



COMMUNICATION MATTERS

INTERNATIONAL SOCIETY FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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COMMUNICATION MATTERS

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The Secret Diary of an AAC User

by Karl Parrish

Karl Parrish is the winner of the 2002 Communication Matters Distinguished AAC User Award. The award is made every year for the best paper submitted by someone who uses AAC, for presentation at the CM National Symposium.

This paper was given at CM2002, Lancaster University, September 2002.

My name is Karl David Parrish. I live near Chepstow but I'm from Newport. The excerpt from my diary is called 'Village Life - Not all Pubs and Cowpats'.

Dad and I have fun in the mornings. He sometimes throws freezing water on me to wake me up and I try to push him in our swimming pool.

I was eating my breakfast. The phone went, it was Rob he wanted to know were we going up the pub tonight. Dad has to push me on the road because the pavements are too bumpy we meet lots of potholes but no cowpats.

I say Dad can I take my electric chair he says not in the winter because it's too wet. This means I can't communicate with my Cameleon I have to rely on my dad and mum and that makes me angry, as I want to be normal.

I get up at 7 o'clock 4 days a week. One night I stay in school.

I like working in school on the youth award scheme I don't like maths. I go out sometimes, not often enough. I'm good at computing.

I go to Cardiff on a Thursday to go shopping. I like the shopping but what I don't like is people talking over me, about me or saying I'm cute.

By the time I'm 50 I will be glad I don't look my age but I wish I looked 18 now. If I looked big rough and tough people wouldn't talk about me.

Back in the village Andrew who owns a farm wants to take me horse riding. This beast is big and mean, fortunately I am allergic to horses so I could say no.

I love flying. The toilets are a bit small but I've been to Hungary, Florida, Lanzarote, Ireland, Portugal and Holland. I love meeting new people and eating new food. But then I really love eating.

I liked America the best because of the accessibility of life and the positive attitude of people there.

I am looking forward to going to the Lion's tour of New Zealand in 2005. It's early to be getting excited but I really want to go.

I would like to travel the world starting off in the UK and then going abroad. I would take my parents. I would take my Auntie Liz and Uncle Steve to help me get around and to squeeze into foreign toilets. I would like to learn about foreign cultures and how other countries feel about disability.

I am really proud of my family. We argue together and have fun together just like any other family. I love them.



In the future I hope to go college at the Star Centre then come home and help my sister with the computing side of her beauty therapy business. Another of my dreams is to have access to equipment that would help me be a really good chef. You can see my life isn't all pubs and cowpats. We village yokels have our dreams too.

*Karl Parrish
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An invitation to apply for the 2003
**Communication Matters
Scholarship
for people who use AAC**

Note that this Scholarship replaces the
CM Distinguished AAC User Award

Please turn to page 35 for more details

The CM Achievement Awards 2002

The Communication Matters Achievement Awards are made to acknowledge the achievements of people who have recently made a major breakthrough in learning to use a communication system other than speech. Below are the stories of four of the seven Achievement Award winners in 2002; the other stories will be published in the next issue.

Ben Davies

Ben is a young man who has cerebral palsy. He is 15 years old, and has attended Treloar School as a day student for the last four and a half years. Ben is able to vocalise some sounds, and can indicate 'yes' and 'no' using head movements. He has a colour coded wordbook which he accesses using his fists; the wordbook has grown in size and complexity over the last few years. In Spring 2001, Ben also started to use a DynaVox with a customised program extremely successfully, and has shown great enthusiasm since this time in familiarising himself with, and making the most of, his new system.

Ben's program on the DynaVox uses PCS symbols, and was designed especially for him taking into consideration his visual perceptual abilities and his own priorities in terms of vocabulary and specific topic pages. He accesses the device using a switch joystick which was also designed specifically for him by the Rehab Engineering team at school. Ben had had a lot of practice using his switches both on his class computer, and when driving his electric wheelchair, but for a long time did not seem that motivated at school to progress to also using a voice output communication device. As a student in the school's conductive education group (FLAME), Ben was used to working with a small and familiar staff group, and his wordbook had always worked very well for him in this situation. However, his attitude towards his communication has changed dramatically over the last year and a half, and as he has moved into the more senior areas of the school, coming into contact with a much wider circle of people, Ben has noticeably shown much more maturity and dedication towards developing his communication skills.

Ben began his trial with the DynaVox at around the time of the last general election in 1999, and the first message that he asked to be added to his program was one expressing his dissatisfaction with the result! He then took great delight in raising this issue with as many people as he could find around school - a topic that he would have found very difficult to discuss with his wordbook. For the first time Ben was able to be an independent communicator, and had so much more control over what he said, and to whom. During the first few weeks of his trial with the DynaVox many people around the school commented on how much more lively and interested he seemed in what was going on around him, and his participation in class activities and general chitchat increased significantly.

Ben's understanding of language is very good, but he has difficulty formulating grammatical sentences, and he tends to rely mostly upon putting together strings of key words. He always arrives for his SLT sessions with a big smile on his face, and has worked very hard over the last year on developing his sentence building skills. I'm often delighted to hear from staff that work with him that he has tried using the sentences we have practised in situations outside the therapy room, and he takes his homework tasks very seriously indeed!



He also continues to be very inventive in the symbols he chooses in order to get more complex, novel messages across. Some guess-work is often required on the part of his communication partner, but Ben is usually very patient, and will continue to give clues and answer closed questions until he has succeeded with what he wants to say.

