

Being Seen and Heard

Slide 2.

My name is Monique Mul. I am occupational therapist and I work with deafblind adults.

My name is Maartje de Kok. I am a student at Social Work and I have worked for two years at Visio as a social worker in education. Also I'm a so-called practical expert of experience in Usher. Since 10 years I'm living with the diagnose of the syndrome of Usher type 2.

3.

Monique:

Being Seen and Heard is the name of a project. This name shows that we want to see and hear our deafblind clients. In this presentation I will tell you about some **points/issues** we learned from the project.

Maartje:

As a practical expert and a student of Social Work I was asked to investigate the experiences and feelings of people with dual sensory loss. The goal is to have more insights in the world and needs of young people between 18 and 45 years old. This group contains mostly people with the syndrome of Usher (1, 2 and 3) and a few people with accidentally combined dual sensory loss.

Most of them are not entirely deafblind. Next to the elderly deafblind people this group is second in visiting Visio for rehabilitation.

With two companion Ushers I did some brain work about the essential themes in living with dual sensory loss. We took eleven interviews and I also took interviews with professionals from different institutes working with deafblind people in the Netherlands. Today I will present some results in addition to the story of Monique.

4.

Monique:

Visio is the organisation we work for. It has a long history of providing rehabilitation, education and care for blind and visually impaired clients from birth to 100 years of age or more. Visio has always made the same services available to clients with dual sensory loss.

5.

Monique:

Visio operates mainly in the north, north-west and south-west of the Netherlands. The national rehabilitation centre is in Apeldoorn in the middle of the country. Each region has a large number of rehabilitation, accommodation and education facilities. Visio has a workforce of 1,100 and helps some 9,000 clients a year. Our current registration system tells us that at least 600 of those clients also have an hearing impairment

I will introduce some of our clients

6.

This is a little participant of a special group for deafblind children near Groningen. For this group Visio works together with an institute for the deaf, the Royal Effatha-Guyotgroup.

7.

This is an inhabitant of one of the houses of Visio. Often these clients do not only have a visual impairment, but they are also mentally retarded.

8.

Our clients between young and old.

9.

This is a woman with elderly deafblindness. People with elderly deafblindness are the largest group of our deafblind clients

10.

Monique:

From May 2003 till December 2005 we had the project Being Seen and Heard at Visio.

We have clients with visual and hearing impairment since a long time.

Up to now, the number of staff specialising in working with clients with a dual impairment has been relatively small. In the 'Being seen and heard' project we're working towards giving deafblind clients the best possible assistance programmes at every centre of Visio and raising the level of our staff's knowledge and skills.

11.

Monique:

The project is closed with a final report and a conference.

What I want to do now is to look at the future. A lot has happened already, but many things have to be done.

Experiences in our project produced some points of interest.

We use them as line of action for the future

You can read them on the slide

- Recognition
- Admission
- Accessibility
- Meeting

We shall use these points to tell you by turns something about some results of the project and about some findings from Maartjes research.

12.

Monique:

It is important to make a good start.

As I said, a client visits us because of his visual problems. He doesn't speak about his hearing problems. When the first problem was the hearing impairment, like with people with Usher syndrome, the hearing problem seems to be a passed issue. Now they want attention for their visual impairment.

When people are mentally retarded there is often no information about the hearing of the person. Often research or screening is necessary to detect problems in vision or hearing.

We would like to do screenings of mentally retarded people together with an institute for the deaf. The first screenings have taken place. Also the inhabitants of the houses of Visio will be inquired into hearing impairment.

We made new forms for admissions interviews with attention for both senses.

Maartje:

Recognition plays an important role within the group of people with dual sensory loss. In my investigation it became obvious that most of the young people don't recognize themselves in the common word deafblind. More over: most people do feel themselves mainly visually impaired and in a few cases hearing impaired. This is because of the ongoing process of degeneration of the eyes and in some cases the ears. In most cases they are used to their hearing loss but when the loss of sight leads to difficulties with orientation, following conversations in group settings and eventually speech reading the hearing loss will again be a great issue in their adaptation and grief and mourning process. When people are getting more and more deafblind the negative interaction of the two impairments will be much more defined and noticeable in daily life.

13.

Betty, 21 years (RP since early childhood & recently diagnosed as Usher 2)

"I do experience my loss of sight as a greater disability than my hearing loss.

The sight loss touches me much more. For example it's a real handicap in sports and leisure.

Things are getting worse; my mobility, my socializing with people and my sense of isolation."

14.

Martine, 27 years (hearing loss & sight loss because of rheumatism)

“My ears have never really been a handicap in socializing with people. When my good eye did relapse I wished I had good ears. Then I could rely more on my ears for compensation.”

This is really a common sound in the interviews. People are dealing fairly well with their hearing loss but their world is falling apart when they have to deal with a serious sight loss. One guy Roy, 31 years old, told me about the feeling that his whole world was devastated by this bad news. He saw literally ruins everywhere; participation, social relations, everything he had worked for was gone.

15.

