COMMUNICATION
MATTERS

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Cover: Natasha Bello (page 9)

Communication: It does help to talk

HANNAH ROGERS
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I gave my first talk at the CM2009 Communication Matters National Symposium describing my early life, and the many different communication aids and programmes which I have had to enable me to communicate. I currently have a Liberator 14 which I used to give my power point presentation.

I live at home with my family and I have full-time personal care assistants.

Some of the following information, particularly that relating to my childhood, has come from members of my family since I was too young to remember.

COMMUNICATING USING MY EYES

Before I was even two years of age, I learnt to eye point. My mum realised that I was staring at the kitchen tap, she could not distract me. Eventually she followed my gaze to the kitchen sink and started touching things in the area of the sink. As soon as she touched the tap I apparently became very excited. Mum asked me if I wanted a drink of water and I became even more excited. This led the way to me developing my need to communicate through eye pointing.

From eye pointing to the tap I then started eye pointing to the fridge, meaning that I wanted a cold drink or some food. I started to use looking upwards as a way of communicating that I needed the toilet. The only loo in our house was upstairs, so there was some logic to this! My need to communicate and my natural inquisitiveness quickly outstripped the possibilities of eye pointing anything, but the most basic information.

Life became quite difficult when I also started looking up to indicate upstairs, night time or holiday. We had been on holiday in an aeroplane.

As I began to want to talk about different members of my family, looking up could also mean the person whose bedroom was immediately above us at that time.

I would look up, in different directions if I wanted to talk about my brother whose bedroom was at the back of the house, my sister whose bedroom was at the front right of the house or my parents. You can imagine how difficult

it became when I wanted to talk about my grandparents who lived 3 miles away! I was very accurate but, you had to know me well.

I still use eye pointing with my family for basic needs. It's so quick and convenient. It also gives me some privacy if I am asking for some personal care but it can go wrong! It can be hard for people to understand what I am communicating, for instance, I look at my jumper, which might mean I am too hot or too cold, if this does not work I look at the radiator, if there is one in sight. It can be confusing, because, I

also look at my clothes when talking about a colour. So people may be clarifying about the colour when, in fact, I am just too hot, and need them to take my jumper off!

COMMUNICATING COMPLEX IDEAS USING SYMBOLS

When I was little, my family began to realise that I could count. My Dad works away from home quite often. The nights he was expected home, Mum would lay the table for four people, and I would get very excited because I knew that my Dad would be home for dinner that evening.

The following story is one which, to be honest, I don't actually remember but my Mum does, very clearly. She says it was the first time that my extended family began to appreciate that I could communicate complex ideas without being able to speak. We were abroad, on a family holiday. We stayed in a lovely villa with a swimming pool and had daily help from a maid who had a young son. One day, my Dad couldn't find his camera. He searched and searched. My Mum noticed that I was becoming agitated and worked out that I wanted to say something. I had seen the young boy take the camera. I kept eye-pointing in the direction of their house. By using my Makaton symbol board and my mum asking me a series of yes and no questions I was able to tell her what I had seen. They investigated and I was right. Dad got his camera back. It was quite an eye-opener for some of my family.

However, there are only a limited amount of things you can say with your eyes. You are completely reliant on the skill of other people to interpret what you are saying.

During the course of writing this article it has been quite interesting for my Mum and I to look back over all the different ways I have communicated, including several different boards and electronic communication aids. It has been as though I outgrew each one and needed something more to fully support my communication needs, some of them look like antiques!

I had my first symbol board when I was about 2 years old - this was the first of several.

COMMUNICATION AIDS

When I reached 7 years of age, my parents paid for me to have a Touch Talker.

At this time funding for electronic communication aids did not exist. The Touch Talker was my first voice and people listened to me. I had to learn where all the vocabulary was stored as there were not any predictive lights to give hints . When I was 13 I had a Delta Talker which, after the first icon was pressed, lit up to indicate which cells had words stored.

In comparison with the Touch Talker, the Delta Talker was more modern looking, slim line, lightweight, with predictive lights and no plastic sheet to programme it. What progress! The Delta Talker was bought for me by my local Education Department. They also bought me a laptop which I could access from my Delta Talker

I then progressed to a Pathfinder which I got in my last year at residential college. This was paid for by the Learning Skills Council. At first, I wasn't sure that I would be able to use the activity row on the touch screen but, I amazed myself. I found the activity row particularly useful for topic based vocabulary but I loved that the vocabulary stayed the same as on my Delta Talker - no having to learn yet another new language!

I now have my Liberator 14 which I have had for about 18 months and was jointly funded by Health and Social Services. I really like it, but I get really frustrated by its short battery life. We have to take a spare battery when we go out and also have to charge it up during the day. I miss having the icon tutor function in Discovery. I think it is because there are too many words in the dictionary of Discovery for it to work properly. I understand that the problems I have encountered are being looked at. I now have access to a more extensive vocabulary and this has re-

duced the levels of frustration for me, my family, and my friends.

I wasn't sure that I would be able to use the touch screen and I found it too difficult with the key guard. However, I have found that by using the rain cover over the screen it has actually helped me to access the keys more accurately without my finger slipping.

Both Mark Street and Tony Jones of Liberator have been very helpful in supporting me.

There have been times when I have had to be very creative by using alternative means of communicating to get my message across. This may be because my battery has run out or I have no other backup. This is where my eye-pointing comes in handy. In sheer desperation I have used a menu, when in a restaurant, or a newspaper to spell out my message.

I will use anything which has letters on. In Sainsbury's I even used the letters on my sister's Glastonbury wristband to ask for a toasted teacake but, it was just my luck, they didn't have any!

SYMBOL SYSTEMS

On my first communication board, which my speech and language therapist made for me, I learned Bliss symbols. It was about an A2 size and had approximately 32 symbols on it. I used this by finger pointing.

When I started at school at 3 years of age, I was the only person using Bliss symbols so I was made to change to Makaton symbols which was what everyone else was using. I wasn't given any choice about this.

When I got my Touch Talker, I used the language IEP, Interactive Education and Play. Although I can't really remember much about learning it my Mum says it helped me to learn language and how to join words together which helped me when I attended my local primary school. I was the first wheelchair user at this school.

My speech and language therapist and my Mum programmed it to make it personal to me and relevant for my school needs. I was the first person in my school to use a touch talker and I still had it when I went to mainstream secondary school at the age of 14. I was one of the first disabled students at this school, certainly the first to use a communication aid. During this time, the speech and language therapist visited

me regularly and I also changed to the programme called LLL (Language, Learning and Living).

I found it extremely difficult moving into secondary education whilst changing from one communication aid to another. At the same time I was learning a totally different language but I was determined to succeed.

I learned most about LLL when I was at Hereward College in Coventry. The speech and language therapist helped me and when I was on my own I would also explore where words were stored. I am still exploring where words are stored on my Liberator 14. I get frustrated when I know where things are stored in LLL but not always in Discovery. Having said that, I think Discovery is brilliant. It has such an extensive vocabulary. In the beginning I was unable to use Discovery with my phone which was frustrating but Liberator has now solved this problem.

My Mum questions whether I would be more fluent with language now if I hadn't had to go through learning Bliss, Makaton, IEP, LLL and Discovery. It's a big question and I will leave you to think about that.

My family and friends know that they have to give me time to communicate. This is probably the most important thing that helps me. Learning to spell has really helped. There are times though when I need help with spelling. People who know me well ask if they can help.

It can be difficult having a private conversation when using a communication aid, so I will say, "Can I speak to you later?" A synthetic voice does tend to attract attention, whether you want it or not.

My speech and language therapist, Cheryl Davies, asked me, "What do you think about people guessing what you are going to say or reading your screen?" I replied, "I don't like it".

DEALING WITH PATRONISING PEOPLE

It is truly amazing just how many different ways people find to be patronising.

Sometimes people talk to the person who is with me and totally ignore me! I have had people talk to me LOUDLY, and s l o w l y! Sometimes I just move away if I can or, I just ignore them.

One day when I was shopping in the centre of Nottingham I bumped into one of my tutors from my local college who was with her husband. The tutor always spoke to me in class as though I was a four year old but then her husband did exactly the same thing. I was very hurt by this. I complained to the college about the way in which I was being spoken to. The college support staff had also made complaints. To make matters worse, their solution was to put me in another group. This hardly addressed the real problem.

When I was much younger and someone was being patronising, I would use the Makaton sign language for 'pig'. My mum would just wink at me because she understood.

There are times when people say some really silly things such as, "What do I have to press to speak to her?" or "I don't know how to use it". I even had someone bend down to try and speak into my communicator which I found very amusing. Nothing surprises me anymore!

When I had my first device which had an environmental control function, I loved to go into John Lewis department store and change all the channels on their Sony TVs. This confused the shop assistants. I thought it was hilarious! But then, I was a lot younger!

HAPPY TO TALK

My communication aid and I have travelled to lots of different countries and attracted a lot of interest. I'm always happy to talk to people, particularly children, who are genuinely interested, as I believe the only way forward is through educating people. ✳

Hannah Rogers

THE VIVOCA PROJECT
DO YOU KNOW ANY EXPERT COMMUNICATION AID USERS?

Barnsley Assistive Technology Team and Sheffield University are looking for participants to take part in a research study - the team is looking for expert communication aid users and also people who have rejected the use of communication aids.

This study is part of a research project developing a 'voice-input voice-output communication aid' (VIVOCA) - a communication aid that recognises some dysarthric speech. The VIVOCA project is focused around including potential users of such a device at all stages of the development process and this study is the first stage of this user involvement. Later on in the project we will also be seeking users to be involved in the development and trial of the device, which already exists as a prototype.

The purpose of this stage is to identify the strategies people who use communication aids employ to make the use of their aid functional and also the reasons why they may not use their aid in all situations. The goal of this stage of the project is to help inform the development of the VIVOCA device by drawing on the experience of people who use current communication aids. National ethical approval for the study has been granted by the Leeds-West NHS Research Ethics Committee.

In these initial stages the team wants to speak to current expert communication aid users - i.e. those who use their aid effectively in a variety of situations and with a variety of people. The project is specifically seeking people who:

- are expert users and have little or no intelligible speech
- are expert users and who have some intelligible speech
- have some intelligible speech and have tried a communication aid but rejected it

Are you one of these people or do you know people meeting these criteria from your caseloads? If so we would like to hear from you!

Please contact Simon Judge or Zoë Robertson at:
Barnsley Assistive Technology Team, Medical Physics Dept,
Block 14, Barnsley Hospital, Barnsley S75 2EP
Tel: 01226 43 2159 Email: Barnsley.at@nhs.net

Helping children find their singing voice!

DOUG BOTT[1] & SALLY CHAN[2]

[1] Drake Music South West Email: dougbott@drakemusicproject.org

[2] Paediatric Communication Aids Service, Claremont School, Henleaze Park, Westbury-on-Trym, Bristol, BS9 4LR
   Email: sally.chan@nbt.nhs.uk

In November 2008, the Government made a commitment to fund *Sing Up,* a 4 year programme running until March 2011; this funding amounted to £10 million per year. The aim of the programme is to raise the status of singing and increase opportunities for primary school children throughout the country to enjoy singing as part of their everyday lives.

This is a commendable aim, but what about our children who use augmentative and alternative communication (AAC)? Will they have a chance to sing with their peers?

Drake Music, in collaboration with the Paediatric Communication Aids Service (PCAS) in Bristol, have ensured that those using AAC have a singing voice as well.

SING UP

Sing Up is the Music Manifesto's National Singing Programme. It is a programme to ensure that singing is at the heart of every child's (in primary schools in England) life. The programme believes that singing has the power to change lives and help to build stronger communities. It believes that the curriculum can be delivered through song. The overall aim of the programme is to raise the status of singing and to increase the opportunities for children in primary schools to enjoy singing as part of their everyday lives.

The *Sing Up* website has songs and resources that can be downloaded and used in the classroom, giving the pupils the opportunity to learn through song and to generate their own music.

Drake Music raised the profile of those children using AAC in schools, namely voice-output communication aids

Figure 1 Children enjoying a *Sing Up* session at Larkrise School, Wiltshire

(VOCAs), and were keen that the *Sing Up* website would include songs for VOCAs that can be downloaded to individual children's devices. Drake Music involvement in the *Sing Up* programme was funded by the programme's 'Beyond the Mainstream' Project.

DRAKE MUSIC

Drake Music's vision is of a world where disabled musicians have the same opportunities to make music as their non-disabled peers, and of a culture of integrated music-making where disabled and non-disabled musicians work together as equals.

Drake Music is a national organisation, using assistive technology to facilitate the use and generation of music for all. It works primarily with people who have severe physical impairments, using assistive technology to explore, create and perform music. However, increasingly, it is collaborating with a much wider range of musicians, including people with cognitive and sensory impairments.

The Drake Music website explains that: "Our focus is firmly on nurturing musical and creative ability, exploring, using and testing technology and new media in imaginative ways. This allows us to extend access to music and to connect disabled and non-disabled musicians and other creatives locally, nationally and internationally."

Doug Bott is the Programme Manager and Associate Musician for Drake Music South West which is based alongside the Paediatric Communication Aids Service (PCAS) in Bristol.

PAEDIATRIC COMMUNICATION AIDS SERVICE

The Paediatric Communication Aids Service (PCAS) in Bristol has and continues to work collaboratively with *Sing Up* and Drake Music in developing downloadable music resources for use with voice-output communication aids.

PCAS speech and language therapists have programmed five songs on high-tech communications aids, and these songs were used during the pilot project running in five schools within the South West during Summer 2009.

Sally Chan is the Clinical Manager for PCAS, and with her speech and language therapy colleagues (Hannah Curry, Nicki Watts and Katy Waddington), was involved in programming the songs on the VOCAs prior to the Pilot Project running during the Summer 2009.

SPECIAL RESOURCES FOR THE *SING UP* SONG BANK

The aim of the project is to develop song resources that can be downloaded from the *Sing Up* website, and used easily within primary schools.

Key objectives

The project's key objectives were to:

- Fully involve disabled pupils in singing activities, including pupils with physical disabilities, sensory impairments or communication difficulties.
- Give these children the opportunity to lead the singing when possible.
- Prepare a range of assistive resources using software and hardware that is likely to be used in most of the 5 schools within the pilot stage. (e.g. Clicker 5, VOCAs).
- Provide teachers & class teams with the resources & training to enable this to happen. We would provide a taster session and then a training session to show what can be achieved. Further sessions were to be implemented by the school staff.

Processes involved in creating SEN resources

The songs needed to be:

- Simple, repetitive and catchy;
- Have a fairly restricted vocal range;
- Able to withstand long silences;
- Non-reliant on physical actions;
- Adaptable, to involve call and response or turn-taking.