Ben regularly arrives for his SLT session with ideas for new words or messages he would like adding to his program. It can sometimes take a while for him to explain these ideas (again, often with much guess work involved!), but he always perseveres, and the messages chosen by him certainly seem to be the ones he goes on to use the most! For example, Ben has relatives living in Ireland, and he recently requested an 'At the airport' page, giving him words and phrases that would enable him to book himself in for flights, check his passport, find out departure times and so on when visiting them in the school holidays. He has also shown that he is able to take an increasing responsibility for his communication needs - asking for the machine to be charged when necessary, for example, and asking for help when there are problems with his program. He is well supported in school by a very encouraging team of staff, and he recently selected a learning support assistant who regularly works with him to be trained to program new vocabulary and messages for him. Ben's mother has also been very involved with his progress, and has really encouraged Ben's use of the DynaVox at home as well as school.

What is great to see is that Ben has found a system that works for him, and is now keen to develop it and his skills as far as possible. As he grows older, he is taking control of his own communication needs in ways which, a year and a half ago, seemed hardly possible. It is wonderful to see how his confidence in himself and his communication ability has really grown. He has been an inspiring role model for other students in his class just starting out with communication aids.

*Caroline Casula, Speech and Language Therapist
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Kavita Basra

Since receiving her Dynamo, Kavita has made startling progress and she is able to use her systems with much more confidence and skill.

When she started with the Dynamo in early 2001 she was finding it very difficult, but with a change in October 2001, she suddenly took off and became much keener to try and use her systems. We put this down to more general confidence and maturity and lots and lots of hard work from her team, including her teacher, speech and language therapist (SALT) and SALT assistant.



Kavita uses her Dynamo to chat

Kavita's family have also backed her up and have attended training sessions and supported her use, for example, at a family party when she was able to sing 'happy birthday' and participate in the celebrations.

She has been a member of a communication aid users group at school and she has wanted to help the others by supporting them, showing how her system can be used to communicate and encouraging them.

She has helped a lot with errands around school using her Dynamo. For example, she was able to get a telephone and deal with the fact that everything was not as predicted and still come back with what was needed and an explanation. She has recently moved on to the new Dyna group at school and is an excellent member of the group.

Kavita currently has a Dynamo VOCA and a matching and complex multi-level communication book in an A4 file which is in Makaton symbols. She also has a pocket communication aid with six pages of symbols for using in the community, where quick access is needed.

We did not know that Kavita was going to be able to do all of this. She was so shy and not a keen communicator. She has really come out of herself and showed her potential. She has blossomed as a helpful and contributing member of the school community.

*Liz Grills, Class Teacher, Calthorpe School
Jo Rotherham, SALT Assistant, Calthorpe School
Chris Sherlock, Speech & Language Therapist, ACT
Karmel Basra (Kavita's mother)*

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John Boyle

John Boyle (known to friends as Jackie) suffered a stroke in 1996 at the age of 53 years while living in South Africa. He subsequently returned to Scotland to live in 1998 after spending 32 years in South Africa.



Jackie now lives on his own in Glasgow with some support from his sisters. He has severe aphasia, which makes it difficult for him to understand what is said if people are speaking too quickly or if too many people are speaking at once. His reading comprehension is restricted to short paragraphs. Jackie is unable to communicate using speech or writing. He relies heavily on a combination of methods which include the use of his Dynamo communication aid which was introduced to him in November 2000.

The Dynamo is a digitised speech device with a dynamic screen display which uses BoardMaker symbols, written words and audio recordings to allow Jackie to express himself. Its lightweight durable case allows Jackie to take it anywhere. The master page contains the following individualised folders which in turn lead onto more in-depth communication about each area: Home, About me, Aphasia, Phone, Stroke Club, Fernan St (Disability Resource Centre) and Shopping.

Jackie uses the Dynamo in a variety of situations:

1. On the phone — Jackie uses his aid to tell unfamiliar callers about his aphasia and how they should proceed with the call in order to facilitate his understanding and expression. He regularly uses the Yes/No buttons to answer specific questions and uses the Home page to let his sister know if there is anything he needs done in the house.
2. Shopping — Jackie shops by himself several times a week. He uses a variety of local shops and he regularly uses the Yes/No button and the Shopping page to request particular items.
3. Post Office — Jackie pays his own bills at the post office and will use his Dynamo to confirm Yes/No.
4. Fernan St Disability Resource Centre — Jackie uses his Dynamo to tell other service users about himself, his aphasia, how they can help him to communicate and to confirm his Yes/No responses.

Jackie has indicated that the Dynamo has enabled him to live independently with more confidence. One of the pages describes his aphasia and how people can help. This allows Jackie to take an active role in educating others in his immediate environment about his communication needs. He continues to attend regular speech and language therapy to develop the Dynamo pages to take account of his changing communication needs. He is an active participant in deciding on the content and the layout of each page.

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Daniel Payne



My first encounter with Daniel was when he and his mother visited Radlett Lodge School for an admissions interview. At that time, Daniel was attending a school for children with severe learning difficulties, but Daniel's mother felt strongly that the school was unable to meet Daniel's needs or cope with his often challenging behaviour. Daniel had complex communication needs, autistic spectrum disorder, learning difficulties and significant behaviour problems.

During their visit, both Daniel and his mother appeared anxious and stressed, and it quickly became clear that their experiences with school life had not always been happy ones. My task was to introduce Daniel to one of the classes.

Walking down the corridor, Daniel looked frightened. He expressed his anxiety through high-pitched, non-communicative vocalisations and also tried to hit out at me. Once in the classroom, he was unable to join the circle time group, but settled when allowed to sit on his own with a book on numbers, which he studied with great concentration, vocalising and showing different numbers using his fingers. Clearly, numbers were something that he used as a strategy for managing his own anxiety. However, Daniel's verbalizations had no obvious communicative intent and while Daniel tolerated me sitting near him, he would immediately lash out if I tried to sit closer or get involved in his activity.

