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THE KEY TO COMMUNICATION IN RESEARCH AND SOCIETY

Innovative communication methods for people born both deaf and blind

A whole new world

President of Deafblind International, Gill Morbey sheds light on the disability deafblindness and the importance of raising awareness…

The combination of a sight and hearing impairment (deafblindness) is a disability with little understanding. In the UK alone, there are currently around 250,000 deafblind people, yet public awareness of what deafblindness is can be low. Deafblindness affects a person's ability to communicate, to access all kinds of information, and to get around.

Deafblindness is not just a deaf person who cannot see, or a blind person who cannot hear. The two impairments together increase the effects of each.

The world around us is organised around hearing sighted people, and this can present many challenges to a deafblind person. If you have little or no sight and hearing, learning to communicate, to be understood, or hear other people speaking is very difficult – and can be isolating.

In a crowded room a sighted hearing person sees who is talking to them and hears what they are saying. A deaf person may use their vision to lip-read what others are saying. If an individual also has sight impairment, they will not be able to lip-read and indeed are unlikely to know that someone is even trying to communicate at all.

Other senses can accommodate for the impairments to some degree. The senses of touch, body awareness, balance, taste and smell can be used to access information, develop communication, and help to understand the world around them.

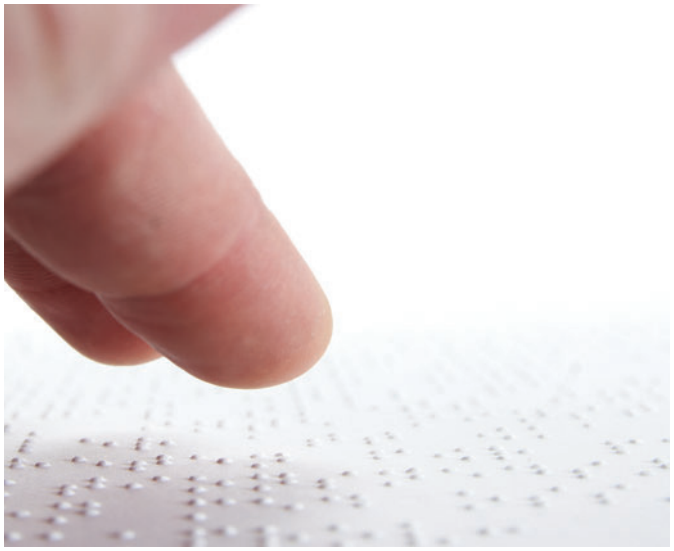
Sadly, for many deafblind people, sight and hearing loss are only part of the picture:

- Sensory loss is known to be prevalent in people with learning disabilities;
- A child may also have difficulty processing information they get from their sight, hearing and touch, and be multi-sensory impaired as a result;
- Many physical disabilities can make communication and mobility difficult;
- Deterioration of sight and hearing is just one aspect of getting older that affects daily life and the ability to be independent.

Many people who are deafblind have rare and varied causes of their sight and hearing loss. They may experience other disabilities and health conditions, meaning that diagnosis and the identification of sight and hearing loss are difficult.

Causes of deafblindness vary across countries. They can include infections during pregnancy, prematurity, rare syndromes, such as Usher and CHARGE, illness and accidents, and sensory loss in old age. In the UK vaccination has almost eradicated rubella, however in some parts of the world the absence of vaccination programs such as MMR means that children are still being born with the entirely preventable Congenital Rubella Syndrome (CRS).

However, whatever the cause, the common thread is people have huge difficulties understanding and processing communication and information, and individuals will have a unique set of needs that require specialist support. Trained professionals who understand deafblindness are key. A practitioner with knowledge of deafblindness can identify and assess hearing and sight loss in a child who 'presents' with complex and multiple needs. Once deafblindness has been identified, communication systems involving touch can be intro-



duced. An elderly person who appears to be confused can be supported in mobility through the use of tactile indicators, and in hearing loss through a range of amplification aids. Sometimes the support needed is complicated involving a range of sophisticated tactile communication techniques. On other occasions it is simpler – for example, a vibrating door alarm can quite literally link an elderly person to the outside world.

I am proud to be the President of Deafblind International (DbI) which, for more than 30 years, has been promoting services for deafblind people around the world. We bring together professionals, researchers, families, deafblind people and administrators to raise awareness of deafblindness.

