

# COMMUNICATION MATTERS

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## IN THIS ISSUE

National Year of Communication: AAC Awareness Raising Events & Many Hands Wave "Hello"

Developing Narrative Skills, Communication & Literacy using Symbol Supported Text

Have you seen my new mobile phone? Merging AAC with mobile telephony

Highs And Lows of Running An AAC Service

How I use the internet and social media

I'll be Asking the Questions: Celebrity Interviews

Launch of User-led Consultancy

Overcoming Patient-Provider Communication Breakdowns in Health Care Settings

Sitting GCSEs: A personal perspective

Vital Voices: Using Digital Stories

Why Sign and Symbol Use Promotes Language

## REGULAR COLUMNS

Trustees' News & BHTA eCAT News

Press Releases & Diary Dates

AAC Evidence Base Research Project



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Cover: Martin Pistorius, signing his book 'Ghost Boy' at the CM2011 National Conference

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Communication Matters / ISAAC (UK)  
Catchpell House, Carpet Lane  
Edinburgh EH6 6SP, UK  
Tel & Fax: 0845 456 8211  
Email: admin@communicationmatters.org.uk  
Website: www.communicationmatters.org.uk  
Registered Charity No. 327500  
Company Registered in England & Wales No. 01965474

**Editors, Design & Production**

Sally Millar Email: sally.millar@ed.ac.uk  
Patrick Poon Email: admin@communicationmatters.org.uk

**Advertising and Overseas Subscriptions**

Tel & Fax: 0845 456 8211  
Email: admin@communicationmatters.org.uk

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# CONTENTS

- 
- 2 Many Hands Wave "Hello": National Year of Communication**
  - 3 Sitting GCSEs: A personal perspective**  
Beth Moulam
  - 5 Have you seen my new mobile phone? Merging AAC with mobile telephony**  
Simon Stevens
  - 8 Developing Narrative Skills, Communication & Literacy using Symbol Supported Text and Transferring to SymWriter**  
Justin Drew
  - 12 Launch of User-led Consultancy: How adults with learning disabilities can train others effectively using a range of communication strategies**  
Celia Harding, Julie Hickin, Saboohi Bukhari & Kirsty Harrison
  - 15 Vital Voices: Using Digital Stories to increase participation for people who use AAC**  
Deborah Jans & Barbara Mathieson
  - 21 "I'll be Asking the Questions": National Year of Communication**  
Anna Reeves
  - 22 AAC Awareness Raising Events: National Year of Communication**  
Sally Chan
  - 29 "How I use the internet and social media": Findings from a pilot investigation with an AAC user**  
Amanda Hynan
  - 33 Overcoming Patient-Provider Communication Breakdowns in Health Care Settings**  
Sarah W. Blackstone & Harvey Pressman
  - 37 The Highs And Lows of Running An AAC Service for Adults with Learning/Physical Disabilities**  
Cheryl Davies
  - 41 Why Increased Sign and Symbol Use in Severe Learning and Language Disability Schools Promotes Language**  
Elizabeth Beattie

## REGULAR COLUMNS

- 19 Trustees' News**
  - 20 Press Releases & BHTA eCAT News**
  - 26 Diary Dates**
  - 27 AAC Evidence Base Research Project**
-

## The National Year of Communication

# Many Hands Wave “Hello”



As part of **International AAC Awareness Month** in October, delegates at the CM2011 National Conference were given giant yellow hands and asked to send Communication Matters photos of the hands being used creatively for communication, or in an unusual place, or doing an unusual thing.

We were delighted to receive over 70 wonderful photos, a selection of which were made into a poster for a parliamentary event to celebrate ‘Hello’ - The National Year of Communication, organised by The Communication Trust.

We wish to thank all the contributors, including: The West Midlands Care Pathway SIG, Heatherwood School, Rowan Gate Primary School, ACE Centre North, Manchester Metropolitan University SLT students, the pupils and staff of Charlton School, Liberator, Sandra Hartley, Janet Larcher and Chris Sherlock.

You can see slideshows of the all the Wave “Hello” photographs at [www.communicationmatters.org.uk/wavehello](http://www.communicationmatters.org.uk/wavehello)

### My Hands

My hands help me in life to do things which help to speak.

Yellow is the sun so I put up my hand to show someone.

Hands I may get a life to help me to live they might get some pay for this, which don't go that far.

A man I am who may need a hand to get my voice across to this world this pays off in so many different way no one cannot say these words don't pay off.

Drink you have and get hand with it sweet I might take alongside with this but I may need a hand to do this please give me one and be my friend as well.

Barry Smith

# Sitting GCSEs: A personal perspective

## BETH MOULAM

Email: [bethmoulam@aol.com](mailto:bethmoulam@aol.com)  
Website: [www.bethmoulam.com](http://www.bethmoulam.com)



**This article briefly covers my educational experiences, my challenges using AAC in school, the exams I've sat, and that I'm still sitting, the support I've had to do this and how I've done so far.**

For me, speaking at the CM2011 National Conference was a personal celebration. If I had listened to some people along the way I wouldn't have been able to talk about taking GCSEs and when I look back now I can laugh because I know I can achieve in life. I wish I knew at 13 what I know now.

I understand I had a difficult start in life although I was a few days late. Right from the start my parents were warned that I might have a disability and following lots and lots of tests and hospital visits I was diagnosed with athetoid cerebral palsy and a high frequency loss hearing impairment.

By two and a half, it was clear I had speech challenges. At 10 my hearing got worse but we never found out why, despite lots of tests. Two years ago things changed and I got a new diagnosis of dystonic cerebral palsy - I get uncontrolled jerks cause by pain, stress, being over tired or physically exhausted. These don't happen all the time so I manage them with pain relief and by talking to people I trust.

## MAINSTREAM SCHOOL

My education started like all other children. I went to playgroup with a

one-to-one, then to the village primary school. I did my SATs like everyone else. The difference was the use of AAC and IT which changed as my literacy skills developed. Also, the many professionals who came into school to give specialist advice. My Annual Reviews were in the school hall as the 18 people present couldn't get into the office or the staff room.

When I was doing Key Stage 1 SATs and again for Key Stage 2, I went for neuropsychological assessments which showed I was developing normally and needed to be doing the same as everyone else. What was different was a need to make the work accessible, having a reader for my own work so I could lip read tenses to know it was right, extra time, etc.

At 10 it was suggested I needed a special school placement that could provide access to a mainstream curriculum. BUT I am stubborn. I didn't want to board and wanted to stay with my friends. So it was my choice to go to the local girls' school. It started well but didn't work out over time. They kept thinking that if I could do something with help I didn't need the help any longer and tried to keep taking it away. They only seemed interested in my typing speeds. Also they didn't like my homework as they didn't think I did it. I did, but Mum knew how to support me and we worked effectively together in the same I do now at Valence.

The mainstream school said I wasn't making progress in working alone. I guess, looking back now, I think they didn't understand my needs. I will always need to direct people to help me. My Educational Psychologist challenged the staff. He asked if I could successfully use a ramp to get up a step in my chair would they take it away when I was doing well. They began to worry they couldn't support me to do my Key Stage 3 SATs or GCSEs, in fact they wanted me to drop all practical subjects like Design & Technology (DT), some Science, Art and PE. I refused although I didn't do French. By Christmas in Year 8 it was clear to me and my family that things were not working out.

## VALENCE SCHOOL

I was off sick a lot. After a big fight, supported by my educational psychologist, my social worker and my AAC consultant, they finally agreed things were not working out. We think they didn't want to admit failure because they were a very successful school. I eventually left the mainstream school in February of Year 8. After seven weeks, out of school, I got into Valence School, thankfully. How refreshing! I loved Valence from the word go. Suddenly I could access the subjects mainstream couldn't offer me like DT and Food Technology. Everyone seemed to understand what I needed and I was happier than ever before at any school.

Valence offers a personalised curriculum for every individual student. It is great. So GCSEs are over two, three, or four years. For example science started in 2008 and is done over three years with two modules each year. I have just completed it this summer, although have a resit to do still. This year I have four sessions of supervised study so I can concentrate on ensuring I finish everything by next July.

### COMMUNICATION AND VOCABULARY

AAC can be a challenge, not just for me as the user but also for the other students and staff. Others have to learn to wait. I am the only one in my class with AAC. Yes, it can be frustrating to be talked over. But even people who speak get talked over sometimes by others. I had to learn to be assertive and patient. We worked on strategies for me to interrupt and ask questions, but I still find it hard in bigger groups. Access to the huge vocabulary needed for GCSEs is essential and my teacher for the hearing impaired gave school guidance on how to make this work. I get a one-to-one session every week to hear new vocabulary in context. This really helps. I love to talk but my speech isn't very clear. My speech is very slow and tiring, but using AAC is also slow. I can write, but again it's difficult to read, slow and tiring. Using ICT (Information and Communication Technology) helps but is still physically tiring. My hearing impairment means that I lip read so it's impossible to make notes and listen. All this means I need one-to-one help but especially for scribing and practical work where I need to direct someone to do what I cannot.

### REVISION

Revision has been a big challenge. I cannot make notes or underline key words. It takes hours to make a mind map so I have listened to DVDs, CDs and podcasts. I've done practice papers and practical activities at home to visualise activities in science like boiling the kettle or using food colouring to learn about chromatography. Revision has taken much longer than I planned. I worked every day each holiday and most weekends. Sadly neither, education or social services have felt funding for revising was important. So revision has been mostly at home with mum or using my direct payment money with a personal assistant rather than going out. BORING! Valence School have years of experience of picking the right exam boards and papers for students. They know it's important for us to have the same sup-

port in exams as we do in class. My GCSEs have a high coursework content to reduce the importance of the exam. Mostly we do Foundation level papers as there is less writing. Taking modules means we can resit if necessary, unless the syllabus changes.

I have been with the same small class now for four years, we are put together by the level of work we do. As my timetable is individual there can be just three of us doing a subject or the whole group. This means lots of one-to-one teaching as we can all be at different stages. Also there is always the chance to recap as the topic is done again by younger students, this has really helped me.

### TAKING EXAMS

For exams I get at least 100% extra time, the exam officer applies to the exam boards for this and is given permission. I get breaks when I ask. The breaks are still under exam conditions so that includes meal times if necessary. My one-to-one types what I say, this is a mix of my voice, my AAC and me taking over the keyboard if necessary. I get a reader, except in English, both for speed and because I need to lipread. The large print papers means I can focus just on the words and not on diagrams or tables. It also means I get a room on my own, but then so does every student sitting an exam at my school.

I spend time doing practice papers at home and school. These are the actual past papers downloaded from the exam board website. The supervised rest breaks are essential. In English literature the two and a half hour exam takes about seven hours. That's five hours plus breaks to go to the loo, have a drink and eat, have a stretch, etc. After a marathon like this I usually fall asleep straight after the exam in the boarding house. On exam days I have to conserve my energy and get fed all my meals and help to do everything I normally do independently.

The science exam was modular. I got overall a C in the six modular tests but the practical and classroom work (ISA) pulled down my grade to a D. I'm now resitting this part of the exam.

Humanities is work in progress. I hope to re-sit Religious Education as I did very little revision because I ran out of time at home revising and I was predicted to do better. But I still have geography and history to do next summer and so could pull up my grade that way.

English Language and Literature was pleasing with Ds but not what I wanted.

I am going to re-sit English Language in November as I need a C. I am unable to re-sit the Literature paper as the syllabus has changed. Learning the literature was challenging but I enjoyed it. I went to see the play 'An Inspector Calls' twice and spent a lot of time learning 'Of Mice and Men'. I had DVDs and audio guides which I listened to in the car, I had the printed works and study guides but best of all I had an inspiring teacher - Miss Brown.

DT was a challenge to say the least! I made a wooden box with 28 dovetail joints and lots of glue. It was designed to go on the back of my wheelchair and swing to the side so I could get things out on my own. With a bit of adaptation it is now used at home for magazines. The teacher asked me to consider A Level but I was pleased when it was over.

### RE-SITS AND MORE COURSES

This year I hope to re-sit, complete and leave Valence with five C Grades or equivalent. That's if everything goes to plan.

I am also doing an OCR (Oxford Cambridge and RSA Examinations) in ICT. It's 100% course work and I'm on course for a Level 2 which is at least a C grade.

In addition, I am doing the ASDAN Certificate of Personal Effectiveness, a Level 3 course equivalent to an AS level which focuses on things like citizenship, global awareness and career planning.

So fingers crossed to ticking all the boxes I need for my college course.

### MY DREAM

I still dream of being a occupational therapist. The five Cs are my stepping stones to a Level 3 course in Health and Social Care, before university. I know that some people are a bit sceptical about me being able to do it with my communication but I am determined to give it a go.

I guess if I was giving my 13 year old self some recommendations and moral support I would say:

*"You can achieve your dreams. But you need to be in the right school and have people who understand AAC support you.*

*Learning is lifelong so time doesn't matter if it takes longer. Find strategies to revise that suit you, choose subjects which will get you there over time.*

*Finally find a school that wants to work with you and home. Then celebrate your achievements. They will come if you work and keep at it."* \*

Beth Moulam

# Have you seen my new mobile phone?

## Merging AAC with mobile telephony

### SIMON STEVENS

Email: [simon@simonstevens.com](mailto:simon@simonstevens.com)

Website: [www.simonstevens.com](http://www.simonstevens.com)

For many people who are non-verbal or have speech impairments, their greatest barrier is often the telephone, and therefore it was only a matter of time before someone combined a communication aid and mobile phone, which can be seen with Toby Churchill's SL40 Connect Lightwriter. The device has all the features that could be expected from a communication aid, including the physical features the Lightwriter is known for, with the ability to make and receive calls as well as sending and receiving texts exactly like any other standard mobile phone.

This technical feat is only a part of the story as what may have started out as a simple additional feature to a well established communication aid is slowly realised and embraced by its current and potential users as a significant advancement in their liberation, social inclusion and empowerment. It is important and interesting to explore the psychological and social impact such a hybrid device may have from the perspective of myself as a current user and independent disability consultant.

In following the personal journey of myself as a so-called AAC user, I had initial resistance to using any formal AAC in its teenage years and 20s as I saw my slurred speech as a result of my cerebral palsy as my main form of communication which I was comfortable with. I had a realisation of my need to be smart with my energy in my mid 30s, which first led me to enquiring at my local PCT (Primary Care Trust) to obtain a Lightwriter specifically, knowing



that the only specific telephony benefit then was text messaging. While I was offered at my assessment the possibility of having a device with far more features than the Lightwriter, my main desire was to have something which was easy to use in everyday situations and something which did not break easily from my heavy handed movements. I also had some general awareness of AAC from friends and work colleagues and I believed the Lightwriter was the most suitable for my impairment needs.

Despite now being an AAC user, I was aware of my many non-verbal peers who had from my perspective made a career in the AAC field, and so when Toby Churchill was first interested in my story, I was wary as I felt I had opportunities in other fields. In further discussions with staff at Toby Churchill it was clear that because I used my Lightwriter as an 'aid' to my communi-

cation, when I was having difficulties (communication breakdowns), as opposed to my main method of talking, I had the potential to be more critical of the device and its development for non-traditional users and not just those who were deemed 'non-verbal'. I also feel that my consultancy background also enabled me to be more objective and on that basis I was delighted to be asked to field test this hybrid device of communication aid and mobile phone I call my Lightwriter.

I could very quickly comprehend the technical advantages of having the mobile phone built into the device but I did not realise the potential of the device in my everyday life. I had a smart phone for my normal calls and this special device was, of course, going to be for special calls, the difficult calls, in the way I had previously used a text phone for when I wanted to speak to people who did not know me. However, it was only after making and receiving just a few calls on the device I realised that it was amazingly easy to use, beyond the communication aid part. It was no longer just about the speech features but the fact that the device is what could be described as 'disabled man size' mobile phone with big buttons, designed to be easy.

I then started to realise that my smart phone was not really very accessible and I could never answer a call in time as I could on the Lightwriter. Once I then saw and quickly purchased with excitement a iPad with 3G as an accessible device with the smart features of a smart phone, I realised that it was possible to



# Papoo Touch communication aid with Grid Player



## System includes

- ✓ Grid Player App
- ✓ The Grid 2 PC software
- ✓ 4x grid sets included with more available
- ✓ Additional Apps for movies, music, calendar, and games
- ✓ Complete system £1950



## Papoo Touch

The Papoo Touch is a dedicated handheld communication aid with a range of pre-built apps, including Grid Player.

The ergonomic shape means the device sits comfortably in your hands and is very lightweight.

It has been drop-tested from a height of 1.2m, and has a battery life of 7 hours (30 hours on standby).

The built in speakers provide high quality speech and sound for movies and music. The Papoo Touch connects directly via USB to your computer for editing using The Grid 2.

## Papoo Touch Specification

Weight: 140g

Screen: 4.3"

Battery life: Up to 7 hours of talk, 30 hours standby

## Features

- Light weight
- Ergonomic shape
- Built in amplification
- Rugged casing

**Contact us now to arrange a free Smartbox product assessment**

make my Lightwriter my main mobile for incoming and outgoing calls and texts, as well as my communication aid.

The iPad and Lightwriter combination had quickly revolutionised my mobile telephony and enabled me to conquer an area of communication I was previously simply coping with. I had gone from hospital-provided crutches to a top-of-the-range electric wheelchair. The iPad had not taken over for me the need for the Lightwriter as a communication aid as it was not as easy to type with. I was also unsure my iPad was going to cope with the pounding it may receive when I have a very frustrating conversation with someone, often because they are not listening to me.

