IN THIS ISSUE
AAC and Self Identity
Acting, Attitudes and AAC
Bowls, Banter, Bocchia and Social Events
BT ChildLine Awards
Celebrating 21 Years of Communication Matters
Developing and Using Signing
ISAAC 2006 Conference
Nice Warm Socks
1Voice National Network Day
Tacpac™

IN THIS ISSUE
The Semantic Organisation Patterns of Adults with Learning Disabilities
What Evidence do We Have for Best Practice?
Typical and aided models of language development
What is the Impact of Access to High-Tech Communication Aids on Children with Autism?

REGULAR COLUMNS
Diary Dates
News Update
Trustees’ News
CONTENTS

2 The Semantic Organisation Patterns of Adults with Learning Disabilities: Implications for People who use AAC
Catriona Bennie

7 Nice Warm Socks – Songs for everyone to sing
Shan Graebe

9 AAC and Self Identity
Meredith Allan

13 Communicating Together at ISAAC 2006
Alan McGregor

15 Making Friends at ISAAC 2006
Beth Moulam

16 Bowls, Banter, Bocchia and Social Events for Everyone
Claire Forster & Helen Dixon

18 BT ChildLine Awards
Toby Hewson & Beth Moulam

25 Celebrating 21 Years of Communication Matters
Janet Scott

27 Acting, Attitudes and AAC
Alan Martin

31 A Grand Day Out – 1Voice National Network Day
Katie Clarke

32 Tacpac™

33 What Evidence do We Have for Best Practice? Thoughts from typical and aided models of language development
Janice Murray & Juliet Goldbart

37 Developing and Using Signing
Ann Miles & Rachel Key

39 What is the Impact of Access to High-Tech Communication Aids on Children with Autism?
Rebecca Checkley & Ali Gaskin

REGULAR COLUMNS

21 Trustees’ News

22 eCAT News

23 News Update

24 Diary Dates

PUBLICATION REVIEW

44 Using Information Technology to Empower People with Communication Difficulties
The Semantic Organisation Patterns of Adults with Learning Disabilities: Implications for People who use AAC

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INTRODUCTION
Clinical observations of a group of high-tech Augmentative and Alternative Communication (AAC) aid users suggested that less cognitively able clients were struggling to locate messages on communication aids.

People with significant learning disabilities particularly appeared to be having difficulty navigating semantically organised dynamic systems.

An honours project was undertaken to look into semantic organisation in adults with learning disabilities.

SEMANTIC ORGANISATION
Semantic Organisation describes the way in which individuals mentally store vocabulary by meaning associations.

Current literature suggests there are two ways that concepts can be organised; schematically or taxonomically (Bauer and Mandler 1989; Rosch, Mervis, Gray, Johnson and Boyes-Braem, 1976). For example, given a list of words a child may put these words together: Ball, Slide, Trees, Grass, Wellingtons, Coats.

The child’s explanation for putting these words together may be, e.g. “They are all part of going to the play park”. This would be described as a schematic organisation as the words are organised in relation to how they occur in one schema or event together.

In contrast, when given these words adults are more likely to group the words taxonomically with hierarchical headings:

- Vegetation: Trees and Grass
- Children’s toys: Ball and Slide
- Clothes: Wellingtons and Coats

Schematic organisation patterns are highly individual relating to events that occur in an individual’s daily life. Taxonomic organisation is more universal however still influenced by the individual’s beliefs and experience.

THE DEVELOPMENT OF SEMANTIC ORGANISATION
Studies have identified a developmental shift from a schematic vocabulary organisation pattern to a taxonomic pattern of vocabulary organisation between the ages of 6 and 7. It is also understood that this developmental process is influenced by conversations with adults and formal teaching in relation to the child’s own language abilities (Lucariello, 1998; Lucariello & Nelson, 1985; Nelson, 1996; Snow, 1990).

Fallon, Light and Achenbach, (2003) conducted a study in which twenty 4 and 5 year olds were asked to place 42 line drawings together in a way they thought they best fitted together. The 42 line drawings represented 42 different concepts including nouns, verbs, adjectives, pronouns, prepositions, questions and one interjection. Half of the concepts were said to be abstract and the other half were concrete.

After placing the line drawings together the children were asked to describe why they had put the drawings together in the groups they had made.

Vocabulary placements were determined meaningfully placed if the child explained why the line drawing was placed there in relation to the other line drawings in that group.

The research found that of the total number of line drawings placed meaningfully 93% of vocabulary concepts were organised according to schematic organisation.

Only 7% of items were arranged according to a taxonomic structure.

This result supports other studies reporting that children’s use of a taxonomic organisational system begins to emerge in the early school years.

SEMANTIC ORGANISATION AND ADULTS WITH LEARNING DISABILITIES
Not much is known about the semantic organisation patterns of adults with learning disabilities. Studies focusing on the semantic organisation of learning disabled children found them to be following a delayed but normal developmental sequence (Winters and Brzoska, 1976).
SEMANTIC ORGANISATION FOR PEOPLE WHO USE AAC

“The way vocabulary is coded into an AAC aid is often determined by what seems logical to the Speech and Language Therapist working with the client.” (Blackstone, 1993)

If an adult with a learning disability is using a communication aid set up taxonomically (hierarchically) by another person the adult with the learning disability may find it difficult to learn where the symbols are located as the method of organisation is not the most natural one to them. This may affect the adult’s ease of communication and confidence in using the VOCA.

AIMS AND HYPOTHESIS

• This study aimed to investigate to what extent the semantic organisation of the adults with and without learning disabilities differs.
• To discuss the implications of delayed semantic organisation for adults with learning disabilities who are learning to use AAC?
• To suggest alternative ways of organising vocabulary on a communication aid for an adult with learning disabilities taking into account their abilities, knowledge and future development?

The hypotheses of the project were that:
1. Adults without learning disabilities will organise vocabulary in a mainly taxonomic way, and use schematic organisation for highly familiar groups of words.
2. The semantic organisation patterns of adults with learning disabilities are comparable to those of normally developing children.

PARTICIPANTS AND METHOD

Four adults with learning disabilities took part in the study. All the participants were speaking and had no previous experience of using communication aids. All had mild learning disabilities and three had a diagnosis of ASD. Ten adults without learning disabilities took part in the study. All were English speaking and had been to mainstream schools.

The method developed by Fallon, Light and Achenbach, 2003 was used in this study. Line drawings of 42 vocabulary items were used and each participant was asked to group these vocabulary items together and later give an explanation of why they had grouped these concepts. The rationales that each participant gave for their vocabulary groupings were analysed using a coding scheme developed by Fallon, Light and Achenbach (2003).

ANALYSIS OF RESULTS

The resulting information was further analysed to identify each participant:

• Evidence of Organisational Structure – Identifying for each participant how many of the concepts were meaningfully placed.
• Type of Organisation Used – To find out if the participant used taxonomic or schematic organisation in their grouping of concepts. This was done by analysing the rationales with the help of the coding scheme.
• And the percentage of each participant’s abstract and concrete concepts placed meaningfully.
• Using the coding scheme developed by Fallon, Light and Achenbach, 2003 groupings were labelled Taxonomic, Schematic: highly familiar, and Schematic: novel. Here are some examples of grouping and rationales given by some of the participants and the coding these were given using the coding scheme. Participants NLD7 and NLD5 do not have a Learning Disability. Participant ALD1 has a Learning Disability and ASD.

Participant NLD7

Vocabulary grouped – read, work, talk, run, cry, drink, make, eat, going to
Rationale – “They are all verbs.”
Coding – Taxonomic

Participant NLD5

Vocabulary grouped – coffee, kitchen, hungry, eat, drink, cake, pizza, cup, finish, yummy
Rationale – “These words are all connected with eating.”
Coding – Schematic: highly familiar

Participant ALD1

Vocabulary grouped – father, in, kitchen, more, cake, yummy
Rationale – “Dad is in the kitchen with more cake, he thinks it’s yummy.”
Coding – Schematic: novel

It can be seen that NLD7’s rational explains that the vocabulary was grouped together using taxonomic organisation because to that participant the words are connected by the fact they all come under the hierarchical heading of verbs. NLD5 grouped words together that were connected by the fact that they are regularly used in one scene or schema. Adults with quite developed semantic organisation skills can choose which organisation they prefer to use. Fallon, Light and Achenbach, (2003) describe Schematic: highly familiar as a vocabulary grouping where ‘The explanation involves a conventional or predictable schema/script that suggests an event based origin’ (Fallon, Light and Achenbach, 2003).

The rational given by ALD1 for the grouping of the words Father, in, Kitchen, more, cake, yummy relates to a very individual event or one that has been made up for the purpose of fitting the words together and so is coded as schematic: novel. Fallon, Light and Achenbach, (2003) describe schematic: novel as a vocabulary grouping where ‘The rationale for placement involves an event based schema, however the script is unique or novel, not predictable’.

RESULTS

The graph (Figure 1) shows the type of organisation used by each participant as well as the percentage of concepts placed meaningfully.

Participants ALD1-ALD4 are the participants with learning disabilities and participants NLD1-NLD10 show the results of the participants without learning disabilities. None of the participants without learning disabilities used a schematic: novel organisation to group concepts. The participants without learning disabilities also used more taxonomic organisation than schematic: highly familiar. Of the participants with learning disabilities only one used some taxonomic organisation. Interestingly participant ALD4 spent her primary school years in a Language Unit receiving inten-
Sara and her Mum have always found a way to communicate. Like most college students, Sara rarely runs out of things to say to her Mum – and we’re very glad that she can. The same technology that Sara uses can help a wide range of individuals who are unable to speak on their own. To learn more call us at 01384-446789, or visit us online at dynavox.co.uk.

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sive speech therapy. This relates to the fact that semantic organisation is a developmental process influenced by formal teaching. It is also interesting that NLD7 is by profession a computer programmer who uses hierarchical planning and organisation regularly in day to day life.

IMPLICATIONS FOR LAYOUT
The event based schemas produced by the learning disabled participants were all very individual and varied from participant to participant. This highlights the fact that wherever possible the client who is to use an AAC aid should be involved in where and how vocabulary is stored, as vocabulary has different meaning and importance to each individual. The learning disabled participants made extensive use of event based schemas in their arrangement of the vocabulary. Organising vocabulary according to familiar and recurring events could promote greater access and learning of their aid, in turn facilitating effective communication.

IMPLICATIONS FOR INSTRUCTION
It is likely that people who use AAC to communicate will have learnt their own communication aid layout to some extent and will then have developed some areas of semantic organisation through experience with their aid.

It is also possible however that some learning disabled users of AAC may still find the layout of their aid confusing and this may affect how well and how often they use it. It would therefore be beneficial to teach organisation skills when introducing a new communication aid to a learning disabled adult. Taxonomic organisation may be difficult for adult with learning disabilities to learn after years of organising vocabulary in another way. This highlights the fact that children learning to use AAC should be helped in their development of semantic organisation in order to help them develop these skills.

One method of dynamic AAC layout has been suggested by DynaVox Systems Ltd (2003) considering the semantic organisation development of young children through the placement of vocabulary on a dynamic AAC aid. It suggests that a page could be made up according to an event based schema such as ‘Eating’. Vocabulary depicting food items could be placed on one side of the page with vocabulary depicting related words such as ‘yummy’ and ‘plate’ on the other side. The food items could be labelled as food in order to promote the development of categorisation skills. The words related to Eating schema would still be easily accessible, promoting smooth communication and the development of categorisation (DynaVox Systems Ltd, 2003).

IMPLICATIONS FOR DESIGN
As has been suggested in Light et al (2004), current aided AAC systems need to be redesigned in order to meet the needs of those who require AAC to reduce the cognitive load of learning the system. One new option for design includes embedding vocabulary into a scene on the communication aid (Light et al 2004). Vocabulary can be stored within the scene so that when a part of the scene is pressed this vocabulary would be available to the person who uses AAC. This type of layout would put vocabulary within a context supporting users to learn vocabulary. It reflects the way people learn to organise vocabulary semantically, first in relation to schemes and then in relation to items taxonomically. It is likely that this; ‘the integrated contextual scene layout’ may also benefit adults with learning disabilities, as it was found that some adults with learning disabilities link vocabulary together in relation to different schemas. * Catriona Bennie Speech & Language Therapy Student

ACKNOWLEDGMENTS
Hons project supervisor: Dr Jim Scobie
Advisor: Alison MacDonald

REFERENCES

INCA TREK CHALLENGE 2007
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Catriona Bennie
Speech & Language Therapy Student

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Nice Warm Socks

Songs for everyone to sing

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This strange title, ‘Nice Warm Socks’ is one of the songs to be found on a new CD of songs that have been specially chosen, adapted and arranged for all children, including those who use AAC for communication, to join in and enjoy. It is the result of collaboration between a Speech and Language Therapist, a Professional Musician and a Music Teacher in a Special School. In September 2006 we had two launch events; one at Ellen Tinkum School in Exeter which received coverage on radio, the Press and television, and the second when we gave two presentations at the National Association of Music Educators Conference at Warwick University.

I worked as a Specialist Speech & Language Therapist at The Avenue School for pupils who have learning disability and physical disability in Reading for nearly 20 years. I also have a keen interest in singing, particularly in performing traditional English songs. It became obvious to me that there were many benefits to using song in my work with students at an early developmental level, and those who use AAC. The singing voice is a powerful tool for eliciting attention and maintaining concentration, and songs give opportunities for learners to respond in any way they are able. There are many songs which 'work' very well for AAC, but all need to be adapted in particular ways to enable every student to be included in singing and interaction. The approach works well for small class groups, 1:1, and also whole school groups.

In October 2000 I was fortunate to go on a week-long study-break in Devon, where I met Paul Wilson and other musicians at Wren, a folk and community arts organisation. Wren often works in Educational settings and had worked very successfully with Helen Baxter, a Music Teacher at a special school in Exeter. The ‘Nice Warm Socks’ project came about as we saw the need for an 'off the shelf' resource to enable other people to use tried and tested songs and to see how to develop their own. We also wanted to make sure that it would be easily used by people who might not consider themselves confident singers. There followed months of fund raising and planning (we were fortunate in receiving a grant from ‘Awards for All’). We then started the process of recording and producing the CD and all the free resources. We were keen to include young people from a special school as well as other singers and instrumentalists. We then sent out copies to a variety of people - therapists, educationalists, parents and grandparents and asked them to use the CD and materials and to feed back their comments to us. We have been pleased to receive many very enthusiastic responses and also more ideas of how other people have used the new resources.

