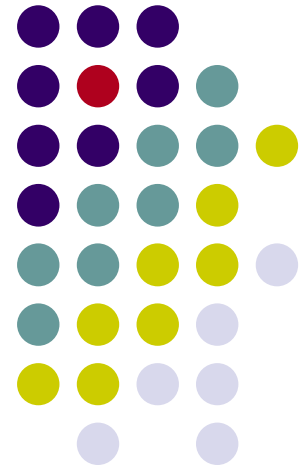
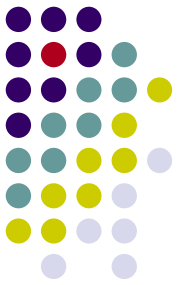


From Information to Knowledge

Workshop
ADBN seminar
Groningen, Holland
4 November 2006



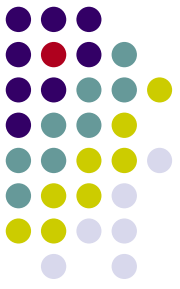


Receiving a diagnosis

”I did follow the others out at night, but felt that there were quite a few things that I couldn’t take part in and so quite naturally, I ended up staying behind at the school. So I didn’t go out much when it was dark without realising why. I ended up staying in while the others went out. I feel I have lost a large part of my youth.”

(48, deaf, moderate vision impairment)



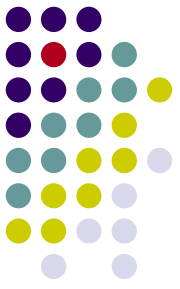


Receiving the diagnosis

“It was awful, I did not get any support, it was dreadful, ...I was in the centre of town waiting for the bus, the weather was bad and I was all on my own. I arrived home all on my own and I thought it was awful. It was horrible.”

(45, moderate hearing and vision impairment)



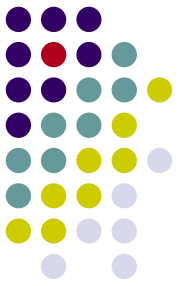


Receiving the diagnosis

“My parents and I felt there were problems with my eyesight when I was 7 or 8 years old so they took me to an eye specialist. There are people in my family who are deaf-blind and my mother had lots of information about Usher, which she passed on to me.”

(17, deaf, moderate vision impairment)

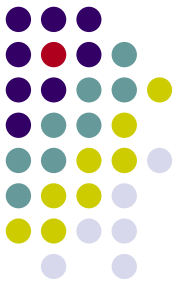




Important factors

- The diagnosis is given early at a point
- The diagnosis is given in a secure environment
- Plenty of relevant information
- Others with Usher in the family



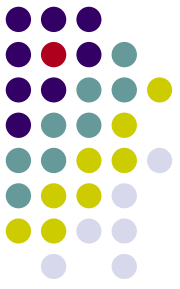


Consequences

"It could have been discovered earlier, and I could have received help earlier. It really is sad to think about. The doctor could have referred me to a specialist earlier. That is exactly why we have this system. My whole youth is lost. All the mocking and the teachers who didn't understand."

(50, moderate vision and hearing impairment)



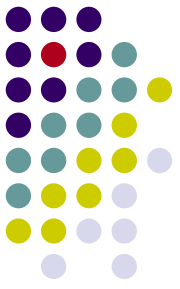


Getting support

“Yes, I have, regarding aids. As late as last Friday, when I was at the eye clinic where the eye specialist said that if I thought it was too difficult to read, I could obtain a CCTV. So I said stop, I can read well today. Upgrading to bigger aids is not for me. I think you must be careful with that; there is not a problem with technology today, but it must occur in line with your need.”

(52, moderate hearing and visual impairment)



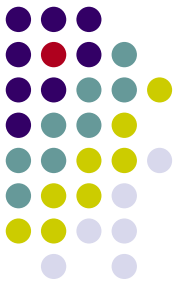


Guide dog

“I see it as an advantage to get a guide dog early to develop the cooperation and be able to feel safe when you go out, particularly when it’s dark. I can now go out and go on walks, go down to the sea, I can go to places where I haven’t been able to go for the last few years (...) My wife can keep on with her interests and I don’t have to ask her.”

(52, moderate hearing and visual impairment)





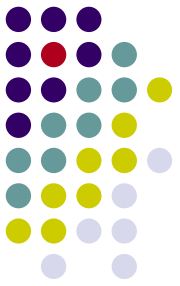
Being active

“I don’t have trouble hearing my children when I am alone with one of them. But when the kids are talking between themselves – I might just as well forget all about trying to keep up. It is getting harder and harder to step in or mediate when the kids start quarrelling.”

(33, moderate hearing and visual impairment)



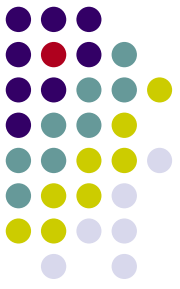
Energy



“Sometimes I can feel that I can’t be together with very many others ... I get tired when there are many people present, because of all that with my eyesight. I would rather do things I can relax with; I read a little, read my e-mail, watch TV in the evening. I’d really like going for a walk in the woods on Sundays, but I don’t have the energy. I have to save my energy for the next workday.”

(48, deaf, moderate vision impairment)



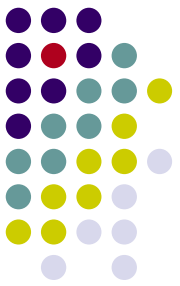


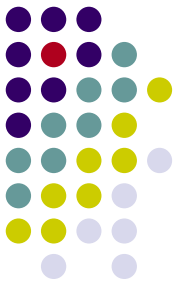
Using an interpreter

“I got a lot out of that, and my family was so impressed...We have always had to write to each other, and now we could just talk via the interpreter. Earlier, the kids might also interpret, but they didn't have to this time and we were able to communicate via the interpreter. It was nice to be able to keep up, even with the speeches that were made.”



GROUP WORK





Questions to discuss

Group 1

The participants demonstrate great creativity when looking for ways to be able to participate. The many ideas for coping with challenges in daily life must be shared between them – what is the best way to accomplish this?

Group 2

How could the professionals' advice to a greater extent be based on the deafblind person own experience of her situation?

Group 3

How can it be explained that the majority of the deaf deafblind people are in work, while this is not the case for the deafblind with a hearing impairment?