While the Lightwriter assists me with communicating face to face with new staff and when I am on my own or away from my personal assistants who can quickly translate what I say, it could be argued that the primary purpose of the device is now to be my mobile phone which also has the feature of being a communication aid for the calls or face to face conversations when I require them. I am therefore now proud to see my Lightwriter more as my mobile phone rather than a communication aid since I use it in the same way as I would use any mobile phone.

While some people may see this viewpoint as a nice but unimportant piece of information to the AAC field, the reality is that in the same way other technological advantages have significantly blurred the primary purposes of devices like mobile phones and televisions, it can be argued that technology advantages within AAC could and will change the primary purposes of previously called communication aids.

In the same way the iPad and other tablets have become the modern day hybrid device comparable to the Swiss Army penknife or Yuppiefilofax, the next generation of communication aids may be new enablement hub devices combining communication assistance and mobile telephony with advanced environmental control, personal alarms, telecare application, GPS mobility assistance and many other features.

This means that AAC may no longer be able to be managed as a separate industry in the future as enablement technology is merged into new specialist devices and software, or even becoming mainstream features of everyday devices. In the same way, as the media industry needs to quickly evolve when the forms of media available merge, the AAC industry may need to

find new partners within the wider Assistive Technology field to work with, for future hybrid devices.

On a personal level, the merging of AAC into mobile phones is not only extremely useful but also important to ensuring greater dignity and respect in a field where how a product had looked has not always been deemed as important in comparison to its function. I feel this ignored how dignity and respect impacts on a person's identity and ability to communicate with pride. The fact the new Lightwriter is nicely coloured and has features that many non-speech impaired people find interesting certainly offers me a pride in the device and adds to my self-worth. There are likely to be many other psychological advantages for me to discover, which I hope to present in a paper at next year's Communication Matters conference.

In having a mobile phone I find very easy to use and that I am proud to use, I have been provided with a device in the guise of an AAC device which actually has benefits far beyond what could ever be imagined, and which can support me to perform a large range of outcomes, including both work and leisure. Rather than being a device I just need to help me communicate, it can be seen as a device which enhances my verbal and text communication in all its applications, turning it from a device of stigma to one of pride.

Technology often advances simply because it can, often without any strategic need to do so. The benefits of these advancements can be huge and can cause major social and political improvements, especially for many disabled people. Without the computer, I would not have any way to make a meaningful contribute to society which has been made easier and greater by the internet, social networking and so on. My Lightwriter is another advancement which will improve my life further as I now have greater control over my communication with others and a mobile telephony device I can actually use without getting frustrated.

We will have to watch this space to see what social, political and psychological effect this Lightwriter, as well as a new generation of hybrid devices, will have, especially for disabled people and AAC users. I cannot wait to see how future technology will improve my wonderful life even further. For now, I am just happy with my mobile phone, my Lightwriter. \*

Simon Stevens  
Independent Consultant



Many children and adults have plenty to say, but are unable to control their mouth muscles to speak clearly. They can use aids such as pictures, written words and technology to communicate.

1Voice takes a family and social perspective on communication and recognises the great need for adult role models to inspire children and families alike. 1Voice promotes families supporting each other to overcome the isolation that being unable to speak can bring.

For more information, visit [www.1voice.info](http://www.1voice.info) or contact by email: [info@1voice.info](mailto:info@1voice.info) or phone on 0845 330 7862.

**1 Voice** is run by a team of families, role models and professionals in consultation with children to provide a network of information and support for children and families using communication aids.

For more information  
please contact:

**1 Voice**  
PO Box 559, Halifax HX1 2XL  
Tel: 0845 3307862  
Email: [info@1voice.info](mailto:info@1voice.info)  
[www.1voice.info](http://www.1voice.info)

# Developing Narrative Skills, Communication and Literacy using Symbol Supported Text and Transferring to SymWriter

**JUSTIN DREW**

Speech & Language Therapy Dept, Glebefields Health Centre, St Marks Road, Tipton DY4 0UB, UK  
Email: justin.drew@nhs.net

## INTRODUCTION

Some speech and language therapists in Sandwell have been using a simple, cost effective approach to develop language, communication and literacy skills for students in mainstream and special school using symbol supported text.

The aims of this approach were to combine a method to develop narrative and literacy using sequence cards to develop story telling and recalling events, and to combine this with a simple yet effective approach to develop literacy (both reading and writing) using Widgit 'symbol-supported text' with colour coding support. The symbolised supported text was created using laminated words that by using Velcro could be attached to a sentence strip in the correct, logical word order to construct sentences to describe a picture that students had just been talking about.

The aims of this approach were to promote spoken language, narrative and story telling skills at the earliest level, vocabulary acquisition, understanding written text, naming and word order. We showed some video of students developing these approaches and extending there skills by using computer software (e.g. SymWriter, Clicker) into independent writing and communication. This could be further developed into Aided

and Augmentative Communication systems.

As a speech and language therapist working in the West Midlands area of Sandwell, both in mainstream and a special school for KS3 and KS4 students, I was keen to look at approaches that developed both narrative approaches and simple literacy using symbol supported text. This approach is appropriate for students functioning from P5/6 levels upwards in schools.

## WHY WORK ON NARRATIVE?

We tell stories everyday - from what we did at the weekend to the latest film or book we have seen. Students in school might want to let us know what has just happened in the playground, the steps they need to make a sandwich, what they are going to do in the next lesson or telling parents what they did in school that day. In an interesting paper looking at personal narratives in those who use AAC, Black, Waller et al (2011) found that the use of personal narratives are seldom (if ever) elicited (especially with peers and other AAC users). Other reported findings include: participants were unused to telling stories; and other communicative partners need assistance in being involved in the story telling process.

Most people love to tell stories about themselves and these stories tell us who we are, where we are going and where we come from. However, all stories need a starting point, and some of my students struggle to tell you something about a simple book (especially when we have closed the book) - even the simplest of questions such as "Who was in the story?" and "What happened?". So I wanted to start at the beginning and work through a simple structured approach to develop narrative and story telling skills. And I wanted to combine this with some symbol supported text writing to comment and describe a picture in the story.

## WHY WORK ON LITERACY USING SYMBOL SUPPORTED TEXT?

Although the use of a toolkit containing only 26 letters allows me to read any book in the English language (and French and Spanish - though I will only decode the words as my lack of knowledge of spoken French or Spanish means I won't actually be able to understand them) - many of the students I work with find a phonics approach too difficult. Maryanne Wolf states "It takes the brain 500 milliseconds to understand a written word - from attention, to pattern recognition to sound connection to phonology to vocabulary denotation and

connotation" (p145-55) in her wonderful book on reading development called 'Proust and the Squid'.

Further to this, to read phonics, you need to attend and to be able to hear and break a word into sounds (phonemes), match sounds to shapes, match shapes to sounds, remember the order and sequence of sounds and letters, understand complex concepts such as first/last and a memory load that can put these things together to make a word – and understand it. And this is just too difficult. Wolf further states "children's reading actually starts much earlier, with their awareness of oral language and the sounds of language. A child's ability to differentiate sounds, recognize rhymes, and engage in word play can strongly predict later reading ability."

Wolf joins this research to other, neurological work on the structure of the reading brain and the absolute necessity for the myelination of brain neurons in the angular gyrus region before a child can really learn to read. For most children this occurs between the ages of five to seven years; before then, the brain simply cannot easily "integrate visual, verbal, and auditory information rapidly" (p 95).

Experience has led me to agree with this statement. These approaches coupled with difficulties in processing and integrating visual awareness and sounds with word meaning and story telling are too difficult. So I have introduced whole text approaches with symbols to help support understanding of the written words. Symbolised text also allows student to become much more motivated by writing than text or phonics alone. It also encourages more sustained and focused attention.

Words laminated on Velcro also reduce additional difficulties such as holding a pencil which may also be difficult. Further to this, work by Buckley and Bird highlights the value for those students who have Down's Syndrome of reading using whole word approaches that develops literacy and how this further develops language skills and speech. This includes learning new words learnt on flash cards increase speech more than just hearing words, practising reading two to three word utterances increases a child length of spoken utterances, and "practising proper sentences in reading leads to the use of function words and increasingly correct grammar and syntax in speech".

### THE APPROACH

This approach was begun in special schools but is now being used in every

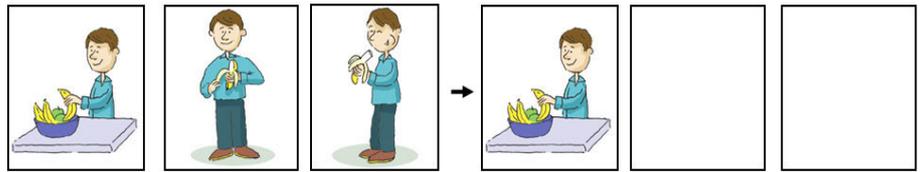


Figure 1 Example of a three-part picture sequence

mainstream school I work in with somebody. It follows a simple structure to build on success and show progression. It is useful for students who are at P6 levels in school or have mastered the commenting parts (e.g. "I see cat", "I hear phone") of PECS (Level 5/6).

### DEVELOPING NARRATIVE SKILLS

The approach begins with story telling. A teacher shows a picture depicting somebody carrying out an activity. Students are asked what is happening and who is in the picture. Choices such as "Is it a man or a woman?", with signs, gestures and pictures all being given as clues to event being described. For example if the picture depicts a man is cutting a cake, we may ask "What is happening?", and "Who is in the picture?". If no response to the question, the teacher could offer alternatives "Is it a man or a woman?" When asked what is the man doing, "Is he cutting or eating?", and further extended to "Is it a man cutting the cake or a lady cutting a cake?", and so on.

The next stage is to turn the picture over or remove it and ask students if they can recall what is happening, who was in the picture, what they were cutting etc. The next stage could be to introduce two, then three part sequence pictures (Figure 1), for example "The man is cutting a cake. What is he going to do next? Is he going to put the cake on a plate or eat the cake?". Students start to develop prediction and build on their story telling skills. I have used symbols and Makaton signs with non-verbal students. This progression adds four and five part sequenced pictures before moving onto story books. My aim following the CM 2011 conference is to begin books and stories that develop a student's personal narrative about themselves.

### DEVELOPING LITERACY

The steps to developing literacy and talking about a picture already discussed can be explored in more detail by checking out the handout of the

CM2011 PowerPoint presentation I delivered which shows the steps to developing writing and reading skills. All that is needed is a folder with laminated sheets to store words, text supported by symbols, and for more able students you can just use text alone resources where you just have the whole word and no visual support such as a symbol.

Starting with *person + action* and the use of colour coding symbols to help students learn structure (a step which can be later removed) we begin by finding a word to say "Who is in the picture?" (e.g. 'girl') and "What are they doing?" (e.g. 'drinking'). What the girl is drinking can be added next (e.g. 'orange juice'). As many words as possible can be offered to the student to increase choice and recognition of words but if they are struggling even with a choice of just two words, go down to one word and build from there.

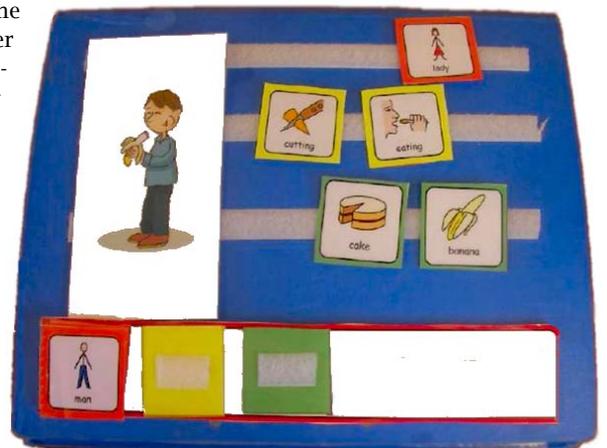


Figure 2 Example of using colour coded symbols to develop literacy

With more verbal students I encourage lots of repetition and repeating of words as the sentence is built up. Adding the high frequency words of 'the' and 'is' can be introduced once lots of sentences have been trialled and students are familiar with *subject + verb (action) + object* phrases. So that "boy washing car" becomes "the boy is washing a car". When first introducing 'the', you can just have the word 'the' on the cover and I now only use the whole words for high frequency words such as 'the' and 'is'.

Descriptive words can be introduced such as colour or size (e.g. "The dog is eating a big bone", "The man is washing the red car", "I see a red balloon", "The

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elephant is big and grey”). ‘Where’ (or place) words can then be introduced (e.g. “the cake is *on the plate*”; “the ball is *under* the chair”). Emotions to describe people can also be introduced (e.g. “The boy is crying”).

This can then be extended to talking about ourselves and describing events in our day, telling stories about our families and friends, what we did on our holidays – and building in the first tools to personal narrative. Developing a book about ourselves that can be shared with others will help to build relationships and discussion that can be shared between those who need AAC and others.

In both mainstream and secondary special schools, some students have gone on to develop the ability to read whole words and use letters to make words, have begun to recognise whole words through sounding out and repetition, and to write sentences which build into independent reading and writing.

Students are motivated and enjoy using this approach as success occurs in reading and speaking (where appropriate) something they themselves have written.

**MOVING ONTO SOFTWARE**

A similar approach can then be developed into using computer symbol or whole word software such as Wigit SymWriter, Clicker or BoardMaker Suite. These early steps in using paper based materials can be transferred onto software that may even lead to some students moving onto high-tech communication aids where appropriate.

**FUTURE DEVELOPMENTS**

I would like to see students build on the narrative work presented so that they are able tell more personal stories about themselves that can be encouraged and developed by those who work with them. \*

Justin Drew  
Speech & Language Therapist

**THANKS AND ACKNOWLEDGEMENT**

I would like to thank Toby Churchill who sponsored me to present this work at the CM2011 National Conference, and for the schools that have helped me to develop these approaches further including The Meadows in Oldbury as well as Great Bridge Primary in Tipton and Albert Pritchard and Wood Green Primary in Wednesbury.

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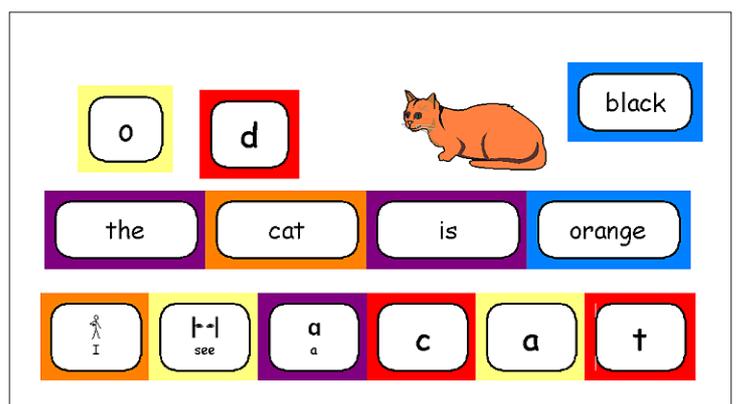
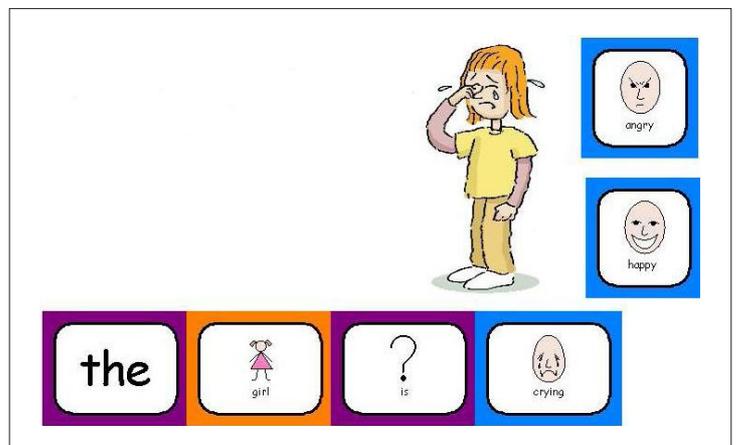
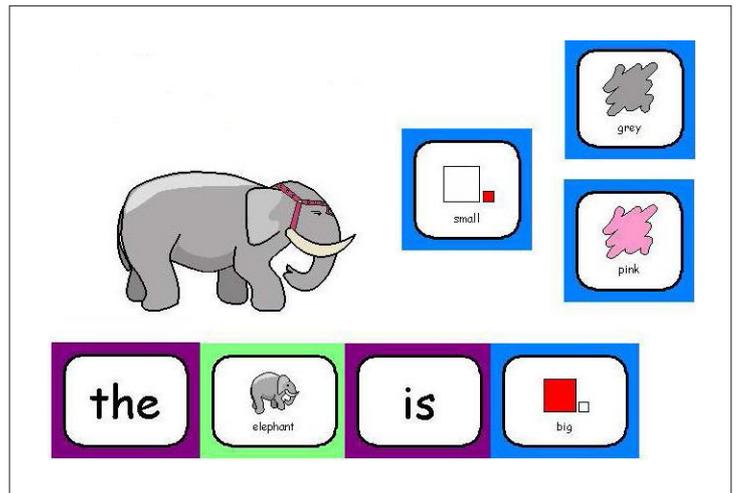
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Figure 3 Example sets of pictures, symbols, words and letters



# Launch of User-led Consultancy

## How adults with learning disabilities can train others effectively using a range of communication strategies

CELIA HARDING<sup>1</sup>, JULIE HICKIN<sup>1</sup>, SABOOHI BUKHARI<sup>2</sup> & KIRSTY HARRISON<sup>1</sup>

<sup>1</sup> Dept of Language and Communication Science, City University, Northampton Square, London EC1V 0HB, UK

<sup>2</sup> People In Control Ltd

In July 2011, City University, London saw the launch of *People in Control*, a new social enterprise devised through a partnership project between The Advocacy Project, Community Access Westminster and Westminster Employment and led by Saboohi Bukhari. This group specialises in employing people with learning disabilities to provide user led training and consultancy to professionals and organisations.

