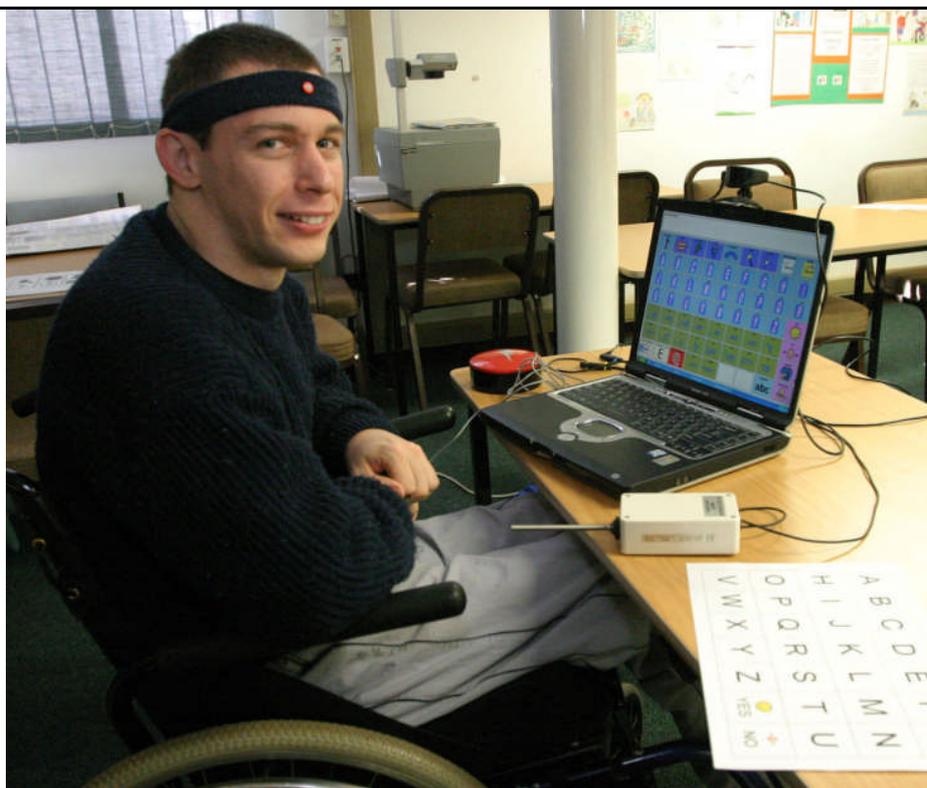

COMMUNICATION MATTERS

INTERNATIONAL SOCIETY FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

UK CHAPTER

DECEMBER 2003 Volume 17 Number 3



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My Story...so far!

by Louise Jones & Tanya Backhouse

Stories from people who use AAC devices are always welcomed by this journal. The following two stories from AAC users have been submitted by Prentke Romich International, the company that markets and distributes Minspeak aids such as the Pathfinder. Other companies may like to forward for publication stories from users of their devices (with the person's permission of course). Indeed, everyone could encourage people that they know who use AAC devices to create and submit their stories for publication. Please also check out (on pages 19) the details of various grants and awards available to people who use AAC devices. As well as getting articles published, people or groups may be eligible for one of these awards.

Louise Jones

Hello Everyone, my name is Louise Elizabeth Jones. I have cerebral palsy. I live in a village in East Yorkshire.

I am 10 and I attend a mainstream school and I am in year 5. I live with my mum Ann, dad Richard, sister Emma 15, and brother Liam 18 who is in the R.A.F. He messes about with weapons, bit dangerous if you ask me! I have two dogs Meg and Sam, two rats (in a cage of course) a rabbit called Pom, two goldfish and a pony called Prince. I go to riding lessons but I enjoy riding Prince more. I like to groom him, but I'm not too keen on the mucking out bit, Yuk!



I enjoy going to the pub to watch Grimsby Town with my dad and being with my friends. My best friends are Emma and Sophie. I think Sophie is to get a communication aid soon. That will be good. We can have some great chats, and probably get into trouble too!

I like to read Jacqueline Wilson books. My speech therapist told me about the worry website where there's a story about Natasha who uses a communication aid and is in a wheelchair just like me. Well done Jacqueline Wilson, it's a great story.

Having cerebral palsy means that I don't walk and I don't talk (that is with my mouth, but I still have plenty to say!). I can do this by using my *Pathfinder*. I did use a *Delta talker*, but with help from the CAP project I have been able to get my new *Pathfinder*. Its been a good swap. I haven't had a lot of new things to learn because I still use Minspeak, and anyway I really like the other things, the activity row, the notebook, and I really like being able to store things myself!

Everyone says how much the *Pathfinder* helps me communicate. I feel more confident, and join in lessons much more than I did before. I am quite good at learning things myself, but I get lots of help from other people, like mum, my support assistant, my speech therapist, who is great with communication aids. I am very lucky to get this help, I'm learning to get the best from my *Pathfinder*.

Before I had a communication aid I had to rely on other people understanding me. This meant I didn't go far on my own, I felt a bit scared, but not now, I can do and say what I like, I feel good about myself, I'm seen as really clever by other people, and I'm good at something even my friends can't do!

My *Pathfinder* is really important to me. I didn't like using a communication aid at first, but I do now. It's good that I can show people that I do think like everyone else, and have as much to say even if I do in a different way.

Louise Jones

(Louise prepared this herself; this is what she chose to say. Her family are exceptionally proud of what she has achieved. Louise is an inspiration to all who meet her. She will reach her goals through her own determination, her fantastic character and a remarkable sense of humour!)

continued on next page...



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:

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PO Box 559, Halifax HX1 2XL

Tel: 0845 3307861

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Tanya Backhouse

My name is Tanya Backhouse and I'm 27 years old. When my mum had me I was suffering from lack of oxygen and I was blue on my body, which caused cerebral palsy. I grew up in Bromley and when I was four I went to Cheyne School where I used Blissymbols to communicate. When I was 8 I went to Marjorie McClure School where I use a real voice communication aid. At the age of 17 I went to Nash House and used a Liberator to communicate. When I was 25 I went to Widmore Centre College. I started to use my *Pathfinder* at age 26. I am still studying at Widmore and really have a ball of a time.



I stayed with my parents until I was 17 and then moved to Nash House residential college. When I was 21 I moved into my own flat with a carer that I employed so that I could live independently. My carer lived with me for 3-6 months. I had bad carers in the past, but nowadays I have excellent carers who can drive me to courses or everywhere I want to go, for example, college, shopping, cinemas and the pub.

Before I had a communication aid I didn't talk, just used my eyes, I was sad and angry because I wanted to talk and communicate with my family and friends, especially when I wanted to ask something or wanted something or when I needed to tell them how I feel exactly. When my brothers went out I was really angry by myself because I wanted to go out by myself and with them, to meet new people. Before I got the *Pathfinder* I didn't like my life because I needed to go out with my parents, like if they wanted to go visiting I said to myself, "Must I go with my parents everywhere?". I wanted to have my own life and go my own way.

As I result I needed a communication aid. Since I got my *Pathfinder* I can easily communicate with my parents, friends, teachers and carers. I am also working in schools, where I teach adults and children how to use their *Pathfinders*. Now I can do everything I want to do, I am not a child, I sit down with mum and have a conversation with her where before we couldn't talk with each other. My carer and I talk about what music, movies and clothes we like or about anything we see on T.V. or hear on the radio. I love to go to the cinema, listen to music and have a beer at the pub or go and shop until we drop.

Tanya Backhouse

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.

What is ISAAC?

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, c/o The ACE Centre, 92 Windmill Road, Oxford OX3 7DR
Tel & Fax: 0845 456 8211
Email: admin@communicationmatters.org.uk
Website: www.communicationmatters.org.uk

If you are outside the UK, you can become a member of ISAAC or subscribe to this Journal by contacting ISAAC, 49 The Donway West, Suite 308, Toronto, Ontario, M3C 3M9, Canada
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Great Expectations

by Imogen Howarth

Martin Pistorius has a very unusual story to tell. Unusual in that he has made one of the most remarkable advances in the past 48 months that I have ever seen in over a decade of working with people who have learning disabilities, or am ever likely to see again. I would like to share with readers of this journal Martin's amazing journey of strength, perseverance and technology. It serves as a valuable lesson to all practitioners in this field who may be inclined to accept a former diagnosis as a permanent state.

Martin lives in South Africa, near the city of Pretoria. At the age of twelve he was a healthy, happy child who could read, write and interact as well as any of his peers. Devastatingly, Martin caught what was thought to be a severe strain of cryptococcal meningitis and became very ill. His family were powerless to help as they watched this dreadful illness gradually strip him of his ability to be independent, to walk and finally to communicate.

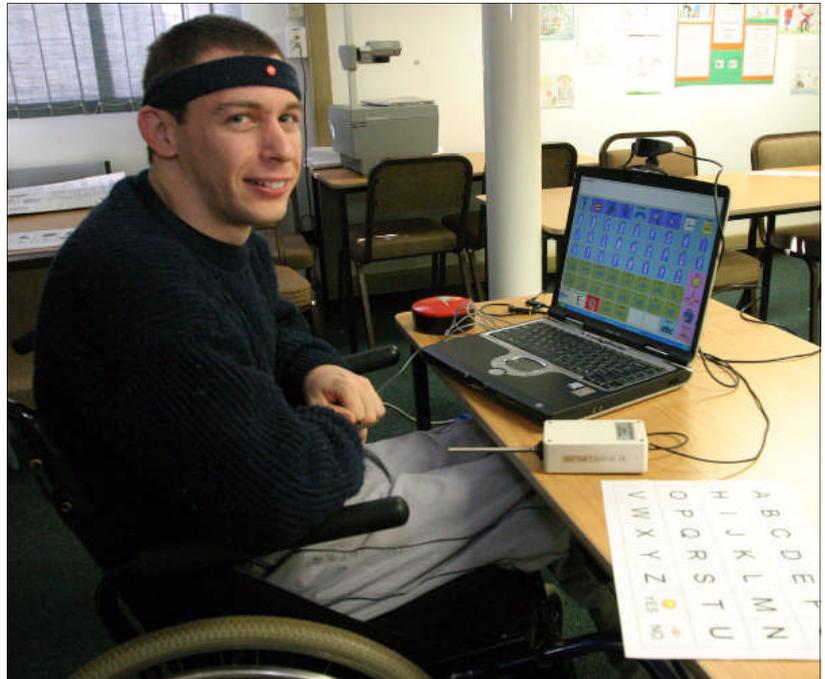
Before his thirteenth birthday, Martin was left as helpless as a baby. The illness, thought then to be a neuro-degenerative disorder, had subsided. This is an umbrella term used to group a variety of symptoms. In Martin's case it meant that his mental age appeared to be that of a young baby. He was terrified, had no memory or speech, and in his own words was "locked inside his body".

Years passed and Martin remained unable to communicate with the outside world. He could not attend school so would sit at home watching television or sleeping. When provision was made for his needs, it came in the form of a day centre for severely disabled people. Here Martin fared little better and the only sensory stimulation he had was a radio. Martin reports that he would spend his time watching ants crawl across the floor and had understandably become passively acceptance of his situation. He was very negative about life and closed to anyone's attempts to make eye contact or communicate.

The Uphill Climb

Martin's steep uphill climb began at about twenty-four years of age, when after over a decade of isolation, a new aromatherapist named Virna who had begun working at the day centre saw recognition and understanding in his eyes. As Martin puts it they "simply clicked".

With great perseverance over many months the new staff member and Martin established consistent communication



through facial expressions. I find it hard to imagine the magnitude of that moment of breakthrough and its impact both on Martin himself and everyone around him, though the best was yet to come.

Virna started looking into the world of augmentative and alternative communication (AAC) and happened across the Centre for AAC (CAAC) at the University of Pretoria. Still very sceptical and unsure of what to expect, Martin was evaluated there in July 2001. The evaluation team recommended a *Macaw* communication device but this proved much too expensive so instead his parents spent every weekend for months on the Internet, searching for alternative solutions. Software was quickly identified as the best way to help Martin.

The Transformation

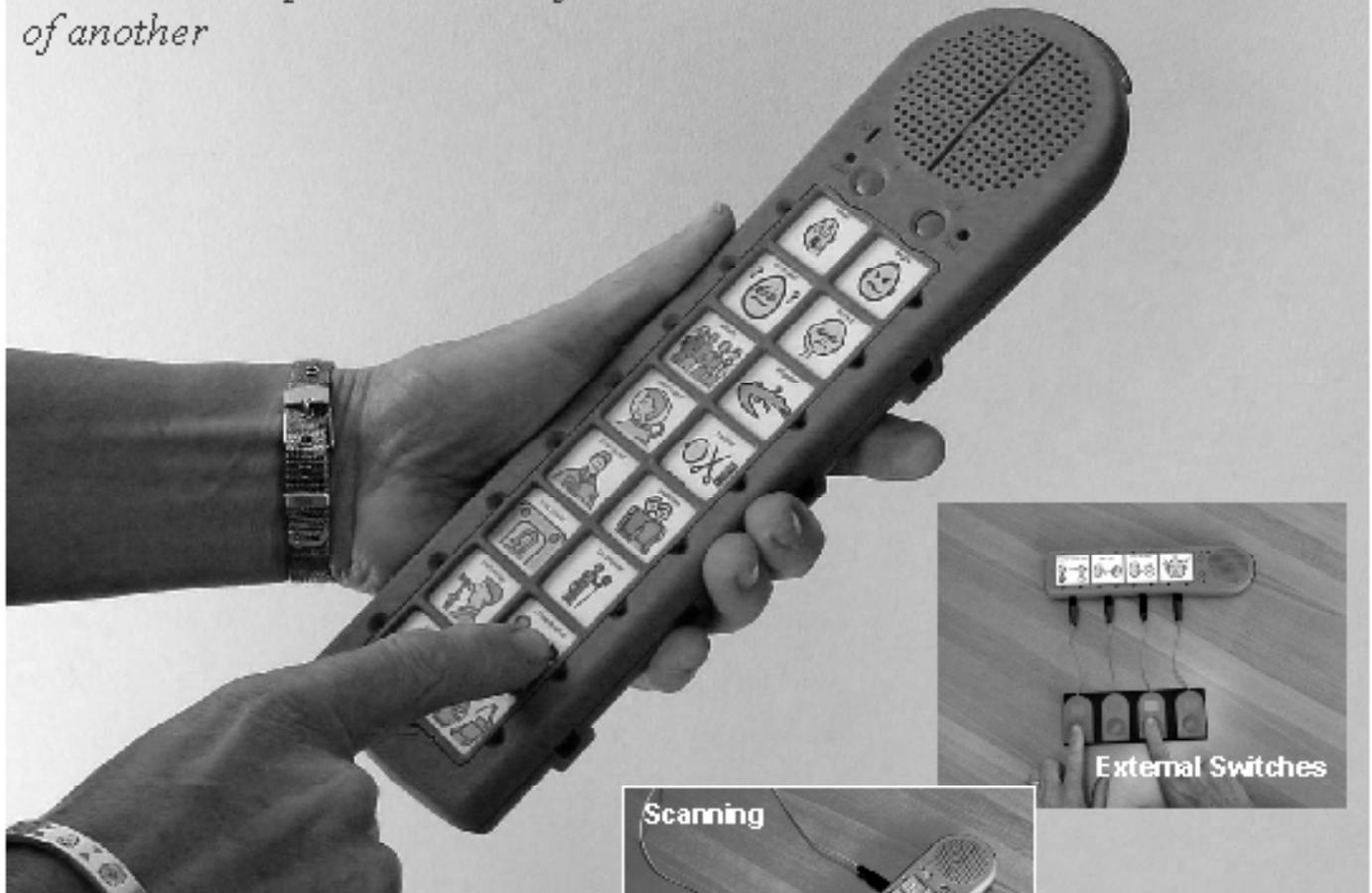
Early in 2002, an inheritance sum paid for a laptop, a *SmartNAV* head-mounted tracker and a selection of software. Martin now had to relearn skills that he had not been able to practise for twelve years, as well as coping with his physical disability and the new technology; it was a mammoth task.

