Professor Marleen Janssen outlines how her team of five PhD students is breaking new ground in unlocking communications techniques for those with congenital deafblindness.

Could you shed light on the term deafblindness?

Individuals with congenital deafblindness are born with serious visual and auditory impairments, which influence all aspects of their lives, particularly access to information, communication and language. These people experience dual sensory loss before they developed a language. There are thousands of people with congenital deafblindness in The Netherlands, many of whom are not diagnosed yet because they are in facilities for people with intellectual disabilities and expertise on deafblindness is still very scarce.

I may be the only professor in the world to have a special Chair solely focused on communication in people with deafblindness.

Through what means do those with deafblindness communicate and what problems does this method pose?

Persons with deafblindness don’t use words to communicate, because most of them cannot speak. Their methods of interaction and communication can be described as ‘conversations with bodies’. Participation in these ‘bodily conversations’ requires a high level of sensitivity, special insights and considerable skills for the hearing and sighted caregivers. You can imagine that in daily practice mutual misunderstandings easily can lead to severe emotional problems and challenging behaviours.

Daily communication with their caregivers is extremely important for the mental wellbeing and social functioning of people with deafblindness. However, in practice, persons with deafblindness and their hearing and sighted caregivers experience serious difficulties in expressing their intentions and creating mutual understanding.

How will your research projects help to improve communication methods for deafblind individuals?

In my research programme we try to develop high-quality communication methods in which caregivers learn new insights and skills in such a way that persons with deafblindness can share their ideas and thoughts with others about all kind of topics relevant within and outside the direct ‘here and now’ context.

The five running PhD-projects are focused especially on meaning-making. Every project highlights different aspects of the first two layers of intersubjectivity and is performed with children and adults.

What theoretical basis underpins your research?

Originally, my own PhD project was focused on fostering harmonious interactions and affect-attunement in deafblind children, the first layer of intersubjectivity. Interaction was defined as ‘the process in which two individuals mutually influence each other’s behaviour’ and communication as ‘a form of interaction in which meaning is created'.
In the past, those born both deaf and blind were consigned to a life of limited or non-existent communications – but a research team based at the University of Groningen in The Netherlands is developing new techniques and strategies to help unlock their ability to communicate.

The five PhD projects on high-quality communication coaching on a more permanent basis. Only with the help of a communication coach, caregivers can be trained in a way and on a level that the person with deafblindness can develop his or her potential for communication.

Caregivers very much enjoyed discovering their own strengths and weakness with the help of video analysis and feedback. They learned quickly when they saw themselves on video and were able to adapt their approaches. All caregivers learned from these interventions, although there were individual differences. In all cases positive effects for the persons with congenital deafblindness were found with also very interesting individual differences.

How will your research evolve in the coming years?

The five PhD projects on high-quality communication will finish in 2013. These studies will deliver 20 articles in international peer-reviewed journals and five dissertations. I hope that these publications will support policy makers and managers in the clinical field in providing them with the necessary evidence base for new communication methods to implement.

Furthermore, I want to expand the research program for high-quality communication internationally, focusing on testing the theory of tertiary intersubjectivity and language acquisition and follow some cases in different countries for five years in collaboration with European clinical institutions and other universities.

by the use of utterances that are perceived, interpreted, negotiated and elaborated by the communication partner. It was then hypothesised that smooth interactions are indispensable to develop high-quality communication.

What will the future hold in terms of real-life improvements for clients?

For me, this means that caregivers need intensive communication coaching on a more permanent basis. Only with the help of a communication coach, caregivers can be trained in a way and on a level that the person with deafblindness can develop his or her potential for communication.

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The meanings and symbolism of these gestures is unique from client to client and their interpretation requires considerable skill of a carer. Misunderstandings are frequent and can give rise to serious and severe challenges, which can manifest themselves in emotional and behavioural problems.

The team hopes to develop high-quality communication methods which will enable caregivers to learn new skills and techniques to facilitate greater communication with clients who are deafblind.

AN INTER-SUBJECTIVE APPROACH

The project members are calling upon previous theoretical and empirical research to base their projects – some of which was completed by Janssen herself. The 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 – turn-taking, for example – with subsequent levels involving higher level and more in-depth and abstract communication. These further stages often involve greater use of symbolic communication and language. The research, conducted entirely by five PhD students under Janssen’s direction, explores the first and second levels of intersubjectivity.

