

# COMMUNICATION *MATTERS*

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# My Communication Story

**KATE NORTON**

[www.livingwithataxia.org/profile/Kati](http://www.livingwithataxia.org/profile/Kati)

Kate keeps a regular blog at: [www.livingwithataxia.org/profiles/blog/list?user=2nly9cw0x9lp5](http://www.livingwithataxia.org/profiles/blog/list?user=2nly9cw0x9lp5)

**The last seven years have taught me a lot about people, not just others but also myself and my ability to cope with whatever life throws at me.**



Although I had a slow start and disabilities as a young baby/child (due to having been born with my thyroid not working at all which was not found out until I was nearly two, and epilepsy), I went to a regular primary school and I remember hearing, being physically able to run about and ride bikes with friends and so on. I could speak and hear, and learnt to communicate pretty much the same way as most people. I know I owe my experience of a 'normal childhood' to my parents who were very dedicated and determined.

When I lost my hearing at 16, it seemed like I had moved to a parallel universe! Words, even if I could hear them with hear-

ing aids in, made little sense. They were just a series of sounds and it was like trying to decipher a foreign language unless someone provided you with the words to read so you knew what they had just said.

Visiting the doctor, bank or anywhere with those glass panels at the reception became somewhat similar to visiting an aquarium as the lips moved silently up and down on the other side of the glass, doing fish impressions! Which, although quite amusing at times, was also frustrating so I soon learnt to carry a paper and pen with me, to ask others to write down what they had said.

My own speech was still clear at this stage. Other people had no problems understanding me, and often didn't realise at first that I was deaf. But by the end of my first year of mainstream local college I was struggling to keep up in classes, and with no knowledge of how to lip-read or compensate I was soon miles behind.

My parents decided I would be better going to a college for the deaf to learn to lip-read otherwise I was never going to be able to hold down a job if I couldn't communicate with 'the rest of the world'. I think it was a hard decision for them after fighting to keep me out of special schools so far, but I am glad I was allowed to go. I went to Doncaster College for the Deaf whose philosophy was 'Total Com-

munication', i.e. using all available methods to make sense of the world and communicate with others, for example you were encouraged to use any residual hearing you had left, as well as developing lip-reading skills and using signs to assist learning.

I learnt a lot from other kids who had been deaf all their life, and I adapted quite quickly. I was fluent in sign by the end of the first term (it was residential so I was exposed to signing all day every day) and although lip-reading took longer to master I was quite good by the time I left and able to follow most people. The other deaf kids taught me other compensation strategies and I learnt to be aware of drafts, vibrations, reflections off any reflective surface and anything that might signify someone else was behind you or something else was happening based on other people's body language and where they were looking, etc.

I found I could lip-read some people more easily than others; some just naturally have better lip patterns that are easier to work out. I also discovered that lip-reading is a bit of a misnomer, as you aren't just reading lips. You have to learn to put visual clues together like a jigsaw: facial expressions, body language and the context of what you are talking about also plays a big part. Some words look identical on all lips, for example *job*, *shop*, *chop*.

In this situation you just have to guess from the context which word is the most likely.

Rather than pure BSL (British Sign Language) which has a completely different grammatical structure to English, at College I used Sign Supported English (SSE). For example "What is your name?" in SSE would be signed in the same order as spoken English (subject, verb, object) whereas in BSL it is topic, comment - 'Name you what?' emphasizing the core of what you are talking about. BSL is a very visual language and for that reason is difficult to follow at first, after having been used to English grammar all your life.

The SSE gave me the vocabulary of signs that I needed and I also learned BSL from my roommate who was deaf-born and a native BSL signer, which was very useful for later accessing University, something I wouldn't have been able to achieve without an interpreter.

It certainly kept your brain sharp if you consider the speed lecturers usually speak; the interpreter had to translate that into BSL (quicker than SSE) and sign it to me, I then had to translate it back again in my head.

My situation seemed to bring out the best or worst in some people. Some people were just shy but curious, and others were plain ignorant! Their body language told me which was which. One lecturer would praise the interpreter, and she would have to explain she was just translating my answer. Another lecturer asked if he must put up with 'this charade', and a complaint had to be made about his attitude.

I never really considered how important everything I had learnt at Doncaster College was, until I had a job working with adults with severe learning disabilities. In the group I was in most of them were non-verbal - they all had different ways of communicating, and with one person (she had autism) you had to guess what she wanted or what was wrong as she had never spoken and wouldn't even point to things. It made me aware of how totally dependent they were on someone else's interpretation of what they wanted or needed. They relied on someone knowing them well, which profoundly restricted their ability to communicate with the world. My heart went out to them - it was hard enough just being deaf, I couldn't imagine what their world was like.

My world involved a lot of guesswork and piecing together bits of information to work out what was happening or being said. Some days were quite exhausting - I never had problems sleeping! It was nice to relax in the company of other signers when communication was much easier.

At this time my circle of friends were mainly all deaf with a few hearing students who were interested in sign and hung out with us because they wanted to learn.

Coming back home and finding work with new people to learn to lip-read again was a new challenge, but I was quite an experienced lip-reader and my speech was still understandable to others.

This lasted until my early thirties when I suddenly started experiencing sight problems. These were the first signs that my thyroid wasn't working as it should (although undiagnosed at the time) but luckily the sight wore off again after four months.

Those four months really shook my confidence in communicating and getting about, as having been deaf since 16 I relied on my eyes totally.

My vision went in and out, subtitles were difficult to read on TV and lip-reading was difficult - I'd get bits, then the rest would be blurred. It was like someone playing with the buttons on a zoom lens and things going in and out of focus.

I started learning Braille but to my great relief the visual symptoms went away after a few months.

But I was getting stiffer in my back and legs and by the following February (2003) I woke up barely able to move I rang my brother who took me to doctors. I was admitted to Neuro ward for further testing for MS, MND, etc.

Hospital is awful at best of times, but when you are in a ward full of people you can't understand, and then nurses coming - flapping their lips at you then sticking a needle in you or something without even checking I understood what they said they were doing - it wasn't much fun! The TV didn't have subtitles and it was very boring. I managed to stick it out until after the MRI then discharged myself as it was Friday and I didn't want to be stuck in there all weekend doing nothing.

By June I needed a walking stick (age 33) and was using a mobility scooter to walk my dog Inca. Getting through the day was exhausting so I didn't go anywhere other than taking Inca out.

They eventually found my T3 levels were dangerously low. Basically your thyroid (when it works) produces a hormone called thyroxine that the experts call T4 then your body converts it to T3 to feed your cells/organs, etc. make everything work. If your Thyroid levels are too low your Thyroid Stimulating Hormone (TSH) will send messages to say you need to make more. As my thyroid has never worked from birth it couldn't respond to these messages so my TSH levels were

getting higher and higher whilst my T3 levels were dropping in spite of the thyroxine drug I took.

I was struggling with my speech by this stage but was told once they sorted my thyroid levels out my symptoms would go away. Some symptoms went, like the exhausting fatigue and constant pins and needles but the Ataxia symptoms stayed and then started progressing despite getting thyroid levels back to normal again.

Having successfully adapted to being deaf, when I later had to start using a wheelchair, I told myself, 'it can't be that hard, just get on with it!'

I met a few people who were paraplegic wheelchair users, who taught me a lot. I was reassured that they still lived independently, so I could too - I just needed a few adaptations. After getting a mobility scooter I was soon managing the dog walking and shopping myself again.

About a year after moving into an adapted property I started noticing other difficulties; my bladder was always playing up and I was clumsy with my hands, knocking plates off worktop, etc. Also, people I didn't know seemed to be having more difficulty making out what I was saying, and I seem to get more tired just from trying to speak - especially long explanations.

Typing was getting frustrating, as I'd hit the wrong key and sometimes the same key several times. This was a problem for text phone use.

I searched on the Internet for a solution for me to be able to type as fast as I used to, which was a futile and impossible mission really considering I was trained in Business Studies and touch typing and used to type over 200 words per minute! I switched to an iMac computer with Key-strokes, (assistive software that provides word prediction, abbreviation-expansion and on-screen keyboards etc) and a special joystick so I could move cursor as fast as I used to be able to use a mouse.

I developed an intensive exercise routine to try to stop the ataxia progressing. In some respects this has worked, but on the other hand it hasn't stopped my arms from getting more 'jerky' movements to them, (though I guess it might have been worse if I wasn't doing as many hand-eye co-ordination exercises everyday). I'm starting to reach stage where I am using wrist weights to steady hands so I can chop vegetables safely without taking my fingers off and they are useful for keeping arm steady when I need to iron or want to paint or draw. They are tiring to wear for long periods though. I have mastered the art of controlling an electric wheelchair without needing fingers and fine motor co-ordination, using a big sponge ball on



top of joystick then using the underneath of my forearm rested on top of it.

Now I seem to have reached a stage where I have accepted that no amount of special software/equipment is going to allow me to move as quickly or fluently as I could naturally, before I had ataxia, and I have had to learn to be more patient with myself and less of a perfectionist.

From walking normally to needing wheelchair most of time took under 18 months and my speech started going downhill shortly afterwards.

It was around the time my speech was becoming unintelligible to new people. I went to a council meeting with my social worker. It was about improving the lives of people with disabilities in my area. A lot of other deaf people were there too and there were several interpreters.

We had to split into groups to 'brainstorm'. Luckily my group was all deaf people and we had one of the interpreters. This was the first time I became aware that the ataxia was also affecting my signing ability, as the interpreter seemed to have difficulty working out what I was signing. I could see that his lips weren't matching my signs when he was translating.

Using my voice didn't give him much extra help either, though he got it in the end as one of the other deaf people helped. I was thinking "but I just signed that, why didn't he understand it when I said it?"

I left there feeling frustrated and wondering how I was going to manage if I couldn't make people understand me with either my voice OR signing. What kind of future was I going to have and what quality of life? (I didn't know at that time that I was going to get funding for a communication aid).

It made me think again of the people I used to work with at the day centre who were dependent on staff's interpretation of what they thought the person wanted or needed.

Last week I finally received my LightWriter 40 communication aid and I can't believe the feeling of confidence it gave back to me, even though I only used it locally in my sheltered complex. I think it was just knowing that if someone couldn't work out what I was saying I could type it on LightWriter. I used a combination of typing and signing with a lady who could sign but had never met me before so I suspect was having some difficulty working out what some of my signs were meant to be.

I think of the deaf school philosophy of 'Total Communication' and I can't think of a better example than the multiple systems I have in place to make sense of the world around me (lip-reading, body language, signing) and my own developing way of communicating with others (signs,

sounds - when I can get any out, LightWriter, pointing).

Combined together these make an effective example of a 'Total Communication' package and highlight the importance way in which different systems work best in different settings and there's no reason why they can't be combined together to create one highly effective communication system.

It has all been a steep learning curve and a long journey so far but as I reach my 40th birthday this summer, seven years after the ataxia started, and although it has progressed quite quickly compared to most, I am still managing to live independently. I think I wouldn't have managed this without the Internet and the ability to communicate with people of all different levels of ability all around the world.

*You Tube* has been helpful as there are many videos of people attempting to dress themselves and do other tasks with limited hand function, which has given me ideas of how I can manage things now and in future as things progress. I love my gadgets and already know which ones I need to get for further down the line. Some of them can be a great help however simple the idea behind them, and can sometimes be used to help in other ways than the original task they were intended for. For example, I also use my grabber - originally designed for picking things up off floor, for opening the curtains and for operating the 'twiddling stick' on kitchen blinds (to open and close them).



And last, but by no means least, I love my faithful little friend and companion through this journey - my 'little girl' Inca. She has been my ears when I needed her to be, my hands, my motivation to get up every day, who willingly learns every new task I teach her, without complaint so that I can stay independent for as long as possible. I definitely wouldn't have got this far without her. \*

Kate Norton



#### UPCOMING EVENT

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1 Voice

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Tel: 0845 330 7862

Email: [info@1voice.info](mailto:info@1voice.info)

[www.1voice.info](http://www.1voice.info)

# The Road to Independence

## DAN STANTON

Email: [danstanton@btinternet.com](mailto:danstanton@btinternet.com)

Facebook: [www.facebook.com/profile.php?id=620822751](http://www.facebook.com/profile.php?id=620822751)

MySpace: [profile.myspace.com/index.cfm?fuseaction=user.viewProfile&friendID=358600782](http://profile.myspace.com/index.cfm?fuseaction=user.viewProfile&friendID=358600782)



**My name is Dan Stanton. I am twenty.** I am going to talk about how I got here with my own flat and a group of great mates. I will mention AAC too.

A year and a half ago, until which time I lived with mum, Mick and Katie my sister, I moved into my own flat.

I have direct payments and choose my own assistants with help from my mum.

It's great to have my own place. I'd be so pleased if everybody with cerebral palsy could be so lucky although it should be your human right not luck.

I'm also out a lot on trips. I went to Windsor castle and the Proms not long ago.

I went to mainstream school until I was 16. There is a video clip of me in school on You Tube at this link: [www.youtube.com/watch?v=pB3yUguXLy0](http://www.youtube.com/watch?v=pB3yUguXLy0)



Figure 1 Communication board

The poem I was working on had to be in the style of the Lady of Shalot. You can read the poem at website: [www.contactcandle.co.uk/about\\_dan\\_stanton.htm](http://www.contactcandle.co.uk/about_dan_stanton.htm)

I don't like it when people treat me like I'm stupid and think I don't understand.

I have my own bank account and sign my name with a stamp. I use the communication board shown in Figure 1 when I go out.

The Passport Office would not accept my stamp, which I was very angry about. It is not fair that different people in powerful positions can just make up rules that make me not a person just like them.

I have used lots of different communication aids. Figure 2 shows some boards I used when I was younger. At the moment I use a head pointer and The Grid 2 software with a touch screen (see Figure 3) or the low-tech spelling board. I'm hoping to try an eyebrow switch soon. I have a Dynavox but it is out of date. It has been difficult getting communication support even though mum works with people who use communication aids.

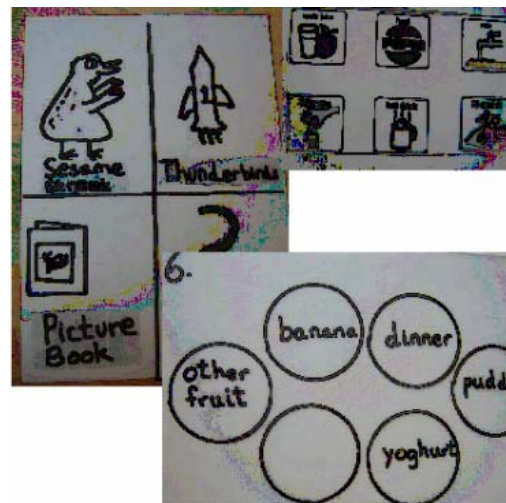


Figure 2 Some communication boards I have used



Figure 3 Using The Grid 2 with a headpointer





Figure 4 With friends on holiday



Figure 5 With school friends

My friends matter more than anything. I had a PATH meeting that sorted out regular times to meet. They help me to build MySpace and we are planning to write some music with me playing SoundBeam [1]. We keep in touch on MSN. A PATH works on planning positive futures helped by friends and family with someone who leads the meeting. You dream then see what is possible. You can find out more about Person Centred Planning at these websites:

- [www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk)
- [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)
- [www.inclusive-solutions.com](http://www.inclusive-solutions.com)

At the Communication Matters CM2008 National Symposium presentation I showed a video clip of me and my friends rehearsing a piece of music.

We had fun making it even if we aren't going to win the 'Britain's Got Talent' contest anytime soon.

