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Connectedness

BETH MOULAM & EMMA GREEN

www.bethmoulam.com www.emmagreen.com.au



We have been friends for over seven years. Beth lives in England and Emma lives in Queensland, Australia. Our daily lives are many miles apart yet the friendship has been built through using technology, and spending time together, both when Emma has visited England twice and at the ISAAC Conference in Barcelona.

BETH - INTRODUCING 'CONNECTEDNESS'

Emma was in England in September 2013 for the CM conference in Leeds. We explored together our thoughts on connectedness.

As part of this process we looked at research into connectedness for young people who use AAC. We considered what connectedness meant to us and we shared some of the ways we have made it happen for us in our everyday lives. Everyone is connected, one way or another. Maybe as a Mother or a Father, a parent or a child. We could be a sister or a brother or a daughter or a son. Or just a friend to someone, a mentor, a sports coach or an employer. No matter who we are, we are all connected somehow.

So, what is 'connectedness'? The Longman Dictionary of English (2013) defines "connectedness as the feeling people have that they are members of a group in society, that they share particular qualities with other members of that group."

Some research implied connectedness is how people are connected by technology but there is little research specifically around teenage connectedness, and even less on AAC and connectedness.We failed to find any on teens and AAC. The research findings don't talk about communication but without communicaconnectedness tion couldn't happen.

Hallowell (1993) suggested connected-ness is that feeling we have of belonging, or the sense, no matter where we are that we are never alone. This comes from feeling welcomed by others in school, home, work and the wider community. The need for connectedness makes every human being want to make friends and build meaningful relationships.

Karcher (2011) used the Hemingway measure of adolescent connectedness to evaluate the social support teens get from peers, friends, adults and the media. This focused on achieving a sense of belonging through social inclusion



and attachment, the importance of safe childhood relationships to key family members and the close circle of support that we all need.

In her research, on loneliness and friendships with people who use AAC, Balandin (2013) suggests younger people who use AAC may feel lonely due to reliance on family and their difficulty forming relationships inside and outside of school. They worry about future limited work opportunities and have poor access to friends, sometimes, because of others being unwilling, or unable, to help them meet up with friends or be in an environment to make friends.

Balandin's work also suggests barriers to connectedness can be created by over-protective families. Developing relationships outside of the family takes time and there may be a lack of skill on the part of some communication partners to help people who use AAC. Frequently there is insufficient support to develop effective use of communication systems ongoing. A further barrier can be the lack of privacy experienced by those of us with complex needs.

Throughout the research there was proof that all teenagers who are connected at home, at school, socially and to themselves are more engaged, achieve more and stay out of trouble. Without connections all teenagers risk being seen as dysfunctional, so why should it be different when you rely on a communication aid to augment relationships and functional communication?

Having little or no natural speech can create huge problems including social isolation, mental issues and behavioural problems. These are exactly the same issues when there is a lack of connectedness for all teens. The main difference for those of us who use AAC is that it can be more challenging to explain we are lonely and to share we have things on our mind. In some cases we may act inappropriately if we can't explain what is wrong or it's a situation outside of our experience. If we need trusted communication partners to explain our concerns to, we also need trusted and well trained staff to support us to put it right.

Connectedness is not just about being asked questions and giving answers, we do not want to be passive communicators. It's about meaningful and purposeful conversations, having a functional dialogue, providing direction and the ability to be creative spontaneously. We want to ask questions, and go with the flow. This means we need well trained and supportive communication partners. Clearly there is a theme com-



ing through here, the right communication partners are vital.

Throughout our short lives, both of us have experienced low and high expectations from extended family, professionals, teachers and other staff. Some people have been incredible, others not so. We have met those who would ask a question but weren't able to wait for a reply. We both know people who made us feel good about ourselves and those who ignored us when we needed or asked for help.

EMMA - THE IMPORTANCE OF CONNECTEDNESS FOR ME

I use multi modal communication. I use a PODD communication book, a Tobii communication device with my eyes, my iPad, facial expressions, signs, gestures and vocalisations. I can also say a few words but only close family understand my natural speech.

On my Tobii I am learning to send text messages, emails, and use face book. My Tobii has been a great way to expand my network of friends and to continue to build on my connections.

I am currently studying at home, having my gap year and I am working to get ready for college, which I hope to go to next year. I hope to go to college and then to university, and eventually be an advocate for those who have no voice.

Being connected to family, friends, role models, therapists, educators and the other people who are supporting me on my journey is important to me. I work hard everyday to stay connected. I use my technology to communicate with people around me and further away. Some of the great connections I have are my family who are always there for me, and my friends. I also have some amazing connections with therapists, and some doctors who have known me a long time.

I like making new connections too. I have just started playing Boccia, and now I have a whole new group of people to meet with and communicate with. They are beautiful people who are patient and encouraging with my communication. I also have my Facebook network of friends that I am building.

With my friend Morgan we send each other text messages, we Facebook, we go shopping and go to movies and shows. I am so lucky to have good friends and role models in my life who include me, inspire me, understand me and motivate me to keep trying.

I have always had to work really hard to communicate and sometimes still communication breaks down, and it can be very frustrating for me, and for the people I'm talking to. Without strong connections in my network I sometimes feel angry, upset, annoyed, depressed, worried, lonely, disempowered, frustrated, uncomfortable and unmotivated.

However I am lucky, most of the time I have good connections. This makes me feel safe, terrific, comfortable, empowered, like I have some control, included and belong. I want connections with people and I want to stay connected. I never forget a strong connection, a bit like an elephant, I never forget.

Some things can be hard for me though, there are challenges to staying connected. It doesn't always work, but these challenges just make me determined to work harder. For example, I can't send text messages to my friends if mum doesn't put credit on my sim card for my Tobii, or if Facebook won't load properly, or when I have a new PA and she doesn't know how a PODD works.

It is always a challenge meeting new people, it can take a long time for people to learn how I communicate so that they understand me. This can be frustrating for everyone.

Also there are emotion and medication side effects, I get so excited, upset or angry sometimes, that I can't communicate as well as I normally do. Some of this is related to the type of CP I have, and some is related to the medication I have to take that keeps my epilepsy controlled. Even my yes and no can be hard to read if I am really upset, and if I get really worked up I have trouble even using eye gaze on my Tobii. So it's really important that I have back up methods to communicate.

I am working hard right now and it is so important that I do. I want to go to college and one day to uni. College and uni will be a big challenge and take me longer than most people because I have to write my notes using my PODD book or my communication device, using my eyes. I also get tired very quickly, and this means I can't work as hard or as fast as other people. I know that I need help with more things than most people, but that won't stop me.

I have hopes, dreams and aspirations. And I need strong connections around me so that I can achieve my dreams.

BETH - CONCLUSION

My experiences and feelings are very similar so I am not going to repeat what Emma has said. I do want however to expand with one example of building new connections. Emma mentioned her dream of going to University. I have finished my first year at The University of York. From the minute I first contacted York, I felt a connection with both the academic and support people I met. The campus is accessible and I have achieved academic success.

Emma and I promised to share with you some of our practical strategies to develop social connectedness as teenagers who use AAC.

Lifelong Support

First we are both fortunate to be part of supportive families. But, we know that families come under huge pressure with all our constant needs. It could have been easy for our families to stay at home, not to have fought for the resources we need or not given us the time to express ourselves. Feeling secure at home has helped us to be more confident in the wider world.

Throughout our lives our parents and other close family members have modelled good communication strategies. They have trained others to work with us, given us the tools and confidence to train others. We are not aware that training courses are available for those who support people who use AAC. This means our future support only be as good as we can make it. We know getting a communication aid is the beginning of communication but it needs life-long support.

Besides maintaining our equipment we need access to the right vocabulary to share our feelings and experiences. This vocabulary needs to grow with us. In school we both found this was supported by staff, in adult life it's our responsibility, and that of our families. Life doesn't stop when we leave school. As we move on it becomes the role of paid staff, and that takes training and commitment.

Trusted Communication Partners

Both of us have access to trusted people, not just family, who know how to listen to our concerns and support us in agreeing a course of action. I also have regular counselling. I find the ability to talk to someone trusted and non-judgmental who is not part of my everyday life essential in making sense of things. Supportive and well trained communication partners are essential. For us a good communication partner listens and doesn't interrupt. Gives us eye contact by getting down to our level. Repeats or rephrases what we say only by agreement. Knows when to be quiet and how to wait for us to compose what we want whilst remaining engaged. If you start looking around the room we might think you are bored! The list could go on but this is for starters.

Friends, Role Models & Mentors

Like everyone else we need friends. This often doesn't happen naturally. Both of us have had parents who go out of their way to create situations where we can make and be with friends. At Uni I have needed my team to model good communication to others so we can begin to build that relationship.

Role models and mentors are vital for everyone. We are both fortunate to have some amazing people in our lives, but none of them live nearby. Technology allows us to create and maintain these. As our relationships have developed with role models some have become mentors, people we can look to for advice and support rather than just observing their communication skills, lifestyle and experiences.

Privacy and Developing Friendships

Balandin mentioned in her research the issue of privacy, being self-contained is an important part of connectedness. This is a tough one for people like Emma and myself. We need support 24 hours a day. Whilst being connected is vital there is the risk of being over connected! We can have few secrets, little in our lives is private. There is a balancing act to agree who supports us in what type of activities and when. You can ask easily a family member to leave you alone and give you space but asking someone who is paid to be with you to go away and give you time alone is harder.

Balandin also quoted gate keepers as being important in developing friendships. People can unwittingly become barriers to those who use AAC being connected if they are unwilling, or unable, to get us to places we want to go or make it hard for us to meet with others in our every day lives. Sometimes people make decisions on our behalf without consulting us in what we want. They might be doing it with good intent but to quote an often used phrase by disabled groups, "nothing about us, without us".

Further Research

These are just our personal views with a little bit of research, but if it were possible we would like to see further research in practical strategies in supporting children and young adults facing transition who use AAC to develop connectedness.

SUMMARY

It does not matter where we live, or if we use AAC, we all form connections with others, to places and a feeling of belonging in similar ways. Connectedness is vital for every human being. *

Beth Moulam & Emma Green

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AAC Support in Rett Syndrome

From light tech to eye gaze

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INTRODUCTION

Rett syndrome (RTT), predominantly affecting females, is a pervasive developmental disorder with cognitive and neuro-motor impairments including a high degree of apraxia. The individuals (referred to in this article as 'girls') experience loss of hand skills and loss of communicative skills during the regression phase of the disorder, and are unable to effectively use switches and keyboards to access a computer. However, there is strong evidence that these individuals can use their eye gaze intentionally. Use of eye gaze technology appears to be a way of bypassing the severe apraxia/motor planning disorder, allowing the individuals to demonstrate otherwise hidden knowledge of vocabulary and concepts.

The loss or limited development of verbal communication and speech is often a great disappointment to parents, carers and teachers, but AAC and language stimulation are important as they help to reduce frustration, and develop receptive language skills.

CHOICE MAKING & YES/NO RESPONSES

Initial work supporting people with RTT in 1984, resulted in the introduction of choice making and yes/no responses for daily activities, using objects and photographs. Such simple means of communication increased the women's control over what they wanted to eat, drink, and wear and what activities they wanted to do. Not surprisingly, this was easy for staff in residential care to implement, and was quickly established into the daily routines.

Outcomes for the women with RTT included acknowledgement by their carers of their previously hidden knowledge and preferences (the staff of one lady aged 42 had been reading her nursery rhymes – through choice making, it turned out she preferred Danielle Steele novels!).

More importantly, an outcome for all the women was an observed increase in their happiness – one lady who had spent her day weeping, no longer cried all the time. These ideas were shared with families and professionals in Ontario.

PLANNED INTERVENTION

It sounds obvious, but intervention for improvement of communication and language skills should be planned through all the stages of the person's life, to meet the needs of the individual as she grows, develops, and matures from a child to a teenager, to an adult, and should provide appropriate vocabulary to reflect the chronological age and interests. Intervention is possible during all four stages of RTT, and should address communication needs, receptive language development, and expressive skills through AAC. A person with RTT needs both aided and unaided approaches.

VOCABULARY

Choosing vocabulary is often the most difficult part of setting up a system. Think about the girl's known needs as well as the words used by other people in the same contexts. The best way to think about this is to listen to the person's peers.

