university of groningen

Royal Dutch Kentalis

THE KEY TO COMMUNICATION IN RESEARCH AND SOCIETY

Innovative communication methods for people born both deaf and blind

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Social care – fit for purpose

Richard Kramer, Deputy Chief Executive at the Deafblind charity Sense highlights the importance of social care for deafblind and disabled people…

Last year was incredibly challenging for many deafblind and disabled people. Changes to the welfare system including the transfer from DLA to PIP and ongoing issues with Work Capability Assessments and Employment Support Allowance have left many struggling financially. But the biggest struggle for many is getting the support they need from social care.

When we talk about social care it is essential that we don't just limit our thinking to helping people get washed and dressed or cooking meals. This kind of support is vital for many, but it isn't where it ends. Deafblind people will often need a much broader range of support; communicator guides to help them move around safely and have the opportunity to get out the house or perhaps the support of an interpreter to help communicate with friends are just 2 examples. Social care can support many different aspects of a person's life, from basic needs to ensuring that they have a social life and the opportunity to make and maintain friendships. This broader support is essential for an individual's emotional and physical wellbeing and should not be overlooked.

At the end of 2014 the Care Act was introduced, a landmark piece of legislation for social care. For the first time it looks at both health and social care and crucially takes in to account the general wellbeing of those that need social care. However, there are several barriers that might prevent it fulfilling this.

Eligibility is a long term issue in social care. This means that those who are considered not to have a high enough level of need, will not receive any support. All too often the bar is set far too high. In fact a recent study by London School of Economics (LSE) showed that there are 500,000 people who would have got care in 2009 but are no longer receiving it. Their needs may not have not changed, but the threshold at which social care is set means that people can't get into the system of social care in the first place.

This rationing of social care is a false economy. Social care has a central role in delivering cost effective, early intervention services. As people struggle on without the care they need they might become more susceptible to falls, or struggle with nutrition and a healthy diet, leading to hospital admissions and an increased burden on the NHS. This winter overcrowded A&E department's, hospital waiting times and delays in hospital discharge have remained high on the media agenda. Without a social care system fit for purpose this will continue.

One of the main barriers to the Care Act fulfilling its potential is funding. If central government does not release enough funds to local authorities to fully implement the Act it will be built on sand. The NHS is high on the public agenda, and it will be a key issue for the general election in 2015. However, social care will not feature as highly and as a result, securing the funding will always be a challenge.

As the population ages the number of people who rely on social care for support will increase. This makes it an issue for us all. We need to get social care right for the future and in order to do this it must be higher up the political agenda.

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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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Do you understand me?

Findings on four effective communication interventions for children and adults with congenital deafblindness

Children and adults with deafblindness express themselves and understand others without a formal language, and using other communicative acts that may consist of bodily movements, tactile cues, postures and natural gestures (Goode, 1994). The hearing and sighted caregivers find it difficult to participate in this world of proximity and touch. As a consequence, this situation can lead to severe challenging behaviors in the person with deafblindness, and a stagnation of their communication and language development. Most people with congenital deafblindness get stuck in pre-symbolic communication and never learn to express their thoughts in a more abstract way outside the concrete here and now. Caregivers, families and clients themselves express a huge need for intervention programs to improve interaction, communication and language with people who are deafblind.

LAYERED INTERPERSONAL COMMUNICATION

In his framework of 'innate intersubjectivity' Trevarthen (2001) describes interpersonal communication as the ability to share meanings from a certain 'alter-ego' awareness. From the awareness their own intentions can be exchanged with another person, and that 'the other' is also somebody with their own intentions and purposes.

The intersubjective development in relation to communication and language develops in three layers, which are complementary to each other. The first layer is characterised by harmonious interactions and affect attunement. The second layer by joint attention and meaning-making and the third layer by symbolic communication and perspective-taking (Trevarthen & Braten, 2007). Our research group focused the last 5 years on different aspects of interpersonal communication and developed 4 successful intervention programs for persons with deafblindness.