You can see the whole presentation with the videos at: [www.youtube.com/watch?v=8YENrHPU\\_xc](http://www.youtube.com/watch?v=8YENrHPU_xc)

Dan Stanton

#### FOOTNOTE

[1] Dan's mum writes: Since the presentation at CM2008, a YouTube video clip has been added to show Dan's progress with SoundBeam – see: [www.youtube.com/watch?v=RtwSo2eunyY&feature=channel\\_page](http://www.youtube.com/watch?v=RtwSo2eunyY&feature=channel_page)

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# The Experience of Providing Rehabilitation for Patients with Locked-in Syndrome Through the Use of Communication Aids: A qualitative study

D NIANIOU<sup>1</sup>, K HASTIE<sup>2</sup>, L MAENDL<sup>2</sup> & A JORDAN<sup>1</sup>

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## INTRODUCTION

It is well recognized that communication between patients and health care practitioners is a crucial factor in the provision of high-quality healthcare (Adair, 1994; Young, 1995). Effective communication contributes to people's overall health outcomes (Di Blasi et al, 2001) and helps to ensure that patients' needs, rights and wishes are respected (Bensing et al, 2000).

People with communication disabilities are at risk of not being able to communicate successfully with their health care providers (O'Halloran et al, 2008). A large number of patients admitted to hospitals are incapable of speaking as a result of developmental, physical or acquired disability (Beukelman & Mirenda, 1998). Patients with Locked-in Syndrome (LIS) have complex communication needs and, as with other patients with severe communication impairments, their communicative interactions with healthcare providers can be problematic (Balandin et al, 2001; Barr, 1997; Hemsley et al, 2001).

Little is known about communicative interactions with health providers when the patient has severe communication impairment. A limited number of studies report that nurses have expressed negative emotional responses and difficulties in caring

for patients who are unable to speak. Most of these negative experiences appear mainly to be related to communication breakdowns arising from limited understanding, availability and use of augmentative and alternative communications (AAC; Barr, 1997; Hemsley et al, 2001; Magnus & Turkington, 2006).

## LOCKED-IN SYNDROME

Patients with Locked-in Syndrome (LIS; Plum & Posner, 1966) have complex communication needs and thus communicative interaction between them and health practitioners can be challenging. LIS is a neurological condition characterised by quadriplegia, mutism, lower cranial nerves paralysis, intact consciousness and paralysis of the facial expressions (Patterson and Grabois, 1986). Although all the voluntary muscles of the body are completely paralyzed with the exception of those controlling vertical gaze and eyelid movement, consciousness and cognitive function remains intact. Patients are completely aware of both internal and external stimuli and are able to think and make decisions normally (Patterson & Grabois, 1986).

Communication for patients with LIS requires engagement of both the patient and the communication partner. Preservation of the eye movements enables patients



Figure 1 A common communication method for people with LIS is the E-Tran board. Communication is established by the person looking at the wanted letter and then at the corresponding colour of the letter.

to blink and establish a basic communication through the use of various alphabetic spelling boards such as the E-Tran board (Foster, 2007). More advanced computer-based communication technology can enable the patients to use a word processor by picking letters from a computer screen coupled to a speech synthesizer either with some preserved bodily movement or the movement of the eyes (Duckowski, 2003).

Research has shown that early multidisciplinary rehabilitation for patients with LIS has contributed to a remarkable reduction in the mortality rate and to an improvement of functional recovery (Casanova et al, 2003). A study by Foster (2007)



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*Leigh: "The Lightwriter® SL40 was essential during a medical emergency when I had to communicate with an on-call doctor after an allergic reaction. I like the new word prediction and also the Notebook feature where I have stored all my personal medical information in case of any more emergencies!"*



*Beth: "The Lightwriter® SL40 has changed my life. I talk with everyone at school, text my friends and use it anywhere. What I like the most is the new word prediction. It's different from before but easy to learn and use."*

*Brian is delighted that he can text friends and family so easily. His wife says: "He used to find it difficult to hold his mobile phone and often dropped it." Now she can go out knowing Brian can always contact her from his Lightwriter® SL40.*



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has revealed that advances in communication spur rehabilitation and that although medical recovery may be slow and subtle, any improvement can make a difference to the patient's quality of life. However, according to Foster (2007) the biggest problem in LIS care is that medical staff stop communicating with the patients and communicate instead with the family caregivers – who do not always fully understand the needs and wishes of the patients.

Because the treatment of many of these patients requires a lengthy stay in hospital, it would seem critical to better understand the communicative interactions between health providers and patients with LIS.

The area of LIS is as yet poorly explored. Additionally, there is limited knowledge in the field of healthcare professionals' experiences of working with patients who use communication aids. In an attempt to build on the limited research in these fields, the present study aimed to add knowledge to the existing literature of LIS, communication aids and rehabilitation by employing a qualitative method to investigate the health professionals' experience of treating patients with LIS through communication aids. This area of research is important as it enables people who are affected by the use of communication aids to express their opinions. A better understanding of the issues that arise during the therapeutic process, and the way these issues are perceived by the health professionals, could inform the content of pre-service and in-service training.

#### THE AIM OF THE STUDY

The aim of the study was to explore the health care professionals' personal experiences of providing rehabilitation for patients with LIS and the issues involved in the therapeutic process when communication is established through the use of communication aids.

#### METHODS

##### Participants

Six healthcare professionals who had provided rehabilitation for patients with LIS were interviewed about their experiences. Participants were recruited from a specialist neurological rehabilitation unit in the UK. Participants were recruited regardless of gender, sexuality, race, ethnic origin, religion or belief, socioeconomic status or education level. The sample was evenly representative of different professions working with patients with LIS including nurses (registered staff nurse and non-registered health care assistant), an occupational therapist, a counsellor, a physiotherapist, and a speech and language therapist.

The mean age of the participants was 39 years (range 28–51) and on average they had been working for 2.5 years (range 1.6–4) with patients with LIS. None of the participants had received any formal training in working with patients with LIS.

##### Interview schedule and pilot study

The interview schedule was constructed by identifying similar key topics from the existing literature (Raval & Smith, 2003) and was reviewed by the research team (a trainee health psychologist, an occupational therapist, a speech and language therapist and a health psychologist). This team included healthcare professionals who had worked with patients with LIS and also had experience of qualitative research.

A pilot interview was conducted prior to the beginning of the data collection which highlighted the strengths and weaknesses of the interview schedule. A final version of the interview schedule was designed addressing problems or gaps identified. The topics covered by the interview schedule encouraged participants to give basic demographic information and to talk about their experiences of providing rehabilitation for patients with LIS. Open-ended questions were used to allow participants to elaborate on their experiences.

##### Procedure

The study employed a two stage recruitment strategy. A poster advertising the study and calling for participants was put in the neuro-rehabilitation unit and at the same time potential participants were approached by the research team through invitation letters sent to their work address.

A member of the research team conducted the in-depth semi-structured interviews individually for each participant and data collected were audio-recorded during the interviews and later transcribed.

All interviews took place in a quiet consulting room at the unit and lasted approximately 50 minutes.

##### Qualitative analysis

The interview data were analysed using Interpretative Phenomenological Analysis (IPA; Smith, 1995, 1996). This method was chosen because of its emphasis on ideographic and phenomenological analysis. IPA attempts to gain access to participants' experiences from their own perspectives and to provide a detailed analysis of the particular cases rather than formulating general causal laws (Smith, Jarman & Osborn, 1999). Analysis was conducted according to comprehensive guidelines of IPA provided by Smith, Jarman and Osborn (1999). An experi-

enced researcher supervised and judged the analysis to be coherent. A reflexive diary, monitoring possible influential factors, was kept throughout the study.

#### RESULTS

Data analysis revealed three themes that captured the extensive impact of treating patients with LIS through the use of communication aids. These themes were labelled: 'A different communication', 'The impact of communication aids on therapy', and 'Challenges in working with LIS'.

##### 'A different communication'

Initially, the health professionals described the importance of communication in treatment and how the nature and the process of communication changed when it was carried out through the use of communication aids.

Clinicians reported that communication with patients was the most important tool for their work as they rely on communication to embrace the patients' personality and needs in therapy and to enable empowerment of the patient. Patients with chronic illnesses usually report high levels of distress and patients with LIS can often be depressed at the onset of their illness (Soderholm et al, 2001) and more emotionally sensitive (Leon-Carrion et al, 2002). In this sense, communication was perceived by participants as essential for a person's need for expression, which in turn helps to reduce the patients' level of anxiety and depression.

Healthcare professionals perceived the process of communication through communication aids as problematic as all these aspects, commonly taken for granted, were not present. Many cues present in a continuous communication exchange, which enable the understanding of the relationships between them (Raval & Smith, 2003), were absent. As most patients with LIS have no facial expressions and the communication aids cannot convey the intensity and the tone of the patients' messages, health professionals felt that communication became 'flat'. They expressed concern at losing important information regarding the emotional state of patients and thus not responding to their feelings and needs. Also, participants noted that the process of communication through communication aids became difficult, slower and lost its spontaneity and momentum.

Furthermore, participants talked about how strongly dependent the patients were on the communication partner, and how much the quality of the communication was influenced by the health practitioner's skills and willingness to communicate.

### 'The impact of communication aids on therapy'

Drawing upon the difficulties in communication that come from the use of communication aids, health professionals made fundamental changes in their therapeutic style in an attempt to adapt to the new situation. Health professionals changed their questioning style by implementing short, direct questions and timetabled longer sessions with patients with LIS. However, although changes in the therapeutic style were implemented, health professionals felt that communication aids restricted them from using their full therapeutic abilities. The rehabilitation treatment delivered to patients with LIS thus became simplified and failed to encompass all the elements of rehabilitation. For instance, although additional time was allocated to the therapeutic sessions, it was not enough to accommodate both the therapeutic lessons and the conversations about the issues the patients wanted to raise. As a result, some health practitioners felt that they had to prioritize the patients' need for communication and postpone the therapeutic exercises, which slowed the progress of the therapy.

Patients' high fatigue level, the slow rate at which communication aids enable conversation, practitioners' limited time available to each patient, insufficient knowledge of treating LIS, lack of opportunity to develop continuity and fluidity in conversation, power imbalances and clinicians' difficulty in using the communication aids were just some of the factors that participants identified as both barriers to a patient-centered approach and reasons for providing a simplified rehabilitation therapy for patients with LIS. Many healthcare practitioners reported that they focused on the more practical aspects of intervention such as physical needs, neglecting the social aspects of rehabilitation which encourage patient's active involvement in the treatment. Moreover, some participants identified the potential danger of relying on assumptions about the patients' needs rather than asking them. The implementation of these practices was attributed to some clinicians' difficulty in understanding the nature of the new communication, which caused them fear and ambiguity.

This theme indicates that aspects of rehabilitation concerning the improvement of patients' emotional well-being and embracing the patient's personality in the treatment could not be fulfilled by all members of the rehabilitation team. Similar results have been reported in other medical settings, where therapists deal with communication problems by adopting a more practical approach to their

treatment (Raval & Smith, 2003, Casbolt, 2002). This is significant as it has been argued that spending time talking with patients about their worries and fears and offering emotional support is one of the most important elements of creating a supportive environment and promoting rehabilitation (Long et al, 2002).

Also, the disempowered position in which patients were placed due to the effects of LIS and their total dependency on the health practitioners was reinforced by their lack of privacy. One modification in the therapeutic style that some practitioners felt that they had to accept was the presence of an assistant during the therapeutic session. Some participants' difficulties in deciphering patients' meaning resulted in the need for assistance from another person, which changed the dynamic of the relationship between the practitioner and the patient. The process of communication through communication aids seems to have altered the relationship between clinicians and patients. It might have prevented the patients from revealing information as they had to disclose it in the presence of another person, a potentially embarrassing experience. Specifically, for some professionals in the rehabilitation team (such as counsellors or psychologists), privacy in the therapeutic sessions is essential for transference to occur. The presence of another person in the session reduces or completely inhibits the transference (Raval & Smith, 2003) resulting in a simplified therapy.

Importantly, opportunities for the patients to express their intentions and needs, to initiate and stop conversation, to define the parameters of a given relationship developed through communication and to establish mutual understanding were restricted, as participants discussed the dependency that the nature of communication aids imposed on patients. Health professionals' skills and knowledge in using communication aids and their physical and emotional strength were prerequisites for establishing communication. The strong reliance on the rehabilitation team for communication has also been reported in a study by Soderholm et al., (2001) where cooperation with device engineers and the clinicians is essential for the use of a computer-based communication method. This dependency made health professionals feel like taking the lead in the therapy, thus creating power imbalances as it placed them in a position of power and control over the patient. Health care workers deemed this situation 'wrong' and contradictory to their role and the purposes of rehabilitation which aimed to increase autonomy and empower the patient.

### 'Challenges in working with LIS'

While working with patients with LIS, participants faced many difficulties which caused them to feel insecurity, frustration and distress, and caused them to employ relief strategies.

Participants' initial contact with LIS was discouraging. The field of medicine regarding patients with LIS at the post-acute phase is ill-explored. The findings are neither extensive nor conclusive (Leon-Carrion, 2002). Similarly, there is a lack of a generally-agreed protocol regarding the therapeutic action for this disease (Leon-Carrion, 2002), and training for the use of communication aids was minimal. As they had no resources to draw upon and no personal experience, participants felt anxious and insecure.

Interestingly, participants noticed that some people had associated lack of verbal communication with cognitive impairment. It seems that people have associated individuals with intact cognitions with certain characteristics, such as physical independency and ability for oral communication, creating stereotypes and mental schemes (Winograd, 1977; Van Dijk, 1977) that are not easy to abandon when these cues are absent.

The feelings of anxiety and insecurity stemming from the difficulty in understanding the nature and the needs of the LIS condition were amplified when participants encountered problems with the process of communication. Participants described communication with patients with LIS as difficult and emotionally and physically tiring. Most of the participants reported lack of training in using the communication aids. Inability to understand the patient's message made participants feel frustrated, disempowered, guilty and self-critical. They felt like they had failed to provide beneficial treatment and that their ineffectiveness was experienced negatively by the patients, which increased their frustration. The paradox of 'being in a powerful position' but 'feeling powerless' (Raval & Smith, 2003) was experienced, making practitioners' work highly emotive.

The study's results are in accordance with the findings of other studies in similar health settings where healthcare providers have expressed negative emotional responses due to communication breakdown with the patients (Magnus & Turkington, 2006; Barr, 1997)

However, treating individuals with LIS through the use of communication aids did not only have negative aspects. Health professionals found it emotionally rewarding and satisfying to help patients with LIS



and perceived the establishment of communication with them as an achievement which contributed to patients' well-being. By contributing to the patients' improvement, participants' feelings of self-worth and self-esteem increased and their negative feelings from failure to communicate reduced.

In addition, the experience of working with patients with LIS was evaluated as being positive as it was perceived to be a learning opportunity contributing to the participants' personal growth. Participants stressed the importance of education and reported having gained an insight into the nature and effects of communication and having developed skills. Similar findings have been reported by other studies. In these studies, health professionals mainly described emotional exhaustion as having a positive impact of their working experience as they gained experience and increased their knowledge (Linley, 2003; Smith et al., 1994).

## CONCLUSION

The study identifies needs as perceived by health care professionals and the barriers opposing the delivery of quality care, highlighting in particular the importance of communication in the treatment process. It informs health practitioners about the difficulties they might encounter when using communication aids and modifications in the therapy that are necessary in order to meet the patients' needs for communication.

Participants in the study reported that insufficient time, lack of training on LIS treatment and the use of communication aids resulted in the practitioners' feelings of frustration and anxiety. The data reveals the impact of the difficulties associated with the treatment of patients with LIS on therapy and on the health professionals. Difficulties and issues that arise during the therapeutic process should be addressed in order to ensure delivery of high quality health care.

Action should be taken to decrease the health professionals' feelings of uncertainty and frustration and to prevent the simplification of the rehabilitation therapy. A need for further research in the field of LIS has emerged, to provide health care professionals with more information on giving care and to generate an adequate agreed protocol for treating patients with LIS.

