix B at the end of this report.

A number of limitations, stated by those completing the survey may have possibly degraded the quality of the research. These limitations included:

- The absence of any statistical data, within the organizations, on the number of persons with additional disabilities,
- Numerical information on a national level as a lot of regional organizations of the visually impaired have their own records and do not share them with the central office,
- The poor representation of persons with additional disabilities among the membership of an organization,
- Variations regarding the definition of the term “additional disabilities”,
- The integration system in some countries that makes it difficult to collect information for completing the survey,
- That people with visual impairment and additional disabilities are often classified under what is considered to be their primary disability and
- The vision of people with such complex needs often goes unassessed because of the lack of expertise that vision professionals have in the assessment of people who cannot respond conventionally.

Chapter Four – Summary Findings

In this chapter of the report, a summary of the key findings is presented. Please note, that for the purposes of maintaining a unified style in the reporting of the findings, some language modifications had to be made to the original text of the answers given.

Definitions

In the first section of the survey, organizations or institutions were asked to state how they define the term “persons with visual impairments and additional disabilities”. In the majority of the responses those completing the surveys listed the definition and the criteria for the term “legally visually impaired”. Below, is a list of the answers:

In countries such as Slovenia, Czech Republic, Serbia, Belgium, Cyprus and Finland a person with visual impairment and additional disabilities is someone with at least 2 disabilities, one of which manifests itself as a visual impairment, without however making any reference to the degree of the additional disabilities.

The members of Polish Association of the Blind, according to Polish law, have a disability certificate which says that these persons are certified as blind in functional aspects of living, in effect of diseases or visual impairments. While in Poland there are 3 levels of disability, within the association services are provided to levels 1 or 2. According to the nomenclature these levels indicate moderate or severe disability. Persons with disabilities have a stated specific symbol of disability according to Polish law. The members of the association besides having certified visual impairments may have also certified additional disabilities such as a hearing impairment, intellectual disability, physical impairment and others.

For Estonia, the term refers to persons with visual impairment and mental disabilities.

According to the survey from Italy, the term additional disabilities is considered an adequate expression to define the disabling conditions of these people ensuring full respect of their human dignity.

In Scotland, the terms mainly in use are MDVI or children with complex needs. These terms were used in the Doran Report that was published in 2012 and

the subsequent ongoing review that investigates the provision for children and young people with additional support needs.

In the United Kingdom, the greatest difficulty in the terminology is that people with visual impairment and additional disabilities are often classified under what is considered to be their primary disability such as severe learning disability or severe physical impairment or, commonly, a combination of the two. The vision of people with such complex needs often goes unassessed because of the lack of expertise that vision professionals have in the assessment of people who cannot respond conventionally.

In Hungary, the definition of WHO is used to define the term visual impairment while “persons with visual impairment and additional disabilities” belong to the category of multiple disabilities. Under the category multiple disabilities a new condition is developing through the combination of two or more impairments. The severity of the condition depends on the complex influence of the impairments on the individual’s development. In Hungary the most common combination is intellectual disability and visual impairment. Physical and hearing impairment are less common combinations. Autism spectrum disorder is becoming a very severe and challenging condition in combination with visual impairment.

In the Netherlands, the criteria of the NOG (Dutch organization of ophthalmologists) for visual impairment are used. These are based on the WHO Criteria and supplemented with a wider range of visual impairments like CVI or lack of contrast. Additional disabilities are described as mental disabilities (as people with intellectual disabilities), sensory disabilities or physical disabilities.

Similarly, in Greece, the terminology adopted for persons with additional disabilities does not make any reference to “primary” or “secondary” disability, but instead to a combination of conditions which operate in a synergetic way creating in this manner a new condition.

In Switzerland, visual disability and visual deficiency are almost the same. In the organization, the use of terminology of visual disabilities includes all the sight disabilities (total or partial). In school, “children with visual impairments and additional disabilities” usually present a visual acuity below 4/10 and other impairments as a hearing impairment, behavior problems, autism, intellectual disability, motor disability, etc.

Needs, Problems and Challenges

The group of people with additional disabilities is very diverse and very heterogeneous. Nevertheless, survey findings showed a great similarity of needs, problems and challenges reported for the people with additional disabilities of all age groups irrespective of their country of residence. More specifically the following needs, problems and challenges were reported for the pre-school age, school-age, adults and elderly:

Pre- school Age

Needs: More early intervention programs, more special facilities, early identification and support for the child and the family, provision of child care, early, good and available diagnostics, treatment and rehabilitation, life in a complete, fully functioning and socially secured family (good living and financial conditions) that is willing and able to participate in the diagnostics. Treatment and rehabilitation, general support and psychological support to parents/families, support in daily care and global rehabilitation, to create a network within and outside the families that is able to accommodate the individuals concerned by fully understanding their limits and abilities and by structuring, as early as possible, a proper special rehabilitation and therapeutic process as well as projects aimed to enhance their capacities/develop their potential.

Problems: The parent child interaction (like playing routines, selecting appropriate toys, enhancing child development), lack of professionals that can support among other things how to carry out daily life activities, difficulty in finding suitable kindergartens or day care as well as inaccessible and limited numbers of special facilities with a global approach to rehabilitation or dedicated to the preparation of school readiness, help for parents to overcome the long-term stress caused by the medical diagnostics and treatment (including the separation from the family during hospitalization) financial problems related to the special care, inadequate social services, inadequate and/or late diagnoses in which assessment of vision may often be overlooked.

Challenges: The growing number of children being born with additional and complex disabilities. Find available resources about appropriate toys and learning materials that enhance the child's ability to actively discover the surrounding world, overcoming obstacles, and improving communication.

