

Opening remarks about the program

Tony Best, Chair Scientific Committee

What can you expect from the next few days? What is in the programme, and how can you make best use of the offerings?

Let me say something about how Dbl expects this conference, with its theme, to support its work, and then I'll tell you something about the content and what you can hear about in the various sessions.

The countries of Eastern Europe have made spectacular progress in the past few years in developing services for people with deafblindness. At this conference are over 40 colleagues from these countries – representing around 11% of this international gathering. This wouldn't have been possible just a few years ago, and so being here, in Romania, is a statement from Dbl both of our recognition of the achievements, and support of the further development of their services.

The theme

This brings me to the conference theme - *Local Solutions to Common Needs*.

This conference will take place at a unique time in our history – we are now becoming very clear about the needs created by deafblindness, and know that many of these needs are experienced whenever deafblindness occurs. At the same time, we have developed as a field, to a stage in which we recognise that there are many different and equally excellent ways of meeting those challenges and supporting people with deafblindness. These local solutions will take account of local culture – the ways families and communities behave and think and live. These local solutions will be excellent in their context, but this is a challenge for each one of us – they may also be relevant to other cultures, or regions. We can each learn and grow professionally by hearing about how colleagues in other countries solve the challenges that are common to all of us.

This stage of maturity, as a field of study, means we are not just consumers or subjects, but men and women with shared interests, common needs, and mutual obligations to each other. The recognition of excellence in different approaches has not always been part of Dbl's thinking. Let me tell you something of how Dbl has reached this situation.

Probably the first ever conference was in 1962 at Condoover Hall School in England. It was organised by parents - the people who at that time were the leaders - desperate to understand what was happening to their children- investigating, sharing, discussing, campaigning. And the main speakers at this conference were nearly all medical people. What was Rubella? How did it affect a young child? What could be done to treat it?

By 1971, there had been considerable progress and a conference, held at Perkins School for the Blind in USA, had many teachers in attendance. Experts were telling us how to teach and what to teach; we all collected the wisdom from these pioneers - people like Nan Robbins, Jan van Dijk, Joan Shields, etc.

By 1991, at the 10th International Conference in Orebro, Sweden we started having themes - this one was Quality of Life, and we came together to try to work out the best way to achieve this for deafblind people. And we had started thinking then about adults and not just children.

Of course, most of the work was still in schools and it was only in 1993, at the 3rd European conference in Potsdam, that the word 'deafblind' was adopted; we began to think of a group of people - children and adults - as the deafblind. Rodney Clark (former CEO of Sense) - here today - was one pioneer who helped create the title Deafblind International and was responsible for many developments at this time. Dbl responded further through developing Networks - the special interest groups that brought together colleagues with similar interests and concerns. William Green, Immediate Past President of Dbl (also here today) was the person responsible for this success, and many other developments.

In 2003, in Canada, the theme of the 13th Conference was '*communication is the key*' and, along with many other topics, there began an effort to better understand communication, and to help achieve it - seeking out the solution, the best way. Stan Munroe, again here today and currently editor of Dbl Review, was one of the Canadian pioneers, who led the organisation of that conference, along with others.

In Australia in 2007 the theme of the 14th Conference was *isolation* focussed on removing the isolation so deafblind people could be part of mainstream rather than being in the backwater. That conference focussed on how services, training, legislation can be organised to ensure the best services for these isolated individuals.

These themes, and the changes in thinking at Dbl conferences, has been reflected in our terminology over the past 40 years: deaf/blind children, the deafblind, deafblind people, people with deafblindness.

So we come to today - but before that I must apologise that in this quick summary, I have not mentioned so many other conferences that were incredibly influential and successful, nor, more importantly, many people who had a significant impact on our field. Never doubt that it is those individuals who have changed the world; in fact it is the only thing that ever has, as Margaret Mead the famous anthropologist so aptly said.

So we come to today, May 26, 2015 when we believe that we understand many of the needs created by deafblindness; but recognise that there is not one solution, but many equally excellent and successful solutions. I believe in the future that this concept may be an important part of our thinking.

The content

What will we learn about at this conference? At this conference 24% of the presentations will be primarily about children with deafblindness, while 28% will include consideration of elderly people and those who acquire deafblindness later in life. For the first time this group of people is a major concern for the field. Adults with congenital deafblindness are the subject of 23% of the presentations, reflecting the continuing interest in this sector.

There will, as usual, be large number of presentations on 'communication'. These cover a wide range of topics, but two stand out- '*tactile linguality*'- the development of language using tactile communication, and '*dynamic assessment*' a form of assessment through intervention. Some of you - our leading experts and practitioners - will be talking about these concepts.

Amongst other topics there are several on leisure activities and on mental health (e.g. coping emotionally/risks/ 'early' intervention on diagnosis) – a new development. There are also talks about digital technology and how it can support people with deafblindness.

Staff development is, as usual, a popular topic but this time there is a changed emphasis on e-learning and on-line training. In part this is making good use of new and emerging technologies, but also a reaction to the needs of isolated professionals working in non-specialist centres. This is where the majority of children and adults now receive services. I make one observation. In many countries specialist medical services are being concentrated in specialist hospital centres to improve effectiveness and efficiency, but the education and social fields are developing fully inclusive and local services - a formidable challenge for a low incidence and complex disability such as deafblindness.

Two other new trends are apparent. Firstly the development of user-led support, with people with deafblindness integrally involved in the design, development and delivery of services ("nothing for us without us") for example, in peer mentor schemes, service evaluation by participants, establishing civic rights/ entitlements, strategies for taking control.

Secondly, there is an increased emphasis on research-led developments rather than the simple exchange of experiences. For example, studies to evaluate impact of a service, to compare different approaches, to discover what aspects of staff training make a difference, surveys to establish key needs, and so on. At the same time, the conference will see the launch of a new Network - on Research, with the aim of ensuring future work on evaluation is coordinated and focused in key unknowns.

Lastly, the trend for examining multi-disciplinary working is continuing, with therapists, medical staff, family members all considered part of the team around the person with deafblindness. However, only a few people with these backgrounds are attending as participants. Perhaps this is something for us to think about for the future?

Your approach

So, finally, how do we make best use of these offerings?

Think of entering a forest. I'm just moving from a house by the sea to one in the middle of woodland. And on entering a forest I realise we have altered perceptions; the horizon changes and we may become more aware of smells or touch or temperature. It is a strange place and in northern Europe forests have fascination – magic or scary – this is where folk tales began - the wolf, the witch, the gingerbread house, and the poor woodcutter.

I want to suggest that you think of this idea in relation to this conference. It is a basic human desire to reach out, to seek the unknown; so be willing to explore, consider the strange, the scary, the magical.

Don't assume that strangers and strange ideas are hostile. Here at this conference I suggest we should think of being hospitable, of welcoming to new ideas. And this means being open to the curious and the dangerous.

But danger and risk is not, I suggest, a sufficient reason for not being hospitable, and we may even experience the great delight of falling in love - the excitement of what might be - when we meet a new idea.

So, that is our conference, a place to seek out the unknown, to risk falling in love, to consider *local solutions to our common problems*. It would be good if we could each discover a new idea; it would be great if we could take home something we could develop and put into practice; it would be wonderful if, by accepting something from a stranger, the people we work with receive a better offering that enhances their lives. I sincerely hope you each have a successful conference.

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