The songs selected for the pilot project were 'Old MacDonald Had A Farm', 'Alice The Camel', 'Little Green Frog', 'A Sailor Went To Sea', and 'Senwa Dende'.
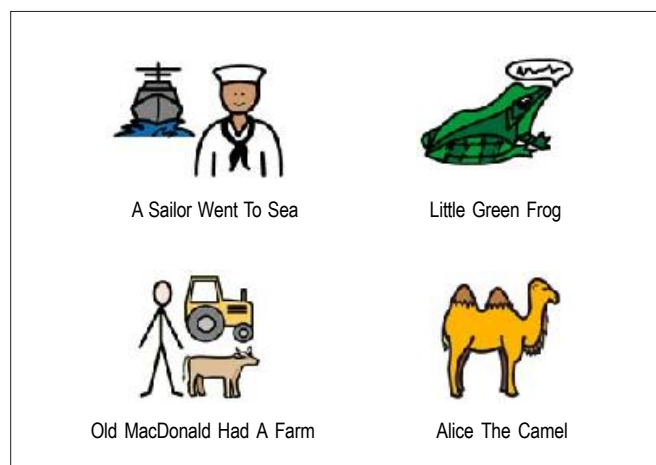
Figure 2   Selection of songs (made in Clicker 5)

Figure 3   Front page for 'Alice The Camel' (made in Clicker 5)
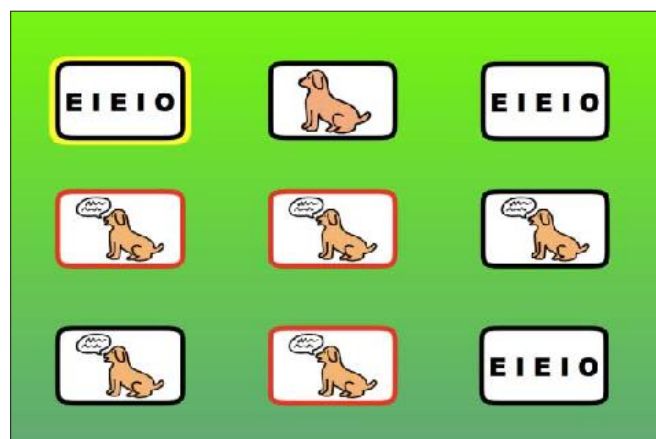
Figure 4   Response grid for 'Old MacDonald Had A Farm' (made in Clicker 5)

The VOCAs and software to include the grids and song files were Mind Express (Tellus), The Grid, Dynavox Series 5 (Dynavox V), Vantage, and Clicker 5. Further resources for use in the pilot project included session plans for each song and general guidelines for including pupils with a range of access needs in singing activities.

THE PILOT PROJECT, SUMMER 2009

The pilot project ran during the Summer Term of 2009, with music sessions running in five schools in the South West. During the pilot, Drake Music worked with each school and speech and language therapy department in running a taster and training day in each school.

Disabled pupils, class teams and therapists had the opportunity to try out the five songs identified above, using the prepared grids and song files for Clicker 5 and the VOCAs.

The sessions were filmed and subsequently analysed by the local team as well as by Drake Music and *Sing Up*. The video footage played a crucial part in evaluating the pilot project. Further evaluation was carried out by:

- pre-session questionnaires for teachers and pupils in relation to confidence in singing activities;
- write-up following the sessions;
- post-session questionnaires and discussion for teachers and pupils to identify improvements in any area.

Initial evaluation has already identified that:

- children who were not previously able to participate in singing, participated in the pilot;
- teachers, SLTs and class teams can see the potential of the resources;
- AAC has been placed firmly on *Sing Up*'s national agenda.

WHAT NEXT?

During Autumn 2009, Drake Music planned to revisit the schools to see how the implementation of the *Sing Up* sessions was progressing. The songs included in the pilot project will be downloadable from the Song Bank on the *Sing Up* website in Spring 2010. A further 10 songs are being developed for Clicker 5, The Grid, Mind Express and the Dynavox Series 5.

Drake Music will be running training days for other schools to help them access and implement these songs. The particular songs used are appropriate for children of primary school age, though the techniques and approaches are also transferable to older disabled children and young people.

The training also explores a range of other approaches to accessible singing, including the use of signing, symbols,

Figure 5 Pupils at Baytree School, N Somerset, having fun at a *Sing Up* session

microphones, multi-sensory resources and, of course, the human voice! ✳

Doug Bott, *Programme Manager & Associate Musician*
Sally Chan, *Specialist Speech & Language Therapist*

WEBSITES

Drake Music: *www.drakemusicproject.org*
Paediatric Communication Aids Service: *www.pcas.claremont.bristol.sch.uk*
Sing Up: *www.singup.org*

INTERESTED IN HOSTING A CM ROAD SHOW IN YOUR AREA?

The Communication Matters Road Shows are great opportunities to learn all about the latest communication aids and software from some of the UK's leading AAC suppliers. About 10-15 Communication Matters Road Shows are held every year at various locations in the UK - and they are free!

At each Road Show, there are usually 12 or so companies presenting. The presentations are given in parallel and repeated five times during the day - participants choose which of the five companies they wish to hear during the day. The current format is: Registration is 9.00-9.25am; the day begins at 9.25am with a short introduction from each company, followed by three sessions in the morning and two in the afternoon, and a short 'exhibition' session after lunch. The day finishes at 3pm.

WHAT'S INVOLVED IN HOSTING A ROAD SHOW?

We are always looking for new venues to hold Road Shows, so if you would like to host one in your area, here are a few things to consider. Don't be put off by the long list of requirements – we will offer you a lot of help and advice along the way!

The Venue: We will work with you to find a suitable, wheelchair accessible venue in your area. The cost of venue hire will be met by the suppliers attending.

Catering: The cost of lunch and refreshments will be met by the suppliers attending.

Advertising: To get a broad cross-section of delegates, you will need to advertise the event to speech and language therapists, teachers, social work staff, people who use AAC and their families, voluntary organisations and other professionals involved with communication aids. Communication Matters does not normally pay for the cost of advertising or mailshots.

Bookings: Communication Matters will provide you with a master copy of a flier/booking form to duplicate and send to your local contacts, the local press, professional magazines, local newsletters, etc. Anyone interested in attending has to complete and send the booking form (by post or online) to Communication Matters.

All bookings will be handled entirely by Communication Matters: delegates will be sent a booking confirmation immediately, and joining instructions (map, directions, timetable) two weeks prior to the event.

On the day: You will be responsible for the smooth running of the day, including: setting up workshop spaces, signage, registering delegates (Communication Matters will provide you with literature, a delegates list, name labels and other information).

STILL INTERESTED?

Patrick Poon would be delighted to hear from you - please contact 0845 456 8211 or admin@communicationmatters.org.uk

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• The Stroke Association
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• Pyramid Educational Trust
• Mencap
• MIND
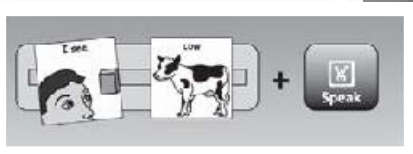
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A Journey with AAC

JULIE BELLO
Email c/o: admin@communicationmatters.org.uk

Natasha's life with augmentative and alternative communication (AAC) journey is punctuated with frequent changes in states, school systems and devices. As a US military family, we moved a lot. This article records the journey so far.

IN THE BEGINNING...

Natasha's was a normal baby reaching typical milestones in development. On May 25 1990 our family was in a terrible car accident. Although we were all hurt, Natasha suffered traumatic brain injury. She was just eleven months old.

THE DAMAGE....

The initial prognosis was not good. We were advised to put her in an institute, as she was stuck in a vegetative state, with seizures. Well, this mum came out fighting! My baby was coming home (July 1990).

I found a home based therapeutic programme that included coma arousal, cross patterning and breathing development by the Kerland Institute (now called Brainwaves). Over five months, working several hours daily with this programme, we got her back into our land of the living, although with many persisting problems. Speech, occupational, and physiotherapy and special education became part of everyday life.

FIRST COMMUNICATION

We began speech therapy at home using verbal and American Sign Language (ASL) and to get Natasha to make choices of tangible objects. She never responded with any sound or sign, but by July 1991 we recorded intent to communicate by looking at the item; by November, she made her first sign: 'drink', and by January 1992 she made eight signs. However, as everything on her right side was paralyzed, would Natasha be able to develop her ASL skills?

Natasha attended the Pine Tree Early Intervention program where they used pictures for communication. At home I made over 100 picture cards and Natasha would search through them trying to tell me what she wanted (see Figure 1 overleaf). I did not know what
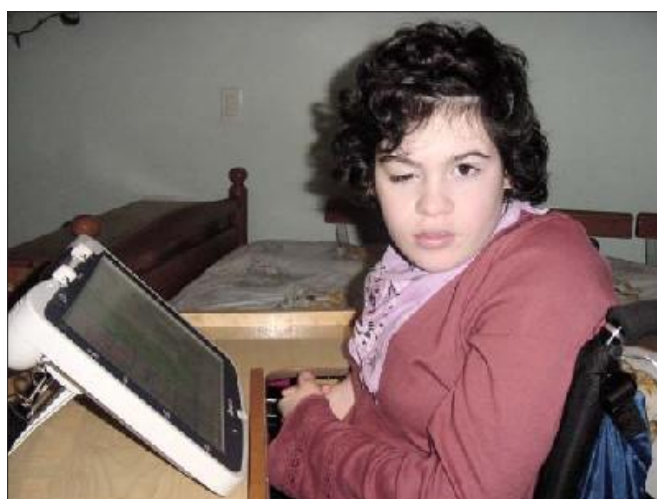
to do next, but my awareness of Professor Stephen Hawking spurred my search for communication tools.

ASSESSMENT AND FIRST DEVICE

Military life moved us to North Carolina which had more facilities and treatments options. Natasha began Onslow County Early Intervention programme, rich in ASL and picture communication. Through an assessment at Duke University Medical Center in '92, we were introduced to Picture Communication Symbols (PCS) by Mayer Johnson. I also

Figure 1   Picture cards

learnt about communication boards and arranging symbols on one page which prompted another production run making communication boards.

In March 1993 Natasha got her first device, the DigiVox by Sentient Systems (now DynaVox), a digitized speech device with 4 levels and up to 32 buttons per level. I programmed the device to make 8-12 buttons per level on themes such as nursery rhymes, mealtime, shapes, colours, classroom activities and social/manners (Figure 2).

Natasha moved to special needs pre-school in September 1993, where I began what was to feel like a lifetime of 'teaching the teachers' about assistive technology (AT) and augmentative communication (AAC). The Speech and Language Therapist (SALT) only knew ASL. There was no cohesive plan to incorporate AAC use in the school day. Natasha became easily frustrated with the set up, impatient for people to change the level for the current activity. By time it was done, the class was on to another subject.

I got a Windows PC computer and installed cause and effect software by Judy Lynn. Natasha became familiar with moving objects and changing screens –

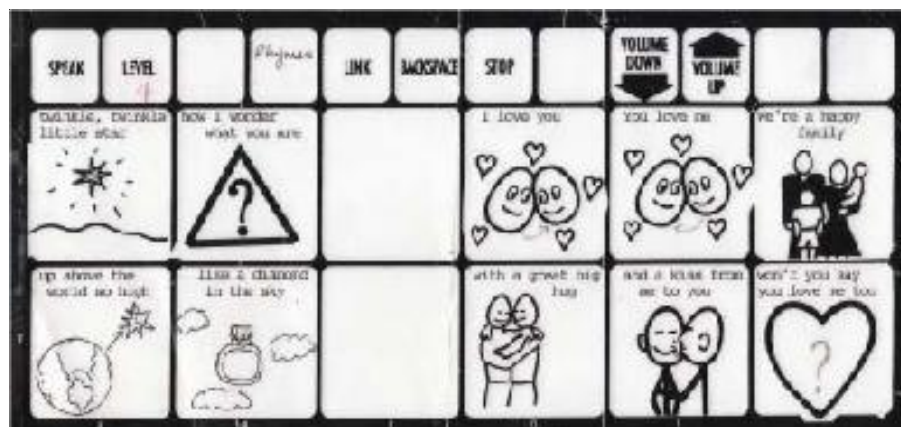Figure 3   The original DynaVox

Figure 2   Overlays for DigiVox

a dynamic environment; pre-cursor to higher level devices.

At a follow up assessment in '94, Natasha was introduced to Speaking Dynamically Pro software. She quickly understood how to use a touch window device, confirming she was capable of direct selection and a good ability to retrace, track back and navigate screens. We were recommended to talk to DynaVox again about the next level of device.

FIRST DYNAMIC DEVICE

We got the DynaVox (original) with black and white dynamic screens. I designed and programmed thematic pages similar to the Digivox levels. In my enthusiasm I added some very busy pages.

Following feedback from Camp Chatterbox in August 1995, screens were re-designed to better accommodate Natasha's visual deficits. My busy pages required her to spend too much time scanning for the button she wanted.

Throughout kindergarten and first grades Natasha continued her particular (non-standard ASL) signing. I photographed every sign (approx 50) she made, and made a 'translation dictionary'.

MOVING INTO COLOUR

A move to California in 1996 gave us opportunities to attend exhibitions, where Natasha saw the DynaVox 2C and fell in love with it. She 'played' with it for an hour or so. The company representative programmed some personal details into a demo unit and let Natasha show off her skills to others. We completed a successful funding package whereby Natasha received the DynaVox 2c in March '97. We saw an immediate improvement in her communication skills, due to the colour and other features. Another step to improve her skills was to break up sentences and phrases into parts.

The education setting was special needs classrooms in mainstream schools. Rich in sign, symbol and AAC approach, Natasha was the only non-verbal student with a device. However, everyone tried hard to incorporate Natasha's developing skills. Looking back through her educational history, I think this was probably the best we ever had it, in terms of AAC support.

We had access to a larger community of AAC specialists and therapists. I took

Natasha to private sessions as the school(s) still did not have an AAC specialist on staff. I worked with another adult AAC user, an 'ambassador' for DynaVox, to create a user support group. Natasha also attended 'Building Bridges', a fun camp experience with AAC users, SALT interns, and specialists in technology, all gathered to expand their skills and knowledge.

In February '98, Natasha signed five words together to 'retell' an event some days prior. This was new expressive communication on her part. Her DynaVox 2c pages were not set up for this kind of communication (word by word). Shortly thereafter I saw a demo of the new DynaVox 3100 with Gateway, a word based system of pages created by a well known SALT in the AAC world. I 'borrowed' the idea and slowly began to add some high frequency word based pages to Natasha's device, thereby introducing her to ways of putting words together (Figure 4).

THE OREGON YEARS

Dad retired from military service and we moved to Oregon, our longest residence in one place as a family. Natasha went through the last year of elementary school, middle and high school and one year of the post-high transition programme in the same school district.

We found great AAC services through the Child Development and Resource Center, (part of Oregon Health Sciences University (OHSU) - a teaching hospital). They uncovered the need for a secondary device. Taking the big device everywhere just wasn't practical or successful. I got a smaller, portable device with phrase-based programming to take out into the community. The first one was Message Mate by Words+ but we soon traded up to a Dynamo, which suited Natasha much better because it had dynamic screens (Figure 5 overleaf).