Locate early intervention facilities at a reasonable distance from the child's home with qualified staff that will meet the implications of all disabilities present. Ensure collaboration between professionals and the child and family for carrying out a vision assessment. Identify/put in place structures that support families in the rehabilitation process. Achieve coordination of educational activities.

School Age

Needs: More aids, equipment and assistive technology, increase awareness of the educational implications that visual impairment may cause, more qualified teachers and qualified assistants while ensuring contact with a Qualified Teacher of the VI, the right to inclusive education with balanced school inclusion that promotes the learning process as well as social interaction, funds to increase subsidies for the development of inclusive education and the provision of special training to professionals.

Problems: Access to the general curriculum and lack of specialised curricula such as orientation and mobility and vision rehabilitation, lack of qualified professionals and classroom assistants, attitudes of educators and parents of non-disabled children towards the participation of children with additional disabilities to inclusive education, low funds and limited resources in the education system, lack of schools tailored to the needs of children and youth with additional disabilities at a reasonable distance from their homes, dealing with overprotective parents whose behaviour might prevent integration and might cause social isolation, physical and architectural barriers, lack of and inadequate accessible transport.

Challenges: find learning materials in accessible formats, work out a transition plan from school to adulthood, prove that students with very severe disabilities also need an educational program, complete education despite health issues, include in the context of non-formal education appropriate staff and means to assist persons with additional disabilities as well as qualified professionals in the field of the different disabilities/pathologies, promote self-awareness, find appropriate communication means (including alternative and augmentative), reach self-fulfilment, ability to live outside the family and in other communities, collaboration between professionals and families of students with multiple disabilities, often the implications of a visual disability are overlooked when the other disabilities are severe, find what is considered to be the best educational

solution for children and parents, empower youth to become advocates for necessary changes.

Adults

Needs: A growing need for the identification of this population (including assessment tools), plan and offer rehabilitation as well as appropriate support, help and services, achieve independent living (in a flat or home, away from family) and be able to use community services, changing social policy respecting the rights of persons with disabilities and the responsibilities of the state towards the citizens, possibility to work (at least in a sheltered workshop), find adequate day-care or residential facilities for persons with disabilities or promote inclusion in general day-care facilities or residential settings.

Problems: access to orientation and mobility programs, access to employment, leisure and other daily activities, limited rehabilitation programs and specialised centres, financial barriers, often caring for an adult with additional disabilities might be a burden for the family since support systems are not always appropriate, dependency on parents or a partner, dealing with feelings such as inferiority, depression, passivity and aggression. Physical and architectural barriers, lack or inadequate accessible transport, lack of expertise in specialist workers that provide support for daily life activities, work duties or leisure and recreation activities, transition to a care centre or residential facility when parents or other care-takers are no longer able to care for the person, finding facilities that allow the family or the care-taker “to have a break” from the care of the adult with severe disabilities.

Challenges: Find trained and appropriate personal assistants, create or locate specialized facilities aimed at providing services and hosting persons in day-centres or residential settings (above all when parents or other care givers are not in a position to look after such individuals), overcome attitudes of staff that often do not take visual disability into serious consideration, advocate and lobby to amend existing laws regarding this population, find a work placement either in sheltered work or in the community (even with or without a vocational certificate), make the individuals more active supporters of their own lives, provide more rehabilitation opportunities, provide more support towards full inclusion such as starting a family or managing their role in the current family,

coping with daily activities with minimum of help, ability to ask for help or to refuse it.

Elderly

Needs: Promote independent living, improve care for the elderly, an increased need for a sense of security and eliminating the feeling of rejection and loneliness, need for everyday care, a dignified, patient and understanding environment, possibility to spend the end of life at home, be able to make decisions on various things concerning the individual's life (flat/house arrangements, finances etc.), availability of good ambulatory and home based medical and social services, physical, psychological and social support on a daily basis to both persons with multiple disabilities and their families, adequate health care and human support often missing when key figures/ caregivers in the family are no longer available, identify the population and then offer appropriate support as oftentimes there is not enough and relevant information, train qualified assistants for care, employment and leisure in general and special facilities.

Problems: Often unawareness of the presence of a visual impairment, difficulties in carrying out daily activities, poor rehabilitation programs and lack of specialist services, especially for those living in smaller towns, finding appropriate care takers while living at home, having difficulties to understand the legal and social system and being able to represent themselves to seek changes in the existing laws or social systems, might fall victims of violence or abuse by the family or other people, finding appropriate day centers or residential facilities when staying at home is no longer possible, lack of qualified professionals to suggest aids, devices and means to overcome implications of the visual impairment.

Challenges: find trained and appropriate personal assistants, maintain personal care and care for own home, ensure individualized, specialized services of transport and assistance in daily life activities, secure that these persons live a dignified life, create residential facilities with specialized staff, improve the quality of life of these persons ensuring they are well looked-after and accepted, and their potential is developed whenever possible, a visual disability is not always taken into serious consideration.

Provisions

The survey attempted to collect information about a number of provisions that exist and are available in Europe for persons with additional disabilities. More specifically, the provisions that the survey concentrated regarded:

1. Any committees or working groups for persons with additional disabilities or their families,
2. Any programs or services designed especially for persons with additional disabilities,
3. The settings where persons with visual impairments and additional disabilities normally receive their education,
4. Any rehabilitation or training facilities that persons with visual impairments and additional disabilities can attend,
5. Any employment schemes for persons with visual impairments and additional disabilities,
6. Any residential settings for persons with visual impairments and additional disabilities,
7. Any other provisions.

What follows is a presentation of the information that was collected from the completed surveys regarding the above-mentioned provisions.