New vocabulary should be added as the girl gains confidence, with attention being given to selecting motivating and functional vocabulary items. So many devices contain pictures for lunch, toilet, bus and timetabled activities. They should also contain words for a variety of other topics, such as favourite videos, TV programmes, or music; social phrases such as "Have you got five minutes?" and "See you later", or "That's NOT what I meant", and symbols to express emotions, and to comment on what others have said.

Choosing vocabulary in the first stages should receive considerable attention, as it will structure the person's success; if the system works, the person is more motivated to continue to use it. Early emphasis should be on functional vocabulary, with the understanding that changes will be made as the person makes progress. No matter what symbol type you choose, you need to select appropriate vocabulary that will enable the person to communicate *her* wishes and ideas. Each person will have different needs and skills, and the approach used to teach must reflect these differences.

The use of symbols can be modelled by the communication partner by pointing to the array when communicating a message. This demonstration of the use of symbols exposes the person with RTT to individual symbols and symbol sequences which will help in developing the understanding of symbol meaning and use. When the partner uses symbols, they should talk at the same time; this approach utilizes at least two possible input modes (auditory and visual); it also helps to maintain normal interaction styles. Place gentle expectations on the girl to use the symbols to express a response to questions, and encourage her to use the display spontaneously to initiate conversation.

USING THE EYES FOR COMMUNICATION

Low tech eye gaze and eye pointing refer to methods of communication which require only that the person fixes their gaze on a specific item, or looks at an item then back to the partner. Developmentally, visual tracking and scanning are skills that develop in early infancy, i.e. before stage one of RTT becomes evident. Tracking requires that the infant fixes her visual attention on an object/illustration, and follows the item as it moves through various planes of movement. Scanning requires that the girl is able to shift focus from one object/illustration to another.

Early development of communication skills often includes referential looking, where the infant looks at an item, and then looks at the caregiver. With infants, we tend to take this eye pointing as a request for information, or as a request for the item. Although dyspraxia will affect eve movements too, most individuals with RTT can use their eves effectively for communication, and frequently use referential eye gaze, but it is essential that the communication partners respond to this silent way of communicating. Just try it yourself! Look at an object you want, and try to get another person's attention about the object using only your eyes. It is not easy, but once your partner becomes aware of your way of communicating, you can request almost anything!

These techniques are simple to learn, and in fact, many girls have already found for themselves how effective they can be. Eye gaze and eye pointing can also be paired with hand pointing if the girl is capable of independent hand movement.

Eye pointing can be used to indicate choice of objects such as clothing, food, drinks, toys, make-up products, or places to sit, without any specialized equipment or materials having to be purchased. The girl can be encouraged to make choices during daily activities such as dressing, meal times, play, and personal care, using eye gaze to select the desired item. If eye pointing is used with a graphic or object system, such as a collection of photographs or commercially available symbols, she will need a method of displaying the objects or photos, on a frame or a commercially available pocket display.

DEVELOPING COMPLEX COMMUNICATION

The opportunities for communication will increase if these materials are carried around with the girl. As she progresses and develops skills with indicating single items or symbols, she can move from simply indicating choices to more complex communication such as initiating requests, commenting on items, asking questions, and later, even structuring phrases and sentences by looking at several symbols in sequence. The girl will also need to develop the use of yes/no responses, which might be as simple as two different coloured wrist bands, or cards with yes and no written on them, or symbols to represent 'yes' (positive) and 'no' (negative).

APPARENT COGNITIVE PLATEAU

Literature review shows that there has been very little research into speech, language, and communication development in RTT. Early research in Australia (Woodyatt et al.) showed that girls with RTT do not appear to develop beyond early sensory-motor levels, and have cognitive levels that plateau around 10-18 months. The researchers have noted that this apparent stagnation continues from childhood into adolescence and longer.

It appears that in most of this research, no modifications were made to the test procedures to allow for the dyspraxia or motor disabilities that occur in RTT. The results were interpreted as evidence of delayed cognitive and linguistic development, and as evidence that the children's level of intentional communication is consistent with their level of cognition. We believe it is more probable that the level of intentional communication and interaction that the children can demonstrate is consistent with their level of motor development, is hampered by their disability, and is not indicative of their cognitive or internal thought and linguistic development.

To find out what a person understands, it is common practice to ask the individual to manipulate objects or toys to specific instructions, or to point to pictures to identify vocabulary items: "Show me the car"; "Pick up the ball"; "Put the doll on the chair". These activities require that the individual being tested should have control of her motor responses, especially the hands. In RTT, a predominant feature is dyspraxia: the inability to carry out purposive movement. People with RTT may also have pervasive hand stereotypies, changing muscle tone, spasticity that increases with age, and problems with delayed responses, either because of dyspraxia, or because of processing difficulties.

Children and adults with RTT will have difficulty demonstrating that they understand as they cannot interact with the environment to manipulate toys or objects on command because of their neurologically based problems. Until more research is carried out, utilizing modified assessment techniques, the situation remains controversial. We believe that assessment using standardized testing is inappropriate unless modifications are made to the procedures to allow for increased processing time, or delayed reactions, or changes are made to the materials and equipment to allow for alternative methods of indicating responses.

The following questions need to be addressed:

- Do children with RTT really plateau at early levels of cognition and intellectual development, or are they just unable to show their inner knowledge?
- Do they develop language receptively in the normal expected sequence, but are unable to show those language skills expressively?

Many people, (parents, caregivers and professionals) believe that the individuals are 'locked in' and unable to demonstrate what they know and understand. This is important to acknowledge, even as a remote possibility, because what we believe about an individual affects the way we interact with them. If we think a person does not understand, we may not talk to that person at all. If we think a person is developmentally delayed, we may talk to them as if they are a baby, or a child, irrespective of their chronological age. If the communication partners of people with RTT believe the research findings, they may not talk to the individual at all. How will the girls and women learn language?

EYE GAZE AND EYE TRACKING STUDY

However, exciting possibilities for demonstration of the hidden inner world of people with RTT exist - because eye gaze can also be used to control a computer. Such access may help to determine the real knowledge and skills of people with RTT. Hector Minto and Sally-Ann Garrett carried out a two year study looking at eye gaze control of computers and eye tracking during play as a means of access that can lead to assessment of cognitive and language development in people with RTT. The small scale study with more than 120 subjects was carried out to determine whether eye gaze technology is a suitable means of access for assessment of cognitive and language development, and if it may have potential for AAC intervention for individuals with RTT.

The UK cohort was made up of girls and women who were assessed during Tobii clinics held in several schools, at regional Rett UK family days and at Rett Clinics in a hospital setting. Using the Tobii EyeGaze Learning Curve as the framework for analysis, following a short session of screen engagement through sensory material, several cognitive and language tasks were attempted. Of the 120+ individuals diagnosed with RTT according to DSM-IV criteria, more than 97% were able to engage with the computers to demonstrate a range of cognitive skills and showed previously undemonstrated language/vocabulary knowledge.

Data collated over multiple sessions showed a high rate of fixation on the named items. Of the children and adults assessed, only two did not present engagement with the computer screen; it is possible that they have a previously undetected vision problem. Several did well in all tasks, and a few responded correctly to all verbal instructions.

The rate of appropriate eye-tracked responses suggests that there is measurable and intentional gaze in girls with RTT that can be used as a path to explore their cognitive performance. The girls performed well to both direct instruction and to indirect commentary, but some individuals achieved better results through indirect commentary; this needs further exploration.

FURTHER STUDIES

The ability to access eye gaze technology should be put to use as a means of accessing AAC. Further studies will be needed to find out what kind of illustrations/level of symbolisation is required, including whether individuals with Rett syndrome can develop traditional literacy – reading written words. *

> Sally-Ann Garrett Independent Speech and Language Therapist

> > Hector Minto Tobii-DynaVox

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FROM COMMUNICATION MATTERS



Other Ways of Speaking

This short booklet provides information about children and young people who use a variety of different ways to communicate, how you can help support them and where to go for further information. You should read this booklet if you live or work with children and young people whose speech is difficult to understand or who have no speech.

Other Ways of Speaking has been produced in partnership by Communication Matters, The Communication Trust, 1Voice, ACE Centre, The Makaton Charity, Scope and Signalong.

The booklet is **free** - you can download an electronic copy or order a printed copy from Communication Matters (you only pay postage & packing).

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Come and see us in the Exhibition Hall where we will be launching our latest Talking Technology device – Smart 3.

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See you there! The Team at **Techce**



COMMUNICATION

COME AND TRY

THE NEW



Increasing the Communicative Opportunities for VOCA Use Through Staff/Parent Training

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BACKGROUND

Learning to communicate using a Voice Output Communication Aid (VOCA) takes time. Korsten (2005) observes that "The average 18 month old child has been exposed to 4,380 hours of oral language at a rate of 8 hours/day from birth. A child who uses a communication system and receives speech/language therapy two times per week for 20-30 minute sessions will reach the same amount of language exposure in 84 years". This stark reminder underlines the need for everyone to be working together in supporting the VOCA user to master their system to communicate across the waking day.

Bousaki et al (2011) notes that "It is the parent/carer who can hold the key to developing effective communication for a VOCA user if they are provided with the appropriate support". Parette and Angelo (1996) highlight the role of parents and carers in facilitating the generalisation of skills being learnt by the AAC user to more natural environments.

The Dame Hannah Rogers Trust (DHRT) in Ivybridge, Devon, comprises a residential school and adult provision (ages between 10-25 years) with moderate and severe multiple physical and sensory disabilities. Some of the school age children and all of the adults are residential. Hence both parents and care staff have a critical role to play in the successful implementation of AAC systems. Both have access to some training, generally on a case by case basis. Yet, we still have a way to go in achieving our ultimate goals of staff/ parents recognising the value of communication aids as essential and in realising opportunities for our young AAC users to communicate beyond the school/college day.

In view of this, we recognised the need to shift the emphasis of our training from teaching technical knowledge and skills to developing a better understanding of the process of learning communication through AAC and developing a greater appreciation of how it might feel to be solely reliant on others, or on a VOCA, to communicate.

Funding through a Plymouth University Vice-Chancellor's Community Research Award enabled us to offer two days of training, based around the 'You Matter Programme' (Bousaki et al, 2011), to parents and key care staff as part of this process. We set out to examine whether offering this training resulted in: (1) any changes in parent/care staff perceptions of barriers to VOCA use; (2) increased VOCA use, particularly beyond the school/college day; and (3) whether any increase in VOCA use would be accompanied by an increase in cognitive abilities.

METHOD

The project took part in three phases: collection of baseline measures; delivery of training; and collection of post-training measures.

1. Baseline Measures

Baseline measures included a questionnaire, data logging, and IQ testing. The questionnaire was completed by 10 parents and 13 care staff, regardless of whether or not they were to attend the training. The questions focused on how often VOCAs are used, situations in which they are used most/least, and barriers to using VOCAs. There was also a more open ended section inviting comments. To obtain a quantitative measure of VOCA use, we also switched data logging on for those devices with that function, having sought consent. This provides a means of demonstrating actual usage of the device in minutes/hours over time (in this case a week). The Leiter Test (Roid and Miller, 1997) was administered to gain a baseline IQ score. This standardised non verbal test is appropriate for a range of learning needs and covers an age range from 2:0 years to 20:11 years. Some adaptations were needed to accommodate our young people's various access issues.







Figure 1 Responses of care staff (upper bar in each pair) and parents. Significant differences are marked with an asterix.

2. Training

Parents of our fifteen VOCA users (aged 13-25 years) were invited to attend two full days of training – only three did so. In addition, nine care staff were selected to attend because of their senior role within the care setting and their familiarity with the VOCA users.

The 'You Matter' training (Bousaki, Lloyd-Cocks, Latham and Moore, 2011) formed the basis of the two day course. As its focus is on young children using AAC it was adapted to be more relevant for our older client group. In addition, we added a number of experiential activities aimed at increasing empathy towards AAC users.

The SLTs aimed to empower the parents/ care staff by building their confidence to support the young people to use



Figure 2 Responses between those who attended the training (lower bar of each pair) and those who did not. Significant differences are marked with an asterisk.

their VOCAs more. Rather than achieve this by teaching technical skills, the course focuses on increasing participants' understanding of what is involved in learning to communicate through AAC and of how their communication matters. It also works through developmental stages of learning to communicate using AAC and goal setting.

