# COMMUNICATION MATTERS

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## Role Models Working with Teenagers Using AAC

## **KATIE CLARKE**

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Since our first Role Model Project at Hothorpe Hall in Leicester in the summer of 2004, sponsored by Communication Matters, we have developed the project further to ensure that teenagers who use electronic communication aids are able to benefit from Role Model input. Being a teenager is hard enough but being a non-speaking disabled teenager is a tremendous challenge and young non-speaking disabled people have to overcome barriers everyday that most other young people never have to encounter. We feel that there are a lot of issues about growing up as a teenage communication aid user and that the best people to discuss this with are of course disabled adults. It is also a vital time for a young person to have positive role models around and for them to have a vision of what is possible during and after transition to adult life.

For these reasons we decided to develop the Role Model Project and applied for a grant from Children in Need to run a weekend summer event for disabled adults, teenagers and to include our annual National Network Day for families on the Sunday. The grant was successful and after searching around the country for a suitable venue we finally came across the beautiful Lilleshall National Sports Centre who were able to accommodate disabled people and families and had appropriate conference facilities.

Katie Caryer has been an enthusiastic member of our original Role Model team and was especially keen to be involved in a co-ordinating role. Katie spent hours and hours preparing for the weekend and planning the workshops for role models on the Friday afternoon, and the all day workshops for teenagers and role models on the Saturday. It was the first time for Katie to be responsible for organising and facilitating such an event and all the 1Voice committee and members are really grateful for her determination, effort, energy and commitment to make the event such a success. Well done Katie!

The event began on Friday 15 July at Lilleshall with Katie happily assisted by Tamsin Crothers and Kate Williams (part of our 1Voice committee) running the Role Model workshops. During the workshop the group discussed what makes a good role model and then set objectives in being proactive communicators with disabled young people and developing skills



Let the workshop begin!

working with teenagers and their families. Handouts included tips for communicating with disabled young people – useful for professionals, persons who come into contact with AAC users and our Role Model team. Toby Hewson, Axel Böhm, Matthew Goodsell, and Shelley Makin travelled from all corners of the country to attend and were most participative especially after a few drinks later on in the evening at the bar!

During the evening some of the teenagers arrived and ended up being 'inspired' in the bar and trying to keep up with the late night chatting of the role models. They were eventually forced to leave by their parents well after midnight. One of the tips should be "communicating with young disabled people after a few drinks of beer in the bar" and, although this was not on the handouts, this year it will be amended for our next event!

By 10am on the Saturday the rest of the teenagers arrived – again travelling from various parts of England to join the 1Voice Role Model team. Gregor, Nadia, Rosie, Beth, Jemima, Jody and Ruth had been asked beforehand to think about some of the good things in using an electronic communication aid and also some of the issues surrounding being a

teenager and relying on assisted communication. There were of course getting to know each other game, including seeing how many communication aid users you can get. Here are some of the comments:

"Even the youngest kids model themselves on others."

"Quite important to know we are not alone, the whole family gets used to some people using AAC."

"Inspirational."

"Very important, as parents it gives us the chance to talk to others and see how they have overcome their difference." "Important to see others, it's a very isolated existence so seeing others who struggle and do well is important."

"Vitally important, inspiring. Encouraged by every event to participate more especially in school. As parents gives us hope."

"Very important, our children have the opportunity to see what they can become – confident and articulate."

"Very important, it inspires my son with what he can achieve as he doesn't otherwise meet VOCA user. It is motivation for the whole family. Good to meet siblings who understand."

"Important to see AAC being used and hearing their views including what communication aids can/cannot do."

"Principle very sound."

"So, so, so important. Nathan is very inspired by them."
"I think I would have got on with my mum a lot better if she had met people with my disability when I was growing up."
"Extremely important and motivational, it inspires us all."



Sharing ideas with a Role Model

Axel Böhm has attended both Role Model Involvement Projects run by 1Voice and also has attended our Blackpool weekends. He writes:

"Lilleshall National Sports Centre and the warm summer weather were a beautiful setting for this year's meeting of role models, teenagers and families. And the food was very tasty and plentiful! Our concerns last summer, that we role models didn't really know how to communicate with the children, was addressed during the role model meeting on Friday. We were asked to think of interesting *open* questions for teenagers. We then chose and programmed two questions each to be ready for the next day, when we would meet the teenagers. We also filled two flip-charts with all the good and bad points about AAC.

It was not surprising that the teenagers the next day came up with most of the same points, for instance, on the bad list: too many breakdowns of the devices, outweighed by:



Even the adults enjoyed the face-painting

being able to talk and joke (not swear) with family, friends and strangers.

I enjoyed playing the story game, because everybody could take part and everybody enjoyed the game. In the pub in the evenings, it was funnily confusing to hear several people talk with the same voice.

In the sweltering heat of Sunday's family fun day with all its activities we had a chance to talk to many new people. I think it is good to meet up with other disabled people to see all the different communication devices in action. It was fun to be able to contribute to Wendy's idea of the filming of a video to tell the role models' stories.

Many thanks to Katie, Tamsin and all the others for this well organised weekend which gave pleasure to so many."

Liz Moulam a mother who came along to participate in our Teenage Project and is also an active committee member of 1Voice and trustee of Communication Matters. She writes:

"What a joy to see my daughter come into her own at Lilleshall. We arrived on Saturday for the Teenager's Workshop. Initially B. was apprehensive and held back on having a say, gradually she became braver and by the end of the day she was in full swing. At dinner Saturday night she joined in joke-telling around the table, laughing so much all you could see was a head balanced on a chin on the table. When we asked her at bedtime if she had learned anything she very proudly said, "Yes, how to talk in a group of communication aid users, taking turns." But more than that we have seen on a daily basis ever since the new confidence in using her communicator in every type of situation.

Working with peers and positive role models has been, and will continue to be, an important part of B.'s development. As parents we were delighted to meet and talk to other families/carers the whole weekend, the chance to network with people who understand our family challenges is always welcome. The highlight has to be meeting role models who are successful in their chosen fields, it shows us that B. can be anything she wants to be. Thank you!"

Matthew Goodsell attended our 1Voice weekend as a role model for the first time, but we are hoping it will not be any means by his last. He writes about 'the power of chat':

"I better open this by saying that, this morning, I feel more comfortable with my world than I have done for two or three years. during that time, I lamented my failings as a disabled person, and generally felt sorry for myself, but the last few months made me realise what rubbish that

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was – I am no more disabled than anyone else. My ramblings may still be ill-informed, but I am not a cripple.

I haven't, however, discovered some magical cure for cerebral palsy, well, not in the medical sense anyway. I have simply realised that I have as much potential as anyone else. With the right accommodation, the sky is the limit, and then only until NASA make a rocket with hand controls. In my chair I can go anywhere. In a sense, I am only disabled by steps, and then a ramp can be put in place. I cant talk clearly, but with my Lightwriter I am as eloquent as anyone. I am only disabled by the lack of ramps and Lightwriters; by environmental and social factors which can quite easily be resolved.

This brings me nicely on to this weekend. A few months ago, a friend – either Becca or Katie, I can't remember – asked me if I would be interested in volunteering to become a role model for 1Voice. This is an organisation which helps children and teenagers who use voice output communication aids, or VOCAs, by organising for them to interact with older voca users, or 'role models'. When Katie asked if I wanted to become a role model, outlining what it would be involved, I knew it would be a privilege. I seem to recall mum once saying she wished I had such a role model. At school, there were only four or five VOCA users, and I was the only non-oral person in my class. Thus, I did not know what could be done. The thought of going to university seemed far fetched - would everybody be patient enough to allow me to speak?

The answer to that is a resounding 'Yes', but I did not know that, aged fifteen or so. This is precisely why the Role Model Project is so great. If we can show these kids what can be done, they can realise their potential is as high as anyone else. There is, arguably, a tendency for young disabled people to think otherwise, but it is total rubbish: they can do GCSEs, A-levels; they can do anything. Yesterday afternoon, I was talking to a mother with a young daughter, and I told her I had no doubt that, eventually, she would go to university. This was not a throw away platitude: the girl was abundantly bright. With the right adaptations, and under the right conditions (this, of course, means a mainstream education) I do not have one iota of a doubt that this girl can fulfil any of her dreams.

I sincerely hope that the young people got as much from this weekend as I did. I remember eating dinner on Saturday with a young lady called Beth. I must admit that I was drawn towards Beth because she was a fellow Lightwriter user. She had a grin so wide and a face so bright that it



"It's good to talk with you..."



Making new friends

would almost dazzle you. We were telling jokes, and we were all falling about with laughter. When Beth told a joke, her face lit up with glee as we all fell about laughing. It had taken her some time to tap it in. I hope to remember that image for the rest of my life.

Then there was Adam, a small boy with hair so red he could almost be a Weasley. I watched him, yesterday, walk around, supported by his mum, picking up and throwing a ball, and I thought 'I remember doing exactly that with my mum'. I saw a lot of myself in those kids, and many of the problems they came up with during the brainstorming sessions were problems I had faced too. I had never felt less alone.

If I can help these kids by being a role model then it is my duty to do so. One parent told me a story. His son had only used his VOCA to do school-work, but after coming to IVoice he used his VOCA to chat to his friends and siblings, which he had ever done before. Chatting is an extremely important part of one's development, as is playing, so it was great to hear that IVoice enabled this child to realise he can do such things.

Thus this weekend made me remember things I had forgotten, and it taught me things I did not know. Katie was worried that I had a negative view of disability – I have waxed lyrical on my blog about how disabled kids were doomed to go into homes et cetera. What b\*\*\*\*\*\*! The day a person like Beth goes into a home is the day Satan wins gold at women's Olympic figureskating.

Thus to associate disability with boundaries is to associate the moon with good cream cheese. I can see no boundaries, no limitations to disabled people, provided that the right support structures are in place. 1Voice is one such structure, as vital as anything else. And if I can be a part of that, then I am honoured."

## FINALLY

As Chair of 1Voice I would like to thank Communication Matters for their constant support, BBC Children in Need, all the volunteers who attended the event, every role model who has participated in our family events since we began in 1998, the teenagers and their families who came for our unique and worthwhile day, all our family members, Katie Caryer and our Committee for their hard work and belief in our organisation. If anyone is interested in learning more about our work or would like to join 1Voice please, contact me on Tel. 0845 330 7862. \*

Katie Clarke, Chair of 1Voice Communicating Together

## **Multi-Level Tray Boards: Problems and Solutions**

### **HANNAH CURRY**

Paediatric Communication Aid Service, Claremont School, Henleaze Park, Westbury-on-Trym, Bristol BS9 4LR, UK Tel: 0117 924 7527

## **INTRODUCTION**

This paper discusses the need for accessible low-tech communication systems and describes a multi-level tray based design aimed at providing children with a larger vocabulary of symbols, photos or words. The author is based at Claremont School which is a local authority day school for children with physical disabilities. It has 59 children aged from 3 to 11 years. Some children have profound and complex learning needs and others are being included in mainstream schools on a part-time basis.

## **BACKGROUND**

Having worked for many years with a paediatric caseload requiring a range of AAC provision my colleagues and I are familiar with the various barriers to successful communication.

Beukelman and Mirenda (1998) discuss two types of barriers that limit communication. Those related to opportunities and to access:

"The mere provision of an AAC system is often not enough. Thus identification of actual or potential opportunity barriers is a critical component of the assessment process."

A range of low-tech systems have been introduced at Claremont school over the years including 'Talking Books', symbol topic boards and tray symbols. Various strategies have been adopted to improve ease of use for the communicator

and for the communication partner. These include page dividers, list of contents and tags on pages, an explanation of how the child accesses the system with photo if appropriate and symbols requesting AAC systems stuck on individual trays. Children whose means of access is eye-pointing, and who require a larger vocabulary will be introduced to a colour-coded method to attempt to maximize vocabulary. Having consulted the communicator and communication partners on relevant vocabulary, design and format and found the time to create the low-tech system we found that we were frequently disappointed at the limited use our 'masterpiece' was getting.

## AVAILABILITY OF SYSTEMS

In order to increase the individual's access to their low-tech system we have tried various strategies including:

- Including use of AAC systems into IEP (Individual Education Profile) targets.
- Hanging books on chairs.
- Positioning symbols onto trays so children can ask for their communication systems.
- Incorporating curriculum topic and activity symbols into individual systems to encourage use during specific sessions.

Although there has been a significant increase in the use of AAC systems, generally we still felt that opportunities for communication were frequently

missed as the systems were not available throughout the day. We observed the following:

- As the AAC system tended to be used at specific times in the day the child would tend to be using it in response to others rather than initiating their own communication.
- Children were using their own nonverbal means to initiate communication very successfully to achieve goals. This would involve eye-pointing, pointing, body movements, gross gesture, yes/ no responses and a process of guesswork (often lengthy) from the communication partner. This reduced the motivation from both sides to access a low-tech system which may not include the relevant vocabulary anyway.
- Communication tended to be restricted to concrete ideas in the 'here and now'. This is severely limiting for children whose non-verbal language skills were at the top end of Key Stage 1 and who need opportunities to use imaginative language, to talk about the future and the past and generally 'play' with spontaneous language.

Calculator and Dollaghan, (1982) concluded that a frequently identified characteristic of the communication of individuals with high support needs is a lack of spontaneity. They report that teachers were much more likely to respond to student responses than they were to student initiations. Carter, (2003) found that the least spontaneous AAC





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modes used by 23 children in class were symbol, graphic and object systems. Grunsell and Carter, (2002) reported an attempt to establish relatively spontaneous out-of-routine requesting. The findings reinforced the need to provide constant access to symbols.

We, therefore, decided to develop a multi-level system of symbol boards which could be 'anchored' to the children's trays.

## **THE PROCESS**

As part of the process of achieving constant availability we decided to give many of the low-tech systems in the school a major overhaul.

## 1. Vocabulary review

- A questionnaire was sent to parents and staff ascertaining views on relevant vocabulary and encouraging consultation of the child.
- The 'social' page from the Boardmaker symbol dictionary was read out to more able children for their views on the inclusion (or not) of particular 'buzz' words.
- Symbol boards were sent back and forth to home for adjustment and fine tuning.

## 2. Design of the boards

- The size and shape of trays: Including the possible presence of a joystick in the centre of the tray.
- The angle of the boards: Some children need symbols presented at 45 degrees. Our local *Remap* volunteer was asked to make wooden wedges to fit individual trays and boards were 'anchored' to the wedges.
- Symbol and text size: This varied according to ability and accessing method of the child.
- A list of contents has been included on more complex boards on every page so the child can request a particular page.
- Tags have been included on some systems though this has proved problematic in some instances due to the shaped edge of the trays.

## 3. Perspex covers

The boards are laminated and to protect them further from strong extension patterns and art and cookery materials REMAP was asked to cut perspex sheets to fit individual trays. This ensured that the boards could be available during messy sessions and meal-times.

## 4. Attachment to the tray

We have been using large ring binder rings (available from stationers) to hold

the boards onto the trays. Two holes are drilled in the outer edge of the tray having sought permission from the relevant parties first. The school caretaker has been very helpful with this and I have also discovered the fun of wielding a drill! As the rings go right through the tray the boards are able to hang vertically from the edge of the tray when not in use. The rings also enable the boards to be removed completely from the tray and for new boards to be added when necessary.