So what are the particular features about a song and the adaptations that need to be made? Perhaps most importantly, the songs are sung at a slow pace. This allows learners to recognise, anticipate and join in the songs. It enables the leader to sign all the words clearly and with engaging facial expression. It also allows time for accurate signing and for juggling symbol resources and multi-sensory props. However, the songs have lyrics and melodies that are strong enough to ensure they do not become tedious.

The songs can be sung unaccompanied. When you are facilitating the use of voice output devices, symbols and also doing the signs, it is not possible to play an instrument as well. You will want to pause and wait for responses, so it is not always helpful to have anyone else playing a piano or guitar. We have included some simple instrumental accompaniment on the CD so that it sounds good to listen to many times, but all the songs can be simply sung just using your voice.

The songs have been selected and adapted to give maximum opportunity for ‘AAC singers’. Some learners may not be able to sing vocally, but can use a voice output device to join in, or even lead the singing. This
works well when there is a regularly repeated line, when choices can be made about what vocabulary should be included, when the AAC singer can lead one part of a song sung as a round and when the song has a call and response pattern. There are examples of all these features on the CD.

The songs have everyday vocabulary which is good for signing the key words and making symbol resources to remind learners (and staff) of the words and support understanding of the verbal concepts.

It is easy to include multi-sensory experiences with the songs. Many of the songs lend themselves to using props of various kinds – textures, smells, objects, lights, instruments and noisemakers.

Many of the songs are ‘flexible’ – that is the words can easily be changed to fit in with any particular setting or subject. It is good if a song has a repeating structure. For instance, you can stop in the middle of the song in order to ask learners to choose, by any means, what item they would like to sing about. You can also make the song personal by including the proper names of learners.

Some of the songs have a chorus, which enables the whole group to join in at certain points. Other songs are deliberately very short and simple. These can be very effective when working with a learner who needs to practice multiple activations of a switch or device without getting bored. I record the first line of the song, using an age and gender appropriate voice, onto the voice output device and put on a switch cap symbol and/or a larger symbol behind the device. The learner activates the switch and ‘sings’ the first line of the song. You can then bring out a stimulating object related to the song and sing the rest of it. When the song ends, the object is hidden and you can wait for the learner to request the song again by activating the switch.

The songs can be sung by anyone – whether you think you can sing or not. One of the advantages of including traditional tunes is that these melodies have been sung by ordinary, untrained singers for generations, and seem come naturally to us. The melodies are not complicated, but are interesting and varied. It is fine to change both words and melodies as necessary. They are best sung in a natural voice and in whatever key suits the singers. The important thing is the interaction, not the quality of the performance.

There are many reasons why using music to promote interaction is so effective. It would be impossible to list them all, but here are a few:

- Singing together is fun and can often promote positive reactions and laughter.
- It enables learners to practice AAC skills in a repeatable structure that is enjoyable.
- It enables AAC singers to be included in singing times and supports peer group relations and self esteem.
- It is a positive way of being with another person which does not depend on speech for communication.
- It is a powerful motivator which brings together cognitive, emotional and physical skills.
- Attraction and attention to music comes very early in the developmental sequence. All human societies have music – we seem to be ‘hard wired’ to make and appreciate music.
- Music can have significant effects within the brain. It has been shown to lower levels of cortisol (the stress hormone) and raise levels of oxytocin (important for social bonding) and also release endorphins, the ‘natural opiates’.
- Music is closely connected with emotions and can be used to explore different moods.
- It can enable learners to show abilities which are not language based.
- It helps learners to develop imitation and turn taking skills.
- It can improve fine motor skills and motor co-ordination.
- Song shares many features with speech, and can help vocal expression.
- It promotes peer interaction and can influence self-confidence and self-esteem.
- It doesn’t matter if there are long pauses or breakdowns within a song. Since it has a repeating structure there are many ways of repairing the break in a positive way and then starting again.
- All learners can be creative and make real choices about what to sing and how to sing it.
- It does, of course, support important aspects of Music Education as outlined in the National Curriculum.

**MORE INFORMATION AND RESOURCES**

There are some important features about ‘Nice Warm Socks’. There is a website www.nicewarmsocks.org.uk containing lots of free resources and where the ‘Nice Warm Socks’ CD can be ordered. Anyone can download and print off pages of the music and the words. There is a section for each song with ideas of how to use it for promoting interaction and AAC and developing musical skills. There are also pages giving links to the National Curriculum and ‘P Levels’.

I am able to offer training to institutions and any other groups who would like to learn a bit more about the background to Musical Interaction, to learn some of the songs and how to make them effective for AAC singers. They would also learn how to gain confidence and to extend their own singing and performance skills.

There is also a large selection of symbol resources created specifically to support the songs – both for visual display and to fit popular voice output devices. These are freely downloadable from the Widgit website www.widgit.com/resources/classroom/nice_warm_socks/index.htm They are in Communication: In Print format. The resources for one song are available in PDF to enable anyone to download.

**CONCLUSION**

This project came about as a result of the ‘hands on’ experience of three practitioners who have a strong conviction that the positive benefits of singing should be enjoyed by all youngsters. We have each been able to bring our own particular skills to make the resource as useful as possible. We were also concerned to keep the price low, so that families and many other care settings could also share in supporting interaction and communication through music. We know that young people love the activities and the singing, and that AAC singers love to add their voices to the songs. *Shan Graebe (formerly Cowan) Speech and Language Therapist*
COMMUNICATION MATTERS

INTRODUCTION
Self identity is a difficult topic and in mainstream sociological or linguistic theory, identity is considered in a framework of being different and assimilating into a new society. However being disabled we have a huge physical identity. Therefore in relating Self Identity to Augmentative and Alternative Communication (AAC), we first must discuss physical identity first and then venture into linguistic theory.

PHYSICAL IDENTITY
I do not think of myself as disabled, it is strange but true. I just think of myself as an ordinary person. I know I cannot do some things but in the normal course of my day, I do not think about it. I know I do spend more time looking after my body than other people, which I will discuss later. When I was at university, I wasted a lot of time on a certain male. I loved him but knew nothing would ever come of it, because amongst other things I did not go to the right school. The unspoken hurts of dating. We were well known on campus, as we were very involved in student politics. Most days I picked him up and drove him to university, as well as drove him home. This one day, we were walking from my car, past the law school, towards the Arts and Economics faculty. I was feeling good with him beside me, and everyone knowing who we were. I looked ahead of me and saw our reflections in the glass doors. It hurt. I saw my body as the world must see me. My sexual identity too went from 100 to zero. It took me years to again accept a sexual identity comfortable in my body. Whether we like it or not, we are identified by our bodies. As a collective group, we are labelled as disabled.

In my youngest niece's, Hannah’s, Friday Kindergarten class, there are deaf children. This is a part of an integration program. We asked her how kindergarten was, and whether she noticed the new children speaking with their hands. Hannah was bemused by all the attention. She had a good day at Kindergarten, nothing else. Then we realised, she has known me signing all her life, it was nothing new to her. I love being Hannah's aunt because that is what I am to her, that's all. After ten months of Kindergarten, Hannah came into my house proudly and sang the Rainbow song in sign language.

I do identify myself as a person who uses AAC (Augmentative and Alternative Communication). As a person who had a voice and lost it, I can say I feel more a part of the AAC world than of the voice world. Firstly I lost my voice at a young age, and secondly when I remember the child who had a voice, I do not like the way I used that voice. I am an adult remembering childhood ways.

The AAC community is identifiable to us, we share the same hurts, frustrations and joys. The outside community would lump us in one basket, as disabled, but within the disabled community, we are our own sub group.

Saliva unites us. Coughing, spluttering, choking, eating with serviettes. All things that we live with but hurt us to the core. There are places I will not eat or drink, to save my own embarrassment.

I remember my first day at a regular high school, I was 16, a few other 16 year olds were allocated as my minders. I dribbled. One girl gave me her hanky, I had my own but did not reach it in time. She gingerly put the hanky in her locker and her face said she was repulsed. She is now a nurse and mother, it was just the age and the situation.

Melinda Smith has a poem, 'Caught', which says everything we feel:

Inside my throat
A muscle spasms
Saliva break
A cough tickles
Eyes water
my chest tightens
Wheeze like crazy
going berserk for air
I lose control of
my self
Till it comes loose
that thing that tries to eat me.
(Smith, 2002)

I have had my saliva ducts diverted, even so, I still dribble. We try our hardest not to dribble, and as Melinda says that when it happens, it "eats" us. Socially, it sets us apart. We never mention it, but it hurts.

I was in a restaurant one evening, it was a train strike day. I had driven to the city to work. A couple of us had decided to see a film and have an evening meal, so we would miss peak hour traffic. I was eating Italian. Normally I would not be so daring with what I eat at a restaurant but I was with friends so I knew it did not matter.

All of a sudden I hear a boy from the table near us say to his father, "I hate the way that girl eats". I cringed. My friends made it easy by ignoring the comment, but it has heightened my awareness of eating in public.
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Don’t Limit Your Choice!
Everybody has fears of being alone. We, however, have an exaggerated sense of being alone, and all the fears that go with it. Mobile phones and the Speech to Speech relay have lessened our fears. Melinda Smith lived through her fears a couple of years ago when a fire broke out in her unit. Luckily her personal care attendant was with her when it happened and the fire was extinguished within minutes. (Smith, 2004)

I personally have a fear of being stuck in a lift.

The Cornelia Rau story where a mentally ill person was held in an Australian detention facility for 10 months, is a very real fear we all have in not being understood. And to those of us who live with a disability, we could have added much more to an Inquiry. It is a all to common situation for the voice-less and the fear remains with us always.

Pain, whether it be physical or emotional, is something that unites us. We all know the physical pain of daily living and the stress we put our awkward bodies under, just to participate in life. Pain, itself, is an individual pain, no one else knows what it feels like. It is hard to describe. Sometimes you can look at a person, as people looked at me toward the end of the Brazil ISAAC conference, and you could see the pain.

I do resent the time and money I spend looking after my body. Especially Monday nights, I get home from work, go to the hydro pool, do 30 minutes in the pool, get home, have my fourth shower for the day, make and eat my evening meal and then go to bed. I accept it as part of my life and cannot see it ending.

Pain cripples me, I usually do not want to acknowledge it. Acknowledging the pain would be giving into it. It is a uniting factor, that goes unspoken but is very much part of our culture.

Emotional pain, hurts more, we build our own armour for protection.

Yes, we have physical identity culture. It largely belongs to the disability culture. As much as I try to ignore it, and pretend I do not belong to it, it is a place where I feel most comfortable, listened to and empa-thised.

I have so far neglected the machine. The machine. My Lightwriter. My life. Betty is my voice. Beautiful Betty. Betty is part of my personality. Other people may use Betty as their voice, but they are not me, they do not use the Lightwriter as I use the Lightwriter. There is still room for me to be me. Lots of room.

People say to me, “what a fantastic machine”. I am blunt in my reply. “The machine is boring, I am fantastic”. I do not care what people think of me for making that remark. The identity behind the machine is what is important.

LANGUAGE IDENTITY

The AAC identity is ‘our’ identity, we prefer to identify ourselves with AAC culture than a disability culture. It is what dominates our lives, we want the ability to communicate!

With in the AAC culture, we all serve an apprenticeship of types, we all learn to use words effectively. Some of us have a few words we can speak with our own voices, but they do not come out legibly and not without a lot of effort. Generally we reserve the vocal voice for familial situations and drastic situations.

Language is the primary function for enacting our social membership and our identity (Miller, 2000). We live within a dominant language culture. We seek to express ourselves in terms of that dominant language. Our acceptance into the community is based upon successful integration into that culture (Miller, 2000).

IS AAC A SECOND LANGUAGE CULTURE?

Communicative competence is critical to being accepted as a member of society, and to be accepted as a member of society is a goal of most people (Miller, 2000). For the person who uses AAC, it may be good enough to say one or two words at home and the family knows what you mean, but when you are out shopping you want 200 grams of shaved ham not two shavings.

Very recently I was at the take away Asian food place in the food court. I know I definitely asked for a small serving, I pointed to the small container, but I received and paid for a large serving. She did not understand my Yes/No signals which I indicated. Luckily my sister was hungry when I arrived home. Something in the cross cultural exchange went wrong. If I had a voice I would have said small and made sure she understood. I would have argued when she said the price. Instead I accepted the larger serve, paid 80 cents extra and reserved my energy for more important things.

I do not realise how much I use gesture. Gesture is quick, and it is acceptable in the verbal world as a communication tool. Sometimes when I reflect on my day at work, I realise I have said very few times I have reached for the Lightwriter. I have laughed at jokes, sent emails to colleagues, listened to conversations and used gesture a lot. I do feel as if I have interacted all day even though I have not actually said much.

A social culture also has infinite rules, which includes not just what you say but the way that you say it (Miller, 2000). Language is a “complex and dynamic process.” (Miller, 2000) Variations can go on forever. It is important therefore that we know the context of the conversation or we set the context to an understandable level (Miller, 2000). My niece, Adara, has become quite blunt, she says “I do not understand you” then goes and gets my Lightwriter.

I am quite bad at not expanding on the context. Anyone that has phoned me, will know that I say “OK” a lot, OK, is very clear, cannot be misunderstood, and will cross cultural boundaries. I was on the phone with a client one day. I kept saying OK to him. Finally in sheer exasperation he said, “You say OK a lot but what are you actually telling me?” I had to tell him that yes, I was listening, the case was being looked at and I will have the case officer call you back when they get back to their desk.

I live in one culture but have to remember when I cross into another culture, they need more words.

Language is a very powerful weapon (Norton, 2000). Very few people, if any, are in a position of power without communicative competence and fluency in the global language of the main culture. I guess, we in our culture, use silence as our weapon, so the words become more powerful.

Language and language use, then becomes an investment (Kanno & Norton, 2003). The reward for the investment is access to unattainable resources (Norton, 2000). In the AAC community, the rewards are far wider than most people imagine. In my own life, the reward has been employment and being able to attain a life beyond being disabled.

What linguists found in the second language culture in schools, is that being visibly different was less important than being audibly different (Miller, 2000). Is this true of the disability culture? As I have previously stated, I want my body back more than I want my voice back (Allan, 2004). Being physically different is too stark a difference. Where those in a second language culture can negotiate an identity through becoming more competent in a language (Kanno & Norton, 2003), we will still be identified as disabled, even if we reach communicative competence.

It is a vicious cycle, in one way we can strive to break through barriers, and reap our rewards, but we will always have a stigma placed on us by the global community.