3. Post-training Measures

A follow-up questionnaire was sent five months after training and eleven were completed, seven of them by people who had attended the training. This second version of the questionnaire contained a few additional questions specific to the training. In addition, data logging was undertaken for a further week five months post training and the Leiter IQ test was re-administered six months after the first time it was performed.

OUTCOMES

Questionnaires: Pre-training at phase 1

The graphs in Figure 1 demonstrate clear differences between parent and care staff responses. Notably, parents report many more situations in which their children's VOCAs are little or not used. Although care staff report more use than parents, their responses tie in with our perception that opportunities for VOCA use were not being maximised in the care setting.

Care staff responses showed that they did not view the above technical issues as barriers. Interestingly, issues concerning the devices themselves (e.g. size, weight and reliability) were not considered barriers in either instance. Parents however viewed set up knowledge, programming knowledge and content as barriers.

Again, some interesting differences were found as regards other barriers to VOCA use. Care staff did not perceive any of the above as barriers, whereas parents identified a preference for other forms of communication (such as vocalisations, facial expression and body movements) and felt that they know what their child wants without the need of a VOCA.

Questionnaires: Post-training

We had hoped to be able to present and directly compare responses on the pre- and post-training questionnaires for all those who had attended the training but unfortunately this was not possible. However comparison of the responses given by those who attended training and those who did not showed



Figure 3 Use of VOCA for each young person – pre-training (first bar in each pair) and post-training



Figure 4 Results of Cognitive Assessment – pre-training (left bar in each pair) and six months later, post-training

some interesting differences as highlighted in Figure 2. The graph suggests that those who attended the training perceived fewer barriers to VOCA use than those who did not. Those who attended the training were significantly more aware of opportunities for their young person to use their VOCA than those who didn't. Not significant but also interesting is that those who attended training felt that they did not know what the young person wanted without using their VOCA.

The training was very positively received: 71% of attendees stated in their feedback immediately following the training that they had positively changed how they interact with VOCA users. Many of the open-ended comments given by attendees were also revealing. For example:

"I model more. I wait longer for responses."

"I understand better now how using her VOCA gives her an independent voice. I am trying to use it more at home."

"I encourage her to communicate her answer to me using her VOCA more now rather than just guessing what I think she actually wants and am amazed at how often I guess wrong!"

Data Logging: measuring use of the VOCAs

Data logging was completed for six of our VOCA users, preand post- training. The findings (Fig. 3) indicate a notable increase in VOCA use in most cases. Further data logging is planned to determine whether these changes have been sustained.

Cognitive Assessment

Overall, there was a significant improvement in IQ scores between T1 and T2, which was unexpected on our part. This suggests that the young people can still learn. However, those young people who achieved the greatest difference in scores were not the main focus of the training.

CONCLUSIONS

In spite of the small numbers involved, the findings have given us useful insight that will shape future practice. The findings confirmed our general feeling that VOCAs are little used at home; parents preferred other forms of communication and feel that they know what their child wants without it. Parents, rightly, know their children well and, at times, AAC can seem inefficient relative to other means of communication, such as body language or yes/no questions (McCord & Soto, 2004; Hodge, 2007). However, there is always a risk that parents may make erroneous assumptions about what has been communicated, may not be empowering their child to express themselves fully, and that their reliance on other means of communication may not communicate a shared belief in the VOCA to their child.

Parents also highlighted some barriers to AAC that cannot be changed, such as issues with reliability. Lack of programming knowledge and lack of knowledge about the vocabulary stored were also recorded as barriers. This was somewhat surprising, given that previous training had focused on technical skills. Changing the emphasis of training to foster a deeper understanding of AAC may help create a stronger foundation for the assimilation of these technical skills.

The following quote from one parent was particularly thought provoking:

"I feel guilty if I do not use the communication aid with [name]. I recognise and appreciate it is important for him to express himself. I just about get through the day, feeding him, doing medicines etc... The aid is one more thing that stresses me..."

A more holistic focus on AAC, including more low technology options, would give parents a less technical and sometimes more manageable means of providing communication opportunities. Given the lack of take-up for the training by parents, and the residential nature of DHRT, we need to consider alternatives. Possibilities include delivering training in smaller, bite-sized chunks; creating virtual training options that can be accessed by parents at their convenience; and/or the use of apps such as PictelloTM to foster greater understanding.

Care staff perceived fewer barriers than parents. However, the data logging pre-training, together with their responses about how often VOCAs are used for different purposes, suggest that VOCAs are not being used as much as they could be and that opportunities for communication are nonetheless missed. Discussion during the training suggested that time pressures and conflicting priorities may have some part to play in this.

Overall, the training was well-received and beneficial, in the short term at least; attendees were motivated to change their communication and perceived fewer barriers. In addition, data logging indicated gains in VOCA use. While some modifications were needed to make the training more appropriate for our client group, the structure and focus worked well. We would like to roll out a programme of experiential training to all staff and to continue to deliver 'You Matter' training (with some adaptations) to key staff and any parents who would like to attend. In addition, we intend to introduce a more regular and more comprehensive programme of data logging to monitor progress in the longer term.

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As regards, the cognitive testing, five of the eight young people tested showed gains in their IQ scores over a six month period and seven showed gains in their age equivalent scores. There does appear to be a trend for those who have shown the largest increase in VOCA use to have made the most marked progress in their cognitive scores, suggesting a link between VOCA use or 'practice' and cognitive abilities. Of course these numbers are too small and on too short term scales to show significance, but are of potential interest nonetheless.

We are aware that within this project we did not consult the young people and

acknowledge that this is crucial part of the overall picture.

We have since carried out a project on their own attitudes to their VOCAs and will continue to consult them in decision making. *

Tamzin Gribble, Speech & Language Therapist Dr Ruth Firth, Speech & Language Therapist Dr Allegra Cattani, Teaching Fellow Dr Lauren Carroll, Plymouth University

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Outcome Measures in AAC

SALLY BOA

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INTRODUCTION

In June 2012 the Scottish Government published 'A Right to Speak', a document which provides guidance for people who use Augmentative and Alternative Communication (AAC) as well as professionals working in this area.

In response to the guidance, NHS Education for Scotland (NES) commissioned research to critically appraise existing methods of measuring outcomes for use in AAC. Sally Boa and Joan Murphy from Talking Mats in Stirling were commissioned to carry this out.

The aims of the project were to:

- 1. Identify and appraise a range of existing methods of measuring outcomes.
- Critically appraise the application of these methods to AAC and investigate how the outcomes of AAC interventions are currently measured

 within Scotland, the UK and internationally.
- 3. Provide recommendations about how the outcomes of AAC interventions can best be measured and on any systems/processes which would be needed to implement/facilitate this.

METHODS

The project comprised four stages (Figure 1):

Stage 1: We carried out a literature search and appraisal of published litera-



Figure 1 Summary of the project

ture using rapid review methods (Khangura et al, 2012). The aims of the literature review were to identify which outcome measures are currently used by a range of health, social work and education professionals.

Stage 2: We synthesised findings from the literature review with findings from the Communication Matters Report on Outcome Measurement and the Framework for Measuring Impact, a web-based resource which aims to provide information for practitioners to help them select and use appropriate outcome measures in their practice.

Stage 3: We conducted an online survey in order to find out what AAC health, education and social work practitioners do in practice in relation to measuring outcomes in AAC. The survey was sent out to people working in AAC in Scotland, the rest of the UK and internationally. We used our existing networks, including Facebook and Twitter in order to reach as many people as possible.

Outcome measure	Purpose	Applicability to AAC	Limitations
AusTOMs (Australian Therapy Outcome Measures)	Measures outcome in terms of functioning and participation	Yes	Validated with an Australian population. Does not currently have specific scales relating to AAC
COPM (Canadian Occupational Performance Measure)	Goal focused. Measures perceived change from client's perspective	Yes	OT based outcome measure. Language used may be inaccessible to other professionals
EQ5D	Non-disease-specific instrument for describing and valuing health	Possibly	Very general measure of health and well being
FIM/FAM	General measures of functioning	No	Does not include communication
GAS (Goal Attainment Scaling)	Goal focused outcome measure	Yes	Outcomes based on patient's perception of goal achievement
Nottingham Health Profile	Measure provides a brief indication of a patient's perceived emotional, social and physical health problems	No	Does not include communication
TOMs (Therapy Outcome Measures)	Measures outcome in terms of functioning and participation	Yes	Does not currently have questions relating to AAC

Table 1 Global outcome measures and their applicability to AAC

Stage 4: We invited AAC practitioners from Scotland to attend one of two expert panel meetings. All those who attended were speech and language therapists, highly specialist in AAC.

The aim of the meetings was to provide a forum to enable experts in the field of AAC to discuss and reflect on the issue of Outcome Measures in the light of findings from the literature review, the CM report and the survey.

RESULTS

Stage 1

The *literature search* identified that a wide range of outcome measures exist and that the purposes and application of these vary. No specific Outcome Measure for AAC exists which can be used across client groups but there are

some global Outcome Measures may be applicable to AAC (Table 1).

Stage 2

An examination of the *Communication Matters Report on Outcome Measurement* identified that outcome measures and assessments appear to exist on a spectrum and that it can be difficult to distinguish between them. The fact that sometimes, assessments can be used as outcome measures further complicates the picture.

The Report highlights that outcome measurement data should be collected at different levels. These can be aligned according to the Framework for Measuring Impact which helps professionals to think about the purpose of outcome measurement and which level and what type of data they need to collect: for

From CM report	From Framework for Measuring Impact	
At the level of the client: to inform interventions; to measure change over time; to measure impact of interventions	Patient experience measures; Effectiveness measures	
At the level of the service: to monitor service delivery	Patient experience measures; Effectiveness measures	
At the level of the purchaser/commissioner: to establish benefits of service; to enable comparison across different areas	Effectiveness measures; Efficiency measures	

Table 2 Measuring outcomes at different levels

example, client, service or commissioner level (Table 2).

Stage 3

We received 153 *online survey* responses. The majority of respondents were from the UK, but people from the rest of the world, including North America, Scandinavia and China also took part. Respondents were asked to name which Outcome Measure was most used for AAC in their workplace. 59% of respondents said that they did not use Outcome Measures with people who use AAC.

Of those who did use a measure, the Therapy Outcome Measure (TOM) was the most commonly used, although many people also said that they used 'Care Aims' as an outcome measure. This approach was developed by Kate Malcomess as a model to support therapists in their clinical decision making and was not developed as an outcome measure. Many people stated that they used a combination of measures, some of which were based at the level of the patient, involving shared goal or target setting. Others used informal methods. some developed in-house, in combination with more formal, standardised measures.

Survey respondents felt that the topic of Outcome Measures in AAC was an important one and that there should be a standardisation and sharing of ideas across AAC practitioners regarding best practice. There was agreement that the use of Outcome Measures in AAC is at best variable and at worst non-existent. There was also recognition of the need for clarity about what Outcome Measures are, what they are measuring and who feedback should be aimed at.

Although many people expressed frustration that existing Outcome Measures could not be applied to AAC populations, some people felt that global measures *should* be applicable to AAC populations. Respondents welcomed this project as a way of helping the AAC community develop its understanding of use of Outcome Measures.

Stage 4

The *expert panel discussions* covered the following topics:

- What is the difference between Outcome Measurement and assessment?
- What are we measuring and who are Outcome Measures for?
- Which existing measures are useful in AAC?

There was much discussion about the importance of having consistent terminology that could be used and understood across different professional groups. As a result of these discussions, expert panel members agreed on *key features* that they believed outcome measures should have:

- They should measure change
- Can be repeated over time
- Can be used across clients, settings and disciplines
- Can be used to give feedback to services, professionals, carers and clients (about what works as well as what doesn't)
- Are robust/standardised/well respected
- Inform discharge
- Are short and straightforward to use
- Allow for comparison with different types of AAC/No AAC.

There was also a consensus between expert panel members that, currently, the most useful outcome measures with potential applicability to AAC were AAC TOM (Therapy Outcome Measure for AAC) and CODES (Competency, Opportunities, Driving communication forward, Engagement and Skill acquisition). Both of these measures are still in the development phase, but panel members suggested that it was both timely and pertinent to explore the possibility of using these as AAC outcome measures.

CONCLUSION

Outcome Measurement in AAC is an important topic, but poorly understood and defined.