The lack of support for AT and AAC in middle school was frustrating. She was not expected to participate much, with or without AT. Teachers had little or no experience of students with technology needs. However, the SALT was good and there were 5 hours per year AAC consultation with the Columbia Regional Orthopaedic Services (CROS) agency, assigned to support special needs students. During the middle school years, Natasha used the Dynamo at lot in school, although it got broken and I couldn't afford to replace it. In high school the SALT assigned to Natasha's case was quite happy for her to grunt her *yes/no* and call it communication. At least the assistant SALT was much
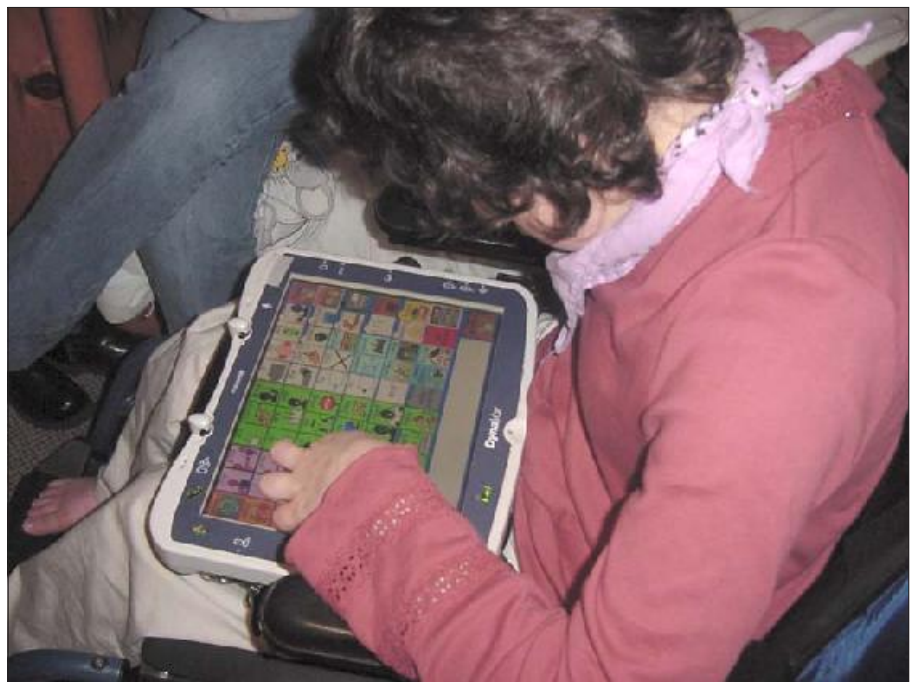

Figure 4 Natasha using the DynaVox 3100

more open-minded and would soak up any information and technical know how of the device, to assist Natasha in school.

We continued private services outside school. A home visiting speech therapist pushed Natasha's boundaries, slowly but surely expanding her expressive language. In 2002 we upgraded to the DV3100. With its new bells and whistles, I created more word based pages trying to emulate the newly launched Picture Word Power (PWP) package developed by a speech therapist. It is a powerful set of pages with high frequency words readily accessible for fast expression. Natasha's goal was to create three word sentences.

THE HIGH SCHOOL YEARS

The next four years were based on life skills with the odd elective class. Again the teachers' abilities to include AT and AAC skills were minimal.

In 10th grade there was a new teacher, full of excitement and promise, who tried to get more AT support for Natasha. With support services from CROS, we worked on incorporating the DV3100 with word processing on the computer, and producing printed work. Natasha enjoyed seeing her work on paper. I persuaded the teacher and support staff (CROS) to do an assessment called SETT (Student, Environment, Tasks and Tools). We gathered a team to seriously look at how Natasha could move forward in the school environment with her AAC skills and apply them to class work. Although everyone on the team considered it a useful exer-

cise, not much happened, and no follow-up was forthcoming, mostly due to the frequent change of staff in all areas.

Little else changed during the remaining high school years. I continued to pursue other avenues for AAC experiences for Natasha. An aide in another school district set up Teen Talk for teenage AAC users. They met once a month during school terms, spending time talking with their devices and doing activities typical of teenagers (coffee shop, zoo outing, shopping). Natasha also had a subscription to News2You, a symbol based news magazine, and accessed Symbol World and other websites offering symbol interaction. I continued to make laminated manual boards for things like our cruise vacation in 2005, for the beach, boards for camp activities (archery, swimming pool) and iron-on symbols for a pillow case for things Natasha might want to say at bedtime.

On the home front, the speech therapist and I decided to try to get the next high tech device through health insurance since speech generating devices (SGDs) were recently qualified as reimbursable within the insurance/Medicaid programme. Natasha tried out a Vantage device using Unity 45 programme and a DynaVox DV4 with Picture Word Power. This proved to the insurance company that we had genuinely considered a range of appropriate tools/devices.

During the trial phase, the CROS AAC specialist had emphasized the impor-

tance of motor memory – something that I had not learnt, but perhaps had been trying to incorporate subconsciously on Natasha's pages. Both devices had screen/pages designed in such a way to capitalize on motor memory techniques. I could truly understand and appreciate this concept, wondering why it was not so clearly obvious in earlier years. Natasha preferred the Picture Word Power, and after using it a short while, I could see her motor memory in action. She received her own DV4 in March 2007.

One particularly interesting development in the last year of high school was the Social Networks workbook. In an effort to make me appreciate all the methods Natasha uses, the CROS team had me complete the workbook. This made me look very hard at how Natasha communicates across all areas of her life with all sorts of people. I learnt that it is OK to grunt and vocalize, as part of complete communication skill set.

LAST DAYS OF OREGON

An interesting development that affected Natasha's communication came from a massage therapist/ chiropractor. Within a month or two of working on Natasha's head and shoulders, she began to make more sound, with a bit more intent on forming a word. She would have outbursts of sound and babble. She considered this to be very funny but often used it in frustration. I call it her swearing.

After high school, Natasha attended the Transition Program for 18-21 year olds. The programme was busy and her AAC/AT needs were finally supported because I was contracted to be the school district's AT specialist. I was able to help staff and students with no, low and high end technology. Natasha's need for a secondary unit reared its head again, as we hadn't replaced Dynamo when it broke. Together the SALT and I researched and chose the ChatPC. It was a private purchase so we did not have to wait for other funding sources.

UK BOUND

Coming back home to England was a whole new set of experiences. We lived near Bedford at first. Natasha attended a one day per week placement at Bedford College, with communica-

Figure 5 Natasha with the Dynamo

tion support by an intern for a few weeks, to help identify communication opportunities and areas for success. As I had done in every other place we lived, I sought a private therapist with AAC experience. The therapist and Natasha spent several months together where she continued to increase her communication skills, now expanding verb and adjective use.

We also joined and attended functions hosted by 1Voice, where we could meet other users and parents and carers.

LAST MOVE

After Dad got a job in London, we moved closer to his work. So far Natasha has been offered a place at the local college beginning of September 2010. Again I found a speech therapist with AAC experience to push Natasha's communication skills forward.

THE WHOLE KIT AND CABOODLE

When one looks at the complete picture, we see that Natasha uses many modes and levels of expressive communication. She vocalizes "m". "v", "f"; and she makes the 'o' shape when trying to communicate a word that includes 'o' or 'oo'. She is also trying to make the 'b' shape. Her signing, although based on ASL is difficult to interpret because of her physical disabilities. We also now have the 'problem' that people use British Sign Language or Makaton here; therefore her signing is even less useful beyond family. I continue to make manual boards for themed events (cooking time at college, horse riding, bath time, and toilet.) She still accesses the ChatPC as her current portable model, with themed pages and phrases for quick communication

that offers wider 'understandability' to the general population. Natasha will initially sign and mouth a word, then turn to her DynaVox if she gets frustrated that the listener is not 'getting it'.

The DynaVox DV4 still is her high-end AAC device with which she communicates her most expressive thoughts. To illustrate how she has moments of greatness this way, we were presenting an overview of AAC, where I used a small ball as a prop to something I was talking about. Natasha made a seven word sentence all by herself when I was doing the talk. (*I want take ball home play outside*) This may not sound that fantastic to some, but for me, on this 20 year journey, it was worth all the time, effort and hurdles she had overcome to get to this point. ✳

Julie Bello

REFERENCES

1Voice:
   www.1voice.info
Building Bridges / The Bridge School:
   www.bridgeschool.org/outreach/camp
Camp Chatterbox:
   www.campchatterbox.org
DynaVox Systems (formerly Sentient Systems):
   http://uk.DynaVoxtech.com
Gateway:
   www.gatewaytolanguageandlearning.com
Judy Lynn Software:
   www.judylynn.com
Kerland Institute (now Brainwave):
   www.brainwave.org.uk/index.aspx
Makaton:
   www.makaton.org
Mayer-Johnson (Picture Communication Symbols, Boardmaker, Speaking Dynamically):
   http://uk.mayer-johnson.com
PRC (Vantage / Unity):
   https://store.prentrom.com
News2You:
   www.news-2-you.com/index.aspx
Picture Word Power:
   www.inmaninnovations.com/ PictureWordPower.aspx
SETT:
   atto.buffalo.edu/registered/ATBasics/ Foundation/Assessment/sett.php
Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners:
   www.augcominc.com/index.cfm/ social_networks.htm
Symbol World:
   www.symbolworld.org

Life Mapping, Transition Planning and Communicating

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INTRODUCTION

We want Michael's Life Plan to be one single speech enabled interactive digital application that has everything in it that he would want or need to show or say, with a paper-based mirror made from all the information gathered during consultation.

This paper describes our early attempt at designing and building this.

BACKGROUND

Michael is a 20 years old young man, fully mobile. He can vocalise but not say any words and uses a Pathfinder for talking and writing, and text to speech software for reading and for presenting some of his talks.

He is not an independent communicator and needs close consultation and lots of support to prepare for and write about everything he does. Without assistance, Michael could be limited to clicking, watching, listening and playing computer games.

We have been thinking of Michael's life plan for some years now, and how to transition from a special education life skills course to mainstream further education and self employment, not an easy task with little more than ASDAN challenges in your portfolio and Literacy below Level 1.

Michael wants to study photography, computer music, video production, animation and advanced use of PowerPoint. But he cannot study any of the courses he wants to do because of his low literacy and so he is doing life skills again – but is at least with other young people and in the college environment, and teachers who are very keen to help his communication and literacy.

We hope that by giving Michael a tool good enough to express all that he understands receptively, people's estimations of his ability will go up, and more doors will open to him.

PLATFORM

There were a number of technical considerations, for example, should it be a website and database application, a Flash application, a set of pages in AAC software, a PowerPoint with sound – or all of them? What else should we consider?

CURRENT SYSTEM

Michael has loads of paperwork, presentations, movies, emails, online material, Care Plan, Direct Payments and In Control files, and messages stored in his Pathfinder… stories, descriptions, campaigns, action plans, budgets, and his many projects with 1 Voice, Communication Matters, ISAAC,

Michael (with a vacuum cleaner from his collection) and mum, Terry, at CM2009 National Symposium

Headlines, The Learning Disability Parliament, Diana Award, Radiowaves, Big Challenge, and FaCE. These are scattered, they can't all be on top at once, and are not all accessible to Michael due to his low level of literacy.

LAYOUT

The application will have two rows of tabbed links at the top of each page to navigate all the main sections.

USABILITY

Michael has good computer and technical skills, has no problems finding his way around Windows or the Internet, and we feel he will easily navigate and use an application with an extensive amount of data, if it's set up right for him.

CONTENT

We've learned a lot about what to include in a Plan by attending workshops on Communication Passports and Person Centred Planning, and by looking at existing systems.

We liked United Response 'Person Centred Planning' and 'My House' presentations, but need to record more data to meet Michael's needs.

We also liked 'My Life Plan' by DISC, a Flash application. It has a comprehensive amount of data and is well laid out. However, the only sounds in this are while you are navigating – a lot of the information is unspoken text, either on the pages or called up from Microsoft Notebook or a database.

POWERPOINT PROTOTYPE

Michael's Life Plan PowerPoint has over 150 slides so far, and that is only the shell, with a page for each main section and sub section.

We don't feel PowerPoint is the ideal platform. Once all the pictures and sounds are added it will be a massive file size. Also we want to have a page with 300+ core words for general conversation within the application but PowerPoint can't handle that many sounds on one slide (but a single sheet display with all the words a person would use for 80-90% of everything he or she would say is a must for us).

At least we have a blueprint for whatever platform we end up using (we might need to consult Tony Jones at Talksense as he is an expert at setting up PowerPoint for communication).

OUTLINE OF CONTENTS

All content is divided into these main sections, shown as tabs on the PowerPoint slide (see above): Facts, Living, Health, Money, Safety, Work, Learn, Communicate, People, Places, Social, My Past, Likes & Dislikes, Interests, My Time, Future Plans, Travel & Holidays, My Pages, Projects and Gallery. The data is stored in the following sections, each displayed on an interactive PowerPoint slide.

1. Facts

Facts: Name, what I like to be called, Age, Birthday, Birth place, Ethnic origin, How I describe myself, What I look like (eye colour, hair colour, hair length, hair type, skin, glasses, etc.).

Symbols: My beliefs. Family beliefs. Celebrities - Who? Why? What happened? What I like about? Why these symbols are important to me.

Thoughts: Starter set of 6 notebooks to write about thoughts.

Events: I go to… I like about… I don't like it because…

Issues: e.g. Michael's current issues are: Choose car, house, equipment, learning, Personal Assistant support, AAC Campaign, Role Model Campaign.

My Services: Which Local Authority? Support Organisations? How support is paid for. Where to find my Care Plan?

Figure 1 'Communication Methods' section

Figure 2 'Food' section

2. Living

Live where? Address. How long there? Map with picture of house and community places.

Live with? Who? Like about? Don't like about?

House Help: Who helps? What they do? How I feel about help and helper.

House Likes & Dislikes: What I like? What I like best? What I dislike? What is worst? What I would change?

House Rules: List of house rules.

House History: Remember places I've lived before. Who with? What happened?

Living Worksheet: My Dream Home: What like? Where? Who with? What do there? Who help? What help? Garden: best and worst thing about. What I like to do there. Being at home: What I do there, what time I get up, meals, self care, help at night, routines, what I do to relax, have fun, who with. Changes I would make. Help I need to change things.

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3. Health

Health Records: Consultants, Doctors, Dentist, Community Nurse, Physiotherapist, SLT, OT, other, Blood Type, NHS No., Hospital Nos., NI No., Immunisation, Medication (What? When? How much? Why?)

Review: Last Review, Next Review, Special Diet Needs, Conditions people need to know about, Training support people need, Family medical history - me, mum, dad, others, Fire drill.

Disability: My condition. I need help with… I can manage by myself.

My Body: body image with arrows pointing to parts and notes on health and special care.

Exercise: Image link to each type of exercise I do, or would like to try. How much do I do? Is this enough? Do I need help to exercise more?

Extra Care: Smoking, Alcohol, Drugs, Sex, Relationships, Other - do I have any worries?

Health worksheet: Questions for men and women e.g. about testicles, epilepsy, mental health, moving, teeth, relationships, sex, and who I want to share Health Records information with.

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4. Money

Links: Bank Details, Chequebooks, Welfare Benefits, Savings Account, Other Finances, Bills and Budgets, Wages, Direct Payments, Individual Budget.

Money Worksheet: Money in, Money out. What am I saving for? How do I spend my Direct Payments or Individual Budget? Where to find my Direct Payments file? Help I need to manage my Personal Assistants, time sheets, payments I need to make.

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5. Safety

Safety at Home: Links: Keeping safe where I am. Things I keep with me. Things that are too difficult. How things can be safer. Things people need to know.

Safety Outside: Links: Keeping safe where I am. Things I keep with me. Things that are too difficult. How things can be safer? Things people need to know.

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6. Work

For each job: Job Title, Workplace name and address, Contact details, What I do? Help I need. Who I work with? Best thing? Worst thing? What I would change?

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7. Lifelong Learning

For each of: Primary, Secondary, College, Day Centre, Other: record Name. Start Date. End Date. What I learned? How I feel about?

Old Friends: Best and Worst memories.

Current Placements: Name. Address. What I do there? Favourite activities? Least favourite activities? What I would change?

Learning worksheet: I want to learn about... be able to do... because... Who will help me? How will they help? What I have learned. How did I learn it?

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8. Communicate

Links: Methods, What I Mean, What Helps, Let's Talk About, My Senses, Remembering.

Methods: Links: Body. Face. Gesture. Signs. Sounds. Pathfinder. LLL Dictionary. Talking Grids. Book Grids. Literacy. Life Plan. Talking Mats. Communication Passport. Communication Book. Multimedia. Internet. (Talking Grids links to slides with varying numbers of core words, up to around 240, with sound added for each word, and a slide with alphabet, long vowels, initial blends, and common word endings).