In May his mother Joan gave up her job as a radiographer in order to spend hours everyday helping Martin. This transformed his learning and he began to start to read – first with PCS Symbols, and then with Widgit Rebus Symbols as his written vocabulary expanded. Martin has a natural flair for computing and proved an excellent student.

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Martin Pistorius and friends on campus

It was about this time that Martin first contacted me in my previous role working for Wigit Software. He had started to use *Writing with Symbols 2000* and I was looking for contributors to the now very popular symbol supported website – www.symbolworld.org. Martin wrote some wonderful stories for the benefit of other *Symbol World* users and I was amazed at the level of expression and range of vocabulary in his writing. It was very unusual to find someone needing symbols but who was obviously very able and produced such long and interesting prose.

I started to email Martin more frequently and quickly we became friends. He has a wonderful sense of humour and is a very charming and likeable person. From a level of emergent literacy only two years ago, Martin has achieved some remarkable goals. He has learned to read and write fluently. He now accesses a computer with switches and *SmartNAV*, and uses to a very high standard Windows XP, Microsoft Office, AAC software, including *Inter_Comm*, *The Grid*, *Writing with Symbols 2000 (WWS)*, *Winspeak*, *Hands-Off*, *Clicker 4*, and many other programs.

What I find astounding is the speed at which Martin is able to communicate. For example, I use *Microsoft Messenger* that allows instant messages to be typed and immediately sent to another user, forming a conversation script on screen. One day a message flashed up from Martin. I asked him how he was able to use the software. He first types the message into *WWS 2000*, using *The Grid* for head switch access to his now endless word banks. His text can then be read out to him using the SAPI Speech voices in *WWS*. He then copies and pastes this text into Messenger and sends the message. To read my replies, Martin uses this method in reverse. Even for a competent IT user, this

process would take time, but imagine having to form each sentence by pointing your head at switch accessible grids! Martin can now use Messenger in real time, replying just as fast, and writing just as much as I do.

Employment and Independence

With all this new found knowledge, combined with such an insightful understanding of the world of AAC, Martin has caused quite a stir in his local community.

He has moved on from the day centre and now works part time fixing computer and network problems at the North Gauteng Mental Health Centre. In a role reversal, Martin is now able to teach his mother aspects of IT knowledge. He has also found employment with the University of Pretoria, in their Centre for

AAC and works as a disability consultant.

After a recent appeal to fund a power wheelchair was successful, Martin is the proud owner of his first mode of independent transport - a Shoprider power chair nicknamed his Ferrari.

His next search for funding will be for a personal assistant and to this end Martin is in correspondence with the South African government. Altruistically, he hopes to secure funding not just for himself, but also for others in similar situations.

Looking Forward

Next year Martin hopes to study as a mature student at the University of Pretoria. It's a far cry from staring at ants for motivation.

There's a lot that Martin wants to do with his life. He's been given the chance to be positive again, and is living life to the full. He can establish friendships, go out with friends, order a pizza, enjoy films, write emails, make speeches, find employment...a never-ending list of choices. For me, the most important of these is that Martin can be proud of his achievements and feels a valuable part of his community once more.

If you'd like to contact Martin, he'd be happy for you to do so via Email: martin.pistorius@up.ac.za

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Making the Curriculum Work for People who use AAC

by Jeanne Eames & Debi Taylor

This paper was presented at the CM2003 National Symposium, Lancaster University, September 2003

Introduction

The National Curriculum was not designed for children with special educational needs and pupils who use AAC are at a particular disadvantage.

Trying to meet the needs of a child who uses AAC can present enormous problems to teachers both in special and main stream schools and can sometimes lead to those needs being ignored to some extent - or the teacher ending up with a nervous breakdown. These problems have not been lessened by the Government's drive for inclusion and, although the Communication Aids Project (CAP) in England has brought very welcome funding for VOCAs, it has resulted in many more devices arriving in classrooms and needing to be used.

There are no easy answers, but there are strategies and methodologies which may alleviate the situation.

Learning Objectives and AAC

Clearly nearly all the elements of the National Curriculum will need to be broken down into smaller steps for pupils using AAC and more time allocated to the achievement of targets. It helps if new skills are practised in a variety of contexts. Children can learn or practise a skill in many contexts and sometimes, by looking at a learning objective in a new way, it can be made more appropriate for a pupil using AAC and more fun too. It is even better if two learning objectives can be combined.

For example, Reception Key Objectives in the National Numeracy Strategy states that a child should:

"...be able to count reliably up to 10 everyday objects."

Performance descriptions in English, Primary 6, states that a child should:

"...use phrases with up to 3 key words, signs or symbols to communicate simple ideas, events or stories to others and follow instructions with three key words and respond to others in group situations, for example taking turns appropriately and co-operating."

Core vocabulary such as "put it there", "turn it on", "take it out", "my turn" and "your turn" can be used in the activity of making a cake. The pupil using AAC can be the director of the activity, giving simple instructions to the others using this core vocabulary with their VOCA. Thus fulfilling part of the English learning objective. Other members of the class will be following the instructions and taking turns. Thus fulfilling the other part of the English target. At the same time all the pupils can count spoonful, grammes, eggs, dollops or any other standard or non standard measure that is felt appropri-

ate. Thus fulfilling the Numeracy target. And there is a cake to eat at the end!

This type of activity can also be used when building a circuit in Science, creating an artefact in Design Technology or playing a game in P.E. The core vocabulary will, of course, be useful to the child using AAC in many other contexts, at home and at school.

Many of the fundamental skills needed by a person using AAC are those which lend themselves very well to being used across the Curriculum. Listening and turn taking in a conversation can be developed as easily in Science, Geography or Music as in Speaking and Listening. The vocabulary does not have to be extensive. Often a simple "yes", "no" or "maybe" can go a long way. Question words with or without the ability to make a simple sentence can be used in problem solving across many subjects and only take a few minutes to programme or put on a symbol chart.

Older pupils who are using AAC at an early level need learning objectives to be appropriate both for their age and level of ability. This means that a decision has to be taken as to whether the child should be taught differentiated work based in their Key Stage or whether it is more appropriate to teach the child work based on the lower Key Stages. This decision must not be taken lightly as OFSTED inspectors can be very pedantic about it. Linking National Curriculum learning objectives to life skills can be one way of achieving this. For example, Key Stage 1 of the History Curriculum demands that children should be taught to "place events and objects in chronological order." Planning for a holiday, outing, party or simply to get dressed can provide opportunities for older pupils to practise this skill. The pupil using AAC can use a symbol chart or a VOCA with perhaps four or eight locations with vocabulary such as, "after", "before" "next" and "now".

Numeracy can present great difficulties for children using AAC particularly if they also have poor hand function which makes access to a VOCA, symbols or objects difficult. Using basic mathematical vocabulary such as "more than", "less than" and "same as" is sometimes more meaningful than trying to enable pupils to rote count.

Lesson Planning and Preparation

Planning and preparing lessons for a group which includes a pupil or pupils using AAC can be *very* time consuming.

Once you have seen how wonderful a lesson can be when a child has all the right vocabulary, readily accessible, on the right device and at exactly the appropriate level for them, it

is hard to settle for anything less. But realistically it is impossible to spend the hours needed preparing for every lesson. Perhaps one way of dealing with the problem is to have one *focus lesson* each week when you pull out all the stops. This does not mean that the needs of the child using AAC are ignored in other lessons, but it does prevent the teacher from succumbing to sleep deprivation!

Supportive Teaching Strategies

There are strategies which will enable a teacher to include a non-speaking child in all parts of the lesson without a lot of pre-programming. Again the use of core vocabulary is vital. A simple page on a VOCA or chart which will enable a child to say, "I know the answer", "I understand", "I don't understand, please explain again." and, of course, "yes" and "no" can be very successful in all lessons if used with a sensitive teaching methodology.

The children will soon learn to use these strategies themselves. It is also possible to use the materials already provided for the lesson as symbols charts, particularly in such subjects as Science, Maths and Modern Foreign Languages. For example, a French lesson on vocabulary for holidays is likely to include some pictures of a beach, swimming pool, hotel, etc. and the pupil using AAC can demonstrate his or her understanding of the words by indicating, in whatever way possible, which of these is being talked about. However, using pronunciation exceptions to try to make a VOCA with a synthesised voice speak French is a different ball game altogether!

Some teaching methodologies can be developed that will be supportive of a child using AAC.

- It is extremely important to include the pupil in every activity, otherwise he or she will simply stop attending. Even a simple "Do you think that's the right answer?" can give a teacher an idea of the child's understanding and also keep the child focused on the lesson.
- Closed questioning can be very effectively used to elicit information as can the use of forced alternatives such as "If you add nine and three, do you get 12 or 14?"
- If the pupils using AAC has a chart or a VOCA programmed with some appropriate vocabulary, the teacher really needs to know exactly what they can say, and ask questions that can be answered. This is much more difficult than it sounds, as teachers are used to matching their questions to the flow of learning in the class and are unused to having to be much more specific about how each question is phrased. The television game "Who wants to be a Millionaire" has suggested another way of making the child using AAC able to participate with a minimum of preparation. The rest of the class is usually very happy to join in as well. A chart containing the letters A, B, C and D is all that is required. The teacher gives four possible answers to a question and the class has to select the letter representing the right answer. A word of caution, however. It is quite difficult to think of four possible answers to a question off the cuff, it may need a little thought beforehand.

- The time that a child using AAC takes to make a response is often another problem that has to be overcome. Speaking pupils in the group will always be able to respond more quickly and, if the pace of the lesson slows too much, will themselves lose interest. Warning a pupil that he or she will be expected to answer a question in a little while can be really helpful. It may give the few minutes it takes for the child to think of the answer and find the word or words necessary without the other pupils having to wait. Sometimes a 'one-step' communicator can be used instead of a device that is more time consuming to use. For example, a pupil who has been working on an assignment and wants to give an account of his or her work to the group may find it quite difficult to locate and use the necessary vocabulary. A learning support assistant (LSA) could, at the pupil's direction, record the information on the one-step communicator and the pupil would then be able to give the account to the group quickly and easily.
- Signing can also be used to support children who use AAC. Using a thumbs up thumbs down sign to identify if they think an answer is correct can work very well with non speaking and speaking children alike, especially if they think that the teacher has got it wrong. Also, by using British Sign Language finger spelling, the child can be given an easy way to answer. They can identify the initial letter sound of their answer, or when given four fix alternatives can identify which answer they wish to choose. They can choose who they wish to answer when in a group quiz situation. Finger spelling can also be used to support the introduction of new vocabulary, by spelling out the new words the child can be given a scaffold to the words' meaning and use.

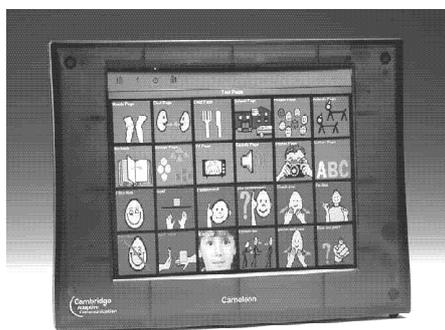
The Importance of Learning Support Assistants

The role of the LSA is crucial, both for the pupils using AAC and the teacher. A well-trained and confident LSA can facilitate the child's performance and give the teacher a clear picture of the child's progress and difficulties. Training in the VOCAs used is obviously essential, but the LSA also needs to know what other devices might be available should they be more effective on a specific occasion. The ability to prepare appropriate charts using available software is also important, but more important are the skills of using those charts with the child. Pupils may need reminding that they have access to vocabulary that they can use and given some gentle prompting. The vocabulary may not exactly fit the question asked but, with a little flexible thinking, could still be used meaningfully.

The LSA is also critical in the selection of vocabulary that can be used to motivate a child they often have a much better understanding of the child likes and dislikes. For example, if the child is fanatical about the Fimbles, the characters and the vocabulary associated with them can act as a great motivator.

The Art of Listening and Accepting

The art of 'listening' is perhaps the greatest skill needed. Often pupils using AAC are not easily understood. Question-



New Cameleon XP

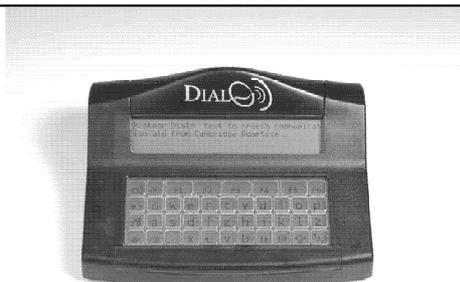
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ing that could clarify the utterance, patience to give the child time to make him or herself clear and the determination to be absolutely sure that the utterance has been fully understood, are crucial elements in working with a child.