Last, the results demonstrate the need for appropriate communication aids which will be easy for both patients and health care professionals to use and will be designed to reduce the patients' dependency on assistance. Training that enables workers

to use communication aids confidently and effectively could enhance treatment for patients with LIS and reduce workers' difficulties and distress. \*

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# Supporting Communication Aid Users in the Transition from Paediatric to Adult Speech and Language Therapy Services in Oxfordshire

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## OVERVIEW

A transition pathway has been developed specifically for communication aid users in Oxfordshire who are moving between paediatric and adult Speech and Language Therapy (SLT) services. The primary aims of the pathway are:

- To ensure earlier preparation and planning for transition.
- To ensure that young people using communication aids are referred to the adult AAC SLT prior to the handover to adult services and supported to maintain and develop their skills in using the device.

## THE NEED FOR A PATHWAY

There are separate adult and paediatric Speech and Language Therapy Services in Oxfordshire, as well as a service for pupils with learning difficulties who attend colleges in the county. For young people using communication aids there are additional challenges posed by transition, and the links between services need to be formalised into a pathway to ensure their needs are being met effectively. There are many areas of potential communication breakdown at transition, which are important to improve for all young people, but when a communication aid is also involved, it is crucial that there is support from the appropriate specialist Speech and Language Therapist (SLT).

A key component to enabling the development of the pathway to take place was the joint working between the adult and paediatric SLTs, who both specialize in communication aids. They identified a need for a transition pathway as it was unclear how transitions had been managed in the past, since there was no care pathway in place.

The adult specialist SLT post had been vacant for 18 months before the current therapist was recruited, and the paediatric role was a new post created for communication aids assessment within the SEN/ICT Advisory Service. Referrals to the adult AAC SLT appeared ad hoc and crisis-led, and SLTs working in the college service were often unfamiliar with communication aids and how to support users. There were several cases of young adults referred to the adult AAC SLT at the point when their communication aids needed replacing; however, they were often no longer using them functionally for a variety of reasons.

## CHALLENGES FOR COMMUNICATION AID USERS AT TRANSITION

The stresses and obstacles involved in transition may be greater for young people with special educational needs, and the use of a communication aid introduces additional demands. There are many challenges that lead to the lack of

use of a communication aid, and these are more likely to occur at a time of transition, where there may be less support and continuity. They need to be specifically addressed by a transition pathway to ensure they are fully explored pre-transition, and prevented where possible.

There may be issues concerning the communication aid including limited information being passed on about the use and set up, and referral for SLT help only after skills and use have already deteriorated. The communication aid may be unreliable and/or at the end of its life, as young people may have continued using the equipment they were issued with at school and not have had access to updated technology and methods unless they are referred appropriately. The pathway highlights this so that the paediatric AAC SLT will pass on relevant information about the device, warranties, software updates and so on to the adult SLT.

Another factor that may contribute to deterioration of use is that vocabulary may not have been updated since school, and will therefore not be as relevant or motivating for college/adult life. This reinforces the view that the device was 'just for school', rather than representing the young person's voice, and can contribute to negative attitudes of support staff who do not see the device as being helpful or relevant for their setting.



There can also be problems caused by lack of support and training during the transition period, which again are emphasized as vital to address in the pathway. There may be changes in location (e.g. college, day centre), which disrupt continuity of initial training offered. Obviously, it is essential that information about the communication aid is passed to any new setting, so that carers/staff are not reliant on the parents to explain how an aid works. Although the paediatric AAC SLT currently offers training to colleges pre-transition, there may be a high staff turn-over rate, so further opportunities for training need to be signposted in the pathway.

There may be resistance to using the communication aid after the young person has left school, due to lack of confidence using the technology, different expectations of the young person's communication skills, and the time someone can devote to incorporating the aid within the day. As there will be an increasing number of people working with the young person, these issues are more likely to have an impact. Adults working with the young person may have lost confidence in the device through lack of training, or reliability issues. Once such failure is associated with the device there is often resistance to using it again. There are also often concerns about the portability and security of communication aids (Newton et al, 2006).

There is also the significant issue that the young person may require a new communication aid. However, evidence from the use of the current device and support available will be needed in order to justify funding a new device. If the current communication aid has rarely been used since the young person left school, skills in using the device may have deteriorated, which will take time and resources to re-establish. Another assessment may need to be carried out, which would lead to increased resources and costs, and may not show a true reflection of the young person's skills.

As these are all problems that the adult AAC SLT may face, it was crucial that we formulated the pathway jointly to make certain that the transition planning from the paediatric service tackles these issues.

#### AIMS OF THE TRANSITION PATHWAY

- To ensure the young person continues to use his/her communication aid;
- To reduce anxiety and improve transition experience for young people using communication aids and their families;
- To improve co-ordination, training and information flow between the team involved with the young person;

- To identify future funding requirements;
- To ensure vocabulary is updated and skills are maintained;
- To ensure the young person is at the centre of the transition process;
- To identify clear roles for the professionals involved.

#### TRANSITION PATHWAY DEVELOPMENT

A clear strategic protocol for communication aids was developed through a transition working group which involved the adult AAC SLT, college SLT, and the paediatric AAC SLT. This clarified and designated responsibilities to members of the team, and led to the earlier identification of communication aid users who were approaching transition and better information sharing between therapists.

As a result of this, the paediatric AAC SLT was assigned further responsibilities, including early identification of communication aid users across the county on the caseload and referring these at an earlier stage to the adult AAC SLT. The paediatric AAC SLT role also involved offering training and support to college staff, in conjunction with the college SLT, and in planning vocabulary, goals and expectations with the young person and their family pre-transition. The college SLT and adult AAC SLT have responsibilities for accepting referrals at an earlier stage, and being involved in working group meetings to receive referrals and information regarding specific devices, updates needed, future funding requirements, skills of user, etc. They are also required to join pre-transition visits and transition meetings as appropriate, to meet the young person and establish a baseline of their AAC skills before complete handover has taken place. By 19 years the adult AAC SLT has full responsibility for supporting the young person with their communication aid.

A local transition pathway and protocol were formulated to ensure the longevity of the project and to reduce dependency on particular individuals. The pathway breaks down the steps involved in transition, and specifies options and responsibilities of professionals at each stage to prevent potential breakdowns.

As the research reviewing the CAP project identified (Newton et al, 2006), there are key transition issues around information flow, training, and monitoring of communication aid use. They identified that a contact person was necessary to co-ordinate information transfer between health, education, families, and young person, and that there was a need for more training to be provided to new

settings. These themes have been assimilated into the pathway, and could be expanded further through a roll-out of training to colleges, therapists and agencies involved in transition to raise awareness of communication aid users.

#### BENEFITS

The transition to the adult SLT service is improved by increased information sharing about pupils using communication aids who are approaching transition, which ensures that these young people receive the specialist support they require. Information about potential future costs involved (e.g. warranty expiration dates, software updates, etc.) help budget planning and funding applications. Pupils and families/carers have clearer expectations of the use of the device as they leave paediatric services, and how they will be supported in the future. Vocabulary is updated to meet the needs of the new setting. The paediatric AAC SLT service benefits as the funding, support and training provided throughout the pupil's time at school will not be lost, and skills in using the aid are more likely to be maintained. The transition process is now pro-active and begins earlier; this enables better information flow between services, and more opportunities for pre-transition visits, training and planning.

#### FUTURE DEVELOPMENT

At present the transition pathway is specific to communication aid users and the Speech and Language Therapy service, although it is implied within the plan that there needs to be links with the wider transition team.

The transition pathway fits with Oxfordshire transition protocols, and government advice on transition planning and involving the young person. We need to ensure the pathway is effective in practice, and improve the quality of data on the number and needs of young people in transition to aid measurement of this. Feedback needs to be gathered and evaluated from young people, families, staff and carers to support the development of the service offered (Morris, 1999). As some communication aid users attend college outside Oxfordshire, we also need to consider how to involve these out of county colleges more thoroughly and build links with them to ensure that the local adult service is informed when the young people return to Oxfordshire.

Many special schools in Oxfordshire are now supporting young people post-16, which has implications for the pathway, and transitions to college may occur at a later stage, or directly from paediatric to adult services.

The college SLT role may now become part of the paediatric special school service, which has benefits in terms of information sharing, joined up working and training. The pathway has already shown benefits to communication aid users, as earlier referrals, identification and planning are taking place. This needs to be continued, and evidence gathered to further improve the experience of transition for young people and their families. \*

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## WEBSITES

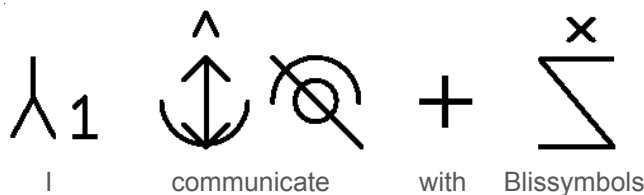
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# I Communicate with Blissymbols



## PETER ZEIN

Email: [azein@btinternet.com](mailto:azein@btinternet.com)



**I am a Bliss user. I use a low tech Bliss board sometimes, and most of the time I use a Liberator-14, with a special overlay with Blissymbols on it and a vocabulary package, called BMW (Bliss Words Strategy).**

Sadly Bliss is not used by many people anymore, in this country. I feel that the few people that do use Bliss can get no help because nobody is trained in it and nobody knows where to get help.

I am able to speak up if I need help, but other people are not confident so they are left behind. Some users have been made to change over from Bliss to other languages because of the lack of training of staff. I think this is unfair to make people change just because the staff do not understand the language.

I have been lucky because I have a specialist that understands my needs and can apply it to my communication device. I am also able to keep my Bliss up to date myself which helps me to be able to keep my device up to date. But some other Bliss users may still only have their original Bliss

books and may be unable to gain access to new vocabulary and to get an up to date version of their book made.

I think we need to remember that every language is special. We need more publicity for Bliss. There are new symbols and some new software options.

If you know of anyone who uses Blissymbols, please can you ask them to contact Blissymbols UK. I am on this committee and I will try to help them if I can; just email me at: [azein@btinternet.com](mailto:azein@btinternet.com)

Firstly, we are trying to find out how many people use Bliss in the UK and who and where they are. Secondly, we would like to know what kind of needs they may have and if we can try to help them. ***I am looking forward to hearing from Bliss users.***

I am interested in all of AAC, not just Bliss. I am a Trustee of the ACE Centre which is an assessment and training centre for people all over the country. They help people from the education system and NHS to assess the patients communication needs. They help them to understand

the communication aids and systems and how to teach them to others.

At the moment, I am working closely on the Bercow Review & Implementation. I think it is very good for younger users of communication aids but it doesn't help adults who are no longer in school or further education. When a person is in education their device will be updated for them but if they are not shown how to do it, there is nowhere for them to go for help when they go out into the world on their own.

I think it is important to give ongoing support to an AAC user and their family after they leave education. An AAC user will constantly need to update their communication aid but without training they will not know how to do it.

I think there is a lack of training about communication aids for professionals who do not directly work with AAC users, for example doctors and social workers. They do not know where to refer a patient or service user for help with AAC, or where to get funding. \* Peter Zein

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AGOSCI in Focus (formerly AGOSCI News) is the newsletter of the Australian Group on Severe Communication Impairment. It is an ISAAC affiliated publication and is published twice a year. **CM Members rate (per year):** £21

## ISAAC Israel Newsletter

ISAAC Israel Newsletter is an ISAAC affiliated publication. Published annually in the spring of each year, in Hebrew with a few English abstracts.

**CM Members rate (per year):** £18

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**COMMUNICATION  
MATTERS**

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CM Tel & Fax: 0845 456 8211 E: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk) W: [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)





eCAT

## NEWS

### SIX YEARS IS LONG ENOUGH!

I can't believe it has been six years since I was elected as Chair of CASC, when Simon Churchill decided to step down from the role that he had held for four years at the end of 2002 – at a time when we were all still excited about CAP and no-one had even heard of John Bercow (perhaps some had – but not in the context we know him in now). So much has happened since then, including the move to come under the BHTA umbrella, when I was elected to continue as Chairman for another three-year term. The BHTA rules state that a section Chair can 'sit' for a maximum of two terms, and as I have just completed my first term in that role I could have stood for election again, but decided that with the CASC chairmanship, a total of six years was enough and time for someone else to take the lead role (rumours that my electioneering campaign to be re-elected was going badly, and that's why I am stepping down, are not true!)

The new Chair of eCAT is David Weatherburn, who has been a very supportive and helpful Vice Chairman for the past three years. I look forward to supporting him in his term 'in the chair'. I am sure the eCAT section is in good hands and will continue to strengthen its links with Communication Matters.

### VAT on Extended Warranties & Service

One of the last things I did before handing over the baton to David was to write to the Chancellor of the Exchequer (on the advice of John Bercow) to ask him to look again at the stupid situation that means people who can claim VAT exemption on products designed to 'alleviate a disability' (Customs and Excise wording, not mine) can claim that same right on accessories and repairs but NOT on extended warranties or service contracts. Well, it has taken the treasury three months to respond but they have finally sent a letter that basically says 'tough!'. In their reply (which you can read, as well as my letter, on the DynaVox website) they state that "A warranty or extended warranty or guarantee offers indemnity for an uncertain event that may or may not happen, they are not a fixed cost for repairs that may or may not be carried out at a later date. As such, where they are supplied separately from the zero-rated product they cover or are offered as an optional extra, they do not qualify for zero-rating."

Frankly this would be mildly amusing if it wasn't so annoying. Of course they are not a fixed cost for repairs (but they are still a fixed cost) and instead of repairs (so they are suppose to be mutually exclusive) – that's the whole point, surely. So if one can be 'zero-rated' (and even that is the incorrect term – they are not zero rated – they are exempt – and there is a difference) then why can't the alternative be zero rated?

They do state that if the extended warranty is included in the price and the purchaser has no option

but to purchase it, then it MAY benefit from zero rating – but that would mean not offering products without maximum extended warranty – which would put all prices up immediately.

Stephen Timms MP (who wrote the reply) then blamed the European Community stating that "...we are allowed to keep our existing zero rates but are not allowed to extend them or introduce new ones..."

So overall we haven't really moved forward, just come up against yet another bureaucratic wall! I think we may have gone as far as we can with this one without taking a different approach. It may be that Communication Matters could join the debate and put more pressure on government but that effort may not be worth it and may distract from the more important issue of funding generally.

However a suggestion from the Director General of the BHTA is that the government may be breaking the new DDA laws and that might be worth considering as a next step. He suggests we take advice on the result of a recent legal case that they were involved in that saw the removal of a new 10% tax levied on mobility scooters – so watch this space but don't hold your breath!!

In the meantime, it's goodnight from me and hello from him!

**Dave Morgan**

Email: david.morgan@dynavox.co.uk



### A MESSAGE FROM DAVID WEATHERBURN New Chair of eCAT Section, BHTA

Thank you Dave for your contribution over the past six years.

It is an exciting and challenging time to take over as chair of eCAT..

Challenging, as our 'traditional' funding concerns are compounded by deterioration in the UK economy and recent dramatic exchange rate shift (many Assistive Technology products are sourced from outside the UK).

Exciting, because there are many opportunities to improve awareness of AAC, and to work for better funding of equipment and support for people who use AAC.

So I look forward to representing the needs of eCAT members as we respond to changes in funding structures, actions from the Bercow review and replacement of the NHS national EAT framework agreement.

I also hope my eight years' experience as Head of Operations at Liberator, and my passion for the AAC field, will be invaluable in supporting the excellent work being done by Communication Matters / ISAAC-UK.

**David Weatherburn**, Chair of eCAT section, BHTA

Email: david@liberator.co.uk



## TRUSTEES' NEWS

### FROM TOBY HEWSON, NEW CHAIR OF COMMUNICATION MATTERS

It is important that I take this opportunity to advise you of some significant changes that have recently taken place within Communication Matters. Some of you may have read what follows in the Communication Matters E-News, so please forgive me if this seems repetitive in any way. However, this Journal is our official channel to a number of different audiences, so here we go!

Liz Moulam has unfortunately had to step down for personal reasons as a Trustee and Chair of the Board of Communication Matters. After careful reflection, discussions with all other Trustees and a proper election process I have agreed to take over as Chair of the Board of Trustees immediately.