Once the other children had left the classroom to go out to play, Daniel felt confident enough to change location himself. He initiated his request by leading me to the door. On our way back to the principal's office, I gently pointed out some of the symbols on the different classroom doors. Daniel showed a noticeable interest in the symbols and made no attempt to lash out at me even though I was trying to direct his attention. On a couple of occasions, he also pointed to the symbols I had indicated to him. Any doubts that he might not actually understand the meaning of the symbols were dispelled when, during our tour of the school corridors, he led me back to the soft play room door, repeatedly pointing to the symbol on the door before trying to use my hand to unlock the door.

Soon after this visit, Daniel started at Radlett Lodge School. Daniel responded well to the visual communication strategies used at the school including his symbol-based timetable and simple negotiation (for example, First English circle, then sweet). It took him no time at all to learn the symbols for different classroom activities or, in fact, any other symbols that he encountered during classroom learning. Within a couple of weeks, Daniel had learned to refer to his timetable to understand what was going to happen next, and he is now more or less independently using a portable timetable to get himself from one activity to the next. Daniel also uses his

timetable as a way of expressing likes and dislikes, and will often try and change the timetable to include all his favourite activities (PE and play).

When starting at school, Daniel's main way of communicating his wants, needs and feelings was to fleetingly point to or tap things or symbols representing things that he wanted. Daniel showed no understanding of the fact that the process of communication involves a speaker sending a message to a receiver and, as a result, quickly got frustrated and angry when his symbol tapping or pointing was not responded to because no one had noticed what he had been doing. Often, adults working with Daniel only realised that he wanted something when he started hitting them out of frustration about his request not being met. Since then, Daniel has learned to exchange, rather than point to, a symbol of what he wants, and as a result communicative exchanges are becoming more successful during structured and motivating activities such as snack time or tuck shop.

However, Daniel's biggest achievement with regards to communication has been his ability to cope and communicate during less structured times and during group activities that he finds stressful. Daniel's coping strategies in these contexts used to involve frequent lashing out which, not surprisingly, caused a certain level of stress and anxiety in the adult working with him. There were few signs of intentional communication attempts; Daniel appeared to be simply reacting to what he perceived to be difficult or stressful situations.

Adults found that Daniel's hitting would often stop if they gently stroked his hair or sing number songs to him. However, there was a danger that this was teaching Daniel that if he wanted someone to stroke his hair or sing to him, all he had to do was hit them - not the most appropriate communication strategy and certainly not a communication strategy we would like to promote! To tackle this problem, Daniel's teacher made a list of possible messages Daniel might be sending during these times including 'move away', 'stroke my hair' and 'run' (i.e. 'I want to go for a run'). Adults working with Daniel had these symbols on a keyring and agreed to show Daniel the symbol keyring every time they sensed he was getting anxious or finding a situation difficult. To start with, Daniel was encouraged to select an appropriate symbol and point to it in response to being offered the keyring. Daniel has been extremely quick to learn the meaning of the keyring symbols and now uses them appropriately to deal with difficult situations. The next step will be for Daniel to carry his own keyring and to use the symbols to initiate requests rather than relying on an adult to offer the keyring to him. While there are still times when Daniel lashes out on impulse in response to an external or possibly internal trigger, the incidents of his hitting and lashing out have decreased considerably. Daniel generally presents as a more relaxed and less anxious boy.

Daniel, now almost 10 years old, uses Rebus, PCS, and PECS. His mum and I are extremely pleased with and proud of his progress and we are delighted that he has won a CM Achievement Award this year.

*Lilo Seelos, Speech & Language Therapist
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My Experience as an AAC Role-Model for the 1-Voice Family Weekend 2001

by Amanda Creely (enabled by Tamsin Crothers)

This paper was presented at the CM2002 National Symposium, Lancaster University, September 2002

Introduction

My name is Amanda Creely. I am 21 years old and I use a Liberator to speak. I have had my Liberator with LLL for six years. I live with my parents (and my dog) in Manchester and at the moment I am in the middle of starting at a Day Centre and going to College part time. We have planned this talk in advance and I welcome your questions at the end of this presentation.

I joined 1-Voice last year, and I was asked to be a role-model for the Family Weekend conference. The conference is a weekend of themed activities for 12 families learning to use AAC. Role-models are very important for the weekend. Communication Matters sponsored some of the role-models to take part. Today, I would like to tell you how I felt about being a role-model and why I think it was important.

When I was first asked to be a role-model, I was scared. I didn't know what to expect and I couldn't imagine what it would be like. In the end I decided I would do it because I wanted to help children and I was interested to see the AAC that other people use.

What I had to do

I had to talk to children. Children came up to talk to me and asked me a lot of questions. They wanted to know all about me. Have I got any pets? Where do I like going out? Have I got any brothers or sisters? They wanted to talk to me and find out what I am like. They didn't really ask any questions about my Liberator.

During the day I went to the parent workshops and listened to the speakers' and the parents' questions. During breaks and other activities, I talked with the children. At night I did an after dinner speech about myself and how I learnt to use my Liberator. I told the children not to give up, and to keep working at their AAC.

I also talked to parents, other role-models and volunteers.

Why it was important to me to be a role-model

When I was a role-model, I got to see a lot of different systems and different switches. I am very interested in the machines people use, and what switches or pointers they use.

At the weekend, I was the same as everyone else. This was very different from usual. At the Day Centre, I am the only person who can speak. There is one other man who can talk but

I don't get on with him, so I don't have anyone to talk to. The others just sit around or watch TV and they don't have communication aids. It is frustrating and I feel different.

When I am with speaking people, they can go too fast, or they can talk over me, or guess what I am going to say. It is frustrating and I feel different.