Crucially, it offers services that include training on learning disability awareness and anti-bullying; service user involvement in recruitment and selection panels; consultation on information and accessibility and multi-media presentations where people with learning disabilities teach others about their lives using a range of communication styles. This was an important event as it was an opportunity for people with a wide range of communication needs to speak about issues of great relevance to them using spoken language and other augmentative and alternative communication.

### WHAT DID THE EVENT INVOLVE?

Julie Hickin and Celia Harding, Senior Lecturers from City University, Department of Language and Communication Science hosted this event. Service users

gave presentations on how *People in Control* evolved; training about disability awareness with the police; selecting staff and specific activities that service users participate in. In addition, presentations were given which focused on supported employment and also University training for future health care and social care practitioners.

The main speaker at this event was John Ladle who presented on using multimedia as a communication tool and as a means to promote inclusion for people with learning disabilities. The important message here was to recognise the importance of providing access for people who need to use other methods of communication other than speech such as signs, symbols and objects of reference.

The World Health Organisation (2006) ICD-10 describes a learning disability as being "A condition of arrested or incomplete development of the mind,



Service users wish to inform other people of their lives and their active participation within their communities

which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities." People with an IQ of 70 and below are considered as having a learning disability. Communication difficulties which include receptive,

expressive and social difficulties are likely to be prevalent, and estimates vary greatly as to the degree of communication need. About 80% of people with severe learning disabilities fail to develop effective speech and/or language skills and are highly likely to require access to augmentative and alternative communication (AAC) to promote communication opportunities; 20% have no verbal skills, but demonstrate some level of communicative intent; around 20% within the whole group have limited intentional communication skills, (DoH, 2009).

#### WHY IS SETTING UP AN ORGANISATION SUCH AS PEOPLE IN CONTROL IMPORTANT?

The *Valuing people: A New Strategy for Learning Disability for the 21st Century* (DoH: 2001) document strongly recommends the following to support people with learning disabilities in the community:

- A range of advocacy schemes on local basis so that people can select the one that best meets their needs.
- A view that communication is central to its four major principles of independence, choice, civil rights and inclusion.

*Valuing People* does promote the rights of people with learning disabilities (LD): "... but in order for people to exercise their rights, other people have to give up their power. That has proved difficult when the decisions a person with an LD wants to make are contrary to what other more powerful people want, or when the person has very high support needs which more powerful people turn against them... Having rights includes the right to make decisions that others regard as wrong." (Jean Collins, Values into Action website).

This document is important for practitioners to be aware of so that some of the key issues can be included in their service delivery as well as in service development planning. A recent document, *Valuing People: The Story So Far* (2005), evaluated how services and supports for people with disabilities had changed since the implementation of the *Valuing People* document.

People felt that good progress had been made in some areas, but not others. In particular, accessing some mainstream services in health and social services, for example has been challenging, and it has also been felt that some organisations have been slow to change. *Valuing People Now: From Progress to Transformation* (DoH, 2007) writes about what the service priorities are for people with



Service user teaching at City University, London

learning difficulties from 2008-2011. This document states that:

"The main priorities for 2008 to 2011 are:

- Personalisation - so that people have real choice and control over their lives and services;
- What people do during the day, (and evenings and weekends): helping people to be properly included in their communities, with a particular focus on paid work;
- Better health - ensuring that the NHS provides full and equal access to good quality healthcare;
- Access to housing - housing that people want and need with a particular emphasis on home ownership and tenancies;
- Making sure that change happens and the policy is delivered - including making Partnership Boards more effective."

*Valuing People Now: The Delivery Plan* (2009), the follow-up document, recognises that much progress has been made in terms of services and support for people with learning disabilities. Examples given include: more people receiving direct payments and therefore being able to purchase services of their choice; an increase in person centred planning; and improved access to healthcare.

However, pages 22-23 of the document highlight that there are still areas that need to be focused on. People with

moderate and severe learning disabilities who are identified as being one of the most excluded groups in our society: only 15% of people with LD have a home of their own; more than 30% of people with learning disabilities live in residential care homes, a significant proportion of which are miles away from their place of origin and their families; many people with learning disabilities are living with older family carers who have their own needs; only one in ten of those known to social services has any form of paid employment, and of those only very few work more than 16 hours a week.

*Valuing People* (2001; 2007) recognises that there are still significant changes to be achieved for people with LD within the community. However, advocacy and employment are essential values required to ensure that people who have learning disabilities are able to effectively integrate into mainstream society and be included in their local communities as active citizens.

The *People in Control* project is one opportunity that is moving towards providing employment and training to others whilst accommodating the individual communication methods of each person. The service user led philosophy is an essential feature of the services provided by *People in Control*. They value the expertise that people with learning disabilities have gained through personal experience and recognise this as a powerful method of teaching.

## WHY CITY UNIVERSITY, LONDON?

In 2005, service users from Westminster Learning Disability Partnership were invited to train speech and language therapy students by giving lectures on issues important within their lives, (Harding, 2009). The training involved presentations by the service users on their involvement in interviewing support staff, work experience, and daily routines. All service users employed their preferred communication mode when presenting.

The purpose of this project was to enable students to reflect on the benefits of the training for them as future practitioners as well as developing their own disability awareness. Students valued the experience in terms of developing knowledge and insight into different communication styles and use of AAC generally to support both receptive and expressive function, as well as challenging their own perceptions of disability.

At this time, student speech and language therapists rated this training opportunity highly. Comments included "I feel more confident about interacting with this group of service users" and "I have learnt to see the needs of the service from a service user's point of view." Informally, staff at City University observed that service users who had been involved in the teaching project from the beginning had developed increased communication competence and confidence when

speaking to others, both during their presentations and informally at the end of the taught element of the session.

It seemed appropriate that as this project had been initially developed at City University that the *People in Control* launch took place here. Service user presentations still give a strong message about empowerment to listeners, especially when a strong talk is made with use of speech as well as AAC.

People gained much from the talks at the launch event, especially "the talk about the police and the talk about multi-media". In particular, one participant wrote: "The active involvement of service users was important" with "powerful user presentations".

People commented that they would have liked greater access to additional resources used such as using the visualiser to highlight a person's communication passport or symbols. In addition, some participants felt it important for the future that people less prepared with AAC be appraised in advance about specific strategies they could employ. Service users mentioned at the end the venue and commented that having the event at a university raised the profile of what they had to say considerably.

This is an event that will be repeated not as a further launch, but more as a conference by and for people with learning difficulties to reflect on issues that are important to them.

Another key message that needs ongoing sharing and development is that using AAC is effective for people who have a learning disability as communication competence and confidence can be dramatically enhanced. Watch out for further information in future editions of the *Communication Matters* Journal. \*

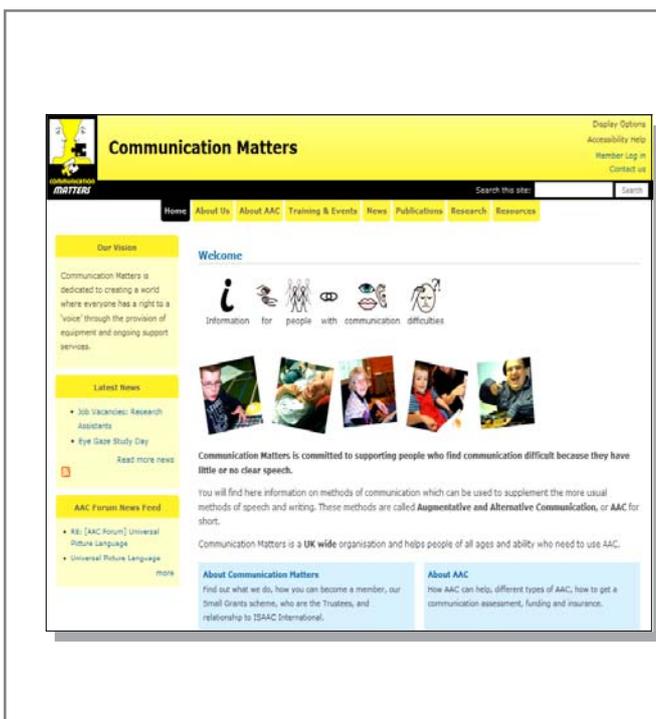
Celia Harding, Julie Hickin  
Senior Lecturers  
Kirsty Harrison, Lecturer  
Saboohi Bukhari, *People in Control Ltd*

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# Vital Voices

## Using Digital Stories to increase participation for people who use AAC

**DEBORAH JANS & BARBARA MATHIESON**

Keycomm, 1c Pennywell Road, Edinburgh, EH4 4PH, UK

Email: [deborah.jans@ea.edin.sch.uk](mailto:deborah.jans@ea.edin.sch.uk)

Website: [www.keycommaac.uk.org](http://www.keycommaac.uk.org)

### BACKGROUND

User Participation and User Involvement in developing health and AAC Services has been an aim of Keycomm (the Lothian Communication Technology Centre) for a long period of time. Within Scotland, involving users in service delivery is a key driver within the health field. The NHS Reform Scotland Act (2004) highlighted the importance of patient “participation, duties of public involvement and equal opportunities” in the delivery of health services.

This translated into a duty of NHS Boards and health services to identify ways that individual service users could participate in service planning and improvement. People who use AAC are often overlooked for inclusion in Involvement projects as it is perceived that they may find it difficult to communicate their opinions.

Keycomm held a number of User Forums and surveyed the participants on how they felt the best way they could be involved in our service. All of them replied they would like to be involved in joint training with professionals. We then identified the best way to take this forward. Some of the users were quite happy to attend training sessions with the professional team using traditional methods. However, others felt they would feel intimidated to present to an unfamiliar audience. Keycomm set out to find tools or methods to address this issue.

### WHAT IS DIGITAL STORYTELLING?

Digital storytelling is an emerging use of multimedia tools to help individuals with long-term conditions to tell their stories in a compelling and emotionally engaging form. Digital stories are being used in many areas: in broadcasting and education to engage young people in their community, by educators as a form of multimedia literacy and in public health to engage individuals in improving local health services.

Digital stories are usually short narratives in the first person that utilise digital images, music and narration to tell a personal story about a specific topic. No literacy skills are required and the participants have the opportunity to use their communication system in conversation.

Storytelling can be an empowering process which values the lived experiences of members of a community. For individuals with severe communication impairments, the medium of storytelling addresses identified barriers such as time constraints, literacy levels and physical access to technology.

Digital storytelling offered each participant the ability to engage with local communities, educators, public health bodies and service providers. It also encouraged each participant to be involved in training various professionals and students and therefore gave them a feeling of inclusion and empowerment.

### THE PROJECT

At Keycomm, we have embarked on a project, *Vital Voices*, to use digital storytelling to compile stories for communication aid users on a specific topic. This allowed each AAC user to address the topic of ‘Communication Really Matters’ by telling their own story and identifying images and music to convey these ideas.

Recruitment to the project was done through letter and individual face to face interviews for all AAC users who were aged over sixteen years on the Keycomm caseload. Each participant had their own communication system and they were using this as their main method of communication.

Each user made a commitment to being available for four sessions over a six to eight week period. Each session lasted approximately 1½ to 2 hours. These sessions were delivered on an individual basis either in the Keycomm Centre or the user’s home.

The project staff identified the equipment required to carry out the project keeping in mind all equipment and materials would need to be transportable. This included: laptop computer; microphone; software Photo Story 3 for Windows; access to copyright free clip art; digital camera; wireless access to Internet; colour scanner; DVDs; speakers for playback; and external hard drive for secure storage of personal information.

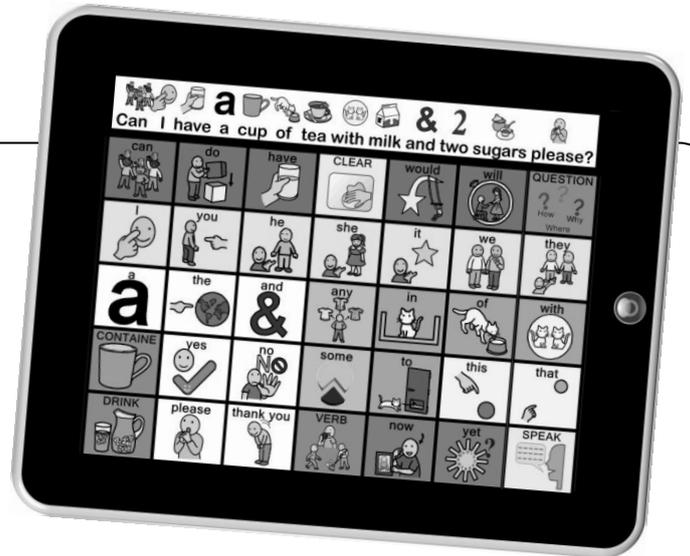


# Voice Symbol AAC

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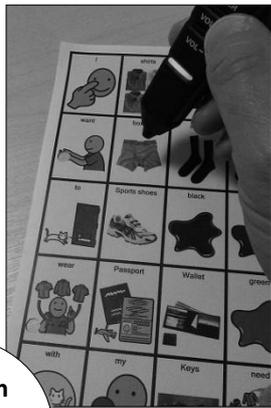
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Statement	 Yes/ happy/ agree	 No/ unhappy/ disagree
I want to share my story with people I know		
I want to use my story to help me take part in speeches, presentations or training for staff that work with me		
I would like Keycomm to use my story to train family, carers and professionals who work with other people like me that use AAC		
I want to be at the presentation when my story is shown		
I don't want to be at the presentation when my story is shown		
I would like Keycomm to use my story for presentations on AAC across the country		
I do not want my story shared with anyone unless I choose at the time		

Figure 1 Accessible consent form

A protocol for delivering this project was set up by the Keycomm team which included what was expected from both the participants and the project staff (Appendix 1). It was also important to put together methods to ensure information for each participant was in an accessible form (Figure 1) and that consent for taking part in the project was agreed. Each participant also agreed how their final story could be shared.

Each participant was sent pre-session information on things to consider before the first session. This included a symbolised topic/theme sheet to begin to think about their story and to begin to gather images that would reflect their key themes (Appendix 2).

During the first session, each participant identified their key theme and a title for their story. An outline of the ideas they wanted to get across through their story was also drawn up. This allowed the project staff to begin to put together a story board (Fig. 2) which included the main ideas for their digital story.

To date we have had three participants involved in the project and the following topics have been completed: *Growing up with Communication Difficulties*, *A day in my life*, and *Communication and the Community*.

A number of challenges have emerged throughout the project so far. These include:

- The number of photos/images required – usually a minimum of fifty.
- Group images may be difficult to use due to permission.
- Recruitment has been slow and has necessitated face to face discussions.

- Gathering historical information can be difficult.
- Consistency of voice-over.
- Commitment from each participant’s carers/family members as support.
- Time required.

**OUTCOMES OF THE PROJECT**

We have looked at the outcomes from the project from both the point of view of the participants as well as the Keycomm service. The participants have benefited from being able to participate in joint training with the AAC team and have had the opportunity to use their communication skills in conversation and take on a leadership role. The project has also allowed each participant to share their views and

opinions and to be creative in the process. As each participant is given a personal DVD of their story, this gave them the opportunity to have a permanent record of their story to share with others.

It is hoped that involvement in this project will give each AAC user the desire to participate in other public involvement projects in the future. As a result of their involvement, two of the participants have already signed up for another event looking at inclusion in the community and knowing their communication rights.

The Keycomm AAC Service has also benefited from the project. We now have a cohort of AAC users who are willing and have the ability to take part in joint training alongside the AAC team. We also have produced a master DVD of digital stories that can be used as a training resource. In addition, this project also gave the project team the opportunity to engage with adults who use AAC, thereby improving their skills as communication partners.

**NEXT STEPS**

Keycomm will be continuing to offer the project to individual AAC users. In addition, we are looking at extending the project to young AAC users who will be leaving school in the next two years, as part of their transition process. We also feel that the digital storytelling medium would be ideal for use within a communication group setting. This may take the form of a group DVD to be able to promote the benefits and impact of their group involvement. We are also hoping to expand the topic to give users the opportunity to give their opinion on local services within the community.

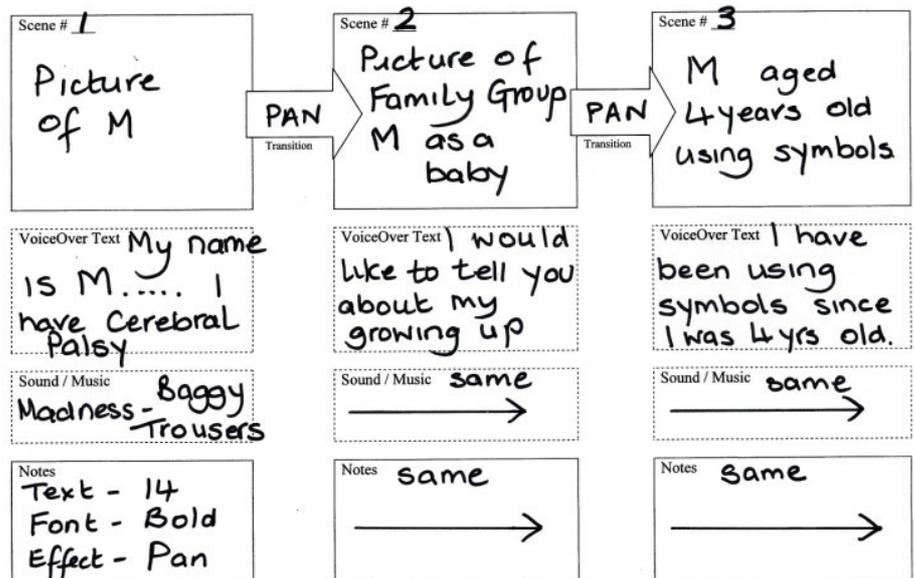


Figure 2 Story board for 'Growing up with communication difficulties'

We have also identified different ways that digital stories may be used by services and individuals. For example, the digital story format can be used as a visual record of a special event or to promote services or projects. During the last year, we have made a digital story about our project *Let's Play and Talk Together*.