Astonishing were the problems of identification within the group of visually and hearing impaired. They did speak about feeling lost; not knowing if they belong to the world of the sound seeing and hearing people, the world of the blind, the world of the deaf and even the world of the deafblind. Most of them grew up in the ‘normal’ world, sometimes attending the school of the hearing impaired or the deaf and in two cases living for some time in institutions.

Manon, 40 years (Usher type 1; deaf and RP)

“I’m living in three cultures: the world of the deaf, the world of the hearing and the world of the deafblind. Formerly I was living only in the hearing world, but slowly on in the world of the deaf. Now there is also the world of the deafblind. My social contacts with the hearing friends are becoming less, because it’s so tiring. The contacts do make a shift to the world of the deaf and the deafblind. I’m still intending to restore my hearing contacts.”

16.

Femke, 32 years (Usher type 2; hard of hearing and RP)

“Living with my deafblindness is not only my struggle but also of the outer world. I do really struggle with other people not really knowing who I am. The impairments are like a veil between me and the outer world. That costs a lot of investment, from both sides.”

During the interviews I did feel a lot of insecurity with the participants about the consequences of the disabilities. I was frequently asked by them if they were not crazy. Was it belonging to their impairments or not? With the three of us we experienced in our brain work the same thing and were truly relieved because of the recognition in each others life stories and experiences.

17.

Monique:

During the project it became clear that deafblindness is a very specific problem. It is important that professionals, politics, health-insurances etcetera admit this fact.

You can't count this problems as one by one makes two. It is not possible to compensate the loss of one sense with the other sense (vision with hearing or reverse). You have to look for other possibilities for compensation.

When we admit that deafblindnes is a specific problem, that has consequences for our treatment, advices and care. The consequence is that we have to make our information accessible, and that rehabilitation and care are adapted to the needs and questions of our deafblind clients.

Working with deafblind clients takes more time. And time is money... (and Money is making deals with health-insurances)

When we admit that deafblindness is a specific impairment, it is important to make special rules for the financial compensation of aids and to develop better suitable aids.

At Visio we started deafblind committees in every region. Several different professionals participate in these committees. Their task is to continue the attention for the deafblind in our institute now that the project is finished.

18.

Maartje:

Admission is a great issue in dealing with deafblindness. I said earlier that having dual sensory loss was evoking questions about what's really belonging to their disabilities and what's normal for everyone. All of the persons are feeling themselves alone in some way, alone in dealing with this tremendously debilitating process.

Essential themes seem to be:

- Establishing and maintaining social contacts;
- The increasing burden on the partner;
- The decreasing mobility with the decrease of eye sight;

These themes are common sense but the next ones were more specific issues in my investigation.

19.

- Difficulties getting information; especially incidental learning in group settings and informal contacts;
- Multitasking: the search for an appropriate participation; especially combining the roles as a parent, partner, colleague and friend.
- Loss of energy what permeates every aspect of life and is forcing the person to make much more choices what to do with their life.

- A satisfying fulfilment of life would take a long time because of all the aspects above.

The most important themes for the young people appeared to be establishing and maintaining social contacts, the decrease of mobility and the tremendous loss of energy with the increase of the impairments. These aspects are strongly influencing their participation in society and the fulfilment of life.

20.

Maartje:

The most undervalued aspect of dual sensory loss in rehabilitation is the big loss of energy. That affects every aspect of life, of participation and the way of fulfilling life. Many of them are complaining about a tremendous fatigue what can only be solved by getting some sleep. Multitasking is difficult. Typical for this group is the difficulty to adjust to their level of energy loss because of the continuing loss of sight and hearing. Just when people were dealing with a particular loss the next one is knocking at the door.

Marieke, 29 years old (Usher type 2)

“That story about energy is tough. I’m planning some things and then I have to drop them. My partner has to do more in the household, shopping and jobs at home. He is okay with that, but sometimes he must watch his limits too. Sometimes I’m feeling independent when my partner has to take over a lot.”

Erna, 39 jaar (Usher type 2):

“I’m taking a nap at noon for 1 or 1½ hours, I’m planning a lot of moments to settle down and I’m varying the moments of rest

and activity. I have a housekeeper. The children went to the day-nursery two days a week when they were not ready to attend school, although I was at home. I'm also limiting my activities with the children to the neighbourhood."

For people it is difficult to imagine what this fatigue would be like. Therefore I will show you a fragment of a Dutch game show Expedition Robinson. Two women are fastened with an elastic cord into the sand. Both are trying to reach their goal; getting the wooden sticks in the middle of them. They have to put in a lot of energy to reach their goal and pulling too hard will bounce them back to their starting place.

Look at this fragment with the next fragment in mind.....

What do you experience when you see this?

Do you recognize it somewhere?

Can you imagine what being visually and auditory impaired would be like, when they are trying to make sense of their life?

Fragment Expedition Robinson (3 minutes)

Some quotes in the fragment are:

"I started to run like crazy, but just before the stick I was bounced back. Ho, you are not allowed to..." (→ Referring to the feeling that everything what would be undertaken seems to fail but only with tough exertion we will succeed.)