## PRACTICAL PROBLEMS AND SOLUTIONS

• As always in this field of work practical problems arise. Round trays are difficult to work with as the boards have to fit the tray and then do not have a straight edge so the width of attachment is very narrow. Some of the children that we have developed the multi-level tray boards for have then been provided with a new chair and tray of a new size or shape, requiring a total re-make of the system. I now ask the physiotherapists when a child's chair may be changing before embarking on a new system.

• Unfortunately over time the hinge on the ring weakens. We have also found that the rings do not withstand being bashed into door frames on the electric chairs. The other problem is that the holes in the laminated boards can tear and the boards then drop off the rings. The systems were requiring weekly maintenance which was an added pressure on staff time.

The idea had met with initial enthusiasm from staff but this was waning in the light of the difficulties with the attachment system.

At this point I decided to contact the Bath Institute of Medical Engineering (BIME) which is a non-profit making charity working in medical engineering, with a major focus on disability equipment. Its designers take on projects from discussions of clinical problems and work closely with disabled people, therapists and others to develop solutions. Once a design has been shown to be successful it is developed for commercial production. BIME are currently working on a diverse range of projects including a wheelchair mounted robot and a portable toilet seat.

Having described my problem to the BIME panel and assured them that the equipment would be beneficial to many people they kindly decided to accept the project. They are currently developing two possible designs for attaching the boards to trays (Figures 1 & 2). When



Figure 1 Prototype ring attachment

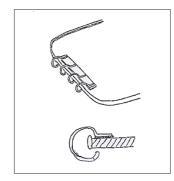


Figure 2 Prototype ring attachment

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the prototypes are ready we will be able to trial them in school.

## **FEEDBACK FROM STAFF**

Most of the feedback from staff, parents and children has been positive. Some children with fewer symbols per board are still only using the boards in response at specific times in the day. The children with more complex boards are using them spontaneously communicate messages. One member of staff reported that after trying the usual 'guessing game' exhaustively she encouraged the child to find what he wanted to say on his master board (the boards were new to him at this stage). Although he was upset he was able to do this and the situation was resolved. The member of staff commented that she would never have guessed what he was trying to say "in a million years". One child does not like the idea of the boards being on his tray and prefers to concentrate on getting to know his new dynamic screen VOCA. We received some negative feedback from staff has been about the attachment problems mentioned previously. One

comment was that it took a child too long to communicate why he didn't want to go with the orthoptist and when he did manage to find the desired symbol it was to be rude about the visiting professional! This led to a useful and interesting discussion with the teacher about everyone's responsibility to reinforce social appropriateness. I was able to point out that as the child became more familiar with the boards he would get quicker at finding the symbol he wanted. Also we agreed that it was not always possible or even appropriate for adults to stop (e.g. in the middle of a lesson) to have a long interaction with an individual child and this was part of the social learning process for the children. However, we should not deny non-verbal children the opportunity to spontaneously communicate any message by not having an accessible system there when they need it.

## CONCLUSION

There have been many highs and lows over the last as year as part of the process of creating multi-level tray boards that remain with the child throughout the day. We know that spontaneous communication has improved for some children. This has been observed in our own group sessions and reported on by other staff. We are hopeful that our collaboration with BIME will result in an attachment design that is easy to use and effective.

Watch this space... \*

Hannah Curry, Speech & Language Therapist

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## **ANDREW BROWN**

It was great sadness that we heard that Andrew Brown had passed away in August 2005.

Andrew was an engineer at Chailey Heritage for many years, and since then has been working in the field of assessment for mobility and assistive technology, as an independent consultant.

During his time at Chailey, Andrew, with groundbreaking Technical Director Nigel Ring and speech and language therapist Valerie Moffat, was absolutely at the forefront of development and support of AAC in the UK. He did pioneering work with many of the UK's first ever AAC users, children starting to use Bliss symbols back in the 1970s and 1980s, and played a key role in getting them up and running with specially designed wheelchair mountings, communication chart covers, E-tran frames, switches -whatever it took!

He spearheaded the introduction of computers and special access systems for individual users and provided much needed encouragement, training and technical support for therapy and teacher colleagues. In those days, he was designing and making equipment, writing software and building switches and interfaces from scratch! As well as pioneering AAC work, Andrew, with his colleagues, worked on many developments, large and small, that have trans-

formed life for people with severe physical and communication disabilities – experimentation with different materials, necklace 'bead' switches, early keyboard emulators, the popular CAPS II seating systems, and with Martin Langner and Carole Thornett, the innovative Chailey track-following wheel-chairs and mobility training platforms.

Developments at Chailey with which Andrew was involved could always be relied upon to be child-centred and practical, as well as innovative. He worked closely with parents, teachers and therapists as well as with medical staff, and created a role-model for the caring and interdisciplinary team-working engineer.

Andrew will be remembered as a dedicated, thoughtful, innovative and helpful colleague who "was always willing to go that extra mile to ensure everything was exactly right for all concerned".

Andrew served as a member of the UK Bliss Symbols Committee for many years (and probably lots of other professional committees and good works that we don't know about, because he was always very quiet and modest) and always remained a loyal and staunch supporter of Bliss.

Our deepest sympathies go to Andrew's wife and family.

The UK Bliss Symbols Committee

# Children with Autism Spectrum Disorder using VOCAs?

## **ALICE GALLIMORE, MIRANDA MACAULAY & NIKKY STEINER**

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## INTRODUCTION

As speech and language therapists working in the field of Augmentative and Alternative Communication in Lambeth, Lewisham and Southwark we have become interested in the issues relating to Voice Output Communication Aids (VOCAs) and children with a diagnosis of Autistic spectrum Disorder. This interest was further developed following the London CAP Brainstorm Day, 'AAC and Children with Autism', in January 2004.

Following this meeting we decided to take three contrasting case studies of children with autism and learning disabilities and explore the following questions:

- What is the added value of introducing a VOCA for this individual?
- Are there specific issues when using VOCAs with children with autism?
- Are there specific support and training considerations?

## **CASE STUDY 1: AARON**

Aaron is a 16 year old student who attends a secondary school for students with complex needs. He also has a link placement in a mainstream school. His understanding of language is at a 2-3 key word level and he has a wide receptive vocabulary. Prior to the introduction

of a VOCA, he used Makaton signs as his primary mode of expressive communication. These were very rapid and not easily understood by unfamiliar people. Aaron used Makaton in school in response to direct questions or when prompted by the context such as using the sign BISCUIT during snacktime. In conversation with his mother, he showed increased spontaneous use of signs and longer sequences of signs. He would typically use signs to make requests, greetings and occasional comments, for example, 'boat' and 'look'. However, school staff, therapists and his mother continued to be concerned about the intelligibility of his signing at school and in the wider community.

The Picture Exchange Communication System (PECS), was introduced but was difficult to support in school/home due to school staff's lack of training and motivation. Aaron has always been highly motivated by computers and has excellent visual skills. The speech and language therapist suggested a trial of a DynaVox (a large dynamic screen VOCA) which was judged to be successful at home by his mother and a speech and language therapist. He was quickly able to use a wider vocabulary and became more intelligible with extended family and friends. Aaron

obtained a DynaMyte (portable version of DynaVox) via CAP funding.

## Outcome with Use of VOCA

Aaron needed a structured introduction to the VOCA. Training was needed to encourage staff to provide frequent opportunities for Aaron to use the VOCA in the classroom. He was initially given verbal and physical prompting including hand-over-hand support and verbal instructions, such as "Press Clear", which was later reduced to no physical prompting and contextual verbal cues such as "What do you want?" Aaron quickly transferred his requesting skills to the VOCA to make needs-based requests, e.g. "I want lotion please" thus increasing the length of his utterance and intelligibility. He is now using his VOCA for communication functions such as greetings and responding to questions with increased intelligibility, wider vocabulary and length of utterance. He has used his VOCA to spontaneously express his emotions, for example, "I feel cross". This was a skill not previously shown through use of Makaton signs.

Aaron initially pressed buttons repeatedly to self-stimulate although this has reduced with adult support. He also explored the VOCA by forming long sentences e.g. "I want waterspray waterspray waterspray". This was inter-

preted as verbal play. Aaron can use command keys such as clear and repeat the message by hitting the message window. A password is needed to prevent him from accessing the programming controls.

## **CASE STUDY 2: KEITH**

Keith is 8 years old with diagnoses including autism and moderate learning difficulties. He is also registered blind and attends a mainstream primary school. Keith's expressive and receptive language skills are at 2-3 year level with limited functional use of speech and some echolalia.

His language includes stereotypical and learnt phrases. For example, he is able to spontaneously say, "I think I prefer today to go on the slide rather than the swing". In contrast, Keith is rarely able to say, "Yes Mr X" to join in registration. This atypical language learning pattern can be a feature of autism, as is the difficulty in attending to adult speech in group settings such as carpet time.

School staff and Keith's mother requested consideration of a VOCA thinking that technology should be able to provide some support for his communication. Two situations where it was felt that communication was difficult were identified. These were answering his name at registration time twice daily and taking a simple message home to his mother.

## Outcome of Use of VOCA

A BigMack was trialled. Keith was able to join in registration when given the BigMack at the appropriate time and was motivated to do so. Staff reported an increase in his verbal response at registration and felt highly positive about the introduction of the device. However this increased verbal response may be attributed to the BigMack serving the function of an object cue rather than a VOCA. It is possible that giving Keith another object cue, such as a small piece of carpet, with a consistent verbal cue ("Yes Mr X"), might also have increased his verbal responses.

Keith was observed to record his voice onto the VOCA and press it repeatedly both at home and school. This was interpreted by the Speech and Language Therapist and his mother as self stimulatory rather than communicative use of the BigMack. For example, Keith appeared to be absorbed in the process of recording and listening to his voice rather than sharing the message with another person.

Future plans for Keith include introduction of object cues to support choice making eg Keith to learn to hand a tape to an adult to request music.

### **CASE STUDY 3: GARY**

Gary is an 18 year old student with autism and severe learning disability. He attends a secondary school for students with severe learning disability. He understands sentences containing approximately 3 key words. He has no speech but can vocalise to express some basic emotions. He has some literacy skills as well as excellent visual discrimination skills. He is an effective and skilful PECS user (Stage 6), e.g. can make requests with symbols: *I WANT BROWN BREAD AND BUTTER*; and comments: *I SEE 4 RED BRICKS*.

Several limitations with PECS were identified which included difficulty for staff in managing and providing large numbers of symbols for Gary to use. Gary's access to vocabulary was also often limited by the task e.g. he only had access to what the speech and language therapist or teacher had put in his PECS folder or symbol topic board.

Gary initially trialled a MessageMate (a small static display VOCA with pre-recorded messages) in structured literacy activities. He was highly motivated by the MessageMate and his Speech and Language Therapist suggested trial of a DynaMyte.

## Outcome of Use of VOCA (DynaMyte)

Gary quickly demonstrated excellent navigation and use of command buttons. In addition to making requests, e.g. "Can I have sweets please", he was able to answer simple autobiographical information, e.g. "When is your birthday?" Questions written using symbols were initially provided to aid Gary's understanding of language. These were gradually faded. Gary became echolalic with his VOCA if the questions were too abstract. For example, in response to the question "What did you do at the weekend?" he replied, "Weekend."

Gary demonstrated good naming skills by using the VOCA dictionary which is organised into categories. This provided him with access to a much broader vocabulary than possible through PECS or a pre-recorded device e.g. MessageMate. He learnt to select from this wider vocabulary to contribute ideas in lessons, e.g. story writing. However he continued to have difficulty with imagination and novel thought.

In addition, Gary's greetings became more formalised with the VOCA but not necessarily more functionally effective. Gary often chose to greet in Spanish but did not always gain joint attention with his communicative partner. Prior to the introduction of the VOCA, Gary had relied on a handshake to greet with. Therefore the handshake was encouraged and felt to be a more appropriate greeting.

There were some unexpected positive benefits for Gary using the VOCA. For example he displayed a sense of humour and developed a friendship with a peer, who also uses a VOCA. Gary enjoyed teasing the speech and language therapist by copying a peer, repeating a phrase and laughing at the therapist and peer's response. Gary and his peer engaged in some simple word play and turn taking games which occurred spontaneously without adult facilitation. For example on school journey they took turns to operate their VOCAs to interact with each other.

Continued support was required to provide Gary with regular opportunities to develop and use his skills within the classroom and wider community. Ownership of the VOCA was well established and he was able to switch between modes e.g. PECS, some gesture/sign, and VOCA. Training and specialist support was identified as being a significant factor in promoting Gary's use of his VOCA.

## **EVALUATION OF VOCA EFFECTIVENESS**

Our case studies suggest that for some children with autism a VOCA can add to their communicative abilities and functions, although these may develop in an idiosyncratic style. Whilst there was evidence of some echolalic and self stimulatory use of the VOCA, it was felt that this did not significantly detract from the overall functional communicative gains.

## **Honest Approach**

We identified that an honest approach with parents/carers and staff is beneficial to encourage realistic expectations and goals. There may be an expectation that technology will solve the child's communication difficulties.

It is our experience that introduction of a VOCA did not 'cure' the autism as the style of communication remained disordered. It is helpful to discuss expectations of everyone involved prior and during the introduction of a VOCA. On-going review and evaluation of the usefulness of the VOCA is essential.

## Vocabulary

The case studies of Gary and Aaron showed there were some positive benefits of introduction of a VOCA.

A VOCA can provide access to a much broader vocabulary than is practically manageable on low tech systems such as PECS or symbol books.

In addition, more novel vocabulary can be spontaneously selected by the individual. Dynamic screens and a dictionary facility or keyboard may also be particularly useful.

These facilities may reveal a previously unknown language skill, such as Gary's ability to categorise words and Aaron's ability to express his emotions. Gary and Aaron both demonstrated particular skills in VOCA use e.g. quickly navigating through pages, excellent visual discrimination and literacy skills. In addition they were motivated by technology.

## **Training and Support**

As with all AAC systems training and support is crucial to ensure success. With our case studies it was found that particular attention needed to be given to training around use of prompting strategies and generalisation of skills.

Prompting strategies may include physical prompting, verbal prompting, imitation, and visual cues. It is essential to consider which strategies will be used and how they will be faded out. Some prompts such as verbal prompts may be more difficult to fade. Children with autism may also have specific difficulties generalising skills, therefore skills should be taught in a range of situations with different communication partners.

## **Ownership**

Ownership of the device was also identified as being essential if the child is to incorporate a VOCA into their everyday communication. The environment often needs to be engineered to encourage ownership of the device. For example using physical prompts to encourage the child to collect and carry the VOCA. All involved need to have high expectations and create opportunities for use of the VOCA.

## **Developing Criteria**

We suggest the need to develop some criteria to help with the decision of when and if to introduce a VOCA. Our experience working with a small number of children/young adults with autism led us to draft the following criteria to help guide our clinical practice. Unless these criteria are met, we suggest that it is unlikely that a VOCA would be successful long-term.