The choice is there, we can respond to imposed marginalisation by creating our own pathways to escape or we can revert to the safety of living within our own communities (Miller, 2000).
We do have a language culture, we identify it by our own struggle for acceptance in a talking world. We do struggle in the same way as a second language speaker struggles for the rewards of communicative competence in a strange land. (Norton, 2000)

AAC has become another intrusion that society has to expand its own tolerance boundaries to accept. Just as multiculturalism has expanded society’s boundaries, where accents are now accepted, so too must our voices become accepted as the norm and not just, “oh, what a fantastic machine”, or “you have an alphabet board, wonderful you know your alphabet”.

CONCLUSION
We are identified by our bodies firstly and foremost. We are perceived as a group member of disabled beings. We have little choice in how we are perceived. Conscious of our own self identity, we strive to “make sense of the myriad complexities of our social experience” (Quinn & McNamara, 1988), and break through the disability barrier to be accepted as ourselves.

Yes, we do have a language identity, but its identity is swollen into a larger identity of disability. Within our own identity of self, it is a large part of our own identity. It pre-occupies our day. Email and SMS has made it easier to communicate in a manner acceptable to a society that demands fluent interaction.

Our need to communicate, our struggles, society’s demand that we communicate, that make form the identity we have for ourselves. It is the sociological dichotomy and “psychological distinctiveness” (Quinn & McNamara, 1988) that AAC creates for us, that becomes our identity in our own minds.

Meredith Allan
President of ISAAC Australia

REFERENCES


Communicating Together at the ISAAC 2006 Conference

ALAN MCGREGOR
Dept of Applied Computing, MicroCentre, University of Dundee, Dundee DD1 4HN, UK

Alan McGregor was awarded some funds by the ISAAC’s ‘People who Use AAC Committee’ to attend the ISAAC Conference in Düsseldorf, Germany in 2006. This is his report to ISAAC, reproduced with permission.

OPENING CEREMONY
The conference ceremony began with a musical performance by people who use AAC playing as a band, with guidance from their teacher. They had had just three days to prepare this: I was very happy and moved that disabled people were involved at the opening ceremony. This was topical for me, because I make my own music and have played live before, twice in Dundee. Over the past months I have been exploring and trying to work out a way of doing better live performances with my teacher at the MacKinnon Centre. It was good, it looked fun, it made me think that I would like to do a performance of my own music, on my own, at the ISAAC conference in two years’ time.

TALKS
I felt both my talks went well. The first was an illustrated talk about my experience of swimming and representing Scotland in the Paralympic Games. I explained how being involved in this was crucial for me to grow and develop as a person. I had felt upset, defeated and depressed about my disability. The discipline and passion for swimming, and the hard work made me forget my problems. My talk appeared to go down well and I got a lot of positive feedback and interest from the audience. Several people came to me during the rest of the conference interested in my talk. My second talk was with the lecturer from the University of Dundee, about how useful it was to have an AAC user involved directly as ‘part of staff’. The advantages or disadvantages this gives to research applications. This also went down well and was of interest to the researchers from other universities.

CHAPTER MEETING
On the first day I went to the ISAAC chapter meeting of the UK. There was a lively discussion about ISAAC and in particular the problems of funding of people who use AAC like myself. I offered to ISAAC UK to use my music CD that I am preparing, as a charity CD that could be used by their organisation to fund other people who use AAC. I think it is so valuable for all that there is a mix at a conference like this, therapists, researchers and people with disabilities, all communicating together. I gained so much from participating in events like this.

ALON’S SMILE
This was a theatre performance of a play written by Alon’s mother. Alon was born with very complex difficulties and grew up with very limited communication abilities but is a bright intelligent person. The play was done with one actress playing all the parts and with accompanying music. It was incredibly powerful and moving as it depicted the struggle the mother had to get the correct care for her child against negative attitudes from social and medical services. The play touched on the sheer difficulty the mother had to face, until at one point she had a nervous breakdown. It was magic because in the end it was about hope. Hope, because through her efforts the child that she loved so much ended up going to school like others and interacting with the other kids. It was great.

SEMINARS ATTENDED
• My Life Story: An amazing presentation by a 12 year old AAC user (helped by her mum). This was just great, she was such a star.
• AAC and Self Identity: This was about self identity and experience. Meredith Allan talked about her new computer voice which was realistic and Australian like her. She also talks about how embarrassed and awkward she felt at times. I related strongly to this because I used to be embarrassed at myself in public but have worked through that.
• Working Full Time with a disability: This interested me because I take my helping with the university seriously. I am still waiting for a small device that could fit on the wrist and could send signals to a speaker on a lapel. Many manufacturers and designers listened to me but I think I have to wait a long time. I was at times disappointed in the technology.

Alan McGregor
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Making Friends at the ISAAC 2006 Conference

BETH MOULAM
Email c/o: admin@communicationmatters.org.uk

I was lucky enough to go to the International Society for Augmentative and Alternative Communication Conference in Germany in the summer. I can recommend it to anyone who uses AAC.

I travelled by car with Mum and Dad going in the Channel Tunnel. We left home on the Friday at 6.30am and got to our hotel in Düsseldorf at 3pm. It seemed to take forever but we had breakfast in the car and then stopped in Calais and bought a McDonalds for me.

The Novotel was great. Our room had a bathroom with an adjustable shower seat and sink and rails for the toilet – just what I needed. The staff were really friendly. One funny thing was my Lightwriter couldn’t say ‘wiener schnitzel’, which made them laugh but they knew what I wanted.

I attended the AAC Camp on the Saturday and Sunday. This was really fun. We had two days learning and planning to do blacklight theatre. This is done in total darkness using special lights that show things in white. Denise and I wore white gloves and we made our hands dance together. We have lots of photos but they are all very dark! My poor Dad had to keep lying on the floor for hours under a black sheet as he was holding a pole for a white ribbon to make the Communication Bridges logo.

In my group I made friends with three girls: Denise from Austria, Nele from Germany and Reke from Hungary. Our parents and carers had to help us talk because the girls all spoke German and I speak English. Denise and I spent all our spare time together playing tic-tac-toe (noughts and crosses) – we didn’t need to talk for this!

On the Monday morning we did our blacklight presentation in front of 850 people who were at the conference. It might have been scary but we couldn’t see them because it was dark. Other groups from the AAC camp played music and showed art.

On the Monday afternoon I did my presentation. I don’t know how many people came but the room was full. It was a great experience and I have had lots of emails from people since to say how interesting it was.

During the conference I met very many people from all over the world and I have stayed in touch with some of them. I listened to a lady called Meredith Allan from Australia talk about identity; she uses a Lightwriter like me and said lots of things that I think about myself. I met Mel who is an artist and poet; her poems about being an AAC user are inspirational for me. Alan McGregor from Scotland talked about his swimming and he made me want to walk on my own even more. I was able to try out the software for the Stand Up programme with Annalu Waller. Stand Up is a joke telling program for children who use AAC, and the jokes were very good.

Over the next three days I also met up with loads of people I already knew. I saw Janet Larcher my IT Consultant who comes into school, friends from 1Voice, and also Peter and Angela Zein, Simon Churchill and the team from ACE Centre Oxford that I see at their family days. In the exhibition I tried out lots of different bits of equipment and I am now hoping to get a mount for my Lightwriter to go on my wheelchair.

Mum had planned I would not go to the conference every day but spend time with Dad. In fact the conference had such a lot happening and there were so many people I knew that I wanted to be there. I am planning what I would like to present in Montreal in 2008 and I hope to meet up with all my new friends again.

Beth Moulam
Bowls, Banter, Bocchia and Social Events for Everyone

CLAIRE FORSTER ¹ & HELEN DIXON ²
Email: ¹claire.forster@cumbriapct.nhs.uk ²helen.dixon@cumbriapct.nhs.uk

WHO’S WHO AND WHAT WE DO!

We are speech and language therapists working for Cumbria Primary Care Trust, although this is irrelevant to the social group for people who use AAC, their families, friends, therapists, teachers, and so on.

We meet six times a year mostly in school holidays. Children and adults using any form of AAC, or none at all, come to the group. It is a good opportunity for people who do not yet have an AAC system to see it in action. We have a variety of activities:

• Bowling and a meal out
• Picnic / games afternoon
• Christmas party

Approximately 25 people who use communication aids come at various times. Twelve of them come to most events including two adults who are very good users of high tech AAC and who act as role models.

WHEN AND WHY?

• The group was set up about ten years ago to provide an opportunity for a 10 year old who used AAC in mainstream school to meet other people who use it.
• The original meeting was a coffee morning at Bleasdale House Residential School in Silverdale Lancashire - thanks to the then head teacher.
• Communication Matters provided a grant for tea, coffee, etc.
• Letters were sent to District Speech and Language Therapists in all the Trusts in Cumbria and Lancashire.

• A lot of people turned up.
• The group was thought to be a good idea.
• With a few ups and downs, the group has gone on very successfully from there.

HOW WE DO WHAT WE DO

• Adjust template letters for the appropriate event (If you would like a copy of these email us and we will send you a copy).
• Mail or email letter to people on mailing list – (people who have been to previous events, therapists, teachers, anyone who has expressed an interest).
• Collate responses.
• Adjust bookings accordingly.
• Turn up and have a good time!

SPECIFIC ACTIVITIES

• Bowling – book lanes, café, find room in park (in summer we sometimes have a picnic or meal in a park after bowling – we recommend Happy Mount Park in Morecambe – good splash pool – take bin bags to cover power chairs!).
• Picnic – borrow school (we have a local residential school with good grounds for a picnic and a very obliging head teacher), borrow and set up games such as skittles, bocchia, parachute.
• Christmas party – arrange special visitor (also the same obliging headteacher ho, ho, ho! (Parents bring a present to put in the sack as we know special visitor is very busy at that time of year!)
• Co-ordinate food contributions, plan quizzes, games, pass the parcel, music, decorations.
• (Christmas is usually the last weekend in November!)

FUNDING AND RESPONSIBILITIES

Apart from tea, coffee, biscuits, plastic cups, plates, etc all the other are activities paid for by families.

We have recently altered our letters to include: “On a serious note (we have to say this these days) you are responsible for any children you have with you. We cannot take responsibility for any items or...
children lost or damaged during this activity! Bowling should cost no more than about £3.00 per bowler.”

**ISSUES RELATING TO THE GROUP**
- CAP has caused a large increase in the number of children who have AAC systems in the area. Many of these come to the group, so it is increasing in size. We need a bigger venue and other possible activities. Things are more difficult to organise with larger numbers (i.e. too many to fit in the school pool – we used to swim, also more difficult to co-ordinate food at Christmas – we don’t really want hundreds of mince pies!).
- Parents at the group talk to each other and compare services. We view this as a positive, but not everyone might!
- Therapists’ feelings of guilt at ‘having a good time’ rather than doing more ‘traditional’ therapy, with no targets or case notes to write. Is this really work?!

**WHAT HAPPENS AT THE GROUPS**
- No specific AAC activities.
- General fiendish quizzes (the harder the better, it gets people talking, moaning about us if nothing else!).
- Total communication approach – anything goes! No insistence on using AAC devices.
- Meet role models ‘without knowing it’ in an informal way.
- See communication through AAC ‘working’ in a natural situation.
- We more or less stand back and let things happen.
- Many of the families who attend our activities also go to 1Voice events.

**BENEFITS OF GROUP**
- People who use AAC systems see others using them.
- “We have been coming to the group for 5 or 6 years since Julie got her communication aid. Initially it was nice to meet other people with talkers as Julie was the only one in school with one. It encouraged Julie to use her talker and we could chat to others. Now it is nice to come and meet friends. Julie and her brother look forward to joining in the activities and are very keen to come to ‘meetings’.” (mother of a 15 year old using a Cameleon)
- Young children have access to role models.
- Parents can meet other parents and discuss issues, ideas, problems, solutions, etc.
- Siblings meet other siblings in similar situations.
- Therapists and families get the chance to see a larger range of AAC systems.
- Therapists gain from the experiences of the people and families who use them in different situations.
- “It gives me experience of different AAC models and builds up my skill level. It gives me insight into how users apply AAC in informal settings in a social setting.” (SLT working with 9 year old who uses a DV4)
- People have fun and make friends!
- “We enjoy meeting up and keeping in touch with friends we have met through the group. We all enjoy catching up, having a chat and having the opportunity to use communication aids with a peer group and family. Many thanks PS Susan and Jane love the pizza and ice cream too.” (Parent of 9 year old girl who uses a DV4)
- “We know people will not be alarmed or judgemental about our kids with disabilities.” (Parent of 5 year old early user of AAC currently using PECS and 4Talk4)

**WHY A SOCIAL GROUP?**
- “Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.” World Health Organisation Constitution (1948) Hogg, C. (1999)
- Not target-led
- Not ‘ticking the box’
- Not ‘measurable intervention’
- “The focus of AAC interventions is to promote communication in natural contexts.” (Balandin & Barnes-Hughes, 2001)
- “People with a disability, including those with no or limited functional speech, are becoming increasing vocal about their right to be valued by the community and to be in the community without having to strive to attain ‘normality’.” (Balandin & Barnes-Hughes, 2001)
- “Children acquiring language through aided means also lack the presence of competent users of the same communication form in the environment, thus reducing the naturalness of the language acquisition process. (Smith and Grove, 1999)” Judith D. Oxley 2003

**NO MORE THEM AND US**
As a result of the social group we feel our relationships with parents have changed, the barriers have been removed between professional and parents and it has allowed each individual to express and share their knowledge equally to the benefit of everyone. This has especially been evident as we are trying to develop our AAC procedures post-CAP and have relied heavily on the input of parents.

If you want to come to any of our events or more information get in touch with us.

* Claire Forster
Speech & Language Therapist
Helen Dixon
Speech & Language Therapist

**REFERENCES**
The BT ChildLine Awards are given to people who have made a real difference to young people’s lives. Children were invited to nominate ordinary people for their extraordinary work with young people. This is the story of how Toby Hewson became one of the 2006 award winners.

AUTUMN 2005 – BETH
I saw something on TV’s Newsround about the BT ChildLine Awards for Superheroes. They wanted children to nominate people who had made a difference to their lives. I told Mum I thought we should nominate Toby Hewson. I have known Toby for three years and he has been inspirational in helping me and lots of other children at 1 Voice events as one of our role models. Knowing Toby has made me feel happy with myself because I know I will be successful in my life.