What I mean: Interpret and help: When I do this… It means… And you need to… (Links to more slides to collect same data on different items).

What Helps: Who I get on with. My best way to tell you. How you can help. My AAC aids and how they work. My choices (link to Talking Mats slides).

Let's Talk About: Notes and pictures to help talk on favourite topics.

My Senses: Links: Hearing, Touch, Eyesight, Smell, Taste - notes on each.

Remembering: How good is my memory? What and who helps me remember? Links to Notice board, Calendar and Timetable slides.

Communication worksheet: I understand… I could understand more if… Help me choose. Who I get on with? How they help me? Other things that help? Do's and Don'ts.

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9. People

Links: Groups, Helpers, Friends, Family, Family Tree, Map, Health & Adult Services, Contacts, (where Contacts is a table (or linked database) with the fields Name, Relationship, Role, Address, Phone, email, Best way to contact, and Notes).

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10. Places

Links: Countries, cities, towns, community places.

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11. Likes & Dislikes

Links: Clothes, Food, Drink, TV, Films, Art & Culture, Activities, Sports, Places, Music, and Books. The pages could be Talking Mats.

Figure 3 'Future Plans' section

12. Interests & Hobbies

Links: My Interests. Things to try. Things to avoid. Things I did well. People.

Interests worksheet: When did you first become interested in...? What made you interested? How do you feed your passion? What are your plans to develop your passion? Who shares your interests? Help to interview people you know who share your interests.

13. My Time

Links: My Ideal Day, My Worst Day, My Routine, My Choices, Timetable, and Calendar.

My Choices: What I want to do more of. What I want to do less of. What I want to stop doing. Help I need to change things. What I do to relax and have fun. Plans and Results both have Action Plans that record Plan, Action, Helper, by when.

Calendar: Links: 2008, 2009 & 2010, one page per month.

Timetables: Life Skills Group 1, Life Skills Group 2, Whole Week.

14. My Past

Links: Home, School, Family, Achievements, Relationships, Good Memories, Bad Memories.

Home: Where I grew up. Who I lived with. Memories. Who and What is important to me.

School: Where? Favourite things? Favourite teacher? Helper? Good memories. Bad memories.

Family: Family tree and notes.

Achievements: Things I did well.

Relationships: Pictures that remind me of relationships.

My Past worksheet: River of Life: What happened to me on my journey? Feelings: What makes me feel excited, happy, sad, upset, angry, afraid, anxious, hopeful, content, depressed, embarrassed, shy, lonely, brave, funny.

15. Future Plans

Links: Skills, Hopes & Dreams, Milestones, Worries, Labels, Meetings, Plans, Results, Helper.

Milestones: 3 months. 6 months. 1 year. 3 years. 5 years.

Labels: Ways others see me that stops me achieving. What they say. Words on label. Bin it.

Helper: Who works on my Life Plan? Name. How they help. Record when they worked and what they did.

Future Plans worksheet: How to plan a meeting. When? Where? Who I want there and who not? Make invitations. What to talk about? Record meeting date, who came, how I felt, will we meet again, any ideas to improve next meeting.
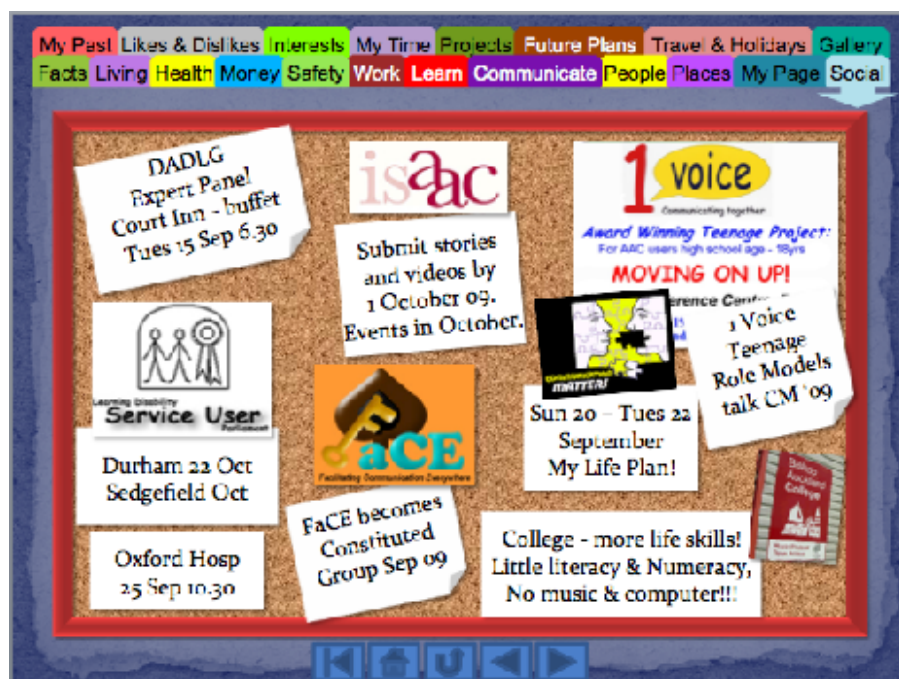

Figure 4 'Social - Noticeboard' section

16. Transport

Links: How I Travel. New ways to travel. Help I need. Places.

How I Travel: I travel by... to go... I like it because... I don't like it because...

New Ways to Travel: I'd like to travel by... because...

Help: I need help with... because... notes.

Places: Where I go? Who with? How I go? What I do there?

17. Travel & Holidays

Links: My last holiday. Holidays at home. My Ideal Holiday.

My last holiday: Was with... We went... What we did.

Holidays at home: What I do at home during holidays.

My Ideal Holiday: Holiday Type. I would go... With... Travel by... Do there...

18. Social

Noticeboard: Flyers, tickets, memos, appointment cards, and notes for Eating Out, Music & Concerts, Parties, Religious Services and Activities, Outdoor Activities, Watching & Playing Sport. Cinema & Theatre. Out for a Drink. Group Activities.

Social worksheet: Where do I like to go and who with? Keep a Journal. Organise an Event: Think about Where? When? Why? Who to invite? What to do? What help I need?

19. My Pages

Anything Michael wants, including pages of vocabulary, pictures and icons to talk about his things and interests - vacuum cleaners, pylons, electricity terms, games consoles, games & online activities.

20. Projects

Links: Who with? What do? Why? When? Action plans, budgets, work done, evaluations.

21. Gallery

Thumbnail links to albums of photos and movies, which may be local or on YouTube, Flickr, etc.

YOUR FEEDBACK

We are using Talking Mats and look forward to the new online Mind Mapping Workspace from Cricksoft to keep finding out more about who Michael is and what he wants.

If you have any comments or ideas about the content and layout of our Life Plan, or which is the most suitable platform, your feedback would be most welcome. ✱

Terry Gibson & Michael Reed

COLLATED BY JANICE MURRAY, CHAIR

It seems that most newspapers and official communications at the moment begin with those cautionary words of "we are entering a new phase of financial house-keeping" but, as my up-bringing attests to, adding a bit more water to the soup may make it go just as far and seems to keep most people feeling nourished.

I guess what we need to be mindful of is that one or two people around the table don't get all the lumps of chicken, whilst the rest get only the liquid! So with that analogy in mind, we are always aware of our responsibilities to maintaining the health of the charity, and aim to carry on with business as usual.

We have some exciting achievements, plans and aspirations to share with you. The Board of Trustees continues to be very busy working on a number of projects. Given this, we have decided that this time we will report on just some of those. Keeping an eye on the website and E-News will alert you to some other things that are in the pipeline and that we hope you will want to continue be involved in.

General publicity, marketing and information exchange continue to be key ways in which we maintain the AAC profile and reach across the UK.

THE NEW WEBSITE

Thank you to the many people who have taken the time to give us some really positive feedback on the new site. It seems to be going down well on many levels including its general 'bling' factor, navigational features, and content. This was a while in the production, so we are delighted it seems to have made the right impact in terms of how CM wants to be seen and represented.

THE PUBLICATIONS GROUP

This group, led by Sally Chan & Gillian Hazell, has been particularly busy over this last quarter. They helped develop the material for the new website, and are continuing with work on other sections. Members of this subgroup have been involved in planning for an online AAC training resource. This development could have significant impact on the children's workforce but we are still in the early stages of its production to say too much more at present. We anticipate calling upon the associate membership for contributions and comment as this unfolds.

As part of our commitment to maintaining the credibility of the organisation we have been completing a review and update of the range of Best Practice documents which are an important part of our Governance and are needed for on-going Charities Commission approval.

THE EVENTS GROUP

Led by Sally Chan & Dithe Fisher, this group has been involved in the National Standards for AAC workshop. This will lead to the production of an updated standards document, which we hope to have ready for launch to coincide with any events that may be happening in 2011, as part of the Year of Speech, Language and Communication. We have also been developing ideas for events for The Year, and will include a day about safe socialising for young adults who use AAC, and hopefully some kind of relay event across the UK - keep an eye on the website in the coming months. If you would like to know more, offer a venue or an event which we could publicise, please email Patrick Poon on *admin@communicationmatters.org.uk*.

THE SMALL GRANTS GROUP

This group, led by Gillian Hazell, has received a number of intriguing projects to consider, and have been delighted to be able to make a couple of awards. We are in the process of reviewing the latest round of submissions and anticipate making further awards. We also issued a specific invitation for applications for funding to attend ISAAC Barcelona, and have sponsored one person.

THE COMMUNICATION TRUST

We continue to be members of the Communication Consortium which supports the work of the Communication Trust (operates in England only). We were delighted to see Jenny Herd (representing 1Voice) recently elected to the Board of the Communication Trust. The Trust continues to be an organisation that can support a number of initiatives and are keen to work collaboratively on issues of awareness raising, workforce education and fund raising activities. Janice Murray is meeting with the Director of the Trust (Anita Kerwyn-Nye) to explore mutually enhancing opportunities.

AAC EVIDENCE BASE RESEARCH PROJECT

The research project 'Communication Matters - Research Matters: An AAC evidence base' is finally starting to move into its first phase of research activity. It is clear that the set-up programme was more complex and slower than originally projected but commitment, drive and dogged determination has seen us through to this more exciting phase – where we actually start exploring the issues that matter to us. This achievement is in no small part down to **Liz Moulam** (Interim Research Lead) and **Katie Holmes** (Project Manager). Thank you.

Our newly appointed Research Lead is **Dave Morgan,** a name that will be very familiar to many. He took up his post at the beginning of August.

Katie Holmes will leading on a presentation at the CM2010 National Symposium in September, which will be an opportunity to provide some detail and offer a forum for discussion about the stated milestones and intended outcomes of the project.

Finally, the Trustees are now busy gearing up for the Symposium. Given that I started with an eye on the current financial climate, it seems appropriate to end by acknowledging the commitment and lengths members of the AAC community go to in order to attend this and other events, such as the ISAAC conference, often at no small cost to themselves. For those of you in the fortunate position of attending the Symposium or the ISAAC conference, I hope you find these stimulating and positively challenging opportunities. ✳

RELEASES

TOBY CHURCHILL RECEIVES HONORARY DOCTORATE

Congratulations to Toby Churchill who received an honorary Doctor of Engineering degree from the University of Bath at a private ceremony in June 2010 that was filmed and later shown at the University's presentation ceremony.

Toby was a student at Bath in 1965. As part of his degree he spent a two-month work placement in Paris and Clermont-Ferrand in 1968. During the visit he swam in a river and contracted viral encephalitis which resulted in him becoming paraplegic with a speech disability. He completed his degree from home and graduated in 1971. As communication aids were few and far between at the time, Toby designed his own – the Lightwriter – a portable text-to-speech communication aid, and founded Toby Churchill Ltd to manufacture and market the device. His inventions and business have earned him many awards, including the British Design Award and the Queen's Award for Export.

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POSSUM ANNOUNCES NEW WEBSITE

Possum has announced the launch of their newly redesigned website which has a dynamic look and feel. The new website marks a dramatic improvement in appearance which includes a complete design overhaul. Jenny Wakely, Possum's Marketing Executive, commented: "Our long term commitment is to develop the resources available on our site. Developments will include key product tutorials to support our clients in using our products to their full potential."

Visit the redesigned website at *www.possum.co.uk*

*

THE CENTER FOR AAC & AUTISM

The Center for AAC and Autism has launched a new website. The Center for AAC & Autism was established in 2009 by Prentke Romich to be a resource for clinicians, therapists and parents who are working to improve the language and communication skills of kids with autism. Visit: *ww.aacandautism.com*

*

MOUNT'N MOVER

Toby Churchill Ltd launched the Mount'n Mover in July at the ISAAC 2010 International Conference in Barcelona.

The Mount'n Mover is a powerful new wheelchair mounting system designed with a focus on access, positioning and ease of use.

For more information, visit *www.toby-churchill.com*

NEWS

TELLING AAC STORIES (TAACS)

Communication Matters is very keen to increase the involvement of our members who use AAC in the activity of the association.

Telling AAC Stories (TAACS) is a new project which we plan to share with you in more detail at the CM2010 National Symposium in September.

TAACS will be a regular feature in the Communication Matters Journal and on the website. We hope it will become a resource for raising wider awareness about AAC. We also hope to enter the stories in the annual ISAAC story telling competition, and use them closer to home to support the awareness campaign to be run in the UK throughout 2011.

If you use AAC, we would love to have your stories on the theme **'A funny thing happened...'** - a lighthearted look at how your AAC has got you into or out of trouble!

To become involved, write a story of no more than 500 words and submit it by email to *admin@communicationmatters.org.uk* by **15 September 2010** for inclusion in launch at the CM2010 National Symposium.

If you know of anybody who has good stories to tell please encourage them to send them to us as well; non-members welcome.

*

INTERNATIONAL AAC AWARENESS MONTH

Message from Sarah Lever, Chair of International AAC Awareness Month Committee:

In October 2010, to celebrate ISAAC's fourth annual AAC Awareness Month, selected stories from the **Many Cultures, One Dream: To Communicate** (MMOD) online collection will be read or viewed in community settings all over the world.

In order to assist people who wish to participate, the AAC Awareness Month Task Force has come up with a list of preliminary ideas of how to plan and facilitate this celebration of communication and AAC users worldwide. These ideas are just a start, and we invite you to comment, suggest new ideas, and let us know about your plans for celebrating by emailing us at *events@aacawareness.org*

A new project for 2010 is the **AAC Awareness Songs - Inclusive Singing Videos Project.** People who use AAC were invited to use their AAC to sing or sign one of our AAC Advocacy songs with family and friends and capture it on video: "If I Had a VOCA" or "ABCs of Communication Rights". The task force will merge videos from around the world to make two harmonies of communication and singing with technology.

Find out more at *www.aacawareness.org*
Please email enquiries to *info@aacawareness.org*

AAC EVIDENCE BASE RESEARCH PROJECT

Communication Matters, in collaboration with research partners Manchester Metropolitan University, the University of Sheffield and Barnsley Foundation NHS Trust, are involved in this ground-breaking three year research project, funded by the BIG Lottery Fund.

After months of behind the scenes work the **collaboration agreements** are in place with the three research partners, and research commenced on 14 June 2010.

The first part of the project, conducted by the University of Sheffield and Barnsley Foundation NHS Trust, will assess the **prevalence of need for AAC** across the UK, whether no tech, low-tech or high-tech and will swiftly be followed by mapping existing services in the UK. Manchester Metropolitan University will commence work in September on the best practice evidence database for early identification and intervention.

