

Commonalities across deafblindness – learning from each other

An edited version of the final plenary at the European Conference on Deafblindness in Lille, presented by Ole E. Mortensen on behalf of the Scientific Committee.

When the Scientific Committee started out the work for this conference we quickly decided to address the issue of the distinction that exists between acquired deafblindness and congenital deafblindness. The two 'sides of deafblindness' have been developing over a number of years now, but without much interaction. We believed we should focus on the potential synergy between the two that has not yet been explored satisfactorily.

Conferences on deafblindness have always had to deal with this duality, since Dbl is an organisation for professionals representing both groups of deafblindness. There has always been a sort of sibling rivalry: "If they get a plenary, we want a plenary. If they get 10 workshops, we want 10 workshops."

Let's focus on what unites us!

Therefore, the Scientific Committee wanted at this conference to focus more on what unites the groups rather than what separates them.

The following represents the Scientific Committee's thoughts on this topic as interpreted by me. I will take my starting point in the work and the discussions we have had in the committee and add my own thoughts on it.

We are not trying to eliminate differences or pushing towards finding commonalities that are not there. But we on the Scientific Committee do feel that there are



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commonalities, or at least that there might be commonalities, that we have not found yet because we have not been looking for them. It seems a pity if we do not make the effort to explore, what we might gain from a closer collaboration between the two groups.

Many different individuals

Deafblindness is a professional field which encompasses many different individuals with very different age, competences, impairments, situations etc. However, they all share one important feature: They can't see nor hear very well. Apart from that, do they have anything in

common?

Many say that the commonalities between acquired and congenital deafblindness are few and hard to find. There may be several reasons for this.

Highly specialized professionals

One reason is that we, as professionals, are so specialized today – and we love to feel highly specialized. We are specialists in communication development, in orientation and mobility, in old age deafblindness etc. This specialization is part of our professional identity and of the way we see and perceive ourselves.

This has been emphasized by the fact that over the years we have had to advocate for deafblindness itself being something special – a unique disability different from hearing impairment and vision impairment and with an impact that is bigger than the two put together.

We are all very much immersed in our tradition and understanding of ourselves as highly specialized professionals in a small and very specialized field. Still, we have no problem gathering inspiration and knowledge from fields sometimes far from our own and taking part in inter-professional learning.

But as soon as it comes close enough to our own field that we see similarities, we start to pay more attention to the differences instead. The differences stand out and seem larger than they are because there are similarities as well. Danish neuroscientist Kjeld Fredens puts it this way: “The more we know about a subject, the harder it is to think new things!”

Similarities

So let’s try and focus on the similarities. What can we say we have in common?

First and foremost, both acquired and congenital deafblindness create massive problems in relation to communication, access to information and mobility.

But there are also a number of other themes that we find on both sides. This has also been seen during this (Lille) conference, where we in the Scientific Committee have set out to find them. All nine of us have only attended workshops in the other field than the one we work in normally – just to see what, if anything, we would recognize from our own experience.

When comparing our notes from the workshops with what we have heard during the plenaries, we get a list of themes that are clearly relevant for both sides. Among the themes on this list are the following:

Denial (in the person, family or society) shame, pride; Need for empowerment; Isolation; Deprivation; Danger of being disconnected; Helplessness; Aggression; Withdrawal; Being labelled; Being met with low expectations (abilities are often underestimated); Feeling of being different; Reactions in and consequences for siblings to people with deafblindness; Both the need for and the threat against quality of life; Need for tactile and alternative communication; Need and wish for pushing the limits; Neither persons with acquired nor congenital deafblindness necessarily see themselves as deafblind first – as opposed to what most other people do.

And as for the services available for the groups there are also a number of similarities, such as the lack of knowledge and awareness; Need for a person centered approach; High ethical standards necessary in professionals; Need for good staff training; Use of various assessment tools; People with acquired deafblindness are often considered experts in their own life. So should people with congenital deafblindness. But how do we find a way for them to express this?