1. Any committee or working group for persons with additional disabilities or their parents

Keeping in mind that about half of the surveys were completed by members of EBU, organizations of the visually impaired, and the other half from members of ICEVI, the findings of this section are not identical since many members of EBU responded that they do not have a committee or working group while in most surveys completed by ICEVI there was a reference to parents' associations. More specifically, the results showed that:

In the Netherlands are two rehabilitation centres (Royal Dutch Visio and Bartimeus) for people with a visual impairment with several locations in the country.

The organization in Slovenia has a self-help group for parents of children with visual impairments. Members of this group are also parents of children with additional disabilities.

In Czech Republic, for each type of multiple disability, there is always a person responsible for that area in Tyfloservis. This person is an expert on the methodology of that particular area, he or she works in it, trains the other employees and may also create working groups if needed.

In Italy, the Italian Union of the Blind and Partially Sighted (UICI) has created ad-hoc commissions on the matter, both at national and local level.

The main United Kingdom organisation for professionals working in education for people with blindness and complex needs is VITAL (http://www.rnib.org.uk/professionals/education/support/networks/vital/Pages/vital_network.aspx).

In Austria, Hungary, Belgium, Cyprus and Greece there are parent associations for children with visual impairments in which parents of persons with additional disabilities can be members.

In Serbia there are working groups and special classes for children with additional disabilities, (5 classes and groups), where the Perkins International model of education is used with the children and their parents.

2. Any programs or services designed especially for persons with additional disabilities

In The Netherlands, there are education centres, day-care centres, residential homes and supported employment for people with visual and intellectual disabilities.

UBPS in Slovenia annually organises a meeting over several days with workshops held by professionals from different fields for families of children with visual and additional disabilities.

In Poland seasonal programs for persons with additional disabilities are planned every year.

In Italy, on a national level, UICI offers general recommendations such as orientation guidelines to local branches where the task is carried out of providing multi-disabled members with ad-hoc services.

In Hungary for school age children there are special departments and in all parts of the school there are special programmes for the MDVI population. For adults, rehabilitation services are growing, offering rehabilitation for MDVI youngsters (leaving school) and adults e.g. VI individuals in wheelchairs, post stroke patients with CVI, the elderly with a severe combination of disabling conditions (poor mobility, hearing and memory).

In Serbia, the Perkins International program and early intervention program is implemented along with a vocational program.

For Belgium, teachers, educators, therapists and staff are dedicated and have a specific building program called Spermalie/ de Kade.

Amymoni, in Greece, runs programs on early intervention and daily living skills as well as on creative occupational therapy.

Finally, in Cyprus the Pancyprian Organization of the Blind through its social services offers general recommendations to persons with additional disabilities and their families. These recommendations mainly deal with welfare and other benefits, brochures on sighted guide techniques including guiding persons in wheelchairs and available schemes to acquire means or devices to assist with daily life. The School for the Blind offers an early intervention and a support program by a peripatetic teacher to students with additional disabilities attending other special schools or special units in general education.

3. The settings where the persons with visual impairments and additional disabilities normally receive their education

In The Netherlands, about 60% of visually impaired children receive their education in mainstream schools, sometimes with support of itinerant teachers. In addition there are 10 schools for special education.

In Slovenia, most students are integrated into mainstream schools. They are provided with additional professional support and adapted materials by the qualified teacher of the visually impaired. In order to overcome learning deficiencies, barriers, disorders or other difficulties, the support can be in the form of additional hours. Furthermore, a permanent or temporary assistant can be assigned to pupils with physical impairments, depending on the severity of their impairments, and to blind pupils.

In Poland, there is a special education system, and a low percentage of persons with visual impairment and additional disabilities have an access to education in the mainstream setting.

In Estonia students with additional disabilities are educated at special schools for the blind and visually impaired.

In Czech Republic, the setting depends on the types of the disabilities a person has, which one prevails or has the biggest influence on the individual's life, the person is educated either at a special school for the blind and visually impaired, at schools for students with physical impairments, mental disorders or in a class for autistic children etc. In some towns, there are also special schools for students with multiple disabilities. In some cases, there is also a possibility of inclusive education in mainstream schools for some students with multiple disabilities. During the educational process these students and their teachers are assisted by experts from special pedagogical centres who give them advice on all kind of matters such as: how to adapt lessons, school premises or educational materials, how to obtain financial support for special aids, social security for the student and his/her family and how to learn some basic skills such as orientation and mobility.

In Lithuania there are different possibilities. Many attend special schools, those with milder disabilities attend regular schools, some with severe problems receive education at home.

In Italy, blind and partially sighted people with additional disabilities receive their education in mainstream schools where they are assisted by qualified support teachers.

In Scotland, children and young people who only have a visual impairment are mainly educated within mainstream schools. A small proportion attend a special school for the blind or a VI unit attached to a mainstream school. Children who are visually impaired with additional difficulties are most likely to attend a special school that is not primarily aimed at those with a visual impairment. However, these special schools are likely to have input from a specialist teacher of the visually impaired on a peripatetic basis. The Royal Blind School does have facilities for children with visual impairment and other difficulties as well as a facility for young adults "Future Vision".

In the United Kingdom, education is completed mostly in special schools for children with severe learning difficulties (not VI). Most of the remaining special schools for children with VI cater exclusively to children with visual impairments and additional disabilities but probably less than 5% of learners with VI and additional disabilities go to these schools.

In Austria education is provided in mainstream classes or special schools, special classes or in the school for children with motor problems.

In Hungary the education for MDVI children is delivered in specialised schools, of segregated form, based on the type of impairment. Most of them get support in their homes by law 10-20 hours a week. This service is poorly delivered typically in regions where there is a need for special education teachers. During the last 10 years schools (typically primary schools for mild intellectual disability – from which children entered to main stream education) established daily support/schooling for those with moderate and severe intellectual disabilities – among who there are also MDVI children.