For those of you who don't know me - I am Toby Hewson. I am 28 years old. I have been on the Board of Communication Matters for the past six years and deputy Chair of Communication Matters for the past two years. In my working life I am Chief Executive of a small charity based in West Sussex called JustDifferent. We visit schools to help young people and the staff that support them to gain a better understanding of what it is like living with a severe level of disability. Last year we spoke with over 10,000 children and young people.

Firstly on behalf of the whole Board I want to express our thanks and deep appreciation for Liz's outstanding contribution to the work of Communication Matters - particularly since she was appointed Chair in September 2007. She has moved us on in a way that would have been almost unimaginable even two years ago. Her work on the business strategy provides the foundations for everything we now do, and Liz led the process of putting in a substantial bid to the Lottery to support significant aspects of the business strategy. We are eagerly awaiting the outcome of that application. In addition, Liz quite rightly recognised the value of ISAAC and worked hard to continue to support its work.

Liz also played a very important role with the Bercow Review. People often forget that we had very little notice of this initiative. Without Liz's enthusiasm and support Communication Matters would not have played the central role it has done in working with many other organisations to take AAC centre stage. It was long overdue.

Liz will of course continue as an Associate Member of Communication Matters. She has also offered to continue with leading work for Communication Matters on the collaborative research bid to the Big Lottery. This will be submitted at the end of May 2009. Trustees have warmly welcomed and accepted this offer. She is also helping and supporting us with the process of handover and we look forward to seeing Liz at our National Symposium and Annual Meeting of Associate Members in September. Communication Matters is in a period of great change and we have some really important oppor-

tunities to influence and be part of the changes that follow the Bercow Review.

I am personally very excited by the challenge ahead. I will work closely with all my Trustee colleagues to build on the successes we have achieved under Liz's leadership since 2007. This also gives me an opportunity to share some other news with you all. Janet Scott and Janet Larcher who many of you will know are both past Chairs of Communication Matters have offered to support and assist both myself and the Board. This is really very good news for us. They both have a wealth of experience that will help to guide us through the next six months when we will be taking some important and significant decisions. I know all the other Trustees are delighted they have been able to give of their time again. I have found it very supportive personally that they are both able to work with me so closely during this transition period.

There is a huge amount of work to do. The time demand on Trustees is immense. At times even unreasonable. Trustees all have jobs to do, families to look after and other commitments. Somehow we have to find a better balance, more effective and efficient ways of volunteers working together if we are to meet our aspirations. Some of these issues will be discussed at a special meeting of Trustees in May 2009. We will of course share with you the outcomes of our deliberations.

More than anything else I want to listen to Members and Trustees to find out what they think and consider the time commitments for all Trustees beyond September this year.

I have agreed to take the Chair of Communication Matters until our Annual Meeting in September 2009. Members who follow these matters will know that I was due to stand down in September 2009. Some Trustees have suggested that I might like to put myself forward for election again but I have not yet decided what to do. I want to see just how far we have got before making any commitments beyond September 2009.

Our first priority is to ensure that the work continues and we push on with the many changes we have been putting in place to carefully position Communication Matters for the future.

I look forward to seeing many of you at the CM2009 National Symposium and Annual Meeting at the University of Leicester in September.

**Toby Hewson**, Chair of Board of Trustees



### FROM LIZ MOULAM, FORMER CHAIR

Many of you will know that I have resigned as Chair and Trustee of Communication Matters (ISAAC-UK) half way through my three year term of office. This sudden and quite unexpected turn of events is the



## TRUSTEES' NEWS

result of many factors; hopefully I can shed some light on these here.

In the last two and a half years Communication Matters has made some giant steps forward and I feel privileged to have been involved in this work. I am not going to go into full details; those of you who read this column will know each new project was seen by the Board as important and necessary, especially contributing to the Bercow Review. This combined with the survey of the Associate membership in early 2008 provided a clear remit for Communication Matters to raise awareness of AAC and those who use AAC, develop networks and partnerships with government, policy and decision makers and other voluntary sector organisations, become a focal point for AAC research, continue with everything we already do well and finally support the AAC workforce. The outcome from this was the business strategy presented to, and agreed by, the Associate membership in September 2008.

Since early 2008 I have spoken about the need for sustainability, that volunteer Trustees could not be expected to have full time commitments outside the organisation and develop networks, initiatives and take a lead without the support of full time paid staff, especially when taking the lead for AAC with other established third sector organisations and government. This resulted in putting together funding applications to various organisations, including a substantial bid for funding to the Lottery. In the current economic climate competition for funds is fierce but the Trustees remain optimistic for success.

Other initiatives have included delivery of a position paper 'Assessment Standards for Provision of AAC'. This document has now been shared with the DCSF and Dept of Health following enthusiastic contributions from assessment centres, services, independent consultants and wider feedback. Work continues on a groundbreaking research application to the Lottery which followed the publication of the Communication Matters Research Strategy which went out for consultation in July 2008. After a transparent selection process, work has commenced on the research application with Manchester Metropolitan University, Sheffield University and Barnsley Assistive Technology Service. I continue to lead this bid on behalf of Communication Matters, working with our partners to deliver an exciting collaborative proposal to the Lottery titled 'Communication Matters – Research Matters: An AAC Evidence Base'. I am sure the Trustees will tell you more about this once the bid has been made at the end of May 2009.

There has been plenty to be proud of. The highlight recently has to be the Communication Matters Story Reading Reception in Downing Street, through the kind invitation of Maggie and Alistair Darling. How lucky were we that, due to access issues, the venue was moved from No. 11 to No. 10 where many guests, especially the young people who use AAC, had the opportunity to talk to Gordon Brown and Alistair Dar-

ling. The many favourable comments Trustees received following this event reinforce the importance of ISAAC-UK in continuing to advocate for people who use AAC and ensuring they remain at the centre of all decision making for the future.

I am also proud of the achievements of ISAAC. Through international efforts, AAC is specifically mentioned frequently in the United Nations Convention on the Rights of the Disabled Person which pervades every aspect of education, health and social care, and has been helpful in influencing policy. Government are now close to ratifying the Convention which signals a great opportunity for change in provision for AAC; this needs to be grasped by everyone in the AAC community and Communication Matters will be well placed to lead on this with paid staff in place.

So, why have I chosen to leave when everything is going so well? We all have different pressures in our lives. Doing voluntary work means very different things to different people, but whatever our motivation it must be fulfilled. The commitment needed as a Trustee is clearly laid out when people consider putting themselves forward, and indeed this should not be underestimated. The level of commitment for the Chair has been far greater than anyone anticipated, in hindsight maybe I should have refused the opportunities offered, and note I say 'I' as my circumstances allowed me more flexibility than others and the Board agreed for me to do this.

I am proud that Communication Matters is to be led, at least in the short term, by Toby Hewson. There can be no greater advocate for people who use AAC than Toby who has been a Trustee for nearly six years. Toby has the full support of the Board of Trustees, which is crucial to the future success of the organisation.

I continue to be passionate about what Communication Matters does, and the potential it has to deliver, for people who use AAC and their families. I would like to thank the individual Trustees and many friends who have given me considerable support since I joined the Board in 2004. However, the most important people I need to thank are my husband and daughter, who have been flexible and considerate beyond measure. Without their enthusiasm and encouragement I could not have given so much time and energy to Communication Matters. As a parent of a young person who uses AAC I am constantly reminded that ISAAC is an amazing international organisation that already means much to my daughter through the many friendships she has made both in Dusseldorf (2006) and Montreal (2008). She is now excited to be attending her first Communication Matters Symposium in September 2009; this time around I will be there as a personal assistant fulfilling the important and essential role of facilitating someone without whom the organisation would not exist.

**Liz Moulam**





## DIARY DATES

5 May 2009 London

### Literacy for ALL

Contact: Tel 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



7 May 2009 Manchester

### Literacy for ALL

Contact: Tel 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



7 May 2009 Edinburgh

### Software Information Day: Inclusive Technology

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

11 May 2009 Dunfermline

### Literacy for ALL

Contact: ACiP: S 0141 201 2619 (SCTCI)

13 May 2009 Edinburgh

### Using ICT with Early Years and Primary Children

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

19 May 2009 Oxford

### Switches – who, why and how?

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

21 May 2009 Edinburgh

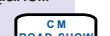
### Software Information Day: Crick Software

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

1 June 2009 Llanelli

### Communication Matters Road Show in Llanelli

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



3 June 2009 London

### The Basics of AAC

Contact: Tel 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



8 June 2009 Bristol

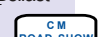
### Switch onto Independence - No matter how young

Contact: PCAS 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

11 June 2009 Belfast

### Communication Matters Road Show in Belfast

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



12 June 2009 Bristol

### Introducing Clicker 5

Contact: PCAS 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

15 June 2009 London

### Clicker 5

Contact: Cenmac 020 8854 1019 [www.cenmac.com](http://www.cenmac.com)

16 June 2009 Oxford

### AAC SIG: Acquired and/or Degenerative Conditions

Contact Julie Atkinson: 0121 6278235 [julie.atkinson@sbpct.nhs.uk](mailto:julie.atkinson@sbpct.nhs.uk)

19 June 2009 Bristol

### Communicate in Print 2

Contact: PCAS 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

24 June 2009 Garstang

### Communication Matters Road Show in Garstang

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



24 June 2009 Oxford

### AAC – What is there to say?

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

## DIARY DATES

26 June 2009 Bristol

### BoardMaker

Contact: PCAS 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

29 June 2009 Bristol

### Grid 2 – Intermediate & Advanced

Contact: PCAS 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

30 June 2009 Worcester

### Communication Matters Road Show in Worcester

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1 July 2009 Bradford

### Communication Matters Road Show in Bradford

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



1 July 2009 Bristol

### Using AAC in Early Years Settings

Contact: PCAS 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

7 July 2009 Oxford

### Communication Matters Road Show in Oxford

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



10 September 2009 Edinburgh

### SQA Digital Papers

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

20-22 September 2009 Leicester

### Communication Matters CM2009 National Symposium

Contact Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



8 October 2009 Edinburgh

### Books for All: Fun with PowerPoint

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

13 October 2009 Oxford

### AAC SIG: Raising awareness of AAC

Contact Julie Atkinson: 0121 6278235 [julie.atkinson@sbpct.nhs.uk](mailto:julie.atkinson@sbpct.nhs.uk)

14 October 2009 Oxford

### Developing and Supporting Low Tech Communication Systems

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

5 November 2009 Edinburgh

### Creating Communication Friendly Schools

Contact: CALL Scotland 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

11 November 2009 Manchester

### Communication Matters Road Show in Manchester

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



23 November 2009 Bristol

### Communication Matters Road Show in Bristol

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



1, 2 & 3 December 2009 Edinburgh, Aberdeen & Glasgow

### Communication Matters Road Shows in Scotland

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



11 December 2009 London

### Communication Matters Road Show in London

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



January 2009 (To be confirmed) Newcastle

### Communication Matters Road Show in Newcastle

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)





## PRESS RELEASES

### POSSUM RECEIVES QUEEN'S AWARD FOR ENTERPRISE: INNOVATION 2009

Possum Ltd has received the Queen's Award for Enterprise in the Innovation category for their Electronic Assistive Technology products. Possum is one of the few Assistive Technology suppliers to have received this award, one of the most prestigious business awards in the UK.

Philip Robinson, Managing Director commented: "We are absolutely thrilled and delighted to receive the Queen's Award for Enterprise: Innovation. Whilst this award has been conferred in respect of the Possum *Primo!* home control unit and other current products, we like to feel it represents recognition of the Company's history of innovation for almost 50 years. It also recognises all our hard work and dedication in developing solutions which provide our disabled clients with greater independence and freedom."

More details can be found at [www.possum.co.uk](http://www.possum.co.uk) and [www.queensawards.org.uk](http://www.queensawards.org.uk)

### BETT AWARD WINNER 2009: THE GRID 2

The Grid 2 all-in-one package for communication and access won the Special Education Needs category of the 2009 BETT awards. The judges chose the software because of its flexibility and accessibility features, and the fact that it gives users a 'voice' and control.

You can find out more about the Grid 2 at [www.sensorysoftware.com](http://www.sensorysoftware.com)

For more information about the BETT awards, visit [www.bettawards.com](http://www.bettawards.com)

### NATIONAL AWARD FOR TOBY CHURCHILL LTD

Toby Churchill Ltd has scooped a national award for its latest product - the Lightwriter SL40 text-to-speech aid.

The prize, given by the British Healthcare Trades Association in the Independent Living Design Category, was presented by TV presenter Angela Rippon at the Association's AGM. More information at [www.toby-churchill.com](http://www.toby-churchill.com)

### SHARE AND DOWNLOAD FREE BOARDMAKER RESOURCES

For years people have been creating some great resources using Boardmaker software but there has never been a centralised and structured way of sharing these boards.

The good news is that Mayer-Johnson has developed a website which is dedicated to the sharing of Boardmaker resources.

Anyone can log on to the site - totally free - and once logged on can upload (share) any boards they have made and/or download (find) boards appropriate to a subject that they are in need of.

Download resources at [www.AdaptedLearning.com](http://www.AdaptedLearning.com)

## HOT NEWS

### THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: E-PETITION

The UK Government has responded to an ePetition which received over 5,000 signatures of support on the Number 10's website:

"We the undersigned petition the Prime Minister to ratify the UN Convention on the Rights of Persons with Disabilities in full, without reservation or limitation, by December 2008."

Read the response from the Prime Minister's Office by visiting [www.number10.gov.uk/Page18674](http://www.number10.gov.uk/Page18674)

### JOIN THE FSI CHALLENGE - 6 JUNE 2009

The **FSI Challenge** is a 4km or 10km walk or run in the Derbyshire Peaks in aid of a charity of your choice. You are invited to help raise money to support the work of Communication Matters, by joining the FSI Challenge on 6 June 2009.

To register your participation and to receive an information pack, please contact Patrick Poon at [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)

### YOUR HELP NEEDED IN NATIONAL AAC SURVEY Devices for Dignity (D4D) Project focusing on Communication Aid Design

If you use aided communication or care for/work with people who do your participation is requested in a national survey being conducted as part of the Devices for Dignity (D4D) project.

D4D is one of two pilot Healthcare Technology Co-operatives in England, funded by the Dept of Health. The D4D-HTC is a collaboration between clinicians, patients, academia and industry, and is led by Sheffield Teaching Hospitals NHS Foundation Trust, with a number of partners.

D4D addresses issues of dignity and independence through its focus on the design, development and evaluation of medical devices to improve healthcare quality and well-being for patients with long term conditions. Three themes are identified within this: assistive technology, renal dialysis, and urinary incontinence. Of particular interest is the Augmentative and Alternative Communication (AAC) project within the Assistive Technology theme which explores users', carers' and professionals' perceptions of communication aid design and aims to identify areas for improvement, future research and development in the design of communication aids.

If you would like to know more or are interested in participating in the survey, either by completing a questionnaire yourself, or by distributing questionnaires to your clients and their carers, you can:

- go to [www.devicesfordignity.org.uk/aac](http://www.devicesfordignity.org.uk/aac) to download the questionnaire after 1st June 2009
- ask for further information or request copies of the questionnaire by ringing 01226 432159 or email [alison.keys@nhs.net](mailto:alison.keys@nhs.net)

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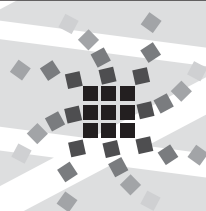
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# Can People with Aphasia Use High-tech AAC?

**TRACY PHILLIPS**

Specialist Disability Service, Oxford Centre for Enablement, Nuffield Orthopaedic Centre, Windmill Road, Oxford OX3 7LD  
Email: [tracy.phillips@noc.nhs.uk](mailto:tracy.phillips@noc.nhs.uk)

## INTRODUCTION

Aphasia is an acquired language disorder that can affect all language modalities: auditory comprehension, reading comprehension, expressive language and written language. Modalities can be affected independently or in combination and with varying degrees of severity. It is estimated that 250,000 people in the UK have aphasia and that 20,000 people will acquire aphasia each year (Speakability 2006).