Similar problems, different solutions

It is obvious that even though two persons may share a similar problem, the approach to solving it may be completely different

depending on the person’s situation and disability. A 10-year-old deafblind child born two months prematurely with a number of neurological and maybe physical problems in addition to the sensory impairment have problems with communication, information and mobility. These problems are similar for the 88-year old blind woman when she loses the last of her hearing. There is a commonality in the characteristics of the problem, but we need to use different approaches for solving it.

Jacques Souriau, the president of the Scientific Committee said it beautifully, I think:

What is unique to deafblindness is this question: “How can two minds connect in a world where most everything happens through vision and hearing.”

Some commonalities in deafblindness are shared with many other groups of people with disabilities. Other commonalities are shared with all human beings. What makes sense for us here is to look at the commonalities in practice, since that is what these conferences are aimed at: improving the practice of the participants.

Direct and indirect learning

Learning comes in many shapes, colors and form. Sometimes we do not even know from where our knowledge comes – it just is there.

Let us take a look at the process of transferring knowledge at conferences, since this was the topic here in this conference. There are two ways of transferring knowledge into own practice:

- Direct – as in “this approach or intervention can also be used by me”

- Indirect – as in “this way of thinking can help me think up my own approaches or interventions”

The information presented at workshops at our conferences often is: “this is what we have done” or “this is what we have found out”. Our target group or intended audiences at workshops are most often much like ourselves with similar backgrounds, who face similar challenges and tasks, and who may use the information presented directly in their own setting.

This is a ‘copy-paste’ approach. Not much translation is needed here. An art project for congenitally deafblind children from Holland or a network group for men with Usher 2 from Denmark can be put in practice the week later in Italy.

It gets very practical and relevant – but it limits the interest to colleagues in similar situations.

Translating knowledge

However, we rarely try to take our experience and knowledge and the learning points one step up to a more general level and thus remove us slightly from the specific situation in which the knowledge has been developed.

This is what would make it relevant for others than your own colleagues as well. This was why the Scientific committee decided to have presenters from outside the field of deafblindness give lectures as plenaries on central and common important topics – but with no direct ties to deafblindness of any type.

The challenge here for us as participants has been to make the information part of our own knowledge base and implement it

in our own practice – translate the knowledge to something that is relevant for each of us.

255 work days

Workshops are a big part of the conference program in our field. There were a total of 82 workshops at this conference. 340 people have each participated in six workshops of one hour. This amounts to a total of 255 work days – an enormous investment of time.

Therefore it is essential to make the workshops really work. Instead of thinking about making sense to someone like ourselves, we should start thinking about sharing our knowledge with someone who does not share the approaches, the way of thinking, traditions and culture in our specific field.

And when we talk about knowledge sharing it is not enough to say, “our workshop is open to all, therefore I am sharing my knowledge”. It is not as simple as that. It requires something from both. It takes two to tango!

There needs to be a motivation from the person seeking the knowledge. This motivation is present, judging from the questionnaire survey that we did earlier in the conference. Around 90 % of the ones who answered said that they feel there is something to be learned from the other side of deafblindness. This is highly encouraging.

But there also needs to be a willingness to make the effort to share one’s knowledge. It has to be a conscious effort and it takes more work and preparation than if you are to tell your story to your own colleagues. On the positive side is that presenters will often gain by getting more and more varied feedback on your project to

take home, making it well worth the effort.

Out of the comfort zone

We have been conducting conferences and seminars the same way for many years now. It feels good, safe, and recognizable. But maybe it is time to get out of our comfort zone – like Svein Olav Kolset said in his presentation “An Exceptional Fellow” and start working on it.

The time is right for a change. The Norwegian psychologist Anne Nafstad, who has worked for many years in the field of deafblindness, recently said: “Professionals are becoming more and more individualistic. The culture is breaking up – the culture of a strong collective identity. It is being replaced by a new and more independent or autonomous approach questioning the prevalent practice and using new pedagogical methods from other fields.”

Maybe this will mean that the old way of doing things – which may include being sceptical towards ‘the other field’ along with a bit of laziness – will change into a culture that is more including and open and generous and innovative when it comes to knowledge sharing.

If Dbl and their members really want this change, here is a golden opportunity to promote this change which should then benefit the field of deafblindness as a whole.

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