The literature review, online survey and expert panel findings indicate that there is a need to determine a definition of Outcome Measures, examine terminology and look at existing measures (CODES and AAC TOM) which offer promise in relation to outcome measurement in AAC. Of these two, AAC TOM appears to fit best with the features of Outcome Measures which were agreed at the expert panel days. CODES is a well-respected and useful framework for assessment, planning and monitoring progress in AAC populations. However, it seems to have a much wider application than just outcome measurement, and was originally developed for use with children.

Enderby's Therapy Outcome Measure (Enderby et al, 2006) is an existing measure which has been tested for validity and reliability and fits with all the features agreed by the expert panel members. Specific scales for using this measure with people who use AAC have been developed but have not yet been fully validated. Our recommendation, based on findings from the project, is that use of this measure should be explored in a future study. *****

> Dr Sally Boa Research Speech & Language Therapist

ACKNOWLEDGEMENTS

Talking Mats Ltd were commissioned and funded by NHS Education Scotland to undertake this project. A copy of the full report can be found at www.talkingmats.com

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RESOURCES FOR AAC RESEARCH

Research Involvement Network

Communication Matters has set up the Research Involvement Network to encourage more people to take part in research into AAC and to help researchers find the participants they need. The Network is made up of people who use AAC, their families and carers, and professionals who work with people who use AAC.

If you are interested in participating in future AAC research projects visit the Research Involvement Network webpage (link below) for more information. We are particularly keen to recruit more people who use AAC and family members and carers.

Communication Matters welcomes applications from UK post-graduate researchers wishing to recruit participants to AAC research projects. Contact Communication Matters to discuss your project, email: rin@communicationmatters.org.uk For more information, please visit: www.communicationmatters.org.uk/ research

Single Case Study Template

As part of the Communication Matters AAC Evidence Base project, one of the collaborative partners (Manchester Metropolitan University) developed a single case study template. This template was developed to support the collection of consistent and relevant case data. It is intended to support more robust data collection.

If you would like to contribute to Communication Matters' ever growing case study database of submissions from people who use AAC, please download a copy of the participants information sheet about how to contribute by following the link below. Alternatively, you may wish to download a copy of the case study template for your own use.

For more information or to download case study template/resources, visit: *www.communicationmatters.org.uk/* research

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FROM CATHERINE HARRIS, CHAIR OF BOARD OF TRUSTEES

As I start to write this, I am

balanced between getting back from the ISAAC Conference in Lisbon (more later) with only just over a month to go before the Communication Matters National AAC Conference in Leeds. The sun is shining and many people are on holiday here in sunny Bourne-



mouth. There is much to do and sometimes it is hard to focus!

The summer is a good time to reflect, although challenges present themselves whatever the season. I continue to be inspired by those who rise above such challenges and are able to achieve more than they might ever have dreamed of. I am working at present with one such woman. I also saw several presentations in Lisbon which renew the drive to make sure that the support is available to enable people to achieve their full potential.

ISAAC

This was my first ISAAC conference as Chair of CM. I attended the ISAAC Council meeting which is a gathering of representatives from all the Chapters. The meeting lasts all day with a very full agenda. It became apparent that - even with English as a first language - it was hard to keep up at times. Key items were updates on the BUILD project, the LEAD project, financial planning and the vote on whether to accept the position statement on Facilitated Communication (see below).

The **BUILD** AAC Project supports the development of services in emerging AAC countries, by:

- forming collaborative partnerships to encourage ISAAC membership from emerging AAC countries;
- coordinating funding for people from emerging AAC countries to attend ISAAC biennial conferences;
- distributing information relating to its discussion topics by electronic and other forms of communication.

The **LEAD** project encourages and supports people who use AAC to take a leadership role within ISAAC. Current LEAD initiatives include:

- ISAAC LEAD Support Group on Facebook This forum is a place to discuss issues and to share and encourage inspiration.
- International AAC Awareness Month International AAC Awareness Month was established by the LEAD Project Committee in October 2007. Thirteen countries participated in the first annual Awareness Month, and events have been increasing in number and scope ever since.
- Information on how people who use AAC can develop the leadership skills necessary to serve on Boards and in the community.

It was great to sit around a table with people from so many different countries who were all passionate about the impact AAC can have. It is also challenging to us, living in a well-resourced country, to look at what we can do to support those who are not as well resourced. The **ISAAC 'Lifetime Achievement' Award** has been awarded to Stephen Hawking, and we hope to be able to present this to him in person in the near future. He sent a video message, shown during the conference. However, equally inspiring were the presentations by a number of people who use AAC about issues that face all of us (e.g. fitness, bereavement, sibling challenges, ageing); these prompted lively

Last year at the CM Conference there was an interesting presentation on the Communication Access Project in Australia. During the year we have been in contact with Hilary Johnson and Celia Todd to find out more. The project has progressed and they presented an excellent session at ISAAC. We are hoping that they may be able to be our keynote speakers in 2015 and that this kind of work can be developed increasingly in the UK.

discussion and debate.

ISAAC POSITION STATEMENT ON FACILITATED COMMUNICATION

The above position statement was a key discussion item at the ISAAC Council meeting on 20 July 2014. A small number of Chapters had some reservations about the position statement in that there were differing views held by their members. Others welcomed the position statement. As the UK representatives, we shared our response document with the council. We tried to reflect the diverse views held by our membership and to explain why, in response to the many comments and concerns Communication Matters received, felt unable to support the proposed document in its current form.

The vote when taken was a majority of 23 in favour with 4 opposed and 1 abstention, so the motion was passed by Council for ISAAC to adopt the position statement.

The full report and research methodology will appear in the ISAAC AAC Journal later this year. It needs to be recognised that this is a position statement and not a decree related to professional practice.

We understand that this will be a disappointing outcome for some of our membership, but have to recognise that we are part of a democratic organisation. It is our hope that Communication Matters can move forward as an organisation that reflects and respects differing views while valuing good professional practice and research. CM greatly values the diversity within its membership. We do not want to get distracted from the primary aim of supporting all those who use AAC to fulfil their communication potential.



TRUSTEES'

ISAAC DISTINGUISHED SERVICE AWARD

We are delighted that **Janet Larcher**, who is an AAC consultant and a former Chair of Communication Matters, is the recipient of this year's ISAAC Distinguished Service Award.

CM2014 NATIONAL AAC CONFERENCE

We are in the last stages of planning and organising this year's Conference. We hope you are sorting your 'Where's Wally' fancy dress costume in honour of Neil Hansen (it was his suggestion!) who is stepping down from being a Trustee after nine years of service. We have four 'experienced' Trustees stepping down this year and I am very grateful to them for all their work and support.

The Conference is obviously central to CM's 'core business' and it has been very encouraging in the present financial climate to have more registrations than last year.

We hope the introduction of a 'Research Stream' and a Poster session, alongside creative workshops and presentations on clinical & personal experiences, will make for another very stimulating conference.



We are looking forward to having presentations from the 'Seen but Seldom Heard' poetry project based in Bournemouth. We are also really delighted that our Patron, Lee Ridley (above), aka Lost Voice Guy, will be joining us straight from appearing in his sell-out show at this year's Edinburgh Festival Fringe.

LOBBYING

The Lobbying has resulted in some significant progress with AAC now being included within Specialist Commissioning in England. We are still working to ensure better joined up working between specialised and local services. It is good to have continued feedback from the membership on how they value the work which CM has done. There will be a need to renew our lobbying activity in the autumn with the run up to the next election to ensure we do not lose momentum on the progress that has been made.

If you wish to contact a Trustee, please email via admin@communicationmatters.org.uk *

Catherine Harris, CM Chair



Many, many years ago, when I was a child, I used

to go to a dentist who was so kind, understanding and gentle that I grew up never being frightened of dentists. But I also grew up having to go to the dentist more often due to ongoing problems with toothache or fillings coming out. The problem wasn't my teeth but my dentist. He just hadn't kept up to date with new thinking and technologies, and was eventually ordered to go on several training courses and to update his equipment! I changed dentist and have since been able to reduce my visits to regular check-ups. But it just shows how, in any industry or profession, training and continuing professional development is so important.

The BHTA run a number of training courses, one of which is the BTEC Professional Certificate Level 4 status 'Healthcare and Assistive Technology' course which includes sessions on social inclusion and diversity, person-centred assessments, neurological conditions, infection control, the MHRA and the BHTA's own code of practice. The opening session is 'Introduction to the World of Assistive Technology'. When I took over the facilitating and running of this course, I realised that there was no mention whatsoever of AAC – but there is now!

There is a final exam and some pre-course work to be completed in order to attain the certification. Although AAC is not in the final exam it is in the pre-course work, which means participants are directed to the CM website to gain more knowledge – and the BHTA AAC section has been very proactive in ensuring the exam questions are meaningful. This is especially important as we have discovered a large proportion of the participants are not from other product suppliers but from local authorities wanting to extend and broaden their knowledge of Assistive Technology in general.

The BHTA also run specific courses (e.g. Pressure Care, Continence). At the last section meeting, we discussed whether there should be an AAC specific one-day course to cover areas such as: why AAC is required, how to get assessments, funding, product types, mounting. There should be input from professionals (e.g. SLT) as well as the product suppliers, and be aimed at industry professionals from areas linked with AAC, such as wheelchair provision, professionals moving into the AAC area, carers for people with AAC needs, and local authority personnel. However, we are unsure if there would be sufficient interest to justify the course.

So this is one area that is still 'under review' but if we do decide to take it further it will hopefully be in conjunction with, and with input from, CM. Meanwhile if any CM member has thoughts of the value of such a course, or ideas about what should or should not be included, I would be pleased to receive them at *meandi@btinternet.com* *****

David Morgan, BHTA AAC Chair



WANT TO HOST A COMMUNICATION MATTERS ROADSHOW?



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We are always looking for new venues to hold CM Roadshows, so if you would like to host one in your area, please do let us know.

Communication Matters will handle much of the adminstration and organisation, including taking delegate bookings.

For more information, please contact Patrick Poon on Tel: 0845 456 8211 admin@communicationmatters.org.uk

Communication Matters Online Survey

TOM GRIFFITHS

c/o Communication Matters, Catchpell House, Carpet Lane, Edinburgh EH6 6SP, UK Email: admin@communicationmatters.org.uk

In 2013, Communication Matters (CM) undertook an online survey to find out what members and non-members thought about the organisation, our priorities and the work we do. A total of 406 people responded, with 206 people completing all of the questions. In this article, we have summarised some of the key results.

WHO IS A CM MEMBER?

Of the 316 people who answered this question, 39% were members and 48% were not. Our Associate membership reflects all the categories of membership, with over half holding individual memberships and 10% of the members being people who use AAC and their families. Of the professionals who hold membership, 40% work in health, 23% in education and 14% work for a charity or Third Sector organisation. The largest professional group are speech and language therapists (35%), with teachers being the second largest group (9%).

WHAT'S IMPORTANT TO YOU?

We asked people to tell us which areas of CM's work they thought were the most important. Most people (84%) saw increasing awareness of AAC and the needs of people who use AAC and their families as a high priority. The education and training activities we organise (CM National Conference, Roadshows, study days) were also generally viewed as a high priority.

KEEPING IN TOUCH WITH CM

Most people (85%) felt that Communication Matters was good at keeping them updated. We asked people to give us ideas about how we could improve our communication. Responses included more use of Twitter and Facebook, as well as email lists for different topics and more regular information about changes in commissioning and the national picture for AAC.

The website is the most widely used resource we produce, with 93% of people having visited it and 82% of people reporting that they found the website useful. Most people who visit the website are looking for information about AAC, with people also looking for information about Roadshows and study days. CM is currently looking at a redesign of the website, which should help address the concerns that some people have about the website not always being easy to navigate.

Communication Matters also produces a range of publications and we're pleased to hear that most people find these useful. The *National Standard for AAC Services* is the publication that the largest number of you found useful (62%), with the *Focus On...* leaflet series and the *Shining a Light* research report also being regarded as useful by many (47% and 46% respectively). The AACknowledge website (our online evidence base project which can be found at *www.AACknowledge.org.uk*) is also a useful resource for many (43%).

CONFERENCES AND ROADSHOWS

Many people cited attendance at the CM National AAC Conference as one of the main reasons that they are members of CM. We were very pleased to see that 90% of people who had attended a conference would like to do so again. People value the chance to network at the conference and to attend the papers and presentations. The chance to learn more about the national situation was also important. Of the people who funded their own attendance at Conference, 29% felt that it was good value for money. There were some very positive comments about our new Conference venue in Leeds!