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THE FIVE SENSES are the gateway for humans to interpret and interact with the world around us. But for those born with congenital deafblindness, also known as dual-sensory loss, communication with the world around them is difficult. A diagnosis of congenital deafblindness involves the recognition that a client has both serious visual and auditory impairments. The causes of deafblindness in newborn children include Down’s Syndrome, CHARGE (a rare condition affecting the whole body), rubella or excessive drug or alcohol use during pregnancy. Whatever the cause, being born with the condition means that individuals struggle to engage with communications and language, with the combination of senses affected posing a unique challenge in communicating and interacting with the outside world. The challenge is twofold, affecting not only the client but also those who interact with them, including carers and medical professionals.

A unique problem demands a unique solution. Professor Marleen Janssen and a team of five PhD students are, in the world’s first and only study concentrating solely on congenital deafblindness, attempting to create strategies and techniques to enable persons with deafblindness to communicate at higher levels. Concentrating on real-life examples, the research could go a long way to unlocking an effective means of communicating for deafblind individuals.

WINDOW TO THE WORLD

In engaging with others, the majority of people with deafblindness do not use language and are unable to speak. Instead, their method of interacting with the world is described by Janssen as ‘communication with bodies’; essentially, using bodily movements, postures and hand gestures to express feelings, meanings and desires.

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As a result, communication with deafblind individuals rarely moves beyond the superficial level, which makes more abstract communication difficult. It is in this field that Janssen and the PhD students are working. By studying and understanding communication
INTELLIGENCE

FOSTERING HIGH QUALITY COMMUNICATION IN PEOPLE WITH CONGENITAL DEAFBLINDNESS

OBJECTIVES

The main objective is to develop and evaluate innovative methods to improve quality of communication between people with deafblindness and their caregivers. This is important for the clients’ mental health and social participation in society and also because these methods can be used for people with other (communicative) disabilities.

KEY COLLABORATORS

Royal Dutch Kentalis • Bartimeus • ZonMW Inzicht • Royal Visio • Deafblind International Network on Communication • Professor Dr J.M.A. Riksen-Walraven (Radboud, University Nijmegen) • Professor Dr S Bruce (Boston College, USA) • Professor Dr S Bashinski (Missouri, USA) • Professor Dr C Schuengel (Free University, Amsterdam) • Professor Dr Y.R.M. Bastiaanse (Linguistics, University of Groningen) • Professor Emeritus Dr J.P.M. van Dijk (Kentalis, Sint-Michielsgestel)

FUNDING

ZonMW

Royal Dutch Kentalis

Bartimeus

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MARLEEN JANSEN has served as Professor (Tenure Track) at the Department of Special Needs Education and Youth Care at the University of Groningen since 2008. She is Chair of Congenital and Early Acquired Deafblindness, sponsored largely by Royal Dutch Kentalis, where Janssen worked previously for 25 years.

process for coaching caregivers into recognising the emotional impressions of their deafblind client.

MORE ACCURATE DIAGNOSIS

Interestingly, often people with deafblindness are misdiagnosed as being autistic or intellectually disabled when this may not actually be the case. This misdiagnosis can mean they receive inappropriate treatment or, in more serious cases, no treatment or support at all.

One particular PhD study is attempting to develop a set of guidelines to facilitate the completion of a dynamic assessment procedure for deafblind persons. 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 clients.

EXPERT PARTNERSHIPS

The studies have thrown up some fascinating insights that have reinforced Janssen’s original belief that caregivers find it difficult to focus on interaction with their deafblind clients whilst at the same time concentrating on the content of their utterances 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 communication coaching. It is insights such as this that seem likely to improve existing and future strategies for communicating with the deafblind.

It is hoped that, once completed, the five projects – and Janssen’s original research – will provide an empirical and clinically rigorous assessment and treatment solutions for the congenitally deafblind. 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 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 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.

HOPE FOR THE FUTURE

The ultimate aim for Janssen when creating a new national treatment system for those born deafblind is to provide clients with a consultant who can support their psychosocial and communication needs and offer ongoing training and development for carers. It is a challenge that will demand the training and development of many coaches as well as a large injection of funding to implement.

In a country where accurate statistics on the number of individuals suffering from deafblindness are not currently available, this may be a long journey. Nevertheless, Janssen’s enthusiasm remains undimmed with plans in place for a large number of new PhD projects and collaborations across the world in the future. For deafblind clients and carers longing to communicate, her work is welcomed news.