The partners will be **recruiting researchers** for the project in the next two months (see below for details of the first of these vacancies). More information about the vacancies will appear in the news section of the Communication Matters website and in future editions of the E-News.

In the coming months the research teams will be **seeking participants,** including people who use AAC, their families and carers as well as practitioners, to join focus groups, take part in interviews and provide other information. To register your interest please contact Katie Holmes, Research Manager (details below).

For more information about the project visit the Research page on the Communication Matters website *www.communicationmatters.org.uk/research* or email Katie Holmes, Research Manager, at *katieholmes@communicationmatters.org.uk*

Vacancies for Research Assistants

The University of Sheffield is recruiting two Research Assistants for the AAC Evidence Base project:

Research Assistant (Quantitative)
University of Sheffield, Job Reference Number: UOS001506
Contract Type: Fixed term for 2 years
Salary: Grade 6 £23,566 to £25,001 per annum
Closing Date: 23 August 2010
www.jobs.ac.uk/job/ABL245/research-assistant-quantitative

Research Assistant (Qualitative)
University of Sheffield, Job Reference Number: UOS001505
Contract Type: Fixed term for 2 years
Salary: Grade 6 £23,566 to £25,001 per annum
Closing Date: 23 August 2010
www.jobs.ac.uk/job/ABL246/research-assistant-qualitative

A PERIOD OF UNCERTAINTY, CHANGE AND OPPORTUNITY

A Chinese proverb says: "To be uncertain is to be uncomfortable, but to be certain is to be ridiculous". Uncertainty and change imposed by our new government are certainly making life uncomfortable for many people! A common question seems to be "How much will be cut from my budget and what are the implications for services, equipment, training and support?"

But we are also in a period of increased technological change, with innovative new products bringing new suppliers into the field: new eye-gaze technology; hand-held devices; apps for consumer devices; products to help people with autism, and more. This is already making AAC more accessible and affordable for a wider group of people – so change can also provide opportunities!

Back to business...

The revised NHS EAT Framework Agreement was finally tendered in May. Technical problems with the tendering process and certain clauses in the agreement meant some suppliers were unable to tender or declined to, leaving us with a contract that not all suppliers are party to. Whilst this is a concern, it makes little practical difference whether the supplier you buy from is on contract or not.

The Naidex Communication Village was a positive step towards creating an AAC event within a major exhibition, that will help raise awareness of AAC and provide a focus for people to find out about and try AAC products and services. We will encourage EMAP to promote it more actively in 2011 to increase attendance, but it's a start.

The BHTA continues to strengthen its role as the leading assistive technology trades association. To maintain its OFT-approved status, the **BHTA Code of Practice** must be rigorously enforced and continually updated. For example, the new **Bribery Act 2010** makes it illegal to offer an inducement that persuades a public servant to act in a biased manner and illegal for them to ask for or accept such an inducement. The BHTA will update its Code shortly to include new government guidance, covering areas such as sponsorship.

The Assistive Technology Practitioners Society was formed recently by the BHTA and I recommend you take a look at the new website: *www.atpsociety.org*. There is an entire section dedicated to healthcare professionals. More next time.

Finally, RI Fitzhenry said: *Uncertainty and mystery are energies of life. Don't let them scare you unduly, for they keep boredom at bay and spark creativity.*

David Weatherburn
Chair of eCAT section, BHTA
david@ability-world.com

13 September 2010 — Bristol
Communicate: In Print 2
Contact PCAS: 0117 3533613 www.pcas.claremont.bristol.sch.uk

20 September 2010 — Bristol
Introducing Clicker 5
Contact PCAS: 0117 3533613 www.pcas.claremont.bristol.sch.uk

26-28 September 2010 — Leicester
CM2010 National Symposium
Contact: 0845 456 8211 www.communicationmatters.org.uk

29-30 September 2010 — London
Naidex Excel London
More information: www.naidexsouth.com

6 October 2010 - 11 May 2011 (4 days) — Oldham
Accredited Training: AAC Unit
Contact ACE Centre North: 0161 358 0151 www.ace-north.org.uk

6 October 2010 - 12 May 2011 (4 days) — Oldham
Accredited Training: Recording & Retrieving Information
Contact ACE Centre North: 0161 358 0151 www.ace-north.org.uk

14 October 2010 — Oxford
Control, Communication and Play
Contact ACE Centre: 01865 759800 www.ace-centre.org.uk

15 October 2010 — Bristol
BoardMaker Training
Contact PCAS: 0117 3533613 www.pcas.claremont.bristol.sch.uk

20 October 2010 — Bristol
Introduction to AAC
Contact PCAS: 0117 3533613 www.pcas.claremont.bristol.sch.uk

20 October 2010 — Newcastle upon Tyne
DNEX 2010: Disability North Exhibition
More information: www.disabilitynorth.org.uk

4 November 2010 — Barnsley
CM Study Day: Eye Gaze in Action
Contact: 0845 456 8211 www.communicationmatters.org.uk

9 November 2010 — Oxford
AAC SIG Day
Contact Julie Atkinson: 0121 627 8235 julie.atkinson@sbpct.nhs.uk

9 November 2010 — Stirling
AAC Study Day: The Eyes Have IT!
Contact ACiP:Scotland 0141 201 2619 www.acips.org.uk

17 November 2010 — Bristol
ICT and Switch Access
Contact PCAS: 0117 3533613 www.pcas.claremont.bristol.sch.uk

18 November 2010 — Oxford
Developing & Supporting Low Tech Communication
Contact ACE Centre: 01865 759800 www.ace-centre.org.uk

22 November 2010 — Bristol
Communication Matters Road Show in Bristol
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

November 2010 (to be confirmed) — Manchester
Communication Matters Road Show in Manchester (TBC)
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

30 November 2010 — Glasgow
Communication Matters Road Show in Glasgow
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

1 December 2010 — Dunfermline
Communication Matters Road Show in Dunfermline
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

December 2010 (to be confirmed) — Inverness
Communication Matters Road Show in Inverness (TBC)
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

8 December 2010 — London
Communication Matters Road Show in London
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

9 December 2010 — Edinburgh
Creating Communication Friendly Schools
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

20 January 2011 — Edinburgh
Personal Communication Passports
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

24 February 2011 — Edinburgh
Multimedia Social Stories
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

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Facilitated Communication

The current 'state of play'

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It may be a surprise to some people that new research is still being conducted in the field of Facilitated Communication (FC). It is a common perception that the topic has already been satisfactorily investigated with the conclusion that FC is at best ineffective and at worst dangerous. However this is a misconception, as there is still considerable interest in and practice of FC throughout the world. The aim of this paper is to give a brief overview and critique of previous research and the reasons for continued interest in the topic.

There are at least two people involved in every communication produced through FC. The 'communicator' is typically someone who has very limited or no verbal communication and who has not developed independent AAC beyond a basic level. The 'facilitator' may be simply the person who gives physical and/or emotional support to the communicator, and at times also the communication partner. Good practice standards require the facilitator to be a skilled individual, who provides the minimal support possible at all times, in a way that promotes the development of the motor skills needed for the task to become independent. They need to be able to prompt and repair communi-

cative attempts, while minimising their own effect on the resulting message.

Most experimental investigations of FC took place in the early 1990s (Eberlin et al., 1993; Hudson et al., 1993; Klewe, 1993; Regal et al., 1994; see Mostert, 2001). These typically set up situations where the facilitator was blind to the information the communicator was required to pass on. These studies demonstrated that the facilitator tended to influence most people's communication, and that when pinned down to give specific messages most communicators did not do so. For a critique of the methodology of some of these studies see Emerson et al. (2001). The overall conclusion of these studies was that communication produced by disabled people had been shown to have been subject to inadvertent influence by their well-meaning but deluded facilitators. FC was banned by many organisations and professionals were warned against its use.

However, its practice did not die out, principally because some of the early practitioners had already seen positive benefits in the people who were using FC. Most of the evidence for its effectiveness comprised anecdotal reports of people giving their facilitators information that was not previously known

but that could be verified. However since this usually occurred only sporadically, seemingly when there was a high level of motivation to communicate, it was difficult to record it systematically and at levels that showed reliability. Other FC users were able to develop independent communication, but this was not deemed to be due to FC practice, but instead held to be a skill they possessed which would have been discovered without FC. Some of the most compelling evidence demonstrated significant reductions in challenging behaviour linked to the use of FC but the results could not be replicated in experimental conditions and therefore the causal link could not be established (see Emerson & Grayson, 1996; Emerson et al., 1998). Practitioners with any individual communicator might justify their use of FC by citing indicators of authorship but these typically occurred sporadically over time and could not be systematically verified.

Evidence relating to authorship has been obtained through frame-by-frame analysis of video-tapes of facilitated interactions. Observation of FC users indicated that they each had a unique style of pointing, which remained constant no matter who was facilitating

Eye Gaze in Action

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Thursday 4 November 2010, Barnsley

This year's study day will focus on integrating eye gaze use into everyday life of school, work and leisure.

The presentations will discuss the pitfalls and barriers which need to be overcome, and share ideas which can be used to inspire and motivate eye gaze users. There will also be representatives from leading suppliers who will demonstrate and give advice on their latest eye gaze products.

The day is intended for professionals (e.g. speech & language therapists, occupational therapists, specialist teachers, clinical scientists), those involved in research, anyone supporting people who use eye gaze technology, and users of eye gaze technology who wish to keep up to date with the latest developments and to meet role model users.

Speakers include:

Dr Jenefer Sargent (Wolfson Neurodisability Service)
Tom Griffiths & Amy Barton (Wolfson Neurodisability Service)
Andrea Kirton (Greenacre School & Barnsley Outreach Service)
Marcus Friday (Barnsley Assistive Technology Team)
Ruth McMorran (Surrey Physical and Sensory Support Service)
Dr Mick Donegan (SMARTlab Digital Media Institute, University of East London)
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www.communicationmatters.org.uk/studydays

them, and conversely, that facilitators would change the way in which they worked to suit their partner. This was captured objectively by measuring the timings of key phases of the pointing movement. Microanalytic studies of FC users (Grayson & Emerson, 2001; Grayson et al.., 2003) demonstrated that the timing of FC users' movements remained consistent within the individual when facilitated by a number of different facilitators.

Equivalent measurements taken for the facilitators, when facilitating different FC users, showed no such consistency. These findings suggest that the FC users were in control of their movements. Indeed it is rather difficult to explain these findings with reference to facilitator influence.

Data presented at the 2009 Communication Matters Conference took this investigation one step further by using eye-tracking technology, describing an investigation of the link between eye-gaze and pointing. Evidence for 7 of the 8 people in the study, that they look for longer at letters that they subsequently go on to type, indicates that they are active in authoring the messages they produce. Additionally the data for one man shows a particular pattern of looking ahead to the letter following the next one to be typed. This really cannot be accounted for by facilitator influence (Grayson et al., in press).

From a practitioner's viewpoint, the most interesting research presented at FC conferences concerns the attempts to investigate the broader phenomena in terms of the dynamic between the facilitator and communicator and to address some of the issues that arise when someone starts to communicate in ways that were previously not possible. Research currently under way in Switzerland is describing many key features of the relationship between the facilitator and communicator, including frequent mirroring of movements. Italian practitioners see FC as a form of neuro-rehabilitation, and their research includes investigations using MRI scanners (Pardini et al., 2009; Schiavo et al., 2005; Tecchio et al., 2003).

To summarise the findings from nearly 20 years of research into FC, the balance of the evidence does not support its use, but there are some studies which raise interesting questions about the technique and suggest that it should not be dismissed.

What motivates many practitioners to continue in the light of negative research, aside from seeing ongoing

practical benefits to individuals, are the intriguing questions prompted by the process. Once there is a view of FC as having been positive for even one user innumerable questions inevitably arise, such as 'why can the person not point independently?', 'why do they not demonstrate communicative competence through other means?', 'how have they acquired literacy skills?', 'why has assessment not shown a more accurate picture and what does this tell us about the nature of disability?' Naturally if one has only seen FC being effective for a single individual it is possible to dismiss this as an exception and not raise these challenges. This becomes harder to do when the use of FC is viewed globally and evidence of many 'exceptions' is compared (Biklen et al., 2005; Blackman, 2001; Mukhopadhyay, 2000; Rubin et al., 2001; Sellin 1995).

FC practice developed prior to any theory of why holding someone's arm would make a difference and why someone with language and possibly literacy skills would not demonstrate them independently. Initial theoretical offerings focused on 'dyspraxia' as an explanation. This was further developed by Leary and Hill (1996) who compared the movement differences found in people with autism (who constitute the largest group of FC users) to those found in conditions such as Tourettes and Parkinsonism. They suggest that FC users with autism need the physical support to help them overcome typical neurologically based difficulties with initiation, perseveration and combining movements, among others. A further development of this thinking was offered by Grayson (1997) who suggests that many of the movement difficulties of FC users can be viewed in terms of executive functions.

If it were to be accepted that people are unable to fully demonstrate competence because of movement difficulties and disorders this would call into question some of our understanding of the nature of disability and our ability to accurately assess cognitive and language skills. There is a high level of incongruence when watching someone like Sue Rubin (Wurzburg, 2004) who can show full engagement with a small keyboard while communicating fully about her views of life and disability, compared to scenes of her playing repetitively with water or engaging in repetitive verbal exchanges. Since all our formal assessments of people with communication impairments necessarily involve at least some level of

motor skill, the idea that some people would not be able to point independently despite being fully aware of the correct answer could lead to significant underestimation of ability.

FC offers someone physical support to point to objects, symbols and pictures, anything which may help them to extend their communication. However most practice has involved people pointing at words and letters. This leads to yet further incongruence as most people who are subsequently claimed to be able to use FC effectively have not been directly taught literacy skills, or have apparently failed to acquire literacy despite efforts at teaching them. This would indicate an ability to absorb literacy vicariously which seems unlikely when many children with no apparent disabilities leave primary school unable to read or write. However research which is currently underway (Emerson and Dearden, in preparation), looking at the independent pointing skills of four children with autism and severe learning disabilities, has identified one twelve year old boy's ability to read complex vocabulary, with understanding, which was totally unexpected and undetected by his teachers.

Similarly the vocabulary and complexity of language produced through facilitated communication would not be that expected from the group of people generally understood to have severe intellectual disabilities. People also demonstrate apparent comprehension skills which they do not manifest in other ways. For practitioners and researchers who accept the validity of Facilitated Communication, at least for a small number of people, the picture is therefore one of assessment being inaccurate and competence not being reflected in performance.

It is therefore evident that there is little clarity in the field of Facilitated Communication, and indeed the topic is complex from every aspect. It could be considered that the safest attitude to have towards the technique is to not use it. However, once one has seen some of the progress which is possible for some FC users it also becomes difficult not to use it. My overall view is to proceed with caution when a given set of circumstances are present. It is imperative to investigate the extent of someone's independent pointing skills in a variety of situations and to look at the difference between voluntary and involuntary movements. Second, a practitioner must find out what motivates the person, perhaps by trying a large range of materials at levels that vary from what they are used to working on to items which are much

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more demanding. Experience shows that some people who are not thought to have literacy skills are more attentive when presented with words than pictures.