In Switzerland persons who have visual impairments and additional disabilities and who cannot follow normal schooling attend the CPHV. Some of them are schooled in other schools for children with special needs, in some of which an ambulant service from the CPHV is active. In Switzerland there are still quite a few disabled people (for example intellectually disabled) whose visual impairment is not properly diagnosed.

In Serbia education is provided in mainstream classes or special schools, special classes or in the school for children with intellectual problems.

In Belgium education is offered in mainstream classes (although this is rare for the severely multiple disabled). Also used are special schools, special classes or the school for children with visual or motor or mental problems.

Education in Greece for students with additional disabilities is mostly offered in Amymoni and in special schools for children with VI. Furthermore, some children receive their education in special schools for children with severe learning disabilities (not VI).

In Finland education is provided in mainstream classes.

Finally, in Cyprus education of students with additional disabilities is offered in a variety of settings, based on the degree and severity of the disabilities.

These settings include mainstream classrooms, units attached to a regular school, special schools for students with multiple disabilities (not VI) while a very small number in the School for the Blind. In all cases advice and support is offered by peripatetic specialists on MDVI.

4. Any rehabilitation or training facilities that persons with visual impairments and additional disabilities can attend

In the Netherlands persons can attend special rehabilitation programs while training is also offered to caregivers of other organisations like day care centres and residential homes.

Despite the fact that Slovenia has all the legislative measures for comprehensive rehabilitation, in practice, so far, only a pilot project has been launched in October 2012. This project aims for the inclusion of a certain number of persons and the result will have a major impact on further development of this service. Also, UBPS together with regional associations conducts several programmes, services and activities, which provide different competences for independent living of members, also those with additional impairments. There is a struggle to meet their needs and enable them to live a full and independent life.

In Austria persons with visual impairment and additional disabilities can attend general training provided by the Austrian Federation of the Blind and Partially Sighted, for example early development of blind and partially sighted children.

In Poland there is one central facility and a few other facilities in some of the regions of the country.

In Estonia persons can attend rehabilitation institutions and training facilities for persons with disabilities.

In the Czech Republic, social rehabilitation is provided to persons over fifteen by regional centres of Tyfloservis, o.p.s either in day-care centres or as home based services. There is also the Rehabilitation and Training Centre for the Blind Dedina which is a residential setting. Other follow-up services are provided either by the regional centres of Tyfloservis, o.p.s. or by the Special centres of Czech Blind United such as Tyflokabinet (the National Adaptive Technology Centre), the Guide Dog Training School or the National Legal Support Centre etc. The Association for Early Intervention and its centres as well as Early Intervention EDA, O.P.S. and others are designated to help

children with visual impairments and additional disabilities. The additional disabilities are rehabilitated in corresponding facilities (physiotherapeutic centres for physically handicapped, special day-care centres for persons with mental disorders, special educational and rehabilitation classes for autistic children etc.).

In Lithuania in some cases visually impaired persons with additional disabilities can attend rehabilitation courses designed for the visually impaired.

In Italy there are some rehabilitation centres and very few training centres. The Rittmeyer Institute in Trieste can be considered as a flagship institution where both rehabilitation and training activities are carried out.

In the United Kingdom there are three specialist further Education Colleges. Two of them cater mostly for MDVI.

In Hungary during compulsory education there are " subjects" like ADL, O&M, vision training included in the students timetable. As adults they can go to rehab centres. During the last 15 years 7 regional centres were established all over the country. These centres serve all kinds of VI clients, in a limited number those with MDVI. During the last 3 years the rehabilitation service in the national institute for blind people in Budapest has developed programs for MDVI people, elderly and post-stroke CVI patients under a project grant. They serve this population from all over the country on a residential basis.

In Switzerland rehabilitation is provided in schools for children with special needs and workshops for adults.

In Serbia rehabilitation is offered in clinics for children, early intervention, activities for daily living, speech and language therapy (communication), sensory integration, psycho-motor re-education, orientation and mobility.

In Belgium, rehabilitation is also offered in clinics and rehabilitation centres and in the rehabilitation section of the centre Spermalie/ de Kade.

In Greece there is one day care centre, Amymoni, and five special schools in major towns of the country within which persons with MDVI can attend training programs.

In Finland the services of the National Federation for Visually Impaired, the services by Onerva support services for municipalities.

Finally, in Cyprus no legislation provides for any kind of rehabilitation, educational, or vocational training for persons over the age of 21. Adults with MDVI can attend private funded programs or some of the courses provided at the St Barnabas School for the Blind as part of its Adult Training Programs.

5. Any employment schemes for persons with visual impairments and additional disabilities

In The Netherlands supported employment is offered in centres as well as elsewhere.

In countries such as Slovenia and Cyprus there are no special employment schemes for persons with visual impairments and additional disabilities. However those persons can attend vocational rehabilitation or in the case of a severe disability, they can be included into shelter-work placement schemes for persons with intellectual disabilities.

Although in Poland there is an employment scheme, but its method of functioning is rather difficult and unsatisfying.

In Italy, Article 12 of law no. 68 of 12 March 1999: "Regulations on the right to employment for persons with disabilities", which is the main legislation governing the employment of disabled workers in Italy, in principle provides also for the possibility of employment of persons with mild-moderate multiple disabilities. For people suffering from severe-profound multiple disabilities it is actually impossible to carry out work activities, so they are financially helped by the Non Self-sufficiency Fund (NSF) - established to guarantee the implementation of base levels of care for non-self-sufficient people - which has been reactivated after having been drastically reduced for a while.

In The United Kingdom there are adult training centres where people with MDVI attend.