Fewer people (17%) have attended the international conference organised by ISAAC, our parent organisation. More people have attended an ISAAC conference in Europe than in America and more people (50%) felt that the ISAAC conference was too expensive for them to consider going. The reasons people attend the ISAAC conference are very

similar to the reasons that people attend the CM conference.

Every year, Communication Matters runs a number of free Roadshows throughout the UK, hosted by AAC supplier members. These are a chance to see the latest AAC devices and to talk to the suppliers. About a third of people who answered the survey have been to a CM Roadshow in the past five years, with 79% saying that they would want to attend another one.

THE COMMUNICATION MATTERS JOURNAL

We asked people how often they read the CM Journal and which sections they found most useful. We were happy to hear that 52% of people read all. most. or some of the Journal. People who read the Journal find the research papers the most useful and relevant to them, with case studies and personal stories also important. Most people (43%) prefer to read the Journal in its printed form, with some people preferring to read it electronically (29%) and some liking to have the option of both (28%). You told us that 40% of you didn't know that previous issues of the CM Journal are available on the website. If you're one of that group, why not check it out now at: www.communicationmatters.org.uk/ page/cm-journal-download

EVERYTHING ELSE

We were delighted that so many people (109) were keen to be more involved with the work of CM through fundraising and working groups, as well as the Research Involvement Network. We also had some excellent and very creative ideas for fundraising activities!

On behalf of the CM Board of Trustees, I would like to thank everyone who took time to fill in the survey: it's been an invaluable tool for letting us know how you feel about the work of CM and how we should move forward as an organisation. If you would like to read the full survey results, you can find them in the membership section on the CM website. *****

Tom Griffiths, CM Trustee

COMMUNICATION MATTERS AAC Study Day

Symbolisation towards Literacy



Janice Murray, PhD Manchester Metropolitan University

> Martine Smith, PhD Trinity College Dublin

Wednesday 12 November 2014



Stirling Management Centre

Download more details & booking form: www.communicationmatters.org.uk/studydays

Free online resource for people with communication disorders

The Aphasia Software Finder

SARAH WOODWARD

The Tavistock Trust for Aphasia, Bedford House, 15 George Street, Woburn MK17 9PX, UK www.aphasiasoftwarefinder.org

In 2011, The Tavistock Trust for Aphasia launched the Aphasia software finder website: a free, online tool enabling people with aphasia, their carers and therapists to identify appropriate aphasia therapy software in the English language. The website has undergone considerable re-design and now includes not only software but also apps for Android and Apple platforms.

Although originally designed for people with aphasia and their therapists, this resource is proving to be useful to many people with *other* communication difficulties.

The apps included on the site cover a wide range of areas: memory, visual daily planners, talking photo albums, text to speech, AAC, reading, talking, spelling as well as software, apps and links which can help to make technology more accessible generally.

The website has been designed incorporating evidence from research about accessible materials for people with aphasia (see Resources below). This hopefully makes it more accessible to those who have a communication difficulty. Several groups of people with aphasia have been consulted about its accessibility and their suggestions have been incorporated.

Software and apps are categorised into 'aphasia specific' and 'general' to make searching easier.

Features include:

- Free resource
- Objective feature descriptions
- Aphasia friendly format
- Videos on how to use the site on most pages

P The Tavistock Trust for Aphasia Aphasia Software Finder	
Welcome	Home
View Edit	Aphasia Software
Welcome Video	Aphasia Apps
** •	General Software
This website has information about software programs and apps for people with aphasia in the English anguage [®] .	What's New
We aim to help people with aphasia to find software that may be useful to them.	EAQ
We have made the first page in the website as aphasia friendly as we could. This has been done without compromising the purpose of the site.	Links

- More detailed information for carers and professionals
- Over 160 software and apps listed
- Useful links to other sites and resources
- Links to evidence based research relating to computer therapy
- FAQ page

There are several ways to find appropriate software/apps:

Finder: select the areas you wish to work on from a list and appropriate programs will be presented with a description of features.

Search: use the name of a program you've heard of to find a description of its features.

Comparison Table: compare the features of several programs to select which one is best for your needs

List: scroll through the alphabetical list of all software programs and apps.

All the aphasia therapy software and apps have been analysed by an independent speech & language therapist and the information is available in two formats. One is designed to be 'communication difficulties friendly'. The other, which uses more complex language and detail, is for therapists and those wanting to find out more.

The website will contain videos on most pages explaining in a visual and auditory format how to use the site, making it easier to use for those with speech, language and communication difficulties.

Over 16,700 people from over 10 countries worldwide have visited the site since its launch, so why don't you visit the website to see for yourself:

www.aphasiasoftwarefinder.org 🔹

Sarah Woodward

RESOURCES

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Facilitated Communication: Asking the Appropriate Research Question

MARION STANTON

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Facilitated Communication (FC), sometimes also known as Facilitated Communication Training (FCT), involves the giving of physical support to a person so that they can more accurately access a communication device, such as a keyboard. The intention is not to guide the person's hand to the target but to provide steadying support usually in the form of backward resistance. This means that the person offering support (usually called a facilitator) may pull the person slightly back from their selection thus creating a tension which can produce steadier movement with the result that the person reaches their intended target. The long term goal of FC is that the person receiving support will eventually, through a process of fading support, become independent.¹

Prior to this session at the Communication Matters Conference 2013, ISAAC (International Society for Augmentative and Alternative Communication) had recently agreed to release a draft position paper on FC. This was apparently in response to requests from the ISAAC membership. An Ad Hoc committee was charged to complete a literature review and to produce a draft position paper on the basis of the outcomes. At this point the UK chapter of ISAAC had already expressed concern with elements of the process and had indicated the desire to try to reflect the views of the diverse membership in their feedback.

The Three Principles of Evidence Based Practice are well understood by most AAC practitioners² (Figure 1).

It appeared that the decision taken by ISAAC to produce a position paper had been made on the basis of a partial element from one of these three principles; that of external scientific evidence. No consultation had apparently taken place with clients, patients, caregivers or clinical experts in the field of FC.

There is no denying that people who rely on AAC can be influenced. There is no denying that people who do not use AAC can be influenced. Influence is a fact of life that is even sometimes considered desirable. Yet it is perhaps the danger of influence that some people who argue against the use of FC rely on. This is despite the fact that there are a growing number of former FC users who now communicate independently. Yet AAC users who are not yet literate are not able to say everything they want to. If you can't



Figure 1 Three Principles of Evidence Based Practice

speak, the only way to do this is by writing or typing your thoughts. Practitioners in AAC use the provision of symbol based communication boards, books and voice output devices to support those who are unable to spell. By their very nature they are limited.

The discussion session examined whether prejudice was operating against those who use FC and went on to discuss alternative research questions that might provide a more balanced reflection on the contribution that FC can make to the AAC community. Interestingly the session was attended by people who either knew about or supported the use of FC or those who were neutral.

Instead of a debate between various viewpoints, we found ourselves working together to try to identify why there are such extreme and polarised views in regard to FC and particularly why some professionals object to it. Some users of FC have, once physical support was provided, been able to express higher levels of ability than they have been formerly assessed at. Amongst the community of users who have autism this occurs quite frequently. Could it be that FC poses a challenge to widely held beliefs about capacity and capability? If so, does this threaten a status quo in the assessment process within AAC? This is a difficult question to answer and one that has not, to my knowledge, been formally researched. Many proponents of FC call for a new paradigm that presumes competence rather than examining deficits.

It was felt by the group that researchers making statements in relation to the efficacy of FCT/FC need to widen the brief to look at all of the issues in relation to FCT/FC. Such areas include:

- Improved motor skills;
- Independent access to communication aids;
- Improved learning/skills measured independently and not involving physical support;
- Increased social inclusion;
- Improved behaviour and/or emotional status;
- Family and other relationship development.

Syracuse University's School of Education is actively involved in research around the efficacy of Facilitated Communication and a visit to their website allows the reader to examine research that supports FC including research that demonstrates authorship on the part of the person receiving support. Such research has included:

- The monitoring of conversations in natural settings where people have provided information unknown to the facilitator;
- Video eye tracking research showing that the participating users of FC looked at the intended target before it was selected;
- Evidence of speech before typing;
- Linguistic analysis of individuals' typing, demonstrating that the individuals with disabilities employ different patterns of word use and sentence construction than their facilitators.

Rosemary Crossley is credited as the originator of FCT. In a recent paper, Rosemary and Chris Borthwick criticise the lack of breadth in examining the evidence by researchers such as those involved in the development of the ISAAC position statement.³ They state:

"Science does not consist of a particular set of laboratory procedures; it consists of using those procedures when they are appropriate and using other procedures when they are not, and applying thought to what makes them appropriate or inappropriate in any given situation... An AAC intervention requires us to work with an enormous number of variables that are not constant, not susceptible to numerical measurement, and not subject to our control. The appropriate recording method for such situations is rich description. and the appropriate format is the case study or case series."⁴

Disabled People Against the Cuts (DPAC) has issued a statement in which there is criticism of the perceived flawed methodology used by the Ad Hoc committee advising ISAAC. It states:

"This outcome appears to have been contrived to protect the power of professionals and academics whilst ignoring the rights of communication for disabled people using FC."

In the UK there has been considerable effort to follow practice standards that emphasise the need to follow protocols aiming to minimise influence by ensuring that facilitators are properly trained. These standards urge the use of independent means of communication so that the person who can type with physical support can independently verify what they have communicated by, for example, pointing to a YES or NO card. The UK standards also expect facilitators to have knowledge of techniques in the wider AAC community so that FC has a place within that sphere rather than becoming marginalised.⁵

For more information about the practice standards or any other aspect of FC please email: *info@candleaac.com* *

Marion Stanton Lead Trainer and Assessor, CandLE Ltd

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JOINING COMMUNICATION MATTERS & ISAAC

Communication Matters is the UK Chapter of ISAAC (International Society for Augmentative and Alternative Communication), so members of Communication Matters are automatically members of ISAAC.

What are the benefits of Membership?

Members of Communication Matters receive this Journal three times a year, reduced delegate rate at the Annual CM National Symposium, and all the benefits of ISAAC membership, including ISAAC publications at substantially reduced rates (AAC Journal, ISAAC-Israel Newsletter, AGOSCI News), and special delegate rates for the Biennial ISAAC International Conference. You can also access the member's area of the ISAAC website and, if you join early in the year, you will receive a Membership Directory.

What is ISAAC?

Formed in 1983, ISAAC is a multidisciplinary organization devoted to advancing the field of augmentative and alternative communication. ISAAC has over 3,600 members around the world, including national chapters in Australia, Brazil, Canada, Denmark, Finland, French speaking countries, German speaking countries, India, Israel, Italy, Netherlands-Flanders, Norway, Sweden, United Kingdom and the USA.

The Mission of ISAAC is to promote the best possible communication for people with complex communication needs. The vision of ISAAC is that AAC will be recognized, valued and used throughout the world.

How do I become a Member?

If you live in the UK, you can become a member of Communication Matters (and therefore of ISAAC) by contacting: admin@communicationmatters.org.uk www.communicationmatters.org.uk

If you are outside the UK, you can become a member of ISAAC or subscribe to this Journal by contacting: ISAAC, 312 Dolomite Drive, Suite 216 Toronto, ON M3J 2N2, Canada Tel: +1 905 850 6848 Email: info@isaaconline.org www.isaac-online.org

Experimental Evaluation of SPEAKall!

An evidence-based AAC app for individuals with severe autism

OLIVER WENDT

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AAC AND AUTISM

Autism is a neurodevelopmental disorder marked by impairments in social interaction, deficits in the development of verbal and non-verbal communication, and aberrant patterns of restricted and repetitive behaviour (Levy, Mandell, & Schultz. 2009). One of the most significant disabilities in autism refers to a "delay in, or total lack of, the development of spoken language" (American Psychiatric Association, 2000). Approximately 50% of children diagnosed with autistic disorder are functionally nonverbal and do not acquire sufficient natural speech or writing to meet their daily communication needs (Light, Roberts, Dimarco, & Greiner, 1998). This indicates an urgent need for focused and ongoing intervention in augmentative and alternative communication (AAC).