An understanding of the importance of accepting whatever the child wants to say regardless of whether it is 'right', expected or relevant, as well as allowing the child to do and say what is possible with support but without doing it for him must be at the heart of all work with a pupil using AAC.

Much of this expertise will come from experience, but opportunities to shadow a more experienced colleague, talk through successes and failures with the teacher, attend such courses in AAC as are available and improve qualifications through Degrees and Diplomas in Learning Support are essential for LSAs. They are in the front line and are in no way second class citizens.

Keeping a Record of the Work

Recording and keeping evidence can be a problem when a child cannot produce written work and cannot speak into a tape recorder. Videos are the obvious answer but it is not always easy to position the recorder so that symbol selections or signing can be clearly identified without the recorder being very intrusive. A separate video tape for each child using AAC

is essential if you are not going to spend hours collating information from various tapes.

A simple log book, filled in by teacher or LSA when a significant achievement or problem has occurred, with a brief account of what happened and the date, is a quick and effective method, particularly if a photograph is added. Tick charts may sound like the epitome of boring practice, but occasionally they can be exactly what is needed, for example if you want to know whether the number of prompts a child needs is decreasing over time.

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Symbol World

by Tina Detheridge

The Internet is probably one of the most exciting and yet challenging sources of information available at the moment. Exciting because of the sheer extent and variety of material. The problem, as we all know, is that it is largely inaccessible for many people with difficulties or disabilities. There are a number of initiatives to give access to people with visual impairments and who need alternative physical access. There is little, however, at the present time that makes it relevant for people with learning difficulties.

In particular, there is very little available for symbol readers. Many young people find that at best they are looking at sites with many photographs, but not able to gather much information. The first really useful symbol site was the Meldreth Manor school site, created by Richard Walter. This has information about the school, pupils and their activities. There are other sites that have symbols for their specific user group, such as the Toby Homes Trust. The *Peepo* site, although not in symbols, provides links to many sites that have suitable material. *Symbol World* is different from these in that it has been set up especially for symbol readers. The aim was to provide a site with easy access, and that has interesting and relevant reading material for symbol readers.

What the Website Contains

There are four main sections: Fun, Stories, Learning and News.

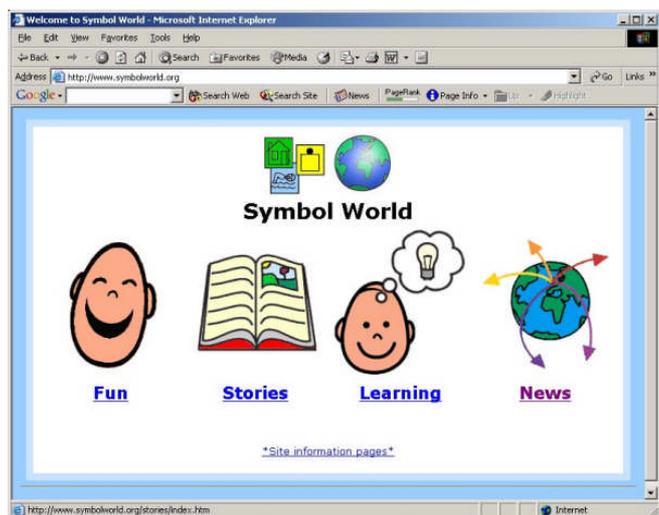


Figure 1 Symbol World's front page

The 'Fun' section has an area called 'All about me' where symbol users can publish their own materials, a 'Jokes' section – with some silly jokes to read together, and a games area.

There is an excellent game based on idea from Imogen Howarth, in which you can look at photographs of different people showing how faces change with different feelings.

The stories section has stories for all ages, including stories for older readers. How often have we all wanted appropriate

reading material for teenagers and adults? The Internet gives us a realistic and affordable publishing medium where hopefully we will at last be able to realise this dream.

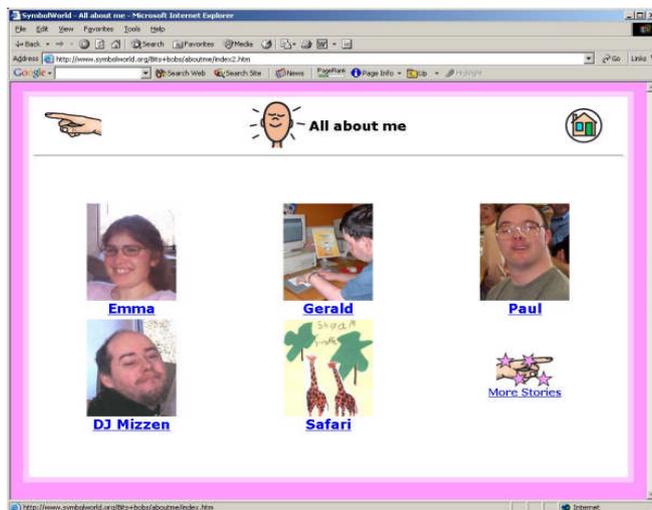


Figure 2 'All about me' page

The 'Learning' section addresses this same problem. Most published curriculum material is text based. At the moment this area has a mixed collection of topics supported by symbols, but with materials at a variety of cognitive and educational levels. At the highest level is a topic on Space from Sue Norton which has quite a high level of symbols and text. Sue has used symbols very successfully with her secondary science students.

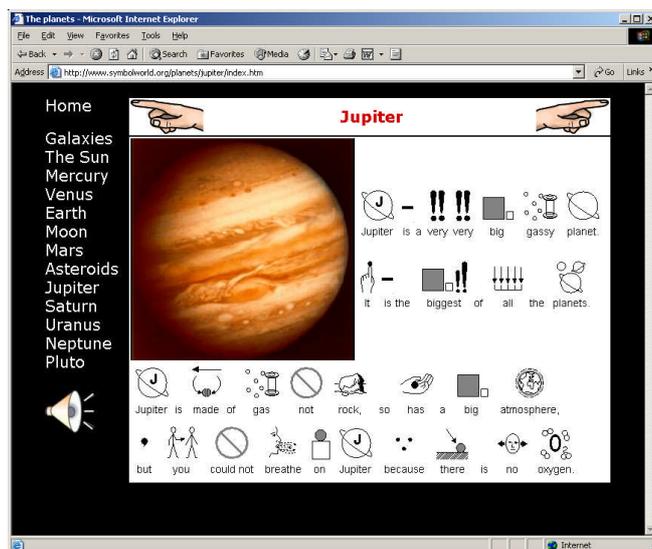


Figure 3 A page from the 'Space' topic

The 'Personal and Social' section, on the other hand, has some introductory materials suitable for adults on topics like 'Making a cup of tea' and 'Sorting the washing' which has a photograph and single line of symbols.

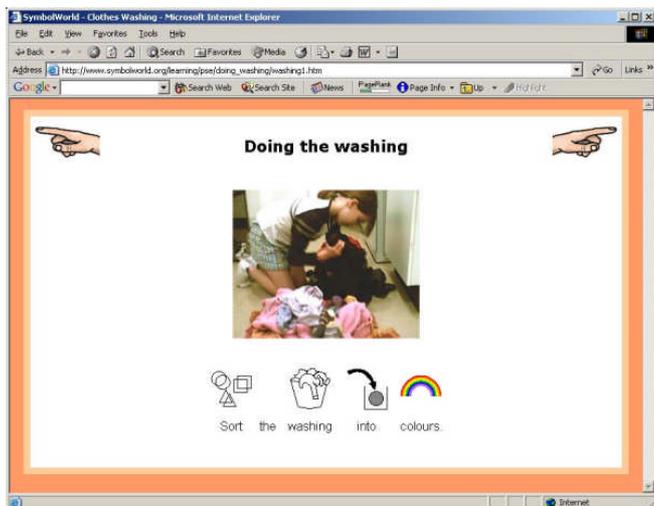


Figure 4 A page from the 'Personal and Social' section

The 'News' section aims to bring topical content in a suitable format to teenagers and adults. It was inspired by work from George Hastwell School on the war in Yugoslavia, and so when the Iraq crisis loomed they decided that it would be useful to bring some of these issues to symbol readers.

This section was created by Eugene Grant, a secondary student who has understanding of the difficulties and issues faced by people with disabilities. Eugene has been a youth MP and is interested in bringing important political issues to others.



Figure 5 A page from the 'News' section

The content is factual, presenting the issues for the teacher or mediator to expand upon. One of the major disappointments is the lack of photographs. Ideally each of these topics should be supported by strong visual images.

We tried to get permission to use images from the Guardian and BBC web sites, but although we met with friendly voices, it appears that all the images are owned by agencies who charge enormous fees for permission.

There are some free sources of pictures, but these rarely cover current topics. This is going to limit some of the potential articles too. It is rather pointless to write about Beckham's new

hairstyle without a picture to go with it. Even if *Symbol World* were a charity, it seems that the fees would still be prohibitive.

Sharing Ideas and Resources

The original concept was that this site would be a shared area with teachers, children and adult symbol writers exchanging ideas and materials, and much of the site is made from these contributors. The personal pieces range from Ellie, aged five, to Martin, an adult with good symbol language skills, writing from South Africa. Lakeside School in Hertfordshire has sent in a number of pieces and so it now has its own button on the menu page.

Writing for *Symbol World* has benefits for the writers as well as the community of readers. Shyam works with his mother to create stories. It is the reward of seeing his work on the web that motivates him to do more.

On the other hand, Julie Barclay creates stories for her son who has learning difficulties. She says that she has to make these stories because there is no other reading material. Her stories cover educational as well as social topics, and have lovely illustrations. For her, the benefit is seeing that her labours are also of value to others. Charlotte is learning about writing and extending her use of ICT by making stories for older readers in the Personal and Social section.

Funding

Symbol World is currently sponsored by Widgit Software and by BECTa. It has been created by Cate Detheridge, from SymData Technologies, who originally developed the symbol area of the Rara Avis Rainforest site.

BECTa have added their sponsorship to develop the 'News' section into something of a topical magazine area for older learners and adults, and to support the development of more symbol supported curriculum materials, particularly to support inclusion. The site will also be hosting a users area for CAP (Communication Aids Project) so that youngsters who have become part of the CAP Project have a place to talk to each other and share ideas. This is due for launching in January 2004.

One of the problems that we have all found is the lack of any commercially available reading material in symbols. Many schools are re-inventing the wheel by preparing their own symbol supported versions of classroom resources, or adding symbol captions to reading schemes.

Copyright

Copyright constraints forbid the free exchange of these materials, and it has proved prohibitive to licence them. Although worthwhile, this is an enormous waste of energy when these materials are of use to many people.

Of course, individual children have individual needs, and in some cases resources need to be created or fine tuned to meet specific needs, but life could be a lot easier if a source of material was available.

The Web is an ideal publishing medium. The production costs are not too high, and access is free. Access is also easy, and available to children, parents and adults with learning difficulties.

Accessibility

Access is always a crucial issue on web sites. Currently *Symbol World* is accessible by mouse pointer and many features have been added to make this easy to understand and manage. Each time the mouse moves over a link the images are highlighted with stars (see Figure 6).

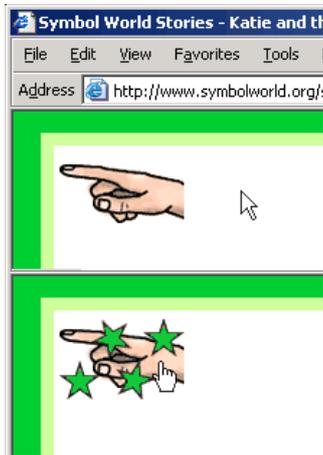


Figure 6 Highlighting with stars when pointer is over symbol

All pages fit on the screen and so there is no need to scroll. And the buttons are placed in a consistent place on each page to reduce the amount of mouse movement needed. Many of these ideas were first developed by Richard Walter on the Meldreth website, which set the starting standards for us all.

At the moment the website is not switch accessible. The first task was to design a site that worked technically and was useful. Once this first objective has been reached, the question of adding switch access can be addressed. There are two problems in adding switch access. The first is that adding switch access slows the whole site down making it very slow to use for everybody. Richard Walter also found switch access a problem and ended up creating two versions of the site, one accessed by mouse and one by switches. The cost of adding the second site is very large. It would need to be maintained in parallel to the other site, and sadly at present there just isn't enough funding. The other problem is that the technologies are still being developed, especially to add single switch access and we really need more research in developing access technologies. At the moment the balance is to go for extensive content or to have a much smaller content available in two formats.

The statistics show that the site is popular and is used regularly by many people, with the number of unique visitors rising from 1400 unique IP addresses in February 2003, 2000 in April and almost 3000 in May. However, a weakness of the project is that no mechanisms were set up to gather feedback from users. There is, therefore no data on how many people would like switch access, nor is there dialogue with users on what they like or would like in the future.

Registration and Getting Feedback

The team decided not to put a registration system up, with user log-in. Although it would have enabled a certain amount of tracking to take place, it would also have created a great barrier to access. You can create a shortcut on your desktop for any

web site simply by dragging from icon in the address bar. A log-in or registration would prevent this simplicity of access. There will be a voluntary feedback form on the site soon, and we hope that readers of this paper will use this to make their comments or contributions.

Further Developments

The BECTa funding will facilitate consistency of content as well as increasing the amount of material. It will allow us to explore other avenues of source materials and give time to evaluate the relevance of such a site. We hope that it will also encourage teachers and carers to share their materials. The project can take these in any format and do the technical work to put them on the site, but for the materials to be of real use they must come from practitioners working daily with potential site users. In the end, however, the success of any resource of this type will depend upon voluntary contributions, or it will be commercially dependent.

Websites with Symbol Content

- Symbol World: www.symbolworld.org
- Meldreth Manor School: atschool.eduweb.co.uk/meldreth/eduweb/index.html
- Peepo: www.peepo.com
- Rara Avis rainforest website: www.widgit.com/rainforest/html/start.htm
- Moorcroft School: www.moorcroft.hillingdon.sch.uk
- Johanna Frohm: www.mycommlink.info
- Toby Homes Trust: www.tobyhomes.freeserve.co.uk

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The booking form for the workshop can also be downloaded from: www.communicationmatters.org.uk

Mounting Issues

The Person ↔ The Wheelchair ↔ The Device

by Eileen Grist & Alison Teague

This paper was presented at the CM2003 National Symposium, Lancaster University, September 2003

The Communication Aid Centre (CAC) at Frenchay Hospital has been running a service for people with communication impairments since 1981. The service is supra regional and patients come from the South West and South Central areas of the United Kingdom. We see adults and children from eleven years.