For Austria and Belgium there are sheltered workshops.

In Hungary there are no paid jobs in day care centres and only a few sheltered workplaces. The sheltered workshops employ VI individuals in a limited number but there is one which is specialized for VI people. This has small groups in different cities in Hungary. Those working in sheltered workshops are mostly VI with mild intellectual, physical or hearing impairments.

In Switzerland there are some productive or occupational workshops (2nd work market).

In Serbia persons with visual and additional disabilities can attend and finish a special secondary school for packing things in factories such as toys, food, medicine, etc. (vocational program).

In the Light House of the Blind of Greece, a center for persons with VI, there are sheltered workplaces where training programs take place for people with MDVI. Also there are Special Training Centers in Education and Rehabilitation (E.E.E.E.K.) within which employment schemes operate for students with MDVI.

In Finland employment schemes are relevant after vocational/ high school studies; Onerva is responsible for supporting education during years 5-18.

6. Any residential settings for persons with visual impairments and additional disabilities

In The Netherlands they offer 10 large and some smaller residential settings.

In Slovenia regional associations provide certain facilities for members, so-called housing groups. In order to support and prepare individuals to live a full and independent life, the local associations run programmes and other activities among members living in those housing groups.

In Poland there are many residential settings that help in daily life, however they are still very expensive. Persons with disabilities have the possibility to acquire some grants to finance any necessary adaptations.

In the Czech Republic there are no special residential settings for persons with visual impairment and additional disabilities. However there are residential settings intended primarily for the blind and visually impaired that also accept persons with additional disabilities (e.g. the Palata home for persons with visual impairments or the Social Service Centre for the Blind in Brno-Chrlice). There are also other residential settings primarily intended for persons with physical impairments or mental disorders etc.

In Lithuania and Cyprus there are no residential settings especially for persons with visual impairment and additional disabilities, but if there is a need, they are sometimes placed in general residential institutions for older people or people with different disabilities. Similarly, in Finland there is no special

residential setting designed only for persons with visual and additional disabilities.

In Italy there are very few residential settings, with just a few bed places, for persons with a visual impairment and additional disabilities.

In the United Kingdom there are three colleges that are residential.

In Hungary there is only one special centre for people with MDVI. The majority of the residents of the national institute for blind people have VI with mild intellectual or physical disability. Persons can also be placed in small group-homes. One is for more severe MDVI, the other is offering placement for those who are able to manage independent daily living activities. Those with more severe conditions can be placed in nursing homes for the mentally disabled or for the elderly.

Switzerland has some residential settings.

Serbia has residential settings for MDVI children and pupils.

Belgium has residential sheltered houses in the region as a part of the offer of Spermalie/de Kade; sheltered apartments as a part of an inclusive project where special support is given if necessary; this in cooperation with regular rental centres at local places.

In Greece residential settings exists in special schools for the blind.

7. Any other provisions for persons with visual impairments and additional disabilities

Poland stated that they have separate provisions for persons with additional disabilities in regards to the dimensions of the living area, the degree of lighting and devices to facilitate safe mobility. The organization also offers help in cases of temporary or permanent assistance in its special facilities.

In the United Kingdom there is an online forum for professionals who work with persons with visual impairment and additional disabilities – VITAL.

In Hungary there is a special vocational training school for the target population.

Finally, in Finland support is offered to the municipalities to implement national “three step service provision for all” according to individual needs (general support, intensive support, special support).

Good Practice Examples

The last section of the survey was to collect any examples of good practice that organizations or centres deliver to persons with visual impairments and additional disabilities. These good practice examples concerned areas such as leisure and recreation, rehabilitation, pre-vocational or information services. Below is a presentation of these examples:

In the Netherlands there is a fitness program for people with severe intellectual disabilities as well as the promotion of “own initiative rehabilitation model” for people with intellectual disabilities. Psychotherapy for people with intellectual disabilities is also available along with a program called “I am on-line”, an e-mail course for people with visual and intellectual disabilities. More good practice examples included play development courses, visual stimulation programs for youngsters, and training relationship for elderly people.

UBPS, in Slovenia, organizes an annual camp for families of children with additional disabilities. Participants to the camp can be involved in numerous activities such as art and craft, sports, physiotherapy and in numerous other workshops run by experts.

Likewise, in the Czech Republic, Czech Blind United organizes camps for their members and their family members or assistants, where Tyfloservis organizes various workshops, trainings, special aids presentations or even competitions in practical skills.

A number of examples were listed from UICI’s local branches in Italy. These included:

- Visual rehabilitation carried out at the “Education and Visual Rehabilitation Centre”,
- Afternoon out-of-school programmes with individualized support activities carried out by professionals, e.g. tiflogists/ blindness experts, neuro-psychiatrists,
- Provision of specific information on nearby facilities accommodating persons with additional disabilities,

- Recreational club for elderly people,
- Music therapy courses,
- Hypotherapy courses,
- Telephone help line,
- Assistance and support in leisure time activities,
- Support at people's homes upon request, e.g. for reading books/ magazines/ correspondence, provided on a voluntary basis.

On the website of RNIB of the United Kingdom, there are extensive advice sheets regarding this population. These can be found at:

http://www.rnib.org.uk/professionals/education/support/guidance/complexneeds/Pages/complex_needs.aspx

The Odilien-Institut in Austria provides very good support to school-age children in local schools with special approaches like materials of Lilly Nielsen, supported communication and use of computers. There are also very good examples in the department for elderly people in leisure programmes like singing, wheelchair dancing, biography work, games or basic stimulation.

In Hungary there is a very close link between the vocational training school and the sheltered workplaces. There is also a database of adult placements and parents which can be assisted to contact these places. In addition, help is available along with a package of information (legal regulations, social laws) in the transition time from education to adulthood. The swimming pool is also available for this population.