We have found that the use of storytelling can be an inspirational and powerful communication tool!

Further information about Keycomm and the Vital Voices project can be found at [www.keycomm.ac.uk](http://www.keycomm.ac.uk) [Note: 'ik', not 'uk'.] \*

Deborah Jans  
Specialist Speech & Language Therapist

Barbara Mathieson  
Speech & Language Therapy Assistant

**ACKNOWLEDGEMENT**

We would like to thank *Communication Matters* for funding this project.

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**APPENDIX 1: PROTOCOL FOR VITAL VOICES**

Session 1	<ul style="list-style-type: none"> <li>• Fill out permission slip with participant; get signed and give them copy.</li> <li>• Go over themes examples sheet and agree on a theme for their story.</li> <li>• Discuss procedure with participant and what the outcome will be.</li> <li>• Show example of a digital story.</li> <li>• Storyboard outline of ideas in template form.</li> <li>• Consider images needed.</li> <li>• Discuss title page and show examples.</li> <li>• Discuss voice-over.</li> <li>• Get email/phone contact for participant to send reminder for next appt.</li> </ul>
Between sessions	<ul style="list-style-type: none"> <li>• Collect images and take extra if needed.</li> <li>• Refine text.</li> </ul>
Session 2	<ul style="list-style-type: none"> <li>• Insert images and decide on sequence of story.</li> <li>• Add text.</li> <li>• Identify voice.</li> <li>• Discuss music.</li> </ul>
Between sessions	<ul style="list-style-type: none"> <li>• Facilitator to scan pictures and put them in the software as discussed.</li> <li>• Get appropriate theme music to go over with participant at next session.</li> <li>• Arrange for voice-over person to be present at next session or for communication aid to be programmed with voice-over text.</li> </ul>
Session 3	<ul style="list-style-type: none"> <li>• Get approval from participant for story so far.</li> <li>• Confirm images are appropriate; find any last minute images required.</li> <li>• Go over music with participant; decide which tracks go with which scene.</li> <li>• Discuss transitions between scenes.</li> <li>• Record voice-over for each scene.</li> </ul>
Between sessions	<ul style="list-style-type: none"> <li>• Put in transitions between scenes and music for each scene.</li> <li>• Ensure images, music, voice-over &amp; transitions working by next session.</li> </ul>
Session 4	<ul style="list-style-type: none"> <li>• Play story for participant; identify any flaws or changes to be made.</li> <li>• Save as final digital story.</li> <li>• Make up CD and identify cover for CD with participant.</li> </ul>

**APPENDIX 2: COMMUNICATION THEMES TO CONSIDER**

Growing up with communication difficulties		Communication and the community	
Communication and school life		Communication to work	
Communication at home – family and carers		Communication and my health	
How I communicate		My communication partners – people who know me	
Expressing humour/ fun		Other people and my communication – people who do not know me/ general public	
Socialising/ dating/ relationships		The highs and lows of my communication aids/ strategies	
Telling people what I think/ giving my opinions		Communication and independence	

COLLATED BY JANICE MURRAY, CHAIR

### CM2011 NATIONAL CONFERENCE

Once again we had an excellent two and a half day conference at Leicester. The number of attendees exceeded all expectations at a very healthy 392, many of whom were attending conference for the first time. The conference had over 60 seminars and workshops on a range of AAC topics presented to a very high standard. The topics offered a mixture of practice, research and user perspectives. Also much talked about were the three keynote presentations from Graham Pullin (Dundee University), Anna Reeves (AAC Co-ordinator for England) and particularly, Martin Pistorius, a person who uses AAC, who received a standing ovation for his challenging yet inspirational and very personal presentation.



The conference has received very positive feedback from delegates, presenters and exhibitors – pictured are enthusiastic attendee Rebecca Marriott and exhibitor Tom Griffiths (Wolfson Neurodisability Service). We thank all those involved for making the event the success it was. We are particularly grateful to the hard work of Patrick Poon and Peter Head, our administrative and conference organising gurus.

### ELECTION OF TRUSTEES

This year we were fortunate that several members of the organisation put themselves forward for election to the role of Trustee. There was competition amongst very skilled and experienced individuals for the few positions available. Trustees duly elected were: Sally Chan, Neil Hansen, Gillian Hazell and Scott Stack.

Liz Moulam continues in her Associate Membership representative role in relation to ISAAC and will attend the ISAAC meeting in Pittsburgh next July, along with Janice Murray.

### STANDARDS AND WORKING PARTIES

We continue to move ahead with various project works including the production and release of AAC

Standards documentation. We have just heard that this documentation is to be endorsed by the Royal College of Speech and Language Therapists. This is a significant achievement.

There is on-going activity with the Competencies and Outcome Measurement working parties. We anticipate some initial documentation from both of these groups during 2012. This work also informs our contributions to the Consortium meetings of the Communication Trust, the AAC Sub-group which informs the work of Jean Gross and the Communication Council.

### REVIEWS OF AAC SERVICES

We are anticipating the release of a report from the office of the Communication Champion to suggest a service structure (England) to support AAC provision.

Members in Scotland and Wales are also awaiting the reports from service reviews specifically related to AAC service provision. Each country's review has been funded and conducted differently.

### ONLINE TRAINING

One further initiative that we are aiming to have available on the website by March is our online AAC training materials. These materials have been informed by considerable consultation with various stakeholder groups, some of whom have also provided some video training resources.

### ACTIVITIES IN 2012

As we move into 2012 we have some old favourites available for members again.

We are in a position to reinstate the small grants award; we are offering a small grant as a fund raising incentive and are in the process of arranging a number of events for people who use AAC (e.g. safe social networking), Study Days and Road Shows.

As part of our on-going awareness raising campaign we are planning to attend exhibitions and conferences such as Naidex and Afasic.

### ISAAC 2012 CONFERENCE

2012 is not only Olympic year, it is also ISAAC Conference year. On this occasion the ISAAC Conference will be hosted by the USA in Pittsburgh. We hope that some of you will be able to be there and enjoy the opportunity to experience the international AAC network.

### FINALLY

These edited highlights affirm the extent and reach of our organisation, which moves into 2012 with much to celebrate and share.

**PRESS  
RELEASE**

**PARLIAMENTARY CELEBRATION OF  
THE NATIONAL YEAR OF COMMUNICATION**

The Communication Trust marked 'one year on' since the launch of the Hello campaign (National Year of Communication) at a celebration event on 19 October 2011 at the House of Commons. Over 200 Hello supporters, including sponsors BT and Pearson Assessment, gathered with MPs and Ministers at The Communication Trust event – sponsored by Annette Brooke MP – to celebrate the achievements of the national year to date. Highlights at the event included a speech from 18-year old, Ben Morfey, a remarkable young man who uses alternative and augmentative communication (AAC) to express himself. Attendees were praised for their efforts in raising the profile of Hello – a campaign, run in partnership with Communication Champion, Jean Gross, to make children and young people's communication development a priority in homes and schools across the country.



Anita Kerwin-Nye, John Bercow MP & Jean Gross

Anita Kerwin-Nye, Director of The Communication Trust, said; "Today, we are one year on since the launch of the Hello campaign, which built directly on John Bercow's landmark review. We have worked with voluntary, corporate and public sector bodies to improve understanding of what 'typical' communication development looks like, how to identify if children are struggling and where to turn for help and support. So far, this collaboration has produced fantastic results. 300,000 resources have been distributed, a new 'good communication' best practice awards scheme has been developed and over 200 Hello co-ordinators are supporting the campaign.

\*

**CORRECTION**

In the August 2011 issue of the Communication Matters Journal (Vol. 25 No. 2) the front cover photograph should have been captioned 'As part of the National Year of Communication, the pupils of Ridgeway School, Farnham, Surrey, used speech, signing and communication aids to greet each other'.

**BHTA eCAT  
NEWS**

The BHTA has been busy trying to raise its image to the same sort of level as ABTA in the Travel business, so that clients (be that the NHS, Education, Private Healthcare or private individuals) feel the same amount of protection when buying a healthcare product from a BHTA member company as the public does when buying a holiday or travel arrangements from an ABTA registered company. The process will continue and the Association has plans to reach every clinician and every professional purchaser as well as the general public over the next two to three years.

Buying from a BHTA member company does not of course guarantee success, just as buying from an ABTA company doesn't mean a trouble free holiday – but at least buying from a company that has signed up to the BHTA Code of Practice, that has been approved by the Office of Fair Trading, means that when things do go wrong, as they do from time to time, and if the supplier doesn't seem to provide any satisfaction, then the purchaser can complain to the BHTA central office and they will review and if necessary, even take action against the supplier.

This is all part of the commercial side of AAC 'coming of age' and being recognised as a really professional sector within the wider healthcare industry. It also shows consumers that suppliers are serious about service and support.

**SUPPORTING AWARENESS RAISING**

We had been considering running an event in October to support the AAC month of the Year of Communication. However, we discovered that there were no free dates at the House of Lords until November and there was also another Year of Communication event, at the House of Commons, booked for October. So we have temporarily shelved the idea and plan to revisit it in the New Year as a possible follow up to the Year of Communication. A lot will depend upon the Communication Champion's final report and recommendations and whether we feel the decision makers and those in government need a gentle reminder to keep the lack of structured access to services at the forefront of their minds.

On the subject of the Communication Champion's final report, we have also been consulted by Keren Down of FAST (The Foundation for Assistive Technology), who has been producing the recommendations for Jean Gross, for our feedback and thoughts on what is being proposed. This shows that BHTA eCAT, as a trade association, is becoming recognised as an important and essential part of the AAC industry. \*

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

*Note: BHTA is the British Healthcare Trades Association; eCAT is one sector of the BHTA, dealing with electronic Communication and Assistive Technology*

## The National Year of Communication

# “I’ll be Asking the Questions”

## Celebrity Interview Competition

As part of the National Year of Communication, Communication Matters organised a competition for people who use AAC to interview celebrities by entering 10 questions they would pose to a famous person, with the prize of doing the interview for real.

The judges found it very difficult to choose from the excellent entries, but they finally selected four winners: **Daniel Barker, Monique Stewart, Courtney Allen, and Beth Moulam.**

### WHEN DANIEL MET ANDY WALKER...

One of the celebrities lined up to be interviewed was **Andy Walker**, who plays Steve Kelly in the TV series *Emmerdale*. Andy’s character was brought into the soap to give positive messages about disability. He believes passionately that anyone with a disability can live life to the full and achieve anything they want to, so the opportunity to appear in *Emmerdale* and spread this message was too good to miss.

In 2006, Andy had a high spinal cord injury when he dived into shallow water whilst on holiday in Goa. Since then, he has continued to live life to the full and inspire others to do the same. Andy has been on the Board of ACE Centre North since 2008 and has met many children and adults who use AAC and is keen to learn more about the field as well as share his philosophy on life when he can.

He was delighted to be approached as a prize for the *I’ll be Asking the Questions* competition and in early October he met, and was interviewed by one of the winners, Daniel Barker.

Daniel is nine years old and is in a mainstream school. He is currently using a Samsung Q1 Ultra and, with the help of his school mates, he composed 10 questions for the competition. Despite the envy of his *Emmerdale* fan older brother (who couldn’t take time off school to meet Andy), Daniel came to ACE Centre North to do his interview.



Sporting his Rochdale AFC football shirt (Daniel had done his research and knew that Andy was a massive football fan) he arrived with his mum, to be greeted by Andy wearing the top from his most famous scene in *Emmerdale*. The two hit it off straightaway and once we had “camera, lights, action”, the interview began.

Daniel was cool as a cucumber, sitting with his legs crossed and firing questions at Andy. He found out about Andy’s favourite football team, food and colour as well as his favourite TV show (not *Emmerdale* but cartoons and anything sports-related) and computer games.

As an experienced interviewee, Andy was able to vouch for Daniel’s excellent interview skills and observed that he was much better than Philip Schofield when Andy appeared on ‘This Morning’.

In recognition of his efforts, Daniel received a framed certificate award and Andy has promised to give him some *Emmerdale* memorabilia.

### WHEN MONIQUE AND COURTNEY MET KERRY ELLIS...

**Kerry Ellis** is well known in musical theatre, appearing in many London West End productions, including *We Will Rock You*, *Miss Saigon*, *Oliver* and *Les Miserables*. She released her debut studio album, *Anthems*, in 2010.

Kerry made her way to University College London to be interviewed by Monique and Courtney. There were

smiles and laughter all round during the day, as can be seen in the photographs below. After the interview, Kerry said:

“I was honoured to be interviewed by two inspiring girls Monique and Courtney, both used computers to help communicate with me. I was blown away with the ease of the whole event. I really felt I got a brief insight into both of their lives and personalities.

I have never been interviewed in this way before and found it very educational. Most of us take it for granted that we have the ability to speak and communicate without even thinking. Monique and Courtney have had to train themselves how to do just that; they do it beautifully and I found the whole experience humbling. It was a pleasure to meet them both and a lot of fun.”



To see videos and photos of the interviews (Beth’s interview with poet **Ian McMillan** will be available soon), visit: [www.communicationmatters.org.uk/page/2011-celebrity-interviews](http://www.communicationmatters.org.uk/page/2011-celebrity-interviews) \*



## The National Year of Communication

# AAC Awareness Raising Events



**'Hello' - The National Year of Speech, Language and Communication** - is a national campaign to raise awareness of the importance of good communication skills for children and young people.

In the *Better Communication Action Plan* in response to John Bercow's review of speech, language and communication needs, the need for a National Year was highlighted. Speech, language and communication underpins everything we do, and the Hello campaign aims to make communication for all children and young people a priority at home and in school.

The National Year is coordinated by The Communication Trust, a coalition of over 35 leading voluntary sector organisations in partnership with the Communication Champion, Jean Gross. Communication Matters is one of these organisations, so it was an opportunity for Communication Matters to become involved in running events during the year that would raise awareness and increase understanding of the use of AAC. Communication Matters took the opportunity to extend the Hello remit to include adults, as well as children.

During the year there have been monthly themes. In October, the theme was 'Not Just Words' - focusing on those children who have little or no speech, and who use Augmentative & Alternative Communication (AAC). The Communication Matters website has had an AAC story for each month.

In May and June, Communication Matters planned to coordinate a wave of AAC activities throughout the UK, moving from the South West to Scotland during the two months. The national launch in London to start the Wave never happened due to difficulties with funding, but this did not stop activities being run in the regions. Here are just some of the many great events that took place during the year...

### MARCH

- **1Voice - Communicating Together** have run Family Fun Days throughout the year, the first one being coordinated by 1Voice West Midlands. The Family Fun Day was held at Wilson Stuart School & Sports College. The theme was "I'm an AAC user - get me out of here!" and involved jungle

themes and bush tucker trials! A second 1Voice day was led by the South East branch at Abbots Langley Community Centre in Watford.

- **The speech & language therapy (SLT) department at Amersham Hospital** in Bucks ran an Open Day to celebrate the achievements and highlight the needs of adults, children and young people with speech, language & communication difficulties.

### APRIL

- **Safe Social Networking Days** - Communication Matters organised two Safe Social Networking Days during the year. The first one was held at Treloar College in Hampshire, and the second one at Beaumont College in Lancaster. These days were for FE students and other young adults living near the College who use AAC. The College and Communication Matters worked in partnership to develop the structure and content of the days. It is hoped that more colleges will be in a position to work with Communication Matters, to run similar days during 2012 and 2013.

- **Naidex** – Communication Matters took the opportunity to have a stand at Naidex at the NEC Birmingham.

## MAY

- **Bristol Open Days** – The two communication aid centres in Bristol, PCAS and Frenchay CAC, held Open Days. Frenchay had developed an AAC obstacle course and PCAS held an AAC competition for the visitors (won by the local PCT Commissioner). A picnic lunch on College Green was held for children who use AAC, with the additional delight of a cake in the shape of a BIGmack.



Open Day at Frenchay CAC

- **Communication Works** launched the South East contribution to the AAC Wave at Charlton School in London. Jean Gross introduced the day, which was a joint venture by CEMMAC and Charlton School. An exhibition and seminars relating to the use of Assistive Technology (AT) and AAC ran throughout the day.
- **The All Wales Electronic Assisted Technology (EAT) Service** at Rookwood Hospital held an Open Day focusing on AAC for children. This involved a free tour of the Centre and demonstrations of services and techniques; EAT staff were available to answer any queries.
- **Milestone School** in Gloucester hosted a coffee morning run by 14 students who use AAC. There was also a musical concert by some students using switches.
- **The Diving Bell and the Butterfly** is a 2001 biographical film based on Jean-Dominique Bauby's life after suffering a massive stroke. The film describes his communication journey and how he communicates using the blink of an eye. Access to Communication Technology (ACT) hosted the viewing of this film at Moseley Hall Hospital in Birmingham.
- **South West 1Voice** hosted a Family Fun Day at Hannah's at Seale-Hayne in Newton Abbot, Devon in May.
- **New Fosseyway School** in Bristol devised a Cookbook to celebrate the

National Year. "The Language of Cooking" is a collection of symbolised recipes submitted by different year groups within the school.