- Use of Baseline assessment of child's functional communication identifies limitations in communication modes and functions eg vocabulary limited by current system, restricted ability to participate in social routines, poor intelligibility, that may be met through introduction of a VOCA.
- Assessment of the environment shows staff/parents are motivated to participate in ongoing training and support. An identified member of the team is needed to lead in programming and maintenance of the VOCA. Ongoing access to specialist support in AAC is necessary.
- A trial period to evaluate functional gains is essential.
- During the trial:
  - 1. The child demonstrates communicative use of the VOCA (although self stimulation with VOCA may also be evident).
  - 2. The child responds to prompts to stop self stimulation with the VOCA.
  - The child shows motivation to use the VOCA eg within a structured situation s/he will use the VOCA with minimal encouragement.

## High & Low Tech

All the children in our case studies had an additional learning difficulty and a unique profile of skills and needs. The relationship between their core deficits within autism further added to the complexity of their profiles. This made it difficult to predict the outcome of using a VOCA.

We continue to believe that for some children/adults a low tech solution such as PECS or Makaton signing will be the most appropriate system. Similarly, for all children who use VOCAs, a low tech back up is essential. Nevertheless, these cases studies demonstrated to us that it is important to consider the use of a VOCA as one of the AAC communication options for children with autism. \*

Alice Gallimore Specialist SLT, Lewisham PCT Miranda Macaulay Specialist SLT, Lambeth PCT Nikky Steiner Specialist SLT, Southwark PCT

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# Assessing Young People with Complex Needs

## How should we do it?

## **GILLIAN TAYLOR, ANN GRESSWELL & RACHEL MOORE**

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### **INTRODUCTION**

The ACE Centre Advisory Trust is a national centre which focuses on how computer and communication technology can help young people who have complex physical and communication difficulties.

This paper, presented at the Communication Matters National Symposium 2004, was produced as a result of the ACE Centre re-evaluating its assessment procedures in the light of the Communication Aids Project (CAP). The aim of the paper was to examine which issues are important when assessing ways to support the communication of young people with complex needs. The ACE Centre's model of assessment was presented as a means to highlight issues and form the basis for discussion.

The session encouraged participants to consider what happens before, during and after an assessment in order to achieve the best possible outcome for all involved, particularly the young person.

## PRE-ASSESSMENT PLANNING

The ACE Centre believes that pre-assessment planning is a vitally important part of its assessment process. ACE Centre pre-assessment planning consists of three main parts.

## 1. Information gathering

This involves gathering information that could impact on the young person's communication and use of technology. The ACE Centre team gathers detailed information about a student's interests, motivation, physical abilities, hearing, vision (including perception), communication skills, seating and positioning issues, education (National Curriculum or 'P' levels), use of technology and medication.

This information is gathered through telephone calls to the young person's parents, school and therapists, a background information form, preassessment visits/meetings where practical, video conferencing and video footage of the student in their home/school environment.

## 2. Practicalities

This part of the pre-assessment planning involves making decisions regarding the following:

- Who needs to be on the assessment team. Interdisciplinary working between speech and language therapist, teacher and occupational therapist/physiotherapist is highly valued at the ACE Centre. Other relevant professionals are asked to join the team as appropriate.
- Who else needs to be involved. This includes parents, the young person's local therapists, class teacher, learning support assistant, LEA advisory teacher, education officer / funder and any other relevant people involved in meeting the needs of the young person.
- Where the assessment will be held. This may be at school, home, the ACE Centre or a specialist centre, depend-

ing on a range of factors. These factors include what is thought to be the best environment for the young person and what space might be available.

When the ACE Centre is used it is fortunate in having an assessment room and adjoining observation room from which people can observe the assessment via video links. This means that a young person can work in a quiet, uncluttered environment whilst the adults can observe and chat. It is accepted that such an ideal situation is not always possible elsewhere, but every effort is made to ensure that the assessment environment is as relaxed as possible, without having to exclude people who are essential to the assessment process.

## 3. Preparation of equipment and activities

When assessing a young person with complex physical and communication needs, it is likely that a wide range of equipment will need to be available. This might include equipment to enable physical control of technology, simple equipment for cause and effect activities, a range of voice output communication aids (VOCAs), computer and appropriate software and other communication aids such as symbols, E-tran frame, etc.

The ACE Centre team plans assessment activities carefully, focusing on what needs to be learned about the young person. Every effort is made to provide activities which are fun and motivating for the young person, based on the gathered background information.

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It is acknowledged that such detailed preassessment planning is time-consuming, but the ACE Centre strongly believes that the benefits for the young person are worth the effort and time spent.

## THE ASSESSMENT

An ACE Centre assessment has three main aims:

- To find a way for the young person to achieve accurate control of the computer, communication aid and other relevant equipment, including symbol charts/books. This starts with considering seating and positioning issues to maximise the young person's physical abilities.
- To identify ways to enhance the young person's existing communication skills. This includes looking at the young person's use of signing, symbols and voice output communication aids (VOCAs), as appropriate.
- To identify ways to enhance the young person's access to learning and the curriculum through the use of appropriate computer software.

## **Principles of an ACE Centre assessment**

- It should be fun, motivating and interesting for the young person. However, even with the most thorough planning, a young person's idea of fun sometimes turns out to be a surprise. For example, writing a story may end up being more motivating than the planned dressing-up game.
- The views of the young person are listened to at every opportunity.
- It should be flexible. Young people with complex needs often present unforeseen surprises, causing all the carefully made plans to be abandoned.

- Open communication between all involved. The assessment team attempt to invite and listen to the opinions of others throughout the process. Also to feed back and sum up regularly to ensure that everyone fully understands what is happening.
- Team working close interdisciplinary working between a range of professionals.
- Assessments are videoed whenever possible.
- All involved should leave the assessment with a clear understanding of the decisions that have been made. They should also be aware of who is taking responsibility for putting different aspects of the recommendations into action.

### AFTER THE ASSESSMENT

• Report writing — The ACE Centre produces a detailed report following each assessment.

Much time is spent on the report and it often includes diagrams or photographs showing the exact positioning of equipment. The report provides a record of the assessment, but the ACE Centre also attempts to make the report into a useful working document, giving the young person's local team clear guidelines for carrying out the recommendations. Parents and/or others may have the opportunity to contribute to the report.

• Feedback to significant people who were not able to attend the assessment — The co-ordinating member of the ACE Centre assessment team will often make telephone calls to those unable to attend the assessment, if necessary.

- Loan of equipment It is often necessary for a young person to have a trial period using a device before a final decision can be made. Equipment is loaned for this where possible, either from the ACE Centre, LEA advisors or device suppliers.
- Support and training One outcome of an ACE Centre assessment is to identify the training and support needs of those involved. Sources of support and training are identified within the young person's LEA, where possible. The ACE Centre also offers post-assessment support and training via information days, video conferencing, email and telephone calls.
- Follow-up The need and timescale for follow-up contact are decided at the initial assessment. The ACE Centre requests a video of the young person after a pre-arranged time and the nature of the follow-up is dependent on what progress has been made.
- Further assessment It is sometimes necessary for further assessment to take place following a trial period of the initial recommendations.

## **SUMMARY**

There is no 'right way' to carry out an assessment with a young person with complex physical and communication difficulties, and no two assessments are ever the same. This paper highlights some of the issues which the ACE Centre believes are significant in achieving the best possible outcome for the young person and their family. \*

Gillian Taylor, Occupational Therapist Ann Gresswell, Teacher and Physiotherapist Rachel Moore, Speech and Language Therapist



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# Developing Mathematical Thinking in Children with Little or No Expressive Language

### **DEBITAYLOR & WENDY CHATTERLEY**

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## INTRODUCTION

The Futcher School in Portsmouth is a small state school for physically disabled children who have associated learning difficulties. There are currently 72 pupils on the school's roll. As with many other special schools the profile of the pupils that attend the school has dramatically changed and there are many more children with profound and multiple learning difficulties and children who have little or no spoken language.

The Communication Department was set up in 1994 and is a fairly unique department. It is staffed by a teacher and three learning support assistants and supports approximately seventy per cent of the school's population. It currently has sixteen pupils using VOCAs as their main method of communication. Part of the role of the department is to support all the VOCA users in accessing all areas of the curriculum, including Mathematics.

## **KEY ISSUES**

The teaching of mathematics, in particular the instilling of understanding of number concepts, has presented particular difficulties.

The key issues have been those of time: time for programming of devices and preparing symbols charts; time needed for pupils to respond and demonstrate learning, and time for staff training. We work to ground mathematical concepts into real life contexts so that they are

meaningful and support independence, and to establish reliable communication particularly for pupils with profound and multiple disabilities including the use of mathematical vocabulary. A further challenge is, of course, motivation.

## **DEVELOPING SKILLS**

Pupils working at the National Curriculum Pre- Levels 1 to 3 need to develop those skills which will lead to an understanding of mathematical concepts.

## **Pre-intentional level**

Some, if not most, of their communication will be at a pre-intentional level and staff will need to interpret their actions in order to give them meaning and power.

For example, a pupil who enjoys rocking in the soft room may give a signal when the rocking is stopped, which can be interpreted as "more". The person working with that pupil can use the word "more" and repeat the activity. It is when this signal becomes consistent that the communication becomes intentional.

## **Object permanence**

The concept of object permanence is important at this level and can be developed through games such as peek-a-boo and very simple hide and seek.

These activities can also be used to encourage anticipation which is another important skill leading to prediction.

## **Body awareness**

Body awareness and the numbers relating to the body can be taught at this stage through activities, songs, rhymes and stories.

## **Exploration and making choices**

Pupils must have opportunities to explore, investigate and experience a variety of environments and make nonverbal decisions and choices about them. This may simply be an indication of like or dislike or more deliberate choices about activities, equipment or personnel.

Mathematics and mathematical vocabulary should permeate the curriculum and involve everyday objects and experiences.

The involvement of mathematics in everyday activities should continue for those working at Pre Levels 4 to 8.

Communication through facial expression, eye pointing, gesture, photographs and symbols and signing can demonstrate understanding of simple numbers (e.g. one or more than one), indicate choice (e.g. the small/big piece of cake), and ask for more. One-step communicators and other first VOCAs enable the pupil to have a voice and use it.

## Time and prediction

The concepts of time and prediction can be developed through sequencing and symbols or photographs creating a time table.

An understanding of shape and space begins with matching, simple puzzles and finding things that are the same and different.

### **MOTIVATION**

It is very important always to use real objects and correct mathematical language, but also to motivate the pupils and enhance their learning through fun. It is always more interesting to make your teacher jump off the chair one more time than to have one more brick. It is more motivating to use your real coins to buy a bar of chocolate in a shop than to use a cardboard coin to 'buy' an empty cardboard box. It is also more supportive of communication and life skills.

## **PLANNING ACTIVITIES**

The National Numeracy Strategy is not very user friendly for pupils using AAC. The oral mental starter presents particular problems. There has to be a compromise between the desire for pace and the need to give a child using a VOCA or written numbers time to respond.

Planning is at the heart of success in this area. A teacher who knows exactly what questions are to be asked can give the pupil using AAC enough possible answers to be taxing, but not enough to make selection very time consuming. Even the choice of two numbers on two one-step communicators, can, if used imaginatively, give a child a real opportunity to join in and demonstrate knowledge.

Software such as Clicker or Talking Textease can be used to give the pupil a voice if a VOCA is not available. The training of the Learning Support Assistant is also vital. It is so easy to respond for a pupil or correct him or her if the wrong answer has been selected, but the child needs to make his own contribution and, sometimes, his own mistakes.

The main activity is easier to manage as each pupil, speaking or non-speaking, can work at his or her own level, independently or with support. Pupils using AAC may need extra help, however, in some key areas of mathematical understanding, particularly if they also have a physical disability.

Problem solving is difficult if discussion and debate are impossible and the pupil has had little experience of having to solve problems because everything has to be done for him. Practice and structure are helpful and, once again, involving the pupil in real life situations where he has to think of solutions to his personal and mathematical problems, for example does he have enough sausages for all his friends to have two each, and how is he going to cook them?

Group work involvement also needs support and careful planning if the pupils using AAC is to benefit from it. They must be given time to respond and say all they want to, but this may cause other pupils to lose interest while they wait. A few key phrases together with a number line which can be accessed quickly and easily will often solve the problem, if the questions are put sensitively and with a knowledge of what responses pupils have available.

### ASSESSMENT OF SKILLS

Assessment of the mathematical skills and knowledge of non speaking pupils must be very carefully planned as many may have difficulty demonstrating what they know.

A communication system which enables the child to say that he or she does or does not understand, that has key vocabulary and phrases such as "It is bigger", "That doesn't fit" or "I know the answer but need a bit more time", and a number line or square are essential. Time and the determination to make the assessment as accurate and meaningful as possible will also be needed.

## **FINALLY**

Research has highlighted a number of impairments suffered by children with expressive language difficulties, which have a particular impact on mathematical learning. These include difficulties in memory, problem solving, poor self esteem and low expectations, poor listening skills and attention span and a lack of experience in everyday activities.

There is also a difficulty for their teachers in knowing what the child knows and understands and what he or she needs more help with.

If the teaching of mathematics is designed to overcome these difficulties and teachers are prepared to give the time and commitment necessary to make lessons accessible and meaningful for these pupils, progress will be made

Perhaps the most important thing to remember is that mathematics is much easier to learn when it is fun and children who are excited and motivated by the work given to them will work harder. \*

Debi Taylor & Wendy Chatterley Communication Coordinators

## JOINING COMMUNICATION MATTERS & ISAAC

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

## What are the benefits of Membership?

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

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Formed in 1983, ISAAC is a multidisciplinary organization devoted to advancing the field of augmentative and alternative communication. ISAAC has over 3,000 members in more than 50 countries, including 15 national chapters in Australia, Canada, Denmark, Finland, French speaking countries, German speaking countries, Ireland, Israel, Italy, Netherlands-Flanders, Norway, Spain, Sweden, United Kingdom and the USA. The Mission of ISAAC is to promote the best possible communication for people with complex communication needs. The vision of ISAAC is that AAC will be recognized, valued and used throughout the world.

## How do I become a Member?

If you live in the UK, you can become a member of Communication Matters (and therefore of ISAAC) by contacting:
Communication Matters
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## **My Life Book**

### KATE M.

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



### **INTRODUCTION**

All children with speech difficulties and walking difficulties have to believe in themselves. I believe in myself, I can do anything if I want!

I think I began to believe in myself when I was 9 and started to go to Mandy at a Conductive Education school. She has made me believe in my talking, she makes me slow down and really work on every word. I can really recommend her to anyone with mobility challenges like me.

When I leave school I think I would like to be a teacher, but first I could be a role model like Katie Caryer and Toby Hewson at



Using the Lightwriter

1Voice Communicating Together<sup>1</sup>. Perhaps I could also be a role model for children who have Janet Larcher<sup>2</sup> as their AAC Consultant. If Janet agrees maybe she can phone me to find out what life is all about with a communication aid. I now have a Lightwriter<sup>3</sup> - it's great! It lets me go out and be able to talk to friends, everyone at school and use it really anywhere.

Now I'm 11 and I will be starting at secondary school in September. This is my life story. It's about how I felt without a communication aid, how I feel now and what I hope for in the future.

## **USING COMMUNICATORS**

Before I had my Dynavox<sup>4</sup> I felt left out, I couldn't talk to my friends, only Mum and Dad and my special friend Carol understood me. I got the Dynavox when I was 4 and starting school, it was difficult because learning all the pages and links took a long time. Often the teachers didn't let me use it as they were busy and it made me very sad. Although I didn't need it at home Mum started to make me use it for a bit every day.