We looked at the ChildLine website and Mum helped me put in a nomination. We thought there would probably be lots of applications so we wouldn’t hear anything.

DECEMBER 2005 – TOBY
I was with Toby at the 1Voice weekend in Blackpool that she had nominated me for a BT ChildLine award for Superheroes. I was very surprised and happy, but I thought that we wouldn’t hear any more.

A couple of weeks before Christmas I was told that I had been shortlisted. I was asked to take part in a phone interview for an hour one evening during which time they also spoke to my Personal Support Assistant. Before the interview they spoke to my secretary who passed on the contact information for my mother, Ruth at Pacso, the after school club, where I work as a volunteer, and the speech and language therapist at Ingfield School.

DECEMBER 2005 – BETH
I was with Toby at the 1Voice Blackpool weekend and we talked about the nominations. A few days later we got a letter saying Toby had been shortlisted. They rang Mum and she spent a long time on the phone talking about Toby. She told the interviewer how important role models were for children who use communication aids, how it also helps their parents and brothers and sisters. Also about the work Toby does for 1 Voice, Communication Matters and schools. Mum also gave them contact numbers for other people who could tell them about Toby.

JANUARY 2006 – TOBY
I received a letter asking me to attend an interview in London at the beginning of February.

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FEBRUARY 2006 - TOBY
I attended the interview in London, which was in front of the panel of judges for the BT ChildLine Awards and these included Esther Rantzen and Jacqueline Wilson, together with two young people, in total there were nine people on the panel.

I was very scared at all the questions that they asked, but they were very kind. Following my interview all the short listed candidates, 10 in total, and the judges had lunch together, which meant we were able to hear about each others work.

A few days later I received an email to tell me that I was one of the four winners. I phoned Beth to tell her my news, she was at home ill, so I think the news helped to make her feel better.

I told Beth that they wanted to film both of us and as arrangements had already been made for Beth and her mum and dad to come to Sunday lunch at the end of
February, we decided that this would be a good day for the film crew to come.

I asked Ruth and mum to come to my house on the day of the filming as they wanted more people to be in the film. They also filmed Sally, who was preparing our lunch that day. The filming took a lot longer than they said, which meant that lunch turned into tea!

FEBRUARY 2006 – BETH

We had another letter to say Toby had made it to the final interviews. I was very excited as Toby came to my house one day after school so we could talk together about what he has done for me and why role models are important in my life.

One afternoon soon after his interview the telephone went and it was Toby. He was so excited as he had won the award. He told me that we would both be going to the award ceremony.

Mum got lots of emails and we found out the NSPCC who have joined with ChildLine wanted to make a film of Toby and me together for the awards.

Toby had invited us for lunch one Sunday and so we agreed it was a good day for the film people to meet us. They interviewed Toby, me and lots of other people. I was very hungry as they said it would take an hour and it took 4 hours. Sally had to turn off the oven for some filming so our lunch was at tea time.

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MARCH 2006 – BETH

By the time the day was over, we found that leaving London was a nightmare and it took us many hours to get home. I feel very honoured to have received this award because I think I am just like everyone else, but obviously Beth thinks different.

It will be a day that I will always remember.

MARCH 2006 – BETH

I got a day off school and went to London on the train with Mum and Dad. Then we went in a black taxi to the BT Tower. Outside we met Toby with his Mum and Dad and Sally.

It was very exciting. Inside I met lots of people including a girl call Chelsea who was a judge, she introduced me to Jacqueline Wilson who writes the Tracy Beaker books. She was a judge and giving the prizes and was wearing some very big rings on her fingers. It was Tracy Beaker who inspired me last year to write my Life Story so I was really pleased to meet Jacqueline.

At the ceremony Esther Rantzen talked, then they showed Toby’s film and Jacqueline gave him a thing to put on his mantelpiece. I got a certificate, then we were photographed.

We went up in the lift to the 34th floor and Toby and I were interviewed for Newsround by Lizo. Lunch was OK but it was not really my sort of food – there was only a little bit of food on very big plates. After lunch the restaurant revolted and we could see all over London.

Mum and I pushed home and Dad went back to work. We arrived back just in time to see Newsround and I saw Toby and me. What a day!

Toby Hewson & Beth Moulam

NOTE

ChildLine joined the NSPCC in February 2006. For more information, visit: www.nspcc.org.uk and www.childline.org.uk
How does it work?

The actual cost of each place is £1,500. We’re asking participants to raise a minimum of £2,500, meaning a minimum of £1,000 go to Communication Matters. If £2,500 sounds a lot, don’t worry - you will be given literature, advice and support on how to meet your sponsorship target. The closing date for applications is 1 February 2007.

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For further information including a fact sheet, itinerary, registration form and more, please email: admin@communicationmatters.org.uk Tel: 0845 456 8211

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It was great to meet up with so many people at this year’s Symposium, and to experience again that positive, vibrant, dynamic community spirit that seems to pervade Communication Matters. Thank you to everyone who helped to make this another special event, a real AAC boost – one to remember in the dark winter months, when it is all too easy to focus on what’s going wrong rather than what’s going right (or right-ish!). Special thanks are due to a small group of people who really help the Symposium run smoothly each year – Patrick Poon for all the pre-conference administration and his organisation during the event, Pat Thomas for all her liaising and co-ordinating with the university staff, Colin Clayton for co-ordinating the exhibition (with the 2 Ps), the team from Communicate whose registration procedure gets slicker and slicker each year (and for all the bag stuffing before the event!), the ‘orange shirts’ for helping out during the Symposium... and, this year especially, to Neil Hansen for his budgetary angst before the event.

FINANCES & INCA TREK CHALLENGE

Those of you who were at the AGM (and perhaps there was no escape for anyone at Leicester on this topic this year!) will have realised that Communication Matters really needs to turn its finances around – and quickly. This could have cast a dark cloud over the whole conference, but instead it resulted in a fantastic ‘Dunkirk Spirit’ – with lots of really good suggestions and offers of fundraising, etc. Any further ideas would still be really appreciated – but look out in this Journal (and on the website) for information about a sponsored Inca Trek Challenge (see page 20)... and there’s also a whisper up north of a sponsored trek along the West Highland Way (maybe not quite as glamorous and exciting as the Inca Trail – and certainly with more midges!). The Trustees met at the end of November to thrash out the finances – look out for information and updates in our e-Newsletter. If you don’t already receive the e-Newsletter, simply send an email with your name in the subject/title line to: enews.subscribe@communicationmatters.org.uk

CM CHAIR

Maybe it is because I am entering my last year as Chair of Communication Matters – but this column is turning into a series of ‘Thank Yous’. I really do appreciate the support that you all continue to give to Communication Matters – it comes in all different shapes and sizes and in every possible manner – but it is all very much appreciated. As an example of this we have a very active group of people who are contributing to the governance review that is currently underway – thanks for volunteering, and a particular thank you to Liz Moulam for pulling it all together and reminding us when we haven’t done what we said we would do! (See Liz’s update below on the Governance Review.) On a personal level I feel very touched by the support and encouragement I have received as Chair, especially recently – thank you very much. Although in many ways I will be really glad to hand over the reins to someone else (and I’m looking forward to being able to go to the Symposium just as a normal punter again!) – I will miss all the contact I had with people. My job as Chair would have been much harder if I hadn’t been surrounded over the years by a brilliant group of Trustees – and a superb administrator. To Carole Cooper and Katie Price, outgoing Trustees at this year’s AGM, many thanks for all your ideas, hard work and laughter throughout the past few years.

OTHER NEWS

If you’re interested in attending the next ISAAC conference, it’s in Montreal in August 2008! We’ve just celebrated CM’s 21st – why not join ISAAC in celebrating 25 years of leading the way in AAC internationally? Visit www.isaac2008.org ISAAC also has a number of awards and scholarships available for members. Check out www.isaac-online.org/en/about/awards.html to find out if you would be eligible and how to apply.

Keep an eye out for another Study Day in London (following on from the very successful day on Play, Humour and AAC organised jointly with the Wolfson Centre). It will be on 7 February 2007 on ‘Recent Evidence for AAC Introduction and Use’ with Janice Murray, Juliet Goldbart and Mike Clarke.

Wishing you all the best for 2007!

Janet Scott, Chair of Communication Matters
Email: janet.scott@sgh.scot.nhs.uk

GOVERNANCE REVIEW

First a big ‘Thank You’ to everyone who has embraced the process needed to get this project off the ground. By the AGM in September 2007 we aim to have a new Memorandum and Articles of Association, the papers that govern the legal running of CM and best practice documentation that supports and guides the day to day practices of our charity. During the 2006 Symposium there were opportunities for delegates to hear and discuss the current documents governing Communication Matters, and importantly what people want from CM in the next 20 years. This resulted in a very comprehensive wish list, headed by the feeling that no-one would want to lose the current multi-disciplinary membership and the desire to appeal to an even wider audience in the future. Other discussions were around the need for a marketing strategy to increase membership and awareness of CM, developing stronger links with both professional and voluntary organisations plus developing a higher profile for AAC generally. There was a general feeling the conference should have additional

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strands for specific membership groups such as people who use AAC and professionals aiming to gain CPD accreditation. Other points included revisiting the vision statement, generating additional opportunities for people who use AAC to network, setting up regional forums/groups and developing further the CM Road Shows. So, just a few things to keep us busy then!

Two groups of people have been working hard on taking things forward. This is a true team effort with feedback from both groups being essential to the process.

The Membership Guidance Group (MGG), made up of 21 people, represents 7 different membership groups: people who use AAC, family members, academics, health professionals, educational professionals, other professionals and suppliers. Since early October they have been reviewing the model documentation, feeding back comments via email. They bring a wealth of knowledge with specific work related experience and have made invaluable contributions about practical issues and empowerment.

The Task and Finish Group (TFG) is made up of six Trustees along with Patrick Poon. Our job is to deliver the final set of documents, initially to the Board of Trustees for approval and then to the AGM in September 2007. We are currently reviewing all the model documentation and re-writing this to take account of feedback. There is still a way to go with getting all the required best practice stuff onto paper, but we are in no doubt that serious steps have been taken to get the job done.

The intention is to have a small number of comprehensive documents that are fit for purpose and will carry us through the 21st Century and needing only to be regularly reviewed to ensure CM keeps abreast of changing legislation and developments within the organisation.

Thank you to everyone involved.

Liz Moula, Chair of Governance Review Committee

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eCAT (electronic Communication and Assistive Technology) has met once since the report in the last edition of this Journal but that doesn’t mean the membership has not been active! The biggest area of concern and effort remains funding (or the lack of it), and several eCAT members have been actively involved in trying to push funding forward one way or another.

The BHTA (British Healthcare Trade Association) - of which eCAT is a section - is a valuable resource for information and contacts for eCAT members, and recently advised us of a meeting being set up by the Department of Health (DoH) to review the Community Equipment Service program. The DoH have brought in outside business consultants to work with its own people to completely review this system and to change it totally if they do not believe it is working effectively. They have set up meetings with users of equipment, suppliers, professionals, providers and practitioners to understand the good and bad points about the system as it works now. Clearly, for AAC, with one or two notable exceptions, it doesn’t work at all. David Weatherburn (PRI) and I (DynaVox Systems) represented both our companies and the eCAT section at the suppliers meeting on 13 October in London and made the DoH very aware of the need to put AAC high on the list of provided products. This meeting was one week after the users meeting, which was attended by a Lightwriter user who clearly made a big impression on both the DoH representatives and the consultants. There seemed to be general agreement that speech aids were a major health issue and should be high on the agenda for better health provision. We will have to keep the pressure on to ensure speech aids and their supporting services are not overlooked in this review process.

In my last report, I mentioned the discussions with Janice Murray to look at the possibility of Manchester Metropolitan University students carrying out research on behalf of the industry. This has moved forward with five students involved, three of whom are due to finish their work by Christmas and the others by March of next year. The first three will be doing an analysis of three Regions in the North of England to try and understand experiences pre- and post-CAP funding by interviewing school staff and parents on subjects such as knowledge of AAC, personal experience of securing AAC equipment and support, and processes involved in securing funding, especially post-CAP, with ideas of how much time is being spent just trying to find funding.

Hopefully this could give us specific data that may show potential cost savings by making funding more easily available (we have anecdotal information about one SLT who spent 100 hours trying to secure funding for one child, the cost of which would equate to a mid-priced AAC device!). The North of England has been chosen to minimise cost of this project as all the students are based in this area and the out of pocket expenses are being met by the eCAT members. One of the other two students will work on a statistical analysis of the unmet needs of communication aids for children and adults in the UK and the other will be doing some international comparisons with funding in the UK (so we can show government where the UK stands in a ‘league table’ of AAC funding in Europe or the world).

eCAT members are also working to continually improve both the relationship with CM and the support of CM Road Shows. The former has meant discussing how eCAT and CM can work together in the future and the latter has involved eCAT members trying to review the CM Road Shows with Patrick Poon to produce a better system that will hopefully benefit visitors and exhibitors alike.

Finally, the BHTA continues to go from strength to strength. The latest change is that the Office of Fair Trading has given first stage approval of the BHTA Code of Practice that all members have to sign and abide by. This is a major step forward for the trade association and should, hopefully, further enhance the standard of suppliers in their service and support of clients.

Dave Morgan, Chair of eCAT section, BHTA
Email: david.morgan@dynavox.co.uk
RCSLT HONOURS CM CHAIR AND CM JOURNAL EDITOR

The Royal College of Speech and Language Therapists awarded RCSLT Honours to Janet Scott and RCSLT Fellowship to Sally Millar for exceptional contributions to the profession of speech and language therapy. The awards were presented on the eve of the RCSLT annual conference in September.

TECHCESS ANNOUNCES NEW PRODUCTS

TechCess has expanded its range of communication equipment. The MiniMerc and LEO were shown at the recent CM2006 Symposium in Leicester. MiniMerc is a Windows XP-based PC and AAC device with 8.4" screen. It has multiple access options and environmental control capabilities. LEO, a lightweight digitized speech device has a total recording time of 32 minutes, is configurable from 1 to 32 cells with 7 levels, and has environmental control capabilities.

Although supply of mounting systems (Daessy) has now been transferred to Mounts & More Ltd, TechCess will continue to supply communication aids and mounting solutions as a complete package. Visit: www.techcess.co.uk

WIDGIT SOFTWARE HELPS CREATE NEW WEBSITE FOR THE CHILDREN’S SOCIETY

Over the years Widgit Software has partnered with several organisations on unique projects to make information accessible for all. 2006 has seen them working in partnership with website design & development firm Solutions Squared, on a project for The Children’s Society, to create Askability, a leading-edge, symbol-supported website for disabled children and young people.