Facilitated Communication should be offered only as a 'last resort' technique, when the person has been given every possible opportunity to communicate effectively through independent means. Once it is being used it is then essential to protect communicators and facilitators by employing guidelines to ensure that the potential for abuse, inadvertent or deliberate, is minimised. Facilitators need to ensure that they are adopting 'best practice' particularly with reference to working on the development of independent pointing skills and ensuring the maximization of all other means of communication at the communicator's disposal. Additionally all users of FC must have multiple facilitators who are trained to use a consistent approach. Ultimately when making the decision about whether FC should be introduced it is helpful to refer to the concept of the 'least dangerous assumption' (Donnellan et al., 1992). Would the benefits of adopting an approach that may help someone to increase their ability to communicate outweigh the risks of contamination of that communication by facilitator influence? Part of this decision is also to look at the 'added value' of being perceived as a more competent person and its effects on self-esteem. These decisions need to be addressed for each individual dependent on their current and potential situations.

The key finding of FC research is that it is often not possible to judge competence by performance. The overall purpose of this article is to reposition FC as a technique that is complex, little understood, and of considerable potential benefit. ✳

Anne Emerson & Andrew Grayson
Nottingham Trent University

REFERENCES

Emerson A, Grayson A & Griffiths A (2001) Can't or won't? Evidence relating to authorship in Facilitated Communication. *International Journal of Language and Communication Disorders*, Supplement 36, 98-103.

Leary MR & Hill DA (1996) Moving on: Autism and movement disturbance. *Mental Retardation*, 34, 1, 39-53.

Mostert, M. P. (2001) Facilitated communication since 1995: A review of published studies. *Journal of Autism and Developmental Disorders*, 31(3), 287-313.

Rubin S, Biklen D, Kasa-Hendrickson C, Kluth P, Cardinal DN & Broderick A (2001) Independence, participation, and the meaning of intellectual ability. *Disability and Society*, 16, 3, 415-430.

Tecchio F, Benassi F, Zappasodi F, Gialloreti LE, Palermo M, Seri S and Rossini PM (2003) Auditory sensory processing in autism: a magnetoencephalographic study. *Biological Psychiatry*, 54, 6, 647-654.

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?

If you live in the UK, you can become a member of Communication Matters (and therefore of ISAAC) by contacting: Tel: 0845 456 211 admin@communicationmatters.org.uk www.communicationmatters.org.uk

If you are outside the UK, you can become a member of ISAAC or subscribe to this Journal by contacting: ISAAC, 49 The Donway West, Suite 308, Toronto, Ontario M3C 3M9, Canada Tel: +1 416 385 0351 info@isaac-online.org 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 3,700 members.
- ISAAC members live in more than 50 countries around the world.
- There are ISAAC Chapters in Australia, Canada, Denmark, Finland, French-speaking Countries, German-speaking Countries, Ireland, Israel, Italy, Netherlands-Flanders, Norway, Sweden, United Kingdom and United States of America.

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

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

What does ISAAC do?

- Advocates for augmented communicators & their families.
- 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.
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Exploring Multiple Factors Affecting Participation Outcomes for Children with Communication Aids

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BACKGROUND AND PROJECT AIMS

Supporting and developing participation in everyday life is an ultimate goal of augmentative and alternative communication (AAC) intervention. Participation is defined by the World Health Organisation as "a person's involvement in a life situation" (WHO, 2001 p.213), where 'involvement' is characterised as "…taking part, being included or engaged in a life area, being accepted…" (WHO, 2001 p.15). While in many cases the provision of communication aids can significantly promote children's participation in everyday life, some children apparently do not benefit fully from communication aids.

It has long been acknowledged that multiple and various factors can influence the take-up and use of communication aids and the impact of communication aids on children's participation in everyday activities. Research in the AAC field has identified many of these factors. Arguably however, the ways in which such factors interact to influence the impact of communication aids on children's participation is apparently less well understood.

This brief paper provides an outline of pilot research being undertaken to es-

tablish a reliable parent-response questionnaire aimed at exploring how environmental, personal and child factors interact to affect children's communication aid use and participation. Some preliminary findings concerning children's profiles of participation are also presented.

METHODOLOGY

Design

The project was designed as a questionnaire study, with responses being collected from the parents of children and young people who use communication aids.

Participants / Respondents

Participants for the study were identified as parents and carers of children assessed for communication aids at either the Augmentative Communication Service at Great Ormond Street Hospital or the ACE Centre in Oxford between March 2006 and March 2008. Because we aimed to investigate within-group variation across the whole population of children assessed for communication aids, we approached all families of children who had been recommended a communication aid incorporating the

symbolic representations of language (e.g. photographs, pictures, graphic symbols, words). We did not approach families of children with progressive

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(Intrinsic) Child related factors

- Disability
- Personality
- Preferences

Communication aid related factors

- Amount of use
- Type of use
- Usability

Support services

- Amount
- Type
- Perceived effectiveness

Family support & demands

- Stress and Coping
- Socio-economic Category
- Personality
- Attitudes towards communication aids

Table 1 Variables identified for analysis

Mean Age	10.6 years
Age Range	1.08 - 21.07 years
Gender	67.1% male, 32.9% female
Child's speech reported as "Not understood by strangers or familiar people, or unable to speak at all"	48.8%
Child reported to have difficulties with vision	48.8%
Child reported to have difficulties with manual dexterity	86.4%
Child reported to have difficulties with mobility	76.8%
Communication Aid Type:	
Complex VOCA and Communication Book	23%
Communication Book only	16%
Complex VOCA only	12%
Simple electronic aid only	5%
Literacy Levels:	
Early (using symbols / pictures)	50%
Emergent (basic sight vocabulary, some spelling skills)	38.2%
Fluent literacy	11.8%

Table 2 Summary of children in study

conditions or profound and multiple learning disabilities, or those known to have suffered bereavement or who presented with especially sensitive personal circumstances.

To date, 97 questionnaires have been returned. An early analysis of 82 responses is provided here to complement the very preliminary data (n=23) presented at the Communication Matters National Symposium in September 2009.

Some details of the children reported on are summarised in the table above.

Procedures

Based on the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF), and the version for children and youth (ICF-CY), a conceptual model was designed to illustrate hypothesised relationships between a range of key factors that potentially affect the take-up of communication aids and children's participation.

The factors were identified from the research literature, the clinical experience of the research team, and a motivation to examine variables that are likely to be sensitive to intervention.

The key factors identified in this model are represented by four domains:

1. Professional services used by families.

2. Internal family characteristics and demands.

3. Communication aid technology.

4. Child's abilities.

The outcome measure for the study was children's participation in social activities.

The conceptual model provided a clear framework for the development of the questionnaire, which was constructed from a combination of scales designed specifically by the research team for the purpose of the study and, where appropriate, the use of existing measures.

For example, in the domain of professional services used by families, no appropriate measure existed to capture key issues relevant to our study (e.g., perceived effectiveness of services, perceived knowledge and skills of professionals). Therefore we designed a number of scales that explored these key issues. Each scale incorporated a number of statements relating to that particular issue, each of which is rated

by parents on a five-point Likert scale: strongly agree, agree, don't know, disagree and strongly disagree. An example of an existing measure used for the study is the Children's Assessment of Participation and Enjoyment (King et al. 2004), which is designed, in part, to measure the diversity and intensity of children's participation.

The questionnaire underwent review by clinical teams at both the Augmentative Communication Service and the ACE Centre, and by a focus group of parents of children attending these centres. Written feedback was also received from two parents unable to attend the focus group. Parents and professionals were invited to comment on the questionnaire content, structure and layout. Their comments led to careful refinement of the questionnaire in a number of specific areas including for example, question wording and the ordering of questions.

Following the period of development the final draft was mailed to prospective participants. An online version was also offered. The initial mail-out was followed up by two reminders; the first of which included a second paper copy and the second a link to the online questionnaire.

ANALYSIS

The reliability of scales designed specifically for the study was assessed using Cronbach's Alpha internal consistency estimate of reliability. This measure tests whether statements in a single scale measure a single construct. For example the degree to which all the statements in the scale relating to 'perceived knowledge and skills of professionals' tended to measure the same thing.

Alpha coefficients normally range between 0 and 1. A high alpha coefficient suggests high reliability. Cronbach's Alpha coefficient threshold of 0.6 was considered suitable for our measure given the relatively small number of items per scale. Descriptive statistics were used to explore profiles of participation

RESULTS

Questionnaire reliability

We were pleased to observe that 23 out of the 27 scales designed specifically for the project attained acceptable to excellent levels of internal consistency with alphas ranging from 0.673 to 0.934. Exceptions that did not meet the required levels of internal consistency will require further development if they are to be employed in any further study.

Participation

The diversity and intensity of children's participation, as derived from parents' ratings of subscales of the CAPE measure, varied considerably between families but mirrored findings from studies of participation in children with disabilities, although not necessarily communication difficulties (Imms et al. 2009; Law et al. 2006).

It is notable that the spread of scores from our study was fairly large compared with other studies suggesting greater variation in diversity of participation in the group of children with complex communication needs than those included in the previous studies.

It has been noted that the amount and type of children's participation is likely to change as children mature (e.g. McConachie et al. 2006) so that older children may show more restricted profiles of participation diversity and intensity. In our sample, mean participation intensity scores are seen to differ significantly between children aged over and under 12 years. Parents of children under 12 years of age gave significantly higher participation intensity scores ($z = -3.695$, $p<0.01$) than parents of children aged 12 and over.

SUMMARY

The primary aim of the study was to produce a reliable questionnaire instrument, and to this end the study has been successful.

It has also been possible to make some interesting preliminary analyses of the data collected, and some interesting observations have been made that would benefit from further analysis with a larger sample. ✳

Tom Griffiths, Michael Clarke, K V Petrides, C Newton, Katie Price, Andrew Lysley

BIBLIOGRAPHY

King, G., Law, S., King,S., Hurley, P., Hanna S., Kertoy M., Rosenbaum P. and Young, N. (2004) Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC). San Antonio, TX: Harcourt Assessment, Inc.

Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., Young, N. and Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. Developmental Medicine & Child Neurology, 48: 337-342

McConachie, H., Colver, A., Forsyth, J., Jarvis, S.N. and Parkinson, K.N. (2006). Participation of disabled children: how should it be characterised and measured? Disability & Rehabilitation, 28: 1157-1164

World Health Organisation (2001). International Classification of Functioning, Disability and Health. Geneva: World Health Organisation

Exploring the Use of Graphic Symbols

An introduction to two pieces of recent postgraduate research in the use of graphic symbols

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At the Communication Matters National Symposium in 2009, Eliada Pampoulou, and Louise Greenstock presented the findings of two separate research projects undertaken in the UK within the last five years. Both studies focused on the use of graphic symbols and explored the experiences and reasoning of groups of practitioners using these symbols. This paper explores both research studies and considers the findings in the context of existing literature and implications for practice.

INTRODUCTION

Graphic symbols play an important role in many high and low-tech AAC systems. Graphic symbols ('symbols') are widely used by SLTs in a variety of settings when supporting a range of individuals, some of whom use AAC systems, as well as others who do not.

Research exploring the use of symbols has frequently had an AAC focus. Research suggests that use of symbols and AAC in many settings is expanding and diversifying. Abbott and Lucey (2005) found that 96% of schools for children with learning difficulties reported using symbols in their survey of special schools in England. This finding

suggests widespread use of symbols with children with learning or cognitive difficulties in schools, a finding that was supported by Greenstock (2009).

PART 1 (ELIADA PAMPOULOU)

RESEARCH TOPIC

This research was conducted by Eliada Pampoulou, a Speech and Language Therapist (SLT) and Assistive Technology consultant (King's College London). There are several available graphic symbol sets, developed by different companies across the globe.

The purposes of the symbol sets include: face-to-face communication; participation in the classroom; and access to information. Picture Communication Symbols (PCS, DynaVox Mayer-Johnson©), Makaton Symbols (The Makaton Charity©), Clarity Symbols (Liberator©), Widgit Symbols (Widgit Software©) are examples of these symbol sets.

It has been suggested that while the number of symbol sets might be beneficial for symbol-users they may also be a cause of stress for SLTs, who are required to choose the optimum symbol set(s) for their users. Therefore this

pilot-study was designed to investigate what factors a group of SLTs take into consideration when choosing symbols or symbol sets for given individuals.

METHODOLOGY

The identification criteria for recruiting the sample was: SLTs working with children aged between 11 and 16, with Severe Learning Difficulties (SLD) and/ or Profound and Multiple Learning Difficulties (PMLD), in schools in London and across South East England. Fifty SLTs were approached through a postal survey, predominantly aiming to identify SLTs willing to participate in an interview.

A total of five SLTs were interviewed. Semi-structured interviews of approximately forty minutes length were conducted, in order to collect in-depth information about symbol practices. A content-analysis method was used to analyse the data and to address the research questions. The data from the questionnaires (open-ended questions) and interviews were coded and patterns and themes were detected.

FINDINGS

The main aim was to investigate the factors influencing the decision of SLTs in

Symbol Variables	User Variables	Environment / Context
Iconicity	Visual skills	Consistency
Amount of detail	Cognitive level	Available resources
Colour	Age	
Vocabulary	Learning needs	
Software special features	Symbolic understanding	
	Previous experience with symbols	
	Experience with the world	
	User's preference	

Table 1 Emerged themes relevant to symbol set selection considerations

choosing a symbol set for a user. Evidence from this study suggests that SLTs are concerned about factors related to symbols used, symbol users and the environment/context in which the symbols are used. The 'user variables' mentioned by participants included cognitive level, and symbolic understanding. Among the factors related to the types of symbols used were colour and iconicity. Table 1 provides a complete list of the factors mentioned by participants.

Some of the most widely discussed factors from the questionnaires and interviews are discussed below.

Iconicity

Of the thirteen participants in the postal survey, six (46%) mentioned iconicity as a factor they consider when selecting a symbol set for a given individual. The therapists defined iconicity as the symbol's "clarity", "abstractness" and "how closely the symbol is related to the real object/ concept". Iconicity is defined in existing literature as the "visual representation of a referent to its symbol" (Lloyd and Fuller, 1990, p.295).

According to the iconicity hypothesis symbols are easier to be learned and remembered if they highly resemble the referent (Fuller and Stratton, 1991, Bloomberg et al., 1990). However, Schlosser & Sigafoos (2002) highlight that most of the studies conducted which explore the iconicity hypothesis focus on symbols representing nouns and not on verbs or modifiers.

Some of the participants also referred to the iconicity of symbols representing various word classes, for example, interviewee E mentioned: "… and from

what I have read it didn't matter too much what symbol you select for nouns and verbs but it became a more symbol thing for abstract vocabulary". (Pampoulou 2005, p. 61)

Semiotic theory suggests that iconicity is relevant to the user's language skills, specifically relating to the semantic concepts within the user's linguistic repertoires (Sevcik et al., 1991). The acquisition and retention of a symbol only occurs when the person is familiar with the underlying semantic concept. Semiotics and psycholinguistic theory seem to suggest that iconicity is bound to experience, culture and time and is actually in the eyes of the beholder (Schlosser and Sigafoos, 2002).

User skills

Some of the participants in this study mentioned the diversity of users' skills and needs and suggested that these are significant determining factors when considering which symbol sets to use and these may be related to the symbol characteristics.

Colour

For instance, participants mentioned colour as one of the factors that they take into consideration in relation to the user's characteristics.

Choosing to use symbol sets that are in colour or black and white was often related to users' skills and needs. Interviewee E stated: "…for some students…colour is confusing… So we will start with black and white if they have autism. If they didn't have autism we tend to use colour PCS symbols." (Pampoulou, 2005, extract from interviews)

For the participants in this study, colour appeared to be a factor relating to their symbol choices, particularly when working with children with autism. Interviewee B reported that she uses black and white symbols when working with pupils with autism, otherwise she would use colour symbols.