- **Penn Hall Special School** in Wolverhampton ran a radio show for their AAC City and Guilds group of students. The local radio station supported the radio show, as well as reported on the event.
- **Coventry Open Day** – There was an Open Day at a special school in Coventry, to which were invited a mix of people – the media, MPs and managers of local businesses. Students made different kinds of Waves: big foam hands, aerial photo of people waving, video of a Mexican wave, and handprints on a giant hand.
- **In Walsall**, a group used the Mayor's Parade on St. George's Day to raise awareness of AAC. They had a stall and ran activities that got people involved in thinking about and using AAC.
- **The Dudley SLT team** took some people who use AAC to a local college to chat to the students.

## JUNE

- **ACE Centre North** held a Network Day for professionals and carers interested in the use of AT and AAC. The day incorporated a varied programme of "Hello" themed topics for discussion, as well as demonstrations.
- **Personal Narratives Workshop** – Communication Matters hosted a Study Day in conjunction with the University of Dundee and the University of Aberdeen – "Talking About Experience: Personal Narratives Workshop" in London. The workshop followed on from the Story Telling Study Day in 2009, and offered an opportunity for teachers, SLTs, parents, family members, and carers to engage in the practicalities of using AAC devices to support the development and sharing of personal narratives.
- **The SLT department at ABM University Health Board** in the Vale of Glamorgan organised a Conference to generate greater service user involvement. Attendees were invited to take part in workshops on health, making choices and having their say.
- **1Voice National** held their summer event at Hayes Court in Derbyshire. The weekend event focused on the "Hello" campaign.
- **The Communication Friends Group** held a special event, "Say Cheese",

in Dumfries to celebrate the National Year. The event focused on four activities: Show & Tell (showing a favourite photo to the group), Snack & Chat, What My Talker Means to Me, and an interview with a local radio DJ.

- **Darlington Association on Disability** has designed a new Communication Toolkit that can be used by professionals who work with people that are receiving a direct payment or a personal budget, and may have communication difficulties. Using Support Plans, the Toolkit guarantees that each person is given the correct support to ensure they can communicate their needs effectively. "Making Communication Work for Us" launched the Toolkit at Darlington Arts Centre in County Durham.
- **ACE Centre North** organised an event for anyone involved in AT and AAC at the Freemasons Hall in Manchester. The event involved demonstrations, consultant appointments and the launch of a series of new short films highlighting the difference AAC can make to people's lives.
- **The Autism Show** – Communication Matters had a stand with the AAC suppliers within the Communication Matters zone at the Autism Show in London.
- **The Ridgeway School** in Farnham, Surrey, held a meet and greet session for the pupils who use speech, signing, low and high tech communication systems.



Pupils at Ridgeway School meet and greet

## JULY

- **1Voice South East** ran their second Family Fun day in Berkshire – an afternoon of fun, games and socialising.

## AUGUST

- **1Voice Oxford** ran a Family Picnic & Get Together at Cotswold Wildlife Park in Burford. The same month saw a dramatisation, book reading – "A Most Curious Detour" in St John's Parish Church in Edinburgh. The

event was part of the Festival of Spirituality and Peace. The first half of this event was a dramatised reading of excerpts from Stuart Hepburn's biography. Stuart had suffered an extensive stroke in 2005; the second half was an explanation of the spiritual aspect of Stuart's life and his recovery.

- **Concert for Communication** - Back to High Wycombe where we started the year in March, a "Concert for Communication" was held at Wycombe Abbey School. Jean Gross gave an introductory address, and there were displays to promote the Hello campaign. The concert was organised by South Bucks Association for Speech & Communication Help.
- **Communication Chain** - Many people came together to form a communication chain across the Humber Bridge. Giving Voice Humber organised this event to demonstrate how vital communication is to all. The communication chain conveyed the message "Communication is Key" using different and many modes of communication, from one side of the bridge to the other.
- **Kick Start Communication** - The International Lawn Tennis Centre at Eastbourne was the location for a fun event for people with autism. This event was organised by Kick Start Communication and involved an information market place, communication equipment, and workshops. Ros Blackburn, a highly respected international speaker on autism, was a guest speaker.
- **Communication Matters** held its annual National Conference at Leicester University towards the end of September.

## OCTOBER

- **iMuse** - In October there was the launch of iMuse at the Museum of English Rural Life at the University of Reading. Access-Ability Communication Technology (AACT) for children is launching the programme to help make museums more accessible, educational and fun for people with communication difficulties. The aim of the afternoon event was to see how IT can improve people's experience of museums.



- **"Got something worth saying?"** was an event run by an AAC support group for children and young people from the age of 12. It was co-hosted by Chatting Independently and Southview School in Essex. Chatting Independently led the day, which involved games, discussion, help and hints.
- **Celebrity Interview Competition** - Communication Matters organised "I'll be asking the questions" competition throughout the year. People who use AAC were asked to submit a series of questions to interview a celebrity. The successful candidates interviewed celebrities during October and November. The celebrities were Kerry Ellis (singer and actress), Andy Walker (actor) and Ian McMillan (poet). The interviews have been filmed and can be viewed on the Communication Matters website.
- **Wave 'hello'** - Many people used Communication Matters' big yellow foam hands to raise awareness of AAC in their local community. See all the photographs sent to us at [www.communicationmatters.org.uk/page/2011-wave-hello](http://www.communicationmatters.org.uk/page/2011-wave-hello)



- **National Year of Communication Parliamentary Event** - Communication Matters was delighted to The Communication Trust and over 200 supporters, MPs and Ministers at the House of Commons to celebrate the achievements of the National Year to date and to unite efforts to ensure that children and young people's communication development remains a national priority.

- **SLT students at Manchester Metropolitan University** have been learning at first hand what it's like to use AAC. Some students have used a Lightwriter for a day, and interviewed the Dean to ask him about his experiences of AAC. They also used symbol boards to converse with other university students in the canteen. Accompanied by the big yellow hands they have visited local hotels, rugby clubs and medieval banquets to spread their message.



## NOVEMBER

- **AAC Pantomime** - Ditte Fisher (Communication Matters Trustee) organised an AAC pantomime - "Oh go on Cinderella" at the end of November in Aberdeen. This was a pantomime performed by people who use AAC, for an audience of people who use AAC, family and friends. The script will be available on the Communication Matters website for anyone who would like to use it for their own pantomime.

## DURING THE YEAR

- **'Other Ways of Speaking' booklet** - Communication Matters worked with the Communication Trust to produce a booklet entitled 'Other Ways of Speaking'. It provides information about children and young people who use a variety of different ways to communicate, how you can help and support them, and where to go for further information.
- **Grants for AAC Events** - Communication Matters has provided grants of up to £100 throughout the year to support AAC events. This has helped enable groups, departments and organisations to raise the profile of AAC.
- **Communication Matters Road Shows** - Throughout the year, Communication Matters organised eight Road Shows, taking these to different venues to ensure that all have access to these informative days. \*

Sally Chan  
Communication Matters Trustee



### Augmentative and Alternative Communication

This is the official journal of the International Society for Augmentative and Alternative Communication (ISAAC), published quarterly by Informa healthcare. AAC publishes original articles with direct application to the communication needs of persons with severe speech and/or communication impairments for whom augmentative and alternative communication techniques and systems may be of assistance.

### Unterstützte Kommunikation

This ISAAC affiliated publication is published four times a year in German by ISAAC-GSC.

### AGOSCI in Focus

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.

### 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.

Members of Communication Matters (ISAAC UK) can order these publications by contacting:

Communication Matters, Catchpell House, Carpet Lane, Edinburgh EH6 6SP

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)

If you are not a member of Communication Matters, you can order in local currency from your local Chapter of ISAAC, or in dollars directly from ISAAC, 49 The Donway West, Suite 308, Toronto, ON M3C 3M9, Canada Tel: +1 416 385 0351 Email: [info@isaac-online.org](mailto:info@isaac-online.org) Website: [www.isaac-online.org](http://www.isaac-online.org)

## JOINING COMMUNICATION MATTERS & ISAAC

### What is Communication Matters?

**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.

**Our Vision:** A world where all individuals have a right to a 'voice' through the provision of equipment and ongoing support services.

**Our Mission:** Communication Matters values people who use any form of communication and promotes the individual's right to participate in all aspects of life by using their most appropriate means of communication to express their thoughts, feelings, needs and desires.

### What are the benefits of Membership?

Members of Communication Matters receive:

- The Communication Matters Journal three times a year.
- Reduced rate at Communication Matters Study Days.
- Reduced delegate rate at the CM National Symposium.
- Regular electronic newsletters with the latest news in AAC developments, Road Shows, study days and more.
- Access the members' area of the CM website.
- All the benefits of ISAAC membership.

### How do I become a Member?

You can become a UK or Overseas member of Communication Matters (and therefore of ISAAC) by contacting:  
**Tel: 0845 456 8211 E: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)**  
**[www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)**

If you wish to become a member of ISAAC directly or subscribe to this Journal, please contact: ISAAC Tel: +1 416 385 0351  
[info@isaac-online.org](mailto:info@isaac-online.org) [www.isaac-online.org](http://www.isaac-online.org)

### 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 3,600 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, India, Israel, Italy, Netherlands-Flanders, Norway, Sweden, UK and USA.

**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.
- Supports the use of AAC around the world. This includes countries that do not know about AAC.
- Has an exciting awards & scholarship program for members.
- Encourages the development of AAC products & services.
- Produces a series of books for people involved in AAC.
- Has an international conference every two years.
- Sponsors a peer-reviewed scientific journal – Augmentative and Alternative Communication (AAC). Visit the website at: [www.isaac-online.org/en/publications/aac.html](http://www.isaac-online.org/en/publications/aac.html) for more details.

### What do ISAAC members receive?

- Full access to *ISAAC Information Exchange*, an international resource for sharing knowledge, experiences & perspectives on AAC.
- An International Directory with a list of all ISAAC members.
- ISAAC members can buy the AAC Journal at 54% discounted rate.
- ISAAC members can attend ISAAC conferences and meetings at 15% or more discounted rate.



## DIARY DATES

- 12 January 2012 Oxford  
**Getting Started with AAC**  
Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)
- 24 January 2012 Oxford  
**Communication Through Play**  
Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)
- 26 January 2012 Oldham  
**iPod and iPad Apps for AAC**  
Contact ACE Centre North: 0161 358 0151 [www.ace-north.org.uk](http://www.ace-north.org.uk)
- 31 January 2012 Oldham  
**Clicker 5 Activities for Early Communication Skills**  
Contact ACE Centre North: 0161 358 0151 [www.ace-north.org.uk](http://www.ace-north.org.uk)
- 2 February 2012 Oxford  
**Look2Talk - Communication Books for Eye-pointing Children**  
Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)
- 2 February 2012 Oxford  
**Getting the Most Out of Communicate: in Print 2**  
Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)
- 22 February 2012 Edinburgh  
**Smart Wheelchairs for Interaction, Exploration and Fun**  
Contact CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)
- 23 February 2012 Edinburgh  
**Technology for Pupils with Complex Support Needs**  
Contact CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)
- 8 March 2012 Edinburgh  
**Switching to Excellence for Pupils with Physical Difficulties**  
Contact CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)
- 15-16 March 2012 Leicester  
**Voice for Life – Leicester conference**  
Contact Afasic: 07950 911004 / 01273 381009 [www.afasicengland.org.uk](http://www.afasicengland.org.uk)
- 22 March 2012 Stockton-on-Tees  
**Voice for Life – Stock-on-Tees conference**  
Contact Afasic: 01287 209882 [www.afasicengland.org.uk](http://www.afasicengland.org.uk)

## DIARY DATES

- 27 March 2012 Oldham  
**Clicker 5 for Language and Literacy Development**  
Contact ACE Centre North: 0161 358 0151 [www.ace-north.org.uk](http://www.ace-north.org.uk)
- 23 April 2012 Cardiff   
**Communication Matters Road Show in Cardiff**  
FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)
- 24 April 2012 Oldham  
**Eye Pointing to Eye Gaze**  
Contact ACE Centre North: 0161 358 0151 [www.ace-north.org.uk](http://www.ace-north.org.uk)
- 25 April 2012 Scunthorpe   
**Communication Matters Road Show in Scunthorpe**  
FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)
- 8 May 2012 Oldham  
**Communicate: in Print**  
Contact ACE Centre North: 0161 358 0151 [www.ace-north.org.uk](http://www.ace-north.org.uk)
- 11 May 2012 Edinburgh  
**Personal Communication Passports**  
Contact CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)
- 15 May 2012 Glasgow   
**Communication Matters Road Show in Glasgow**  
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## Research Project News

# Communication Matters – Research Matters: An AAC Evidence Base

Katie Holmes

Communication Matters, Catchpell House, Carpet Lane, Edinburgh EH6 6SP

Email: [katieholmes@communicationmatters.org.uk](mailto:katieholmes@communicationmatters.org.uk)



**The Communication Matters CM2011** National Conference in September provided a valuable opportunity for the research team to make useful contacts and to get feedback and comments on our work to date.

In her introductory plenary talk on AAC provision in the future Anna Reeves, the National AAC Co-ordinator for England, highlighted the need for a better understanding of the level of need for AAC as one of four key challenges in making the case for AAC provision.

We were pleased that she referred to the aspiration that the AAC Evidence Base project will make a significant contribution towards this. We believe the research will indeed be a significant step forward in understanding need and will also identify further work that may be required to build a complete picture.

We had an exhibition stand at CM2011 for the AAC Evidence Base project and were pleased to talk to a wide range of delegates who came to visit the stand.

**The University of Sheffield** distributed a practitioners' survey, the responses to which will be used to structure a survey about AAC provision that will be distributed to practitioners across the UK.

In addition, **Manchester Metropolitan University** distributed a questionnaire on the topics discussed in their focus groups on the development of the AAC Evidence Base.

We also officially launched the **Research Involvement Network** at the conference and were pleased to be able to recruit a number of new members. Our first member who uses AAC was

Simon Stevens who is an independent disability issues consultant.

This Network will be made up of people who are interested in participating in AAC research for example as research subjects, as advisers to researchers or as members of steering panels for research projects. It is hoped that the Network will make it easier for AAC researchers to find participants and widen the pool of people they can draw on. Membership of the Research Involvement Network is open to people who use AAC, family members and carers of people who use AAC, and practitioners. If you are interested in joining the Network please contact me for more information. Once we have recruited enough members to the Network we will invite researchers to use the service.

**Manchester Metropolitan University** demonstrated an early prototype of the AAC Evidence Base at the conference and there was an interactive session to get feedback about it. There was also a discussion of the first draft of the case study template that is being developed by Manchester Metropolitan University. The aim of developing the template is to make evidence from case studies more widely available, and create a body of studies that can be used in research (longitudinal cohort data). This builds on the work of Pennington, Goldbart and Marshall (2004).

**The University of Sheffield & Barnsley Hospital** are investigating the evidence of need for AAC in the UK and mapping existing service provision. Their

presentation was attended by over 50 people. It reported on the findings from the systematic literature review and explained the next stages of the research.

### LOOKING FORWARD

Over the next six months the University of Sheffield will undertake surveys, interviews and focus groups. Manchester Metropolitan University will hold further focus groups on the AAC Evidence Base and develop the user interface. The mid-year report to the Big Lottery Fund will be submitted at the end of 2011 and we will continue to build our communication and dissemination activities. We have also recently submitted a proposal for a presentation at ISAAC 2012. \*

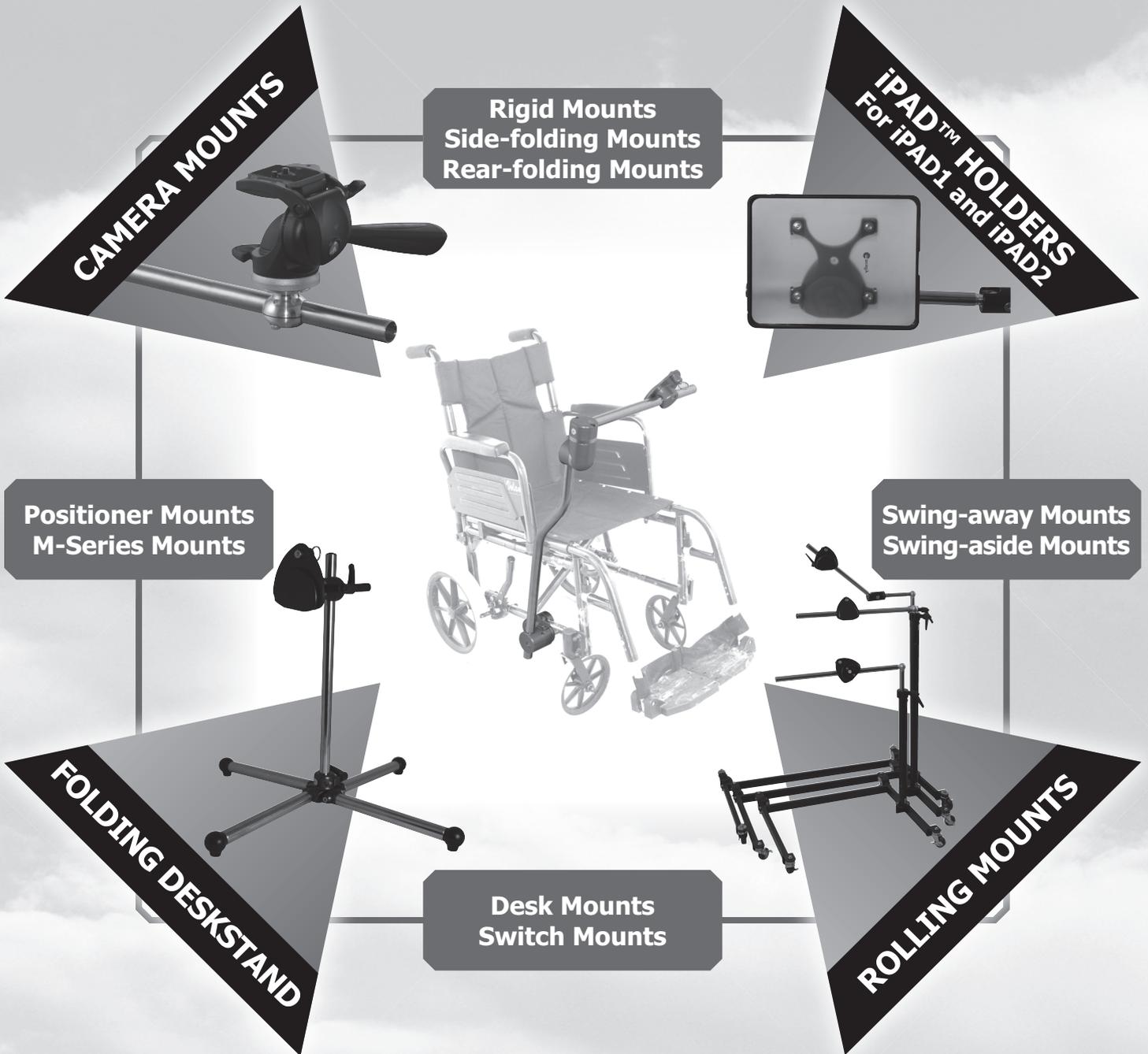
Katie Holmes, *Research Manager*

### ABOUT THE PROJECT

The AAC Evidence Base research project is a three-year project funded by the National Lottery through Big Lottery Fund. Communication Matters is leading the project and working with three research partners: the University of Sheffield, Barnsley Hospital NHS Foundation Trust and Manchester Metropolitan University.