DbI comprises of over forty major deafblind organisations from across the world. Countries include Australia, India, America, Canada, most European countries and many African nations. Sense and Sense International contribute and support the work of DbI in a number of ways. Along with our international colleagues we campaign and inform on all matters related to deafblindness. This varies from advocacy where important achievements have been made. For example, having deafblindness recognised as a unique disability in individual country legislation results in entitlements to education and social care support for thousands of individuals. Many of us also provide direct projects such as vocational training for young people in Africa, family support in India and the next World DbI conference in Romania in 2015.

In recent years, technology has also helped to improve the lives of deafblind people across all ages. From computing aids such as screen readers and Braille displays through to sensory toys for children, these items can play a key role in helping deafblind people live independently, and to make the environment more comfortable and enjoyable. Advancements in communication technology have had a huge impact on deafblind people. At last, through computers and tactile displays, deafblind people can be supported in employment and complex tasks through to simple but important things such as directly contacting friends. More advances in technology have the potential to make real life changes for people who are deafblind and disabled.

As shown above, deafblind people can face significant challenges on a daily basis. However, with support, advice and guidance people can and do achieve great things. It is important to celebrate this and also recognise the everyday achievements that enable people to be part of their families and local communities, doing ordinary things that we too often take for granted.

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Communication research in relation to daily practice

In collaboration with the Kentalis Deafblindness Center of Excellence, seven PhD students from the University of Groningen, under my supervision are attempting to create strategies and techniques to help people with congenital deafblindness to communicate at higher levels, by sharing experiences and emotions with their daily carers.

Our research group is concentrating on real life settings and examples to find the key for unlocking effective means of communicating for deafblind individuals.

The PhD studies focus on inter-subjectivity – a conceptual construct used to describe the interactional relationship between individuals. Within the concept, communication is described as having certain layers. At the bottom is basic communications – asking for a drink, for example – with subsequent levels involving higher level and more in-depth and abstract communication. These further levels often involve greater use of symbolic communication and language. The research program explores the first and second levels of intersubjectivity.

Tested on both children and adults, one PhD project involves understanding and evaluating the way carers recognise the emotions of their clients and how to change their behaviour accordingly.

In another study a student is investigating how the carers learn to understand and process the various sounds and noises of the deafblind person. A sound or action can have many different meanings, inevitably defined by the context in which they are delivered. The study aims to create new approaches to the problem which will hopefully enable deafblind people to be more spontaneous and communicative and in-tune with their carer.

Additional studies feature practical approaches to develop interventions that will allow people with deafblidness to use tactile initiatives, gestures and signs to aid communications and a process for coaching carers into recognising the emotional impressions of their deafblind persons.

One particular PhD study is attempting to develop a set of guidelines to facilitate the completion of a dynamic risk assessment of a deafblind person. The belief is that, should their condition be more accurately and appropriately diagnosed, interventions and treatments can be provided that are more applicable, resulting in happier and more engaged persons.

CASE STUDY

Leon's case is an excellent example to demonstrate how a communication coach with the help of video analysis can support a whole team of caregivers. Leon is an adult man of age 22. Before the intervention his 12 caregivers (in the group home and in the day activity center) requested coaching because they felt unsure how to attain mutual contact, how to deal with the negative emotions of Leon and how to increase his positive emotions by sharing and talking about these emotions.

Talking about and sharing emotions with Leon takes place without words, because Leon can not speak. He is talking with his whole body. To share his laughing can be expressed by shaking, rubbing or tweaking Leon's hand while laughing together. Letting Leon feel that you as a companion really share his positive emotion and really understand him. Showing video fragments about these kind of examples and discussing these individually or in a group with the caregivers, gave them new insights and skills to communicate with Leon.

The intervention took 30 weeks, after which a considerable increase in Leon's positive emotions, as well as in the sharing of emotions between Leon and his caregivers was demonstrated. The caregivers indicated it was easier to share positive emotions than negative emotions.

This case study showed that it is possible to improve the sharing of emotions in such a way that an adult man born both deaf and blind learnt to express his feelings and thoughts better and that his negative emotions and behaviour disappeared almost immediately after introduction of the intervention.

EXPERT PARTNERSHIPS

The studies have thrown up some fascinating insights that have reinforced my original belief that carers find it difficult to focus on interaction with their deafblind clients, whilst at the same time concentrating on the content of their sounds and actions. In essence, a level of communication is being lost as a result of a lack of communication perception – a situation which can be improved by specific coaching. It is insights such as this that seem likely to improve existing and future strategies for communicating with people who are deafblind.

It is hoped that once completed, the research projects will provide an empirical and clinically rigorous assessment along with treatment solutions for people with congenitally deafblindness. The practical application of the research is obviously something that has been of interest to the private sector, with the Royal Dutch Kentalis – an organisation in the Netherlands who provide diagnostic treatment and specialist care for the deafblind – funding a number of the projects.