AAC (alternative and augmentative communication) is often seen as a logical communication strategy for people with expressive language difficulties. Although a small number of clients use high tech AAC to varying extents, in the author's experience, many clients who demonstrate good potential to use AAC in a clinical setting fail to use strategies or equipment provided for everyday functional communication. Discussion with other clinicians working with this client group indicates that this is a widespread finding, as does some published work (Kraat 1990, Jacobs et al 2004; Wieggers et al 2006). The purpose of this article is to investigate the evidence base for AAC use by people with aphasia, highlight some of the resources available and issues involved with intervention. The focus will be voice output communication aids (VOCAs), however, low-tech AAC will also be considered

where appropriate, as many of the skills and principles involved are the same.

## EVIDENCE OF AAC USE BY PEOPLE WITH APHASIA

There is a limited number of published studies involving high-tech AAC intervention. Kraat (1990) summarises AAC research from the 1960s to late 80s and Koul & Corwin (2003) review research studies dating from 1989 to 2001. Both find that the majority of published studies have focused on aphasics' ability to acquire skills and strategies rather than investigating the functional use of these. However, there are some more recent studies that demonstrate successful functional use of high-tech AAC.

Scott (2003) describes his own successful AAC use, following the onset of aphasia in 1997. He has functional auditory comprehension, but has difficulty with speech, reading and writing. He uses a combination of low and high tech methods: a communication book with written words and symbols, maps, business cards of health professionals, gestures, a calendar and a Dynamyte VOCA, programmed with phrases which he also uses, via a link to his computer, to send emails. Scott reports successful communication in a range of situations and with a variety of communication partners, however, despite this range of strategies, there are still times when communication breaks down. He indicates the need

to train people in the community how to interact more successfully with people with communication difficulties.

Reeves & Harris (2001) summarise AAC input spanning a two and a half year period with "Ruth", a lady of working age, with two young children. One year post-onset Ruth had no "useful" speech, had significant auditory and written comprehension difficulties, and was unable to spell. Ruth was using some non-verbal communication and drawing to communicate at this time, but wished to use a computer based system. A SL35 Lightwriter was trialled, using the pre-stored messages with a crib sheet, and a Spokesman with 16 pre-stored messages; both of these were unsuccessful. A year later, Ruth's communication skills had improved and the Lightwriter was tried again with regular input from speech therapy staff. As Ruth's skills developed, she was able to use the prestored messages and abbreviation expansions successfully and was also able to type some single words communicatively. She was also reported to be using a low-tech list of phrases (with symbol backup).

The PCAD (Portable Communication Assistant for people with Dysphasia) project involved a multi-disciplinary team of aphasiologists, AAC specialists, speech and language therapists and technicians. They designed and evaluated the functional use of a VOCA with groups of aphasic people in three countries. This aid

(now commercially known as TouchSpeak with updated functions and features) was set up to be a modular system that is portable and easy to operate with one hand. Pictures, symbols and written words could be used with digitised or synthesised speech output and drawing was also available, allowing the device to be customised for individuals with a range of aphasic impairments.

Twenty two people with supportive partners, good cognitive skills, good comprehension and specific communication needs were selected. Functional goals were set for two communicative situations, e.g. shopping and telephone conversation, and a significant amount of training was provided. The number of vocabulary cells programmed for individuals varied from 32 to 382 (average 159). 77% of the participants were reported to use the VOCA successfully, i.e. to use PCAD for at least one of the preset goals and some generalisation was reported to other communicative situations for a few participants (Wiegers et al, 2006; van de Sandt-Koenderman et al, 2005 & 2007).

Three years after the training with the system, twelve of the participants were interviewed about their use of PCAD. Quality of communication was felt to be higher with the PCAD than without and overall communicative ability improved, however, only 6% continued to use PCAD (van der Sandt-Koenderman et al, 2007).

Koul & Corwin (2003) also summarise studies that show some effective use of low tech strategies such as written-choice communication, gestures, drawing, writing and communication books/charts etc., however, performance tended to vary across participants.

#### BARRIERS TO AAC USE

There are many factors that impact on AAC success or failure with any clients, with or without language impairment. Lasker & Bedrosian (2000) discuss these factors, which are summarised as the AAC Acceptance Model in Table 1.

There are also other factors that are particularly significant when working with people with aphasia; these are discussed below.

#### Acceptance/Expectations

Kraat (1990; 327) reports that AAC interventions up to that date were often global with the expectation that they would replace spoken language to "restore the person to functional levels of communication" so that they can communicate spontaneously and independently. This is often still the expectation/hope of some people with aphasia and their carers, but

| Milieu          | Person   | Technology              |
|-----------------|--|-------------------------|
| Partner         | Time since onset/course/<br>potential for recovery | Durability/reliability  |
| Environment     | Attitude   | Customising/programming |
| Funding Options | Personality/emotional state                        | Service delivery        |
|                 | Age and age cohort                                 | Ease of use             |
|                 | Skills   | Appearance              |
|                 | Needs  | Compatibility           |
|                 | Intervention history                               | Size/weight             |
|                 |  | Cost                    |
|                 |  | Voice quality           |

Table 1 The AAC Acceptance Model Lasker & Bedrosian (2000)

any system that tries to do this will fail (van de Sandt-Koenderman, 2004).

Bloch (2002) highlights that if realistic goals are negotiated from the outset then the chances of successful AAC use and acceptance are much higher. Lasker & Bedrosian (2000; 2001) describe other factors that influence acceptance of AAC, including reluctance of some individuals to work on communication through strategies other than speech and a reluctance to draw attention to their communication difficulties.

The support of communication partners is vital as they are often involved in providing information about needs, assisting with vocabulary selection, supporting conversation and providing encouragement to use AAC, as well as providing some technological support for some high-tech devices. Without the partners' acceptance of AAC and this support, the person with aphasia is unlikely to use AAC successfully.

#### Training

Code & Heron (2003) investigated the amount of speech and language therapy input available for people in the UK with aphasia by sending questionnaires to managers of 264 adult speech and language therapy services. They concluded that the amount of treatment or therapy that aphasic clients receive is well below that recommended by the literature. This has significant implications for AAC intervention for people with aphasia, as studies report that a large amount of training is required to achieve some functional use of the aid. For example, in the PCAD study the following amount of training was needed for each stage of intervention: vocabulary selection (2-4 sessions), training with the PCAD (5-20 sessions), *in vivo* training (0-7 sessions), training of the carer (0-5) sessions (van de Sandt-Koenderman et al, 2005). Also, ongoing support is often required to ensure that vocabulary is regularly updated.

Van de Sandt-Koenderman (2004) reports that non-aphasic AAC users usually receive 40 hours of therapy annually, yet it

is estimated that 200 hours are required for people learning English to communicate in basic conversation. It is highly likely that people with aphasia require substantially more input than non-aphasics due to the nature of their language impairment. Garrett & Kimelman (2000) also reviewed some case studies and concluded that when functional use of AAC occurred in real life situations, it was as a result of situation-specific intensive training.

#### Cognition

Severe aphasia often co-occurs with cognitive deficits and it is likely that this may be a factor in the lack of functional use of AAC. Impairment of executive functioning is believed to be a significant factor. Garrett & Kimelman (2000) summarise the cognitive processes that can co-occur with aphasia. Perceptual difficulties such as visual field deficits, neglect or difficulty filtering out background noise can occur and short term memory appears to be affected in many people with aphasia.

Attention can also be affected; maintaining attention is vital as it often takes many attempts to communicate a message. The person with aphasia needs to remain focused on the target message, despite possible incorrect guesses from the communication partner, or mis-selection of messages using VOCA, and needs to be able to identify when the target has been conveyed. It is also hypothesised that people with aphasia have impaired resource capacity and/or resource allocation. This may account for the increased difficulties observed in dynamic communication situations when compared to structured situations. Some examples are given of the cognitive processes involved in very simple communication situations, e.g. Using a buzzer to call a nurse to request a blanket. Nine steps/skills are identified, including self awareness of the need and that help is required, thinking of how that need may be met, generating an action plan to meet the need, attending to the environment and sustaining attention until the need is met, identifying a modality to express the need, expressing the need,

determining whether the message has been understood, and the ability to try an alternative strategy if the message is not understood.

Garrett & Kimelman (2000; 350) highlight that "people with aphasia must still engage in these processing steps; AAC does not make the process any easier. In fact, AAC strategies and technologies add several cognitive and linguistic demands." One of the key demands involves learning the meaning of symbols and where they are stored. Good working memory and attention is required to use multi-level devices; which are often selected as they provide a means of storing a larger number of messages. People with aphasia also appear to have difficulty shifting from using an internal language system to an external system, and often require significant support to establish the cause and effect of using AAC to communicate.

Purdy & Koch (2006) looked at a novel scoring system for the Communicative Activities of Daily Living (CADL) assessment, which they found was a valid measure of cognitive flexibility. Cognitive flexibility allows people to perceive, process and respond to situations in different ways, consider alternatives formulate ideas. People with aphasia require this skill to determine alternative ways to communicate their messages and switch between communicative strategies. These authors reported a significant relationship between the cognitive flexibility score and strategy use during a functional communication task, and that cognitive flexibility is a stronger predictor of strategy use than the severity of aphasia.

Van de Sandt-Koenderman et al (2007) analysed the data from 30 participants originally enrolled in the PCAD project retrospectively and found there was an effect of semantic processing on functional use of the device. The group that did not use PCAD functionally scored significantly lower on semantics. People who used PCAD independently and extensively had normal or near-normal visual semantic association test scores. The vocabulary on PCAD was organised using semantic principles and it is likely that semantic processing is needed to use the messages communicatively.

### Vocabulary

Vocabulary needs to be customised for any individual using AAC. Little is known about how non-aphasic people organise vocabulary, therefore, the way vocabulary is structured on communication aids may be difficult for aphasic people to learn. Many people with aphasia will be unable to use systems that allow them to spell out novel messages using text or iconic

encoding, therefore, systems are often provided that allow selection of prestored phrases (van de Sandt-Koenderman, 2004). King et al (1995) studied the use of small talk by adults of different ages. They found that a third of utterances for each group were classified as small talk and that 50-60% of these were unique. This has significant implications for people with aphasia using pre-stored messages as a lot of small talk words are difficult to represent graphically and there will not be the opportunity to formulate unique messages. Also, these phrases are often seen as "unimportant". The majority of high frequency words in English are also of low imageability and are more susceptible to damage in aphasia (high imageability words tend to be represented more diffusely in the brain). This creates difficulties for vocabulary selection as it is often difficult to assess whether someone with aphasia understands these words, and they are difficult to represent graphically; non-aphasic speakers often have difficulty labelling symbols for less concrete concepts, e.g. *worried*, *miss*. Many of the words that can be represented symbolically and learned more easily often communicate messages that the person with aphasia can communicate in another way e.g. requests for objects, drinks etc. This also has an impact during AAC training; initially it is useful to start with the more concrete items to help the client establish the cause and effect principles of AAC.

Concrete requests or choices allow the clinician to check that the client understands the meaning of the symbol and that the message used is consistent with the client's communicative intent. However, as the goal of AAC intervention is to enhance what the client communicates, rather than replacing how they do this, this methodology can be counter-productive if there are messages/requests included that the client can convey in another way. This may affect the client's motivation to use the aid as it is not enhancing their communication.

### THE WAY FORWARD

There are several useful tools available and articles providing ideas for supporting AAC use with aphasic people. Some of these are described below, however, this is not a step by step approach and some stages in implementation are not mentioned. Several of the resources have been devised by Kathryn Garrett and Joanne Lasker and they provide a very readable, concise summary about using an AAC framework in their article *Aphasia and AAC in the ASHA Leader* (2008).

### Assessment and Goal setting

Kraat (1990) reports that AAC techniques are often randomly assigned to individuals with aphasia, however, clients tend to use their own spontaneous strategies rather than those taught. The spontaneously acquired strategies should, therefore, be taken into consideration when selecting strategies, so that the client's strengths are used as much as possible. Standard aphasia assessments will provide information about aphasics' levels of impairment, however, there are two useful tools for assessing the skills and abilities of people with aphasia that are specifically relevant for AAC use:

1. CAC-Frenchay Screen for AAC. This includes assessment of visual acuity, visual processing, visual perception, identifying symbols by word class, categorisation, reading with and without symbol support, spelling and coding.
2. The Multimodal Communication Screening Task for Persons with Aphasia (MCST-A) (Garrett & Lasker, 1997, revised 2005) is specifically designed to determine whether people with severe aphasia can communicate using symbols.

The test consists of eight tasks that involve using the picture stimuli to: (a) request basic needs; (b) combine symbols; (c) categorise; (d) use topic based phrases in a specific context; (e) tell a story by sequencing pictures; (f) retell a story; (g) use a map to give information; (h) spell.

The amount of prompting and the types of cue used is also detailed on the form. For use with clients in the UK or with younger clients some of the target items and pictures should be altered to make them more appropriate to the client group, as the test is currently targeted at the elderly American population. Lasker & Garrett (2006) looked at the scores of four individuals assessed with this tool and found that the scores corresponded with the individuals' abilities to use AAC strategies for functional communication after functional training.

The assessments will also provide information about how to represent the vocabulary, size and number of cells, whether the client can use multiple levels etc., which will provide essential information when selecting a low or high tech system.

The Aphasia Needs Assessment ([aac.unl.edu](http://aac.unl.edu)) is a useful starting point to identify the communication needs of the client and it can be adapted to the level of the client as appropriate (e.g. using a Talking Mats approach to identify the most



important topics/situations and to rate levels of skill). There is also a section in the CAC-Frenchay Screen for AAC (Black et al, 2002), which uses symbols to guide a discussion about situations in which the client feels he/she may use AAC and the tool provides support to identify regular events/activities the client is involved with. This information, along with the information gained from assessment, can be used to formulate patient-led goals.

The results of the MCST-A and observations of the client during other conversation and assessment should provide sufficient information to complete the AAC-Aphasia Categories of Communicators Checklist ([aac.unl.edu](http://aac.unl.edu)) which is used to categorise the aphasic person as a Partner Dependent Communicator or as an Independent Communicator.

This is an essential distinction when selecting AAC strategies for the client as different AAC strategies are appropriate depending on the client's skills and abilities. It also helps determine how much support will be required. This checklist can also be used as an outcome measure to indicate how the person with aphasia is developing his/her skills throughout AAC intervention.

Garrett (1992) proposed a slightly different classification of Communicators:

- Basic Choice Communicator
- Controlled Situation Communicator
- Augmented Input Communicator
- Comprehensive Communicator
- Specific Need Communicator

A useful description of each of these types of communicator and AAC treatment goals has been compiled by Augmentative Communication Inc. [www.augcominc.com/whatsnew/ncs3.html](http://www.augcominc.com/whatsnew/ncs3.html)

### Vocabulary

The Aphasia Needs Assessment will provide some information to aid vocabulary selection. Ideally (dependent on the goals set), vocabulary selection should take into consideration the four categories of communication proposed by Light (1998 cited in Garrett 1992):

- Expression of wants and needs
- Information transfer
- Social closeness
- Social etiquette

The proportion of use of these categories tends to vary depending on age, e.g. in a normal elderly population a person who is independent uses limited expressions of *wants* and the basis of conversation is often social closeness. In acute medical settings, needs are often encompassed by the daily routine, however, information transfer is often very important for the patient. The issues identified in

the above section about vocabulary selection should also be taken into account and vocabulary needs to be updated as a person moves between different settings.

### Support

If the client is identified as a partner dependent communicator, then significant support is essential to the use of AAC. Independent communicators also require support. If communication partners feel unable to adapt their communication to provide the support required or there are no consistent communication partners to train, then it may not be a good use of resources to continue AAC input.