Askability contains a range of topical material for children and young people including local, national and sports news, jokes, stories and films & music reviews. The website also encourages contributions from readers, enabling them to create and showcase their own work, giving them a voice and helping to build their confidence. Visit: www.askability.org.uk

Widgit Software advises organisations like The Children’s Society about symbol accessibility and the creation of new symbols for specific projects. For further information call 01223 425558 ext 773, or email symbols@widgit.com

AAC TRAINING AVAILABLE

Check out the links below for AAC training days - some of the centres also offer bespoke training courses:

ACE Centres Oxford & North: www.ace-centre.org.uk
CALL Centre (Scotland): www.callcentrescotland.org.uk
CENMAC (London): www.cenmac.com
PCAS (Bristol): www.pcas.claremont.bristol.sch.uk

THINK ABOUT! SHORTLISTED FOR BETT AWARD

SEMERC’s Think About! 1 has today been shortlisted for the BETT 2007 Award for SEN Solutions. The CD-ROM and accompanying workbook are designed to stimulate discussion and develop language, communication and memory skills with students aged seven and above. The results will be announced at the BETT Award ceremony on Wednesday 10 January 2007.

Think About! 1 is designed for all learners, including those with specific learning difficulties associated with dyslexia, autistic spectrum disorders, language disorders, and concentration and memory lapses. The engaging and motivating presentation of animations also make it appealing for older and more reluctant learners. The program has a range of accessibility options, including switch access and voice input.

For information on the BETT Awards, visit www.bettawards.com

SPECIAL NEEDS FRINGE 2007

The 7th Special Needs Fringe exhibition will take place at the Olympia Hilton from 10-12 January 2007. There will be a resources exhibition with product suppliers and advisory services, new hardware and software, and a themed seminar programme.

The themed seminars will focus on ‘Communication in the Classroom’ (Wednesday), ‘Severe and Complex Special Needs’ (Thursday) and ‘Supporting Pupils with SEN in Mainstream Schools’ (Friday). Seminars are free of charge and there is no need to book. Visit: www.inclusive.co.uk/exhibitions

INCLUSIVE COMMUNICATION CATALOGUE

Inclusive Technology has released a Communication Catalogue - a new AAC and VOCA resources guide for speech and language specialists.

The catalogue has lots of hints and tips and advice for those choosing and using a communication device, as well as new resources and old favourites, including: FLASH Scanning Communicator; LEO which allows for scene-based communication and environmental control; Boardmaker Activity Pad; MightyMo and MiniMo digitised speech output solutions with dynamic colour display screens.

There is also an expanded range of single message and low cost communicators. Visit: www.inclusive.co.uk

BLISSYMBOLS LINKS

The CALL Centre website has a page of useful links to Blissymbols resources in the UK and overseas: callcentre.education.ed.ac.uk/Useful_Links/results.php?country=uk&topic=Blissymbols

NICE WARM SOCKS CD AND RESOURCES

The Nice Warm Socks CD (see page 7) is available for £11 (includes p&p) from Wren Music. Tel: 01837 53754 www.wrenmusic.co.uk

Downloaded resources are available from Widgit Software’s website: www.widgit.com/resources/classroom/nice_warm_socks/index.htm
INCA TREK CHALLENGE 2007

Join this trek for the adventure of a lifetime, and help to raise much needed funds for Communication Matters.

The ACE Centre is organising a sponsored trek along the Inca Trail in October Half Term (20-29 October 2007), and has kindly made available three places to anyone wishing to raise money for CM. The Closing date for applications is 1 February 2007.

Interested? To learn more about this great opportunity, please turn to page 20 of this journal or you can email: admin@communicationmatters.org.uk
Celebrating 21 Years of Communication Matters

JANET SCOTT
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Communication Matters / ISAAC (UK) celebrated its 21st anniversary in October 2006. The theme of the CM2006 National Symposium reflected this achievement.

People were invited to share their memories of AAC in the mid 1980s...

Alan Martin said: “In 1985, I never dreamed that one day, I’d be attending a conference for AAC professionals, and giving them a dance workshop! I was 22 when CM was born and I’d just been ‘released’ from Banstead, an independent living college. We had a huge Apple computer, which I tried to communicate with, but as I’d had very little literacy education, it was slow, difficult and I didn’t bother much with it. My communication was with one-handed signs which I developed for myself, facial expressions and body language, all of which I still use today to supplement my communication aid.”

Janet Larcher remembers using the Lightbox – an early switch controlled device that allowed a square of light of any pre-specified size to move in any pre-specified pattern around it. It was a scanning device on which pictures, toys or real objects could be placed, with the child moving the light to be under the requested item. Janet adapted the Lightbox for use with the Reynell Language Development Scales (beloved of many speech and language therapists!).

Scott Barbour remembers that 20 years ago AAC devices were just new and very basic, until the introduction of the Minspeak program developed by Bruce Baker in 1985. He says that “expressing my views and talking about more personal points to doctors, etc. is now a lot more easier for me, and certainly a lot less embarrassing.”

Toby Hewson was four years old in 1985. He started at Ingfield Manor School, where his AAC journey began involving the successive learning of new and different ‘languages’ – English, Blissymbols, Makaton, LLL, etc. Toby remembers particularly the arrival of one speech and language therapist who changed his life with her development of his word book ... and another “wonderful, loud, pushy, Aussie SLT” who drove him to a Liberator and LLL – and how “that Liberator did liberate me, and the loud, pushy Australian SLT changed my life!”

By the time Communication Matters (ISAAC UK as it was then) was formed in 1985 there was a fledgling network of AAC services and centres already in existence:

- CENMAC had been in operation since the late 1970s.
- The first Communication Aid Centre funded through RADAR and the Department of Health opened at Frenchay Hospital in 1981, with the other centres in London (Charing Cross and Wolfson), Birmingham, Newcastle and Wales following soon after.
- The ACE Centre in Oxford and the CALL Centre in Edinburgh were established in 1983.
- The SEMERCs were becoming established.

Around that time, Bruce Baker was beginning to take the AAC world by storm with his concept of Minspeak.

However, even before then people in the UK were active in the world of AAC:

- Blissymbols were introduced from Canada and a manual signing system based on British Sign Language, Makaton, were introduced.
- Toby Churchill had developed his first Lightwriter and TCL was established.
- Possum were at the forefront of developing environmental control units, switches and typewriters.
• Canon had produced their Canon Communicator – a portable text based aid which you could print messages out on ticker tape.

• Patrick Poon was working at King’s College, London on a research project developing the Microcomputer Assisted Communicator - in a briefcase! This eventually became the MAC-Apple switch input writing/communication aid which ran on an Apple II computer.

In 1991 ISAAC UK adopted the trading name of Communication Matters. After much debate and the conference was held at Portland College – also its home for the next 2 years.

Between 1994 and 2003 the Communication Matters Conference was held at Lancaster University. With increasing demand for places, we had to find a bigger venue to accommodate more delegates, so in 2004 we moved back to the University of Leicester for our annual symposium.

Thoughts for the Future

In the ‘80s we worried that we couldn’t understand the speech synthesisers available, in the 90s we were concerned that we should be able to choose a male or a female voice…and in the 2000s we are working on having regional accents!

Scott Barbour has an interesting suggestion for all you inventors out there - “I can’t see the screen of my talker in bright sunlight, but am excited at what changes could be made e.g. why can’t we use the sun’s power and incorporate solar panels for easier charging?”

AAC changes lives and people’s perceptions. I cannot imagine life as a speech and language without AAC – how much more so for people who use AAC?

Alan Martin says that raising the profile of AAC motivates all his work now. However he also remembers: “One curious thing about having no speech was, that people used to confide things to me, that they thought I’d never be able to pass on. I always kept confidences, but some folks must have panicked when they saw me getting a communication aid.”

We all know that a communication aid can be expensive - but did Scott Barbour really think of this consequence? “I was at a club with my Dad, and with the talker I asked him “What would you like to drink?” Then a packed bar of people turned round, held up their glasses and all shouted “Cheers Scott!”

We have all contributed to this part of history that is the story of 21 years of Communication Matters. However, certain individuals have helped particularly in terms of the research: thanks to Jon Brough, Colin Clayton, Trish Davidson, Prue Fuller, Peter Head, Nicola Jolleff, Janet Larcher, Alison Mackenzie, Sally Millar, Patrick Poon, Katie Price and Allan Wilson.

And many thanks too to all those people and organizations who added memories, artifacts and fantastic AAC museum pieces to the time-line at the conference.

What is important is that we take this piece of shared history forward, build on these strong foundations and work together to raise awareness and educate people about AAC. Here are some suggestions:

• Put AAC on the undergraduate curricula for teacher training, speech & language therapy, occupational therapy, physiotherapy, etc.

• Highlight funding needs and inequalities.

• Promote more equitable services.

• Inform software developers about the needs of users of AAC technology.

...and to make this world a better place for everyone, including those people - it might be you and it might be me - who use AAC.

Janet Scott, Chair of CM
INTRODUCTION

If you don’t know me already, then I’ll tell you a little about myself. I live alone, independently supported by staff who I choose and employ myself. I’m a dance practitioner, a speaker on disability issues, and just recently have started appearing in TV comedy.

I’m self-employed, don’t claim welfare benefits, and am now purchasing my home. My future hopefully, will be fulfilling and interesting. Until I was 31, my only means of communication was facial expression and my own version of signing. As a child I had segregated education, of a sort! Then I attended a Social Services day centre, was bored almost to death, and lived in almost constant conflict with family, who took all my decisions for me.

You may have been watching a new BBC 3 comedy called, ‘I’m with Stupid’. It’s on six times a week until mid-October 2006. I’ve been acting in it as a character called Graham, who uses a DynaVox. Now, I know I’m not the first person who uses AAC to appear on TV or to do any acting. We all know plenty of famous people who have been on the box, and have also acted in theatre, made great informative videos, and raised the profile of AAC in a fabulous way. For example, Toby Hewson, Katie Caryer, Nadia C., and many more. Oh yes, not to forget that scientist bloke!

In this paper, I will be telling you about TV comedy acting, not acting in general. Until I did it, I had no idea of the difference. I’ll try to give the reasons why I did this work, the attitudes I encountered, how the series is being received, and I will explain the practicalities. Also, I’ll try to tell you how I hope this will contribute to greater acceptance and social inclusion of people with disabilities, including people who use AAC.

FIRST AUDITION

One day I got an email, quite unexpectedly, from a casting director from the BBC asking me to audition for a part. She had been searching for Northern sounding disabled actors, and had stumbled onto my website by following a link from the site of Mat Fraser, a well known disabled actor. I explained that my accent was more American than scouser. However, she still wanted me to audition.

I was sent a draft script and told to choose a scene. I had no idea what I was getting into! The audition was at BBC Manchester, and I travelled there on my way to a job in London. I went to the casting room, which was tiny, and the producer and casting director read the other parts. I wasn’t really nervous because I was just doing it for a laugh, and didn’t dream they would want me. It was good fun, and I went off to London and gave my speech about assistive technology at Assist UK conference without thinking much more about it.

AN ACTING PART

Some days later a phone call told me that I hadn’t got the part, but went on to say that the producer was asking the scriptwriter to add a new character to the pilot episode, a man who used AAC. That was the birth of Graham.

I agreed to take the part. My reasons for doing this were many. Honestly, the first was that I imagined earning loads of money to set up an inclusive dance studio, which is still my ultimate goal in my life. I had many other reasons for wanting to play this part.

Ever since I got my first communication aid, I’ve experienced the way it’s changed my life, and I’ve learned about all the issues surrounding funding and accessing these lifelines. I believe that people need informing about the existence of AAC, and the profile will be raised by a person who uses it being seen regularly my thousands of TV viewers.

Also I want to help change attitudes about disability. If people can be helped to feel
less strange and uncomfortable about disabled people, it could help inclusion in ordinary life and society. I feel that humour is a great way to do this.

CHANGING ATTITUDES

Generally, disabled people are almost invisible on TV, which is very wrong when you think that it’s supposed to be representative of the population, and 1 in 8 people has some form of disability. The media, and much art and literature, tends to focus on tragic, heroic, or medical aspects of disability. This is most unhelpful in promoting full inclusion of people with disabilities in ordinary daily life.

Before I became self-employed, in early 2004, I attended a conference at RADA in London. It was about disability, performance, and employment. I went as a dance delegate, but there was also much discussion about the lack of good, positive parts for disabled actors. There are several issues. Non-disabled actors should not be cast as disabled characters. This has often happened in the past. Disabled actors want to play parts which are not specifically disabled, and aspire to play the doctor, headmaster, or banker. Then people will get used to seeing disabled people in ordinary, everyday jobs. TV is so powerful in influencing attitudes.

As with so much else in life, it’s all about attitudes. I wasn’t really expecting my experience to be so very positive. In other areas of my life I still see discrimination and ignorance. I can honestly say that the disabled actors surprised some film crew with our professionalism. Lots of staff told me that they’d learned a huge amount, and completely altered their opinions about people with disabilities. I am hoping that both through wide exposure on TV, and through humour and laughing with us, attitudes of many viewers will also become more positive towards all people with disabilities.

This week, the third out of six episodes of ‘I’m with Stupid’, is being shown. If you missed it on Sunday, you’ve plenty more chances to watch it. It’s repeated 8 times a week. Also it’s on broadband, and at the end of the series, all six episodes will be on broadband for a week. There’s talk of producing a DVD and I may do some of the director’s commentary on one episode.

HEALTHY DEBATE

I can’t say yet how successful the series will be, or how success is measured. At the very least, it’s caused some healthy debate!

Some of you may know the BBC website www.bbc.co.uk/ouch! If you visit www.bbc.co.uk/ouch you can follow the debate on the message boards. I wasn’t surprised that some disabled people hated it. Some criticised it as if it was a factual documentary, with comment about the realism of the sheltered housing situation. In fact, that is just a device to get the characters together, and there would have been loads more comment if it’d been set in a prison or a hospital, for example. If you view all 6 episodes, this setting will be challenged. Plenty of moans from people who sounded as if they’d never be satisfied with any media portrayal of disability, unless they had personally produced it. Some with huge chips on their shoulders. Happily, the vast majority of comments I’ve had personally and seen in the press have been excellent.