So it was nice to meet other adults and talk to them, because I have never met any adults before. It was nice to chat.

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It was good to get straight into conversation
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...people talked straight to me.
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It was good to get straight into conversations. When I started at the Day Centre, people looked at my Liberator and said, "What's this? Look everyone, come and see what Amanda's got". There were about 10 of them standing round looking over me. They didn't see me, only my Liberator. When I was a role-model, people talked straight to me. They already knew about communication aids, so we could talk about important things, like where we go out, fashion and things that are interesting.

I liked hearing Anthony Robertson and his wife talk at the parent workshops. Anthony cannot read and spell so I identified with him because I can't read or spell either. It was good to meet someone the same. I also like going to the parent workshops because I got some good ideas for myself, and I got some good ideas for low-tech boards.

I liked doing the after dinner speech, but people didn't ask as many questions as I had expected.

Why it was important for the children

I think it was important for the children to see adults using a communication aid.

When I was little, I started with a pad and drawings. There were eight pictures with the word written underneath. They said things like, 'drink', 'eat' and 'toilet'. It was good because I could communicate eight messages. Then I got a LightTalker and we put the eight messages on. I thought it was fantastic, because now I could say, "Can I have something to eat?", "Can I have a drink" and "I need to go to the toilet". I'm not being sarcastic. I really thought it was great that I could say those

things. It was the best thing I had ever seen because at least I could talk. But I didn't look beyond that. I thought I would be saying those eight things for the rest of my life.

If I had seen a role-model when I was young, I would have thought, "Will I be able to do that?" I would have thought to myself, "I am going to be able to say more things when I grow up". It was hard to learn LLL. I never gave up, but I did think to myself, "Will I ever be able to do this?"

I think it is important to have role-models because children can't ask questions like that. They don't know how to ask those questions because they are only learning. They need people to say, "You are using eight pictures now, but you will use more and more, and you will be able to say more and more things". They don't just need to know that it is worth all the hard work, they need to know that there actually *is* something to work towards.

*Role Models can answer the questions
that children don't even know to ask.*

The role-models can show them what they are aiming for, and the role-models can answer the questions that the children don't even know to ask. They are learning their AAC and they need the role-models to tell them things like, "You will be able to say more things if you keep working at it".

Why it was important for the families

I think it is important for families to meet role-models for the same reasons that it is important for children. Also, they know to push their children and to encourage them to work at the AAC because they can see that it is worth it and what the role-models can achieve.

It is important for families to meet role-models socially so they can see all the things we enjoy and achieve, like drinking, dancing, getting married or having children. AAC can help us do all the things we want to.

Why it was important for professionals and volunteers

I think it is good that volunteers and professionals can see how important it is for children to meet role-models. When I was at school, there were some younger children learning to use communication aids, and I did a talk to them and I hope they could see themselves using AAC fully when they are older. I hope professionals will make sure that their children get to meet older people using AAC. They could meet other people at their school or in their area, or they could get a role-model to visit them.

I think it is good that professionals can know what adult role-models thought about AAC when they were children, so they can talk about what will help children learn about AAC. Then the professionals can work well with young children.

It is good for new volunteers to socialise with adult role-models. They will find that they don't need to be nervous about communicating with us. We understand that it is difficult for them at first. I found that new people talked to my parents at first, but once they got to know me and chat with me, they talked to me. So I think it is important to spend social time together, so they will be confident when they meet others using communication aids.

Why it was important for brothers and sisters

It is important for brothers and sisters to meet adult role-models because they know that people can communicate well, and then they might expect more of their brothers and sisters, and they could expect more for them as well.

It is important that they know that one day, their brother or sister will move on and use more than eight pictures. They know that this is just the beginning.

Conclusion

I would like to thank Communication Matters for sponsoring the role-models to attend the Family Conference in 2001. I think the experience has helped me in using my Liberator, and I feel I have played a valuable role in supporting others in learning about communication.

Amanda Creely
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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.

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Employed, Self-Employed or Un-Employed?

by Alan Martin

This paper was presented at the CM2002 National Symposium, Lancaster University, September 2002

When I wrote my abstract for this presentation some months ago, I had hoped to have some good news about my job hunting. I am sorry to report that this paper should have been titled, 'Going around in ever decreasing circles'.

I have done my best, and followed all the advice given to me that I was capable of following, but I am still an unemployed person who finds himself actually working full time. Why is this? I will try to summarise the barriers still in my way.

The welfare benefits trap

First, the welfare benefits trap. It is still there, maybe a little smaller than before, but as anyone who uses a wheelchair knows well, one big step makes a building as inaccessible as 20 steps! Everyone's circumstances are different, obviously, but the system is simply not flexible enough to allow for this. In my case, I do not have a family or spouse to fall back on if I get into a financial mess. I live on my own independently and my income is all from welfare benefits. To make the huge jump from the way I am now to earning my living is still too risky for me. The trap seems to me to be that I am basically on income support benefit, rather than invalidity benefit. I have spoken to welfare benefits advisors again and again, and they have all agreed with me that I am stuck in a trap.

The next barrier, which I can't get over, is my dealings with MPs (Members of Parliament) and government departments. I have asked questions, through my own MP and also other MPs. They always answer questions which I never asked, and fail to grasp the actual problem.

The most practical thing I was offered was that my MP got in touch with my local job centre, and put me in touch with the disability employment advisor. She agreed that I was in a trap but had to refer me to a job broker. After trying to find a wheelchair accessible job broker, (you may imagine that people who have disabled jobseekers referred to them would be accessible - not so!) I went to see one, who also said (off the record!) that I was in a trap too. He still sends me job advertisements - for jobs which are completely unsuitable, but then that is all he can do.

