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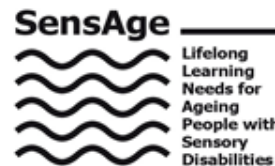
Deafblindness and mental health: Awareness leads to better intervention

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Réseau francophone en déficience sensorielle et du langage



- 7 Canadian Agencies
- 14 European

Québec (Canada)

- French is the official language
- Population : 8 M



Fundamental principles



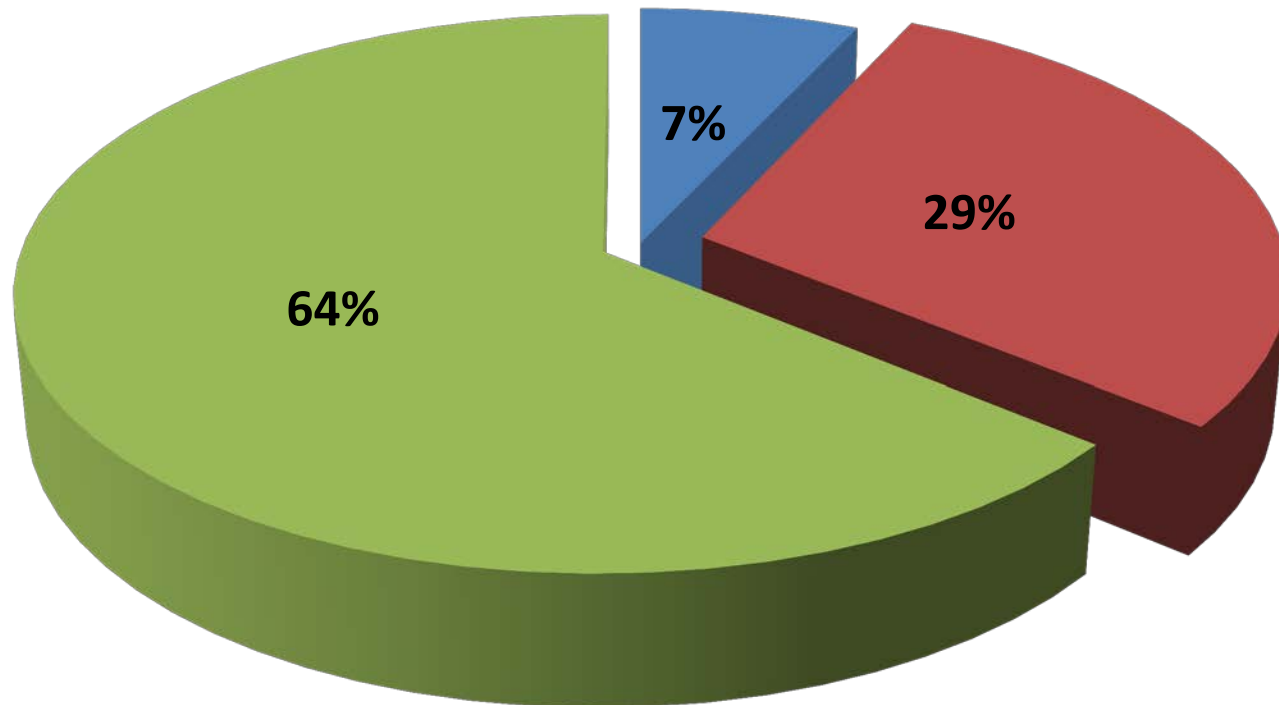
1. Respecting individuals
2. Growing and maintaining independence
3. Respecting the life contexts
4. Recognizing the person's abilities and capacities

(...) Fundamental principles



5. Inciting the person to participate in the decision-making process
6. Responding to individuals in a comprehensive manner and defending the right to a decent quality of life

Age distribution in rehabilitation services at INLB



■ 0-17 years old ■ 18-64 years old ■ 65 years and older

Dual sensory loss program



Dual sensorial program team




- Audiologist
- Speech pathologist
- Occupational therapist
- Vision rehabilitation specialist
- Orientation and mobility specialist
- Educator
- Optometrist
- Social worker
- Psychologist

Our clients



- Different degrees of hearing or visual loss
- All have communication problems
- Sign language users or oralists
- One or two cochlear implants
- Congenital blindness with acquired hearing loss or the opposite
- Usher syndrome

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- Not specialists in mental health but we intervene with many deafblind people in their process to be more autonomous
 - Well-being is a major factor – distress is an obstacle to learning new skills

What is mental health?