The Early Years

During the 1970s and 1980s the relationship between the person, the wheelchair, the communication aid and the mount was not too complex. Wheelchairs were usually fairly standard and robust and this meant that mounting poles and clamps were pretty interchangeable. The choice of mounting systems was limited. Adjustments had to be made then engineers, technicians, occupational therapists, teachers, caretakers and speech and language therapist got out the appropriate tool and made adjustments so that the person could get on with communicating. Communication devices, too, were limited in number and housed in very robust cases that made them easier to adjust for mounting, if a bit heavy for ambulant people to carry around!

Meeting Individual Needs

During the 1990s, huge changes took place. Wheelchairs were no longer standard in either shape or substance. Mounting systems became more flexible and more thought was given to the health and safety of care staff, the dimensions of the communication device and the comfort and safety of the person. The range of communication devices increased dramatically.

Some of the above changes resulted from a common desire to meet the unique requirements of each person. The person with physical and/or speech/language impairment wanted to achieve more. Their family, care staff and professional helpers strove to help them to gain as much independent control as possible. Throughout the 70s, 80s and 90s the drive to meet the specific requirement of each individual remained the constant factor in the equation between:

- The person
- The wheelchair
- The communication aid
- The mounting system

Health and Safety Issues

In the post 1997 era, however, some changes were driven by raised awareness about the Health and Safety aspects of connecting a device to a particular wheelchair. Unfortunately, the opportunity to approach these changes in a concerted and collaborative way was thwarted by the fact that in most cases

the provision of wheelchair, mounting system and communication aid was dealt with by separate providers. Wheelchair services assessed the safest and most comfortable wheelchair for the person, but had no brief to consider the implications if the person already had, or was being assessed for a communication aid. Managers and teachers in residential homes and schools looked to the health and safety requirements of their care staff and wanted mounting systems that were flexible enough to allow personal care and other needs to be met without undue physical strain.

Manufacturers and suppliers of mounting systems were responding to this need by developing quick release backplanes for devices and mounts with moving joints. Voice output communication aid (VOCA) manufacturers and suppliers were making adjustments so that the devices met the safety issues concerned with CE marking. Communication aid assessment centres in the health and education services were aware that in certain situations items of equipment could be described as medical devices. This, in turn, led to the need to make risk assessments so that best practice could be achieved and thereby reduce the likelihood of injury to the person and their carers.

Equipment Loan

Meanwhile, the Communication Aid Centre at Frenchay Hospital was continuing to offer a comprehensive service to people with speech, language, physical and cognitive impairments. The opportunity to use a device during periods of loan has been part of our assessment and evaluation process since the early 1980s.

We believe that people who come to the Centre should be able to use a suitable device. We therefore arrange loan periods so that the potential to increase communication opportunities in their own environment can be monitored. During our assessment and loan periods, we try to enable everybody involved in the process to experience having a device available as a part of their daily routine. In approximately 60% of our assessment and loan periods, this involves mounting a device to a wheelchair. Throughout the latter years of the 90s, we heard and read about the health and safety issues around attaching a VOCA to a mount when placed onto a wheelchair, with growing concern.

Policy of Equipment Mounting

Throughout the years from 1997 to 2000, our department liaised with the Medical Devices Agency, wheelchair services, wheelchair suppliers, agencies involved with the supply and purchase of wheelchair mounting devices and our own Health and Safety Department. We were looking for guidance and

help to identify what we should be doing to ensure we continued to give best service whilst operating in a manner which considered the person's safety. Our Health and Safety Department were unable to help because they were not informed enough about the field in which we work. Their advice was to develop our own risk assessment guidelines, which they would then assess!

Firstly, we contacted all the rehabilitation engineers, wheelchair services, disability living centres and wheelchair manufacturers that we knew, in order to understand exactly what was being done already. This resulted in lots of hands on advice and examples of risk assessments, but none of these actually included the attachment of a device to a mount on a wheelchair. It became obvious that we would have to use these as a basis, but make radical modifications in order to develop our own risk assessment.

In May 2001 we reluctantly decided to introduce a policy not to mount heavy devices until we had a viable risk assessment in place. The following year was spent collaborating with some very patient rehabilitation engineers and wheelchair assessors, who agreed to advise us on the development of our risk assessment. In June 2002 we finally got the document signed off by the Health and Safety Manager and were once again able to consider mounting heavier devices as part of our service. This gave us clearance to continue mounting devices as part of our service to North Bristol NHS Trust patients. However, we still felt there was a need to collaborate with other professionals who had experience of working in the field of mounting devices onto wheelchairs.

Risk Assessment Procedure

Meanwhile, our approach to mounting devices onto wheelchairs has radically changed since 1997. On the initial referral document we now alert the professionals involved about the need to collaborate with us, and their local services, about wheelchair specifications, if a device is likely to be mounted on the person's wheelchair.

A patient leaflet has been developed to inform the person involved what will need to be done if a device is going to be attached to their chair. The risk assessment form is filled in at every stage during which a device is mounted onto a wheelchair and relevant people have to sign that they have observed, understood and agreed to each decision. Guidelines are given at the end of the session so that the person and their carers have an aide memoire about sensitive issues such as removing the device during transportation in any vehicle, and during personal care.

RISK ASSESSMENT		
NAME:		
Is the wheelchair physically unaltered?	YES	NO
Is the user within the equipment weight limit for the wheelchair?	YES	NO
Is the wheelchair stable at 12 degree incline on tilt test table?	YES	NO
Is the wheelchair stable at 16 degree incline on tilt test table?	YES	NO
Has the carer/user been instructed as to how the equipment works, as noted above?	YES	NO
Does the carer/user/OT/ST understand safety issues and realise the importance of complying with instructions?	YES	NO
Photographs taken?	YES	NO
CARERS AND ANYONE INVOLVED WITH OPERATING THE WHEELCHAIR AND/OR MOUNTING SYSTEM MUST BE INFORMED OF THE FOLLOWING GUIDELINES.		
<i>NOTE THAT VIOLATION OF THESE GUIDELINES MAY COMPROMISE THE USER'S SAFETY</i>		
The device and mount must always be removed when the wheelchair is in transit in any vehicle.		Care should be taken when negotiating any slope or incline.
The device must be removed when the mount is in the swing away or folded position as the dynamics/stability of the chair will be affected		Special care should be taken when negotiating kerbs to ensure that the chair remains stable.
If the person is lifted out of the wheelchair without removing the mount, the carers must ensure that the wheelchair remains stable.		The mount should not be modified or altered in any way.
If anyone has any concerns as to the stability or safety of the mount in relation to the person, chair or any other aspect, the CAC should be contacted immediately.		Advice leaflet given out. _____
<ul style="list-style-type: none"> • We are happy with the mounting system supplied and understand the operating guidelines. • We agree to remove the device and mount whilst the wheelchair is being transported. • We have been informed of, and are aware of the safety issues detailed above and agree to adhere to the existing manufacturers' instructions in all aspects. • We have received, read and understood the advice given in this leaflet. 		
Signed Name.....		
Relationship..... Date.....		

Figure 1 Risk Assessment Form

In April 2003, we finally took possession of a 'tilt table'. This allows us to check how the wheelchair behaves at different inclines when it has the person, the mount and the device in place. This has become a very important part of any assessment that involves mounting devices onto wheelchairs.

Further Developments

At a recent meeting of our South and South West Augmentative and Alternative Communication Special Interest Group (AAC SIG) we devoted the day to the issue of mounting devices onto wheelchairs. After this day, several organisations and one supplier agreed to collaborate with us on trying to establish a more definitive risk assessment that all contributing services could adhere to.

We have called a meeting of these interested parties for later this year and hope that this will result in a document that becomes the basis for common practice in our region.

*Eileen Grist & Alison Teague
Communication Aid Centre
Speech and Language Therapy Department
Frenchay Hospital, Bristol BS16 1LE*

The Role Model Involvement Project

by Katie Clarke

The Project

Ever since *1 Voice - Communicating Together* was born in 1998, feedback and evaluation have shown that role models are a valuable part of the organisation. They provide inspiration, vision, motivation and support to children, and to their families, volunteers and professionals who attend *1 Voice* events.

As the membership of *1 Voice* continues to grow, so does the need for more role models to join and to become active members in this national network. Members of *1 Voice* come from all over the country and the need for developing the organisation and increasing the number of events is therefore apparent. Role models encounter real barriers to their full involvement and *1 Voice* aims to be as fully inclusive as possible. The organisation's Development Plan specifies increasing work with role models and the number of events held over the next two years.

Communication Matters has given *1 Voice* a grant that will go towards our Role Model Involvement Project. *1 Voice* would like to take this opportunity to thank Communication Matters for its support and involvement in ensuring that *1 Voice* can best meet the needs of adult role models.

1 Voice will be holding an event on 2nd and 3rd July 2004 at Hothorpe Hall, Leicester. It is hoped that nine role models will come together for the event with two experienced facilitators to look at issues surrounding role models' involvement and development within the organisation. Areas of discussion will be objectives, good practice, access and practical support needs, skills of role models, areas in which role models would like to get involved in relation to working with disabled children and their families, training and skills development needs, and any other issues role models feel *1 Voice* can learn from. This forum will provide opportunities for new ideas, celebration of successes and for role models to experience an equal partnership to create change within the organisation.

1 Voice will receive a report from the facilitators after the event which will be used in the Development Plan. Role models will take an active part in its implementation and evaluation. *1 Voice* is looking for people who are keen to share their experiences, enjoy being around young people and their families, can work with and relate to parents and be able to answer their queries, want to play a positive part and be involved in an organisation dedicated to communication and people using communication aids, and who have the time to commit to attending our family events.

Via letters and email *1 Voice* will work closely with role models and carers to ensure that all needs are catered for during the event. *1 Voice* will give role models the option of staying an extra night at Hothorpe Hall to be a participant in the National Network Day at the same venue on Sunday 4th July 2004 (*1 Voice* is raising funds for this separate event).

Aims of 1 VOICE

- ♦ To bring families of disabled, non-speaking children together to overcome isolation, share experiences and to learn about augmentative alternative communication.
- ♦ To enable disabled young people and their brothers and sisters to come together as peers in a communicative, accessible and understanding environment.
- ♦ To create opportunities for successful adult communication aid users to become role models for younger disabled people and their families, and to build up their own positive self image.
- ♦ To raise awareness of issues affecting disabled non-speaking children and young people who use augmentative and alternative communication.



A role model for *1 Voice*

Objectives

- ♦ Through publicity and existing networks, *1 Voice - Communicating Together* currently facilitates supportive family events, at accessible venues around the country, including weekend events for families with children who use communication aids, and National Network Days for non-speaking children, their parents, brothers and sisters.
- ♦ To have an accessible and inclusive committee that involves professionals, parents and users of communication aids.
- ♦ To continually develop the *1 Voice* website, email support group and family link scheme.
- ♦ To raise awareness by submitting articles to magazines and journals, workshops at conferences and networking with other disability organisations.
- ♦ To enable our children to become successful alternative communication aid users, with the aim of inclusion into the wider community and to access mainstream services.

If you would like to know more about *1 Voice - Communicating Together* and the Role Model Project please get in touch for further information:

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

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Trustees News

from Janet Scott, CM Chair

It was good to meet so many of you at the CM2003 National Symposium. I hope that those of you who were able to attend found the presentations stimulating and had a chance to meet and talk with others involved in AAC. The conference is an ideal opportunity to meet people who use AAC techniques and their family members/enablers, to meet people from different professional backgrounds, to meet the suppliers and developers of the various communication aids and AAC related software...to share ideas and learn from each other...with the ultimate aim of improving the communication opportunities for the people we are involved with.

Over the past couple of years, some of you will be aware that the number of people attending the conference and the exhibition of communication aids and software has grown and grown. The numbers of people wanting to attend the conference is now exceeding the accommodation available to us at Lancaster University and the Trustees have been exploring alternative venues for future conferences. At the Trustees' meeting in November there was a formal agreement to book Leicester University for CM2004, 19-21 September 2004.

This is both exciting and rather sad as Lancaster University has become synonymous with Communication Matters' conferences for many years. Lancaster University has served us well. However, as the number of delegates has increased, it has progressively become more difficult to cater for individual needs (e.g. more accessible accommodation, increased exhibition space, more seminar rooms). I can imagine that some of you reading this will be thinking, "Great, not so far north...easier to get to!", while others will be thinking, "Oh dear, it's too far south!", and others may well be thinking, "How do I get to Leicester?" So, start planning now! Leicester is just off the M1, with good train links north and south...East Midlands airport may also be an option with its cheap flights for those of us from Scotland and Northern Ireland.

Pat Thomas was formally co-opted onto the Board of Trustees help us with this transition to Leicester and to carry on in her role of conference co-ordinator, having served her very successful apprenticeship at Lancaster!

For the past few years Communication Matters has been keen to support projects and activities through its Small Grant Scheme e.g. to help with the costs of organising an event for people who use AAC, the costs involved in publishing an information leaflet, or to enable you to carry out a small research project. We are very keen to receive applications for this grant from individuals or groups - there are two deadlines for applications 30th January and 31st June 2004. Last year we also established a grant to support people who use AAC and their families. This grant is NOT to provide funding for a communication aid or to pay for therapy/training - but IS to help with the costs of something like organising/setting up a support group, a mentoring scheme, etc. This grant is available to groups or organisations who can demonstrate that the money will go to empowering and supporting people who use AAC and their family members. Please let appropriate organisations in your area know about both of these

CM BOARD OF TRUSTEES 2003-4

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Patrick Poon (Administrator & Secretary)

grants. Application forms are available from Patrick Poon at the Communication Matters address.

As well as this Journal, the website is Communication Matters' main vehicle for keeping in touch with its membership and for communicating with the wider world. It pays to check out the website as Patrick Poon, our administrator, updates it regularly with news of new products, publications and events. We are currently looking into ways of making it more interactive and of developing the current Bulletin Boards. If you have any ideas/skills in this area, let us know.