Lack of understanding about disability

Another barrier is lack of understanding about some disabilities. In my own case, I have tried working full time, six days on the run. Afterwards, I was so exhausted that I needed a week's break. I am not being lazy. I think people do not realise how much effort I have to put into working. To get ready, I have to get up very early because it takes me a long time to wash and dress. I am often tired before I start work. The level of stress is extremely high because of things like worrying about access in buildings. It's very stressful to think that you may not be able to get into a toilet all day. How many able-

bodied people would happily work all day knowing that they were not able to go to the toilet? I have done this quite a few times, and, believe me, it is stressful to know that, although dying of thirst, you daren't drink, just in case! Also, I worry about my equipment letting me down. If my electric wheelchair goes wrong, I am in a mess. If my communication equipment fails for some reason, I am in an even bigger hole. Then I have to make sure I have a supportive personal assistant working for me who is not always clock watching. I have to put in a lot of time preparing for work too. If I am asked to give a talk about services for people with disabilities, I can't just write it on the back of an envelope while having a coffee! I have to spend days working on it, and programming my communication aid. These are all inequalities which are not faced by the non-disabled worker.

I am very glad to say that one big barrier to employment has now gone. From April 2002 any money I earn will not now be deducted from my care money. Before, if I earned more than £40 a week, I had money taken off my Independent Living Fund money. What a massive disincentive to work was that?

Why bother working?

People often say, "Why bother to try to get into work?" I answer that I want to work for my money for the same reasons that anybody else does. I want the self-esteem of knowing that I am a productive member of society. I do realise that working voluntarily as I am doing now is a way of paying society back for my social security benefits, but I have able-bodied ambitions. I do not want to be always stuck on a low income, and able to 'just get by'. I want to increase the quality of my life. I want to be able to afford to travel. I want to be able to buy all the equipment that could help me, which I can't get from statutory bodies. I want to go to the theatre and do all the things that everyone else aspires to.

I know that what I do is wanted and valuable. It is something which I have developed for myself and is not fitting into a job which already exists, so I am not really looking to be employed by an employer. I need to be able to work freelance and self-employed. If an employer took me on, he would have to pay me a full wage to replace my benefits and give me a little extra, for just two or three days a week's work. Although he could take me on for one year and pay me £60 a week under the permissible earnings rule, and I could still keep my benefits, he would then have to pay me a salary of around £15,000 plus expenses take home pay, for a half-time worker. I would be very lucky to get an employer to do this! Employers can claim some of the cost of taking on a disabled worker through the Access to Work scheme. Many employers don't know about this. I wonder why there isn't more publicity about it?

Has anyone truly worked out the cost to the country of keeping someone like me on welfare benefits compared to enabling me

to do a job where I would be paying taxes and being productive. Is it all just down to money?

Going round in circles

Up until when I got my first communication aid about eight years ago, all I was offered was voluntary work for parks and gardens, picking up rubbish with a stick. I have spent five years getting qualified and experienced in what I want to do for work. I have attended performing arts, computer, and business management courses. I have done the work voluntarily for expenses only for about four years. My work is giving inclusive dance workshops and performances, and working with dance projects. Also, I give presentations on disability issues. I have worked for many organisations, education and health services, charities and arts groups among others. I am often offered a fee for my work. I have to say, "Thanks, but, no thanks." I could only give workshops or presentations for about two days a week because it takes me another two days at least to prepare individual presentations and program my aid with what I need to say. My work is unpredictable and varies from week to week. One week I may be asked to work, then I may not have anything for a month. I cannot say how much I could earn in any one week. It could be £300 one week, then nothing for a month.

I've seen benefits advisors, disability employment advisors, and told them of my dilemma. They have all said to me that the system is not flexible enough to allow me to do what I want, and that the law has to change before I can do that. I've been told about the New Deal scheme, Access to Work scheme and tax credits - I have heaps of leaflets about them. They are all very difficult to understand, but I think that none of them help in my case. I have been told that I could be in trouble for what I am doing now, that is, turning down pay, in order to stay on benefit. I feel very frustrated.

Does anyone see what I meant by going round in circles?

I've been told to set up as a charity or as a company, and claim expenses, but not a wage. This is a dodge that some disabled people use, but I am not happy to do it. I want to be honest and open about what I do, and not worry about getting caught. I am not particularly unusual in this conflict. I know very many other disabled people who could work freelance like me but who have the same problems. It is particularly difficult for disabled artists. I would like to be able to earn perhaps £2,000 a year without coming off benefits. If my work developed in future and I earned more, I would then come off benefits. I can only just now manage on my money. I was told by a benefits advisor that if I needed something like a new washing machine, I could get an emergency payment from social security. It seems crazy when I could earn that money for myself.

Many people do not realise the hidden costs of living with a disability. Just things like the cost of specialist transport or buying equipment which seems very expensive because it is sold to a relatively small market. Do you know what it costs to replace wheelchair batteries, tyres and an annual service? At least as much as it costs to do the same to your car! Then there is the insurance of your wheelchair. My NHS wheelchair is covered for repairs by the NHS, but then I have to insure it for third party and theft. With my private electric chair I have

to insure for all risks. I have less choice when shopping, because many shops are still not wheelchair accessible, so my choice is limited, often to the more pricey shops. Another hidden cost is the cost of keeping warm. I have cerebral palsy, which gets considerably worse when I am cold, and as I do not move a lot I quickly get very cold feet. There is no automatic heating allowance for people with disabilities until the temperature falls below freezing. I estimate that my heating bill is double what it would be if I was not disabled. I could go on about hidden costs, and that is not what this paper is about, but it is all part of the bigger picture.