Barrow et al. (2000) conducted a study exploring the "effect of colour on developmental picture-vocabulary naming of 4-, 6-, and 8- year-old children". A selection of line-drawings representing picture-vocabulary items were shown to 30 'normally developing' children. The investigators concluded that the "introduction of new concepts may be more readily understood and accepted if presented in colour" (Barrow et al., 2000. p.317).

These findings suggest that colour supports children to recognize line-drawings when the vocabulary level introduced exceeds their chronological age level.

Consistency

Consistency was also widely discussed in the interviews. Data collected in the pilot study indicated that symbol policies usually involve the use of only one symbol set across the school or local area for various reasons. Consistency was believed by some to be important for school staff, so that "they don't have too many things going on" (Pampoulou, 2005, p.66).

Moreover, participant E mentioned that she tends to use one symbol set for her "own convenience…because it is easier to produce symbols and also to manipulate things like colour" (Pampoulou, 2005, extract from interviews). Participants A and D mentioned that consistency is also important for the students, as they move from one setting to another, from nursery to primary and then from secondary to college.

Although some SLTs may use one symbol set across the school, region or borough due to symbol policies that had been decided in the past, evidence is lacking as to the origin of these policies. There is little existing literature exploring the importance of consistency when using symbols.

CONCLUSIONS

Despite the evidence from this pilot study that symbol practices relating to selection of symbols vary from school to school, or even from one therapist to another, the literature lacks evidence to support professionals deciding which symbols to use.

Participants in this study mentioned factors related to users and the symbols

used, as well as to external factors such as symbol policies and available resources. Further research is needed in order to investigate in depth the symbol practices regarding choosing the optimum symbol set for users.

PART 2 (LOUISE GREENSTOCK)

RESEARCH TOPIC AND METHODOLOGY

This research was carried out by Louise Greenstock, Speech and Language Therapy Division, De Montfort University. The primary objective was to explore the experiences of using symbols of three groups of practitioners working with children in Foundation Stage (3-5 year olds) school settings in the East Midlands. A sample of 53 practitioners were recruited (n=9 pilot study, n=44 main study).

Participants in the main study were recruited from the following three professional groups, teachers n=13, teaching assistants/nursery nurses (referred to as Early Years Practitioners; Letts and Hall, 2003) n=18 and SLTs n=13. Participants were recruited through employing organisations and the appropriate ethical applications were adhered to.

Semi-structured interviews were carried out by the researcher who led the interviews by following a framework of questions. Interviews were digitally recorded and transcribed. The data was then analysed using a form of thematic analysis.

FINDINGS

The findings indicated that the practitioners interviewed followed a subjective process of reasoning when they considered using symbols in school settings. The factors they considered led them to make decisions about: which children to use symbols with; the child's needs and developmental capabilities; how symbols could be used; and how the strategy could be implemented. Four themes were identified:

1. Practitioners' beliefs about which children to use symbols with

In general, the practitioners were divided in their opinions about whether symbols should be used with just specific children or with all children. This reflected a tension in the data and both sides of this debate were represented by practitioners in each of the three professional groups. Many practitioners expressed the belief that symbols should only be used with children with a specific 'need' for them and these needs were often related to their diffi-

culties in certain areas of learning and communication. In contrast, a number of practitioners discussed the value of using symbols with a wider range of children and argued that they could potentially benefit all children.

The reasons given for using symbols with all children varied among the professional groups. Educational practitioners tended to suggest this approach because they felt that symbols could support all children in the setting. In contrast, SLTs often suggested using symbols with all children as a way of ensuring communication opportunities and making available communication partners to facilitate participation of individual children using symbols. These differences between the professional groups reflected some over-arching differences in professional background and roles.

2. Practitioners' thoughts about children's understanding of symbols and representation

Practitioners' accounts of using symbols were frequently related to their perceptions of children's understanding of representation and their ability to understand the referential nature of symbols. This aspect of cognitive understanding was seen as a developmental process. Many practitioners referred to children's development in understanding representation and gave accounts of assessing their development in this area and differentiating their use of symbols accordingly. Many practitioners suggested that the development of children's symbolic ability occurred in stages, reflected in their appropriate use of symbols and other representational items.

Children's understanding of symbols was often related to the modality of various forms of representation. Practitioners referred to objects of reference, photographs and symbols as possible modes used to represent ideas and information to children.

Many times in the data, practitioners referred to the use of 'multi-modal' or 'multi-channel' approaches to representing information. Using more than one mode (for example, text and symbols), and/or more than one channel (for example, auditory and visual), was believed to increase the accessibility of the message to a range of children.

3. Practitioners' accounts of the ways symbols are used

Practitioners appeared to have some firm ideas about how symbols should

be used, incorporating: developmental differentiation; how to produce and introduce symbols; the consistency of symbol use; and specific purposes for symbols use. Relating to their beliefs about children's developmental understanding of symbols, many practitioners gave accounts of the ways in which they would differentiate activities so that they were 'developmentally appropriate'. These practitioners frequently referred to the need to assess children's level of symbolic development before making decisions about which mode of representation to use.

Most of the practitioners were in agreement that objects of reference would be most suitable for use with children at an earlier stage of development. Symbols and text were considered to be more advanced. The hierarchy of modes of representation was referred to by practitioners in each of the three professional groups and there was agreement about the need to differentiate for different developmental abilities.

Many practitioners expressed clear views about the need to produce and introduce symbols in certain ways to children in this age group. The production of symbols was usually supported by software and practitioners were in agreement that they should be introduced to children in small numbers. It was suggested that introducing symbols in large quantities would 'overwhelm' children.

There was some level of agreement about the need to use symbols consistently. Practitioners appeared to believe that symbols used throughout the school environment should be visually similar. This was seen to support children at times of transition by providing something 'familiar' in other environments. In contrast, some practitioners argued that individualised strategies were more important when symbols were being used to enable individual children to communicate and participate.

Practitioners gave accounts of using symbols for a number of specific purposes. The most frequent of these were visual timetables, choices and exchange systems, developing literacy skills and representing rules and expectations of behaviour.

The most dominant way of using symbols across all three professional groups was as part of symbol-supported visual timetables. Visual timetables were used to represent sections of time and activities within the session and symbols were displayed in a vertical or horizon-

tal line. This was seen as a tool to support children experiencing anxiety about separating from caregivers and to support children with difficulties in attention and staying on task.

4. Practitioners' experiences of implementing symbols in schools

Most of the practitioners interviewed gave accounts of their experiences of the actual implementation of the use of symbols in schools. The implementation process appeared to be influenced by contextual factors relating to ways of working in the school setting. Some practitioners highlighted that SLTs were 'visitors' in the school and this appeared to affect the amount of influence they felt they had. A number of SLTs expressed frustrations at the way symbols were implemented in schools - mainly related to symbols not being used 'enough'.

Practitioners' accounts of their use of symbols in schools appeared to suggest that in some settings there were specific roles associated with each professional group. SLTs were frequently seen as 'experts' and expected to deliver training and support in the ongoing implementation of symbols. EYPs were frequently seen as responsible for carrying out the strategy or programme suggested by the SLT and for maintaining resources.

The role of the teacher was the most ambiguous in the data and it was not clear if teachers had any consistent role in this area of practice. These findings reflected a number of tensions in the data relating to discrepancies in interpretations of the roles of various practitioners. In some cases there appeared to be resistance and conflict between practitioners and their colleagues.

Practitioners' accounts of their experiences of using symbols were frequently related to working with other professionals. The most dominant factors influencing collaborative working were: time and availability; communication; and perceptions of professional roles. Many practitioners commented on the lack of time available to discuss the use of symbols with colleagues, and many highlighted the difficulty of 'releasing' educational practitioners from duties to talk face to face.

Communication and interpersonal skills were frequently mentioned as a factor in the success of collaborative working and SLTs in particular referred to the need for 'diplomacy'.

CONCLUSION

Both of these research studies develop our understanding of the factors considered by practitioners when thinking about using symbols.

Eliada Pampoulou's research demonstrates that SLTs consider characteristics of the symbol-user and the symbols themselves when deciding how and when to use symbols.

Louise Greenstock's findings reflect the complex reality of using symbols in school settings. These findings suggest that practitioners are guided both by their individual subjective reasoning, and by their interaction with other practitioners. Each of the practitioners in the network has perceptions of their own professional roles and those of others (Greenstock, 2009a).

In order to learn to allow practitioners to share their experiences and to learn from good practice, more research in this area is essential. As the number and range of children accessing symbols increases, further scrutiny must be given to the ways symbols are used and decision-making of the professionals involved. ✳

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REFERENCES

Abbott, C. & Lucey, H. (2005) Symbol communication in special schools in England: the current position and some key issues, *British Journal of Special Education*, 32 (4), 196-201.

Barrow, I. M., Holbert, D. & Rastatter, M. P. (2000) Effect of Color on Developmental Picture-Vocabulary Naming of 4-, 6-, and 8-Year-Old Children. *Am J Speech Lang Pathol*, 9, 310-318.

Bloomberg, K., Karlan, G. R. & Lloyd, L. L. (1990) The Comparative Translucency of Initial Lexical Items Represented in Five Graphic Symbol Systems and Sets. *J Speech Hear Res*, 33, 717-725.

Fuller, D. & Stratton, M. (1991) Representativeness versus translucency: different theoretical backgrounds, but are they really different concepts? A position paper. *Augmentative and Alternative Communication*, 7, 51-58.

Greenstock, L. (2009) *'Using graphic symbols': An investigation into the experiences and attitudes of a range of practitioners using graphic symbols with children in the Foundation Stage (three to five year olds) school settings*, De Montfort University [Unpublished PhD thesis].

Lloyd, L. L. & Fuller, D. R. (1990) The role of iconicity in augmentative and alternative communication symbol learning. IN FRASER, W. (Ed.) *Key issues in mental retardation research* (pp. 295-306) London: Routledge.

Pampoulou, E. (2005) *Graphic Symbol Set Selection Considerations by Speech and Language Therapists: a pilot study*. London, King's College London [Unpublished thesis].

Schlosser, R. W. & Sigafoos, J. (2002) Selecting graphic symbols for an initial request lexicon: integrative review. *Augmentative and Alternative Communication*, 18, 102 - 123.

Sevcik, R. A., Romski, M. A. & Wilkinson, K. M. (1991) Roles of graphic symbols in the language acquisition process for persons with severe cognitive disabilities. *Augmentative and Alternative Communication*, 7, 161 - 170.

An introduction to the D4D AAC project

What Do Users Really Want From Communication Aids?

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BACKGROUND

In the past 10 to 15 years, rapid developments in technology have resulted in a tremendous expansion in the range and number of VOCAs available commercially, even though the number of specialist VOCA manufacturers and suppliers remains small. However, despite the increase in device availability and choice, factors influencing the successful use of these devices are relatively under-researched.

A number of surveys in recent years have considered issues of VOCA supply and provision. These surveys have highlighted inequalities in funding, training and support for users (or potential users) of communication aids which lead to disillusionment and disempowerment. Furthermore, the surveys identify that issues of device design and performance, and the lack of consideration of users' opinions when selecting devices, add to the likelihood of abandonment of the device by the user.

Other authors have also highlighted the complexity and poor usability of some communication aids and, indeed, some have argued that simplicity of design is key to reducing abandonment in (electronic) assistive technology including AAC devices. However, there seems to be little research on the real user requirements for AAC devices.

Inclusive Design and User-Centred Design (UCD) are now well established design principles. Yet, there does not appear to have been significant application of UCD and user-involvement to the design of VOCAs.

This paper describes an AAC research project, led jointly by Gill Townend and Simon Judge, which is funded through the 'Devices for Dignity'[1] (D4D) programme and explores users', carers' and professionals' perceptions of communication aid design. It aims to identify areas for improvement, future research and development in the design of communication aids.

RESEARCH OVERVIEW

Primary Research Objectives

An exploratory study:

- To identify what users of Voice Output Communication Aids (VOCAs) want from their devices.

- To establish which factors contribute to the perceived success and dignity of use of these devices.

Additional Research Objectives

- To support the development of a best practice guide for VOCA provision.

- To establish areas of need for future research, based on views expressed by users.

- To provide insights into the current population of VOCA users to support development of theory, practice and service provision.

The project was designed in two parts: the first stage involving face-to-face interviews with communication aid users in South Yorkshire and neighbouring areas, and the second stage consisting of a questionnaire for users, carers and professionals working with AAC which was advertised and distributed nationally[2].

INTERVIEWS - INTERVIEW FORMAT

The structure of the Stage One interviews was focused around the use of a topic guide. This was developed following a review of existing frameworks for Assistive Technology, including the Matching Person and Technology (MPT) model (Scherer 2005); the Human Activity Assistive Technology (HAAT) model (Cook 2002), a study looking at AT usability (Arthanat 2007), and on preliminary work by one of the researchers (Townend 2007).

In addition to the topic guide, a pre-interview guide and interview prompt sheets were produced in both text and symbolised formats. At the start of each interview a broad opening question was asked, for example, "what do you think of current communication aids and their design?" This was followed by the use of the topic guide and/or prompt sheets to facilitate discussion with participants who would, by the nature of their inclusion in the project, have speech, language or communication difficulties.

The guide was split across a number of domains of design consideration, encompassing the areas of 'context', 'individual', 'activity' and 'technology' which were highlighted in the existing assistive technology frameworks. For example, the prompt sheet headings were: about myself; communication environments and situations; reasons for communicating; topics; physical environment; ease of use; build quality; speech; access and control; performance; language system; options/additional functions; cost, security and safety; training and support; and, ideas for the future (see Figure 1). In addition there was a prompt sheet of words describing levels of 'importance' and also one of more general 'descriptive words'.

INTERVIEWS - PARTICIPANTS

As the interviews aimed to investigate the users' and carers' experiences, and their perceptions of their use of voice output communication aids, participant inclusion criteria were necessary. Participants were to be:

- Able to engage in an interview.
- Express opinions about their use of a communication aid.
- Currently using a medium- or high-tech VOCA.
- Able to produce more than 20 utterances (ideally, able to produce novel utterances).
- Secondary school age and above.

Participants for interview were recruited through local AAC specialists and interviewed by one or other of the two researchers.