When I was 8 I started using word prediction so I didn't have to go through all the pages to find the words I wanted. Janet Larcher found me a different notepad to use when I was 9 but it didn't have a loud voice. When I was nearly 10 Janet got me a Tellus Lite<sup>5</sup>. This was good because it was small and I could carry it with me, also I had my typing packages on it. I found learning the new layout really hard and often I didn't want to use it to talk. When Ian put on word prediction it got much easier.

In January this year Janet changed everything. She gave me a Lightwriter and a new laptop. These are much better. I type in everything I want to say although I sometimes find spelling hard on long words even with the prediction. Now I use the Lightwriter in the car, at home, at school, when we go shopping and at the doctors. It's incredible, anyone with a speech difficulty needs to have the right communicator for them so they can talk to everyone when they want.

## WHAT I THINK AND HOPE

When I first started school I realised I was different from everyone else because I was given the Dynavox. When I am



Leading a 1Voice workshop

thinking in my head I have always In Year 6 Mrs Minchin helped me by giving me a Circle of Friends. There are 5 girls and 1 boy who understand how I feel. They all want to work with me and be with me. Before that I used to feel left out and always on my own especially at lunch time. The only friends I had were Jessica, Greta and Carly my Special Needs Assistant. This has made me much happier at school. I still often feel lonely at home because I don't often see my school friends unless I am invited to a party or they come to my house.

I am looking forward to going to my new school. It is a girl's school, there will be more new girls than all the children in my school now. I hope to have a new Circle of Friends and meet lots of nice people. Some friends in my current school are also going to the new school so I hope we can stay friends.

## WHAT I DO AT HOME

After doing my homework I do other activities:

## **Riding for the Disabled**

I go each Tuesday to ride Bilbo. I love riding because it is excellent exercise for me. I am getting stronger and now I have just a leader and Mary walks further away from me so I have to do it all myself. When I first started I used to have a leader and two helpers. I would like to do dressage and maybe I can be in the 2012 paralympic team.

## **Art Club**

I was going to Art Club every Thursday but Jackie was ill and has closed down. I felt incredible when I went as she and Pam showed me how to do different things and then let me try all on my own. Everyone was really friendly and I felt part of a happy family. I will really miss it now.

## Boccia

I played Boccia<sup>6</sup> in the Surrey Youth Games last year and I am in the team again for this year along with my friend Laura. Boccia is a game where you throw or roll a ball down a chute whilst sitting in a wheelchair. The winner or winning team is

the person who gets closest to a jack ball. Mum and Laura's Mum, Jo, are setting up a proper club for us and we will be able to play every week which will be fantastic.

I also like everything to do with Harry Potter, my favourite music is James Taylor, and to go swimming.

## **THE FUTURE**

I would like to teach but I know this might not be very easy. Maybe I can work with children who need communication devices. A good way for me to try this out would to be role model. I have met some good role models at 1Voice weekends. It is really good to see other people who are like me and are successful. Toby is a trustee with my Mum on some committees and Katie is doing a degree.

I am not old enough yet to be a 1Voice role model, but maybe I can be one for Janet if she has children in our area who need help. I think I will be good because I am a good listener, I am experienced in finding lots of different ways to get people to understand me and I want others to be successful too. \*

Kate M., April 2005

### **ABOUT KATE**

Kate has athetoid cerebral palsy. She uses a walking frame and sticks for short distances and a power chair for longer distances. Kate decided she wanted to do a lifebook. It was her idea and she was extremely focused wanting to work on it continually until it was finished. She began by writing but this very quickly became physically challenging.

### REFERENCES

- 1. 1-Voice Communicating Together: www.1voice.info
- 2. Dr Janet Larcher: janet@larcher.co.uk
- 3. Lightwriter from Toby Churchill Ltd: www.toby-churchill.com
- 4. Dynavox Systems Ltd: www.dynavox.co.uk
- $5.\ Tellus\ Lite: www.techess.co.uk$
- $6. \ Boccia \ (pronounced \ botcher): \ \textit{www.cpsport.org}$



1 Voice is a network and support for children and families using communication aids.

1 Voices takes a family and social perspective on communication and recognises the great need for adult role models to inspire children and families alike.

1 Voice promotes families supporting each other to overcome the isolation that being unable to speak can bring.

www.1voice.info

1 Voice, PO Box 559, Halifax HX1 2XL Tel: 0845 330 7862 Email: info@1voice.info

## SUCCESSFUL LITERACY

for children with severe communication difficulties

## WHAT DOES IT TAKE?



Presented by

## Dr Karen Erickson

Director & Literacy Specialist Teacher
Center for Literacy and Disability Studies, North Carolina, USA

Dunfermline, Scotland 8 November 2005 London 11 November 2005 Manchester 14 November 2005

For a registration form or more information, contact:

0845 456 8211

admin@communicationmatters.org.uk www.communicationmatters.org.uk



## **Augmentative and Alternative Communication**

The Official Journal of ISAAC

Editor: John Todman, UK

The only publication integrating AAC theory, research and practice. Augmentative and Alternative Communication is of special value to speech therapists and professionals who have a clinical, educational and research interest in this growing field. Each issue includes:

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- · Related studies sections list topical articles and their abstracts
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International in scope and transdisciplinary in approach, the AAC Journal presents articles, case studies, position papers, conference abstracts, with direct implications on program development, assessment and intervention. This Journal stimulates development and improves service delivery in non-speech communication.

Published Quarterly: March, June, September, December

CM Members rate (per year): £38 airmail (£25 student/retired)

## **AGOSCI News**

AUGMENTATIVE COMMUNICATION IN PRACTICE: SCOTLAND

BY COMMUNICATION MATTERS

ORGANISED

AGOSCI News is the newsletter of the Australian Group on Severe Communication Impairment. It is an ISAAC affiliated publication and is published twice a year.

CM Members rate (per year): £19

## **ISAAC** Israel Newsletter

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

CM Members rate (per year): £17 (airmail)

## **Unterstutzte Kommunikation**

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

CM Members rate (per year): £32 (airmail)

Members of Communication Matters (ISAAC UK) must send their orders to CM (address at bottom of page)

Readers outside the UK can order in local currency from their local Chapter of ISAAC, or in dollars directly from ISAAC, 49 The Donway West, Suite 308, Toronto, ON M3C 3M9, Canada Tel: +1 416 385 0351

Email: secretariat@isaac-online.org Website: www.isaac-online.org

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COMMUNICATION MATTERS



## TRUSTEES'

**This year** Communication Matters celebrates 20 years of existence. Have things changed since 1985? Of course they have, but it's also amazing how much is still the same!

Advances in technology, and its increasing availability, have certainly made a huge difference in what we are able to do, but it is still only a tool – the means to an end rather than the end in itself. In AAC terms it is the communication that we are now able to have with other people that is fantastic rather than the machines or the techniques themselves (wonderful as they are!). I think people are now (quite rightly) more aware of what might be possible and of what might be of assistance – but issues such as support, funding and education remain as crucial now as they were in 1985. However, a lot has been achieved – Communication Matters' membership reflects the growth in the use of, awareness of and interest in AAC.

Together – and I don't believe we would have come as far as we have if we hadn't been working together (people using AAC and their family members, therapists, teachers, engineers, hardware and software developers and suppliers, doctors, psychologists, family members, researchers, etc.) – let us celebrate what we have achieved and show that communication really *does* matter. Let us continue to work towards our vision:

A world where speech, language and communication difficulties are not barriers to opportunity and fulfilment. I hope to meet up with many of you at this year's conference at the University of Leicester in September – to put faces to names, to learn about new approaches and products, to remember that I am not alone in finding things frustrating, exhilarating and exhausting...and just to enjoy being part of the UK-wide AAC family. If you're not able to make the conference this year, do try to join us next year. In the meantime, I hope you enjoy reading up on some of the papers in forthcoming issues of this Journal.

## **PROPOSED BYLAWS**

You will be receiving (or may already have received) a copy of the proposed Bylaws for Communication Matters. It is an important document and I urge you to examine it closely. In drawing up the proposed Bylaws, the Trustees have tried to reflect the changes that have happened over the past 20 years. The original Constitution, written in 1985, is a formal document filed with the Charities Commission and Companies House. The proposed Bylaws cannot alter the meaning of any clause in the Constitution - their purpose is to clarify some of the ambiguities in the original document or to formalise some practices that have crept in over the years (e.g. giving all members of CM the chance to vote for the Board of trustees, not just those attending the AGM). In essence, the bylaws should add to the constitution, not replace it. The Bylaws are the 'working rules' of CM, and are in-

tended to help the Board of Trustees run CM fairly and well. At the AGM you will be asked to vote on these Bylaws – there will be an opportunity to discuss them and you can ask questions or make suggestions.

### TRUSTEES'

## NEWS

If the Bylaws are accepted they can be changed or added to by you – the membership – at future AGMs. To make the reading easier, you should note the following main areas:

- We have tried to clarify the various categories of **membership** and outline your membership rights and responsibilities. We are also proposing a new category of membership Honorary Membership to be granted to an individual who has made an outstanding contribution to CM.
- We have outlined the methods of voting permissible at an AGM or other special meeting (e.g. postal, show of hands) as well as to allow for voting by proxy.
- We have tried to clarify a number of things to do with **Trustees**:
  - Being more specific about the term of office and how often an individual can be re-elected.
  - Conditions of being a trustee, e.g. code of conduct, registering interests, and attendance at meetings are stated rather than assumed.
  - Our desire to ensure that people who use AAC (as well as their family members) are represented on the Board is also stated rather than being implied.
  - Who can and cannot attend a meeting of the Board of Trustees.
  - The election of office bearers, e.g. Treasurer and Chair.

Janet Scott, Chair of Communication Matters

Email: sctci@sgh.scot.nhs.uk Tel: 0141 201 2619

## CASC NEWS

## **NEW CASC MEMBERS**

The main topic of conversation over the past couple of months between CASC members seems to have centred internally around additional memberships and the potential effect on CASC Road Shows.

There have been three additional members added in the last couple of months, being:

- Richard Hill and Associates (this is a reinstatement of lapsed membership).
- TechCess (Europe) Ltd a separate company set up by TechCess Ltd to concentrate on the mounting side of the business, whilst TechCess Ltd continues with the Tellus and communication aid products.
- Mayer-Johnson UK a new division of DynaVox Systems Ltd.

As with all new members of CASC memberships, these last two had to be proposed and seconded and then other CASC members had 14 days to lodge any objections. This started two strands of discussion, one was "What constitutes a communication aid?" and the other, "Are CASC Road Shows going to become over-subscribed with these extra members?"

continued on next page...



## CASC

## NEWS

...continued from previous page

In practice, when I started as the Chair of CASC there were 22 members, of which two were from the same 'group', so there were, in effect, 21 specific organisations represented. Now, even with all the changes, there are only 24 members, with three companies having 2 memberships each, which means that there are still only 21 different organisations represented! However, the whole subject of CASC Road Shows will be discussed (again) at the annual CASC meeting at the CM2005 National Symposium in September.

## **VAT CHANGES**

The VAT changes only raised its head very recently following a Customs and Excise audit at DynaVox Systems. The VAT man (or in this case VAT woman) has ruled that Medical Devices (products and accessories) can be exempt in the right circumstances (depending upon who is purchasing/paying), as can repairs to those devices, but extended warranties cannot be exempt!

Is that daft – or is it just me? If you pay in advance to cover repairs you cannot be exempt, but if you pay *when* it breaks, you can! This would have a knock-on effect for every supplier, so needless to say, I intend to fight it. I will provide more information when I can.

## **Dave Morgan**

Chair of CASC (Communication Aid Suppliers Consortium)

## PRESS RELEASES

The publication of these press releases does not constitute endorsement by Communication Matters

## **COMMUNICATE: WEBWIDE / BY CHOICE**

Widgit Software has created the first genuine symbol browser, *Communicate: Webwide* which enables users to view web pages either normally, as plain text, or supported by symbols and speech. This innovative concept in web browsing aims to meet the diverse needs of students working in inclusive settings and studying at home, as well as those in specialised centres.

Another new product in the Communicate series is Communicate: By Choice which gives new and improved learning opportunities to those who benefit from symbol support. The software encourages users to learn by choosing, and utilises symbols, pictures and words to bring new activities within the range of symbol users and those struggling with text. Like other Communicate products, Communicate: By Choice comes complete with the new Widgit Rebus Colour Symbols, and acts as a comprehensive set of line drawings for use in supporting literacy.

For further details Tel. 01223 425558 or visit www.widgit.com

\*

## **PRESS**

## RELEASES

The publication of these press releases does not constitute endorsement by Communication Matters

### SUPPORT RESOURCE OFFERED BY AXEL BÖHM

Axel Böhm is offering a new support for people who use AAC, their family members, carers and therapists, by sharing his first hand experiences of disability, assistive technology and of being an augmented communicator. He can offer insight into what can be possible for other people with disabilities (see page 7).

For more information Tel. 0121 358 6280 or email: axel@ashmill.freeserve.co.uk

\*

## HANDHELD COMMUNICATION AID SAY-IT! SAM SM1

A new symbol and text-based portable communication aid is now available from Possum AAC (formerly Cambridge Adaptive Communication). The SM1 is part of the Say-it! SAM family of communication aids that also includes the pocket-sized Communicator. Designed to be easy to use and set up, it contains both a dynamic text and symbol display and an intelligent keyboard. Speech can be both synthesised and digitised. The user can build powerful and complex vocabulary and sentence structures, using Mayer-Johnson PCS symbols, pictures or text.

For more details Tel. 01296 461000 or visit: www.possum.co.uk

\*

## **WORD WHEELS**

Word Wheels is a system to help deaf students understand basic grammar. The software accompanying the book contains interactive exercises that enable students to practise using simple sentence structures - with optional BSL and audio support. Word Wheels is a structured programme that will appeal to all age groups, including adults.

Contact David Fulton Publishers on Tel. 020 8996 3610 or visit www.fultonpublishers.co.uk

\*

## WEB RESOURCE - WWW.CHECKTHEMAP.ORG

It's hard to find out about all the thousands of opportunities, resources and services that exist for people with learning disabilities. *Check The Map* is a web resource that puts everything in one place.

This accessible website covers the whole range of learning disability services: public or private, independent or affiliated, for children and adults. Visitors to the site can search by town, region and keyword to easily locate services both locally and nationally. There is a calendar of events, links to web-based services, free online games and activities, forums and recommended books. This website also gives free promotion to anyone, regardless of the size or scope of what they do - simply register your details online.