Why employ a person with a disability?

I have said why I want to work. Now I would like to consider this from the employer's point of view. Why would anyone want to employ, either permanently or just for one day, a person with a disability? There are many good reasons why it is in the best interests of an employer to use disabled employees. One reason, which I disagree with most strongly, is that it makes the employer look good in the competitive world. If it makes the employer look good, well then that is just a bonus for him. The real benefits are far more far reaching than such a cynical and exploitative one.

The benefits in employing disabled people as far as I can see are, firstly, that they are extremely motivated to succeed and prove themselves, and so will perform far better than their non-disabled counterpart. I have seen this in many disabled employees. They get to work early, put in extra time unpaid and are loyal and supportive to their employer. I feel that to try to prove themselves equal to non disabled employees, they feel they have to be not just equal but better. If employed in a business which has disabled clients, the disabled employee will have more empathy and understanding than the best intentioned able-bodied worker.

Many employers would find physical barriers to taking on disabled staff, and here the Access to Work scheme can help. Access to Work can pay for such things as making a building accessible, and any reasonable adjustments to the work place. It can pay for the cost of personal assistants, sign language interpreters, special equipment such as adapted computer equipment or communication aids. Access to Work, as far as I understand, will not pay for communication aids to help a person find work. But all these financial incentives should encourage employers to take on people with disabilities.

Why is it then that with all these incentives more disabled people are not in work? Is there any point raising disabled children's expectations about getting a job, putting them through an increasingly inclusive education system, and then letting them face the reality of being jobless when they are adults. I get the impression that many employers still think 'disabled' always means the same as 'sick', and that if they take on a disabled person, then he will always be absent through illness. Employers whom I have met have told me that their disabled employees are a genuine asset to the firm.

Is there a typical 'disabled person'?

I believe that within the group labelled as 'disabled people' there are as many or more variations and differences as

between the non-disabled and disabled category. There is no such thing as a typical disabled person. What suits one does not necessarily suit another. It is most important that all people with disabilities do not feel under pressure to get work. For some it will not be right, and that is fine for them. For those who choose and want to work, then the barriers that I have told you about should not be allowed to prevent them getting work. But what should and does happen are two different things.

.....
What should and does happen are two
different things...
.....

In my case, I have not been able to break through yet and get into employment and off benefits. I feel very frustrated. Let me tell you about a good friend of mine, also with cerebral palsy, who has always worked for her living, has never been on benefits, and at the age of 40 has risen as high in her job as she could go without changing jobs. She then went through the examinations and tests to work for MI5 (government security services) in London, got the job, but had to refuse it in the end because there was no accessible affordable housing in the area. A very different case from mine, but how very sad for my friend, and also for MI5!

Conclusion

Yet again, while I have been writing this paper, the phone has rung with the offer of work leadin dance workshops with a group of severely disabled people, one hour drive away, one day a week for a year. The job is paid, but I had to say that I would do it for my expenses only.

I really feel as if I am just going round in circles still. If I took the fee offered, it would be less than my benefits, but I would have to come off them and then re-apply next year. The red tape and paperwork involved would then give me a full time job for another year.

I know that the social security system is designed to prevent fraud and abuse. In my case, it is keeping me in my place. I have heard that in some other countries it is not like that. Perhaps I need to move to Denmark to do what I want...

I'd love to hear from anyone with any suggestions to keep me in Britain, because at present the system is not enabling me to go forward with my life.

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EASIAIDS

Advertisement

Combining Literacy and Communication for Pupils who use AAC

by Debi Taylor and Jeanne Eames

This paper was presented at the CM2002 National Symposium, Lancaster University, September 2002

The Futcher School in Portsmouth is a day special school designated for children with physical difficulties and long term medical conditions with associated learning difficulties. There have been increasing numbers of pupils with communication needs in recent years. The Communication department supports nearly half the school's population of seventy-four. Fifteen pupils have their own VOCAs and many more take advantage of using the school's devices during language support sessions. The difficulties many of the non-speaking pupils have in acquiring literacy have been a concern for all the staff for some time; those working in the Communication department had identified specific problems and developed some strategies for improving practice. There was no consistent, structured programme, however, and although many of the strategies were proving successful, no formal evaluation of the work had been carried out. It was decided to try to provide a structure which, it was hoped, would give these pupils opportunities to learn to read, and which would also support their communication skills.

The initial difficulties were perceived to be that:

- children who had acknowledged learning difficulties were being asked to learn two different sets of vocabulary, one for reading and one for communicating
- non-speaking pupils often had little understanding of phonics and were unable to use them for word building in reading or spelling
- combining locations, symbols and signs to make meaningful phrases and sentences needed a great deal of practice before becoming spontaneous
- the pupils with severe expressive language difficulties had little understanding of grammar and, therefore, found it very difficult to construct sentences
- all the children found using question words very difficult and rarely asked questions in any context
- teachers working with the pupils did not have a literacy structure which offered coherence and continuity, which linked to the P. Levels, and would support those children for whom the National Literacy Strategy was not appropriate, at least initially

The most important element of the work was seen to be that communication and literacy must develop together.

All the work that had already been done by the department to support literacy for pupils who use AAC was collated and a literature search completed to identify current research into the first high frequency vocabulary for speaking and reading and the early development of sounds. The key elements that were necessary to make the scheme comprehensive and functional were discussed and eventually the format was decided on and the structure completed.