I am learning a lot about attitudes towards disability, and about people. The original ideas and the person who collaborates with the writer is a young man with CP. This should validate the plot, but there’s no pleasing some people. It was just intended as a funny new sitcom where some of the characters are people with disabilities who create comic situations. I don’t think it was meant to be deep. I will now describe the practical AAC aspects of TV acting.

PRACTICALITIES

I will attempt to tell you about the practical points I learned during the making of ‘I’m with Stupid’. I hope this will help others who will follow me into TV work.

Can I please remind some people that I was speaking the words written by the BBC script writer, when I was acting in ‘I’m with Stupid’; the script and plot were nothing to do with me, personally. Some people confused me with the character I was playing, and told me that I shouldn’t use bad language. It wasn’t intended as a children’s program, and also, actors once under contract have to do as instructed. I’m delighted that the producer has asked for my ideas how my character might develop if they make a second series. The script for Series 2 has been commissioned, but that’s all so far.

First, I do not see any way around needing to pre-program an AAC device with the lines to be spoken. I often do this anyway for my workshops. You can’t expect people to always have the time to wait for creation of unique sentences a word at a time. I just think it’s my equivalent to speaking actors learning their lines off by heart.

I created a new page set on my DynaVox 3100. I do now use a DynaVox DV4 but when the original pilot episode for this series was recorded, over almost two years ago, I was only just learning to use the DV4, and still felt more confident with my older device. If there’s a second series, I’ll probably change, but it will be noticeable and so will need to be written into the story in a funny way. So, I created a new page set for the series, one page per episode, each scene had buttons along one row, with each button one line of script. It was important to be able to navigate to my lines very quickly and accurately.

Very often there were script changes during filming, and I had to ask my assistant to
make changes for me on set. Usually, I had the scripts in plenty of time, but there were frequent rewrites, and I had pink sheets to insert in my white script, followed by different shades of sheets until I got the final shooting scripts. Even then there were changes at the last second.

It was interesting to see how the different scenes were filmed. I’d expected to start on Scene 1 of Episode 1, but it wasn’t like that at all. It was hard to remember where a particular scene fitted into the story. It was amazing how long it took to film each scene. I estimated that each full day, 11 hours of work produced about six minutes of film. It took over a week to make a 30 minute episode, and seven weeks to make six episodes.

I could be needed in costume at 7am. On set at 8am. Speak one line, and then be waiting till late afternoon to speak again. Sometimes it was very cold and boring waiting, but other days I could chat with other cast and crew, or watch a few scenes being made, on the monitor screen. Filming one line could take hours, and had to be repeated several times filmed from different angles.

I only anticipated speaking each line once, when I began TV work, but soon saw that my communication aid battery would be empty before the day’s end, as it was on and off again maybe hundreds of times a day. The extreme cold temperature also caused my aid to freeze once while filming the pilot episode. On discussion with my aid suppliers, they agreed to lend a spare, just in case of problems. This was vital during filming the series. It was bad for the DynaVox 3100 battery to keep topping up between scenes, so I would use it till almost empty, then swap over.

I had a mike strapped to my chair, and also the sound technician separately recorded all my lines. All the technical stuff was fascinating. I had no idea that making TV was so complicated.

For this first series, I had to be available every day for seven weeks. I was free the first week, we all had 1 week off at different times. Then, it was almost full time for six weeks, with a few days off. It was very tiring to do, but exciting as well. The filming was done in Bury, north of Manchester. Most actors stayed in local hotels, but I chose to go home at night. This meant a 90 minute journey each way, every day. Some days, I had to get up at 5am. Some days, I got home at nine in the evening. It was very hard work both for me and my assistants, but we thought it worth the effort. I hope it was!

My clothes for the series were supplied by the BBC, and there were often changes during the day as we filmed scenes from different episodes. I had to try keeping my hair looking the same length for seven weeks, which was a challenge. They didn’t use much make-up on me, which was a relief! There was one scene where I was supposed to look sick. In fact, due to getting up very early after a late night, I was really truly unwell and quite green anyway. There were lots of jokes about my method acting, and dedication to my craft. Remember, if you do watch the episode where I get food poisoning, I am not acting! Before going to the filming location in the mornings, we had to go to the unit base, where make-up, costume, and production details were arranged. We could also return there during the day, if not needed for filming. Unit base was about a mile from the filming location, and was set up at the rear of an old factory. To see it you’d have thought we were a gang of travellers. Several small caravans, some larger vans and an old double-decker bus were parked in a group. The actors each had a separate van. Food was cooked freshly for us by chefs who provided varied interesting dishes each day. I enjoyed the food!

The number of crew working with us was amazing. There must have been at least 100. There were unfamiliar names to their jobs. I don’t think any AAC software programs have: gaffer focus puller, grip, best boy, boom operator, stunts coordinator, and such like. Then there was the chuck wagon, honey van, and other confusing names.

The filming was mostly done in a long disused residential home. Lots of carpenters were busy making scenery and moving walls around. My character had a trendy flat, including kitchen, furnished in a way that I quite fancied myself. After a few weeks, when all the scenes in my flat were complete, I arrived at work to see my flat being taken apart and walls re-papered for someone else. I felt sad. Then I saw a long brick wall moving down a corridor and saw how temporary it all was. At this stage I cannot reveal what happens in Episode 6. Just try to imagine how two heavy power chairs got into that position! I’ll say no more about that!

ACHIEVEMENTS

However much of a success or not, this first series of ‘I’m with Stupid’, has achieved a great deal:

• It has shown that actors with disabilities can work with the same standard of professionalism as other actors.
• All the crew and production staff have learned from the disabled actors, and will feel confident and more at ease working in similar situations in future.
• The actors with disabilities have all had a very positive experience and will hopefully progress to do more acting work.
• The viewing public will have had some exposure to actors with disabilities behaving in ordinary, sometimes amusing, situations.
• A lively debate about the portrayal of disabled people on TV is underway, and this can only be a good thing.
• The struggle for disability equality, which is currently about 30 years behind sex and racial equality, will have been moved forward significantly.
• The profile of AAC will have been raised.
• The trail opened for future AAC using actors.

Very importantly, I hope it has made lots of people laugh, and being at ease laughing with people with disabilities is a great bridge builder.

GETTING STARTED

If any of you know people who use AAC, or other disabled people who fancy TV acting, you must think about how casting directors find their actors.

You’d be extra lucky to be sought out like I was. My web site led to my TV work. Other actors all had agents, and that’s how they were contacted. There are very few agents specialising in using actors with disabilities. I was asked if I knew people who’d like to be extras, because the producers couldn’t find any. There are many disabled artists organisations around the country, and several acting organisations. The problem seems to be that mainstream organisations and those for artists with disabilities do not cooperate enough. If anyone is interested in any performing arts, they need to be sure that they can be found. Get onto Internet artists newsletters and so on.

FINALLY

Good luck to anyone who tries it. It is sadly not a way to get rich easily. I was paid a fair enough wage for my time, but in my real job, giving presentations and dance workshops, I can earn as much in one day as in a week of TV acting. And, although this programme is repeated eight times a week each episode, I only get paid the once. It’s not all about the money, but I just want you to know that most actors are out of work, much of the time.

The pilot episode shown last year, won an RTS (Radio and Television Society) award for best new comedy. I hope the first series does equally well.

Thanks for reading this, and if you watched ‘I’m with Stupid’ and enjoy it, please let the BBC know about it. If you do, I could be here next year telling you about Series 2.

* * *

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A Grand Day Out

1Voice National Network Day 2006

KATIE CLARKE
1Voice, PO Box 559, Halifax HX1 2XL, UK
Tel: 0845 3307861 Email: info@1voice.info Website: www.1voice.info

1Voice - Communicating Together works with disabled children, young people and adults who use augmentative communication aids, and their families. We bring families from around the country together at two events: one in summer and one in the winter.

Our summer event is very much action packed and this year we returned to the very beautiful Hothorpe Hall to continue with our already developed Role Model Project and our second Teenage Project on the Friday 14 July and Saturday 15 July. We then held our annual National Network Day on the Sunday.

Many disabled children, young people and their families have little opportunity to meet disabled adults who use electronic communication aids. Our unique Role Model project works with a team of communication aid users who provide inspiration and motivation not only to the young people and their families but also our volunteers who come to support us at all our events.

We have personal development training for Role Models which is very much centred around working alongside children and young people over the last few years. This year, four of our Role Models arrived on the Friday lunch time to be greeted by sunshine and the wonderful ambience of Hothorpe Hall. Hothorpe Hall is set in its own grounds with views across Leicestershire’s rolling landscape. The house itself is like a mini stately home with a variety of meeting and conference rooms overlooking the delightful gardens. It very much lends itself to a successful weekend!

This year we had the theme of ‘First Impressions Count’ which involved Role Models working together to discuss and share their ideas and experiences. Throughout the afternoon Katie Caryer, Toby Hewson, Shelley Makin and Axel Bohm looked at themes around developing assertiveness, communication skills and self presentation, with the aim of increasing self-esteem and confidence in working alongside young communication aid users.

This year, our Teenage Project was called “Be confident - Be cool” attracted 13 young people on the Saturday. Katie, Toby, Shelley and Axel led workshops scribed by Tamsin Crothers and Kate throughout the day. The outcomes for teenagers were to increase confidence when meeting and talking to strangers; to increase motivation and confidence when joining in a conversation; to have increased opportunity to develop peer relationships. All this, plus of course to enjoy and achieve!

We encouraged parents not to be around and several of the families with siblings joined up for a trip out to explore the nearby canal. This also involved a necessary visit to a local beer garden with the aim of breaking down barriers and a bit of bonding for dads.

During the heat of the late afternoon more families arrived to take part in the dinner and then our 1Voice Annual General Meeting. Young disabled people and their brothers and sisters hung out around the pool table or outside to get the last of the daylight before the end of a very successful and meaningful event.

Our National Network Day attracted over 100 people on the Sunday from all over the country. Families on arrival were greeted by two of our teenagers who were able to show them around and direct them to the various outdoor activities.

Role Models took it in turns to sign people in and volunteers were available to assist new families to 1Voice events. Parents were able to share ideas and information and chat about some of the many issues in their everyday lives while children and young people could take part in the 1Voice poster display, face-painting, magic show and karaoke, inclusive sports or just explore the gardens. Dads played football with some of the siblings and wished they had brought
Volunteer: "I've got the 1Voice bug! I've attended two summer fun days and three Christmas weekends and I'm always inspired by the commitment of the 1Voice organisers who ensure that everyone has so much fun.

The young children are clearly thrilled to meet with the role models and learn so much from them. It's also really great to see the siblings mixing and sharing their experiences. Until you've attended an event, you can't really appreciate how valuable 1Voice is - with everyone communicating together in their own special way, and having so much fun."

Parent of a young child: "Everything that I would like to see happening for the kids where we live, happens here at 1Voice. Everything that we all need to know about communication on behalf of our children is demonstrated here, by the children themselves, and by the Role Models. And the Role Models say it all. And the children's smiles prove it all works. Brilliant weekend."

Speech and language therapist: "1Voice gives the professionals the opportunity to learn from these real experts, the families and the adults who use Augmentative and Alternative Communication. Professionals gain hugely from their experience and their practical knowledge of using AAC in real life."

Mother of a young communication aid user: "I've seen for the first time the immense difference the "1Voice experience" makes. The communication aids and the advice, make the world of difference. It must be a whole new world opening up for these young people. I really admire their determination - they're inspirational, absolutely fantastic."

Parent: "The progress my son has made since the 1Voice weekend has been fantastic. Now he so wants to do it, the Role Models showed him what he could do. A big thank you to all."

Personal Assistant to an adult communication aid user: "1Voice has once again surpassed itself. It is truly a pleasure to be part of such a project that enlightens the lives of those who participate in whatever capacity."

Katie Clarke
Chair of 1Voice

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TACPAC™ PROVIDING A COMMUNICATION BRIDGE FOR CHILDREN WITH MULTI-SENSORY IMPAIRMENT

People often ask whether the old TACPAC™ (cassette tapes) can still be obtained and if so, where it comes from. Here is the answer! The current/revised pack is now CD based.

"It is quite amazing the effect on the children! You could consider they love it because as soon as I get the bag of equipment out I have children coming over and getting ready of their own accord - the wooden spoons, fan and blowing are very popular!" This was one delighted email message from a teacher using TACPAC™, a tactile multi-sensory awareness pack designed for children with sensory impairment. TACPAC™ is particularly popular with children in the early years, speech and language groups, and play skills groups, as well as children who have profound and multiple disabilities.

It was created by Hilary Wainer and two colleagues, due to the lack of resources for people working with children with sensory impairment. Hilary explains where it all began:

"I was working with children with severe learning disabilities, autism, Down’s syndrome, visual impairment, communication difficulties, and a host of other learning difficulties. The way it all started was that a colleague was running a movement session in the hall of the school I was working. Her tape recorder broke down. She ran into my room (where I had my first free non-contact time in months!) and asked me to wheel the old piano into the hall, to improvise some music so that her lesson could still progress. The result was very exciting. The improvised music, with the feely sensations we gave to the children, was a hit. To cut a long story short, we repeated the session for many weeks. The other staff became enthusiastic, and asked us to make it into something they could do. Hence - TACPAC™! A tactile pack for sensory awareness."

There are six activities for each of the three sets in each TACPAC™. Each activity has a common everyday article which is used as a tactile object. Each object has its own specifically composed music, reflecting the feeling of the action of the object on the body.

With regular use, the child who cannot talk comes to form a bond with his carer, who in turn becomes familiar with the wishes and intentions of the child. In this way, the child learns to rely on his pre-intentional speech, and the adult interprets what the child’s wishes are. Over a period of time, TACPAC™ gives the child the opportunity for meaningful communication with the carer, and intentional speech can overtake the pre-intentional phase, with the child making his wishes and needs known to the carer who in turn does less and less interpreting.

Having a regular session of TACPAC™ allows for relaxation, fun and participation by all. The anticipation of the tactile sensations, the music and the sequence, all help to make the atmosphere one of quiet and calm, which, in the middle of a noisy and busy day, is very welcome. Speech therapists, occupational therapists and language therapists all report improvement in the children by way of their bodies relaxing, their vocalisations increasing and their eye contact.

It's exciting to find a resource that is obviously making such a difference for the children, their families and their helpers. As one special needs educator wrote: "It has been fun to see the faces of the parents as you get out your dish mop, pan scourer, baby oil, chains and more! Their amazement at the response of the children is worth bottling too!"

For further information about TACPAC™ visit www.tacpac.co.uk email: info@tacpac.co.uk or tel: 01865 772213.
What Evidence do We Have for Best Practice?