One of the most popular AAC intervention strategies to enhance functional communication skills in autism is the Picture Exchange Communication System (PECS). PECS relies on behavioural strategies and a series of training phases to teach the exchange of graphic symbol cards in return for desired items, an approach that can lead to spontaneous communication with others (Bondy & Frost, 1994). PECS has been documented to be effective for several reasons (Preston & Carter, 2009): First, few prerequisites are necessary; the only prerequisite is that the client is able to indicate basic wants. Second, the primary skill taught in PECS is requesting which is an adequate goal in early instruction of individuals with developmental disabilities. Third, PECS tries to increase spontaneous communication acts, a particular problem in autism. And fourth, the graphic symbols used for picture exchanges can be made highly iconic, that is, closely resembling their referents. Thus, they are easy to acquire by the learner and are more recognizable by communication partners.

TABLET DEVICES FOR AAC INTERVENTION IN AUTISM

Another AAC strategy that is currently gaining popularity within the autism community is the use of iPads and other tablet PC devices. These iPad applications have benefits of their own that seem to go beyond those found with the PECS: iPads can display the same highly iconic graphic symbols on the display and appeal to visual-spatial processing strengths in autism. In addition, iPads are lightweight and very portable, highly motivating to use, easy to program, and socially appealing (Flores et al., 2011). Furthermore, such tablet devices provide the benefit of speech output via pre-recorded or synthetic voices. These can serve as additional auditory stimuli for the learner, which in turn may facilitate receptive and expressive language development.

THE NEED FOR AN 'AUTISM-FRIENDLY' APP

Many AAC apps have recently appeared for iPads and other tablets, but the vast majority of them tend to ignore particular behavioural and learning characteristics of individuals with autism. Available apps are often equipped with complex user interfaces that tend to overwhelm the autistic learner with visual stimuli. One particular sensory processing deficit in autism is the inability to select and attend to salient and truly important incoming stimuli within a stimulus-rich environment

(Minshew & Williams, 2007). For the starting communicator with autism, the user interface should be as easy to handle and navigate as possible, avoiding confusing and superfluous visual stimuli on the screen.

Many current apps also present with a hierarchical organization of graphic symbol vocabulary. This means, in order to locate a specific symbol, the user has to browse through a sequence of several broader, theme-based folders (e.g. 'Foods' > 'Snacks' > 'Popcorn'). Such an interface tends to increase cognitive load and adds a level of abstraction that learners with severe autism may struggle with.

Finally, users often encounter apps including graphic symbols that bear very little resemblance to their referents and are not highly iconic. Again, cognitive processing difficulties in autism make these a less favourable choice.

SPEAKALL! – AN IPAD APP PARTICULARLY FOCUSED ON AUTISM CHARACTERISTICS

Taking into account the specific learning characteristics in autism, an interdisciplinary team of Purdue University students from engineering, industrial design, and speech-language pathology created an iPad app similar to the PECS approach. This app is called SPEAKall! (see Figure 1). Instruction with SPEAKall! can incorporate all six major stages of the original PECS protocol, starting with the teaching of requesting skills up to more elaborated and spontaneous communicative acts.

Instruction differs by a variation of the graphic symbol exchange act. While in PECS graphic symbol cards are combined into little sentences on a



Figure 1 SPEAKall! app for augmentative and alternative communication in non-verbal autism

'sentence strip' for static display of the symbol(s) and subsequent exchange for the desired items, the SPEAKall! interface shows a "sentence strip that actually speaks"; whenever a graphic symbol is dragged onto the sentence strip area, the iPad provides either prerecorded or synthetic speech output.

The SPEAKall! interface can be tailored to individual needs. Any graphic symbol or photo taken with the iPad camera can be uploaded to its image library. To reduce issues with cognitive load and visual processing, selection area and sentence strip are clearly distinct and graphic stimuli on the screen are kept to a minimum. Graphic symbol vocabulary is organized by a range of 'activity sheets' for different contexts that the user can browse with a simple swiping gesture.

Typical autistic behaviours are addressed by a 'hidden lock button' and a randomization option for the graphic symbols. The lock button keeps the learner from (un)intentionally exiting the app and exploring other iPad functions. The randomization option shuffles graphic symbols to different screen locations forcing the learner to always look at the symbol and truly acquire symbolic comprehension instead of a simple, automated selection sequence. Overall, such a more 'autism-friendly' design allows users that come from PECS intervention to make an easy transition to communicating via an iPad (Figure 2).

RESEARCH EVIDENCE FOR SPEAKALL!

SPEAKall! is a research-based app that originated from clinical investigations into the benefits of AAC for learners with severe autism. Behavioural data as well as neurophysiological data were collected in the Purdue AAC and Autism Research Lab to document efficacy and effectiveness of iPadbased AAC intervention.

Behavioural evidence for intervention effects

A series of three different single-subject experiments were conducted to investigate different approaches to intervention with SPEAKall! Single-subject research designs represent a rigorous method to evaluating treatment efficacy and are ranked equally to quasi-experimental group designs in evidence hierarchies for AAC (Schlosser & Raghavendra, 2004).

Experiment 1 sought to investigate generalization-across-setting effects when iPads were used within the instructional framework of the PECS (Wendt, Hsu, Boesch, & Subramanian, 2012). Four students between 10-13 years of age were introduced to a modified PECS protocol (with infused iPads) across clinic, home, and school environments. Experiment 2 aimed to replicate the prior intervention results with a cohort of three young adults between 14-23 years while focusing on response generalization to untrained stimuli (Hsu, Wendt, Cain, Dienhart, & Simon, 2013). Finally, Experiment 3 evaluated the effects of a parent-training protocol for iPad-based AAC intervention (Wendt, Hsu, Cain, Dienhart, & Simon, 2013). This study involved three participants between 6-7 years of age. Specific emphasis was placed on response generalization to untrained items and procedural fidelity of parent implementation.

All study participants met the following criteria: (1) an official diagnosis of autistic disorder; (2) little or no functional speech operationalized as no more than 5-10 spoken words; (3) visual and auditory processing within normal levels; (4) adequate hand coordination for graphic symbol pointing on a tablet device; and (5) understanding simple



Figure 2 Boy with non-verbal autism making the transition from PECS to an iPad Courtesy of Purdue Speech-Language Clinic. (Parental permission obtained.)

verbal commands (e.g., "Sit down") and responding to yes-no questions.

Target skills and dependent measures included (a) the number of correct requests during a 20-trials session; and (b) the numbers of non-intentional utterances versus intentional vocalizations or word approximations.

Inter-observer agreement (IOA) for dependent measures and treatment implementation was established by rescoring 33-40% of all sessions and met acceptable standards of more than 80% agreement or accuracy.

Figure 3 shows an example of the data from one of these studies (Experiment 2). Three adolescents with severe autism were taught to request. Their initial baseline performance indicates very poor abilities to ask for either food items or toys. Requesting skills improve significantly as iPad-intervention with SPEAKall! is introduced, following the phases of the PECS protocol. Generalization probes show that once requesting is acquired for foods it can be extended to toys. The newly learned requesting skills are maintained eight weeks after intervention ended.

In general, the strongest results across all three studies occurred for mastery and generalization of requesting skills. The majority of participants was able to complete five out of the six phases of the modified PECS-iPad protocol, and acquired requesting behaviours could be generalized across settings as well as across item classes (from foods to toys). Mixed results were observed when targeting speech skills: whereas some participants made large gains and ended up speaking full sentences, others advanced to the level of increased vocalizations and word approximations while some remained non-speaking throughout the entire intervention.

Results from the parent-training study suggested that parents can implement an iPad-based SPEAKall! intervention with sufficient fidelity as their accuracy to follow the protocol never dropped below 80%.

Neurophysiological evidence for intervention effects

An emerging clinical application of brain imaging in autism is to conduct a quantitative electroencephalogram (qEEG). A qEEG measures electrical activity produced by the brain and displays states of neural functioning in the form of a brain map (see Figure 4). Such information allows to pinpoint anomalies in brain function and to document neurophysiological changes over the course of intervention. This technique was



Figure 3 Multiple-baseline design documenting the effects of SPEAKall! intervention on requesting skills for three participants between 14-23 years of age

used with some of the participants from the experiments 1-3 described above. Figure 4 is an example for one of those participants, a 14-year-old male with severe autism and no functional speech.

In the two rows of the brain maps, anomalies of electrical brain activity appear as red-shaded (too much activity) or blue-shaded areas (too little activity). The upper row shows the total amount of electrical activity going through the autistic brain, the lower row shows where unusual amounts of electrical activity occur relative to other brain locations. Improvement from pre- to post-intervention is demonstrated by a significant transformation of electrical activity to green-shaded areas (normal). The effect impacts five major areas of neuro-cognitive functioning (vertical columns) including arousal (delta), emotion and sensation (theta), alertness (alpha), decision-making and information processing (beta), and agitation (high beta).

CONCLUSIONS

Results suggest that an iPad-based AAC intervention can produce effects on behavioural and neurophysiological functioning of individuals with severe, non-verbal autism. This is an important finding as available research evidence for the use of mobile technologies for AAC purposes is still scarce (Wendt & Miller, 2014). These findings also validate the instructional principles of the PECS approach; these behaviourallybased strategies seem to be effective no matter if the communication modality is picture exchange or activation of symbols on a tablet device.

Intervention effects are most noticeable when targeting requesting skills. A facilitative effect on natural speech development cannot necessarily be expected, but did occur repeatedly for some participants. Such patterns are consistent with previous research on the PECS protocol (Preston & Carter, 2009). The parent-training results underscore the potential of including parents for maximizing benefits of



Figure 4 Quantitative electroencephalogram documenting the effects of SPEAKall! intervention on brain functioning for a 14-year-old research participant

such interventions. In summary, iPadbased AAC applications hold great promise for autism intervention and it is now important that these results are replicated and extended to build up the evidence base for the use of new mobile technologies. *****

> Dr Oliver Wendt Assistant Professor

DISCLOSURE STATEMENT

By 2013 SPEAKall! was being downloaded more than 500 times per month. Users asked for additional improvements and features and sought a more professional support organization. Hence SPEAK MODalities LLC was formed and licensed the technology from Purdue. Oliver Wendt is Chief Science Officer for SPEAK MODalities, LLC.

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What the Exam Boards Said

MARION STANTON

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For the past 24 years I have been supporting students who use AAC to communicate and to access the curriculum. As an advocate of universal inclusion, much of my work has been with mainstream schools but I have also supported numerous special schools. The focus of the input has tended to differ in each environment. I have worked with a number of special schools to support their use of AAC, assess individual students' access needs, and to support the teaching of literacy. In mainstream there is often a lot more work to do as school after school appears to be reinventing the wheel of inclusion. I currently work for a communication and learning aid centre that offers AAC support across the UK.

Assessing the real ability levels of students who rely on AAC and, more importantly, their potential to learn is very varied. There are no national standards guiding the support and development of the pupil who uses AAC within the mainstream. However, an agreed standard that falls short of meeting some individual's needs could stifle rather than support a student. Without a national standard, schools are free to be innovative, have the highest expectations, use dynamic rather than static assessment procedures, and to think outside the box. On the flip side, without a national standard that incorporates high expectations for this low incidence group of learners schools, there is a risk of falling short in meeting needs. Despite the lack of cohesion in inclusive education, however, a number of students who use AAC are managing to undertake the same GCSE level, and even A level exams, as those that their nondisabled peers can automatically expect to end their school life by tackling.

In order to be able to undertake a GCSE course and sit the relevant exam, the student who uses AAC will almost certainly require substantial support and quite complex access arrangements for which there does exist a set of guidelines. These are produced on an annual basis by the Joint Council for Qualifications (JCQ). The 2013/2014 regulations can be accessed at the following

website: www.jcq.org.uk/exams-office/ access-arrangements-and-special-consideration/regulations-and-guidance

This article needs to be read in conjunction with the JCQ regulations and guidelines, as they form the basis of the decision making process that the exam boards go through when they decide whether or not to allow a particular arrangement.

The regulations have been substantially changed for the current year and, although there may be minor adjustments for when the new ones are produced in 2014, it is reasonable to expect the regulations to largely remain as they are. However, keep an eye on the JCQ website, as updated regulations appear each year in August.

The exam boards are now expected, in law, to act within the Equality Act 2010.

"The intention behind an access arrangement is to meet the particular needs of an individual disabled candidate without affecting the integrity of the assessment. Access arrangements are the principal way in which awarding bodies comply with the duty under the Equality Act 2010 to make 'reasonable adjustments'.