The project will produce fundamental evidence of the need for, and the provision of, AAC which can be used to improve services across the UK. The project will also create an online AAC Evidence Base that will make current knowledge about AAC available to all.

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# “How I use the internet and social media”

## Findings from a pilot investigation with an AAC user

### AMANDA HYNAN

Manchester Metropolitan University, Elizabeth Gaskell Campus, Manchester M13 0JA  
Email: amanda.e.hynan@stu.mmu.ac.uk



This paper presents findings from a pilot investigation I have carried out as part of my PhD research. I am looking at how technology can potentially support social participation for young people who use AAC by looking at how the Internet and social media are utilised. I use the term ‘social media’ to describe any website that allows social interaction, for example:

- social networking sites (e.g. Facebook, MySpace, Twitter)
- online gaming
- second life sites
- video sharing (e.g. YouTube)
- email and instant messaging (MSN)
- Skype
- contributing to forums
- blogging

### ADOLESCENTS, SOCIAL MEDIA AND RESEARCH

Lenhart et al. (2010) reported 93% of young people in America have access to the internet and 73% use social networks. In the UK, Livingstone and Bober’s 2005 study reported 75% of young people had access to the internet at home, rising to 92% through school, and highly valued being in constant contact with their local friends. Recent data reports 91% of 5-15 year olds in the UK have access within the home with 50% using social networking (Ofcom, 2011). Young people are the first generation to have grown up ‘digitally’ and mainstream research is increasingly exploring the positive and negative effects of internet exposure. O’Keeffe et al. (2011) reported much adolescent social

development is occurring online with benefits for communication, social skills, education and health awareness but concerns for cyber bullying, inappropriate exposure and personal safety. I am interested in the implications for young people who use AAC of this rising use of mainstream technology for social participation.

### DISABLED PEOPLE, SOCIAL MEDIA AND RESEARCH

Research is scarce concerning internet and social media use by young disabled people but some findings show:

- Online interests are similar to non-disabled peers (Lathouwers et al. 2009).
- Safety issues are highlighted more intensely and access may be controlled by parents (Lathouwers et al. 2009).
- Girls are more interested than boys in using the internet as a social tool (Suris et al. 2010).
- Long distance friendships are easier to maintain (Soderstrom, 2009).
- Characteristics of offline social ties reflect on how disabled young people use online social media (Soderstrom, 2009).
- Being online offers choice about the management of identity (Soderstrom, 2009).

Since 2007, high-tech communication aids have integrated computers, and many young people who use AAC have access to mobile phones and traditional computers. However, there is a gap in the literature on how people with

complex communication needs might be accessing and using the internet and social media.

### RESEARCH AIMS

My research aims to investigate the experiences of young people who use AAC in four areas:

- *The accessibility of the internet and social media.* As Newell (2008) argues a blanket approach to accessibility for disabled people is not sufficient, and data is required from specific groups.
- *The ways the internet and social media are used.* As Lathouwers et al. (2009) found, physically disabled young people have similar online interests to non-disabled peers but might face tighter parental controls. Suris et al. 2009 suggest gender influences content choice.
- *The perceived role and importance of the internet and social media* and how this relates to Bowker and Tuffin’s (2002) discursive work on the ways disabled people might position themselves in the online social world.
- *How existing social ties affect online friendships.* As Ahn (2011) and Soderstrom (2009) claim existing social, psychological and emotional characteristics are brought into online communities and influence networking and communication.

### PILOT INVESTIGATION

In order to explore the relevance of these issues for people who use AAC and develop my skills as a communica-

tive partner, I spoke to an adult male who uses a Liberator 14 with an integrated computer, as well as a home computer and mobile phone. When conducting a qualitative interview, Kvale (1996) suggests ‘thematizing’ forms the ‘why’ and ‘what’ of the investigation and keeps objectives in focus, whilst Patton (2002) says it ensures enquiry lines are consistent between participants. My thematic interview guide was built around the research objectives outlined above.

**DATA ANALYSIS**

I analysed the pilot data using a thematic network approach described by Attride-Stirling (2001). This builds thematic networks by successively coding the data into basic, organising and finally global themes. Figures 1-4 show the networks but in order to fully reflect the data I will discuss some of the issues raised in more detail and illustrate points using the participant’s own words.

**Thematic Network 1 – Accessibility**

Besides the participant’s own literacy skill, he identified Penfriend XP software as a support for access. It acts as a word prediction programme and he says, “it’s like my best piece of software” because it “makes my work on the computer fast”. He also finds the voice feature to check individual words and completed sentences useful as it “can tell if what you are typing sounds right”. He discussed a limitation to access in connection with online banking. He said, “I do my banking online, but to get in to it, you have to use a card reader which I can’t do myself”. He also identified he can have problems accessing websites “if you have a time limit”. Newell argues this level of detail is required to illustrate the disablement of different populations online.

When speaking about his communication aid computer he reports, “this is not very powerful as a computer” and when I asked if he could use the Penfriend XP software on it, he replied, “it could but saying the processor in this is like a snail”. He says he only really uses the computer component to pick up emails when on holiday.

I felt accessibility issues were the easiest theme to explore and it made me reflect on how this is somehow ‘safe’ territory.

**Thematic Network 2 – Use of the Internet and Social Media**

The participant co-runs an online business and identified he “used to be heavily

**Thematic Network 1**



Organising themes	Basic themes
DEVICES USED	1. Liberator 14 with integrated computer 2. Home computer 3. Mobile phone 4. Electric wheelchair controls Liberator 14
ACCESSIBILITY SUPPORTS	1. Keyguard 2. Personal assistant 3. Penfriend XP software on computer 4. Joystick
ACCESSIBILITY CHALLENGES	1. Time limits on websites 2. Internet banking keycode device
PERSONAL SKILLS	1. Finger pointing and knuckle control 2. Accurate and fast joystick control 3. Self-taught computer skills 4. Literacy
LIMITATIONS OF INTEGRATED COMPUTER IN COMMUNICATION AID	1. Slow processing speed – uses only as basic computer 2. Can be a mobile phone but if not using aid then no phone connection
BENEFITS OF INTEGRATED COMPUTER IN COMMUNICATION AID	1. Can be used for email if away from home

**Thematic Network 2**



Organising themes	Basic themes
SITES USED	1. Facebook 2. Email 3. MSN 4. Skype
ACTIVITIES	1. Co-running business 2. Supporting hobby interest 3. Organising social life 4. Playing game on Facebook 5. Personal profile updating 6. Supporting romantic relationship 7. Communicating with family and friends 8. No political activity online

into communication radio and I used the net to find things out”. However, he also reported a range of hobbies which he did not supplement with online activity.

He values email as he says, “just about everybody living uses that” and suggests 70% of his friends use Facebook. He also uses Facebook to play an online city building game but not interactively and when asked if he used the internet for political activities said no because “they are all the same”. He did not mention using interactive gaming, blogging, second live sites, forums or posting videos but I did not ask about these directly.

In future interviews, I need to explore ‘use’ more extensively to look at issues of content, online safety, and control to establish if unique characteristics exist for young people who use AAC including gender differences. However, this will be a difficult area to investigate, as questions have the potential to invade privacy. Livingstone (2004) discusses the methodological difficulties of internet-based research saying people often use it in a private space to explore personal concerns, such as health or sexuality. She also points out people are producers as well as receivers of information which makes content analysis

difficult and participants may find it hard to recall potentially trivial details.

**Thematic Network 3 – Role and Importance of the Internet and Social Media**

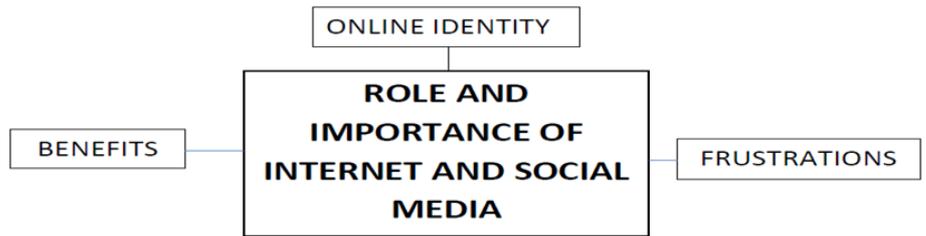
There is concordance between the participant’s online and offline identity management. He uses a photograph of himself on Facebook and says he shares news and photographs with friends if he is “*doing something out of the ordinary*”. He goes onto say he “*can’t see why people write things like I am eating a bar of chocolate*”. Online identity management is something I am keen to look at, as Bowker and Tuffin (2002) and Soderstrom (2009) both discuss how disabled people sometimes find being online offers them freedom to focus on different aspects of their identity other than their disabled status. In future interviews I will try to explore online identity representation in more detail.

Benefits and frustrations were identified for privacy and independence. He said, “*I could ring mum but how could I have a private conversation when I have twenty four hour care*”. He enhanced privacy by teaching his family to use Skype and said, “*I can write messages*” explaining he now has the immediacy of video yet privacy through text. A frustration, as previously mentioned, is online banking and he says, “*I ask my staff but they could get to see how much I have*”. He identified a city building game on Facebook (of which I was unaware) as beneficial and said, “*when I am quiet I can just play a game*” and called it “*stupid but addictive*”. At first, I thought he meant a second life game and although he realised my error he found it easier to wait until I mentioned Facebook again to say, “*like I said about building*” to correct me. This exchange showed me how difficult conversational repair can be and provided valuable information for future interviews.

**Thematic Network 4 – Online Relationships**

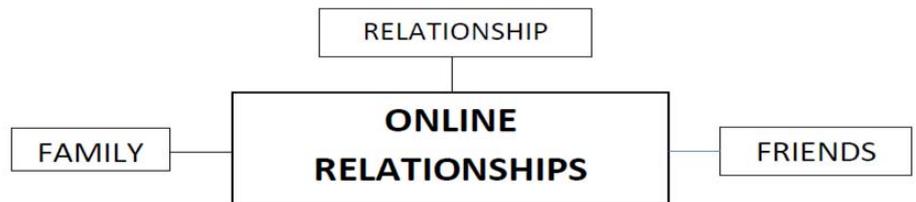
The participant reported he only contacted people online who he knew in the offline world and he had not made friends with anyone he *only* knew in an online context. How widespread an application was appeared to dictate how useful he found it for supporting online friendships. When asked if he could only keep one form of social media, he identified it would be email. He reported using social media to support a relationship he had with another person who used AAC and when asked what differences he felt there were between offline and online relationships he said “*always better seeing and hearing the person*”.

**Thematic Network 3**



Organising themes	Basic themes
ONLINE IDENTITY	1. Only posts things considers to be interesting 2. Uses own photo on Facebook profile
BENEFITS	1. Increased privacy - texts with Skype phone calls to family 2. Increased independence 3. Communication 4. Fills time with Facebook game 5. Widespread use of email
FRUSTRATIONS	1. Keycode equipment required by banking site 2. Requiring help for online activities from staff

**Thematic Network 4**



Organising themes	Basic themes
FAMILY	1. Skype increases family intimacy
FRIENDS	1. Only contacts people online known offline 2. Prefers to see and hear people 3. 70% of friends use Facebook 4. Nearly all friends use email 5. No friendships via solely meeting online
RELATIONSHIP	1. Social media supported relationship with another AAC user

Soderstrom (2009) feels her data revealed that disabled participants had special characteristics within their offline social ties that influenced how they managed online social ties. This particular area was difficult to explore and I have to reflect on how to frame questions in future interviews to look more closely at the characteristics of offline and online friendships and perceptions of social participation.

**FEEDBACK**

The participant thought I had good interview skills but need to be careful

about how many questions I ask in one turn. The audience at the conference presentation session gave me the following feedback:

- Facebook was identified as important for one young boy by his mother because he can interact with friends independently when online. She said at school the presence of his personal assistant impacted on his social interaction with peers.
- Facebook was reported as rewarding for a child with low literacy as he enjoyed looking at friends’ photos and posting his own.

- A 25 year old speech therapist felt there were differences in how she used Facebook compared with her brothers aged 19 and 16.

As this pilot investigation forms the basis for my on-going project, I would welcome feedback via email.

## CONCLUSION

At the CM2011 National Conference, Tom Griffiths and Scott Stack discussed the Communication Matters 'Safe Social Networking' project for colleges, and explained it had evolved in response to the desires of young AAC users to engage with social media and many equipment suppliers demonstrated how they are integrating social media access into their devices.

However, the most powerful words for me come from the conference plenary speaker, Martin Pistorius who, in his 2011 book *Ghost Boy*, has written a chapter about his laptop. He explains the terror, panic and physical sickness he felt when it died and he realised his only communication tool was a "battered old alphabet board that won't reach around the globe the way I need it to". (p. 154)

If you want to take part in this research, are aged 16-20, and use AAC and social media, please contact me by email: [amanda.e.hynan@stu.mmu.ac.uk](mailto:amanda.e.hynan@stu.mmu.ac.uk) \*

Amanda Hynan  
Postgraduate Student

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## NATIONAL CONFERENCE

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The Communication Matters / ISAAC (UK) National Conference is an annual event embracing a wide range of issues relating to augmentative and alternative communication. The two and a half day event provides a forum to meet and to exchange information with representatives from all disciplines associated with AAC, including people who use AAC and their family members.

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There are a number of subsidised places for people who use AAC, and their family members. Book early to avoid disappointment.

### BOOKING FORM & INFORMATION

For further information and a booking form, please visit [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk), or ring Communication Matters on 0845 456 8211 or email: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)



# Overcoming Patient-Provider Communication Breakdowns in Health Care Settings

**SARAH W. BLACKSTONE & HARVEY PRESSMAN**

Augmentative Communication, Inc, One Surf Way, #237, Monterey, CA 93940, USA

Email: [info@augcominc.com](mailto:info@augcominc.com)

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The world of healthcare has much to learn from the field of augmentative communication, and from the strategies and technologies we've developed over the past decades. For too long, AAC practitioners have contributed to a narrowing of the definition of who can benefit from AAC. Now there is a chance to broaden that definition and to demonstrate the effectiveness of AAC, by actively working to support patient-provider communication across healthcare settings.

Communication breakdowns between patients and staff in hospitals and other healthcare settings contribute to far more problems than most people realize. Deaths from medical errors, as well as unnecessary, expensive and often counterproductive treatments, inadequate pain relief, extended hospital stays, patient anguish and disorientation, interference with patients' rights—all these can too frequently be traced to communication breakdowns between patients and those who care for them. For example, in a six-year (1997-2002) study of the root causes of “sentinel events” in hospitals, the U.S. Joint Commission on Accreditation in Health Care Organizations (JCAHO) placed “communication” at the very top of the list of root causes.

Fortunately, a growing number of healthcare providers and administrators,

as well as governments, are beginning to recognize that effective communication between patients and healthcare providers is a key component in reducing costs and increasing positive patient outcomes and overall patient and family satisfaction.

Concurrently, many AAC professionals are beginning to realize that practical AAC tools and strategies can help a much broader group of people than previously considered. Many people who become sick, have surgery, have an acute, chronic or degenerative disease or condition, are in a hospital intensive care unit, or are in nursing homes or under hospice care are ‘communication vulnerable’.