### System Setup and Training

There are a great variety of factors to take into consideration when setting up an AAC system. It is not possible to detail all of them here, however Garrett & Kimelman (2000) provide some useful tips regarding implementation and training with AAC:

- Training with specific vocabulary in context is crucial to success
- Using whole phrases rather than combining symbols reduces cognitive processing
- One page of a system should be taught at a time
- Lay out vocabulary in the sequence of conversational turns
- People who may have difficulty with dynamic pages may be able to use a low tech book more successfully as they can physically search for the target page
- Use visual association where possible, e.g. colour coding
- Keep symbols in the same locations on different pages
- Categorical lists may be most suitable for names and places
- Topical categorisation may be helpful; all phrases needed in a specific situation are on one page

### Reviews

Some clients who demonstrate effective AAC use cease to use their strategies/communication aids after a period of time. This can be for a variety of reasons, but a key factor is often that the vocabulary has not been updated. Topics of conversation change for normal speakers over time and this also needs to be reflected in the vocabulary available for AAC users.

There should be regular reviews of vocabulary, although this does not necessarily need to be with an SLT. A key person should be identified to review the vocabulary with the user and update it accordingly. Also, any new communication partners may require training in how to use and support a system.

### THE FUTURE

Although there are limited published accounts of successful use of high tech AAC by people with aphasia, the accounts that are published give some hope for the future of AAC in aphasia rehabilitation. There are useful resources available to help identify appropriate AAC strategies and match these to needs and to determine which people may be most suitable to use high tech AAC. Some of these resources have been available for several years, however, many clinicians working with people with aphasia appear unaware of them and the relevant literature.

There also appears to be relatively little information provided about AAC intervention on Speech and Language Therapy training courses. Ensuring that clinicians are aware of the skills required to use AAC and are confident to set more realistic goals is likely to result in more cases of successful AAC intervention and more integration of AAC into treatment programmes rather than using it as a 'last resort'. \*

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

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### What is ISAAC?

- ISAAC stands for International Society for Augmentative and Alternative Communication.
- ISAAC is a big international organisation that focuses on AAC.
- ISAAC was formed in 1983 and has over 3,700 members.
- ISAAC members live in more than 50 countries around the world.
- There are ISAAC Chapters in Australia, Canada, Denmark, Finland, French-speaking Countries, German-speaking Countries, Ireland, Israel, Italy, Netherlands-Flanders, Norway, Sweden, United Kingdom and United States of America.

**ISAAC's Vision:** AAC will be recognised, valued and used throughout the world.

**ISAAC's Mission:** To promote the best possible communication for people with complex communication needs.

#### What does ISAAC do?

- Advocates for augmented communicators & their families.
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- Produces a series of books for people involved in AAC.
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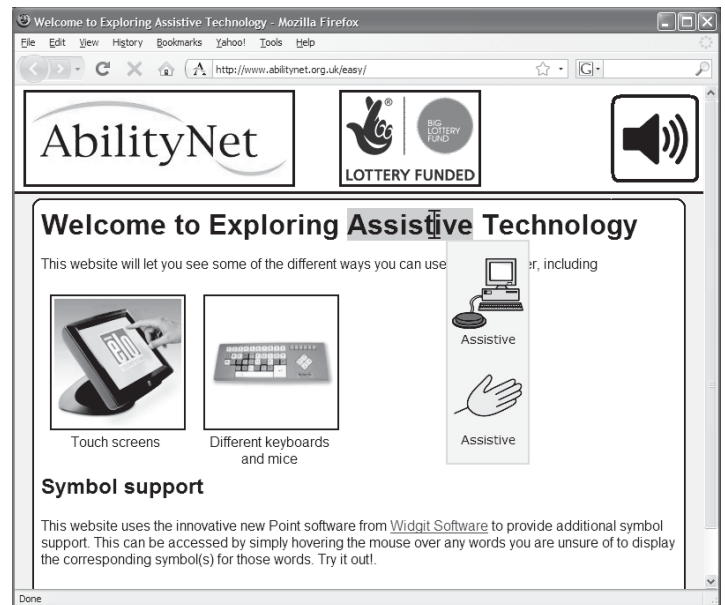
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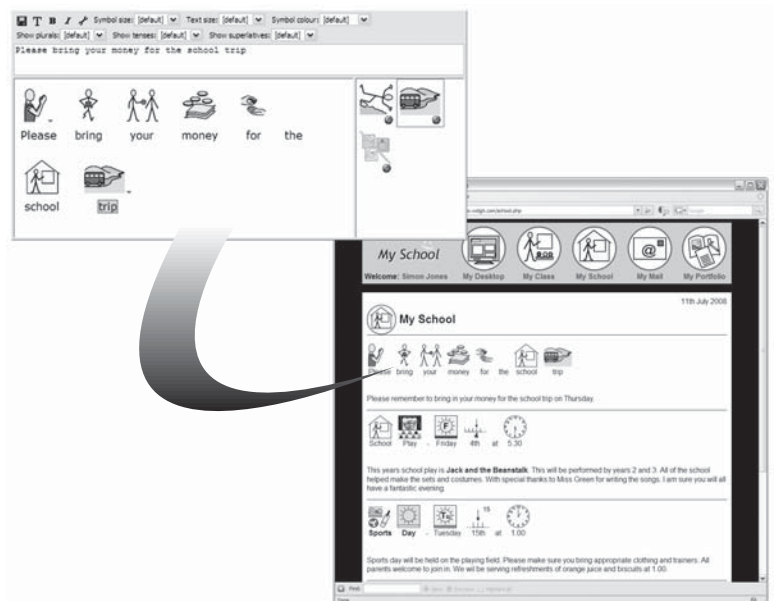
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# Smoothing Transition From Special School To Adult Services For Young People Using AAC

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**Leaving school and moving into adulthood** is a challenging time for all young people and their families and an AAC user is particularly vulnerable when leaving a familiar setting for new situations when no-one knows him or her (Millar 1998). It is therefore important to make the transition process as smooth as possible.

Braidburn School in Edinburgh caters for children and young people from 3 to 18 years old, with a nursery, primary and secondary departments. The majority of the children and young people have a physical, cognitive and/or sensory impairment with an associated communication difficulty. Due to their complex communication needs the school promotes a total communication environment. The school has a large therapy team based onsite.

From the age of sixteen the young people at school come into the leavers group where the main focus is on promoting independence and preparing for adult life. The school has its own transition process following the guidelines within the Additional Support For Learning Act (Scotland) 2004 which ensures better planning and preparation for transition to post-school life. Although the therapists are involved in the school process, I was aware that our own speech & language therapy transition

process was in need of review. To begin, certain areas were identified that I needed to find out more about and these included:

- All the options that were available to the young people post school.
- An increased understanding of the role and input offered by the adult learning disabilities team.
- The speech & language therapy transition processes in other special schools.

In the process of obtaining this information I found the following five different areas were significant in developing and improving the transition process over the past two years:

- Creating a sub-group of SLTs from other special schools.
- Liaising with colleagues from the adult learning disabilities team.
- Meeting with the school career advisors.
- Visiting staff from Further Education college.
- Developing a transition pathway.

## **SUB GROUP**

In Lothian we have nine special schools and there is a long established speech & language therapy special schools care

group which meets twice yearly. From this care group a sub group was created to look specifically at how we could improve the transition process in each of the different schools which has a secondary department. Our aim was to achieve consistency in how we each addressed the transition process. Firstly we looked at what each of the therapy teams were doing in the different schools, what was core to each of the schools and what was different. From this information we felt that developing a core transition pathway that would highlight time scales for each step of the process would help us to work towards providing a more equitable service. Each therapy team could then make additions to the pathway to make it more specific for the population of the young people in their school.

## **COLLEAGUES FROM ADULT THERAPY SERVICES**

Two adult therapy colleagues joined our sub group to look at how we could develop closer working relationships in order to try and achieve more effective and coherent plans for our young people during transition. At our initial meeting we discussed the areas that were impacting most on our transition process, which were:

- short time scale for a comprehensive hand over period as we often did not

know where the young person was going post school until late on;

- the adult team work geographically and this often meant the school therapist having to liaise with several adult therapists;
- the school therapists having limited understanding of the kind of input the adult therapy team provide in different placements.

Our adult colleagues then took these issues back to the rest of their team to discuss. In order to address both the issue of time and the number of therapists to contact they proposed to having one identified link therapist for each of the different special schools that would support involvement at a much early stage and the requirement to liaise with only one adult therapist.

The benefits of a link therapist would be that:

- one adult therapist would be familiar with their identified special school and its population;
- they would visit the school at least once in the young person's final year;

- they would be a point of contact for the school therapist;
- they would be a named person for parents/careers after the young person had left school even if the young person had previously been discharged from SLT;
- the link therapist would disseminate information to her colleagues which would allow for planning in advance for the young people coming into their team.

It would be the school therapists' responsibility to contact the link therapist at least one year before the young person was due to leave school and arrange a time for meetings. Whenever possible the adult therapist would attend the young person's last review meeting, thus providing an opportunity to meet the young person, their family and other professionals involved.

The school therapists are now more confident in advising parents and carers on what kind of service their child is likely to receive once in adult services.

From a clinical perspective working closely with the adult team and learning

about the types of activities the young person will be involved in and the vocabulary they will require has allowed for more effective goal setting for transition.

#### LIAISON WITH CAREERS ADVISORS

Braidburn has two career advisors who meet with all our young people to find out what they are interested in, to tell them about their options on leaving school and ascertain how they feel about leaving school. They were, however, beginning to find it increasingly more difficult to communicate with the young people due to the school's changing population and the increasing number of young people with complex communication needs. In the past we had met up to discuss the individual young people and how they communicated but because there are a wide range of communication systems to meet the young people's needs it was too difficult and time consuming for the advisors to learn about them all.

We therefore decided it would be easier for them to use a low tech system that would be accessible to the majority of the young people that would support both their comprehension and expressive communi-

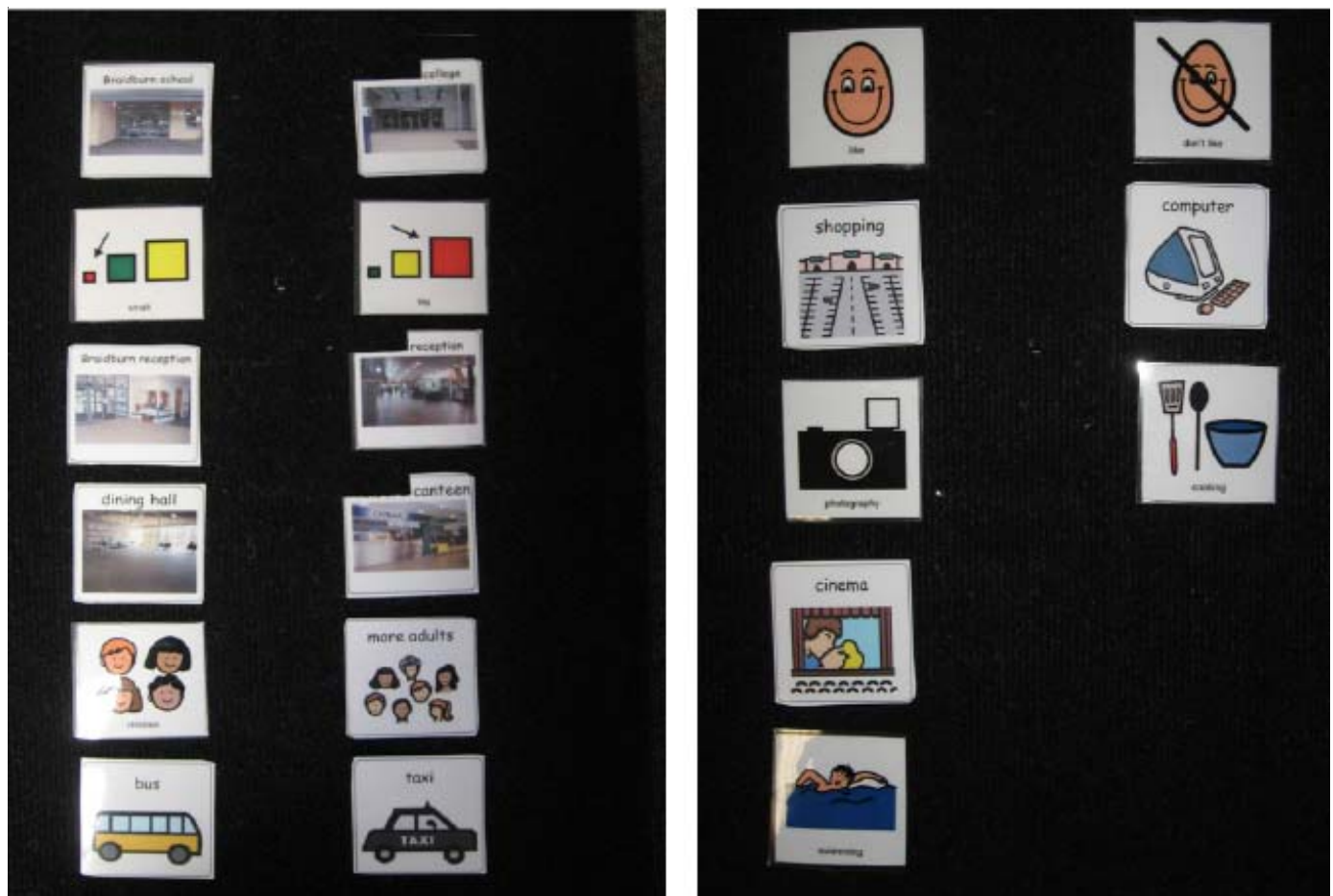


Figure 1 Photographs of different areas and symbols of different emotions

cation. It would also be easy to produce and maintain. As visual supports are used throughout the school many of our young people have a good symbol based knowledge. A low tech pack of photographs, pictures and symbols was produced which included photographs of areas around school, the local college and in the community and symbols of areas of interests and feelings. As Talking Mats was devised to help people with communication difficulties to think about the issues discussed and to express their opinions (Boa & Murphy 2003) we felt that this would be a good approach to use. This would help support our young people to make informed choices and for the careers advisors to find out their hopes and aspirations for the future.

The photographs (Figure 1) of the different areas around the local FE College and school were used to try and show the differences between the establishments, e.g. school lunch hall, college canteen. Symbols of different emotions were used to find about how the young person felt after visiting college and to encourage them to ask questions. Pictures and symbols were used to find out what was important to the young person, e.g. exploring the environment (shopping, cinema) or if they had particular interest (photography, computing).

#### COLLEGE VISIT

Most of our young people have the opportunity of spending some time at college while still at school. By visiting our local further education college and meeting with the staff there I was able to learn in more detail about the courses and activities they offer. By taking some photographs of key areas around the college e.g. canteen, main reception, computer room I was able to add this information on to the young peoples' communication systems so that they could talk about their experiences when they got back to school, or at home.

#### TRANSITION PATHWAY

This is designed to sit in the young person's case notes and act as a guide on when and what steps need to be carried out in the transition process.