For further information Tel. 07971 494706 or visit www.checkthemap.org

\*



## DIARY DATES

19, 21, 22 & 28 September 2005

How to Represent Language with Pictures Presented by Bruce Baker in Manchester, Cardiff, Limerick and Leicester

Contact PRi: 01733 370470 info@prentkeromich.co.uk

25-27 September 2005

Leicester

CM2005 National Symposium

Gilbert Murray Conference Centre, Univ. of Leicester

Contact: 0845 456 8211 www.communicationmatters.org.uk

6 October 2005 Middlesbrough

Models of Intervention, Communication Profiles & Vocabulary Choice for Adult Acquired Disorders

Contact Communicate: 0191 219 5640

20 October 2005 Newcastle upon Tyne

Models of Intervention, Communication Profiles & Vocabulary Choice for Children and Adults with Special Needs including Learning Disability

Contact Communicate: 0191 219 5640

21-22 October 2005 Islington, London

Specialneeds IT London

Contact Inclusive Technology: 0800 975 6090 www.inclusive.co.uk

31 October 2005 Gloucester

**CASC Road Show at The Milestone School** 

FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

2 November 2005 Newcastle upon Tyne

Disability North Exhibition (DNEX)

Contact: 0191 284 0480 marketing@disabilitynorth.org.uk

8 November 2005 Dunfermline

AAC & Literacy Study Day with Karen Erickson

Contact ACPS/KEYCOMM: 0131 443 6775

11 November 2005 London

AAC & Literacy Study Day with Karen Erickson

Contact: 0845 456 8211 www.communicationmatters.org.uk

14 November 2005 Mancheste

AAC & Literacy Study Day with Karen Erickson

Contact: 0845 456 8211 www.communicationmatters.org.uk

16 November 2005 Newcastle upon Tyne

Coaching the best out of people: Communicative competence in AAC

Contact Communicate: 0191 219 5640

17 November 2005 CALL Centre, Edinburgh

ICT and Alternative Assessment Arrangements for Exams

Contact: 0131 651 6235 www.callcentrescotland.org.uk

18 November 2005 Dublin

AAC & Literacy Study Day with Karen Erickson

Contact Yvonne Lynch: ylynch@crc.ie

1 December 2005 CALL Centre, Edinburgh

**Digital Movie Creator** 

CALL Centre: 0131 651 6235 www.callcentrescotland.org.uk

6 December 2005 Glasgow

**CASC Road Show at Cardonald College** 

FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

## DIARY DATES

7 December 2005 Dingwall

CASC Road Show in Dingwall (provisional)

FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

8 December 2005 Dunfermline

CASC Road Show at Business & Learning Centre

FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

14 December 2005 Newcastle upon Tyne

**Beyond Cut and Paste: How to make Low Tech really rock!**Contact Communicate: 0191 219 5640

24 January 2006 Middlesbrough

BoardMaker Version 5

Contact Communicate: 0191 219 5640

26 January 2006 CALL Centre, Edinburgh

Listening to Children

CALL Centre: 0131 651 6235 www.callcentrescotland.org.uk

2 Febuary 2006 Newcastle

Engineering the Classroom Environment

Presented by Carol Goossens' Contact Communicate: 0191 219 5640

\_\_\_\_\_\_

16 February 2006 CALL Centre, Edinburgh

ICT Tools for Independence

CALL Centre: 0131 651 6235 www.callcentrescotland.org.uk

1 March 2006 Newcastle upon Tyne

**Creating Communication Opportunities** 

Contact Communicate: 0191 219 5640

2 March 2006 CALL Centre, Edinburgh

Interactive Whiteboards

CALL Centre: 0131 651 6235 www.callcentrescotland.org.uk



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

For more information please contact:

1 Voice

PO Box 559, Halifax HX1 2XL Tel: 0845 3307861

Email: info@1voice.info

# **Evidence Based Practice and Language Activity Monitoring**

## **PAUL HARKNESS**

Prentke Romich International Ltd, Minerva House, Minerva Business Park, Lynchwood, Peterborough PE2 6FT, UK Email: info@prentkeromich.co.uk Tel: 01733 370470

## INTRODUCTION

Dr Katya Hill published a paper in 2004 titled 'Augmentative and Alternative Communication and Language - Evidence Based Practice and Language Activity Monitoring'. The paper discusses goals in AAC, models for Evidence Based Practice (EBP), types of evidence, target areas for consideration in AAC, and software tools for gathering evidence.

It refers to studies by a number of researchers along with Hill's own results utilising software tools called 'LAM' - Language Activity Monitoring and 'PERT' - performance report tool.

Dr Hill is an assistant professor at Edinboro University in Pennsylvania teaching AAC and assistive technology. She is also an executive director at the AAC Institute, a charitable organisation offering support and development in AAC communication.

She is involved in researching Evidence Based Practice (EBP) and through the AAC Institute contributing to the development of software tools that can assist in the EBP process.

As a result of her research Hill has also produced models for evidence based assessment and evidence based clinical practice to guide the design of therapeutic and educational activities in the EBP process.

## FINDINGS

Hill describes factors that affect the two most important values expressed by people she's worked with who rely on AAC; that is, 'saying exactly what you want to say' and 'saying it quickly'.

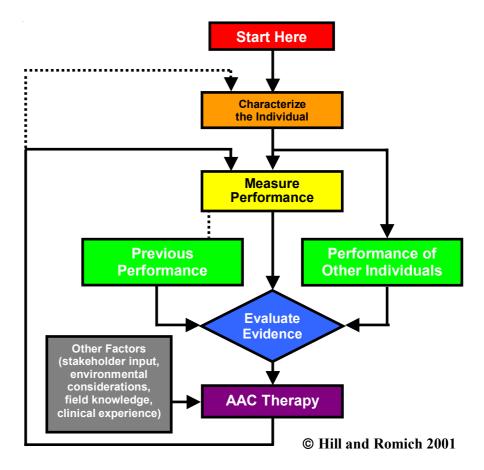


Figure 1 A model for AAC Evidence Based Practice

In doing so she identifies 'the use of Core and Extended vocabulary' as a primary target area for consideration because of its effect on 'saying exactly what you want say' speedily.

Core vocabulary consists of the lexical and morphological units that account for around 85% of everything we say. Extended vocabulary is any other vocabulary.

The nature of core vocabulary words is described in Halliday's Functional Language Model (1978), which shows how certain words perform certain functions that affect the environment, for example 'regulating someone else's

behaviour' or 'providing someone with information'.

These words facilitate functional communication. They are not a list of nouns and are therefore hard to represent as pictures in AAC. Core words (e.g. where, somebody, this, there) represent more abstract concepts than nouns and can include the use of morphology, when marking tense for example (e.g. played, cooked, went, gone).

Hill provides recent findings and evidence to support that a group of up to 450 core vocabulary words, such as *like, me, mine, give, gone, a, about, again, after, all, always, did, different,* and *do,* actually account for 85%+ of our expressive language.

She cites evidence from social conversations of normal cohorts in the workplace, that illustrate this high usage of Core vocabulary in interactive dialogue (Balandin and Iacono,1999). Similar vocabulary patterns are found to occur across age groups and in very different contexts.

Studies into Vocabulary-Use Patterns in Preschool Children (Marvin Beukelman and Bilyeu, 1994), toddlers (Banajee, Stricklin and DiCarlo, 2001) and older adults (Stuart, Beukelman and King, 1997) show high usage of the lexical units and morphological units, like pronouns and tense markers, that are considered to be elements of 'Core vocabulary'.

The significance of Core vocabulary is evident at different cognitive levels where Core vocabulary and morphology are seen to occur once again (Mein and O'Connor, 1961).

## **MODELS**

Research into Core vocabulary is the type of 'External Evidence' from the literature, that helps identify evidence based targets and is recommended in a model for Evidence Based Clinical Practice (Hill and Romich in 2001) (Figure 1). Hill and Romich suggest combining External evidence with linguistic and metalinguistic data at a 'Personal level', for example Minimum Length Utterance (MLU) or total words produced, together with the knowledge and skills of practitioners, in designing evidence based targets and intervention.

The LAM and PERT tools allow us to obtain Personal level data about an AAC user's communication and gauge it against models such as Brown's stages of language development and data from External evidence sources.

The model's measurement and evaluation process is an ongoing one with

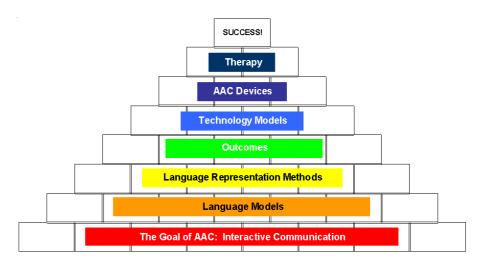


Figure 2 AAC Language-based model for assessment and intervention

recurrent measurement and review of evidence and goals over time. In doing this practitioners can more effectively identify and target an individual's 'zone of proximal development' (ZPD) (Vygotsky, 1979), the area where competency is unreliable but a person has some ability. It is vital to identify and target the ZPD as this is the only point where learning can occur and therefore intervention goals can dictate the limits of what language is possible for an AAC user to develop. When a child, for example is using AAC and ready to learn the word for 'pencil' but is not provided with a button for 'pencil' on their device, they will not learn to express the word 'pencil' as there is no opportunity to do so. If a child using AAC has no ready access to Core vocabulary on their device, similarly they will never use it.

If we decide a person has plateau'd and has no chance of further language development, we have made a very significant decision for that person. It is important therefore to ask "How do I know?" and to be confident that our data is relevant and objective. As such, the data will have been considered alongside evidence based research and models, leading to reliable conclusions and rational goal-setting.

Hill (1998) presents a model addressing assessment in AAC (Figure 2) to guide this process and suggests understanding the communicative challenges, abilities and needs of the communicator and caregivers, by *first* collecting evidence at the 'Personal Level'. Specific performance measures of an individual's current and potential language abilities gathered about a communicator's use of semantic, syntactic, and pragmatic skills can then be considered alongside milestones such as Brown's Stages of Development and other normative data. This Personal

Level data assists us in asking effective questions of the literature, and external evidence sources, thereby gathering the most appropriate external evidence. The LAM and PERT software tools can be instrumental in conveniently and accurately extracting this data.

## INFLUENCES ON COMMUNICATIVE DEVELOPMENT IN AAC

Hill's own research into language activity monitoring, and performance measurement with the tools, have highlighted particular factors found to affect performance on AAC devices, in particular client groups. The results offer areas for consideration in the assessment and intervention process. Access to Core vocabulary has been one consideration and Language Representation Methods (LRMs) is another.

In the model for evidence based assessment Hill suggests identifying how the language level, the vocabulary that will be targeted, can be represented and generated on a variety of LRMs, and whether a particular icon set allows access to the vocabulary to develop a user to the next stage.

There are three LRM mediums (Fig. 3):

- Single meaning pictures
- Alphabet based mediums
- Semantic Compaction/Minspeak (use of multi-meaning icons)

EBP requires that teams evaluate the evidence, comparing an individual's performance differences with each LRM because LRMs have specific characteristics that influence access to Core and Extended vocabulary. They also have particular attributes that affect the use of morphology and syntax, and impact on communication rates.

The need for literacy will be a consideration, as will preferences about length of sequences or number of hits required.

Visual and cognitive demands dependent on the sizes of symbol sets must also be considered along with the long term communicative potential of a particular symbol set. In addition, ease of programming, the ease of use on first encounter and ongoing training requirements are important factors.

Hill's research highlights specific factors particular to AAC that affect vocabulary use, and speed of expression. Studies into Fixed/Static and Multi-level displays (Hill and Spurk, 2003) show an effect on the use of Core vocabulary dependent on whether fixed or multi-level iconic displays were used. Core vocabulary was used 70% of the time in the group using a fixed or static level display and 44% of the time in the group using multi-level displays. This indicates a high proportion of Core vocabulary being used in spontaneous expression and that fixed displays were found to facilitate access to Core vocabulary more readily.

Further research into Communication Rates as a function of LRMs (Hill, Romich and Holko, 2001) identified that communication rate differences between LRMs were very apparent. Research with adults using AAC systems that support the three language representation methods showed use of semantic compaction (Multi-meaning icons) was significantly faster in communication.

The results of studies like this can be considered with client's whose profiles match those of the research participants and can provide guidance in the assessment process.

Method Attribute	SINGLE MEANING PICTURES	ALPHABET-BASED SYSTEMS	SEMANTIC COMPACTION
LITERACY	Not required	Required	Not required
SYMBOL SEQUENCE	Short	Long	Short
LENGTH			
SYMBOL SET SIZE	Large	Small	Small

Figure 3 Language Representation Methods

Hill's model suggests gathering this battery of External and Personal level evidence before proceeding to formulate outcome measures and designing goals and strategies. Hill recommends systems that support LAM and PERT and assist in the EBP process. At this point decisions can be weighed against how technology considerations influence the chosen LRM, selection rate, and communication rate.

### **SUMMARY**

Katya Hill's research and models propose the following considerations for assessment and intervention in the EBP process.

### **Assessment and Intervention**

- 1. Collect information/data on client
- 2. Ask the best questions
- 3. Seek and appraise the evidence
- 4. Implement intervention
- 5. Monitor change

## **Levels of Evidence**

The key elements identified in this process are the knowledge and skills of the provider, use of External Evidence and use of Personal Level Evidence.

### **Tools**

Performance measurement data is crucial to decisions about the appropriateness of particular AAC devices. It provides a starting point for intervention, effective measurement of change over time and strengthens the case for funding proposals.

At this point informed intervention can begin, leading hopefully to successful learning. LAM and PERT tools are available to assist the EBP process. The LAM's function is to collect raw data from an AAC device, that can be uploaded to a PC for examination.

The function of PERT is to analyse and report about the data collected with the LAM tool.

The language activity monitoring tool (LAM) and performance report tool (PERT) can be utilised with a number of AAC devices including PRi, DynaVox and Saltillo products. They are available now for download from the AAC Institute website (www.aacinstitute.org) along with comprehensive instructions for use. \*

Paul Harkness, Speech & Language Therapist

## **ESSENTIAL PUBLICATIONS**

## 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 or use AAC. It is useful for staff development, especially for those working with adults.

Price: £30 including 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.

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

## Beneath the Surface

In August 2000, the creative works of 51 authors and artists from around the world were published in 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.

Price: £15 plus £1.50 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

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

**Communication Matters** 

c/o ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR

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## **Communicate: By Choice**

Early Learning activities for switch and symbol users



Over 100 activities included in the pack for

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Language comprehension

Letter work

Memory

Number

Science

Sequencing & sorting

Visual discrimination

Word work

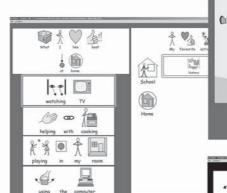
Includes the

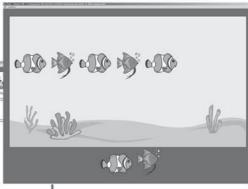
## new Widgit Rebus colour symbols

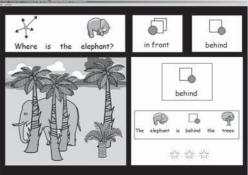
Easy to edit or add your own content.

Works well with switches and with witeboards.

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## The world's first symbol-supported web browser

Make browsing the web more accessible to people who find text difficult. Visit websites in normal view, in simplified layout or with symbol support; with full speech support in any view.



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# Moving Towards a Portable Total Communication System for a Mobile Day Service

## **Community Presence vs Inclusion**

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## THE DEVELOPMENT OF THE COMMUNITY PROJECT SERVICE

Over thirty years ago, in the London borough of Southwark, the government white paper *Better Services for the Mentally Handicapped* (1971), led to many changes in service provision for people with a learning disability. These changes reflected those occurring to differing degrees throughout the country as the large institutions made way for smaller, community-based services. This move was largely fuelled, from a theoretical perspective, by the principles of normalisation and social role valorisation (Nirje, 1969, 1980, 1985, Tyne & O'Brien, 1981, & Wolfensberger, 1972, 1983, 1992).