"Although they say they don't care if you loose, I do care! I'm feeling tensed."

(→ referring to the event that a lot of people keep on saying that we don't have to work or do something else but we would like to for ourselves).

"You have to see this as a penalty. Someone has to do it." (→ Referring to the felt pressure of society to get to work)

These quotes are outlining the difficulties in reaching their goals despite their loss of energy.

21.

Monique

Successful contacts with a deafblind client depend on the accessibility of the professionals. He must be open for adapted communication and methods.

Very important is that we stay accessible for the real questions of the client, also for the deeper questions that can come up later during the rehabilitation process.

Maybe for some questions we don't have an answer. We must be open for that, think about it and maybe develop new treatment products in the future.

It is important that people with a dual sensory loss can manage their own lives. We have to give custom-made care. At Visio every professionals who has contacts with clients have to follow a trainings program of two half days. Next year all the therapists will do an extensive trainings program which takes 3 days.

Maartje:

When recognition and acknowledgment of these specific problems will be more clear to professionals and the people with a visually and auditory impairment themselves there is no other way than to make society, rehabilitation and financial compensations en social services accessible. Certainly because the European Union recognized and Admission the unique problems of the deafblind and issued a declaration about the rights of deafblind people.

22.

Maartje:

When recognition and admission of these specific problems will be more clear to professionals and the people with dual sensory

loss themselves there is no other way than to make society, rehabilitation and social services accessible. Certainly since the European Union recognized and acknowledged the unique problems of the deafblind and issued a declaration about the rights of deafblind people.

Bottle-necks in relation to social services in the Netherlands are apparently:

- Compensation for the best possible hearing aids, waking and warning system, loopsystem...

Why? Since a lot of people are having problems getting compensation for their hearing aids because of the permitted limits in hearing of the health insurances.

Also I would like to mention that full compensation of hearing aids is only possible when people have a low income, but the hearing aids are too expensive for many people. They cannot afford the best hearing aids they need for better functioning in mobility and social contacts.

Guus, 35 years old

`For a long time I had no hearing aids, but I do hear less without them... I have a loss of 30 dB. Therefore I had no permission for compensation for hearing aids, although the aids were much higher adjusted than the hearing test did show.`

- **Compensation for household care or more elaborate practical care**
- **The need for a special rehab program for dual sensory loss**
- **The need for a personal coach in some cases.**

There are some people who give signals that rehab is mostly short term related. Some clients do have the idea that they cannot easily ask minor questions in later phases of dealing with deafblindness. They need a person to whom they can turn to for telling their daily experiences, doubts, questions etc.

It is important that the politics in the Netherlands and elsewhere do learn about the fact that people with dual sensory loss do need special social services what can not be done with the same rules and services for people with either a hearing or visual impairment. A new list of social services must be made for this special group!

23.

The number of people with a dual sensory loss is relative small. Besides the consequence of this impairment is the restricted communication. Deafblind people only have a small chance to meet companions in their own neighbourhood by chance.

In the project Being Seen and Heard two forms of meeting are developed where people with dual sensory loss can meet each other.

In the regional centres we have theme groups. People with dual sensory loss can exchange information, get information and practice skills.

Visio Het Loo Erf, the national rehabilitation centre, developed a short program. People stay one week, from Monday till Friday, in Apeldoorn. They also talk, exercise and experience a lot during this week.

In both groups rehabilitation is central to the programme.

People can learn from each other and we can learn from them.

Together they become stronger.

Meeting people with the same impairment produces recognizing, which people don't find at people with only a visual or only a hearing impairment.

Maartje:

Rik, 36 years old:

Meeting companions in distress is very important for me. I do have regularly contact with other patients on the internet. I'm

talking much easier on the computer. I love it when the issues are about anything and not only about the problems I'm dealing with.

Piet, 29 years old:

"Meeting companions means knowing that I'm not the only one and I'm getting acknowledgement from them."

Recognition and acknowledgement are very important benefits of meeting each other. There are different opinions about the way of meeting each other: some do like the internet, some do like the meetings at Visio and a few do visit associations for deafblind or blind people. But there are very few meetings organised by several associations because of the trouble to organize them by the deafblind people themselves.

24.

It is important that professionals and people with dual sensory loss do meet each other...

Listen to each other means learning from each other.

The project Being Seen and Heard and also the interviews with people with dual sensory loss by the deafblind people themselves are good examples of meeting each other halfway. We did experience that this co-presentation is a good example of meeting the professional and the client with dual sensory loss. We both learned from each other, especially we became both much more conscious about what impact dual sensory loss has in life. It is not just combining visual and hearing impairment but it is a whole new unique impairment.

It is not only a process of gaining consciousness from the side of the client or the professional.

No, we do need both to support people with dual sensory loss.

Conclusion

1 + 1 ≠ 2

Meeting leads to: recognition, more admission, more accessibility and... meeting again.

Thank you for listening