Although I'm finding it very hard to believe that 2004 is just round the corner...this year has flown past...I'd like to wish you all a very happy holiday season and all the best for the new year. I hope you have a 'restful' time writing a paper for this year's conference, an article for the Journal and filling in an application form for a grant...while looking up the website for contact details for AAC services and events!

GRANTS AND AWARDS 2004

Communication Matters Small Grants

Consideration will be given to applications for UK projects or activities that further the aims of Communication Matters. Closing dates for applications are 31 January 2004 & 30 June 2004. More information on page 20.

Communication Matters Grants to Support People Who Use AAC and Their Families

Communication Matters has a sum of money to help achieve its objectives in relation to people who use AAC and their families. Closing date is 16 April 2004. Please turn to page 20 for more information.

Scholarships to Attend ISAAC 2004, Brazil

Communication Matters is making available a number of scholarships to people who wish to attend the ISAAC 2004 Conference to be held in Natal, Brazil. Full details and application forms from: Communication Matters, c/o ACE Centre, 92 Windmill Road, Oxford OX3 7DR Tel: 0845 456 8211 Email: admin@communicationmatters.org.uk

ACiP: Scotland Project Awards

Augmentative Communication in Practice: Scotland has up to £2,000 available for a number of awards. Further details from SCTCI Tel: 0141 201 2619 sctci@sgh.scot.nhs.uk



Need funding from Communication Matters in 2004?

Grant to Support People Who Use AAC and Their Families



Communication Matters has identified a sum of money to help achieve its objectives in relation to people who use AAC and their families. We welcome applications for this grant from individuals or organisations (applicants must be resident in the UK). Applications must indicate clearly how people who use AAC and/or their families will benefit from this grant.

The priorities for Communication Matters for the years 2003-2006 are:

- Awareness raising and information for professionals and policy makers.
- Education and training for people who use AAC and their family members as well as for professionals.
- Campaigning and advocacy on behalf of people who use AAC and their family members in relation to policy makers and the general public.
- Empowering and supporting people who use AAC and their families as well as professionals.

Successful applications will be required to meet the following conditions:

- Six-monthly progress reports to be submitted.
- The support received from Communication Matters must be acknowledged in any materials produced or publicity resulting from/associated with the grant.
- A report/article (depending on the nature of the project/grant) must be submitted for publication in the Communication Matters Journal on completion.
- A paper must be submitted for presentation at the Communication Matters National Symposium (for a grant made in 2004, there is an expectation that a paper will be presented at the 2005 Symposium).

Closing Date

Funding is allocated by the Trustees after review by a sub-committee. Please ensure that we receive your application before the closing date of **16 April 2004**.

Small Grant Awards



Communication Matters welcomes all applications for small grants (applicants must be resident in the UK). Consideration will be given to applications for UK projects or activities that further the aims of Communication Matters.

Examples of the kind of project that may be awarded a grant include:

- The costs of organising an event for people who use AAC, or travel expenses to get to one.
- The costs of publishing an information leaflet.
- The costs of a social research project.

Aims of Communication Matters

- To increase awareness, understanding and knowledge of good practice in the field of augmentative and alternative communication.
- To provide a forum for the exchange of information and ideas between professional workers, AAC users, and their families.
- To promote the positive role of AAC in the empowerment of people with severe communication difficulties in society.

Successful applications will be required to meet the following conditions:

- Present a paper about their project at the next Communication Matters National Symposium.
- Provide a write up of the project for the Communication Matters journal.
- Acknowledge Communication Matters involvement in the funding or part funding of the project in any published materials that relates to the project.

Closing Date

Funding is allocated by the Trustees after review by a sub-committee. Please ensure that we receive your application before either of these closing dates: **31 January 2004 and 30 June 2004**.

For an application form, please contact:
Communications Matters

Tel & Fax: 0845 456 8211

Email: admin@communicationmatters.org.uk



News from CASC

by Dave Morgan, CASC Chair

It's been a busy time! The late summer months have been hectic for many CASC members, with not just normal everyday business to attend to, but also the onslaught of at least five different exhibitions in four weeks.

It started with RAATE 2003 in Dublin at the end of August, followed swiftly by CPOOL (European Speech & Language Therapist conference) in Glasgow the following week, and then Communication Matters Symposium and Study Day in Lancaster 10 days later. There was the Independent Living show at Wembley, with Special Needs London running at Olympia and, indeed, overlapping by one day. Of course, not all CASC members attended every event, but at least two were at all five events.

As I write this, in Birmingham Airport, I am awaiting a flight to Düsseldorf for REHA - one of the biggest exhibitions in Europe, if not the world. I know of at least two other CASC members who will also be at the show, either exhibiting directly or through distributors.

All this activity emphasises the point that we need to ensure we maximise the opportunities of CASC Road Shows, which was why this was one of the main topics of conversation at the recent CASC committee meeting at Lancaster in September. As I reported last time, two cancellations in mid-summer had left several members calling for a review of how and when we have CASC Road Shows, and whether a more planned geographical area/region, with several shows in a week, and then not returning to that area until the next series (as already happens in Ireland and Scotland), might be better than the more scattered approach we have now for England.

Much of the discussion centred around the fact that we rely on the generous help of local organisers, and that we cannot always dictate when Road Shows should happen. It was agreed that during 2004, we should try to group shows as much as possible, but that we should not totally abandon the approach that we will try and react to public demand, as in the past. This then gives us a year to see whether this type of planning might be feasible and whether it is better than the old format.

Breaking news: We are pleased to announce that the first 'Regional' Road Show, in SW England, is set to take place on 5-7 July 2004, visiting Portsmouth, Bristol and Plymouth. And the next Road Show in Ireland will be on 17-21 May 2004, visiting Galway, Tralee, Limerick, Dublin and Belfast.

The other major topic of conversation at the meeting in September was the proposed move to Leicester University for next year's Communication Matters Symposium. CASC members applauded the idea of finding a venue that is more accessible for people who use wheelchairs, and allows the event to expand from its current limit of 350 delegates. We look forward to being at Leicester University for CM2004, where the exhibition will be in a smart, spacious marquee next to the lecture theatre and seminar rooms.

COMMUNICATION MATTERS

CM2004

National Symposium

LEICESTER UNIVERSITY

19-21 SEPTEMBER 2004

CALL FOR PAPERS

You are warmly invited to contribute to the Communication Matters Symposium in 2004, which will be held at the new venue of Leicester University.

The programme will be a mixture of seminars, platform presentations, video presentations, mini-platform presentations and workshops.

Although papers on any topic are welcome we would be especially interested in the following topics:

- The use of AAC with different client populations
- Assessment
- Implementation and intervention, including outcomes and evidence based intervention
- Parent and carer issues
- Using the Internet
- Employment
- Advocacy
- Training
- Care in the community
- AAC and the curriculum
- AAC and the home

Papers can be in the following format:

- ◆ Seminars
- ◆ Video presentations
- ◆ Case studies
- ◆ Research based
- ◆ Traditional platform presentations

We welcome presentations from people who use AAC, family members and professionals.

Please contact Communication Matters for a copy of the abstract submission guidelines.

All abstracts to reach us by **31 March 2004**.

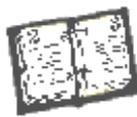
COMMUNICATION MATTERS

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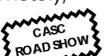
Email: admin@communicationmatters.org.uk

Website: www.communicationmatters.org.uk



Diary Dates

- 7-9 January 2004 Hilton Olympia, London
Special Needs Fringe 2004
 Contact: Inclusive Technology 01457 819790
 Website: www.inclusive.co.uk/exhibitions
- 7-10 January 2004 Olympia, London
BETT 2004
 Contact: 0870 429 4574 www.bettshow.co.uk
- 21 January 2004 ACE Centre North, Oldham
Assistive Technology Module
 Contact: 0161 627 1358 www.ace-north.org.uk
- 21 January 2004 CALL Centre, Edinburgh
Special Access to Computers
 Contact: 0131 651 6236 www.callcentrescotland.org.uk
- 21 January 2004 CENMAC, London
Clicker 4: An Introduction
 Contact: 020 8854 1019 www.cenmac.com
- 28 January 2004 CALL Centre, Edinburgh
Making Personal Passports
 Contact: 0131 651 6236 www.callcentrescotland.org.uk
- 30 January 2004 ACE Centre North, Oldham
Voicing Choices
 Contact: 0161 627 1358 www.ace-north.org.uk
- 3 February 2004 CENMAC, London
Literacy and Recording
 Contact: 020 8854 1019 www.cenmac.com
- 10 February 2004 CALL Centre, Edinburgh
Making Symbol Materials
 Contact: 0131 651 6236 www.callcentrescotland.org.uk
- 10 February 2004 CENMAC, London
Writing with Symbols: An Introduction
 Contact: 020 8854 1019 www.cenmac.com
- 21 January 2004 CALL Centre / SSC, Edinburgh
Communication Needs of Deaf and Visually Impaired Children with Complex Needs
 Contact: 0131 651 6236 www.callcentrescotland.org.uk
- 4 March 2004 Newcastle upon Tyne
The Efficacy of Augmentative and Alternative Communication...Towards Evidence Based Practice
 Presented by Ralf W Schlosser, PhD
 Contact Communicate: 0191 2195640 karen.lewis@nap.nhs.uk
- 4 March 2004 CENMAC, London
ICT for Severe and Profound Learning Difficulties
 Contact: 020 8854 1019 www.cenmac.com
- 10 March 2004 CALL Centre, Edinburgh
Computers and Dyslexia
 Contact: 0131 651 6236 www.callcentrescotland.org.uk
- 19 March 2004 CENMAC, London
Language and Communication (Unit 3)
 Contact: 020 8854 1019 www.cenmac.com
- 22 March 2004 Stirling, Scotland
Communicating with Pictures & Symbols
 Organised by ACiP:S Contact: 0141 201 2619 (SCTCI)
- 23-25 March 2004 Edinburgh, Aberdeen, Kilmarnock
CALL Centre's ICT & Inclusion Exhibitions & Workshops
 Contact: 0131 651 6236 www.callcentrescotland.org.uk
- 26 March 2004 ACE Centre North, Oldham
PowerPoint in Practice
 Contact: 0161 627 1358 www.ace-north.org.uk
- 26 March 2004 ACE Centre North, Oldham
BoardMaker Brilliance
 Contact: 0161 627 1358 www.ace-north.org.uk
- 22 April 2004 CENMAC, London
Accessing Technology
 Contact: 020 8854 1019 www.cenmac.com
- 23 April 2004 ACE Centre North, Oldham
How to Decide on an AAC System
 Contact: 0161 627 1358 www.ace-north.org.uk
- 7 May 2004 CENMAC, London
Developmental Co-ordination Disorder (Dyspraxia)
 Contact: 020 8854 1019 www.cenmac.com
- 11 May 2004 CENMAC, London
Clicker 4: Beyond the Basics
 Contact: 020 8854 1019 www.cenmac.com
- 12 May 2004 ACE Centre, Oxford
Introduction of Low Tech AAC and Fixed Overlay VOCAs
 Contact: 01865 759800 www.ace-centre.org.uk
- 13 May 2004 ACE Centre, Oxford
How ICT can Facilitate Inclusion
 Contact: 01865 759800 www.ace-centre.org.uk
- 17-21 May 2004 Galway, Tralee, Limerick, Dublin, Belfast
CASC Road Shows in Ireland
 Cost: FREE Contact: 0845 456 8211
 Website: www.communicationmatters.org.uk
- 17 May 2004 ACE Centre North, Oldham
How to Decide on an AAC System
 Contact: 0161 627 1358 www.ace-north.org.uk
- 19 May 2004 CENMAC, London
ICT for Severe and Profound Learning Difficulties
 Contact: 020 8854 1019 www.cenmac.com
- 4 July 2004 Hothorpe Hall, Leicester
1 Voice National Family Network Day
 Contact: 0845 330 7862 info@1voice.info www.1voice.info
- 5-7 July 2004 Portsmouth, Bristol, Plymouth
CASC Road Shows in SW England
 5th Fatcher School (Portsmouth), 6th Claremont School (Bristol),
 7th Novotel (Plymouth)
 Cost: FREE Contact: 0845 456 8211
 Website: www.communicationmatters.org.uk
- 19-21 September 2004 Leicester
CM2004 National Symposium (at Leicester University)
 Contact: 0845 456 8211
 Website: www.communicationmatters.org.uk
- 4-12 October 2004 Natal, Brazil
ISAAC 2004 Biennial Conference - Brazil
 Website: www.isaac-online.org



Integrated Community Equipment Services

by Eileen Grist & Sally Chan

This paper was presented at the CM2003 National Symposium, Lancaster University, September 2003

Background

“Communication aids for people with speech impairments have been an underdeveloped area in the current provision of equipment services...the Government’s intention is that some of the additional funding for equipment services should be directed to improving provision of communication aids”

The NHS Plan states the Government’s commitment to modernising community equipment services by developing local integrated services, previously managed by the NHS and local councils. Such development would enable “50% more individuals of all ages and types of disability (including sensory and learning disabilities) to benefit from equipment that helps them be cared for, or maintain their independence, at home” (DOH, 2001). As well as target more people, the aims of the integrated services are:

1. To increase efficiency by modernising purchasing, supply and record systems.
2. To extend the use of technology in supporting vulnerable people.
3. To ensure the prompt, flexible provision of equipment and facilitates the objectives of intermediate care.

Community equipment is defined as follows: home nursing, minor adaptations (grab rails), ancillary equipment for people with sensory impairments (hearing loops), wheelchairs, telecare equipment and communication aids for people with a speech impairment. It is worth noting that communication aids were omitted from the early drafts of the government’s guidance, and was only included after John Hutton, Minister of Health, met several users and representatives from the field of AAC at the launch of the SCOPE’s report ‘*Speak for Yourself*’.

£100 million has been made available from the Department of Health to fund the development of these services with similar funding from social services. The project was initiated in 2001 and will run until 2004.

The Government’s Guidance identified the following criteria that needs to be met when setting up an integrated service:

1. Revenue funding from pooled health and social services contributions.
2. A single operational manager for the service.
3. A board to advise the manager for the service, whose members include representatives from stakeholders organisations.
4. Unified stock.

Integration is regarded as key to delivering a service that provides a single access point to information, assessment and equipment provision for the user.