For one service in particular, the Community Project day service, the emphasis placed upon social integration and participation by this model was fundamental. The Community Project developed as a service that supports adults with a learning disability to access community facilities over a wide area of South London. The principles of normalisation and social role valorisation also centre upon the commitment and involvement of community members and this is another tenet which moulded the final shape of the service. It is a day service that, for its service-users, has no fixed base or centre as, according to the precepts upon which the service has its foundations, such a building would separate or exclude them from the wider community. Instead the service is based within leisure centres, cafes, theatres, parks, bowling alleys and other generic community facilities that are accessed by minibuses running from a (purely) administrative centre.

The very shape of the service however, is also at the heart of its challenge, both to achieving its own aims, and to the local community speech and language therapy service in supporting this. As Jones (2000) states, "social inclusion without shared communication is impossible" (p25) because nothing is more excluding than the inability to share a 'common language' (p26). The Community Project service ensures only 'community presence' (Tyne & O'Brien, 1981) by virtue of its design. The risks of exclusion from effective 'community participation' (Ibid.) still remain and, in fact, are potentially exacerbated by the lack of access of service-users and their support staff to professional support services such as Speech and Language Therapy.

## OVERCOMING THE CHALLENGES OF THE COMMUNITY PROJECT

Since the setting up of the Community Project service, the local Speech and Language Therapy team in Southwark received only a relatively small number of separate referrals for input around the use of manual signs and the use of symbol-supported communication. However, the most effective form of service delivery to these individuals and the team from which they were referred was felt to be in a combination approach, incorporating both an individual and an environmental focus (Money, 1997). Numerous comparative research studies with different client groups have shown that such an approach has greater efficacy than direct one-to-one therapy alone (Money, 1997, Thompson & Swisher, 1985, Sisson & Barrett, 1984, Berrera & Sulzer-Azaroff, 1983, Wells, 1981). Furthermore, even before the government white paper Valuing People (DOH, 2001), which recognises this central importance of environment to the development of the individual, legislative changes such as the NHS and Community Care Act (1990) and the Disability Discrimination Act (1995), emphasise the responsibilities of the environment, whilst acknowledging that services must have a basis in individual need. The subsequent Amendment Regulations to this act (2001), due to come into force from October 2004, go further still, detailing and serving to enforce these responsibilities, thereby placing further emphasis upon the role

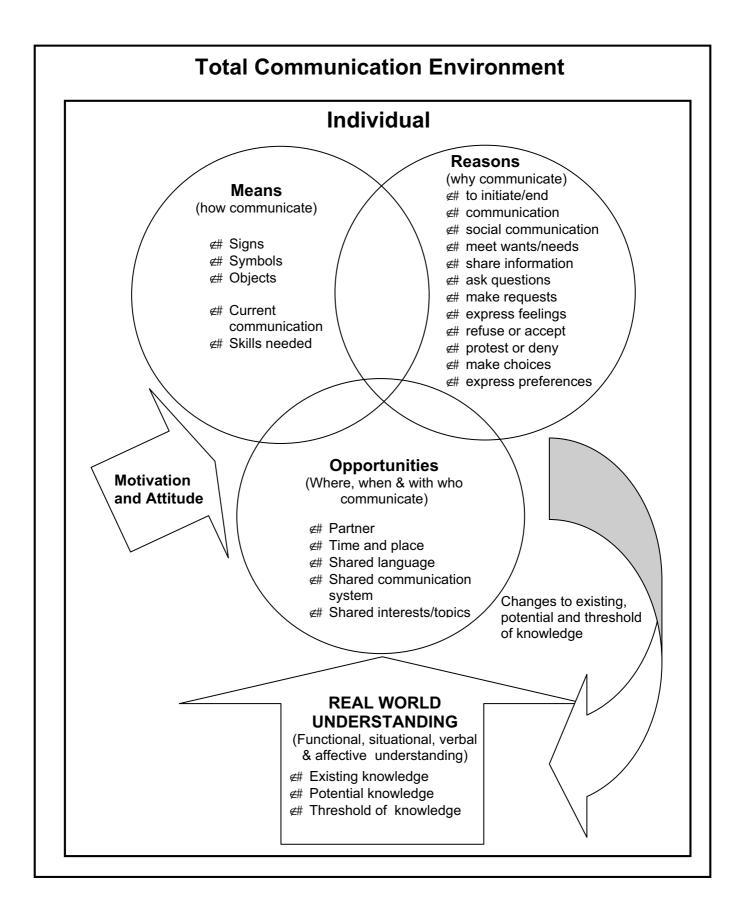


Figure 1 A working model of inclusive communication (adapted from Money and Thurman, 1996)

of the environment in supporting the individual's needs.

The challenge then, was to create 'the key to inclusion' (Matthews & Dean, 1997); a total communication environment, in a service with no one stable physical environment. Although one definition of 'communication environment' sees the properties of the physical environment as only one of a set of considerations within this overarching term (von Tetzchner et al., 1996, cited in Bradshaw, 1998), this still means that at least one variable that effects communication was relatively uncontrollable and not amenable to traditional environmental support approaches such as wall-mounted symbol and photographic 'labels' and visual timetables. Other aspects of the communication environment, however, could still be utilised to overcome this impediment in any intervention approach, so long as they could be identified and mapped onto a model of the total communication environment

Total communication environments are increasingly seen as 'best practice' when working with people with a learning disability (Jones, 2000, Bradshaw, 2000) yet no one agreed definition exists as to what they are. The RCSLT has referred generally to 'an approach that seeks to create a supportive and effective communication environment, using every available means of communication to understand and be understood' but a specific model of how this overall goal can be achieved was needed in order to create such a communication environment in the context of varied community settings.

## A WORKING MODEL OF TOTAL COMMUNICATION APPLIED TO THE COMMUNITY PROJECT SERVICE

Money and Thurman (2002, p5), have developed what they refer to as 'a working model of inclusive communication' (Figure 1, in adapted form).

Their model has at its centre the concepts of means, reasons and opportunities or 'the how, why, who, where and when of communication' (p4). When applying this to the Community Project service the means or 'how' of communication translated as both the media through which communication was achieved and the skills needed by both communication partners to use these support resources. The reasons, or 'why', and the opportunities, or 'who, where and when', are specific to the individual (Light & Binger, 1998) and need to be assessed (Bradshaw, 1998).

The first step in attempting to apply this model to the *Community Project* service involved identifying members of the staff team with a particular interest in supporting communication. Two such team members were identified and regularly attended meetings and training sessions with the Speech and Language Therapist. These *communication representatives* were essential to the implementation of any changes to the service as they were well-regarded and long-standing team members who were an intrinsic part of the running of the *Project* itself.

The assessment of reasons and opportunities for communication is completed, according to suggested best practice, with both the AAC user and their key supporters (Beukelman, McGinnis, & Morrow, 1991). For the key supporters, a simplified version of the Working Model has been adapted to function as a checklist and record form which prompts them into consideration of each of the factors involved in determining an appropriate draft vocabulary list (Figure 2). A record form for devising this list is also used, importantly, containing a section for recording suggestions from peers who attend the same groups (Mirenda, 1993, cited in Light & Binger, 1998) and prompts taken from the reasons section of the model.

The communication representatives have reported that the visual cues of the model have helped them to focus upon what communication entails and to apply this when thinking through issues that affect vocabulary choice.

In terms of actual resources, a central 'pool' to code information in as many different forms as possible has been developed and is stored at the Community Project administrative base. This includes an extensive sign programme, a PCS symbol programme, and a body of photographic resources, all of which are designed to be dipped into when creating individualised communication support systems developed 'at the point of need for the individual' (Jones, 2000, p26).

## THE RESOURCE BANK

The resource bank was itself developed in close collaboration with both support staff and a small number of service-user volunteers. This meant that, from the start, both staff and service-users were directly involved in the process of designing effective communication support systems, a factor that service-users themselves have reported as important to a programme's

continued success (Hodgkinson, 1998). Jones (2000, p25) states that successful development of a total communication environment is about 'winning hearts and minds' as much as policy and system creation and, although this aspect is not explicit in Money and Thurman's model, willingness and motivation by all concerned were the fabric that created this process and enabled its development.

In order to effectively use the resources created and adapted from the pool, the service-user is then supported to develop a range of linguistic, operational, social and strategic skills (Light, 1989) and the support staff need to develop a range of strategies such as natural cues, expectant delays, pointing and modelling (Light & Binger, 1998) to focus upon the target skill areas. The two communication support representatives from the Community Project staff team were able to support the staff team to pick up and develop these skills. These volunteers also worked with the rest of the support team and the therapist to create accessible guidelines on developing an individual's communication support resources and using them. They also helped, working alongside the serviceuser representatives, with weekly training sessions within staff team meetings. In these meetings, which are one of the rare times at which the staff team are all together, sign skills are maintained and developed using scripts, role-plays and games. This is in addition to ten minute 'sign-revision' slots before driving to their next session, which the support team representatives have set up themselves.

Money and Thurman's model also incorporates the effect that a client's level of understanding has upon their means, reasons and opportunities and breaks this down into verbal, situational and functional understanding, the relationship between which makes up what they term 'real-world understanding' (2002, p5). This formulation, whilst itself effective, misses the reciprocal nature of the relationship understanding has with means, reasons and opportunities; when either one changes or develops this leads to change, or potential for change, in the other. This links to a social model of disability (Finkelstein, 1980) in which an environment lacking in opportunities, reasons or means for communication will result in 'under-utilisation' and a consequent decrease in communication skills (Van der Gaag, 1989). This is important to highlight in any presentation of the model, as it places emphasis on the importance of an effective communication environment for the individual.

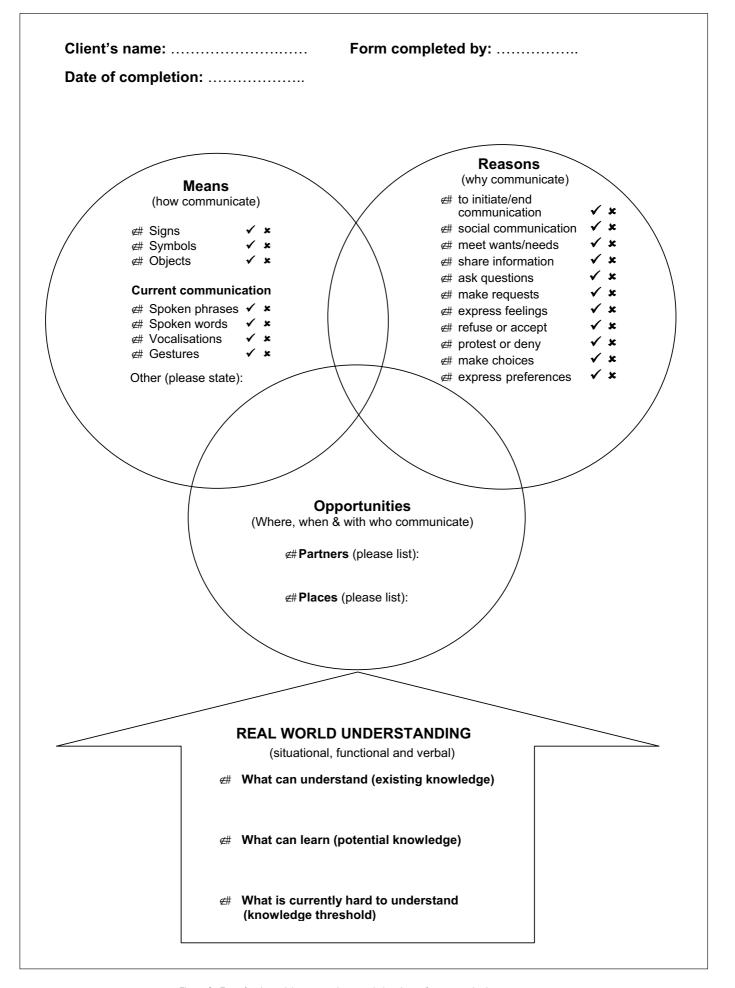


Figure 2 Form for determining appropriate vocabulary items for communication support resources

Another key component of 'real-world understanding' that could be integrated into Money and Thurman's model, is that of affective understanding. Even when the more complex cognitive aspects of understanding are not possible to engage, an individual is able to experience and engage on a nascent cognitive and an emotional level; to 'apprehend' rather than fully comprehend (Grove & Park. 1996). The sights, sounds, smells and textures of a situation can be assimilated and responded to by an individual, without an understanding of exactly what this information means in the real world. Grove and Park point to the centrality of repetition in achieving this primarily emotion-based level of understanding; as the individual becomes familiar with the set of experiences within a situation or activity, so it begins to take on meaning. In educational psychology, since as early as the 1960s researchers have stressed the importance of this level of affective understanding and apprehension in facilitating the development of more complex processes of comprehension (Krathwohl, D., Bloom, B., & Masia, B., 1964) and this link is even supported by studies in neuro-biology (Davidson & Cappiopo, 1992; Levy, 1983).

It is only more recently, however that this has become further extrapolated into a series of stages that may form the building blocks of all social communication. In their study Carpenter, Nagell & Tomasello (in press), conclude that communication development begins with an awareness that others attend to and behave intentionally towards external entities of interest; 'understanding That' (p132), and moves onto an understanding of what the other person attends to and behaves intentionally towards; 'understanding What' (p133). In this way, an affective level of understanding can be defined as the realization that other people have psychological relations to the world, a realization that makes it possible to understand exactly what these relations are. Once this is achieved further development becomes possible as the individual can then follow, influence and manipulate these psychological relations.

In addition to the concept of real world understanding, the model used in the *Community Project* included the concepts of existing knowledge (words and concepts that are understood), potential knowledge (words and concepts that could be learnt), and threshold of knowledge (words and concepts that would be too complex for the individual at that point in their skill development). These

were felt by support staff to be more readily useable concepts when consideration was being given to issues of understanding during the development of individualised communication support.

The model used to inform the communication programme at the Community *Project* also differed from Money and Thurman's Working Model in its emphasis in targeting service delivery at the individual and their communication environment, a term which subsumes the distinction made between immediate environment and local community in the original model. This was a necessary adaptation as the essence of the Community Project service is that the immediate environment of the serviceusers is their local community. It also assumes this level of importance for other services as the government follows through on its stated aims in Towards Person Centred Approaches; Planning with People of ensuring that people with learning disabilities can become an active and valued part of their local community (DOH, 2001).

The focus upon a communication environment within the local community led to an emphasis upon the development and use of effective introductory strategies (Light & Binger, 1998). These had to be designed to tell a communication partner how the person communicates, and how they can best communicate with that person (Ibid., p45). These introductory strategies also sometimes rely upon the support staff from the Community Project service, either to facilitate the use of the strategy and the communication, or to deliver the introductory strategy in some circumstances (such as communication with a member of the community who does not read English). Guidelines and training, facilitated by the communication representatives therefore also encompassed this essential function of resources that has the potential to aid the realisation of the service goals of community inclusion and participation.

## PORTABLE TOTAL COMMUNICATION: A CASE STUDY

To illustrate the reality of exactly how some of the service developments outlined above may have affected participation and inclusion one *Community Project* service user's case will be explored.