COMMUNICATION-COACHING LIKE IN TOP SPORTS

Building on the Intervention program (Janssen, 2003), we developed different programs in which a communication specialist has a central role as a coach. The coach analyses a communicative situation, and on the basis of this, trains the caregivers, just as a coach would in sport. Caregivers watch a filmed segment of their own behavior in communication with a client and the coach gives comments: what can be done differently or better, which skills need more training, at which point can a new concept be best introduced, and in what way is the client motivated enough for a new concept, etc. The caregivers are also coached when they are working with a client. During this time they learn skills to help them consider the life history of a client, and to communicate as a team about their findings. In 4 different PhD-studies we saw that by coaching the caregivers, the children and adults with deafblindness made enormous progress.

AFFECTIVE INVOLVEMENT AND REDUCING NEGATIVE EMOTIONS: INTERVENTION 1

This PhD-study is focused on the essential role of affective involvement – mutual sharing of emotions – during interaction and communication. Affective involvement is crucial for wellbeing because it evokes positive emotions and reduces negative emotions. Fostering affective involvement based on the tactile modality can be challenging for caregivers. The Intervention Model for Affective Involvement (Martens, 2014) was developed to train staff members in how to communicate and interact with persons who have congenital deafblindness. Three intervention studies were performed, in which in total 9 participants with deafblindness, and 34 caregivers took part. This intervention program proved to be effective for: a) fostering affective involvement, positive emotions and reducing negative emotions; b) fostering affective involvement on the first and second layer of interpersonal communication; c) for children and adults with congenital deafblindness across different caregivers, situations, settings and organisations.

INTERSUBJECTIVE COMMUNICATION: INTERVENTION 2

The central aim of this PhD-study was, to evaluate the effectiveness of the intervention program on intersubjective development in three layers, for the support of communication between persons with deafblindness and their caregivers (Damen, 2015). In two studies, 6 participants with deafblindness, and 25 of their caregivers were involved. All participants demonstrated significant improvements on the first and second layer, and 4 of the 6 participants showed a significant improvement on the third layer. The most impact was seen during the communication phase in which caregivers were coached in their efforts to transfer and share meanings with the client. In a third study the intervention was evaluated on the effects for 9 caregiver-client couples (dyads). Positive outcomes were measured for all dyads on the first and second layer, and in four of the nine dyads for the third layer. It was further demonstrated that the level of intersubjective behavior was significantly related to the level on which the caregiver demonstrated intersubjective behavior. This study proved how valuable it is to support intersubjective communication.

TACTILE COMMUNICATION: INTERVENTION 3

The aim of this PhD-study was to foster the use of the tactile-bodily modality in caregivers of persons with deafblindness. Because carers of people with deafblindness lack the natural skills in tactile communicating, interaction and communication is hampered. An instrument called the Intervention Model for Tactile Communication was developed (Huiskens, submitted, 2015). Interventions based on this model are evaluated in 3 studies with 9 participants with deafblindness and 9 caregivers. The intervention proved to be very effective for the participants with deafblindness. They all improved the use of tactile initiatives and tactile gestures and signs. The impact on tactile initiatives and tactile gestures and signs increased in most cases, but unexpected outcomes were also measured. Suggestions for practice and further research were given.

INTERACTION AND BODILY EMOTIONAL TRACES: INTERVENTION 4

This intervention study, as part of a PhD-project (Bloeming, submitted 2015), was focused on fostering harmonious interactions and the use and recognition of expressions based on Bodily Emotional Traces (BETs) (Daelman, 2003). Because experiences and tactile impressions of daily activities are important for people with deafblindness, it was assumed that the support of caregivers on interactions and recognition of expressions should improve the quality of interaction.

The intervention was evaluated with 5 adults with congenital deafblindness and an intellectual disability and 8 caregivers. During the intervention all target behaviors increased: attention between the client and caregiver, confirmation by the caregiver, affective involvement, number of expressions based on a BET by the participant, percentage of these expressions recognised by the caregiver. During follow-up most target behaviors decreased but stayed above baseline level.

IMPLICATIONS FOR FURTHER RESEARCH AND PRACTICE

The outcomes of these studies suggest that much can be done for the improvement of interaction and communication of people with congenital deafblindness by supporting their caregivers. Communication-coaching proved to be effective in preventing challenging behaviors and negative emotions and proved effective in bringing the communication to a more advanced layer of intersubjective communication. However more international research is needed on the third layer of intersubjective communication and language in this area. Daily practice of communication-coaching on a more permanent basis proved to be a necessity.

To find out more, visit: www.rug.nl/staff/h.j.m.janssen and www.kentalis.nl/deafblind

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