Concerns About Implementation

The Communication Aid Project (CAP) was launched in April 2002 to meet the needs of school-aged children. The Integrated Community Equipment Services was an opportunity for other possible users of communication aids to access funding for long and short term loans, as part of community equipment provision. However, there was minimal evidence of any integrated services as the project entered the second year of implementation (2002). Discussion with other SLTs across England as well as other stakeholders within the south-west region highlighted the lack of progress generally in developing inter-agency collaboration as an initial step. There was additional concern that the minority group of communication aids would be marginalised and overlooked in the plethora of community equipment. Taking the above into consideration, the need to be pro-active was recognised in promoting the interests of our clients in relation to the government’s initiative.

Pan-Avon’s Response and Proposal

Bristol is host to two regional communication aids centres - the Frenchay Communication Aids Centre (CAC) and the Paediatric Communication Aids Service (PCAS). North Bristol NHS Trust manages the two regional services, and their combined services ensure that assessments are available to people of all ages.

In July 2002, Eileen Grist from Frenchay CAC took the initiative to contact all SLT managers within the ‘Avon’ area to invite them to a brainstorming meeting. (Avon had been disbanded to be replaced by Bristol, South Gloucestershire, North Somerset and Bristol, and North-East Somerset authorities.)

At this time, the Avon Community Equipment Services Group was working on a draft action plan to develop integrated services for each authority within Avon. The brainstorming session was designed to determine the viability in producing a document that would be a step towards meeting the government criteria, particularly as the government initiative had emphasised the lack of investment in communication aids and services.

A SWOT analysis confirmed that the strengths and opportunities of this project outweighed the weaknesses and threats.

However, particular problems with the current system were identified as follows:

1. Paucity/surplus aids at specific times.
2. Restrictions and inequity of budgets to provide communication aids for short/long term loan.
3. Maintenance and insurance problems.
4. No corporate unified vision.

It was therefore decided to produce a document that would aim to:

1. Highlight how current budgeting and funding systems lead to inequity of provision, duplication of equipment and inefficient storage distribution.
2. Provide a model of service integration that could be developed and supported through the various funding bodies in the Avon area.
3. Inform education, health and social services that integrated services must include specialist equipment providers so that people who have communication difficulties can have assessment, loan, training and provision of a device that will allow them to express their needs and opinions.

Subsequent meetings with the group of SLT managers within the 'Avon' area and an audit of current practices concerning assessment for, and the provision and maintenance, of communication aids took place. These processes informed the development of the final document.

The Proposal

A document entitled '*Proposal from the Communication Aid services to people with severe communication difficulties in the Pan Avon area – for submission to North Bristol Healthcare Trust College and the Avon ICES Commissioning Group*' was finalised in July 2003.

The proposal provided a model for service integration that could be developed and supported by the statutory organisations within the Bristol area. In line with the Government's Guidance, it was advocated that communication aids and associated equipment (switches, mounting systems) would be held in a central store, and accessed via the operational manager. The store will include equipment for both adults and children, though it was recognised that a division within the single store may ensure better access and control for the different age groups. It is anticipated that the majority of users will be adults initially, as the local education authorities or the Communication Aids Project provides current funding for children.

The two communication aids centres will continue to act as assessment and training centres, and hence will need to maintain a library of communication aids for assessment purposes. Access to the excellent support for AAC that is provided by non-statutory services such as the Motor Neurone Disease Association and Speakability will be maintained.

Proposed Funding

Funding would be sought from the local Primary Care Trusts and the local councils (social services). However, the current

budgets available for communication aids from the SLT budgets would be pooled to partly finance the integrated store.

Capital revenue included administrative equipment and additional stock of communication aids required to further advance the library of aids available: this would amount to £17,000. Recurring revenue included: human resources (single operational manager (SLT), administrative support, technical staff, rent for accommodation, maintenance and insurance for equipment and the annual renewal of equipment. The recurring cost was reduced by the possible use of a room in the local Disablement Living Centre, rather than the capital cost of a new building. The recurring revenue required, taking into account the pooled budget from the SLT budgets, amounted to £67,000.

Presentation of the Proposal

There has been continued involvement in the Avon ICES Commissioning Group, which holds monthly meetings in Bristol. The meetings are chaired by a dynamic and pro-active manager within social services who has taken the lead in developing ICES within Avon. The committee members include commissioning officers from social services, who maintain dialogue with their counterparts in the corresponding PCTs. Eileen has attended most of these meetings, and in July 2003 the authors were able to present the draft proposal before final completion. The committee has been responsive and welcomed the initiative taken by the SLT group.

The Current Situation

Further discussions are taking place, particularly in relation to accommodation and funding agreement from the PCTs. If progress continues to be made, it is hoped that the Pan Avon Integrated Communication Aids Service will be operational in 2004.

Conclusion

The Eileen Grist attended a Communication Aids Stakeholders Day in June 2003, led by the Department of Health's community equipment services policy team. It was an opportunity for the civil servants and stakeholders to identify and explore key issues in relation specifically to communication aid services. A suggested way forward was agreed. Heightened awareness of communication aids within the parameters of community equipment can and does bring results, but perseverance and a receptive audience are crucial for success.

*Eileen Grist
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*Sally Chan
PCAS, Claremont School
Henleaze Park, Westbury on Trym, Bristol BS9 1DR*

REFERENCES

A Guide to Integrating Community Equipment Services, DOH, 2001.



Community Equipment Services

Integrating the CAP Model for the Provision of Communication Aids for Adults

by Anna Rourke

This paper was presented at the CM2003 National Symposium, Lancaster University, September 2003

Background

Communication Aids Project (CAP)

The Communication Aids Project commenced in April 2002 for a period of two years. £10 million is being administered on behalf of The Department for Education and Skills by BECTa (British Educational Communications Technology Agency) in order to provide assessments, equipment and initial training for and on behalf of pupils with communication disabilities. Equipment provision includes communication aids, supportive software (e.g. voice recognition, word prediction, symbol-based software), access devices (such as alternative keyboards, mouse, switches) and hardware (e.g., portable writing aids, laptops, mounting systems).

The Project is being delivered in partnership with six CAP Centres, based around the country with different areas of expertise, including The ACE Centre-North. This Centre provides multidisciplinary Assistive Technology assessments and training in the North of England for individuals with complex physical and communication disabilities and has been involved in the implementation and development of CAP since January 2002 (pilot phase). In addition to managing referrals, the Centre has established and is supporting the development of local multidisciplinary teams of expertise within 66 local education authorities. Typically, these teams comprise teachers from special schools and support services, speech and language therapists, occupational therapists and SEN LEA Officers.

Community Equipment Services

Following the publication of the NHS Plan, in 2001 the Department of Health issued The Guide to Integrating Community Equipment Services to rationalize and expand the health and social service community loans stores. For the first time, communication aids for speech-impaired people were specifically mentioned as possible stocks for local equipment services. An additional £105 million was allocated by central government over three years to the NHS with additional funding to Social Services Departments to fund the integration process. None of the monies allocated to the integration process were ring-fenced.

Joined up thinking

A meeting was established between representatives of the SEN (Special Educational Needs) Division of DfES, ICES

(Integrated Community Equipment Services, DoH), Chris Stevens (Head of Inclusion and SEN at BECTa), and Anna Rourke (ACE Centre-North Manager). The aim of the meeting was to explore opportunities to build on the success of CAP in order to inform on the development of provision of communication aids for adults from funding identified from local Community Equipment Services.

It was proposed that two pilot projects would be established in order to investigate possible shared learning, including administrative infra-structure, expertise, communications and good practice. Any emerging issues from the pilots would then be addressed in an evaluation report to be disseminated at the end of the pilot period.

The two pilot projects, based in Liverpool and Nottingham, are described below.

Pilot Project – Liverpool Adult Communication Aids Project (ACAP)

Project outline

The ACE Centre-North will oversee the referral, assessment, provision of equipment and initial training for communication aids, access devices and mounting systems for 18 adults over a fifteen month period. The project will run in partnership with the Liverpool Community Equipment Service, Merseyside CALL (a communication assessment service) and acute and community speech and language therapy services for adults in Liverpool.

The project will be in two stages. Stage one, funded by ring-fenced slippage monies from the Liverpool Community Equipment Services' budget for 2002/03, will focus on referrals from a single point of contact – MOSAIC, the transition speech and language therapy service for adults in Liverpool.

Stage two, funded by ring-fenced annual revenue from the Liverpool Community Equipment Services' budget for 2003/04 (and beyond), will open the project to the wider speech and language therapy services for adults in Liverpool.

This pilot aims to identify strategies to facilitate the successful provision of communication aids for adults from Community Equipment funding and to inform on any emerging issues resulting from this pilot that may be shared with other services within the Health sector.



**Sensory Software
Advertisement**

Referrals

For stage one of the pilot, the MOSAIC speech & language therapy transition team have prioritized 6 adults from a list of 17 potential referrals for the purposes of this pilot project.

In stage two of the pilot, referrals have been accepted from all parts of the acute and community speech and language therapy services for adults in Liverpool.

The referrals include people with a range of disabilities such as Cerebral Palsy, Multiple Sclerosis, Stroke, Parkinson's disease, Motor Neurone Disease, Myotonic disease, Cerebral Nerve Disorder and head injury. Criteria for prioritization included rate of degeneration, available support and ability of the individual to communicate effectively without assistance.

The range of communication needs also varies considerably from people who would benefit from a device that would meet their needs in a range of contexts, to those who may need some form of augmentative communication system in specific situations.

Assessments

Merseyside CALL is a voluntary organization that has developed a loan bank of AAC equipment and a limited assessment, training and support service. As a result of CAP, Merseyside CALL has been able to extend the range of its activities in order to support people into education, who may require a communication aid. This service employs a speech & language therapist on a part-time basis and is responsible for the administration of assessments, equipment and initial training in its use for the individuals referred.

The service has also used CAP to develop expertise, increase its assessment resources and improve its administration system. Its function within CAP emulates the local multidisciplinary teams evolving in LEAs as a result of CAP.

Training

It is anticipated that any training needs arising from this pilot project will be met by ongoing training available from The ACE Centre-North within its service level agreement for CAP. This will include training for both Merseyside CALL and identified speech and language therapists from the acute and community speech and language therapy services for adults in Liverpool to develop their knowledge and understanding of Assistive Technology and augmentative communication systems.

Resources

CAP has overseen the procurement of Assistive Technology suppliers for this project and has developed a website, which provides information on all resources available for purchase as a result of a CAP assessment.

In addition to being a valuable training resource, CAP suppliers have agreed to advantageous terms and conditions for equipment recommended from CAP.

As a result of discussions with the Chairman of CASC (Communication Aids Suppliers' Consortium), these sup-

pliers have agreed to the same terms and conditions being applied to any recommendations for equipment resulting from this pilot.

Administration

Documentation and procedure developed by CAP will be used as the basis for the administration of the pilot, including referral forms, assessment reports and claim forms. Merseyside CALL will act as the central administrator, processing referral forms and assessments in collaboration with local speech and language therapy services. Where appropriate, support will be provided by The ACE Centre-North for referrals of individuals with complex needs.

Quality Assurance

Once the assessment has been completed, a report will be produced detailing recommendations for equipment, support and any training implications. The report will be submitted to The ACE Centre-North for scrutiny and approval. Once approved, Merseyside CALL will submit the appropriate requisition form to the Liverpool Community Equipment Services Manager.

Funding

£10,000 slippage funding has been identified within Liverpool's Community Equipment Services' budget for 2002/03 and ring-fenced for the purpose of this pilot project. It is anticipated that this will meet the costs of assessments and equipment for 6 referrals by March 2003.

£20,000 has been identified within Liverpool's Community Equipment Services' annual budget for 2003/04 and ring-fenced for the purpose of this pilot project. It is anticipated that a further 12 adults will then be provided with appropriate equipment by December 2003.

It is believed that in excess of 12 referrals will be received in the second stage of the pilot project. A record of this unmet need will be used to support a bid for additional funding from slippage monies and for an increased allocation from subsequent Community Equipment Services' annual budgets.

Pilot Project – Nottingham

Project outline

This pilot aims to identify strategies to facilitate the successful provision of communication aids for adults from Community Equipment funding and to inform on any emerging issues resulting from this pilot that may be shared with other services within the Health sector, including The Department of Health. The pilot aims to build on good practice established by the DfES-funded Communication Aids Project.

The ACE Centre-North will work in partnership with the specialist speech and language therapy service and the ICES Project Manager to establish effective processes and explore possible funding sources for a small focus group of adults with learning disabilities who require communication aids.

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Local context

The speech and language therapy service for people who use or require communication aids in the Nottingham area falls within the remit of the team of therapists working with adults with learning disabilities. A part time post was created in January 2002 to provide this service and a technical instructor has been appointed this year to assist with the technical maintenance of devices being supported.

To date, all existing AAC users have been reviewed, assessments have been initiated for potential AAC users and staff training needs identified. A small user group has also been established.

The Health Authority has also identified a small budget for the provision and maintenance of communication aids, although this is grossly inadequate for this purpose and barely covers the cost of warranties for existing systems leaving almost no funding for new equipment.

Referrals

Four adults have been identified for the purposes of this pilot:

- Adult A is 23 years old and used a communication aid whilst at school. However, this device has been broken for over two years and as a consequence, she is unable to express her needs in any context outside her immediate family
- Adult B is 22 years old and has severe expressive language difficulties and learning disabilities. The communication aid he used at school was retained by the school when he left and therefore he has had no aid for the past four years. This has significantly limited his opportunities for independent living, including social and learning opportunities in his Day Centre, FE College and the pursuit of employment opportunities.
- Adult C is 38 years old and has some speech, but this is difficult to understand, particularly in relation to subjects outside of the context in which he is communicating. He is currently in further education and attends a Day Centre.
- Adult D is 25 years old and has access to a very old communication aid; however she can no longer recall how to use this device other than occasional use of the spell mode feature. Her inability to communicate effectively limits her opportunities for social interaction and independent living, e.g. shopping or expressing her personal care needs.

Centre-North

Support will be offered to this pilot as appropriate to the needs of the context. The specialist speech therapist with responsibility for AAC has considerable experience in the assessment and support of adults in the uses and applications of AAC. However, she has limited access to resources for trial purposes.

ACE Centre-North will provide loan equipment in order to inform on assessments as required and will assist with the provision, dissemination of information and good practice

from CAP. In addition, the Centre will provide access to the administration set up for the Liverpool ACAP pilot.