N. had been known to the Speech and Language Therapy team repeatedly since taking up adult services within Southwark. However, as a five days a week *Project* member there had always

been restrictions upon the amount of direct work that could, realistically, be done with him. Work from previous therapists had lead to an individual Makaton sign programme, a symbol communication book and communication support guidelines. None of these were in place when service development work began at the Project, they had become lost within a large, demanding and difficult to alter support service. As other communication referrals were also being tackled on an individual basis only, the work with N. had nothing long-term to link into and maintain its momentum once Speech and Language Therapy input was withdrawn.

Later work with N. was able to link into service-wide communication programmes including regular sign training slots, sign discussion groups, pools of symbol-based resources and communication representatives who had taken on special responsibilities for the promotion and development of communication support programmes.

One of the communication representatives was able to work with N. and his keyworker to update and maintain his sign programme using the means, reasons and opportunities form to consider what vocabulary items to include. This ensured that not only were the signs chosen able to be used for as wide a range of communicative functions as possible considering N's level of understanding, but also that signs were chosen that could be used at home, at the Community Project, shopping and at church. N. was also included in a timetabled 'sign discussion group' with fellow Project members and the signs in his individual programme were included in the sign slots taking place within staff team meetings. This helped to ensure that a relatively large number of other staff and service users could understand and use the signs in N.'s programme, taking the responsibility away from just the keyworker.

The communication representatives maintained regular contact with the Speech and Language Therapy team regarding both the generic communication programmes and some of the individual work that they were doing with service-users and their keyworkers. This meant that, in the longer term, N. was able to receive ongoing support with his communication programme from a relatively wide range of sources within the service itself.

A keyring symbol book that matched the sign programme was developed by N.'s keyworker and the communication representative and this was created by

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a volunteer member of the team who took responsibility for organizing the pool of symbol resources and for making the books themselves. The symbols used in the central pool have been initially developed by the Speech and Language Therapist, together with the communication representatives, and then agreed or rejected by the staff team as a whole when presented and used in staff team meetings. Similarly, many of the symbols have been discussed and commented upon by the service-users in an advocacy group for Community Project members. This again helps to ensure that a wide number of people can understand and use the symbols, and could be involved in maintaining or updating the communication book.

Difficulties have been encountered with developing N's communication support resources however since one of the communication representatives has been off on long-term sickness leave. Finding a temporary stand-in proved difficult and so work with N. has been significantly delayed. Future developments need to look at introducing more flexibility to the process of identifying and developing support programmes, if at all feasible, by directly including more staff and service users in all aspects of the process.

## PERSON-CENTRED PLANNING AND SELF-ADVOCACY

One aspect of a total communication environment that is essential as services for people with learning disabilities move towards user involvement, self-advocacy and person-centred planning, is the realisation of their rights and power to affect change (Jones, 2000). This includes the right and power of individuals to change and shape their own communication environment and is a dimension that should be an integral part of any comprehensive model of a total communication environment.

In line with this, Speech and Language Therapy support was also targeted at increasing attendance at a self-advocacy group at the *Community Project*, called the *Service user forum*, to include AAC users. This input was at the centre of support to the day service as it creates the possibility that marginalizing the role of specialist services, one of the indicators of empowerment, according to Dowson (1997), will also mean increasing the roles of the individual, their peers, support staff and the community at large.

The *Forum* is a self-advocacy group run and owned by the participants them-

selves. Although there is an external facilitator, they are present to neutrally model and encourage relevant skills and behaviours, but without in any way controlling proceedings or imposing their own views (Williams and Shoultz, 1982). As recommended by the People First group, the largest network of selfadvocacy groups in the UK, the power held by the group all belongs to its members (McGill,1982). The chairing, minute-taking and planning are all done by group members themselves and so any development of the Forum had, crucially, to be agreed by, and actively involve, the whole group at every juncture.

Although the Service user forum had been running for several years, during this time it had only ever been attended by able verbal communicators, many of whom were also literate. This had never been adopted as a form of exclusion criteria, but simply occurred because these were the people who came forward and were able to express an interest in joining the forum initially. They were also, perhaps, the people that key-workers and care staff at the Community Project considered able to take an active part in such a group and so it was with these individuals only that joining the group was discussed in any depth. It has, however, been stressed by some of the first self-advocacy groups for people with learning disabilities in the US that self-advocacy should include 'the voice of those we once thought incapable of speaking' (International League of Societies for the Mentally Handicapped Newsletter, 1980, cited in Williams and Shoultz, 1982, p51).

The first step to the inclusion of these individuals with greater support needs, who had missed out on access to the forum initially, was to construct a more accessible means of presenting and discussing the option of attending the group. A simple 'discussion template' form was produced, with help from the communication representatives, to facilitate this screening process. The template consisted of six different features of the group (meeting, tea and coffee, payment, talking about the Community Project, etc.) supported using colour PCS symbols together with corresponding Makaton signs. Keyworkers then used these templates to structure a one-to-one discussion of the forum with their key clients and ascertain levels of interest.

The next stage in facilitating effective involvement in the forum for those people who did express an interest, was 'to give the means and opportunity' to make decisions, express what they want and try to ensure that service providers respond (Palmer and Dawson, 1992). This statement draws us back to Money and Thurman's model and highlights that, to 'effect real change' (Williams and Shoulz,1982) in an individual's environment, that environment already needs to provide the means, reasons and opportunities for 'self-determination' (Brechin and Swain, 1988). This circularity, with means, reasons and opportunities within and environment both dictating the power to change to an environment and, as a consequence, becoming changed by this, also needs to be portrayed in the mapping of a total communication environment.

In order to move towards setting up these means, reasons and opportunities for two non-verbal volunteers within the Community Project, a support package that incorporates signs, symbols, video and peer support networks has been trialed. Prior to the two new group members attendance at the group, a period of around 6 months of preparatory work was completed by the existing members of the Forum. During this time signs were drawn from the Makaton and BSL sign systems and symbols drawn from the PCS and Change symbol systems. These related to what the group members decided were the most commonly used words and concepts in group meetings. A volunteer from the Forum was then filmed demonstrating each of the chosen signs and this video was then both played and matched to the corresponding symbols. This was done both within the group and at home for those people who requested copies for home use.

A system of peer-support was also developed in order to facilitate the learning process during this preparatory stage. Research into the development of sign knowledge has shown that peer-tutors reap rewards for both parties in terms of the effectiveness of interaction, and in terms of self-esteem, confidence and assertiveness (Hooper and Walker, 2002).

This has been supported by research into the literacy development of people with learning disabilities where findings have identified benefits in social skills (Fuchs, Fuchs, Mathes and Martinez, 2002) and in terms of effectiveness of learning and positive changes in behaviour (Byrd,1990). For these reasons, effective peer support structures were also developed to facilitate the involvement of the two

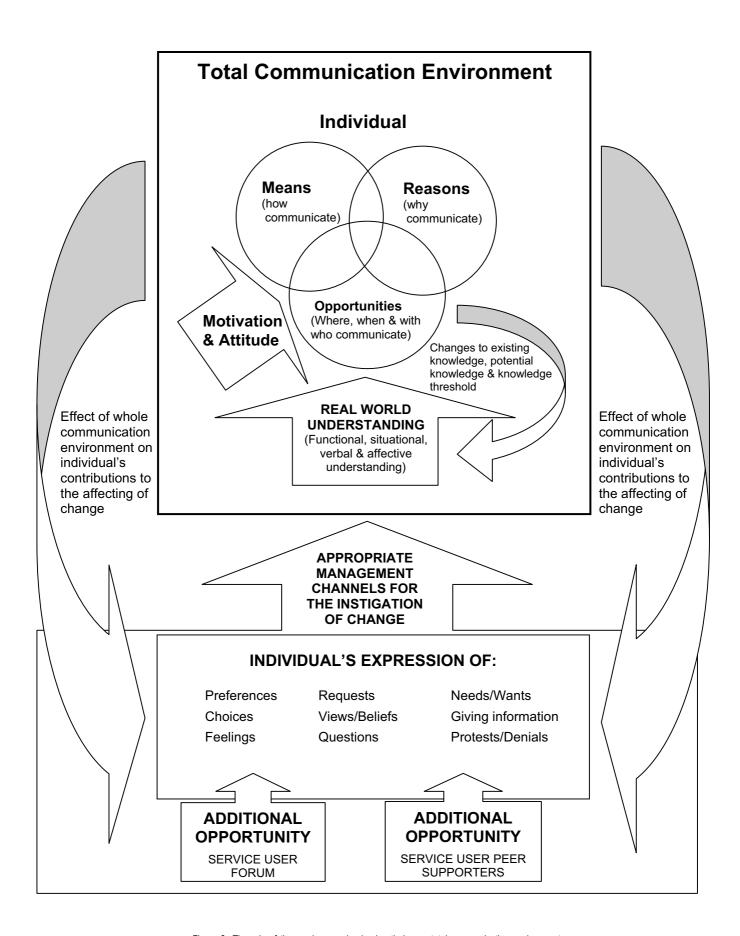


Figure 3 The role of the service-user in shaping their own total communication environment

new members in the *Service User Forum* group.

Figure 3 shows a further adaptation to Money and Thurman's reflects the potential that exists in a group like the *Service User Forum* for individuals to change their own environment and shape the means, reasons and opportunities that together constitute all communication.

Reflecting the importance that peer supporters have assumed in this instance, the revised model highlights their role in providing a further opportunity to effectively communicate ideas and opinions that may instigate change. As all of the means of communication (symbols, signs, vocalizations, etc.) were only effective in achieving this when supported by close and appropriate peer support they have not been delineated again in the additional self-advocacy section of this conceptualisation.

#### **NEXT STEPS**

The increase in access to the self-advocacy group is still in its infancy. At present only two members of the group are non-verbal communicators and this represents less than 5% of the total attendance. This is not an accurate reflection of the service-user profile at the *Community Project* service. Additional volunteers have been identified and may also be provided with the opportunity to make decisions that could effect their communication environment.

Additional means are also being incorporated into the *Forum*, again to be facilitated by peer supporters. A *Talking Mats*<sup>TM</sup> system has lent itself well in the past to groups in which decisions, opinions and choices are to be made (Murphy, 1996) and this system is currently being incorporated.

#### **FINALLY**

The whole self-advocacy section of the revised model depends upon the ability of the *Forum* to actually effect real changes. In order for the changes in means, reasons and opportunities to be instigated by groups such as the *Service-User Forum* there must be a system by which they can be listened to and actions taken based upon their information. Without this the circle is broken and the self-propagating model shown above does not come into play.

The ultimate goal of all services to people with learning disabilities has been described by the government as the enabling of people with a learning disability to lead full and purposeful lives within their community (DOH, 2001). In



Figure 4 Using Talking Mats™ in a Service User Forum

order to achieve this, their own voices must be listened to. Self-advocacy groups provide an opportunity for people to make statements that have the potential to effect significant change and whilst it is true that 'the rightness or wrongness of decisions is not nearly as important as having the opportunity to make decisions' (Welter, Hanna and Kitch, 1978, p1), the real test for services will be how much these empowering decisions are listened to and acted upon.

Nicolas Ponte, Speech & Language Therapist

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COMMUNICATION MATTERS VOL 19 NO 2 AUGUST 2005

# An AAC Service for Adults with Learning and/or Physical Disability

#### **CHERYL DAVIES**

Email: cheryl.davies@nottshc.nhs.uk

#### INTRODUCTION

An AAC service to support the needs of people with learning and/or physical disability in Nottingham was set up in January 2002. This followed five years of negotiations for funding by the manager of the Speech & Language Therapy Service for Learning Disability. The aim was to dovetail the children's AAC service to include both learning disability (LD) and physical disability (PD). The post is now substantive with .5 WTE Specialist Speech & Language Therapist and one day of allocated Technical Instructor time.

This paper will give an overview of the service, the professional networks, describe the client group, some aspects of the speech and language therapy input and also focus on the User Group and transitions. It will conclude with examples of frustrations and successes plus future plans.

Whilst newly in post, I established a professional network of contacts. The managers of these departments receive a regular report which updates on service developments. The list is presented to illustrate the broad scope of a community based post: Adults with learning disability Speech & Language Therapy team, Hospital AAC Speech & Language Therapy, Children's Team AAC Therapist, Disablement Service Centre, Disabled Person's Act Workers, AAC Special Interest Groups in Trent and Nottinghamshire, Social Services for the City and County, Advocacy Services, SCOPE, Connexions, Independent Living Team for the City and County, four Community Learning Disability Teams (CLDTs) and Learning Disability Health Managers.

#### **CLIENT GROUP**

There are currently 19 service users aged between 19 and 45 with the majority under 25. Six are ambulant, 16 use direct access and there is almost an even split between people with learning and physical disability. Seventeen live with their families.

The service users attend a range of day services provided in the City and County, including five Further Education colleges. One person is out of county.

This spread of abilities and services is a challenging aspect of this post.

#### **COMMUNICATION AIDS**

The service users on the caseload use a wide range of communication aids from the major communication aid companies from sophisticated 84 or 128 location devices with Minspeak and dynamic features such as the Vanguard or Pathfinder to 8 or 32 location devices with single recorded messages. At the last count it was 13 different devices from six companies plus five software programmes. This is a daily challenge to keep up to date, remember how to programme each device and to be at least one step ahead of the users.

There are few software programs available for this client group. I have introduced Expressions for Daily Living (written by Philippa Robinson and Alison

Woods, specialist speech and language therapists, available from DynaVox) to two people in their early 20s who have DynaMytes. We found that they have liked the way that it is organised and the vocabulary available to them. It is easy to personalise and teach.

#### SERVICE DELIVERY

I have divided the caseload into three groups:

- 1. Those who have never had a communication aid before.
- 2. Those who have been introduced to AAC at school or college.
- 3. Those who are proficient users.

They require varying degrees of support, summarised as:

- 1. Speech and language therapy for familiarisation with the aid and for staff training.
- 2. Training new staff, identifying and supporting new environments and communication needs.
- 3. Updating vocabulary, staff training and re assessment for communication aid equipment.

Supported by what Pam Enderby said in her keynote speech at the Communication Matters 2002 National Symposium, a person with a communication aid will require the on-going support of speech and language therapy.

#### **ASSESSMENT AND REVIEW**

Since being in post, I have assessed six new service users and re-assessed three existing VOCA users.

These are some factors that have informed the process:

- The life-span of a communication aid and replacement costs
- Improvement in spelling ability. One service user is now able to use a Lightwriter which would not have been considered an option when younger.
- Replacing aids that were purchased 10+ years ago when there was limited choice.
- Staffing levels available to support AAC.
- Long term support needs such as moving into supported living.
- Considering transfer from a Minspeak to a dynamic system. This has been successful for three service users and has been easier to teach to staff that have everyday experience of touch screens and computers.
- Portability of devices.

There are still questions and it is rarely a straightforward decision. It is not clear what options for upgrading will be available for an ambulant service user with visual difficulties who is a proficient user of a Delta Talker with LLL Version II.

#### **COMMUNICATION GUIDELINES**

Communication guidelines are being developed for all service users. Coming from the premise that the majority of people have never seen a communication aid before and have little knowledge of how to communicate with a person using an aid, brief but easy to follow guidelines have been written. They have one page to describe the aid, the programme and how it works, a second to outline the person's communication skills, a third to give suggestions on how to support and encourage aided communication and a fourth page for troubleshooting, contact details and repairs.