"The Equality Act 2010 requires an awarding body to make reasonable adjustments where a candidate, who is disabled within the meaning of the Equality Act 2010, would be at a substantial disadvantage in comparison to someone who is not disabled. The awarding body is required to take reasonable steps to overcome that disadvantage. An example would be a Braille paper which would be a reasonable adjustment for a visually impaired person who could read Braille. A reasonable adjustment for a particular person may be unique to that individual and may not be included in the list of available access arrangements."1

There are two fundamental principles that are important when you are preparing to apply for special access arrangements for your students, that are acknowledged within the guidelines:

• Every student is an individual with their own specific set of needs. This means that requests for special access arrangements are made on a case by case basis. Whilst the guidelines are fairly extensive and most eventualities are covered by them, it is recognised that a need may be identified for which a guideline has not yet been written. This doesn't mean the need can't be met. It does, however, mean that examination centres (normally the school the student attends) may have their work cut out demonstrating how the need can be met without compromising the integrity of the exam.

• A student's normal way of working is the one that would normally be accepted for working through a GCSE exam. Again it may be necessary to demonstrate to the exam boards that a normal way of working does not compromise the integrity of the exam.

When I am working with students who use AAC that have just started in secondary school, usually in year 7, I immediately begin the process of supporting the student in developing a consistent way of working. I emphasise independent working where at all possible. By this I mean the use of technology so that the student can access everything that the other students access. The text books and worksheets need to be accessible to the students electronically via whatever software they can most easily and efficiently access. The technology also needs to be utilised so that the student is doing the work themselves and not relying on a teaching assistant or other student to turn pages for them, read to them and scribe for them.

Students who are unable to work independently are being disadvantaged in a number of ways. If an assistant is taking notes for them they can lose engagement with the learning materials. If they have no way of independently opening their version of learning materials and worksheets they are substantially dis-

¹ www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration/ regulations-and-guidance/access-arrangementsand-reasonable-adjustments-2013-2014standard-pdf-version, p3.

advantaged in comparison to their nondisabled peers who can just open the book or the worksheet and read or write as required.

If students have literacy difficulty, as is often the case with those who use AAC, an intense programme of literacy instruction, with special reference to developing spelling skills is implemented. It is highly unlikely that a student who is unable to spell (with word prediction if it is their normal way of working) will be able to undertake a GCSE. If a student is not spelling by the time they reach secondary school an intensive programme to ensure that they learn this skill and how to make the best use of word prediction is essential.

There may still be a group of AAC users for whom spelling, and consequently GCSE access, is not attainable despite the school's best efforts, and there are other examination routes that this group can go down. However, as a teacher I would never go down the alternative route until it has been absolutely established that the student cannot learn to spell and use word prediction. The only way to do this is through an intensive literacy programme which is generalised into assignments throughout the subjects that the student is following.

How do teachers decide that a student should be entered for a GCSE? Here are some pointers. If the answer to these three questions is Yes then I suggest you enter them:

- Are they able to construct and spell grammatical sentences, using word prediction if necessary?
- Are they able to understand the subject sufficiently to obtain a GCSE grade? Grades currently range from A through to G. For users of AAC the predictions that are normally made through end of primary testing may be less reliable than for their nondisabled peers as grades can be significantly raised through intensive input during Key Stage 3 (the first three years of secondary school).
- Are they able to work over the sustained extra time that they might need in order to tackle a GCSE exam? (This could be up to 4 or more times the hours that their non-disabled peers are given and, with breaks, this could mean some exams going over two whole days).

If the answer to the following three questions is Yes then entering GCSEs may present more of a challenge, though I would never say never!

• Are they unable to spell but able to produce grammatical sentences us-

ing word banks of core, fringe and subject specific words?

- Do they tire easily and/or lose concentration frequently?
- Do they take more than 4 to 6 times longer than their non-disabled peers to complete work?

If you have decided to enter your student for one or more GCSE you need to carry out an assessment of the student's needs in ways that conform with the requirements of the exam board that produces each exam. Before you approach the exam boards though, make sure you have read all of the guidance and made notes of how you feel it applies to your student. Also, and most importantly, gather evidence! If you think a student will need extra time then make sure you analyse the time they take in both end of unit and end of vear tests throughout secondary school. Keep records of this as well as the number of rest breaks they need. If there is a way of working that is consistent, ensure that all end of unit and end of year tests are completed with the student's normal way of working. Keep video, photographic and written evidence of the student's way of working and also of what adaptations you have needed to make to tests. Do this from the start of secondary school.

Below are some example of the kinds of access arrangements that might be considered, but bear in mind the need for evidence, some of which may involve standardised testing as advised by the exam board. Also be aware that the details of access arrangements change from year to year.

- adapting assessment materials;
- adaptation of the physical environment for access purposes;
- adaptation to equipment;
- assessment material in an enlarged format or Braille;
- assessment material on coloured paper or in audio format;
- British Sign Language (BSL);
- changing or adapting the assessment method;
- changing usual assessment arrangements;
- extra time, e.g. assignment extensions;
- language modified assessment material;
- practical assistant;
- prompter;
- providing assistance during assessment;

- reader;
- scribe;
- transcript;
- use of assistive software;
- using assistive technology;
- use of CCTV, coloured overlays, low vision aids;
- use of a different assessment location;
- use of ICT/responses using electronic devices.

Even if you have managed to create an independent way of working for your student, there will be times when the equipment breaks down and then you need a backup plan. At a recent access arrangement situation in which I participated, we took the precaution of having a back-up computer which turned out to be crucial. We were grateful for the suppliers of the student's learning device for helping us out by loaning a second device for the duration of the exams. On the occasions that both devices broke down throughout the exams - and it did happen once - we had to fall back on the use of a scribe with the student dictating using his communication aid. It is therefore important that you apply for **all** the supports you might need in every eventuality.

Finally, the exam boards want to help, but they must be seen to be fair and they cannot agree to any adjustments that they believe will compromise the exam in any way. As long as you have thought this through and are able to offer evidence and reasoned arguments regarding the access arrangements that your student requires, you have no reason to expect the exam boards to turn you down. However, just ringing them up with open questions about what they suggest a student that they have never met requires is not likely to get you very far. In this instance, the exam boards have nothing to fall back on but the standard guidance and no way of being able to ascertain your student's special case. That case is up to you to make.

Do contact me for more information on how we support schools in developing consistent and independent ways of working with students who use AAC. I am also very keen to research the ways in which schools have experienced their relationship with the exam boards and to gauge the numbers of students who use AAC that are managing to obtain GCSEs. Please email me with your experiences as a starting point. *****

> Marion Stanton Lead Trainer and Assessor, CandLE Ltd

Using *Kinect* as an Engagement and Emerging Communication Tool for Low Functioning Pupils with Autism and SLD

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This article looks at how using the Kinect motion sensor with adapted PC programs can help in engaging pupils with low functioning autism and other severe learning difficulties, giving them a reason to communicate. It is the result of a postgraduate SLD/PMLD action research case study completed for Swansea Metropolitan University in 2013. The author is a teacher at Trinity Fields School and Resource Centre in Caerphilly. This school has 134 pupils on roll from ages 3-19 and was given Sector Leading Practice by Estyn, the inspectorate body in Wales, for their use of gesture-based technology with pupils with severe learning disabilities in 2012.

Tom is 14 years old and is a very shy and withdrawn young man who is happy to be left alone. Tom has had a diagnosis of ASD since 2003 and has significant impairments in all three aspects of the Triad. He is working at a P5-8 level and has very limited communication, being immediately echolalic in direct conversation. Tom can, however, name flashcards of common objects such as 'car', 'ball' and 'house'. He is very vocal at times, when he will repeat words, tones and short phrases repetitively. Tom shows some understanding of concepts as he can match pictures and group in categories such as 'cars' and 'planes'. Tom is very prompt-reliant and

he needs prompts to transition, to eat his food, to drink and to go to the toilet.

He does not generally engage with peers or staff. If demands are overtly made of him, Tom will exhibit distressing selfharming behaviour. Frequently Tom will not move from his desk and he shows very little motivation to complete tasks or to enjoy himself. "A feature of autism, after all, is the lack of a need to make sense of the world" (Jordan & Powell, 1995, p40). Tom enjoys a very limited set of activities. He will complete jigsaw puzzles and he will play a Scooby Doo switch activity over and over again. This is worrying as "apparent lack of interest in anything can seriously affect access to education and quality of life" (Jordan, 2011, p148).

THE RESEARCH ISSUE

Tom therefore does not engage socially, is resistant to transitioning, is very prompt-reliant and has very low involvement levels. At the same time that I was wondering how to assist Tom, I was in contact with Dr Wendy Keay-Bright from the University of Wales Institute who kindly offered me a trial version of the PC version of the *Somantics* program to use in school. I had tried many different and varied approaches with Tom, so I decided to try Somantics with him too, to try to increase his engagement, to get him to interact and enjoy something, in fact to enjoy *anything* new.

SOMANTICS & GESTURE-BASED COMPUTING

Gesture-based computing involves the control of computers through the motions of the body, facial expressions, and voice recognition via new input devices. Some systems such as touch screens are already familiar equipment in many SEN schools through interactive whiteboards and touch screen monitors. Tablets such as the iPad respond to pressure, motion and the number of fingers used in touching the devices. Some devices react to shaking, rotating, titling or moving the device in space and gesture-based technology is a feature in mainstream gaming, e.g. the Nintendo Wii.

The Kinect takes gesture-based systems further as there is no need for buttons, touch screens or controllers because it uses a motion sensor camera to "recognise and interpret patterns in gross motor movements, including body movements and facial expressions" (Johnson et al, 2012, p26).

Somantics is "a suite of applications that use touch, gesture and camera input to encourage, capture and amplify the interests of young people with Autistic Spectrum Conditions" (Keay-Bright, 2012). The system is an 'interactive mir-





Kinect – start of the project

Kinect – increased movement

ror' where pupils can see themselves and their movements on screen in real time. With the 'mirror' and instant feedback element of Somantics, it supports developing both play and thinking in pupils with autism as it gives almost literal opportunities for "the learner developing an awareness of him or herself as a reflecting problem solver" (Jordan & Powell, 1995, p94).

ACTION RESEARCH METHODOLOGY

Tom completed eight sessions using Somantics starting with Session 1 on March 16th and ending with Session 8 on April 5th. All the sessions took place in the school ICT suite which ensured a distraction free area where I hoped Tom would feel safe, and during the testing I used the printout of the Somantics front screen as a transition aid.

I collected video evidence for the project. Sessions 1 and 8 include one minute video recordings of Tom using five of the Somantics applications: Sparkles, Kaleidoscope, Painter, Split Scanner and Ghost. These two sessions were my main 'opening' and 'closing' evidence to show any progression during the study. As the intention was to improve Tom's involvement and well-being, the Leuven Involvement and Well-Being Scales for Young Children were an ideal assessment tool (Laevers, 2005). These scales are usually used to judge how involved children are in their educational settings and how they are displaying well-being. The scale is 1-5, with 1 being very low involvement and well-being and 5 being extremely high.

To give a 'control' score for Tom's general everyday well-being and engagement in school, I filmed him at random on four occasions: completing a worksheet, a whiteboard activity, in the yard, and also transitioning. These four sessions adequately represent Tom's well-being and involvement levels in a typical school day. They were scored using the Leuven scales in the same way as the Somantics activities. All the scores showed that Tom's levels of engagement and well-being in school were low to extremely low.

RESULTS OF THE SOMANTICS SESSIONS

Session 1

It was very difficult for me to anticipate what Tom's reaction would be to the first session. He was a bit unsure of what to do and why he was there at first, and his well-being stayed at around low to moderate. His involvement scores were also generally low for four of the Somantics activities: Kaleidoscope, Split Scanner, Ghost and Sparkles. The Painting session was very successful, however, and Tom scored both high wellbeing and involvement scores for the whole session. This is why I decided to focus on the Painting application for the remaining sessions.

Session 8

The results for session 8 showed Tom improving to score a moderate to high well-being level for all the sessions. In the video, Tom is seen experimenting and interacting with Ghost and Kaleidoscope in more varied ways than in the first session. The Painting application was the greatest success and Tom is extremely highly involved for the majority of the session. He is moving around the whole space, making quick and slow arm movements, exploring how he can interact with the system and he presents as very happy indeed. The video evidence gives a practical example that "A child who is involved is completely absorbed by the activity" (Laevers, 2005, p10).