Evaluation and dissemination

In December 2003, an interim evaluation report will be produced summarizing emerging issues to be forwarded to DoH, DfES, BECTa, ICES, Liverpool Community Equipment Services, and Nottingham Community Equipment Services. The final evaluation report will be produced in March 2004.

Emerging issues

• Ring-fenced funding

Central to the success to date of the Liverpool pilot has been the identification and protection of funding specifically for this pilot.

Whilst the level of funding may be considered to be inadequate at this stage, it is a start that has enabled at least the identification of need.

• CES Manager remit

The role of the Community Equipment Services Manager in Liverpool has been critical in assisting with the identification of key issues. His requirement has been for a requisition order only, and he has relied on the available local AAC expertise in order to identify resources, suppliers, and take responsibility for the administration of referrals, assessment reports and quality assurance.

• Identifiable client group

With such limited criteria from ICES guidelines, there has been a need for local service providers to identify criteria for referrals.

• Assessment, support and quality assurance

The assessments have been undertaken by local expertise, which can be variable and may benefit from some quality assurance process in order to validate any recommendations.

In addition, there will need to be identifiable responsibility for ongoing support and coordination of training implications arising from the assessment recommendations.

• Administration

Invariably, there is a need for an administration system which addresses referrals and referral criteria, an analysis and justification of the assessment process and details recommendations, including suppliers, costs and any training or support implications and costs.

• Funding

Initial ring-fenced budgets for both pilots have been reliant in the first instance on slippage money. However, this has been a 'first step' towards securing ongoing revenue, which can be monitored and reviewed as the identification of need is refined.

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Goal Setting for People with Communication Difficulties

by Sally Boa & Lynn MacFadyen

This paper was presented at the CM2003 National Symposium, Lancaster University, September 2003

Introduction

This paper details the findings of a pilot study, funded by Forth Valley Primary Care NHS (Research and Development Committee) and conducted by the Augmentative and Alternative Communication (AAC) research group at the University of Stirling in collaboration with Area Rehabilitation Service in Forth Valley.

The project investigated goal setting for people with communication difficulties and refined and piloted a tool – Talking Mats™ – for this purpose. The project ran from May 2002 until February 2003 and involved the researcher working on the project for 1 half day a week for nine months.

Background

In recent years the importance of setting goals with patients as a focus for rehabilitation has been highlighted. The Brain Injury Resource Center (Seattle) states that *“The ability to set goals is essential to effective problem solving; and by default, is essential to self management, and self determination”*.

Schut & Stam (1994) comment that *“Goal setting is a prerequisite for interdisciplinary team work”*. They state that goals must be:

- Relevant and motivating
- Expressing what you want to accomplish
- Positively defined
- Put in behavioural terms
- Explicit and commonly understandable
- Attainable and enabling well-balanced planning

Given that authors have suggested that goal setting is essential to planning effective rehabilitation, it is important that all users of a service should be allowed to participate as fully as possible in the process.

It is recognised that it can be difficult for people with communication and/or cognitive impairments to become involved in the goal setting process and often rehabilitation teams rely on their own “ingenuity and persistence” in order to obtain the views of this group (Wade, 1999).

In previous research projects Research Speech and Language Therapist Joan Murphy (1998) developed a novel framework (Talking Mats™) which enabled people with communication, cognitive and physical difficulties to express their views.

Aim

This pilot study aimed to explore whether or not the use of Talking Mats™ could enable people with a communication difficulty to express their views and set their own goals for rehabilitation.

Setting

The project was set in the Forth Valley NHS Board area and was conducted by Sally Boa, Speech and Language Therapist with the Area Rehabilitation Service. The Area Rehabilitation Service in Forth Valley is an interdisciplinary team comprising a range of allied health professionals, medical and nursing staff as well as generic rehabilitation assistants. The Team was set up in 1998 to provide a service for adults aged between 16-65 years who have a physical disability and live in the community within the Forth Valley NHS Board area.

Many of those referred to the Team have acquired neurological conditions such as Multiple Sclerosis, Parkinson’s Disease and Motor Neurone Disease, brain injury as a result of stroke or Traumatic Brain Injury.

A typical pathway as a patient with the Area Rehabilitation Service is outlined as follows:

- Referral
- Assessment using multidisciplinary screening tool (developed by the Area Rehabilitation Service)
- Goals set
- Intervention carried out
- Review
- Discharge

Following referral to the Area Rehabilitation Service, patients are assessed using a multidisciplinary screening tool. Rehabilitation goals are set prior to intervention commencing. This pilot study explored the use of the Talking Mats™ framework to enable people with a communication difficulty to become more actively involved in expressing their views and setting their own goals for rehabilitation.

Topic and Symbol Selection

The symbol selection for use with Talking Mats™ was informed by The World Health Organisation (WHO) International Classification of Functioning (ICF), Disability and Health (2001). This provides a standard framework for describing health and health related states, enabling health professionals

to look at human functioning and disability at four levels of detail. It also takes contextual factors into account.

The Activities and Participation component from the ICF framework provides a comprehensive list of domains covering a full range of life areas which enables the health worker to build and record a systematic picture of a person's functioning. It provides a structure to articulate the goal setting process.

Using the Activities and Participation component, it was possible to identify areas which are relevant to people who use the Area Rehabilitation Service in Forth Valley. In collaboration with the interdisciplinary team, a list was drawn up from the ICF categories.

The areas were then translated into more "user friendly" topics, as outlined:

- Applying knowledge
- Emotional well being
- Domestic life
- Communication
- Relationships
- Mobility
- Self care
- Health
- Transport
- Work and education
- Leisure
- Environment

Each broad topic was further divided, again using the ICF categories as a guide. Using Boardmaker™ software, symbols were produced to represent each broad domain as well as the sub-categories within each. This provided a symbol library so that Talking Mats™ could be explored as a method to help people with communication impairments to more actively participate in the goal setting process. The symbols were used to:

1. Illustrate the **main topics** that are important so that participants could identify areas that they wished to work on with the ART.
2. Illustrate **sub-categories**, so that particular issues could be examined in greater detail and translated to goals for rehabilitation.
3. Represent possible positive and negative factors relating to each issue.

The Study

The study comprised two in-depth interviews with patients recently referred to the Area Rehabilitation Service.

Interview One took place at the beginning of the participants involvement with the Area Rehabilitation Service. This was designed to help participants set their goals.

Interview Two took place three months after the first interview and was intended to assess the participant's progress. In

addition, the participant's views were sought directly from a brief questionnaire and a participant case-study. Ethical permission was obtained from Forth Valley Ethics of Research Committee.

Twelve people newly referred to the Area Rehabilitation Service with communication difficulties were approached and given an information leaflet about the project. All indicated that they were interested in being involved and the researcher then visited them at home to explain the details of the project and the nature of their involvement. All consented to take part and a date for each interview was agreed. Their communication impairments ranged from severe receptive and expressive dysphasia to mild dysarthria.

The interviews were semi-structured which allowed for focused, two way communication. Open-ended questions were used which provided the interviewer with greater freedom and less restriction (Kadushin, 1990).

Participants used Talking Mats™ to choose from the options identified from the ICF categories to build up a personal picture of their specific goals in order of importance to them. Initially participants were asked to think about broad topic areas as outlined in the section 'Topic and Symbol Selection' above. Participants then selected issues or topics that they wanted to explore in greater detail.

Digital photographs were taken of each participant's completed mats as a visual record, and where appropriate, a video recording was made so that nonverbal communication and discussion that took place around the goal setting could be recorded.

Where appropriate, participants were interviewed again three months later to ascertain how successful intervention had been, how realistic goals were and to measure any change. All those who took part in the pilot study were asked to complete a questionnaire about how they felt about using Talking Matsä to set rehabilitation goals at the follow-up stage.

Results

Initial interviews were completed for 11 out of the 12 participants who consented to take part in the study (one participant withdrew from receiving treatment from the Area Rehabilitation Service). Follow up interviews (three months after the initial interview) were carried out with five participants. The high withdrawal rate was due to a variety of factors:

- Deterioration in a participant's condition making it inappropriate to reset goals (one participant had a rapidly deteriorating condition).
- The initial use of Talking Matsä had not been successful (two participants – one had severe cognitive difficulties and one had a very severe receptive aphasia).
- Insufficient time between the person being referred to the Team and the end point of the pilot project (three participants agreed to take part in the study during the last three months of the project).

For most participants, using Talking Mats™ enabled them to be more actively involved in the goal setting process. For exam-

ple, because of his cognitive difficulties, one participant found the concept of thinking about goals hard to understand. Giving him symbolised options to think about and manipulate on the mat enabled him to identify very clear, specific goals, and thus informed the Team's input with him.

There were some occasions where issues identified by participants using Talking Mats™ were unrealistic. For example, another participant specifically wanted to "get back to work". A more realistic option, identified as a Team goal was to explore the options in terms of part time voluntary work. This points to the need for further investigation in this area.

For some people, the use of Talking Mats™ did not help them think about their rehabilitation goals. The two people who were unable to use the mats had severe cognitive problems and poor insight into their difficulties. It was not possible for the Team to involve either participant in the goal setting process.

For one of the participants, rehabilitation was not an option. The other participant had a very supportive partner who was able to become involved in the rehabilitation process, and was helpful in supplying information about goals that would be motivating and realistic for the participant.

This highlights the importance of a person's environment in relation to rehabilitation.

Summary and Implications

This pilot study has demonstrated that Talking Mats™ is a useful tool which enables people to think about goals for rehabilitation.

Using the ICF categories as a framework, it has been possible to generate symbols which can be presented to people to help them think about rehabilitation goals.

Observation of video material and field notes taken during the research has provided useful information about the patients' perspective of rehabilitation and the process of goal setting.

The following points have emerged:

- The participants in this study initially found the idea of thinking about rehabilitation goals a difficult concept
- The use of Talking Mats™ helped people with very mild communication impairments as well as those with severe difficulties
- The patients in the study had some different priorities to those of the rehabilitation professionals who were working with them
- Using Talking Mats™ helped people to focus on and talk about specific areas of their lives
- Use of the digital photograph as a visual record of a participant's goals could be used to track any changes in the patient's priorities.

Feedback from those involved in the study suggests that this system of involving people in setting their own goals for rehabilitation is very valuable.

It helps to:

- Break down concepts into small units
- Generate ideas about the type of help available
- Allow people to move ideas around, and therefore gives them control.

However, the study also demonstrated that it is difficult for some people to be actively involved in the goal setting process. Further research is required to investigate to what extent people with severe cognitive difficulties can realistically be involved in setting goals for rehabilitation.

Feedback from members of the Area Rehabilitation Service has been very positive. The pilot has shown that further refinements to the symbol selection needs to take place. Moreover, further investigation is needed with regard to other members of the multidisciplinary team using Talking Mats™ with patients.

More generally, the pilot points to the need for further research in the following areas:

- The use of Talking Mats™ as a tool for goal setting at different points in the rehabilitation process (for example, prior to discharge from hospital, and during/after community rehabilitation).
- Interviews with a range of health professionals with the aim of expanding and further refining the use of Talking Mats™.
- Quantitative survey with patients and their significant others to get hard data on the use of Talking Mats™.
- Further investigation regarding how to enable people with severe and complex difficulties to become involved in setting rehabilitation goals.

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This pilot study was funded by Forth Valley Primary Care NHS Trust (Research and Development Committee)

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Extending the Bridge Between Cause/Effect and Scanning

by Sally Conner

This paper was presented at the CM2003 National Symposium, Lancaster University, September 2003

Many children that I work with have the linguistic potential to use VOCAs but are hampered by accessing difficulties. Too often, I have seen early enthusiasm wane as despondency and frustration set in. This article outlines a few practical ideas for breaking down skills into achievable but motivating steps.



Background

I am fortunate in being well supported in the acquisition of assessment and training equipment. We have a plethora of switch training toys, PCs with a wide-ranging selection of switch training software, and devices on which to introduce symbol software.

Ostensibly, we have the resources to take children on a well-planned journey from cause and effect to communication. What has been lacking (hopefully, not for much longer) has been OT and technical input. I have learned so much at specialist appointments; but faced with day-to-day management, one has to be inventive.

I am so grateful to Carol Thornett from SCOPE's Microtechnology Unit for the wisdom and practical advice she always leaves behind when she visits. Carol has inspired most of what I shall describe here. The result has been a significant reduction in despondency and frustration in both children and myself!



The problems described below are ones that are frequently encountered in a group of children presenting with similar ICT needs. Skills, such as isolated motor movements, attention control, memory, timing, understanding scanning, etc., need to be mastered and integrated. This can and often does take years. I wonder if integration can happen earlier by being more focused on individual skill components.

Problem 1: How Many Switches?

Faced with complex accessing difficulties, in the early stages it can be hard enough to find one reliable switch site, let alone two. Some children may manage to operate two head switches, but where do they rest their head? One switch should be the answer.

However, timing skills are not the only requisite for single switch operation. Sustained attention is also needed; and this can be the biggest problem. Involuntary movement, a sudden noise, thoughts about the boyfriend – any interruption to

concentration can mean missing the target. That may mean going back to square one again...and again...and again. It may result in navigating to the wrong page, or needing to delete an error again...and again...and again! By which stage, the child may have forgotten what they set out to do. In these circumstances, perhaps children shouldn't be using software that allows these errors.



Cognitive overload should be reduced whilst assessing switch control. However, as I shall describe, I have found that the motivation for specific switch training and assessment tasks may not last long enough to enable one to make these important early decisions.

Solution: Assisted Scanning

When Carol Thornett suggested setting software up for two switches, and sharing the task with the child, I couldn't understand why I hadn't thought of it before. It takes away the need for early decision making about one or two switches. A child can concentrate on one skill at a time. If you do the scanning, you can evaluate responsiveness. You can vary the speed, and you can pause whilst they readjust their position and regain focus. You can pause to give verbal reminders without disrupting concentration.



Hopefully, you can graduate progress successfully. You may start by scanning at slow and erratic speed to match the child's attention. You will aim to increase speed and rhythmic consistency until they are ready for single switch use.

James can now use one switch independently in one-to-one sessions; but in class concentrating on switching disrupts thought processes. Skills are not yet fully integrated. He prefers Assisted Scanning in these situations. In the coming year hopefully he will become less and less dependent on assisted scanning. However, his early experiences with switches were very frustrating. Assisted scanning has built his confidence – and mine!