Example from L.'s communication guidelines:

- The Lightwriter is to support me if I cannot make myself understood.
- The device has a speech chip called DecTalk.
- It can be taken off the plate and put on the table.
- The Lightwriter is a *backup* for my speech.
- My spelling isn't perfect. But it's improving!
- I am practising repeating a word or phrase rather than the whole sentence. What you can do to help L's communication:
- When talking to me you can stand or sit in front of me or at a slight angle to the side.

- Be honest if you have not understood my speech.
- Be clear with me which part of what I am saying you do not understand.
- Introduce a new topic for me to listen to and maybe join in.
- Give me plenty of time to talk.

Positive feedback has been received so far about the first person style of presentation and the detail for each individual. They have been put together with the service user and their family and/or support workers. It has taken some time to produce but will be useful in a range of settings, with new staff and can easily be updated or added to.

#### **USER GROUP**

I was keen that AAC users and their parents/carers met together to practice social communication, share experiences of AAC and to be supportive. We have so far met three times a year, had Stuart Meredith as a guest speaker and had a range of discussions. It has been a place to provide information on local and national groups such as Communication Matters and 1Voice.

The last meeting was more of a social evening in a local hotel bar. The users bought their own drinks. One person who uses AAC thought it was funny to ask for "Half a lager. It's for my Mum". She asked questions of everyone and leaned in towards them to listen to the answer. Her mother reported that previously she would not have listened.

There were lively conversations and we became aware that there are a lot of shared experiences within the group such as school, riding lessons.

The evening was a lot of fun and I came away thinking 'This is why I do this work'.

#### **TRANSITION**

As a receiving therapist there are several practical details that are good practice around transition from one service to another. These include information on how the person's device is set up, perhaps with photos, ownership and warranty, what training the family have received and a hard copy of any vocabulary stored or changed. It is also helpful to have information on how they learn. This information can then become part of staff training in the user's new environment.

I have recently undertaken a review of a person who transferred into the service following five years at a specialist residential college. Limited specific information was received and this slowed down her learning at a local Further Education college as there was a certain amount of 're-inventing the wheel' that could easily have been avoided.

Locally I have done a joint hand-over home visit with the Speech & Language Therapist from the children's Speech & Language Therapy service, set up links and training with the communication aid company, collated relevant information on their communication skills, set up regular visits to their new college and am in the process of compiling Communication Guidelines.

All of the above work is supported by the additional work of a Technical Instructor. She has been in post for eighteen months and can now programme devices, do observational visits to identify vocabulary needs, work one-to-one and take part in training. She is also putting the finishing touches to the guidelines and is an invaluable member of the team.

#### FRUSTRATIONS AND SUCCESSES

Here are some examples of frustrations and successes we have experienced:

#### **Frustrations**

- A day centre with no time/personnel to support an AAC user to ask for their meal.
- Staff shortages at a residential centre new to supporting an AAC user.
- Limited opportunities for multi-disciplinary work.
- Difficulties predicted in transferring EDL to an MT4.

#### Successes

- A Day Centre starting to record sessions and practice with a client during the loan period of a device.
- Contributing to a Social Services Best Value Review.
- Joint funding Health/Social Services/Learning & Skills Council.
- A 40 year old new to AAC using his aid to repair communication breakdown, to do his eye test and when out shopping.

#### **FUTURE PLANS**

- To gather more feedback from Communication Guidelines and ensure they are a useful, working document.
- To run regular small groups for social communication and assertiveness.
- For the User Group to meet 4-6 times a year in social settings.
- To secure further funding for aids and a loan bank. \*

Cheryl Davies Specialist Speech & Language Therapist

COMMUNICATION MATTERS VOL 19 NO 2 AUGUST 2005

### **Home Insurance for Communication Aids**

#### **SALLY CHAN**

Paediatric Communication Aid Service, Claremont School, Henleaze Park, Westbury-on-Trym, Bristol BS9 4LR, UK Tel: 0117 924 7527 Email: sallychan@blueyonder.co.uk

Some of you will have had been confronted with the problem of obtaining home insurance for your own, your child's or your client's communication aid. One parent told me that she had contacted 30 insurance companies, to be told that (a) they do not know what a communication aid does and hence can not insure it; (b) they can insure but only when an adult is always present; or (c) they will only insure at a ridiculously high premium.

#### **NEW REGULATIONS**

Several of you would have read David Morgan's article in the last CM Journal (Vol 19 No 1, April 2005) relating to stricter regulations when selling insurance. The Financial Services Authority (FSA) has laid down strict guidelines for those offering insurance or even recommending insurance. Any supplier offering 'insurance' is required to be a member of the FSA Insurance Register and hence subject to regulation. Even the recommendation of an insurance company is viewed as regulated activity. Hence, the information below identifies an insurance company that is able to offer cover for communication aids at a competitive cost. It is not a recommendation of any insurance company or service.

It is important, when purchasing a communication aid, to be aware what warranty is on offer and what it includes. The meaning of 'warranty' varies depending on the supplier.

#### **THE PROCESS**

I decided to pursue the issue of home insurance further and attempt to identify an insurance company that would listen, and in so doing offer home insurance for communication aids at a competitive premium. Communication aids below a certain cost (this will depend on the householder's policy, but may be £1,500 or £2,000) are likely to be covered by the household contents policy. It is the more expensive aids that exceed that maximum amount that will need to be separately named and insured under the policy.

In 2004, a committee was formed of interested organisation (Communication Matters, BECTa, The ACE Centre (Oxford), CASC, and an insurance broker) to facilitate dialogue between the insurance world and the AAC representatives, and myself. We have only had one meeting but since then, dialogue has continued via correspondence, emails and telephone calls.

#### **RESULT**

After approaching several companies through our intermediary (insurance broker) it has come to our attention that Norwich Union is happy to insure communication aids as medical equipment under Personal belongings within their Home Plus Policy. The specifics of the policy are as follows:

- The condition of insuring the communication aid would be that the client/family would need to take out a household (contents) policy with Norwich Union.
- The cost of insuring the aid would be 1.05% to 1.58% of the cost of the aid, depending on the rating area of the accommodation. Therefore, to insure a complex communication aid valued at £5,000, there would be an additional cost of approximately £50-£75.
- Guildhouse Financial Services (insurance brokers), who have been

involved in this investigative work for the past two years with no charge for their services, have stated that they will offer a 10% reduction on the total premium.

Prospective clients would need to contact Guildhouse on tel. 01934 641 999 or email: *global@guildhouse2000.com*.

#### **LEA FUNDING**

It transpires that some LEAs do have insurance that covers equipment at home. I am only aware of the following but would be interested to hear of any others: Nottinghamshire, Portsmouth and Swindon. Surrey LEA also have insurance that covers equipment in the home but with an excess of £2,500.

#### SOCIAL SERVICES FUNDING

One of the local MPs in Bristol has taken this issue further and approached Bristol LEA and Social Services concerning funding home insurance. This was initiated by a local mother whose son had recently acquired a complex communication aid through the statementing process. The result is that the local social services have agreed to fund the home insurance so that the equipment can be used at home. This has been quite a breakthrough locally as previously social services did not fund any part of communication aid provision. Now precedence has been set.

#### CONCLUSION

The project appears to have achieved results, but we need to test the system before becoming too complacent. I would be very interested to hear from anyone who can offer any additional information on this subject of home insurance. \*

Sally Chan, Speech and Language Therapist



#### **PUBLICATION** REVIEWS

#### Ispeek 1 VISUAL COMMUNICATION

JANET DIXON

ISBN 0-9549595-0-7 £25 plus p&p CD-ROM www.ispeek.co.uk

Reviewed by Sally Millar, CALL Centre, Edinburgh

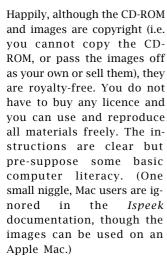
Ispeek is a bank of communication visuals designed and published by Janet Dixon, to assist with approaches to communication and independence, for children with autistic spectrum disorders.



This is a huge body of work, from scratch from a dedicated parent and educator. CM was asked to review Ispeek 1, the first CD-

ROM in a series of two (Ispeek 2 has just been released). Each CD-ROM contains over 1,000 coloured images, in both .wmf and .jpg format, which can be inserted like any other clip art or graphics into whatever software you want to use.

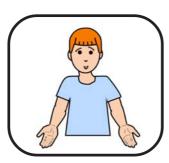
The images are organized into folders, by topic. Across the two CDs topics include: At Home; Auditory Sensitivity; Behaviourals; Cooking; Everyday Things; Feelings; Facial Expressions; In School; Holidays; Please Listen; People; Places; Shopping; Savoury Food: Sweet Food: Drinks: Tasks and Hobbies; Time and Number; Health & Hygiene; Concepts and Understanding; Things We Use; Clothes; Actions.



You can get further information about Ispeek from www.ispeek.co.uk where there are also a number of



'I'm itchy'



'Help'



'Fish and Chips'

useful visual schedules downloadable as freebies (e.g. Making a cup of tea; Making a ham sandwich; Having an injection; Getting dressed for outside). Ispeek products can also be bought from eBay (an interesting new angle for AAC suppliers) on stores.ebay.co.uk/Ispeek. Additionally, there are other communication products



'I don't know'

such as a 'Toilet Routine pack' (£5), a Key-Ring Communicator (£7.50), and a Pocket Reminder' (£7) plus p&p. On eBay, 100% of feedback from customers is positive - the following quote is typical: "Great service great product really helpful can not praise or recommend highly enough A1."

Ispeek represents a convenient and value-for-money new source of AAC materials, from an interesting new publisher. The *Ispeek* images will certainly be very valuable in settings where there are no other graphics. In settings where symbols are established, it's not so clear what Ispeek will add: a rough count showed that there were few meanings on the Ispeek 1 CD-ROM that are not already represented in Rebus or PCS. However, Ispeek 2 adds more ASD related vocabulary areas (though the more that is added, the harder it will be to find what you want, as there is no search facility).

The Ispeek images are highly specific and pictorial. Concrete objects (food, clothes, etc.) are well illustrated, and they bring in some of the detail so keenly needed in ASD (e.g. 'silver MPV car', 'clothes for winter'), although with some oddities (e.g. 'telephone' is neither a mobile nor a home phone but a strange hybrid). Some symbols rely on some text ability (e.g. days, months).



'Telephone'

Predictably, a wide range of feelings and facial expressions is available, but many of these will still be difficult for children with ASD to understand. Symbols for more abstract concepts can be obscure (e.g. 'enough'). There is no non-gender specific person, and often only



one gender picture is available, rather than a choice of male or female (e.g. only a girl showers; 'friends', 'hug' and 'together' are exclusively female). Ethnic and colour choices are there but not comprehensive, and there are other gaps.

Maybe the choice of symbols these days for some is just a question of personal taste and convenience. As anti-discrimination legislation comes into force and progression towards more inclusive education (and society) develops, there is an ever-widening awareness of the need to create a visual environment and to make information accessible and inclusive, so use of images is far more 'out there' in the public domain and less and less the exclusive domain of AAC specialists. Interesting times indeed! \*

[An information sheet listing basic details about currently available/ used picture and symbol sets is downloadable from www.callcentrescotland.org.uk (Go to: Communication > Developing Communication > Guide to Pictures and Symbols for Communication).]



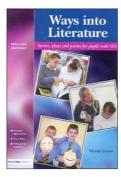
#### **WAYS INTO LITERATURE**

STORIES, PLAYS AND POEMS FOR PUPILS WITH SEN NICOLA GROVE

ISBN 1-84312-205-7 129pp £20 David Fulton Publishers, London 2005

Reviewed by Sally Millar, CALL Centre

This new book is an updated version of 'Literature for All' (1999). The philosophical underpinning of both books is that "the best literature has a power that goes beyond words - and that literature is too important to be restricted to those who can read".



The book is a practical guide to introducing novels, plays and poetry to learners across the whole range of ability, and showing teachers how to engage students with learning difficulties, ASD, or difficulties with hearing, language and communication, reading and writing in particular.

The book will be useful, perhaps inspiring, to staff tasked with delivering the English language curriculum, in both inclusive and special education settings, who may struggle to find age-appropriate literature for these students. In some ways, this book is also a validation of the creativity in the teaching of language and literacy already going on day to day in our classrooms and should reassure SEN/ASL practitioners wrestling with 'The Curriculum' that they are 'on the right lines', and enthuse them to be even bolder in their choice of texts.

It starts from the premise that providing a rich language experience can have a powerful stimulating and illuminating effect (even if every word and grammatical structure is not fully understood) and can help students to form and communicate ideas (rather than the developmental model of

language acquisition in which language comprehension must precede expression).

The book contains a wealth of ideas on how to adapt and 'bring alive' texts appropriately for different learners, hopefully at a detailed enough level to be practically useful to teachers. In the process, a good deal of extremely valuable background information about different areas of communication disability is put across.

The final chapter provides a brave exploration of the issue of how to evaluate students' responses to literature, and presents a framework for assessment based on levels of experience in four key areas: experiential, affective, cognitive and aesthetic perspectives.

The chapter on 'Getting Started with Creative Writing', co-authored by Tina Detheridge and Olivia O'Sullivan, highlights the role of writing in the process of developing the literary experience, by discussing examples of the use of symbols and software amongst other approaches. For me, this chapter - for all its interesting content - didn't sit very comfortably, as it changed the voice of the book from a 'how you can do' to a 'can be done'. Along with this, the interesting discussion in Appendix 2 about 'translating' into graphic symbols and/or signs, underlines how difficult it is to achieve an affective experience of literature, when crossing language modalities, especially with the added barriers of introducing extra equipment, and the time this can take - a difficulty of which Grove, Detheridge et al are undoubtedly aware.

The book refers to Story/Symbol pack resources from the CALL Centre at Dundee - this should be Edinburgh - and gives an incorrect web address. The address should be: www.callcentrescotland.org.uk/resources.

Anybody who 'does' language and literature with children (or adults) will want to read and put this book into practice. \*

#### **E-BULLETIN ON ASSISTIVE TECHNOLGY**

In May 2004, the Assistive Technology (AT) Forum began producing a **free** monthly email bulletin with breaking news and current issues in AT.

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We are looking for reviewers of the following items (for publication in future issues of this journal):

Word Wheels (by Kathryn Clark) - Targeting the specific problems learners have with English language, the book and interactive program exercises provide essential practice in the use of grammatical structures, with optional BSL and audio support.

Meeting SEN in the Curiculum:

Art (by Kim Earle and Gill Curry)

Design & Technology (by Louise Davies)

English (by Tim Hurst).

History (by Richard Harris & Ian Luff)

Educating Children with Acquired Brain Injury (by Sue Walker & Beth Wicks) - Describes the common difficulties that children with ABI experience, and how to support these pupils and families

**Discovering and Developing Talent in Schools** (by Bette Gray-Fow) - Contains a range of practical and inclusive strategies to help schools enable and encourage pupils to make the most of their talents

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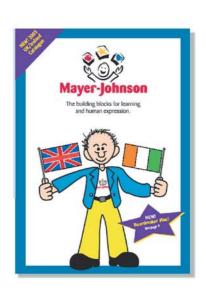
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