#### TRANSITION PACK

It is hoped that this pack will be helpful to new staff working in the area of transition. It consists of:

- Transition pathway
- Example of low tech communication book
- Symbols pack for career advisors;

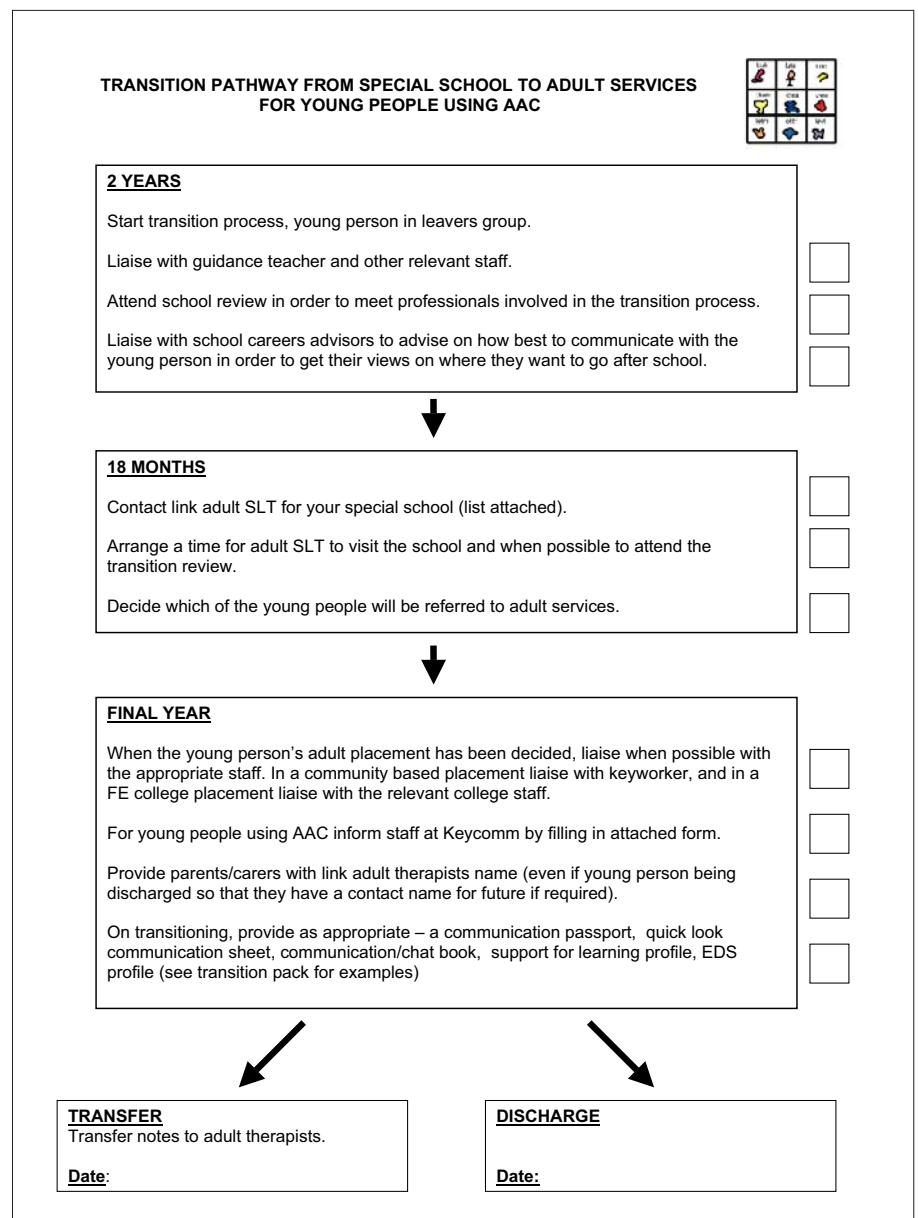


Figure 2 Transition pathway from special school to adult services for young people using AAC

- Template for communication passport (CALL Scotland)
- Example of support for learning profile
- Referral to Keycomm
- Referral report to adult services
- Meeting with our allied health professional colleagues to find out about their transition process. \*

Julie Gray, Speech & Lang. Therapist

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# An AAC Challenge

## What happens when the shoe is on the professional foot?

### KATRINA MOORE & LUCY DOBSON

National Star College, Ullenwood, Cheltenham, GL53 9QU

Email: kmoore@natstar.ac.uk

**Katrina is a speech & language therapist,** and Lucy an AAC Systems Developer, at the National Star College. They gave up the power of speech for one week in December 2007 in order to find out what it is like to use an AAC device. This is an account of their experiences.

The National Star College near Cheltenham, Gloucestershire, is a leading national provider of further education for young adults with physical disability and/ or acquired brain injury, and associated learning difficulties, sensory impairments and/ or medical needs. The college currently has 165 students. 82 students have communication impairments and of these, 36 use a high-tech AAC device.

The idea for the challenge was born following a conversation that we had with a young AAC user at the CM2007 National Symposium, during which the AAC user bet that we could not use a communicator for a day! Just two weeks prior to CM2007, Helen Sexton, Principal of the National Star College, set a challenge for each member of staff to raise £100 towards the Star Appeal. The Star Appeal aims to raise £15.4 million in order to develop and improve a range of residential, educational and therapeutic facilities at the college.

We were both immediately inspired to take up the challenge set us by the AAC user in order to raise money for the Star Appeal and even to take the challenge a step further! Planning for the challenge began...

#### THE CHALLENGE!

After much discussion within our department at team meetings, we created some basic ideas and objectives for the challenge:

- To use an AAC device for one week, absolutely no talking allowed (50p fine for any spoken outburst!).
- To use the communicators at home, at work and in the community, everywhere we went in that week.
- To raise awareness of AAC, this meant handing out cards with our blog addresses on, using our communicators to tell people about what we were doing (pre-stored messages are often a blessing in these situations), and never shying away from opportunities to communicate.
- To experience the realities of AAC, and to use these experiences to inform our work with our students and colleagues in the future.
- Central to the development of the plans for the challenge was the immense responsibility we felt to all AAC users, students, staff and the reputation of the Star College.

#### THE AAC DEVICES

In order to fulfil the aims of the challenge, much consideration was given to deciding which AAC device to use and this was influenced by the following factors:

- *Portability of the device.* Essentially the device needed to be “hand-held” to enable us to use the devices in a variety of contexts.
- *Facility to use symbols or icons as well as text.* This enabled us to compare and contrast different vocabularies, text and symbol based systems. This was particularly significant as most of the students at the Star College use

primarily symbol based vocabularies and therefore we felt the experience would be more akin to that of our students if we were also forced to rely on symbols as well as having the option of using text.

- *Level of prior knowledge/ competence with programming the device and using the vocabularies available for the device.* We wanted to use the experience to learn more about the different features of the devices we used such as visual display options, programming methods/ procedures, use of different voices and becoming competent in using the vocabularies available for the device.

Katrina chose to use Liberator's Vantage II communicator with 45/84 LLL (Language Living Learning, Minspeak application programme developed by Tony Jones for Liberator), Wordpower/ Picture Wordpower/ Wordpower Phrases and Categories (Nancy Inman) and Word Core (Liberator). One of the user defined keys on the device was programmed to toggle between the different vocabularies.

Lucy chose to use the Say It Sam handheld communicator from Possum with standard Sam software which uses both symbols and text.

We both received one training session from the suppliers approximately one week before the challenge began and also had the devices on loan from this time which enabled us to “brush up” on programming, practise using the features of the device that were new to us (taught during the training session) and to pro-

gramme some useful phrases into the devices.



Vantage II and Say It Sam Communicator

## EXPECTATIONS

Just before the challenge began, we recorded a short video of our expectations. Our key expectations were that:

- People (i.e. the general public) might be curious about what we are doing, but they would also ask us lots of questions which would enable us to raise their awareness and understanding of AAC.
- There would be additional pressure in some communicative situations e.g. need to increase rate of communication when communicating with staff in a shop or post office when other customers are waiting to be served.
- There might be a lack of spontaneous communication e.g. quick quips, social commenting.
- Communication style would change as the challenge progressed e.g. substituting words and phrases for those more easily accessible on the communicator, emphasis on getting the message across rather than grammatical accuracy.

## OUR EXPERIENCES DURING THE CHALLENGE

On completion of the challenge, we decided to reflect on and evaluate our experiences relating to a number of communicative contexts and themes.

We have illustrated our findings using extracts from our on-line blogs, written during the challenge.

### Communication at home

Of all our experiences, we both agreed that the affect of using an AAC device on our communication at home was one of the most surprising outcomes of the challenge. We both commented on how our close relationships with our husband/partner affected our communication. We have both known and lived with our partners for some time and they have developed a significant sensitivity to our non-verbal communication signals. This means that much communication at home is actually unspo-

ken. Therefore we both found that we used our communicators very little at home.

Another factor that influenced this was the effort it took to use the device resulting in increased fatigue in the evenings of the challenge. We felt so exhausted having used our communicators all day at work that we tended to resort to non-verbal communication such as signs, gestures, pointing to/ holding up objects e.g. for choices "tea or coffee?", or on occasion, written communication. However, the effect of this was also a significant reduction in social 'chat' at home. Even routine social communication e.g. discussing that day's events, was virtually non-existent.

We also found that making basic decisions such as agreeing what to have for dinner took longer than usual and that our contact with family and friends, particularly telephone contact, became far less frequent. Communication with pets was also challenging as they did not recognise the synthesized speech of the communicators. Katrina particularly found this challenging. She did not realise just how much she actually talks to her cats until she ran up a £2.00 (4x50p) fine by accidentally speaking to them!

One especially poignant experience was an argument that Katrina had with her husband. To this day she cannot recall the reason for the argument, but she will never forget the frustration, anger and distress she experienced as a result of being unable to communicate quickly and effectively. No matter how fast she tried to build her message she was unable to match her husband – the speaking person undoubtedly has the upper hand in such situations!

### Communication at work

To ensure the experience covered every area of our lives, using the communicators at work was essential. However, as it was unexplored territory and we knew it would be a steep learning curve, it was important to ensure that it would not interfere with working with the students, while at the same time, we wanted to speak with the students using our communicators and see if it were possible to carry out our jobs using them.

It was for these reasons that we chose the week before the Christmas holidays to do the challenge. This week was a week that the students would still be in college and still had some sessions with us, but it was also a week in which most students 'wind-down' and prepare for the Christmas break, giving us ample opportunity to use the communication aids in other areas of college and with the students, and yet not interfering heavily with our jobs should it prove difficult to use

them in the office or with students in sessions.

Our colleagues were very supportive, which we would have expected from a Speech and Language Therapy Department, although many staff from other departments were a little thrown by the idea. Most were very open and intrigued by the challenge, some didn't quite understand why we might be doing it, and a small number consistently referred to us as the people doing the sponsored silence – we were constantly correcting them. Overall, it was a very positive environment and we even shared in the college Christmas dinner whilst using our communication aids! This was only a problem from the point of view of where to put the communicators down on the table, or trying to eat or pull a cracker and use a communication aid at the same time!

We were still able to carry out most of our day-to-day tasks at work with a little more effort than usual, but it was certainly still possible. Students will often still mention the experience and many deliberately sought us out during the week of the challenge to talk to us using both our and their communication aids. Katrina was given the compliment of being a 'safe girl' by one particularly impressed AAC-using student.

There were one or two things that emerged as a focus for training after the challenge. The communication style of many staff members changed with us for the single week we were using communication aids, some even signing at us with Makaton despite knowing us and working with us very closely, and therefore knowing that we did not need signing to support our understanding of what was being said. Some staff slowed or simplified their speech, and strangely (this may be a connection to the belief it was a sponsored silence) some even went quiet and put their hands over their mouths when they spoke to us as if they had spoken when they weren't supposed to.

Work was essentially a safer environment in many ways. The staff there are very used to seeing communication aids used and most were very patient and excellent communication partners, and we had the comfort of being around each other, and going through the same experience. Although we still avoided some situations, we were much more confident at work than out in the community, which goes to show how daunting using a communication aid with strangers can be.

### Communication in the community

Possibly the strangest thing to come out of this whole experience and the last thing we could have expected was how normal people were in response to us using AAC

in the community. Again, as with our experiences at work, there were a few people who tried signing at us and the like, but the vast majority didn't even seem to notice anything was out of the ordinary and happily served us in shops, market stalls and pubs without a moment's hesitation.

When Lucy was with her fiancé Matthew (now her husband), she did communicate herself, but also found herself backing away from certain complex situations and instead looked to him to field complicated queries. But in the Farmers' Market in Stroud, she asked the market stall holders many questions to which they happily replied, and due to the noise of the market, she showed them the screen of her communicator to read her questions from, which again, they barely reacted to and happily went about business as usual.

Katrina attended her husband's Christmas party with her Vantage, and wasn't sure what to expect. She was very surprised to find a queue of people wanting to talk to her and ask her what she was doing! The noise of the party made it difficult for Katrina to use the voice on her communicator, and like Lucy, she found herself showing people the display for them to read what she was saying. It was a very successful evening, though, and she raised a huge amount of money for the Star Appeal from the other intrigued guests.

#### **Impact of AAC on our style of communication**

We also shared similar experiences regarding the impact of AAC on communication style. Before using our communicators we found that we asked ourselves three questions:

1. Is it (what I want to say) important?
2. Can I be bothered?
3. Will it still be relevant by the time I've prepared my message?

If the answer to all three questions was "yes" then we would use our communicators but if not we perhaps used a different means such as signs, gestures, objects or writing to get our message across.

We both found that there were communicative situations that we avoided and that, to our surprise, there were situations that did not require spoken communication at all, such as shopping in our local supermarkets. Even at the checkout, a smile, nod or gesture was sufficient for a successful purchase.

Other affects we experienced included:

- Reduced social communication and opportunities for communication. This was particularly evident when communicating with a group of speaking communication partners as the con-

versation naturally moved on very quickly. We were able to use our communicators successfully if the topic conversation was maintained through a number of turns taken by the rest of the group, but if the topic changed more quickly our messages could become irrelevant by the time we composed them.

- We found ourselves planning our utterances more than if we were speaking. It was like having our own silent monologues in our heads.
- We often paraphrased our intended message, substituting words we would usually have chosen with those easily accessible on our communicators, for example, words that appeared in the word prediction, core vocabulary or that were familiar, e.g. familiar icon sequence or navigation pathway.
- Functional communication i.e. just being understood, became a greater priority than the choice of language used, so our communication style became more direct. We missed the richness of language characterised by devices such as idioms and metaphors.
- We experienced less pleasure in communicating as a result of the above.

However, one regret was that Katrina did not turn on the Language Activity Monitoring on her Vantage which would have enabled her to analyse her language use more objectively.

#### **Effects of AAC use on our mood and self-esteem**

The amount of physical and mental exhaustion we encountered during the challenge is hard to describe. Physically, there was a lot to do, many people to meet and talk to, and we had to carry our communicators with us everywhere, so it was expected we'd be tired. But the emotional rollercoaster we both experienced was far more exhausting than we'd anticipated.

We experienced every emotion imaginable. There were so many happy, elating experiences, from the amazing reactions and support of friends and family and even complete strangers, to recognition by students and a new camaraderie with them. There were many trying times, frustrations with the communicators, frustrations with people not being patient enough or giving us time to communicate and even anger at ourselves for accidentally speaking!

We at times felt lonely and isolated, and other times unique or part of a select special little club. We went from being confused at some reactions, to finding others very humorous and then finding some incidents absolutely hilarious. Katrina had a moment on the phone where the person who called misheard a very innocent word for some-

thing very different and entirely out-of-context, we had a good giggle about this and thankfully, the caller eventually understood what she was trying to say!

Overall, we were both highly emotional during the challenge, and our image of self changed as well. We became quite connected to the communicators, beginning to see them as part of our personalities, the voices our own. Which in Lucy's case was particularly strange as she had to use a male voice most of the time as it was the most intelligible on the Say It Sam!

We also felt a new understanding of our students and what it was like to have to rely on AAC for communication. Throughout the challenge, we were looking for ways to improve our practice with the students and this new perspective on using AAC from the first person point of view gave us a whole new approach to working with our students, and gave them a new respect for us, as they know we aren't being hypocritical when we say "I know it's annoying when it doesn't work", etc.

#### **Telephone conversations**

Using the telephone was undoubtedly one of the most challenging communicative situations to master and is extremely daunting for the AAC user. As this is an aspect of communication we often work on with students at college, we were particularly keen to improve our skills on the telephone. Initially it would be fair to say our attempts to use our communicators on the telephone were pretty unsuccessful resulting in being cut-off from the caller and one or two slightly embarrassing misunderstandings. The main problems we encountered arose from:

- Inconsistent ease of access to a working speaker phone.
- Receiving calls was far more difficult than making calls due to the lack of time to prepare our message, even using pre-stored phrases.
- Lack of visual cues for the listener, therefore they do not know whether or not the AAC user is still composing their message or not.
- Poor sound quality – synthesised speech was often quite distorted by the time it reached the listener. This difficulty was further compounded when the listener had a degree of hearing loss.