- Enjoy life, and create a balance in daily activities
- Achieve psychosocial resilience
- Express emotions and adapt to a range of expectations
- Use personal abilities
- Cope with normal stress of life
- Contribute to community

Psychosocial impacts of sensory loss



- The strenuous efforts to cope with a new sensory loss can have a profound negative impact
 - ▶ Impaired access to information/partial and unreliable perception/situational misinterpretations.
 - ▶ Stress
 - ▶ Change in personal relationship
 - ▶ Increased dependence on others
 - ▶ Low self esteem
 - ▶ Depression, sadness, anxiety

Experiences with deafblind clients



- Deafblind person living alone suddenly starts yelling late at night
- Deafblind client is intimidated by a monkey
- Neighbor complains because a deafblind lady strikes the floor at night
- Elderly lady sees moving patterns and bright shapes

Strategies to cope with distress and hallucinations

- Reduce isolation/increase stimulation
 - ▶ Increase number of social contacts, especially those with good communication
 - ▶ Stimulation: access to a computer, go out, owning a pet, etc.
- Strategies to redirect attention
 - ▶ Can help the person to regain control on hallucinations
- Cognitive-behavioural techniques

Charles Bonnet syndrome

- A person with a visual impairment can experience complex visual hallucinations without any mental health problem
- Frequent condition among people with age-related macular degeneration and retinitis pigmentosa (at least 10% and as many as 40%)
- Visual field is partially impaired



Research (Wanet-Defalque Ph.D. and al)

- Building a questionnaire based on:
 - ▶ Literature review
 - ▶ Focus group
 - ▶ Interviews 14 clients
 - ▶ Content analysis and questions production
 - ▶ 1st Version Questionnaire
- Test of the questionnaire:
 - ▶ Symptomatic clients and control clients
 - ▶ Psychological Distress /DPESQ-14 (French version of PSI)

1st questionnaire



- 3 main parts
 - ▶ differentiating screening
 - ▶ Psychosocial impact
 - ▶ Characteristics
- 61 questions (+++ subquestions)
- Between 1 to 2 hours to administer

Participants



- Visually impaired clients (INLB)
- 24 participants with hallucinations
- 18 participants without
- Age: 55 to 90; mean: 78
- >90% female participants

Results: revised questionnaire



- Reduced number of items
- Reformulation
 - ▶ Better standardization
- Need to further validation with target population (clients entering services)
- Psychological impact can be considerable

Clinical case : Mary



- Woman, 50 years old, proud and independent personality
- Usher syndrome type 1, uses sign language
- Two adult children living on their own
- Lives alone, very few social contacts

Symptoms



- Started to yell and make noise during the evening
- Hit the walls and the floor
- Complained about noise in her ears and lights on the wall, wondered if there is a party upstairs
- Stressed out and afraid

Hypothesis

- Is the noise real?
- Tinnitus?
- Auditory hallucinations? Charles Bonnet syndrome?
- Needs attention?
- Isolation?
- Expression of distress?
- Reaction to family events? (sickness, death...)
- Anxiety or other cause related to mental health?