Besides a ski week or weekend, in Switzerland persons with additional disabilities can attend afternoon games and coaching to be able to enter a vocational training.

In Serbia, children with MDVI and their parents along with special teachers have the opportunity to participate to some excursions where activities for daily living (eating, dressing, etc.) are taught. In addition parents can receive information or participate to workshops on various subjects suggested by parents and teachers.

In Belgium, during school age, there is a very good support in local schools with special approaches like materials of Lilly Nielsen, supported pre-symbolic communication, use of computers and visual stimulation programs, basic

stimulation aids, cooperation on the level of the individual child/ youngster/ adult. There are also very good examples in the department for adults. For leisure programs, for example, like singing and making music (cd's!), farmer activities and care of animals, vegetables, and flowers. There are also cultural activities such as naive painting, making sculptures, exposition for the neighbourhood etc.

The Polish Association of the Blind is the owner and operator, managing specialized medical facilities, training, rehabilitation, recreational, welfare, cultural and leisure activities that are also directed to persons with additional disabilities.

In Finland, there are one-week long courses for special education needs for students, during which the aim is to find relevant issues concerning each student.

Finally, in Cyprus, the St Barnabas School for the Blind runs an early intervention program for MDVI babies and their families and supports MDVI students attending either regular education or special schools, by providing information and suggestions for overcoming the educational implications that the visual impairment has on the student. Also, the Pancyprian Organization of the Blind runs shelter basket weaving workshops, where persons with additional disabilities might be employed.

Chapter Five - Conclusions and Recommendations

This final section of the report presents the conclusions and recommendations that resulted from the findings of this mapping exercise.

The goal of the mapping exercise was to collect, analyze and assess information from EBU and ICEVI member countries in order to answer to the following research questions:

- How is the term “visual impairment and additional disabilities” defined in each organization?
- What statistical data is available for this group?
- What provisions and services are available for this population?
- What are the needs, problems and challenges faced by this group?
- What best practice examples exist in various countries and regard this group?

Once a review of the relevant literature was carried out, a questionnaire was prepared and circulated among EBU national members and ICEVI national representatives via email accompanied by a cover letter stating the purpose of the survey as well as timeframes for its completion.

The survey was divided into seven small sections. The first and last sections collected some demographic information regarding the country, organization and personal details of the person completing the survey. The rest of the sections contained tables for completion and open-ended questions that asked for information such as:

- Definition of the term “visual impairment and additional disabilities”,
- Statistical information of this group,
- Provisions
- Needs, problems, challenges,
- Best practice examples.

A total of nineteen completed questionnaires were received. The information was then analyzed in the best possible manner and was presented in section four.

The fact that the surveys were completed by two different European Organizations prevented the collection of accurate statistical data for this population. Unlike the difficulty in collecting qualitative statistical data, a great number of very interesting findings were collected in regards to the other sections of the survey. The majority of these findings present a lot of similarities, especially when it comes to the needs, challenges and problems, clear evidence that greater focus should indeed be placed on people with visual impairments and additional disabilities. Moreover, most of the findings were in accordance with the relevant literature review that was performed.

From the findings of the conducted survey a list of important recommendations were put together that can be shared not only by organizations representing people with visual impairments, but also by institutions, academics and policy makers across Europe.

These recommendations include:

- To agree on a common definition for the term “persons with visual impairment and additional disabilities” as this can assist in the early and effective identification of this population while securing for support services to be put in place.
- To explore the possibility of an EU funded project (strategic partnership) that will conduct research on children and adults with additional disabilities in order to increase awareness on the growing number, age range, needs and organised services.
- To encourage national organizations of the visually impaired to incorporate the needs and problems of persons with additional disabilities in their agendas.
- To produce a training manual for personal assistants of persons with VI and additional disabilities.
- To set up a mailing list (interest group) for interested persons from both ICEVI and EBU to exchange good practice examples and ideas on vocational training, curriculum adaptations, rehabilitation programs etc. for persons with VI and additional disabilities.

For the early and school years:

- Set up a working group that will put together a list of available visual assessments and good diagnostics for the early years to be shared on both the website of ICEVI Europe and EBU.
- Carry out e-training on how to successfully set up and run early intervention programs.
- Set up a working group to put together a list of resources that are available to parents such as play routines, selecting appropriate toys, enhancing child development and residual vision.
- Create an action sheet available for nursery centres and kindergartens that care for children with VI and additional disabilities on ways to enhance communication skills, promote social skills and integration, build up daily routines as well as sighted guide techniques for children who are wheelchair users.

Adults:

- Find those organizations active in the field of visually impaired and additional disabilities (include information such as if they run on NGO or governmental sources),
- Find out what is the educational background of their care takers, what daily routines they perform, what supporting conditions they have, what kind of medical care especially eye care they offer, their rehabilitation needs and services including vision rehabilitation etc.

This mapping exercise was conducted in order to collect, analyze and assess information about persons with additional disabilities, a rapidly growing population with diverse and unique needs and challenges. This report is the product of this mapping exercise and it should not be an end in itself. It should be considered as a fundamental step that enabled the identification of challenges, the assessment of needs and better targeting of interventions for persons with additional disabilities of all ages. The findings and recommendations of this survey can set the basis for future programs, projects and collaborations as well as define common policies all aiming to enhance the development of these individuals, to promote their inclusion and to secure a dignified and independent life for every person with additional disabilities.