In addition to financial support, the researchers are able to use the facilities and expertise of the Deafblindness Centre of Excellence owned and managed by Royal Dutch Kentalis. This state-of-the-art facility is an internationally renowned centre for those with congenital deafblindness, providing researchers with access to the best equipment and experts in the country.

Additional partners, including Bartimeus, ZonMW Insight, and Royal Vision, two Dutch organisations specialising in care for the visually impaired, are supporting the projects. With such important and influential partners, knowledge transfer can be optimised.

KENTALIS DEAFBLINDNESS CENTER OF EXCELLENCE

The aims of Kentalis Deafblindness Center of Excellence are high quality support in assessment, education and healthcare for people with deafblindness throughout the whole country. That is achieved based on evidence based methods, individual attuned to every client with deafblindness, in good collaboration with national and international partners.

Innovation and research are very important. The big advantage of this good collaboration between University of Groningen and Kentalis is that evidence based methods can be implemented immediately in practice and that new questions raised in practice can be scientifically investigated.

The main objective for the short term is to start a communication consultancy system in the Netherlands or even at a European level. This means that all the people with deafblindness will get a consultant who is an expert in deafblindness, and in particular communication methods. Such a consultant will facilitate psycho-social support and communication for the person with deafblindness and will update and train the team around the client. They judge what is needed and coordinate this support including communication coaching.

We will set up an education program for consultants and communication coaches with a specific accreditation and do this in close collaboration with the Deafblind International Communication Network and colleagues in Denmark and Norway, where such a system is already in place.

However, a lot of funding is needed in the coming years to set up this system and to run an excellent education facility for communication coaches and consultants, in the meanwhile to perform a survey study, because we still don't know how many people there are in the Netherlands with deafblindness.

DEAFBLIND INTERNATIONAL COMMUNICATION NETWORK

International there is also interest for research. In collaboration with the DbI Communication Network we run a Master's program on Communication and Deafblindness now for 7 years. We delivered already 40 graduated masters all over Europe and two in Africa. These young people are setting up new networks on professionalising caregivers in German speaking countries and in an alumni network connected to the University of Groningen. The lecturers for this program are experts in the deafblind field and come from 6 different European countries; Norway, Denmark, UK, France, Belgium and The Netherlands. They supervise the students and attune to their individual needs and cultural differences.

The Master's degree in Communication and Deafblindness is a unique program (60 ECT's) during which students acquire theoretical and methodological skills. These skills will enable them to analyse communication in situations that are specific to the field of deafblindness. They will learn to apply this knowledge in the contexts of research and intervention.

The program starts with specialised theoretical themes and an introduction to communication with people with CDB. This is followed by the masters' project consisting of 3 parts: Coaching and support in methodology; practical training; and, learners report, research and thesis. To complete the program the students have to link their master project to overall theories and models.

What is good about the program is the very short stay of the students in Groningen. While the program lasts for one year, the students only come to the University of Groningen during the first four weeks of the first semester. The four weeks are very intensive for both the students and the lecturers. After the first two days "we are like a family".

This group cohesion, formed during the first weeks, is essential for the rest of the program. After these four weeks, the students go back to their home country and conduct their master thesis research. The supervision of the individual theses is performed by the lecturers only by email and skype. And every year in March we organise an interesting seminar on deafblindness for all students and graduates

INTEREST IN STUDENTS AND YOUNG RESEARCHERS

It is not a problem to get new young researchers for this unique area. The students who study deafblind education and healthcare are very motivated. It is like in other fields of persons with disabilities, students are very motivated or they are not motivated at all. Also my PhD students are very dedicated and they want to do something important for the field. They are very conscious that this is a pioneering scientific field which is very special, and that everything they investigate not only contributes to science, but also to the clinical field.

I am very happy that I have some students now from linguistics, who did the International Master Communication and Deafblindness at the University of Groningen. These young researchers are very interested in how people with deafblindness learn language. They see that in clinical practice the focus is more on quality of life and wellbeing then on language input and language learning. I am convinced that with these researchers I can in the coming years put more emphasize on language acquisition based on good interaction and a good relationship. Collaboration with sign interpreters from deaf education is a necessity.

Furthermore I want to expand our research program for high quality communication by internationally focusing on testing the theory of tertiary intersubjectivity and language acquisition and follow cases in different countries for several years in collaboration with European clinical institutions and other universities. Once again more funding is needed for the development and investigation of these innovative methods.

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