The key elements were seen to be:

- key words for reading and communicating
- phrases in which the key words were combined meaningfully.
- Key phonics, which could be identified at the start and end of words and would eventually be used to build whole words for reading and spelling
- books and other resources, which were age appropriate, about situations and events the pupils could identify with, and which used the key words in communication contexts
- identified communication contexts and skills at each level of work
- practical activities, which would be fun to do and which would give pupils opportunities to practise skills in different contexts.
- assessment methods
- success criteria

The structure was found to fall quite naturally into eight stages, and in view of the steps, stages and levels already associated with various educational systems, it was decided to call the scheme 'The Language and Literacy Ladder', and each stage called a 'Rung'.

Rung 1

The first words of Rung 1 were identified as 'more' and 'no'. Both are in the first five words most frequently spoken by infants and, in the opinion of the Communication Team, offer the most powerful communication opportunities. They can also be combined meaningfully. The other key words in Rung 1, 'Mummy', 'me', 'my', 'here', 'hello', 'help', 'home', 'your' and 'not', were chosen using the same criteria. It was important when identifying the phonics for each Rung to choose sounds which linked to the key words, which matched the developmental model of sound production and, essentially for those children working on oromotor skills and sound production, looked different when spoken. Eight of the eleven first words started with 'm' or 'h' and these sounds fitted all the other criteria, so the decision was easily made.

The activities that were suggested for the Rung involved reading the words in books, combining them to construct simple phrases and, most importantly, using them to communicate in everyday situations in the classroom. Thus, the children were expected to read 'more' and 'no more' in their reading books and to use 'more' and 'no more' to direct an adult at meal times and to choose whether to stop or to continue with an activity.

Grammar

It was decided that communication clarity was more important than grammatical accuracy and children would be encouraged

to combine words in whatever ways seemed appropriate to them without being corrected, if the phrase made some sense. For example, "No Mummy here" while not grammatically correct, certainly conveys a message. The need to learn grammatical rules and the skills required to construct grammatically correct sentences could not be ignored, however. There was also a problem concerning the position of vocabulary on the dynamic screen devices that most of the pupils were using. Many of the children could only manage eight or ten buttons on a page and quickly needed more than one page as their vocabulary needs grew. Previously, the school had trialed the concept of using literacy pages for older pupils, in which words were sorted by part of speech and children were expected to read a word, recognise which part of speech it was and then search for it on the appropriate page. This had worked well, much to the amazement of many of the staff whose own grammar skills were hardly up to the task! It was recognised, however, that the younger and less able pupils would find this very difficult at first and a system of colour coding was suggested. The children would learn to recognise words by their colour and eventually go on to learn the correct grammatical name. Initially, therefore, pupils would refer to nouns as 'red' words but eventually would learn that red words were in fact called nouns. The colours chosen linked to those suggested by ICAN.

Punctuation

It was thought that the pupils would not need to be introduced to the concept of punctuation until the later Rungs, but as many of them were using VOCAs to read with, punctuation was needed to make the sentences sound sensible. This was an unforeseen bonus because the children could actually hear the difference a question mark or comma made, and punctuation made sense to them!

Assessment and success criteria

Most of the work involved in the scheme would be carried out by class teachers or support staff, and it was decided to make clear what skills would be expected of a child who had finished that Rung and how to recognise those skills. It was hoped that this would ensure a level of consistency to the assessments.

Resources

It was immediately obvious that the standard reading schemes were not going to be able to provide appropriate resources for all the Rungs, particularly the lower ones. The Communication team all had to become authors, and the lists of 'things to do' always ended with 'write another five books'! Writing and illustrating a story that made sense, that was exciting and meaningful to children, and which contained only two words, was more challenging than was realised at first, and the vocabulary of the some of the team became very basic indeed. Games for word and sound recognition, pictures to write captions for, piles of words and letters for each Rung, laminated and velcroed, also had to be produced. The task was enormous and still is not finished. It was possible, however, to introduce some books from other reading schemes when the vocabulary matched. Ginn 360 proved particularly valuable in this respect and specific stories could be written for books, such as Stage 1 of the Oxford Reading Tree, which were

purely picture books. Material which was age appropriate for older pupils also had to be considered. The books and other resources that have been made have proved very popular with the children, however, and many have used their 'more' communication to ask for the same story again and again.

Continuity and progression

Clearly it was important that each Rung built on the skills developed in the previous ones, and great care was taken to ensure that there was an appropriate hierarchy throughout the scheme. There was also a need, however, to show where the scheme was leading, and the upper Rungs of the scheme have been developed to blend into the lower levels of the National Literacy Strategy. A pupil reaching the end of Rung 8, therefore, would be able to:

- combine words and phrases to communicate appropriately in a range of contexts
- able to communicate using all of the first hundred, high frequency words
- able to read and spell the first hundred, high frequency words
- able to use phonics for reading and spelling
- show some understanding of correct sentence construction
- able to use colour coded pages to find vocabulary and show some understanding of nouns and verbs
- able to use software, such as Clicker, to record work

It was also recognised that some of the pupils would be in the Secondary phase of the school by the time they had reached Rung 8, and that literacy linked to a life skills curriculum would be more appropriate. Extensions to the scheme were therefore developed, which linked to ASDAN qualifications and the City and Guilds Certificate in AAC competence.

Training

Training in supporting pupils who use AAC has been a first focus for staff training for some years, and has resulted in all professionals - teaching, support staff and other disciplines - being very aware of the needs of non-speaking pupils. This made it much easier to introduce the scheme. An in-service training day was used to introduce the Language and Literacy Ladder to the whole school, and further sessions were given to individual teachers and members of the support staff who would be working with children starting on the scheme. Training will, of course, be on-going and it is hoped to begin workshops for parents during the course of the next academic year.