Their communication challenges can be pre-existing; caused by a current medical problem; caused by the treatment; or due to language and cultural barriers. Healthcare staff can learn to use AAC tools, techniques, technologies and strategies to help individuals and family members deal with the many

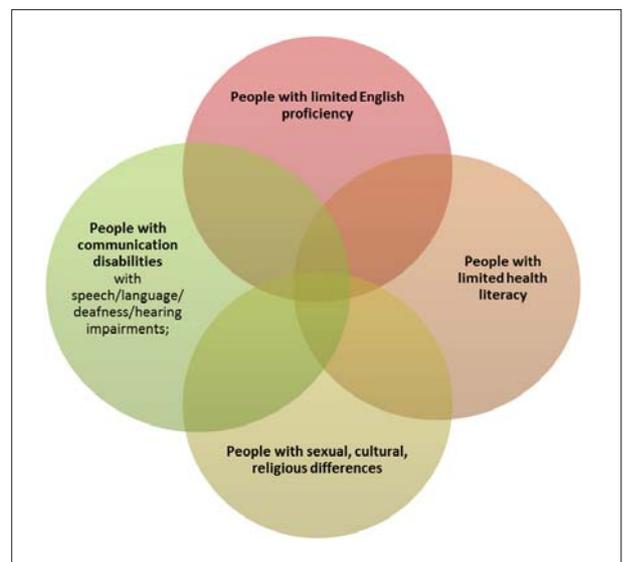


Fig. 1 Communication Challenges: A convergence of problems in healthcare

difficult and dangerous communication barriers experienced in healthcare settings.

Augmentative communication and assistive technology supports and technologies are useful to individuals with existing communication disorders, as well as people with temporary communication challenges and to some extent, those who experience hearing, language and cultural issues in a healthcare setting. The problem is that nurses, doctors, aides, emergency room person-



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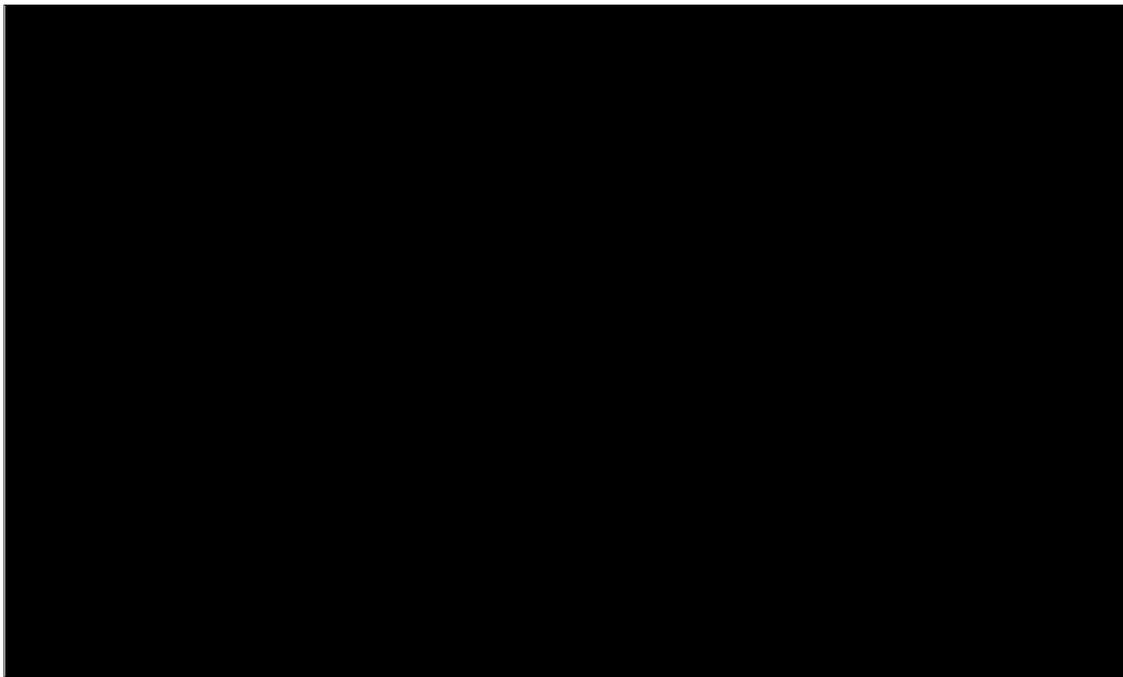


Figure 2 Screenshot of patient-provider communication website

nel, emergency responder technicians, nurses' aides, and even some speech-language pathologists and audiologists are often unaware of existing tools, and thus do not use them at all, or to their maximum benefit.

A small interdisciplinary group of individuals, including AAC specialists from several countries, are now pioneering efforts to solve or mitigate communication problems in healthcare settings, using a wide variety of AAC tools, techniques and strategies. Unfortunately, only a very small percentage of those who "need to know" about these tools and strategies are yet aware of their existence, and there is only sporadic use in the U.K. Current efforts to spread the word about them are underway.

An important goal is to infuse readily available (and often quite inexpensive) communication enhancement tools into situations in which they are useful, and do so across the broad continuum of healthcare settings, not just in hospitals, and not just for people who enter treatment with pre-existing complex communication needs.

The authors have developed a web site ([www.patientprovidercommunication.org](http://www.patientprovidercommunication.org)) that emphasizes the most cost-effective and practical approaches, strategies, and tools for improving patient/provider communication in healthcare settings. Visitors to the site have opportunities to see, hear about, and explore uses of the many of the tools, forms, communication boards, and strategies that have proven their value in the field, and to find out how to connect up with

the most useful sources of continuing information on the subject.

In summary, successful patient-provider communication is needed across the entire continuum of healthcare settings, from first responders to intensive care units to acute and rehabilitation hospitals, post-hospital release and community care, home-based or nursing home care and even hospice settings. The populations that can benefit from these tools range far beyond those who normally depend on augmentative communication technologies and supports. People with hearing and vision loss, people in intensive care units, people whose medical interventions cause a temporary loss of speech, stroke victims, people whose first language differs from their medical support team, people with psychiatric complications... these and many more can benefit when communication enhancement supports are made more readily accessible in healthcare settings. \*

Sarah W. Blackstone  
President,

*Augmentative Communication, Inc*

Harvey Pressman

Managing Editor,

*Augmentative Communication, Inc*

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# Smooth Talker

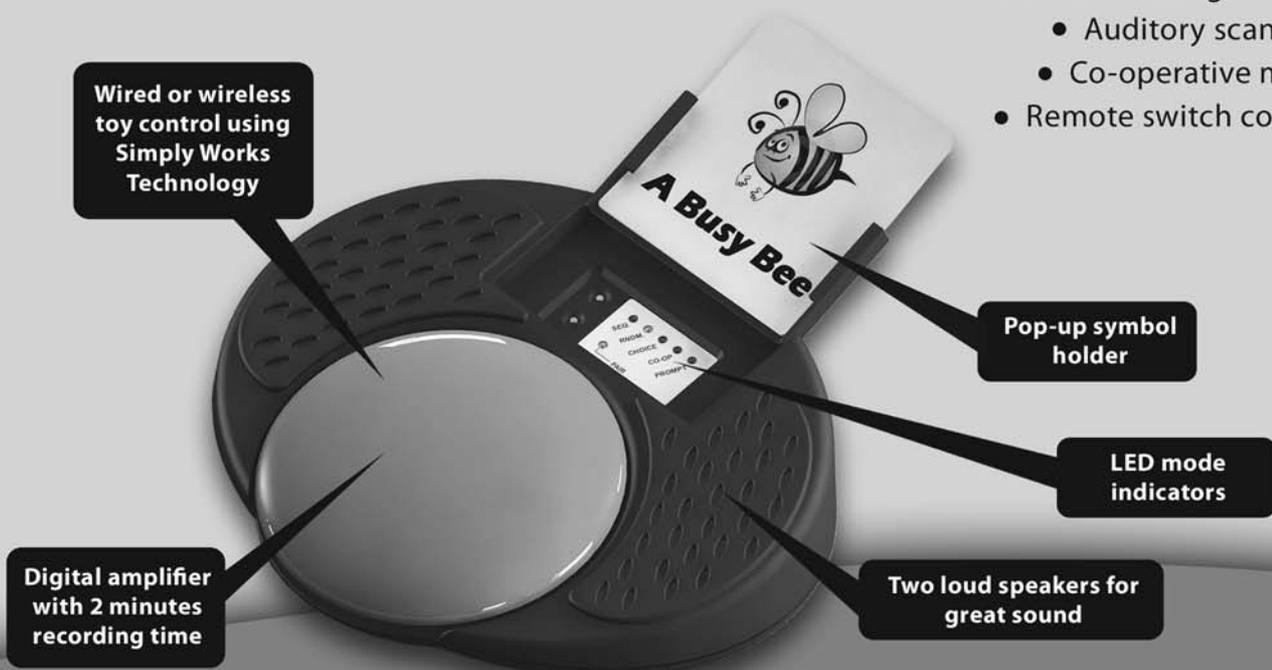
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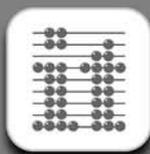


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# The Highs And Lows of Running An AAC Service for Adults with Learning/Physical Disabilities

**CHERYL DAVIES**

Email: [cheryl.davies@nottshc.nhs.uk](mailto:cheryl.davies@nottshc.nhs.uk)

**This paper describes the setting up and maintenance of a service for people who require support to use voice output communication aids in Nottinghamshire.** It outlines how the service was set up and later expanded, numbers, staffing, funding, geographical details and some of the good practices developed. It includes the challenges this service has encountered and concludes with a case example.

## BACKGROUND

As far back as the mid 1990s the Speech and Language Therapy service managers for Adults with Learning Difficulties and Children's Team put together a case of need to fund a service for people leaving college or school with communication aids, to include funding for staff and equipment. Meetings with Commissioners extended across five years and the service for South Nottinghamshire and Nottingham City was set up in 2001 with a 0.5 Specialist Speech and Language Therapist, some Assistant time and an equipment budget. Meetings with Social Service colleagues led to a contribution towards equipment for service users living in the County and the same person made a bid for further funding to extend the service to the North of the County in

2008 following a scoping exercise identifying potential users of the service. A 0.5 Assistant Speech and Language Therapist (ASLT) was appointed and the Lead therapist extended her role to cover the whole of Nottinghamshire, Nottingham City and Bassetlaw.

The current caseload has mainly been referred by Speech and Language Therapists or were previously known as having a communication aid. They are aged 20-55 and are aging with the service! Referral rates are variable with an expected high number from children's services in a few years time. They are almost evenly split between learning disability and physical disability services. The criteria for physical disability referrals is a life long disability therefore excluding people with a diagnosis of a progressive or degenerative condition. These are seen by the hospital teams. There are currently 31 people open to the service, eight of whom have been known for 10 years (+). There has been an increase in referrals from the Adult Neurological Service for assessment for people with cerebral palsy in their 40s who are struggling to be intelligible.

A large proportion of the communication equipment has been funded by the budget from Health and Adult Social

Care (71%). With joint funding this rises to 86% with the remainder coming into the service with equipment funded by Further Education. The funding extends to cover warranties, mounting solutions and replacement devices.

There is a small equipment loan bank which this year is being extended to include an iPad, iPod Touch, V Pen and ProxTalker.

A proportion of the service users have been assessed for communication equipment at an earlier stage. This requires the AAC service to have a knowledge of a wide range of devices and language packages (Figure 1). Fortunately both the Lead SLT and the ASLT have extended experience of working with devices using the Minspeak programme Language Learning and Living (LLL). Several on the caseload attended Portland College near Mansfield, a Specialist Further Education College with an AAC department, and have chosen to stay in the area.

## EXAMPLES OF OUR PRACTICE AND WORKING WITH A SKILLED AAC ASLT

- All service users have detailed and individual Communication Guidelines. These are written to target new staff and people unfamiliar with AAC. They outline basic information

AAC Company	Device	Language Package
<b>Liberator</b>	ECO 2 (2)	LLL/Discovery
	Pathfinder (5)	LLL version 1 & 2 Word Strategy
	Vantage (2) Vanguard (1)	Unity LLL 80
	Lib Talk 32 (3)	
<b>DynaVox</b>	DV4 (1)	Portland College own
	V max (2)	Portland College own
	EyeMax (1)	Personal pages
	Palmtop3 (1)	Teen user
<b>Possum</b>	Say it Sam XP1 (2) Say it Sam (3)	IDV B/C Personal pages
<b>Toby Churchill</b>	SL40 (4) SL40 (1)	

Figure 1 Range of devices and programmes in use by service users

about the device, description of how the person communicates, usually multi-modal, and strategies to help and support their communication. These are developed with the service user, parent/carers and are written in the third person.

- Low tech support such as situation specific boards, key rings, updates of boards used since childhood.
- Ongoing work to personalise devices.
- Teaching the language programme. This can be long term work lead by the individual. Several service users in North Nottinghamshire had been without a working device for years and are being supported to re learn and extend skills. This can include improving syntax and vocabulary knowledge.
- Support to learn switch scanning skills. A change in physical ability can mean that direct access is no longer an option.
- Staff training focused on the individual. This needs to be repeated particularly in care homes with a high turn over of staff.
- Dictionaries and paper copies of the contents of devices. We have found this invaluable for teaching and to give to support staff but acknowledge that it can be very time consuming. It also helps to map where vocabulary is stored.
- Reassess/review/replace devices. Having a long term service has seen

devices broken beyond repair and new products become available. We would aim to keep new learning to a minimum but do not always achieve this e.g. changing from a DynaMyte to a Palmtop3.

- Offer social group meetings such as a pub/meal/ bowling. Distances and transport costs make this difficult in North Nottinghamshire, but it has been a supportive experience providing opportunities and reasons to communicate.
- Extended time to assess and loan devices. Initially it seemed to be taking a long time but on reflection this has been necessary to cover a number of factors such as motivation, staff support, opportunities.
- We have enduring relationships with service users, their families and carers. This has many benefits and feels a privilege.

**EXTENDING AAC SUPPORT ACROSS THE CITY AND COUNTY**

- We provide second opinions, joint working and training to Speech and Language Therapy staff in the ALD Team to extend the Team’s knowledge of AAC.
- An AAC resource box was purchased for each Community Learning Disability Team across the City and County. This includes BIGmacks, Go Talk 4 & 9, iTalk2, Portable Bifold Communication Folder, E-Tran frame, Talking Photo Albums,

Communication Link Book. It includes information on ‘How to...’ and suggestions for using them.

- Dissemination of information on AAC to the Team such as the autism specialists.
- Demonstrations of low tech equipment and software.
- An annual AAC newsletter is sent to team leaders across Health and Health Adult Social Care Services to help maintain the visibility of the service.

**CHALLENGES AKA DIFFICULTIES!**

Challenges include:

- Working with a wide range of residential and day services. We have encountered rapid staff changes of both managerial and support staff. This makes it difficult to have a key person to liaise with, has big implications for training and carryover and building working relationships.
- The many changes occurring within Day Services and the provision offered. We are aware that when we go in the staff group can be demoralised due to job and location uncertainty.
- Limited multi-disciplinary team opportunities. We work across all the Learning Disability and Physical Disability Teams for the County and City. It can be hard to find an OT or Physio who has current knowledge. We are well aware that it is not best practice to work in a uni-disciplinary way.
- In many instances there are reduced communication opportunities in the adult settings compared to education establishments. Some service users have a small care team and do not go out frequently.
- Service users can be the only communication aid user within a larger community whereas they were part of a group of users at school and college. We have observed a big reduction in aid use where previously the young people had been encouraged and prompted and *expected* to use their aid.
- Changes in communication aid companies impacts on the support available.
- We need to consider the long term needs of users where equivalent replacement devices may not be available. These are small numbers but include a person who requires a portable static Minspeak system. She has a visual impairment but has learned LLL version 2 to a high standard.

- h. Communication aid users transfer in to the service with aids which are inappropriate e.g. a Say it Sam Tablet for a Minspeak user.
- i. This does not include the devices that have not been charged, or been lost or sold on eBay!

### SUCCESSION PLANNING

We are in the process of extending the role of the Assistant Speech and Language Therapists to support users with a learning disability. Within the Team there are therapists who have worked at a Specialist College and are gaining AAC knowledge. We plan to use the AAC Competencies Framework by Amanda Bousaki and Clare Latham plus other work in progress by Communication Matters projects.

### TIFF – A CASE STUDY EXAMPLE

- Tiff started to learn to use a communicator with LLL at school. She then transferred to a Specialist College and a Pathfinder Communicator was bought for her. She quickly progressed from using single words to sentence building – within one term.
- When she left college there was no AAC or Speech and Language Therapy service available for some years. The Pathfinder no longer worked and had been broken for over one year when she was seen. She is now 30 years old and spends most of her time at home. Mum said they had managed okay without the Pathfinder.
- The new AAC service for north Nottinghamshire had a record of students who had attended the college so we ‘tracked her down’.
- We arranged for her to see the ECO2 and after a loan a device was purchased for her. She was set up with Internet access, phone for texting but her TV was not compatible with the Environmental Control commands. The family have gained in confidence with the technology and have been well supported by Liberator.
- She is successfully using two buddy button switches attached to her head rest.
- She gradually built up the time she could spend using the device. It is physically effortful for her. She has recently received a new wheelchair and is more comfortable.
- She uses FaceBook a lot and was devastated when she needed a Res-

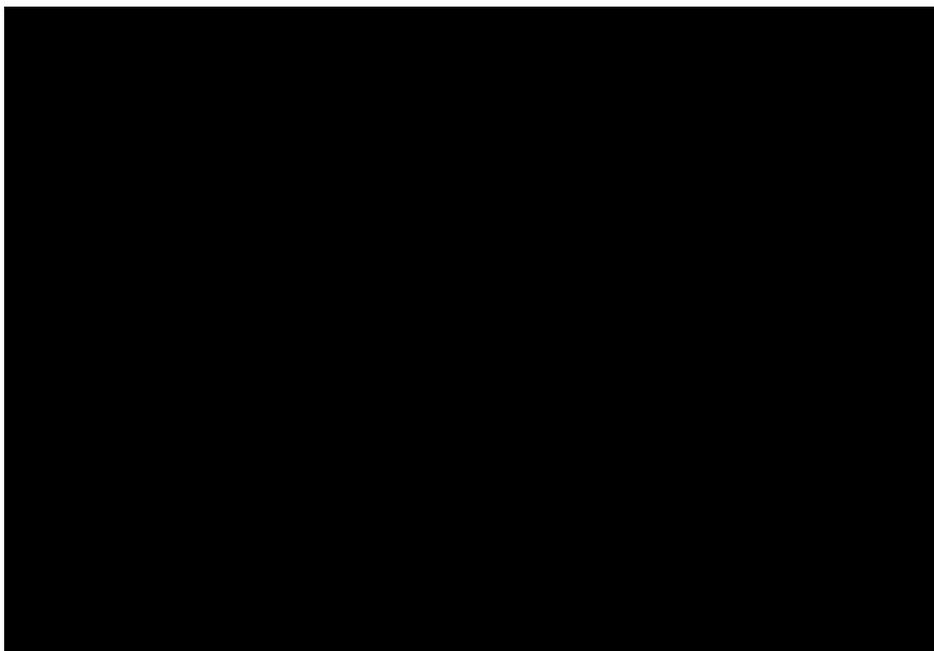


Figure 2 An example of an individual communication board for skiing

cue device and there was no internet access available. She can now have private conversations with family members abroad and has learned that there are consequences if you make a rude remark on it! She loves playing games and going on to YouTube. It is impressive to see her using the onscreen keyboard.