Bibliography

AMD Alliance International. (2011 April). Increasing understanding of wet age-related macular degeneration (AMD) as a chronic disease.

http://www.amdalliance.org/user_files/documents/AMD_ChronicDiseasePolicy_M03_NoCrops_Low_Res.pdf

Bazargan M, Hamm-Baugn VP. (1995), The relationship between chronic illness and depression in a community of urban black elderly persons. *Journal of Gerontology: Social Sciences*. 1995; 50B (2):S119–S127

Boerner, K. (2004), Adaptation to disability among middle-aged and older adults: The role of assimilative and accommodative coping in *Journal of Gerontology: Psychological sciences* 2004, volume 59B, No.1, P.35-P.42.

Capella-McDonnall, M. (2007), The need for health promotion for adults who are visually impaired in *Journal of Visual Impairment and Blindness*, March 2007, 133-145

Erin. J. (1996), Children with multiple and visual disabilities, in Holbrook, M.C. (1996), *Children with visual impairments. A parents' guide*, Bethesda, Woodbine House.

Evenhuis, H.M., Sjoukes, L., Koot, H.M, Kooijman, A.C. (2009), Does visual impairment lead to additional disability in adults with intellectual disabilities?, in *Journal of Intellectual Disability Research*, volume 53 part1, pp 19–28, January 2009

Holbrook, M.C. (1996), *Children with Visual Impairments. A Parents' Guide*, Bethesda, MD., Woodbine House.

Jacobson SW, Jacobson JL, Sokol RJ, Martier SS, Chiodo LM. (1996), New evidence of neurobehavioral effects of in utero cocaine exposure in *Journal of Pediatrics*. 1996;129:581–588.

Kirchner, C., & Diamant, S. (1999). Estimate of number of visually impaired students, their teachers, and orientation and mobility specialists: Part 1. *Journal of Visual Impairment & Blindness*, 93, 600-606.

Krinsky-McHale, S., Jenkins, E.C., Zigman, W.B., Silverman, W. (2012), Ophthalmic Disorders in Adults with Down syndrome in *Current Gerontology and Geriatrics Research*

Volume 2012, Article ID 974253, 9 pages

Leonard, M. (2013) J.O.B.S. MDVI An Overview. MDVI Euronet Summer Newsletter 2013. <http://www.mdvi-euronet.org/site/files/MDVIEuronetSummer2013.pdf>

McLinden, M. and McCall, S. (2002) *Learning Through Touch: Supporting Children with Visual Impairments and Additional Difficulties*. David Fulton Publishers

MDVI Euronet <http://www.mdvi-euronet.org/site/impact-mdvi.php>

Minnes, S., Lang, A., Singer, L. (2011), Prenatal Tobacco, Marijuana, Stimulant, and Opiate Exposure: Outcomes and Practice Implications, in *AddictSciClinPract*, 2011, Jul 6 (1): 57-70

Moore, J.E., Graves, W.H., Patterson, J.B. (Eds.)(1997), *Foundations of Rehabilitation Counselling with persons who are blind or visually impaired*, New York, AFB Press.

Patel, D.R., Greydanus, D.E., Omar, H.A., Merrick, J. (eds) (2011) *Neurodevelopmental Disabilities. Clinical Care for Children and Young Adults*. Springer Dordrecht, Heidelberg, London, New York

Poggrund, R.L., Fazzi, D.L. (2010), *Early focus. Working with young children who are blind or visually impaired and their families*. Second Edition, New York, American Foundation for the Blind

Rogow, S. (2005), A developmental model of disabilities in *The International Journal of Special Education*, 2005, vol 20, no.2, 132-135.

Rosen, S., Crawford, J.S., (2010), Teaching orientation and mobility to learners with visual, physical and health impairment, p.564-624 in Winer, W.R., Welsh, R.L., Blasch, B.B. (Eds.), *Foundations of Orientation and Mobility*. Third edition: Volume 2, Instructional strategies and practical applications 2010, New York, AFB press, American Foundation for the Blind.

Singer LT, Arendt R, Fagan J, Minnes S, Salvator A, Bolek T, et al. (1999), Neonatal visual information processing in cocaine-exposed and non-exposed infants. *Infant Behavior and Development*. 1999; 22(1):1–15.

Scholl, G.T.(Ed.) (1986), *Foundations of Education for Blind and Visually Handicapped Children and Youth. Theory and practice*, New York, American Foundation for the Blind.

Swaminathan, M. (2011), Cortical visual impairment in children- A new challenge for the future in *Oman Journal of Ophthalmology*, 2011, Jan.-April, 4 (1): 1-2

Taub, M., Bartuccio, M., Maino, D.M. (2012), *Visual Diagnosis and Care of the Patient with special needs*, Philadelphia, Wolters Kluwer Health, Lippincott Williams and Wilkins.

Tellevik, J.M. and Elmerskog, B. (2009) Activity-based intervention for multiple-disabled visually impaired people *British Journal of Visual Impairment* 27 (3):204-220

van den Broek, E.G., Janseen, C.G., van Ranshorst, T., Deen, L. (2006), Visual impairments in people with severe and profound multiple disabilities: an inventory of visual functioning in *Journal of Intellectual Disability Research*, 2206 June, 50 (part 6), 470-5

van Splunder J., Stilma J. S., Bernsen R. M. D., Evenhuis H.M.(2006) Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study. *Eye*20, 1004–10.

van Splunder, J., Stilma, J.S., Bernsen, R.M., Evenhuis, H.M. (2004), Prevalence of ocular diagnoses found on screening of 1539 adults with intellectual disabilities in *Ophthalmology* 2004, August, 111 (8): 1457-63

Warburg, M. (2001), Visual impairment in adult people with intellectual disability: Literature review in *Journal of Intellectual Disability Research*, volume 45, part 5 pp.424-438, October 2001

Webster, A., Roe, J. (2007), *Children with Visual Impairments. Social interaction, language and learning*, New York, Routledge.