Despite our initial failed attempts, we persisted in our efforts to make a successful phone call. Katrina in particular had a number of opportunities to practise her skills as a number of telephone calls were required in order to confirm arrangements for events e.g. radio interview, which took



place during the challenge. She found it heartening to find that with practice, experience, increased speed and confidence, it was possible to achieve a telephone conversation with reasonable success. She now feels much more equipped to support students wishing to work on such skills.

#### PROS & CONS OF OUR COMMUNICATORS

Overall, Katrina liked the Vantage. It was reasonably portable and could be carried in a small shoulder bag; it was very reliable and had a good battery life. A good range of vocabularies is available and Katrina used Wordpower most frequently. She also liked being able to access the different vocabularies easily using the user defined key programmed with this function.

However, Katrina would have preferred a smaller, lighter and more “stylish” looking device. She did not like the DEctalk voices on the device.

Lucy liked the look and size of the Say It Sam. She also liked the access methods and the full-screen text display function.

However, Lucy disliked the speed of the device which was particularly slow processing and speaking longer messages. She also disliked the DEctalk voices and the sound quality of the voice. The female voice was so distorted that Lucy used a male voice throughout the challenge.

#### FAVOURITE EXPERIENCES

Our favourite (and below, least favourite) experiences during the Challenge are described in extracts from our blogs.

##### **Katrina: Hubby's work Christmas party**

“Last night we went to my husband's work Christmas do! I was especially nervous as I hadn't met any of James' colleagues before and was worried they would find it difficult to talk to me. It felt slightly strange to start with and some people commented on how it affected the conversation e.g. “The pauses feel awkward ...you feel like you need to fill them” and several people said they were aware they were slowing down their speech and doing a lot more gesturing than usual even though they were aware I had no problems understanding them. I thought it was good that they were aware of this and were reflecting on the experience themselves. A lot of people introduced themselves to me and seemed genuinely interested in what I was doing and why.”

##### **Lucy: Stroud Farmers' market**

“We accomplished buying everything we wanted to... Overall, I was pleasantly surprised at how easy it was! I was expecting a full-on battle to get vendors' attention and then to be ignored once they got

bored with waiting for my responses, but every vendor was patient, quite a few very curious, none were unpleasant or against us filming them, and the only real difference I noticed between their usual behaviour and that of today was that when it took me a while to type in my message, they might start serving another customer, then jump right back to me when I was ready (it was very busy, I didn't begrudge them this at all!), and one vendor was obviously a little thrown by my lack of vocality and hesitated a bit, giving quick glances to Matthew for reassurance or guidance (I'm not sure which).

“I was actually quite surprised at how some of the vendors even took it entirely in their stride and didn't even seem to register it as anything out of the ordinary. In any case, I managed to hand out quite a few cards with this website on it, so if any of you are reading this, kudos on your people-skills (and a big pat on the back for such lovely produce!)”

#### LEAST FAVOURITE EXPERIENCES

For Katrina, the least favourite experience was her argument with her husband, described above in ‘Communication at home’.

For Lucy, it was her experience with the telephone: “I tried to answer my phone twice already but it takes time for me to get the communicator ready with relevant phrases and by the time I've psyched myself up enough, it's stopped ringing!”

#### RETURNING TO ‘SPEAKING’

As returning to speaking was something we'd been looking forward to since starting the challenge, and especially since both of our slip-ups when we accidentally spoke, we hadn't expected there to be a transition like there had been when going from speaking to using AAC. We were wrong, it was quite a process.

We both experienced a bit of dysphonia (like we were losing our voices) and some dysfluency (stumbling over words often). It was so strange to hear our voices in our heads again, it felt buzzing and loud and was very similar to the first time you hear your own voice on tape, as we had only heard our own voices on tape for a whole week, hearing them in our heads again, we both thought, “That's not what I sound like!”. Our throats felt strange with the vibrations of our voices and we both felt extremely thirsty for the first day or so.

As we had been suppressing the urge to speak for a week, it was very difficult to ‘turn off’ that impulse and feel as if it were allowed for us to use our voices. We also found ourselves planning out what we wanted to say next in our heads and then speaking it, as if we were typing it out on a communicator first, not a bad habit, but it

didn't last. It was very difficult returning to our natural styles of communication and returning to the natural ‘flow’ of speech we had been used to before the challenge. It is funny to watch the video of interview we conducted immediately after the challenge, as you really can't tell we found it so strange!

#### THE EXPERIENCE

Although very, very tiring, quite stressful, and a steep learning curve, the experiences of the challenge were so very valuable. It has taught us to value every utterance an AAC user produces even more than we did previously, we know the true amount of work that goes into each word and phrase, and the thought that goes into them beforehand. We now recognise even more that due to the extra effort that goes into communicating using AAC that what an AAC user expresses is very important.

Although we may not want to do it all again without serious consideration, neither of us would change the experience for anything, and would heartily recommend any person who works with or knows someone who uses AAC, or even those completely new to the idea of communication aids, to try using one, maybe not for a whole week, but perhaps a day, an evening at home, or a lunchtime at work.

#### AND FINALLY...

Our heartfelt thanks and appreciation go out to all who supported, helped us or donated to the Star Appeal on our behalf. Especially Liberator and Possum for the loan of devices and huge amounts of technical support along with generous donations to the Appeal; our colleagues Jon, Ashleigh, Heather, Jackie, Karina and Dave for all their support and encouragement; National Star College, Bruce and the Fundraising department for giving us the opportunity to do it all and for helping us record and promote it; the students at National Star College for their interest, support and wit; Communication Matters and a certain AAC user for the inspiration to do it and a forum to present it in; and finally, our husbands, James and Matthew, who put up with two stressed, emotional, but determined to communicate ladies, all the while being as loving and supporting as ever.

If you'd like to donate to the Star Appeal or learn more about the college, please visit our Just Giving website:

[www.justgiving.com/aac-starappeal](http://www.justgiving.com/aac-starappeal)

And if you'd like to read our blogs in full, visit: [aac-starappeal-katrina.blogspot.com](http://aac-starappeal-katrina.blogspot.com) or [aac-starappeal-lucy.blogspot.com](http://aac-starappeal-lucy.blogspot.com) \*

Katrina Moore, Speech & Language Therapist  
Lucy Dobson, AAC Systems Developer



# ESSENTIAL PUBLICATIONS

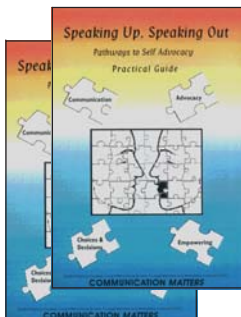
## FROM COMMUNICATION MATTERS



### The Power of Communication (DVD)

This DVD has been produced by Communication Matters to provide an introductory presentation on Augmentative and Alternative Communication (AAC). The film delivers a powerful message that communication really does matter. The DVD celebrates and promotes communication in all its forms - central to the values of Communication Matters, a UK charitable organisation concerned with the needs of people who use AAC.

Price: £8 each (£20 for three) including p&p



### Speaking Up and Speaking Out! Pathways to Self-Advocacy

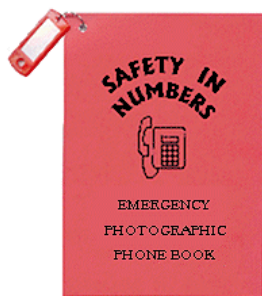
This pack is intended for carers, facilitators and others concerned with the advocacy needs of people with severe communication difficulties who need or use AAC. It is useful for staff development, especially for those working with adults. The pack comprises two books: a comprehensive Handbook and a Practical Guide.

Price: £30 including p&p available from **Communication Matters**

### Michelle Finds a Voice

This book is a story about a young adult with disabilities who is unable to speak or communicate effectively. A number of events cause her to feel unhappy until she and her carers are helped to overcome the communication difficulties. Michelle's story is told through pictures alone to allow each reader to make his or her own interpretation. Published by Royal College of Psychiatrists.

Price: £10 plus £1.50 p&p from **Communication Matters**



### Safety in Numbers: A Photographic Phonebook

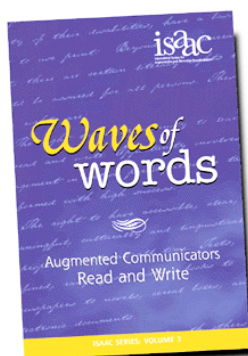
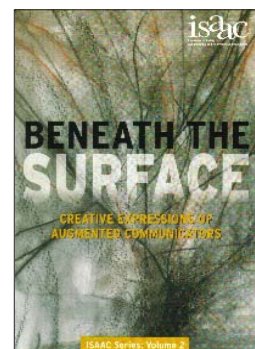
This photographic phone book is for people who find reading difficult. The pack includes an information page with key information about the person, several blank pages ready to add photographs or symbols, space for additional notes for an enabler, babysitter or other adult, a tag to make the book easy to hold as well as identifying the owner, and a page of symbols for common services printed on labels ready to stick in.

Price: £3.50 including p&p from **Communication Matters**

### Beneath the Surface

In August 2000, the creative works of 51 authors and artists from around the world were published in this ISAAC book, Beneath the Surface. What these writers and artists have in common is that they are unable to speak and thus rely on assistive technology to communicate.

Price: £15 plus £1.50 p&p from **Communication Matters**



### Waves of Words

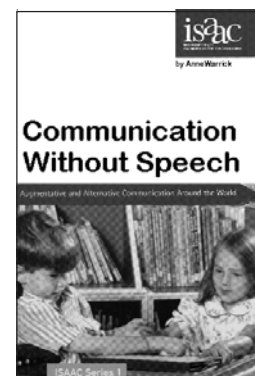
The challenges confronting individuals with severe communication disabilities are chronicled in this ISAAC book. The focus is on the strategies that teachers, therapists and individuals who rely on augmentative communication from around the globe have used to produce ultimate success in the struggle to learn to read and write.

Price: £15 plus £1.50 p&p from **Communication Matters**

### Communication Without Speech

This ISAAC book is a highly accessible introduction to AAC. It contains lots of questions and practical tips such as vocabulary selection, assessment, education and vocational considerations, making communication boards, and includes excellent photographs and illustrations.

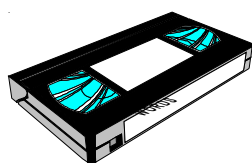
Price: £15 plus £1.50 p&p from **Communication Matters**



### In Other Words (ISAAC video)

This 30 minute awareness raising video was produced in the UK by Caroline and James Gray. It is an excellent introduction to the field of AAC and would be great to show parents and students from a variety of disciplines, as well as to staff new to AAC.

Price: £12 to CM members (otherwise £17) including p&p  
**ONLY AVAILABLE FROM ACE CENTRE (Tel: 01865 759800)**



When ordering from Communication Matters, make your cheque payable to **Communication Matters**, and send to:

**Communication Matters**  
c/o ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR  
CM Tel & Fax: 0845 456 8211 Email: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk) [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



## The Powerbox 5

Powerful and stylish, the new Powerbox 5 from Smartbox is our most versatile communicator yet.

The design allows for hand-held, table top or wheelchair mounted use.

Powerbox 5 with The Grid 2:

### £3950

- Battery: around 6 hours continuous use
- Weight: 2.6 Kg
- Screen: 12.1" touch screen



### The Tablet PC

With a Core 2 Duo processor and 2 GB memory, the computer is both an effective communication aid and a true replacement for a standard laptop. The 12" finger touch screen is readable in sunlight.



### The Back Unit

- Built in desk stand and handle
- Mounting points for wheelchair
- Amplified loud speakers
- Infra-red and radio environment control
- Wired switch connection inputs
- Optional wireless switch inputs





# DynaVox DynaWrite

Allows **fast** and **efficient** communication..

- Easy to use, the DynaWrite allows you to just type the message and press the Speak key
- Compose messages quickly and easily with full-size standard keys
- Adjust access methods to suit any communicator's abilities as they change
- Add a scanning option at any time for even more accessibility
- Read messages with ease using the clear, multi-line screen with variable type size
- Communicate in no time with rate enhancement features such as word prediction and abbreviation expansion
- Choose from multiple voice options, including digitized and synthesized
- Record hours of your own speech for playback later using the Voice Banking feature
- Control objects in your environment with infra red capabilities
- Enjoy long-lasting communication with the 8-hour battery life

**And now, there are even more benefits!...**

**Buy a DynaWrite before June 26th and choose one of these two great offers!**

## Full Five Year Warranty

Five full years of continuous use with no unexpected bills!

**OR**

## A 25% discount

Reduce the price from £2,395 to £1,795 – A savings of £600! Our way of helping you beat the credit crunch.  
(For Irish clients 25% will be discounted from the current Euro price)

The DynaWrite, combined with our special offer, delivers big benefits at little cost to you! (All prices quoted are exclusive of VAT)

**Wait, there's more! ...You could even win a FREE DynaWrite!**

To help you further during this time of financial challenges, **we will also be giving away three DynaWrites** – one each month in April, May and June! To enter our random prize draw, simply complete the form on our website at [www.dynavox.co.uk](http://www.dynavox.co.uk). If you don't win during the month you entered, your name will automatically be entered into the following month's prize draw.

**For more details about our offers or our free drawing contact:**

DynaVox Systems Ltd  
Sunrise Building  
High Street, Wollaston  
West Midlands DY8 4PS  
[www.dynavox.co.uk](http://www.dynavox.co.uk)

Tel: +44 (0) 1384 446789

Fax: +44 (0) 1384 446799

## NOTES:

- The two offers are mutually exclusive and cannot be used with any other DynaVox offer.
- Purchasers must state either 5 year warranty or 25% discount on the order to benefit from either offer.
- Neither offer can be added to an order after despatch.
- This offer is for UK and Ireland direct purchases only and is not available to any resident outside of the UK or Ireland.
- The offer is available only for products ordered and despatched before June 26th, 2009.



# Scrolling Cells

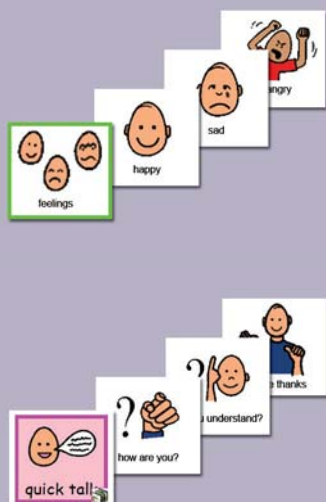
## Unique to the Possum Jive!

### Jive! features:

- Comprehensive message building
- Full letter, word and sentence prediction
- High quality Acapela speech
- Possum Environmental Control (ECS)
- Keyboard and PCS symbols
- Recorded speech and sounds
- Scrolling cells
- Free IDV4Life vocabularies
- Setup on device or PC
- Long battery life
- Cell magnification
- Auditory Prompts
- Configurable tool bars



### Scrolling Cells



Traditionally on AAC devices, the user links to another page, and chooses a message. With Scrolling Cells, simply press your subject and press again when you see your message – no navigation, no change of topic focus!

You never know when you might need that common phrase. Choose 'quick talk' and choose a message without ever leaving the page!



### Scrolling Cells Benefits:

- Reduced page navigation
- Easy access to a variety of phrases
- Quick message building
- Maintained topic focus
- Larger target areas
- Changes in verb tense
- Context specific message variation ie: Hi, Hello
- Ability to stack ECS commands
- and much more!

### Warranty

The Jive! is designed, manufactured and fully supported by Possum. The Jive! Package includes a 2-year return-to-base warranty, including 2 accidental damage repairs, which can be extended by up to 3 years more.

### Contact us now for further information or a demonstration:

Possum Ltd  
8 Farmbrough Close, Stocklake Park Industrial Estate Aylesbury, Bucks HP20 1DQ  
T 01296 461000 F 0871 666 3520 E sales@possum.co.uk W www.possum.co.uk

Possum reserve the right to amend, supplement, update, revise or modify these features and/or the functionality without notice. E & O excepted.