Thoughts from typical and aided models of language development

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This article aims to consider some key issues relevant to a range of working practices in the field of AAC. These issues will be contextualised within a framework of current research evidence. This perspective enables us to consider the robustness of such evidence and consequently our currently accepted working practices.

EVIDENCE BASED PRACTICE (EBP)
It is useful to begin with an overview of the concept of evidence based practice (EBP). This is a framework for evaluation that is not new to medical research and is the basis of such things as random control trials, used to prove the effectiveness of new medicines. However, as a concept in the social science field of research it is a more recently adopted construct for evaluating the effectiveness of therapeutic and educational interventions.

Schlosser (2003) cites some definitions for EBP, suggesting that it is the integration of best research evidence with clinical expertise and patient values (Sackett et al, 1997); OR: It ‘...uses research evidence together with clinical knowledge and reasoning to make decisions about interventions that are effective for specific clients’ (Law & Baum, 1998, p131).

WHY IS EVIDENCE BASED PRACTICE IMPORTANT FOR US?
Evidence based practice is important because it:

• fills the research-practice gap, aiding justification of current working practices
• meets the ever increasing demand for accountability
• provides the best possible assessments and interventions for our clients
• improves our critical thinking and research skills and promotes life-long learning
• provides a common language for use among multi agency teams and promotes transparency for service users.

(Pring, 2005; Schlosser, 2003)

SO HOW DO WE GO ABOUT CONSTRUCTING A RESEARCH PROJECT TO REVIEW WORKING PRACTICES?
Firstly, we need to be clear what it is that our research evidence is commenting on. To clarify this we need to take a moment to consider efficacy research. Efficacy research is interested in looking at clinical effects, effectiveness and efficiency. Specifically, efficacy research tests therapy under optimal conditions whilst effectiveness research tests therapy under typical clinical conditions and lastly, outcome research considers the changes attributed to an intervention (positive, negative or unplanned) (Pring, 2005).

The process through which these elements of efficacy research can be explored is explained in Robey & Schultz’s (1998; Pring, 2005) five phase model.

1. Identify if a therapeutic effect exists for a small group or individuals in a series of case studies (N=1 participant). These effects may be noted and commented on as part of every day work activity. Within a research context - we need to formalise the type and amount of detail noted within N=1 design. This facilitates moving to phase 2.
2. Decide on client group, exclusion criteria, outcome measure(s) & the duration & method of therapy delivery. This would be based on issues considered at phase 1.
3. Large scale efficacy studies are carried out to provide stronger evidence that a treatment works. Interventions would be carried out under optimal conditions to provide the best possible opportunity for an observable effect. If demonstrated you could move to phase 4.
4. Effectiveness studies conducted. This would result in studies varying client groups, therapy & delivery, i.e. more typical clinical conditions. If a positive effect was still observable you can move to phase 5.
5. Effectiveness studies continue to determine cost effectiveness & to assess consumer satisfaction & quality of life issues. The aim here is to collate evidence to identify not only what is the most effective intervention but also, within the climate of accountability, the most efficient service.

So, let’s look at a selection of evidence that is available to support clinical decision
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making. The following review is neither extensive nor exhaustive but is meant to highlight some interesting sources of possible evidence.

SOME CLINICAL QUESTIONS

1. When should we introduce someone to an AAC system?

A thorny issue, so how might the literature help us decide? One theoretical perspective to start from is the consideration of executive functions and attention.

Executive functions and attention

Executive functions are the higher-order processes that enable us to plan, sequence, initiate, and sustain our behaviour towards some goal, incorporating feedback and making adjustments along the way. According to Zelazo & Muller (2002), executive functions emerge towards the end of the first year, showing major developments between 2 and 5 years. Interestingly, there seems to be very little if any research exploring executive functioning in young non-typically developing children, except in the area of autism and ADHD.

One of the important functions we can consider here is attention. There are several aspects to this:

• Stimulus orienting and sustained attention control are the earliest elements (Anderson, 2003) but these will not be considered further here.

• From 18 months executive attention emerges, and develops until the mid teens. This executive function enables the child to control behaviour, allocate cognitive resources, evaluate behaviour progress, and direct activity with goals and plans. These developments may explain Shepp, Barrett & Kolbert’s (1987) finding that, out of 4, 7 and 10 year old children, the youngest group struggled to selectively attend to visually complex material with some requiring cueing to succeed in a task of this type. The younger children attempted to process the whole picture, whilst the two older groups processed the salient information and ignored the irrelevant components (semantic judgment task).

• Joint attention is the more social or communicative aspect of attention, ensuring that your conversational partner is attending to the same event, object or person as you are. Cress (2004) found that joint attention behaviours were reduced in young children (1-2yrs) with physical disabilities relative to their language level. In a paper on Turkish speaking children, Topbas and colleagues (2003) found that children with language delay used a lower proportion of joint attention behaviours. These reviews, although limited in number, suggest that it is never too early to introduce AAC but that demonstrable executive functions will dictate the type of system most appropriate to the individual, e.g., real objects, photographs, etc.

2. How should the AAC system be organised?

How are our minds organised and how are they modified by our experiences and opportunities for communication? What evidence do we have?

Concept knowledge

• Reflective to intellectual. According to Conway (1997) percepts have no meaning until processed on through the semantic system, where they are computed as a new experience or one that is recognisable and interpretable.

• An agreed view of a concept is that of a mental representation of a class of objects or experience (Conway, 1997). Developing a bank of categorical knowledge allows the individual child to generalise what has been learned to another object or event and so — over time, adapt responses and behaviour according to the demands of the environment. The process by which this may occur has been debated and described in a range of ways by such authors as Piaget and Vygotsky.

Concept knowledge and AAC

Concept development is perhaps one of the most crucial issues if children are to learn to use a symbolic communication system with flexibility and social competence.

In the AAC literature one study to consider is from Falkman, Sandberg & Hjelmiquist (2002). They looked at the preferred communication modes of a group of non-speaking preschool children who used Blissymbols. The participants were observed in a fairly unstructured communication context that was based around themes, readily available to them through their Bliss books.

Results showed that Bliss was seldom used spontaneously by any of the children. In total 12% of the communication included the use of Bliss, leaving 88% to a range of pre-linguistic modes including vocalisation, gesture, facial expression and eye-gaze. This raises some interesting questions as to the flexibility of each child’s conceptual and semantic system in the context of a naturalistic dialogue.

Semantic development

• The single word stage of vocabulary acquisition has long been agreed as a time of variability in typical language learners. Studies of language components typically available during early AAC intervention have consistently observed that noun and noun concepts greatly outweigh any other word class (Blockberger, 1995; McNaughton, 1993; Raghavendra & Fristoe, 1990; Schlosser and Sigafos, 2002; Schlosser, 1997).

• The predominance of nouns is actually fairly similar to normal language acquisition around the first 50 word stage, although this rapidly changes as the typically developing child moves through into the two-word stage.

Might we conclude that much AAC intervention may be encouraging restricted word class knowledge and later limited communication development? Indeed, Von Tetzelchner (2000) addressed this particular concern in the teaching of multi-sign utterances and the choices educators have in attempting to move children on to the more flexible and powerful two word level.

• Learning styles. Nelson in 1973 first introduced the idea of differing language learning styles: the terms she used were referential and expressive styles of communication. The referential communicator showed a preference for labeling, using a predominance of nouns, and remaining at that single word stage for longer. The expressive communicator preferred to use learned phrases (allgone now) and was perceived as being much more sociable, and perhaps precocious, in their conversations. Both styles were observed around the 2 year age group. Nelson later concluded that both styles were required to become linguistically competent.

There are obvious implications for the child using AAC in regard to language learning styles, with possible consequences for language use and later linguistic or social competence. Iacono’s (1992) consideration of this topic challenged the reader to think about issues of AAC organization that offers the child a range of communication styles, with opportunities to consolidate concept knowledge in a flexible way that is sensitive to differing rates of language learning.

• Event theory. Katherine Nelson (1985, 86) focused on the familiarity of Events and their impact on language flexibility. Events were originally described in terms of scripts, suggesting a range of predictable activities, sequences and semantic components. Strong scripts happen frequently, in the same sequential order with the same adult input and child output, e.g., dressing, storytelling; whilst weak scripts happen regularly but do not have the same sequence or language input on each occasion, e.g., TV programme, or something that happens fairly infrequently but may have some predictable components, e.g., birth day party.

Interestingly, Light et al (2004) discuss the technological option for presenting symbol vocabulary by embedding linguistic concepts into contextualised schemes:
sometimes called ‘the graphic metaphor’. Here language concepts are stored under ‘hot spots’ on the screen. Accessing the hot spot causes the item to become the focus of the screen but allows the label and concept to be learned within an appropriate scene, e.g. kitchen scene. This certainly fits Nelson’s original Event descriptions and current information suggests that introduction to new vocabulary in this way speeds up the acquisition process. How this works as a long term and efficient communication system is still under consideration and development.

3. Is it OK to change systems?
The need for greater flexibility in concept and word knowledge experience suggests that significant changes in AAC system may be less detrimental to the learner than is commonly believed. This can be further considered from a language structure perspective, namely grammar.

Grammatical development
There are numerous sources of information on typical grammatical development which will not be expanded further here (Aitchison, 2001, Crystal, 1989, Brown, 1975).

Grammar and AAC
Typically, a sequence of nouns may be produced as an utterance, even when other parts of speech are available (Raghavendra & Fristoe, 1990). This reinforces the earlier suggestion that word type knowledge and sentence construction knowledge may be limited in young people using AAC systems. Investigating issues of grammar versus the potency of the message Sutton, Soto & Blockberger in 2002 and again (Sutton, Morford & Gallagher) in 2004 suggest that word adjacency rather than word order within a graphic utterance is the more powerful primer for the listener when decoding the message. Could this suggest that when messages are not produced with typical spoken grammar that listeners automatically become more semantically primed too?

Light et al in 2004 reviewed the performance of typically developing 4 & 5 year olds’ use of AAC systems. The systems used four differing language organisation techniques. Results suggested that both groups were consistently better at locating language on the 3 dynamic display systems. Initially, the iconic system was not at all transparent to the children whilst the dynamic systems were only moderately transparent. Nearly all children improved with all 4 techniques. Concrete items were more recognisable than abstract items but rates of learning varied across systems.

Before leaping to a unitary assumption about these findings, it is worth asking ourselves what it is that we understand about the initial cognitive demands of a system and the motivation to keep trying versus the potential for much later metalinguistic sophistication.

Finally, another similar study by Fallon, Light & Achenbach (2003) found that preschool aged children preferred to organise vocabulary into semantic groups (pairs) rather than a taxonomic arrangement.

SO WHAT DOES THIS TELL US ABOUT OUR KNOWLEDGE AND PRACTICE?

AAC Systems
• Memory demands may facilitate memory development and promote cognitive flexibility, influencing consideration of both concrete and iconic encoding techniques.
• Language learning styles should be considered in the early phases of AAC introduction, influencing the organisation of the system.
• Embedding concrete language concepts within children’s daily contexts or integrated scenes (hot spots) may offer script experience to developmentally young users of AAC.
• Sentence construction knowledge may be limited by the implicit organisation features of an AAC system.
• Different developmental levels would seem to benefit from different schematic organisation, and so it seems appropriate to have a view that organisation of vocabulary may need to change over time to promote sophisticated language development.

AAC Practice
• Similar but delayed patterns of memory rehearsal in those with complex communication needs suggests that memory practice could have a positive consequence for later development (working on covert rather than overt articulatory skill).
• Over-use of nouns and noun concepts in initial and later vocabularies may impact on later cognitive flexibility constraining children from moving on to the much more flexible two-word stage of language use.
• Scaffolding techniques may not automatically help the child’s language development. Typical preschool children tend to learn most language skills through incidental teaching and learning opportunities whilst AAC users experience most language learning in a more formal way (Von Tetzchner & Martinsen, 2000).

OUR EVIDENCE BASE
This review suggests that most research evidence in the field of language development through aided means is based on studies constructed at Phase 1 & 2 of Robey and Schulz’s (1998) model. This implies that in our field we are still at the stage of exploring the parameters that need more extensive research.

SO WHERE NEXT?
• Acknowledging that we all have a role to play in the development of evidence based practice.
• Working collaboratively.
• Carrying on asking questions of ourselves and others.
• Doing what we do best, which in most instances of clinical practice will be at Stage 1: N=1 (case studies). *

Janice Murray
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Juliet Goldbart
Psychologist and Researcher

KEY REFERENCES
The full reference list is available from the authors - please email: j.murray@mmu.ac.uk

DVDs AVAILABLE
How Far We’ve Come, How Far We’ve Got to Go: Tales from the Trenches
Written and Performed by Michael B Williams
This is the extraordinary story of the life of Michael B Williams. See the potential of AAC as you journey through the past with Michael.
DVD available from: Augmentative Communication, Inc.
Tel: +1 831 649 3050
Email: sarahblack@aol.com
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The Power of Communication
This film by Communication Matters delivers a powerful message that communication really does matter. The DVD is an introduction to AAC, and celebrates and promotes communication in all its forms. It is of general interest, and in particular to service managers and purchasers who have responsibility for AAC services.
Preview it online: www.communicationmatters.org.uk
DVD available (£8) from: Communication Matters
c/o The ACE Centre, 92 Windmill Road, Oxford OX3 7DR Tel: 0845 456 8211 admin@communicationmatters.org.uk
Developing and Using Signing

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As with many schools for children with Severe Learning Difficulties, signing was our first experience with Alternative Augmentative Communication (AAC). In the years that followed our first attempts to use a non speech form of communication, we embraced symbols, photographs, simple electronic aids and eventually, very sophisticated communication devices.

We are rightly proud of our Total Communication Approach. However, whilst teaching approaches for low and high tech AAC have developed, our approach to signing had not changed in the past 25 years. But it remains the first experience of AAC for many children and the one they are most likely to fall back on in times of communication stress. Developing and Using Signing is the result of revisiting our approach to the teaching of signing with the aim of providing high quality teaching and learning for this essential skill.

Signing is something everyone can implement immediately. Properly introduced, it gives a foundation for moving into other forms of AAC; it helps focus children on visual clues and trains staff in scaffolding language. Signing is becoming more familiar these days, we see sign interpreting on the TV and many parents know about baby signing. Signing is a familiar way into AAC for parents/carers and untrained staff.