Nicholas also used the 'select' switch whilst I scanned. However, he selected the first cell in each row repeatedly. Carol suggested that he be given the scanning task, and this was a turning point. The partner's 'select' switch has a 'yes' symbol on it, and is positioned where he normally looks to signal 'yes'. With his head switch, he scans to the row or column he wants, and then looks at 'yes' telling his partner to select. Nicholas has

problems with sustained attention; taking control of scanning keeps him on task.

There is also now a possibility of mounting a second switch in a position that will afford him somewhere to rest his head. When looking at 'yes', he spontaneously moves his head down, forward and to the right. He may therefore use two head switches at staggered heights.

Problem 2: Motivation

A few years ago, I was so relieved to have finished IDV, I was keen to launch all symbol users onto it. However, it will come as no surprise to those of you with more sense than I, that for those who needed to work on accessing first, a frustrating path lay ahead. So, I stocked up on switch training programmes. The policy was 'Holdfire on Quickfire!' until certain accessing criteria had been reached.

However, another feature shared by this group of children is that they are not impressed when told that they need to work towards communication grids! They have the same linguistic potential as peers communicating with symbols using touch screens and joysticks etc.

James and Nicholas are two of several children who indicated unequivocally that they wanted to use symbol software, despite logical explanations about the need to master switching skills first. The training software may be fun, but they want to say something with symbols too.

I programmed accessible Clicker grids so Liam could talk about his holiday in Ireland and his passion for trains. They were motivating...for a day each! I needed to keep ahead of programming needs with something that might motivate various children for more than one session!

Solution: Creative Writing Clicker Grids

Story vocabulary is generally popular in Communication Books. The Clicker Grids, described in more detail in the next section, were written with that in mind. They started out in the 'Ghost Story, and 'Design a Monster vein. Recipes and quizzes were added later. At level 1, children are offered series of 4 alternatives to progress the stories and descriptions. This hardly constitutes true creative writing for the child with a really vivid imagination – but so far activities have proved motivating enough to hide the fact that were switch training!

A whole session introducing children to Quickfire or Ingfield grids when they haven't mastered row/column scanning, can be demoralising. Spending most of a session using a Clicker switch training Grid, followed by creation of a Quickfire message feels much more jolly!

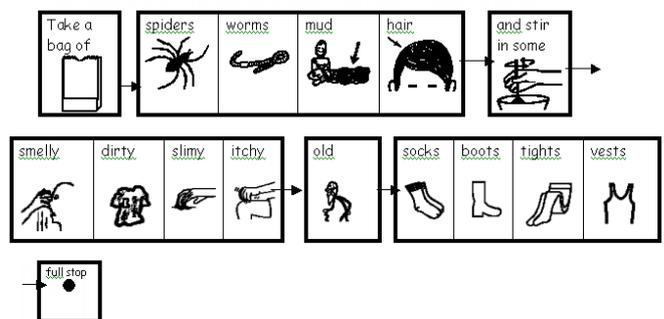
Problem 3: Understanding Scanning

I used to introduce rows into the row/column equation too early. The transition from one axis to another can be a huge, frustrating leap. Even when a child has mastered the basic concept, double-hitting the first cell in a row can be a persistent problem. The crucial change from one axis to another is a skill that can need teasing out for focus.

Solution: Clicker Grids designed to teach transition from column to row/column scanning

The grids that I started to describe in the previous section were designed to target two areas – motivation, and breaking down row/column scanning. A basic training structure is now in place; but grids are under construction, developed either according to the needs of a particular child, or when the Muse strikes (planning a Clicker Story Board occupies a Dorking to Victoria train journey very nicely). The grids are currently organised into three Levels:

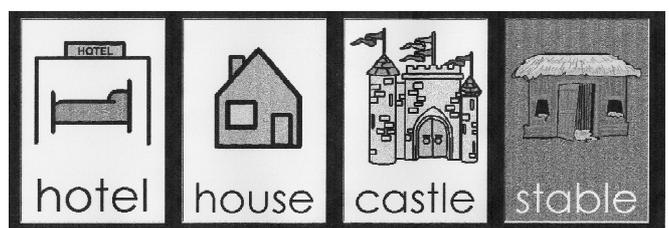
Level 1 focuses on scanning along single rows only, and should be set up for simple scan. It consists of pages with either single cells or single rows offering a choice of 4 symbols. Selection of any symbol will progress the child through the story or description. Each story comprises a set of sentences arranged in a consistent pattern of structure on single cells, and key word choice-making grids. A single cell with a full stop signals the end of each sentence. When selected, it will speak the preceding sentence. The following illustrates a series of grids from Level's 'Revolting Recipe':

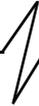


The penultimate pages comprise cells that read back the story. The final selection prints the document before returning to the beginning.

Level 2 again focuses on single row scanning. It follows the same format as Level 1, except that some accuracy is demanded. At Level 1, any switch selection progresses the child through the grids. They may make active choices, or they may choose the first symbol in every row. If it is felt that they need more help in making accurate, considered choices, they may need Level 2. Here, one symbol in each row is correct. Only that symbol results in auditory feedback and navigation to the next screen. Target symbols have a purple background. This introduces the concept that in Ingfield/Quickfire vocabularies, page navigation is signalled with purple. By giving visual clues, it also identifies the task as more an accessing than a cognitive one.

The following screen is an example of a page from the Christmas Story:





Liberator Advertisement

Level 3 focuses on introducing the second axis. Rows and columns are now on each screen; but only one row will contain choice symbols. The first symbol in that row will be 'yes – all the others will be 'no. Thus, the child is encouraged to consider how to change direction, and can learn that the 'yes symbol only requires one switch press. Hopefully, this will help to establish the usual rhythm for axis change on communication grids.

A new level of grids may need to be added where the first symbol is sometimes the target, and therefore requires a double switch press – a bridge to be crossed when the time comes! As at Level 2, there is one correct answer in each row, so active selection is required. At the time of writing, files programmed at this level consist of Quizzes and 'Making a Sandwich'.

The following illustrates a grid from Level 3 Quiz 2, in which the child has been asked who has sharp teeth:

no 				
no 				
yes 	dentist 	goldfish 	worm 	crocodile 
no 				

Conclusion

The strategies described above may be stating the idiotically obvious or be challenged by people who have the background and experience I lack in switch training. I come from a position of one who has needed to troubleshoot in unfamiliar territory to pave the way for the more familiar task of VOCA training.

What I am conscious of is a significant reduction in my frustration, and more importantly, that of several children. This is largely the result of some very practical observations and solutions offered by Carol Thornett from SCOPE's Microtechnology Unit.

My enthusiasm for creating Clicker Grids has also helped; and this project has afforded an excellent milieu for Clicker Training in school. Several of the story files represent the programming debut of Ingfield staff. Because of the consistent and repetitive structure, programming the grids gives plentiful opportunity for practising key skills, such as page linking and making cell changes.

Anyone with a train journey imminent is liable to be presented with a storyboard template – just in case the Muse should strike!

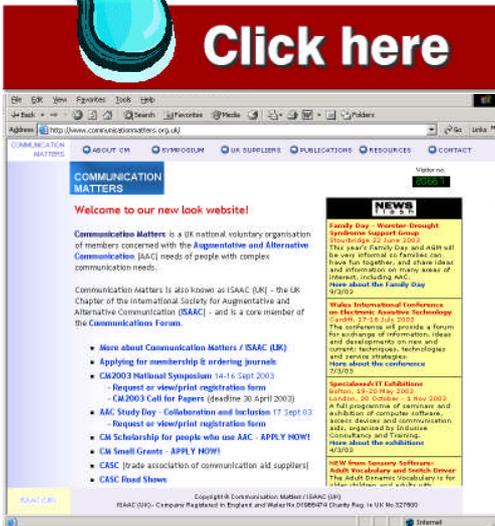
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Product Review

P+G Inclusive Scan4

The *Scan4* is a scanning version of the popular *4talk4*. It is a speech output device from Penny & Giles and Inclusive Technology.

Four large, coloured buttons each with its own message, and four distinct levels, allows up to 16 pre-recorded messages. With switches attached, it also encourages users to understand scanning and choice-making. Its bright scanning lights and auditory scanning reinforce learning of these concepts. It has traditional single switch scanning; two switch scanning; and a single switch 'dwell' scan mode, where pressing the switch controls the scan and dwelling on the required selection causes it to activate.



I was delighted when the scanning *4talk4* – the *Scan4* – came on the market. Four single message devices in one go, a tool to develop an understanding of scanning, auditory scanning and two switch access – all together in one device. The leap from the use of a single message device was too huge before. Now we have the next stage.

My first question was, "Are the lights going to be bright enough?". Yes they are, and you can reinforce the scan with the use of auditory scanning. I work with many pupils who have been using two BIGmack single message devices to develop an understanding of choice. I have been using the *Scan4* to move pupils on to the next step, to use as a tool to develop scanning skills. This is not the only means to learn scanning: it should be used in conjunction with simple scanning software on the computer as well as a symbol book where the educator scans the symbols/photographs, reading out the names and allowing the learner to indicate when to stop. The *4Pic4* binder of plastic inserts for use with the *Scan4* is also useful for introducing a parent to the use of symbols or to practise your communications skills by finding the right symbol or photograph.

As well as developing the use of a switch and scanning skills, the *Scan4* allows direct access – just press a button and hear the message. Four levels allow you to store four sets of messages for use throughout the day. If you have the symbols

ready, it is very easy to record new messages. I would often suggest to schools that the device is used at the same time every day to increase the confidence of the adult using it and to build it in to supporting the curriculum. Real voices, music and sound effects can make it a fun tool to use to develop skills. It is up to the imagination!

I really like this device as it allows users to build up an understanding of scanning in a practical activity, whether it is by joining in with a story by saying a repeated line, reporting an event that has taken place, carrying a message, joining in with a school play, singing a song in assembly or all of those inspiring things that are done on a single message device but with more scope.

Trish Davidson
CENMAC/London CAP Centre
www.cenmac.com

The P+G Inclusive *Scan4* is available from Inclusive Technology Tel: 01457 819790 www.inclusive.co.uk

CENMAC is a team of advisory teachers with backgrounds in special schools and mainstream inclusion. They work in the Greater London area, with children aged 3 to 19 who have a physical disability that prevents them communicating in writing. All their pupils have a physical disability. Some of them are able to use a keyboard while others may need switches to give them a means of recording, communicating or controlling their environment. CENMAC is able to assess need, loan appropriate equipment and monitor progress.

1-Voice UK Internet



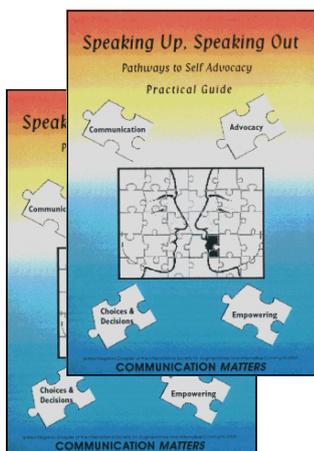
The group is for all UK users of communication aids (electronic and 'low-tech' aids), their families, carers and enablers.

Also welcome are support workers, teachers, therapists, suppliers and advisors. Membership is free.

To join the group, send a blank email to:
onevoiceuk-subscribe@yahoogroups.com

Further information from:
onevoiceuk-owner@yahoogroups.com

Essential Publications from Communication Matters



Speaking Up and Speaking Out! Pathways to Self-Advocacy

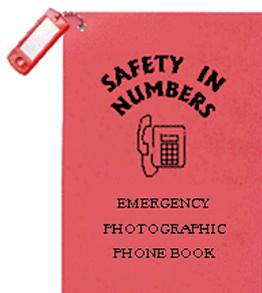
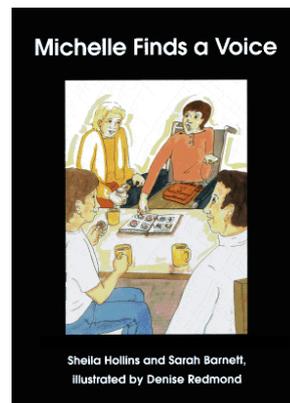
This pack is intended for carers, facilitators and others concerned with the advocacy needs of people with severe communication difficulties who need or use AAC. It is useful for staff development, especially for those working with adults. The pack comprises two books. One is a comprehensive and detailed Handbook which includes case stories, discussion points and references. The other is a Practical Guide which summarises the main points of the Handbook in a series of photocopiable overheads, checklists and activities designed to help users build an advocacy plan for individuals.

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

Michelle Finds a Voice

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

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



Safety in Numbers: A Photographic Phonebook

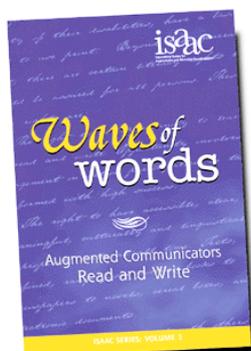
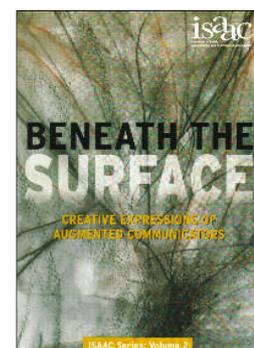
This photographic phone book is for people who find reading difficult. The pack includes an information page with key information about the person, several blank pages ready to add photographs or symbols, space for additional notes for an enabler, babysitter or other adult, a tag to make the book easy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

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

Beneath the Surface

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

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



Waves of Words

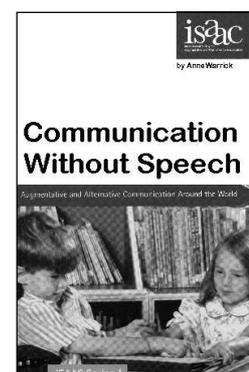
The challenges confronting individuals with severe communication disabilities are chronicled in Waves of Words: Augmented Communicators Read and Write. The focus is on the strategies that teachers, therapists and individuals who rely on augmentative communication from around the globe have used to produce ultimate success in the struggle to learn to read and write.

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

Communication Without Speech: 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, and includes excellent photographs and illustrations.

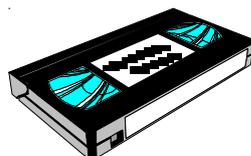
Price: £15 plus £1.50 p&p from **Communication Matters**



In Other Words (ISAAC video)

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

Price: £12 to CM members (otherwise £17) including p&p **only available from ACE Centre (ring 01865 759800)**



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

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