Development through Sessions 2-7

The scores showed an improvement between sessions 1 and 8 but perhaps the most important results came in the developments between them – especially in the way that he interacted with the Painting application of Somantics, and they are worth describing. During session 2, I increased the field of play so Tom would have to move his legs to change the colour. He did reach right down to touch the floor without bending his knees but his legs stayed rooted to the spot and he would not move at all! In session 4, I introduced a large physio ball and Tom used this to paint, first by rolling it on the floor, then by picking it up and rotating it around himself to paint, still without moving his feet. During session 5, I started to name the colours myself as they changed and Tom moved a little to retrieve the physic ball. I asked Tom "What colour?" on a few occasions and Tom answered me a few times. One minute and 28 seconds into session 6, after he had chosen the paint application by touching the icon on the wall, Tom moved his feet to sidestep! This was one 'eureka moment' as it was not prompted at all, Tom sidestepped a few times in this session and also showed slower, more controlled hand movements. Session 6 also includes a very important moment; at 7:53 into the session, after a quiet period when the colour changed to orange, Tom says "orange" clearly and without any prompting. This was the first time I had heard him say an unprompted word to describe anything, not just in the Somantics sessions but since I had known him.

The Somantics activity suited Tom very well – "having the freedom to explore and reflect on the effect of their actions through a combination of sensory and cognitive processing gives rise to developmentally appropriate uses of ICT" (Keay-Bright, 2011, p4). The sessions brought to life for me the idea that "Gesture-based technology can be considered a medium within itself that students can learn from, as an interactive, active learning platform, rather than simply a means to play or access study material" (Osborne, 2012).

The most important aspect of this study for me was that "communication does not occur unless the child has a reason



Kinect - choosing activity independently

for communicating" (Jordan, 2001, p54). The use of non-fail, exploratory graphical gesture-based software can greatly facilitate and improve the engagement, interaction, movement and communication of pupils with low functioning autism and other severe learning difficulties.

REFLECTION

In our school and in the SEN community in general, we are just exploring gesture-

based technology and what it can help our pupils to achieve. We are used to thinking 'out of the box' in SEN teaching and with these gesture systems the possibilities are there "to create entirely new forms of interaction, expression and activity" (Johnson et al, 2011, p25).

There need to be more resources such as Somantics made available for the Kinect; the mainstream gesture-based



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systems are mainly games to play, but to our pupils they open up a whole new world of opportunity. "As an enabling or assistive technology... gesture-sensing systems are already having profound implications for special needs and disabled individuals" (New Media Consortium, 2012, p27).

I am genuinely excited by the whole field of gesture-based technology and its potential uses with SLD and PMLD pupils. *

> Anthony Rhys *Teacher*

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HeadBanger

Tracking Head Position as a Controller

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INTRODUCTION

Prolonged use of head switches can lead to user dissatisfaction, fatigue and rejection of the technology. At Beaumont College, Lancaster, we have been experimenting with a system to enable the operation of virtual controls through head movement without the need for physical switches. We have written custom software to repurpose off-the-shelf equipment to implement this idea. The operator interacts with the system through head motion and no markers need to be worn.

The desire for a non-contact and noninvasive human computer interface using head gestures was identified by the Assistive Technologist and Occupational Therapist professionals at Beaumont College in Lancaster who have extensive experience of working with people with disability. Beaumont College is an educational establishment of Scope and has around 94 students, aged 18-23; many have impaired mobility due to conditions such as cerebral palsy. Some of the students utilise physical head switches to operate software such as Sensory Software's Grid 2.

All testing took place in the technology evaluation room at Beaumont College using volunteers from the student community under the supervision of the College's staff.

TECHNOLOGY

Two depth camera systems were selected for tracking head movement, the Microsoft Kinect and the Asus Xtion Pro (Figure 1). Both of these are designed to enable people to interact with leisure software, such as games or fitness programs, by body movement. These depth cameras project an infra-red pattern of dots to allow the three dimensional structure of objects in their field of view to be calculated.

The Microsoft Kinect was released in 2010 as a controller for their popular Xbox game platform. We are using an enhanced version of this controller, known as the Kinect for Windows, which enables tracking at a closer range than the Xbox version. Microsoft released a software development kit (SDK) for the Kinect in 2011. The Kinect has a motorised base to allow the tilt of the camera head to be adjusted through software control.

Depth cameras are being used rather than web cameras as a long term aim with this work is for recognising gestures with other parts of the body, not just the head. As the depth cameras



Figure 1 Microsoft Kinect for Windows (left) and Asus Xtion Pro (right)

were developed as game controllers, it seemed an obvious approach to repurpose them for this research.

The Asus Xtion Pro, developed by Primesense, has the same functionality as the Microsoft Kinect apart from lacking a motorised base. The Xtion is programmed using the OpenNI (Open Natural Interaction) software library. We used the Processing language and development environment which is a simpler programming platform than Microsoft's environment. Unfortunately, Apple acquired Primesense at the end of 2013 and closed down any further development of the Xtion hardware or the supporting software.

The smaller size of the Xtion in comparison with the Kinect and the fact that it can be powered directly from a USB port give it the potential to be mounted on a wheelchair tray. Programming the Xtion is easier than programming the Kinect, but the Kinect can be programmed to recognise a seated user more easily.

Now that Apple has ended any further development of the Xtion's software, there will be no extra functionality for this system in the future. The Kinect can be given greater functionality through the more developed programming platform (the C# language, using Microsoft's Visual Studio 2012 development environment), but is physically obtrusive in comparison with the Xtion.

SOFTWARE

Two approaches for displaying the head position and creating an interaction with virtual controls were tested. The first was to display the three dimensional depth image directly from the depth camera and to position virtual controls around this. The second approach is to create a cartoon representation of the



Figure 2 Asus Xtion depth camera data, front view. Left hand figure shows two inactive controls. The right hand figure shows one control activated by the participant moving his head to the side.



Figure 3 Asus Xtion depth camera image, as if looking vertically down on the participant. Left hand figure shows a control activated by a sideways head motion. Right hand figure shows a control activated by a forwards nodding motion.

student's head, which moves along with their head.

Depth Image View

Figures 2 and 3 show screen grabs from the depth image based software. The participant's head is displayed using the camera's depth image data. Figure 4 shows the system being tested at Beaumont College by a volunteer student. Virtual controls are placed around the head which are activated by moving the head into them.

The controls can be positioned to allow for the movement range of the user. For instance, it may be easier for one student to nod into the target with a forwards motion and another may prefer moving their head to a particular side to activate it. Figure 2 shows screenshots of an interaction with the virtual controls.

The software can calculate what the user would look like from a different viewpoint. Figure 3 shows an inferred view as if looking vertically down onto the participant. This allows the controls to be accurately placed in front of or behind the user within the comfortable range of motion of the student. The aim is to reduce user fatigue by minimising the motion necessary to operate the controls. In this figure we can see two different arrangements of controls. In



Figure 4 Testing head tracking at Beaumont College

the first, the user operates a control to one side, in the second the control is operated by nodding into it. Some students find it easier to nod their heads than to move their head sideways. The positions of the controls for different students can be saved, so each user would have an arrangement of controls customised to their individual movement characteristics.

Participants with reduced cognitive ability may have problems with relating the image on the screen to their own head movement. Preliminary testing in the college showed that students who were experienced with using a head mouse were able to interact with the software successfully. Students who were not used to this modality of interaction required coaching. It was apparent that the display was not intuitive enough for all users.

As this software used the absolute position of the student and places the controls in fixed positions relative to the depth camera - not relative to the student - the controls do not move with the student. So the student needs to be in a fixed position relative to the camera to interact. If the depth camera were to be mounted to the student's wheelchair, this would not be a problem. However, the current technology is too bulky for this to be a realistic user scenario. The range that the depth camera detects at can be set through software, which is a way to tune out somebody in the background interfering with the system.

The experience and problems encountered with this initial system led to the development of a second approach for head tracking.

Skeleton Tracking

The depth cameras can be programmed to recognise the joint positions of whoever is in the camera's field of view: this is known as skeleton tracking. To enable head tracking, the software specifically looks for the head and neck nodes. Tracking these in three dimensions enables the head's tilt and inclination to be calculated. This data is then used to control a cartoon icon which moves with the student's head (Fig. 5).

To operate a control, the cartoon icon is moved through one of the control blocks. This changes colour to give a visual feedback that a control has been activated. A different cartoon icon would be used for an older age group of users! The software can track several people at once. To avoid confusion, only the closest user to the depth camera has control over the icon. The virtual



Figure 5 Screen grab from the skeleton tracking software showing inactive controls

targets will be placed around where the student is detected, so interaction can take place anywhere in the camera's field of view as the controls will move as the student moves. The head movement is amplified in the display to give a clearer visual feedback to the student.

A balance has to be found between minimising the work done by the student to activate a control and ensuring that the controls are activated intentionally. Filtering is applied to the head position to remove any jitter from the tracking. A minimum time for a control being allowed to reactivate prevents a student from inadvertently double tapping a control: this is known as debouncing. The parameters for the filter applied to the head position and the debounce time values need to be adjusted to balance removing false target activation against slowing the interaction. Testing and student feedback are necessary to arrive at a happy medium.

The same interaction was tested with both of the depth cameras. The Microsoft Kinect proved to have more stable identification and tracking. The Microsoft software development kit has an option to look for a seated user and ignore the lower half of the body, whereas the Xtion software looks for a full skeleton model before starting to track, so it takes longer to recognise a seated user.

Initially the cameras were mounted on top of a desktop display, slightly above eye level for a seated user. Head tracking with the sensors mounted at this level was reliable for students in wheelchairs so long as their bodies were not occluded by a communications device attached to their chair.

Attaching the communications device partially occludes the student's body and the software could not build a model of where the student was. To enable reliable head tracking with a communications device attached to the chair, we raised the Kinect on top of a tripod (Fig. 6). This gave the camera a clear line of sight to the points of the skeleton that the software uses to calculate the head position with.

INTEGRATION WITH SENSORY SOFTWARE'S THE GRID 2

We aim to enable the students to control Sensory Software's Grid 2 through

head movement. This software is used extensively throughout the College. Zak Sly, a Technologist at Beaumont, created two test grids.

One is a single grid square, that toggles a network enabled light on and off (Fig. 7). The second is a simple music player that allows the operator to select a track, play or pause, move forwards or backwards by a track (Fig. 8). Getting the test software to act as a controller for the Grid presented some problems, but these were overcome. Barney Hawes, Software Development Director of the Grid, kindly sent some example code that allows the Grid to be controlled through the brain computer interface option.



Figure 7 Grid controller for a light, that toggles the light on and off



Figure 8 Test Grid music controller with the play function active

PROPOSED IMPLEMENTATION

The initial deployment is planned as a television controller in a shared space. A Kinect will be mounted on top of a large screen television, connected to a tablet computer which contains the Grid software. The tablet will be connected to an infra-red remote controller mounted on the room's ceiling, which controls the television. The students will be able to operate the television using a Grid controlled by the head



Figure 6 Testing the skeleton tracking software with the Microsoft Kinect at Beaumont College

tracking software. The software will be tuned only to activate when a student is within a certain distance from the television and will only track the student closest to the television.

FUTURE DEVELOPMENT

The skeleton tracking software will be extended to enable the students to activate a control with a nodding motion, as was possible with the depth camera image software.

Depth camera technology is being miniaturised by hardware manufacturers with the aim of embedding it into devices such as laptop displays. When this happens, we hope to leverage these offthe-shelf devices to enable wheelchair mounted personal devices, perhaps mounting a suitable device on top of the communications device. Depth cameras have the advantage over web cameras of being able to remove any unwanted input from behind the intended operator. However, until the depth camera technology is suitable for mounting on a wheelchair, we intend to port head tracking to a web camera to implement the head control interface.

> Matthew Oppenheim, Researcher Zak Sly, Assistive Technologist

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- Asus Xtion: www.asus.com/Multimedia/ Xtion_PRO_LIVE (accessed January 2014)
- Kinect for Windows: www.microsoft.com/enus/kinectforwindows (accessed June 2014)
- The Grid: www.sensorysoftware.com/ thegrid2.html (accessed March 2014)

PROJECT WEB SITE

https://sites.google.com/site/ hardwaremonkey/home/headgesture



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