Lots of children need a package of AAC. Experience in recording children’s use of language on The Redway School Communication Assessment (Latham and Miles 2001) show that many children use several different forms of AAC to communicate information, for example, Emma used her device to say Nanny, signed house and pointed to the calendar to indicate a time meaning – nanny’s coming to stay tomorrow: Drew, who did not have his high tech device for months was forced to be resourceful in using everything available to him, he resorted to his first experience of AAC which was signing in the school environment.

Milton Keynes LEA and the PCT supported us in developing an approach to signing which supports normal language development.

The Redway School’s approach to communication has very simple basic principles; communication has got to be functional and is learnt in a dynamic social setting, serves a purpose and you can only talk about things you understand.

The course is accredited through The Signalong Group, it works through the book which is open to all. The course provides a short description of what we expect the children to be able to understand and communicate, and tie this in with the Pre-level one indicators (P Scales). The section entitled Readiness, describes what the child will be doing if they are ready to learn signs with more complex ideas. We have also listed Aims for you, which is intended for the people who will be teaching signing. This is a very important section designed to help parents and carers with little experience of signing to immediately begin to work with the learner. The final section is called Aims for the child, these may be used for IEP targets. The book is designed to be as user friendly as possible so that parents and professionals alike can pick it up and immediately begin to use signing.

Helping as many people as possible to use signing is one of the underlying principles of the guide. The Redway School runs a Signalong Foundation Level Course based on the book which is open to all.

The course is accredited through The Signalong Group, it works through the book and teaches participants both the signs and how to implement them in a natural context. It is designed to be as practical as possible, advising the participants in how to support learners in using signing.

Please contact the authors at The Redway School for more information and a copy of Developing and Using Signing. ®

Ann Miles, Teacher
Rachel Key, Speech & Language Therapist

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What is the Impact of Access to High-Tech Communication Aids on Children with Autism?

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INTRODUCTION

In this paper we want to share our experience about the positive impact of high-tech AAC on the language and communication of children with autism as a contribution to this under-researched and controversial area. Our paper describes a pilot project carried out at Sutherland House School which aimed to evaluate the impact of access to high-tech AAC and so systematically review our informal experience of a range of positive outcomes for children with autism.

During the initial stages of the project we did not have access to dedicated high-tech voice output communication aids (VOCAs). Consequently, we used the hardware and software available in school to create VOCA facilities. We used Clicker 4 running on a laptop to replicate the dynamic display technology of VOCAs (Figure 1). Additionally, we secured funding for a DynaVox MT4 during the project period and one child accessed this.

THE RESEARCH BASE FOR VOCA USE IN AUTISM

It is estimated that up to half of all people diagnosed with autism do not use speech functionally (National Research Council 2001) and yet the use of high-tech communication aids for people with autism is controversial.

For example, Helena Goldman (2002) states in her AAC assessment protocol for non-verbal children with autistic spectrum disorders (ASD).

"High-technology AACS are not generally considered for this client group...learning about communication and why and how we interact with others would not be greatly aided by the use of high-technology AACS. The ‘cause and effect features’ of such aids may also serve as communication distracters, and could therefore hinder rather than promote communication." (Goldman 2002, p2)

Discussion with colleagues suggests that this perspective may be widespread and has informed decisions about the allocation of resources to buy aids for children with autism. Goldman’s advice contrasts with recent practice based literature from the USA on autism and AAC (Caferio 2005) where high-tech and low-tech AAC are presented as a continuum.

Research in this area is extremely limited. In a unique paper, Mirenda (2003) sought to identify what is known about the use of VOCAs by students with autism. She concludes that both computers with communication software and dedicated VOCAs can be used successfully in school to support the communication of students with autism. Mirenda (2003) also refers to the “growing body of research” which indicates that AAC facilitates the growth of spoken language in people with autism.

At last year’s Communication Matters Conference, Gallimore et al (2005) described their introduction of high-tech dedicated VOCAs to two young people with autism. They reported a range of positive outcomes and suggest that VOCAs may “reveal a previous unknown language skill”.

Von Tezchner & Grove (2003) make reference to children with autism. They stress that the language achievements of all children with AAC are critically shaped by the
When choosing a communication aid never underestimate the importance of fast access. The MyTobii system allows users to select cells on the screen, simply by looking at them. It is widely considered the most accurate and effective form of access available on any system and must be seen to be believed.

The release of The Grid 2 coincides with the release of the new P10 from Smartbox. As pictured, the P10 houses a powerful PC, a touch-screen, switch connections, as well as the integrated MyTobii eye-gaze technology. Combined with The Grid 2 from Sensory Software, users can communicate, email, text message, surf, and write just by looking at the screen.

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attitudes and expectations within the child’s communication environment. Williams et al (2002) review the research into computer assisted learning in autism and describe positive outcomes which they link to its visual mode of presentation. Dinah Murray (1997) has suggested that computers provide a unique context for building communication with students with autism.

PROJECT OUTLINE
Our project aimed to explore the language and communication achievements of students with computer based VOCAs, in a functional context with their usual communication partners. We aimed to answer the question:

In what ways does access to a VOCA change the language and communication of primary aged children with both autism and severe expressive language disorder in class curricular activities?

Our methodology was based on principles of evidence-based practice and guided by Schlosser’s (2003) work in this field.

Two children Owen (aged 10) and David (aged 11) were included. Owen had no intelligible speech, he vocalised using a narrow range of single syllable sounds. David had some speech, typically single words of poor intelligibility, but little functional language.

The project ran for 12 weeks. The children were initially videoed in a science and maths lesson with no VOCA access, to collect baseline communication data. The children’s VOCA skills were then developed in individual sessions with their key worker and the speech and language therapist (SLT) throughout the project period. After 6 weeks, the VOCA was introduced into one class subject only, with no direct SLT support.

At the end of the project period, each child was again videoed in science and maths to investigate changes in their communicative behaviours. Parents and teachers completed a questionnaire at the start and end of the project to provide evaluative evidence for this review.

We attempted to evaluate each child’s attitude to the VOCA by providing them with a photo of the laptop within their PECS system; this enabled them to request it independently. Their key workers kept a diary to record the children’s laptop requests and other observations.

VOCA INTERVENTION
The programme for developing the children’s individual skills was based on principles drawn from sources including SCOPE (Hazell & Larcher 2005) and ACE Oxford (Moore & Gresswell 2004). We aimed to raise staff awareness and provide opportunities for discussion, but this project did not work directly on partner skills and the communicative environment. The main focus was expanding the child’s VOCA skills.

The intervention aimed to:

- **Build the child’s independence in accessing vocabulary.** Children were introduced to a master screen and practised vocabulary finding.
- **Expand language.** New vocabulary was regularly introduced and children worked on sentence building. Children’s interest materials were used to encourage creative and extended language.
- **Expand functional use.** Self expression cells were included. Games were introduced which encouraged children to use the VOCA in pragmatic ways, for example, directing, questioning and guessing.
- **Provide opportunities for unplanned learning.** Time was made to follow the child’s lead; building screens with the child which reflected the language of their interest.

DATA COLLECTION AND ANALYSIS
Changes in the boys’ language were measured by recording the total amount of vocabulary they used in the video records, expressed through sign, symbol, speech or VOCA. This provided quantitative data for analysis.

Changes in their communication were measured by recording their range and frequency of verbal and non verbal communicative acts. Communication behaviours were categorised using criteria drawn from The Pragmatics Profile of Everyday Communication Skills in School-Age Children (Dewart & Summers 1995).

Samples of video were re-analysed by three independent therapists to produce a measure of inter-observer reliability and support a consistent analysis of the video data (Figure 6).

Qualitative evidence was collected through the analysis of the questionnaires completed by parents and staff. The questionnaires explored feelings about communication aids, their priorities for the child and their observations of the child’s communication. The key worker diaries were used to find evidence for the child’s evaluation of the VOCA.

RESULTS
Video analysis showed that both children used most vocabulary when they had access to a VOCA and they included vocabulary in a greater proportion of their communicative acts (see Figure 7).
David used the VOCA and speech with similar frequencies often using the VOCA to answer and then repeating with speech, while Owen's VOCA use dominated his communication. After the intervention, the boys showed broadly similar individual patterns of communication when they had no VOCA access. However, when the VOCA was introduced, both students showed a marked fall in self expressive behaviours (Figure 8) while another behaviour increased.

Self expressive behaviours included Owen's hand biting and paper shaking, David's musical vocalisations, face tapping and putting fingers to his ears. For David, 'responses' increased as he continuously answered questions while Owen more often 'gave information'; shouting out relevant vocabulary to his teacher.

The questionnaires and interviews with parents and carers described generalised changes in the children's expression and communication.

"David's verbalising with other people. He asked Dawn to put his shoes on – and it was loud! Before he started using it I think he would have just sat there with his shoes...He's less passive". "David uses a lot of the language that we've been putting in the computer. He's used that knowledge that he's picked up from that particular screen and used that." (Class teacher)

"You can see him having a joke. A lot more interaction is initiated by him." (Owen's Key-worker)

Both teachers described changes in the boys' speech:

"He is starting to self correct when he talks – he'll say a word, then press it on the computer then he'll say what he hears." (David's teacher)

"He tries to vocalise and his vocalising's getting clearer." (Owen's teacher)

Parents' priority for their children was that they could express their feelings and needs. Both parents described positive changes in the boy's mood and self expression at the time they had access to the VOCA.

"He seems much more able to communicate his feelings/needs." (David's parents)

"It's relieved his frustration...he's more relaxed...mood is so much brighter." (Owen's parents)

Two recurrent themes in the parents' and staff records were a belief in the child's potential and a description of them as having exceeded expectations.

"Owen surprised us, we thought he'll never know all these words or use so much of it...he's making us adapt it to his needs." (Owen's key worker)

"David's communication has improved dramatically...he's exceeding expectations, with lots of hope for the future." (David's parents)
We were unable to collect enough data to draw reliable conclusions about the boys’ views.

CONCLUSIONS AND DISCUSSION

There are a series of challenges to the validity of the quantitative (video) data, as variables proved difficult to control in this busy specialist school. However taking the data as a whole, at the time the children had access to high-tech communication aids, changes in the children’s language and communicative behaviours were recorded which were evaluated very positively by those involved.

We suggest that the aids may have been doing three things.

• Supporting the boys’ language learning due to the aid’s visual organisation and consistent voice.

Our data describes spoken language progress during the VOCA intervention. Romski and Sevcik (1996) linked such progress to consistent auditory models and both children’s persistent VOCA voice imitation would corroborate this.

However, the speed with which children memorised word locations suggested that the VOCA’s visual organisation helped students to memorise, organise and access vocabulary and would agree with Williams et al (2002) that computers’ visual presentation may promote learning in students with ASD.

• Changing the expectations of the children’s communication partners; who expected more and understood the children better.

The video data pointed to very specific communication changes for each child when the VOCA was present. David responded more and Owen gave more information. Both of these behaviours could be explained through changes in their communication environment, rather than as changes in the child’s motivations.

In Owen’s case the stability recorded in his communication patterns supports the interpretation that it was not Owen who changed, but rather the listener. When Owen used the VOCA, he appears to have been better understood. Caregivers described their changed perceptions of the child’s abilities and potential; staff reported that students communicated with them more successfully and that their communications were easier to hear and understand. A primary impact of the VOCA may thus have been on staff, promoting changes in their understanding and expectations of the child.

• Provided a shared medium of communication which adult and child both understood and could use to explore and work out meanings together.

Informal review of the videos suggested that the aids became a communication mediator, they provided a commonly understood vocabulary and structure around which child and adult negotiated meaning. For example, Owen tried to label ‘hippo’ but had no word cell for it. As his teacher watched, he searched through his screens and finally offered “rhino”. “Yes, you know it isn’t a rhino” she replied, “but it is similar isn’t it?” This positive exchange illustrates how a skilled communication partner was able to work with the child and aid to establish the child’s meaning.

ASD practitioners take the development and support of visual communication to be central to their practice. However, high-tech AAC, which offers a voice and high memory capacity, is assumed not to be a tool to be explored with children with autism. We share Mirenda’s (2003) concern about the ways in which such decisions are made, given the lack of research and protocols for using AAC with people with autism.

This project supported our earlier observations that high-tech AAC could benefit students with autism and pointed to the need for proper research to inform practice in this area. On the basis of this pilot project Sheffield Hallam Autism Centre is working with us to secure funding to enable us to carry out a partnership research project in this area.

ISSUES ARISING FROM PRESENTATION

The presentation at Communication Matters raised a number of questions which we briefly answer here.

We also use lower tech AAC in school and find that it may act as a bridge to using high-tech. This was not necessary with the boys in the project. Their immediate level of interest and competence suggested that high-tech AAC was appropriate and after a period of exploration led us to this project to systematically evaluate their use of it.

However, with students who are distracted by the sensory or Internet access features of computers, we may use lower tech to introduce highly motivating communicative activities which can transfer to the computer.

Currently we do not have a clear view on the pre-requisite skills needed for aid use. We have generally found that we can usefully incorporate Clicker on a computer (with touch screen where needed) into the communication strategies of a range of children with autism, whatever their level of cognitive function, using a child centred approach, with expectations expanded very gradually.

Children with autism may have significant language difficulties; the aid is not simply giving them a voice, they explore language and learn new meaning through using it. This may take time. *

References


ESSENTIAL PUBLICATIONS
FROM COMMUNICATION MATTERS

The Power of Communication’ DVD
This DVD has been produced by Communication Matters to provide an introductory presentation on Augmentative and Alternative Communication (AAC). The film delivers a powerful message that communication really does matter. It celebrates and promotes communication in all its forms. The film is of general interest, and in particular to service managers and purchasers who have responsibility for AAC services.
Price: £8 (£20 for 3) inc. p&p from Communication Matters

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 AAC. It is useful for staff development, especially for those working with adults.
Price: £30 including p&p from Communication Matters

Waves of Words
The challenges confronting individuals with severe communication disabilities are chronicled in Waves of Words: Augmented Communicators Read and Write.
Price: £15 plus £1.50 p&p from Communication Matters

Safety in Numbers: A Photographic Phonebook
This photographic phone book is for people who find reading difficult. The pack includes an information page with key information about the person, several blank pages ready to add photographs or symbols, space for additional notes for an enabler, babysitter or other adult, a tag to make the book easy to hold as well as identifying the owner, and a page of symbols for common services printed on labels ready to stick in.
Price: £3.50 including p&p from Communication Matters

Communication Without Speech: AAC Around the World
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.
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Beneath the Surface
In August 2000, the creative works of 51 authors and artists from around the world were published in one 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.
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