Our intervention

- Enabled her to understand reaction of hearing people
- Checked possible noise sources in the apartment, found practical ways to have her to reduce noise
- Information about tinnitus, difficult concept for a congenital deaf person. Information on Charles Bonnet syndrome
- Encouraged her to experiment: does she hear the noise when she visits her sister?
- Increased social contacts
- Let her express what is bothering her
- She refused help from mental health specialists

Current situation



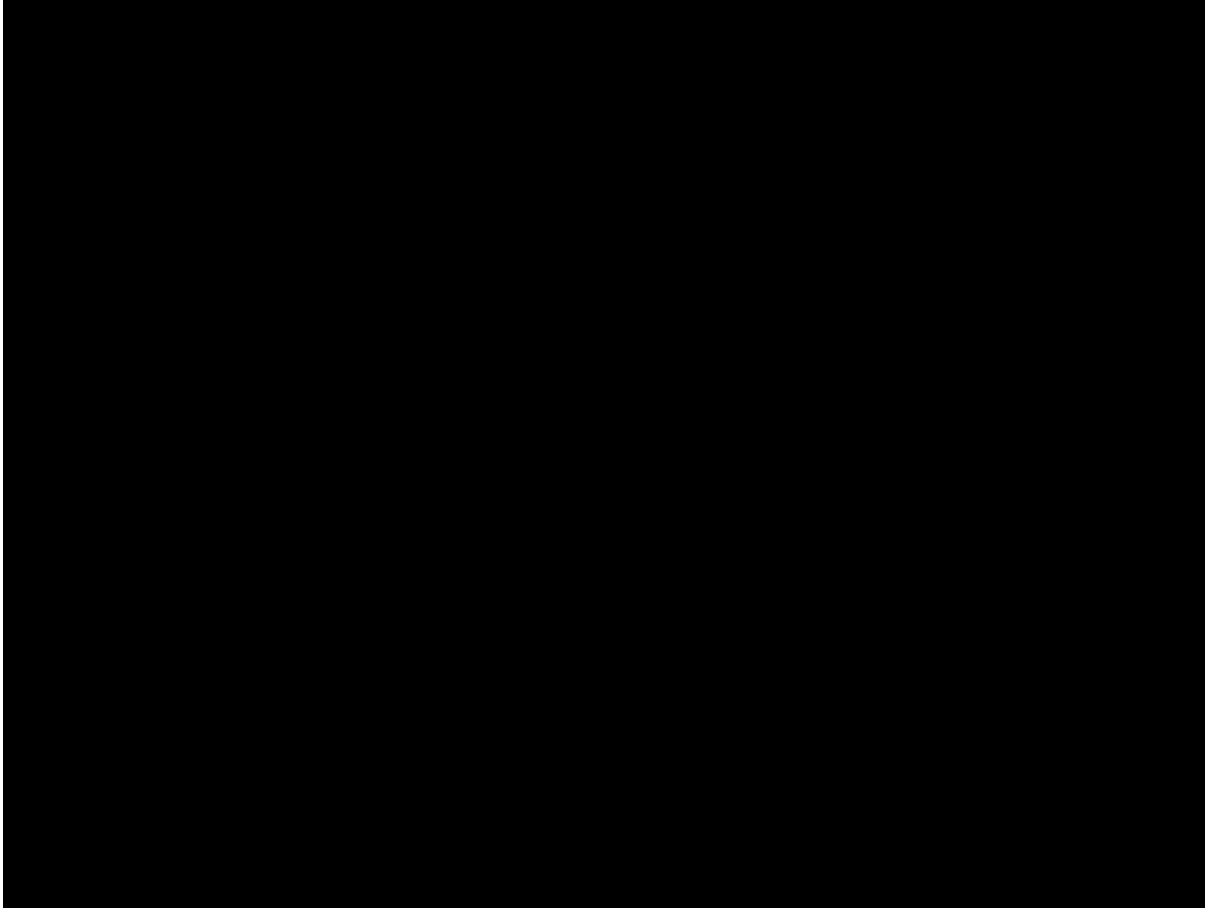
- Still lives alone
- Can control two sources of noise in her apartment
- No recent complaint about noise
- Involved in a regular physical activity
- Visual hallucinations are not an important issue anymore
- Other tenants reported these symptoms recurred each fall

Conclusion

- Delays in access to service, could worsen mental health problems
- Referral for a primary mental health care service is essential
- Importance of social network support
- Good quality relationship, professional support and trust
- Cooperation between all concerned



Video



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