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2. Ethical approval for both stages of the project was granted by South Yorkshire Research Ethics Committee. The project was a test case for the change in powers of individual RECs, enabling SYREC to grant approval as 'site-specific exempt'. This allowed for interviews outside of South Yorkshire, and for the questionnaire to go out nationally to NHS sites without needing ethical approval from each local REC. Clinical governance approval was obtained for the interviews from the four local area NHS Research and Development groups involved.
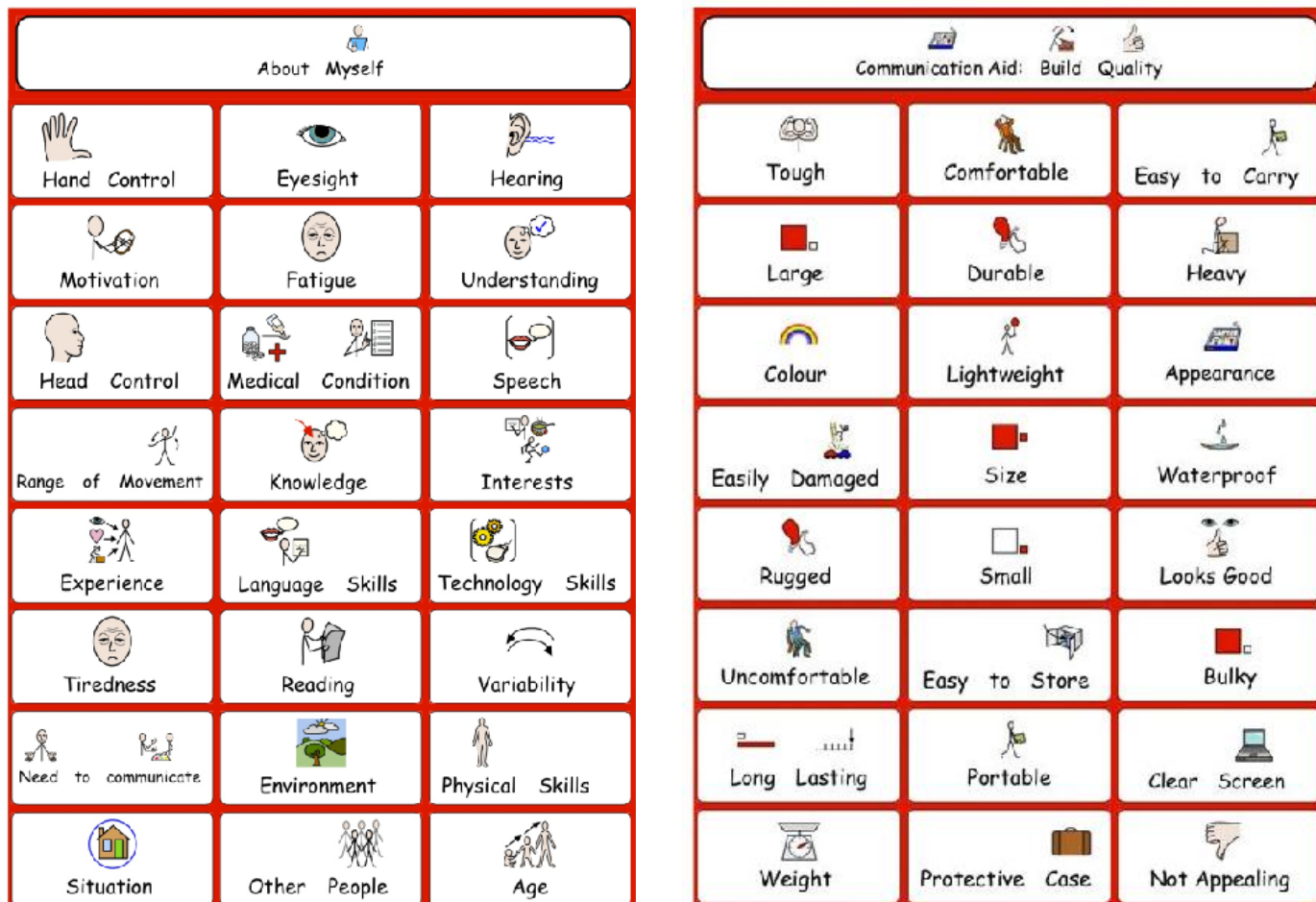

Figure 1 Examples of symbolised interview prompt sheets

In total 18 participants were interviewed, in a range of settings which included their own homes, day centres and schools/colleges. Ages ranged from 12 to 70 years, whilst medical conditions included cerebral palsy, CVA, and a number of progressive neurological disorders.

Communication included a range of high-tech VOCAs and other AAC methods, and often the participant's preferred means was not to use their VOCA. In some cases advocates and carers were indirectly involved in the interviews by assisting the participants to express their views and contributing to the areas of conversation which were relevant to them.

QUESTIONNAIRE - QUESTIONNAIRE DESIGN AND PUBLICITY

The second stage of the study, the national questionnaire, was developed around the same framework as the interviews, but influenced by the responses of the Stage One participants. Issues of accessibility, format, length and complexity were also taken into consideration in the questionnaire design.

Two versions of the questionnaire were prepared: one for users & carers, and one for AAC professionals. Each was then offered in a number of paper and electronic formats to promote as wide an uptake as possible: paper - standard text, large text, symbolised[3] (WLS and PCS); electronic – online (standard text) or downloadable (standard text, symbolised). The online version was created using Lime Query, an open source survey package (see Figure 2).

The questionnaire was available from July to October 2009. It was advertised through the CM journal and website, the Royal College of Speech and Language Therapists' Bulletin, the Speech and Language Therapy in Practice journal and website, and through mailshots to AAC centres and professionals across the UK, and support organisations and charities whose membership included potential participants (e.g. SCOPE, MNDA). Paper copies of questionnaires could be requested from the D4D research office; these were posted with a self-addressed envelope to encourage their return. The online version could be accessed through the D4D website.

QUESTIONNAIRES - PARTICIPANTS

This stage of the project was intended to capture opinion from a wider group of participants than Stage One, so the criteria were broader. We sought participants who:

Figure 2   Example of questionnaire pages (text version)

- Have an opinion about communication aids.

- Are able to answer a questionnaire with or without support from a carer.

- Clients who currently use any form of aided communication (high- or low-tech), or have done so in the past.

- Clients of any age, medical diagnosis, language level, and physical ability.

- Carers of clients who use or have used aided communication.

- Professionals with experience of working with clients who use aided communication.

Both positive and negative views and experiences were welcomed.

In total, 43 questionnaires were returned by users (paper 28, online 15) and 68 by professionals (paper 33, online 35).

ANALYSIS

Qualitative analysis was carried out on the interview data, based on a template analysis methodology, using NVivo 8 as the analysis tool. This provided a framework of themes around the use of VOCAs. Analysis was carried out by both researchers.

The questionnaire data was collected from the paper-copy returns and the online software, and collated into a statistics package.

The results of the qualitative interview analysis and analysis of the questionnaire data will be reported elsewhere.

DISCUSSION - DEVELOPMENT OF A DECISION-MAKING TOOL

During the project the researchers became aware of a deficit in the tools available for use in the AAC decision-making process. There are no tools which currently facilitate the user to consider in detail all the features of an AAC device.

It is proposed that the use of an effective tool in this process could save time and resources by reducing trial periods and abandonment of devices, and lead to more appropriate and functional provision.

The AAC decision-making process can be represented as shown in Figure 3 overleaf.

A number of the interviews in Stage One relied heavily on the use of the prompt sheets in order to facilitate discussion. This demonstrated their ability to elicit information about communication aid design from users. Qualitative analysis of the interview data has highlighted the issues of particular importance on the prompt sheets. Analysis of the questionnaire data has also identified the features of importance to users and professionals, allowing for links between features to be investigated.

It is proposed that the prompt sheets used in the interviews, along with the questionnaire, could form the basis of a new decision-making tool, with a degree of validation provided already through their use and adaptation in this project (see Figure 4 overleaf).

It is envisaged that the tool could be used in a number of ways:

- Used independently by (potential) AAC users to help with their decision making.

- Used collaboratively by a (potential) AAC user and professional to promote discussion around the details of device design.

- Used by professionals to help with device selection – i.e. mapping desired features to potential devices.

The tool could be used as part of the consideration, trials, selection, provision and review processes. It could be provided either as a booklet designed to be used in a partnership (with pointing or partner assisted scanning), or as a questionnaire designed for independent use.

It is the intention of the researchers to develop this tool further, and to apply for funding to further validate and test its effectiveness within the AAC decision-making process.

SUMMARY

A two-part research project (interviews and questionnaire) was carried out around the topic of AAC device design. One aim was to contribute to the development of a good-practice model when working with AAC.

As part of the project, a topic guide and prompt sheets were created (in a number of formats) and used in the interviews, and a questionnaire developed and circulated nationally.

It is proposed that the topic-guide, prompt sheets and questionnaire form the basis for a decision-making tool to aid AAC device selection by users and/ or professionals.

The findings relating to users' perceptions of communication aid design will be published at a later date. ✳

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Senior Clinical Scientist

REFERENCES

S. Arthanat, S. M. Bauer, J. A. Lenker, S. M. Nochajski, and Y. W. Wu (2007) "Conceptualization and measurement of assistive technology usability." *Disability and Rehabilitation: Assistive Technology*, Vol. 2, No. 4, pp. 235-248.

A.M. Cook and S.M. Hussey (2002) "Assistive technologies principles and practice." (2nd ed.) St. Louis, Mosby.

M. J. Scherer and G. Craddock (2002) "Matching person & technology (mpt) assessment process." *Technology and Disability*, Vol. 14, No. 3, pp. 125-131.
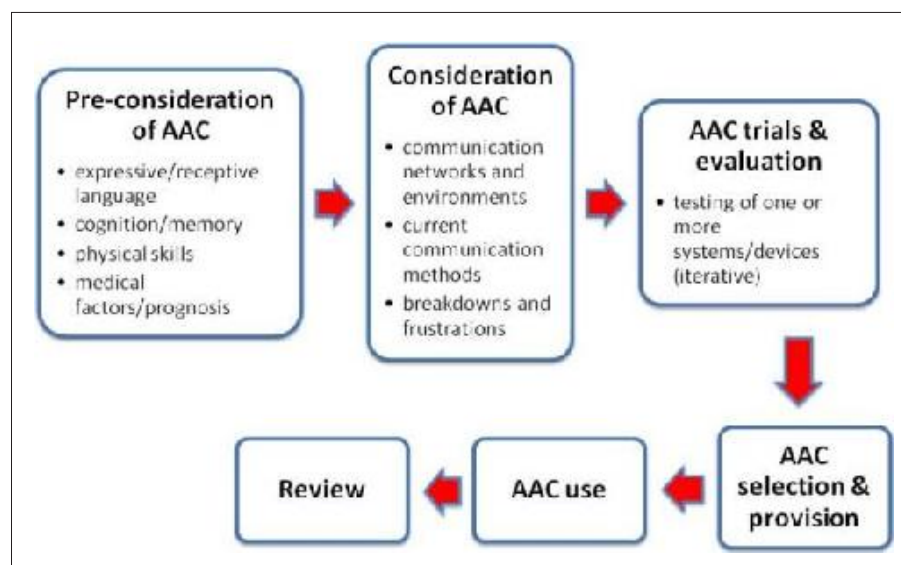
G. Townend (2007) "I want *this* one! Is it possible to formalize the decision-making process when comparing communication aids on trial loan?" *Communication Matters*, Vol. 21, No. 1.

To request a more extensive reference list, please contact Gill Townend at *gill.townend@nhs.net*

WEBSITES

D4D: *www.devicesfordignity.org.uk*

Speech Bubble: *www.ace-centre.org.uk/ index.cfm?pageid=6B18152B-3048-7290-FE99D2573C6EAC3E*

ACKNOWLEDGEMENTS

Figure 3 AAC / Aided Communication decision-making process
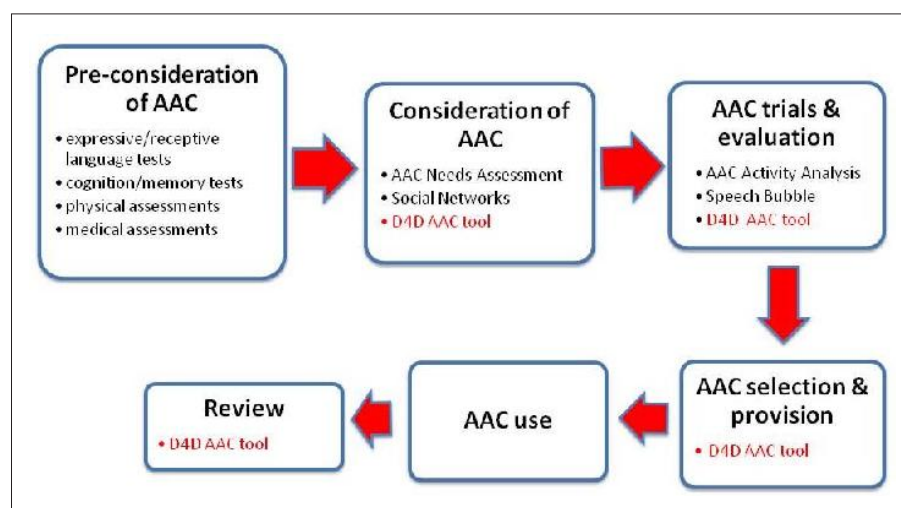
Figure 4 Use of proposed D4D AAC Decision-Making Tool

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ESSENTIAL PUBLICATIONS
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The Power of Communication (DVD)

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

Price: £8 each (£20 for three) including p&p
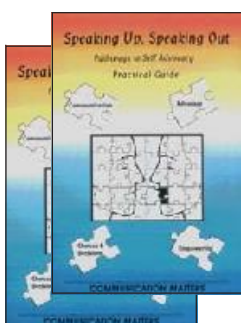
### Speaking Up and Speaking Out! Pathways to Self-Advocacy

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

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

Michelle Finds a Voice

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

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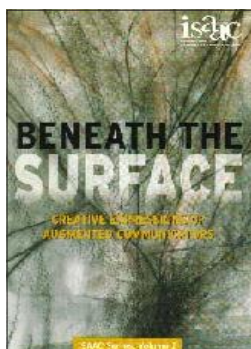
Beneath the Surface

In August 2000, the creative works of 51 authors and artists from around the world were published 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**
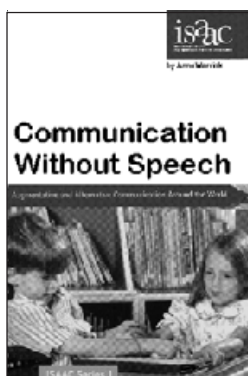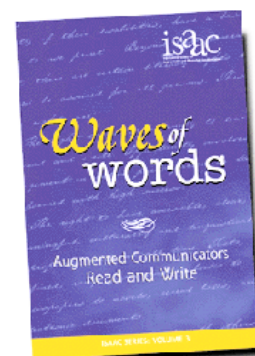
Communication Without Speech

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**

Smartbox

PowerBox 7

New wheelchair mounted communication aid.

The PowerBox 7 has a protective cover, extra loud speakers, universal wheelchair mounting point, environment control, switch access and 8 hour battery life.

We supply the PowerBox with The Grid 2, providing symbol and text communication and control of other Windows applications.

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- Windows 7 PC with Core Duo processsor
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- Loud, clear speakers
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- Integrated stand

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- USB Model
- Z-Wave environment control
- Keyguard

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The **Logan ProxTalker,** developed by a dad for his autistic son, is an easy to use mid-tech device which adds a new dimension to picture communication. Now Logan uses his ProxTalker to 'talk' to new people and to phone to home.

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- 5 location buttons allow language to develop from single word to simple phrases

- unique Programming Tags and inbuilt microphone enable easy management of sound tags

- 2 – 8 seconds of sounds per tag sound tags can be labeled with wide range of symbols, photos, text or objects of reference

- stores up to 10,000 words easily adjustable volume

- robust, water resistant design survives even the heaviest use

- portable in a backpack or binder

- 6 month battery life

MegaBee

The MegaBee is an assisted communication tablet. Easy to use, low tech, eye pointing device for people who have no speech and are unable to have direct or switch access to other AAC devices.

- Portable and easy to use for both speaker and listener
- Dual screens accommodate 20 characters in 2 lines
- 260 easy to access abbreviation possibilities
- Bluetooth pc connectivity for large, remote display and text storage/printing options
- Ideal secondary aid for any eye gaze user

FAB

A range of key guarded alphabet boards, developed with Frenchay Hospital, which can be used anywhere, even in the bath! Used to support clients across the hospital or as a secondary aid to high tech devices.

- qwerty or matrix layout
- Pocket or tabletop sizes
- Built in E.Coli and MRSA resistance
- Non-slip anti-bacterial rubber base
- Washable

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