- Speech and Language Therapy are supporting her to learn more of LLL. She has requested to learn ‘small words’ and her spelling is improving.
- She has detailed Communication Guidelines which outline what the ECO2 is, how she communicates and how to support her communication. Tiff and her Mum were part of this work to support the people she meets who have no AAC knowledge.

### COMMENTS

Here are some comments that Tiff and her Mum made when asked what difference it has made having the communicator:

*“I feel good as I speak to friends and family.”*

*“I can make people laugh.”*

*“I can’t do without my talker now.”*

*“I say good luck to Gary (Barlow) every Saturday and Sunday morning.”*

*“It begins with ‘p’, sounds like ‘press’, when I am (with) out talker.”*

*“She would go absolutely crazy if she didn’t have it.”*

*“It’s opened up a whole new world for her.”*

*“We message each other in the flat.”*

*“She has more independence and we have a lot of fun.”*

For further information please contact [cheryl.davies@nottshc.nhs.uk](mailto:cheryl.davies@nottshc.nhs.uk) \*

Cheryl Davies  
Speech and Language Therapist

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# ESSENTIAL PUBLICATIONS

## FROM COMMUNICATION MATTERS



### **The Power of Communication (DVD)**

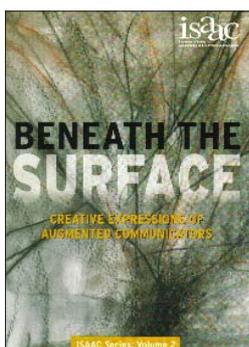
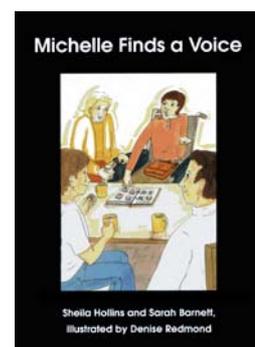
This DVD has been produced by Communication Matters to provide an introductory presentation on Augmentative and Alternative Communication (AAC). The film delivers a powerful message that communication really does matter. The DVD celebrates and promotes communication in all its forms - central to the 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

### **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**



### **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**

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# Why Increased Sign and Symbol Use in Severe Learning & Language Disability Schools Promotes Language

**ELIZABETH BEATTIE**

Mayfield School, Gloucester Road, Chorley PR7 3HN, UK  
Email: lizbt@mac.com

It is commonly accepted within special educational provision, that students with learning and language disability are supported by alternative and augmentative systems such as signs, symbols, drawings and photographs in their communication within the classroom (DeThorne et al (2009), Nunes (2008) and Millar et al (2006). There is also evidence to suggest that cognitively age appropriate children who are late talkers and normally developing pre verbal infants are supported into expression through use of sign (Goodwyn et al 2000).

Whilst there are studies that purport to show the link between augmentative communication and language development in various different client groups, they often concentrate on the introduction as augmentative communication, as therapy, or as qualitative support for communication. This approach whilst establishing a beneficial link does not enhance our understanding of “why?” such an effect should be found. I aim to establish a possible theoretical basis for why AAC should help children communicate more effectively.

## THE INFLUENCE OF WORKING MEMORY

Understanding the theories around the capacity of working memory and how the information from our various senses

is assimilated and transferred to the long-term storage of the long-term store is fundamental to the theories around how language is absorbed and then utilised by the individual.

Working memory was described by Baddley (Baddley 2000) as being composed of areas which are adept at storing material of a distinct sensory type: *verbal-short term memory* holds spoken word style material; *visio-spatial short-term memory* concerns storage of pictures and concepts of spatial awareness. There is also a third component: *the central executive*, which integrates information and combines the tasks of holding and processing information.

There is a further body of research around multi-sensory perception which gives credence to the theory that experiences which are perceived as relying on one sense, actually depend on several, and that to build up a comprehensive memory of an event our memories utilise all the senses available to us (Foxye and Molholm 2009).

The awareness of the role of visual, kinaesthetic, and proprioceptive memory in learning gives us insight as to how the properties of sign and symbol, in offering non-auditory stimuli alongside

speech, might be enhancing the understanding and retention of verbal information.

Specialist teachers use cross-sensory teaching/therapy techniques to support children with dyslexia into reading. Multi-sensory teaching of dyslexic students embraces the notion that laying down auditory, kinaesthetic and visual relationships between phonemes and graphemes allows for stronger associations and more robust memory relationships to form, which creates the automatic recall essential for fluent reading.

The argument for the deployment of pictorial representations of real objects with students to aid understanding, be they photographs, symbols or text is one of augmenting understanding through providing a memory aid. By providing a permanent 2D representation we are providing the student with a stimuli that can be revisited. There is reduced degradation of information in the working memory allowing an opportunity for that information to be integrated with information from other sensory sources (auditory).

The evidence of the use of sign to support understanding of language is less routed in the support of working

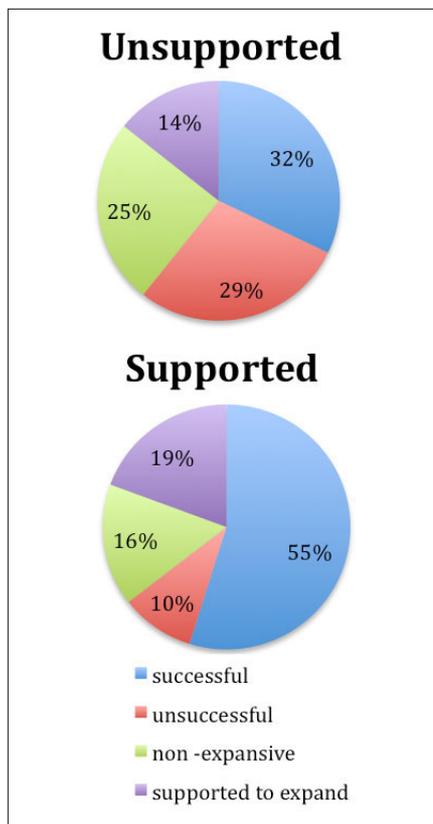


Figure 1 Comparison of the communication of a *non-verbal* student in unsupported and supported news giving sessions

memory, as like a word a sign is transitory, and therefore will require visual and kinesthetic memories to be held in the working memory whilst integration occurs, however again recent studies have shed light on how this input does indeed have an impact on the understanding of the listener.

Our understanding of how memory works has been greatly enhanced by recent the developments in non-invasive brain imaging techniques, such as Positron Emission Tomography (PET), Magnetic Resonance Imaging (MRI)/functional Magnetic Resonance (fMRI), and Electroencephalography (EEG) scans. These imaging techniques allow neuroscientists to build up pictures of brain structure, and how and where, within its structure, the brain reacts to stimuli. Researchers can now see the brain at work whilst it is thinking, remembering and learning.

Brain imagery techniques have also enabled the description of the process of bonding or strengthening of connections between neurones, described by Sousa (2006); the environmental stimulus or sensory event triggers a neuron to release neurotransmitters, which in turn stimulate a second neuron, this continues, causing other neurones to become stimulated. Should these neurones experience repeated firing, which

occurs through practice and repeated exposure, a memory is created. The biological explanation of memory is therefore that the neurone cluster becomes hyper-sensitive to the stimuli, eventually resulting in all neurones associated with the memory firing, even if only one is alerted. Sousa cites Fields (2005) in Sousa (2006) as stating that this simultaneous reaction of related neurones firing together, is functionally creating stronger memory traces of the stimulant.

Sousa relates the biological process of neurone pathway-building to the memory models of people like Baddeley (2000); in that the repeated firing of neurones related to a stimulus, can eventually lead to the alteration the neuron structure, at which stage the memory will have entered long term storage.

Sousa describes how different stimuli create memories in parts of the brain in associated with different sensory input (Sousa 2006). He believes the more storage sites involving neurones receptive to different sensory input may give the learner greater access to retrieval of the memory and more potential storage areas where new learning can be referenced.

Studies by Skinner et al (2007) and Fadiga and Craighero 2006) explicitly link the use of natural gesture in speakers with the excitement of neurones in

the part of Broca's area associated with semantic processing. If natural gesture supports the mapping of meaning, how much more powerful is the use of a sign, which has a formal semantic relationship with a vocabulary item.

Work by Beveridge (Beveridge1989) illustrates how imperative it is that these recent insights into brain processes are integrated into our understanding of how these non-speech supports may be enhancing language and learning impaired individuals' ability to converse. Beveridge investigated the educationist's role as conduit to language and learning within the special school environment and found that children with severe learning disabilities are at a disadvantage, as their lack of language skills means that they do not have the capacity to use communication to further their learning through discussion.

Beveridge cites Edwards and Middleton (1986) who showed that we remember situations through a discourse either with ourselves or others. It follows that a lack of core language elements such as vocabulary items and basic syntax puts the individual with learning difficulties at an educational disadvantage. Beveridge sees the language and communication of people with learning disabilities as central to their learning disability. Critically then, communication difficulties may be being excluding students with Severe Learning Disabili-



Figure 2 Example of a student profile showing an apparently poor working memory: single words are understood and used more readily than grammatical structures

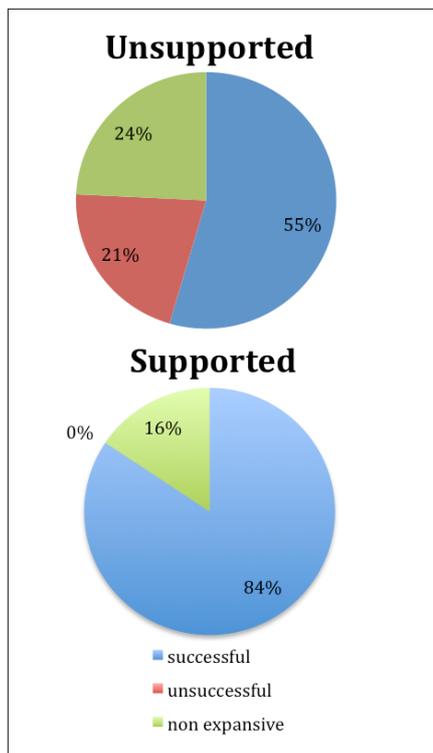


Figure 3 Comparison of the communication of a verbal student in unsupported and supported news giving sessions

ties (SLD) & Language Disabilities (LD) from the learning process itself, and compounding their learning disability.

It is my belief that if we can enhance the receptive processing and subsequently support the expression of people with learning disabilities, their access to learning opportunities will increase and their learning potential develop. The experimental component of my dissertation showed that the students were able to absorb more information from speech when it is accompanied by AAC used to support understanding. The use of multimodal language systems, such as sign, symbols and visuals can support a student's understanding of what is being said and taught. By using these systems in everyday teaching it is possible to enhance engagement within the learning and consequently learning capacity.

The experimental component of the dissertation compared the engagement of students with severe learning and language disabilities in an educational setting on two occasions; once where multimodality supports are not being generally used, and once when where they are. The interactions between staff and students were recorded and analysed for qualitative interaction markers, such as student turn-taking, student response indicative of understanding, and student spontaneous expansion of interaction (Figure 1). The

quality of unsupported and supported communication was evaluated in terms of the student's individual language profiles based on assessment (Figure 2).

When this study was originally envisaged, it was felt that the experimental data would verify that students who had limited spontaneous formal expressive language, when provided with visual mediums or encouraged to use sign, would increase their expressive repertoire to reflect their level of understanding (Clarke 1986). Increasing nonverbal, but receptively able, students' access to an expressive vocabulary by providing them with signs and symbols to stand for spoken words would necessarily improve the quality of student expression and raise the standard of adult/student conversation.

What was not necessarily envisaged, was that the adult's use of AAC would impact on the student's comprehension of speech and subsequently effect that had on the quality of the adult/student interaction.

Even verbal students were not overtly using multimodalities responded to the AAC supported adult communications in a way that indicated that increased comprehension had impacted on their ability to form a coherent utterance (Figures 3 and 4).

At very least this can be explained by the idea that a student who is able to

understand his communication partners' utterances fully is better placed to answer questions accurately and to comment on conversations occurring around him, thus enhancing the quality of the interaction as a whole.

The students' communicative success when they used multimodalities can also be seen in terms of increased working memory capacity. Support of the spoken word through multimodality resulted in the integration of sensory channels (Moats in Birsch (Eds) 1999) with the auditory. Not having to struggle to understand speech subsequently freed up working memory capacity and allowed more opportunity for topic learning rather than decoding language. Gathercole and Packiam (2008) recognised this premise to be true of students in mainstream education and recommended similar strategies for the reduction of the burden on working memory.

The consequence of the finding that the multimodality support of students' comprehension had a significant impact on the quality of adult/student discourse has potential ramifications for the role of multimodalities within special schools.

The present emphasis around the introduction and use of multimodalities is the provision of an expressive format that is a substitute for the spoken word. In this scenario the student is viewed as



Figure 4 Profile of the verbal student from Figure 3

having the responsibility to use the AAC, and multimodality use is seen to be an exclusive support for those with higher receptive language than they are able to express.

This study's findings suggest that multimodalities could improve communication across the board for children with SLD & LD. In this scenario, adults would have the responsibility to use multimodalities to support comprehension of language and enhance working memory capacity providing an advantage for all students with SLD & LD, including those who are perceived as verbal.

This study provides a sound evidence base which can be utilised by people working with children and adults with SLD & LD, allowing them to make a more

informed decision about the use of multimodality supports. \*

Elizabeth Beattie  
*Communication Consultant*

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## Look at us

Barry Smith



Been in my body with a physical disability is a hard thing to do,  
Eyes looked at you but don't see you as real person.  
Everybody try to help you but no one ask what to do.  
No one must know how you are feeling,  
In your heart you might be hurting but no one to tell,  
No one know how you feel.

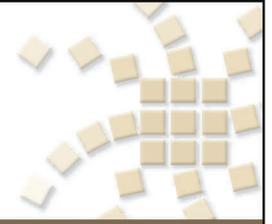
My body I am but no one knows how I feel.  
On with living I go on with.

Open your eyes and see the person who I am,  
Don't worry I am here to support you.  
Put up your head and be happy,  
I am here to help you too.  
Eyes open and we see a person.

Many words people can't make up  
but if I had a communication aid they should understand me need.

I am just like you.

Photograph courtesy of Toby Churchill Ltd



## LAMP, has people talking!



### Language Acquisition through Motor Planning (LAMP)

A therapeutic approach developed by The Center for AAC & Autism that uses AAC technology and language fundamentals to promote communication in non-verbal children with autism.

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## THE LOGAN® PROXTALKER® IS NOT JUST FOR CHILDREN



John has cerebral palsy and recently had a stroke which affected his speech.

- John uses his ProxTalker every day, it has given more independence and helped him make new friends in the community.
- Staff found it easy to store sentences that John uses every day so he is able to say what he wants and not what others think he wants.
- John has much more fun as he enjoys joining in with the banter in the home and at his Day Centre.
- The activities coordinator at the home says he has seen a great change in John's independence and enjoyment of life.



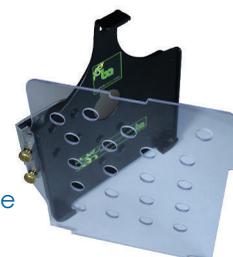
## NEW iPad keyguards

A range of standard and customised keyguards are available from Logan Technologies in two formats, basic or hinged, compatible with iPad1 and iPad2.



### Basic keyguards:

- 1/8 inch laser cut acrylic with programme specific configurations
- Mountable using suction cups, 3M adhesive strips or compatible with some iPad cases



### Hinged keyguards

- High quality polycarbonate with programme specific configurations
- Mounted using custom aluminium and stainless steel hardware
- Stand alone or mountable cradle

Available for growing range of Apps including Proloquo2Go, TouchChat, Assistive Chat, Grace, My Talk, Speak It, Talkboard, Tap To Talk, TapSpeak Choice, iMean, iclickitalk, My First AAC, Sono Flex...or simply customise your own keyguard using our downloadable template.

## Try me...

The Try Me programme lets users, parents and professionals have a first hand look at the ProxTalker. Just fill out the 'Try Me Agreement' form on our website, return it to us and we will arrange a free trial.



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