Zihl, J., Dutton, G.N. (2015), *Cerebral visual impairment in children. Visuoceptive and visucognitive disorders*, Wien, Springer

Appendix A

European Blind Union Commission for Persons with visual impairments and Additional Disabilities Survey

IMPORTANT

Please note that this survey will not deal with persons with dual sensory impairments, deafblind, as this is the work of the DeafBlind Committee of EBU. We therefore kindly ask you not to include any statistical information about persons with deafblindness.

A. General Information

Country:

Name of Organization:

Address:

Telephone:

Fax:

E-mail:

B. Definition

How do you define, within your organization, the term “persons with visual impairments and additional disabilities”?

C. Statistical Information

How many members does your organization have?

What is the age group of your members?

How many members have additional disabilities?

Of those, how many are women?

Please complete the table given below by providing some statistical information on the various types of additional disabilities the members of your organization have:

Additional disability	Number of members	Percentage
Mild-moderate intellectual		
Severe – profound intellectual		
Autistic spectrum		
Spastic quadriplegia		
Physical (only Hans)		
Physical (only legs)		
Hemiplegic		
Speech and language		
Other ...		

D. Provisions

Does your organization have a committee or working group for persons with additional disabilities or their parents?

Does your organization have any programmes or services that are designed especially for persons with additional disabilities?

In your country, where do the persons with visual impairments and additional disabilities normally receive their education?

Are there any rehabilitation or training facilities that persons with visual impairment and additional disabilities can attend?

Are there any employment schemes for persons with visual impairments and additional disabilities?

Are there any residential settings for persons with visual impairments and additional disabilities?

Please include any other provisions your organization or country has for persons with visual impairments and additional disabilities:

E. Needs, Problems, Challenges

We are aware that the group of people with additional disabilities is a very diverse and heterogeneous one. Still, please try to list the greatest needs, problems and challenges that these individuals face in the various age groups:

Age Groups	Needs	Problems	Challenges
Pre-school			
School age			
Adults			
Elderly			

F. Good Practice

Please list any examples of good practice that your organization delivers to persons with visual impairments and additional disabilities such as leisure and recreation, rehabilitation, pre-vocational or information:

G. Further Information

Please list any additional information you wish:

H. Contact details

Name of person that completed the survey:

Position within the organization:

Email:

Thank you for taking the time to complete this survey!

Please return all completed surveys to Maria Kyriacou at m.kyriacou@cytanet.com.cy with a copy to ebucamb@euroblind.org

Appendix B – List of Countries Completing the Survey

Country	Name of Organization	E-mail	Person completing the survey
The Netherlands	Eye Association Netherlands	info@oogvereniging.nl	Geert Joosten rgjoosten@home.nl
Slovenia	Zveza društev slepih in slabovidnih Slovenije (ZDSSS) Union of the Blind and Partially Sighted of Slovenia (UBPS)	zdsss@zveza-slepih.si	Polona Car polona.car@zveza-slepih.si Karolina Doltar karolina.doltar@zveza-slepih.si
Poland	Polish Association of the Blind	pzn@pzn.org.pl	Anna Woźniak Szymańska prezes@pzn.org.pl
Austria	Austrian Federation of the Blind and Partially Sighted	international@blindenverband.at	Stefanie Steinbauer international@blindenverband.at
Austria	Odilien-Institut	spz@odilien.at Gertrude.Jaritz@odilien.at	Gerti Jaritz Gertrude.jaritz@odilien.at
Estonia	Estonian Federation of the Blind	epl@pimedateliit.ee	Monica Lõvi monsalovi@gmail.com
Czech Republic	Tyfloservis, o.p.s.	centrum@tyfloservis.cz	Mgr. Iveta Langrová langrova@tyfloservis.cz

			CZ
Greece	Panhellenic Association of the Blind	pab@otenet.gr	Ilias Margiolas Pab@otenet.gr
Lithuania	Lithuanian Association of the Blind and Visually Handicapped	centras@lass.lt audra@lass.lt	Ramune Balcikoniene ramune@lass.lt
Italy	Italian Union of the Blind and Partially Sighted	inter@uiciechi.it	Luigi Gelmini inter@uiciechi.it
United Kingdom	ICEVI	s.mccall@bham.ac.uk	Steve McCall s.mccall@bham.ac.uk
Scotland	Scottish Sensory Centre	janis.sugden@ed.ac.uk	Janis Sugden janis.sugden@ed.ac.uk
Hungary	School for the Blind, Budapest	igazgato@vakisk.hu	Krisztina Katona katona@vakisk.hu
Switzerland	Centre Pédagogique pour élèves Handicapés de la Vue - CPHV	frederic.schuetz@fa2.ch	Frédéric Schütz frederic.schuetz@fa2.ch Jacqueline Gyger jacqueline.gyger@fa2.ch
Serbia	School for Visually Impaired Pupils "Veljko Ramadanovic"	skolaveljkoramadanovic@yzhoo.com	Snezana Pejakov spejakov@gmail.com
Finland	Onerva Mäki Centre for learning and	Onerva@onerva.fi	Tarja Hännikäinen tarja.hannikainen@on

	consulting / Onerva Mäki School		erva.fi
Belgium Flanders (Flemish spoken part of Belgium)	BC Spermalie/ De Kade	Eliane.bonamie@de- kade.be	Eliane Bonamie Eliane.bonamie@de- kade.be
Greece	AMYMONI	amymoni@otenet.gr	Maria Papazafiri papazafirimaria@gmail.com
Cyprus	Pancyprian Organization of the Blind	pot@logos.cy.net	Maria Kyriacou m.kyriacou@cytanet.com.cy