Evaluation so far

The Language and Literacy Ladder has been in place for less than six months and evaluation is still at the early stages. It is possible to make some claims, however. There are children working successfully on Rung 1 who would not be able to start a conventional reading scheme. All the children are using the words they have learnt during literacy to communicate in other contexts. The resources which have been developed are functional and popular with the pupils. They have been fun but very time consuming to make. There are never enough. A further evaluation will be completed after the scheme has run for a year to assess its effectiveness.

*Debi Taylor & Jeane Eames
The Futcher School, Drayton Lane, Portsmouth PO 1HG*

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
Tel: +1 416 385-0351 Fax: +1 416 385-0352
Email: secretariat@isaac-online.org
Website: www.isaac-online.org

Need funding in 2003 for an AAC project or event?

Apply for a Communication Matters Small Grants Award

Closing date 1 May 2003

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.

Closing Date

The applications will be reviewed by the Small Grants Committee and by an external reviewer, and the decision of the Committee will be ratified by all the Trustees.

Please ensure that we receive your fully completed application before the closing date of 1 May 2003. Applicants will be informed of the result in June 2003.

For an application form, please contact
Communications Matters:

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



Trustees News

from Janet Scott, CM Chair

After each year's CM Symposium in September there always seems to be a little bit of a lull before things pick up again for another year. The Trustees met in November to really get going with the plans for 2002-2003, as well as to think about longer-term activities. It was good to meet so many of you at the CM2002 National Symposium - to catch up with old friends and to make new ones. Thank you for your feedback - we really do value it and use your comments to try and improve things for future years. Hopefully many of you will be able to attend CM2003 - put the dates in your diary now: 14-16 September 2003, with a Study Day on 17 September 2003.

This is a positive and exciting time for Communication Matters:

- The web site is a useful and immediate form of communication (remember to check it regularly!) with opportunity for discussions on the various Bulletin Boards, links to other useful websites and advance notice of CASC Roadshows and other AAC related events. A new link to the FAST website from CM's home page should make it easier to find out about current AAC research projects. Why not add your project (no matter how small) to this database?
- The Small Grants scheme carries on, and this year again we have up to £5,000 to give away to deserving projects. To get a copy of the application form all you have to do is contact the CM information line on 0845 456 8211 (our new local rate number) or admin@communicationmatters.org.uk. The deadline for applications is 1 May 2003.
- The Award scheme for people using AAC is being overhauled and revamped...let me know if you want to get involved in these discussions.
- CASC, which is the suppliers sub-group of Communication Matters, are to investigate possible alternative venues for even bigger CM conferences in the future.
- The membership (i.e. you) will be consulted about proposed changes to the Constitution which aim to make CM more transparent and more in line with current practices and ways of working. We need your input and ideas on this, so please don't ignore the draft amendments to the Constitution when they are sent to you.

And finally, thank you all for your support and willingness to participate and be involved in Communication Matters activities. Without your input there would be no CM as we know it now. Reading all the background material while redrafting the Constitution has made me realise how far we have come in really a very short time. Much of this is obviously down to the direction set by the previous and current Boards of Trustees and Chairs, to our administrator, Patrick Poon, and to the hard work of Sally Millar, the Journal Editor, and to the links with CASC...but a lot of our success is down to you - the 'ordinary' members of CM. Let's build on this together to "widen our sphere of influence" (Pam Enderby, 2002), to banish the "villain" (Keith Parks, 2002) and let other people know about the importance of communication in all its forms.

Update on ISAAC

by Janet Scott

Following on from the article on *Joining Communication Matters and ISAAC* in the last issue, I thought you might be interested to read some more background information.

Communication Matters was established in 1985 as the UK Chapter of ISAAC. Communication Matters is run by an elected group of Trustees. There are 14 other national/regional Chapters: Australia, Canada, Denmark, Finland, French speaking countries, German speaking countries, Ireland, Israel, Italy, Netherlands-Flanders, Norway, Spain, Sweden and the USA. ISAAC Chapters are groups of members who address the ISAAC mission 'to promote the best possible communication for people with complex communication needs' within their country or region.

ISAAC, our parent organisation with its Secretariat in Canada, has an Executive Committee and a Board of Directors. What do they do? The ISAAC Executive Committee (EC) is the body responsible for carrying out the policy and planning on an ongoing basis as directed by the ISAAC Board of Directors.

Members of the EC are elected for a minimum two-year term by the ISAAC Board of Directors and are responsible to the Board. The officers of the EC must come from a minimum of three countries and must reflect the multi-cultural, transdisciplinary nature of ISAAC.

The ISAAC Board consists of elected Directors, plus the EC and the editors of ISAAC's official publications (*Augmentative and Alternative Communication* and the *ISAAC Bulletin*). The responsibilities of the Board include establishing the policy and direction of ISAAC (including Bylaw amendments), approving the biennial operating budget, electing the officers of the EC, and establishing Standing and Task Force Committees. The Board meets biennially in conjunction with the ISAAC Conference.

The International AAC Family

So what does this mean for us in the UK? Basically it means that we are all part of a big international AAC family. For those of us who have been lucky enough to attend one of the international conferences this is something that we have been able to benefit from. However, the majority of ISAAC/Communication Matters members in the UK do not have the opportunity to travel abroad to attend a conference. What do you get from being part of an international organisation? The international speakers we have had at recent conferences (e.g. Mats Granlund from Sweden, Gail van Tatenhove, Carol Goossens' and Linda Burkhardt from the USA, Hilary Johnston, Karen Bloomberg, Susan Balandin and Marnie Cameron from Australia) have all presented at the CM National Symposiums as a direct result of us being part of an international organisation. The Communication Matters Trustees would like to build on this and increase the international dimension to your CM membership – perhaps by inviting articles from overseas for this journal, organising joint activities (e.g. a conference/workshop) with neighbouring Chapters, etc. If you can think of any other ideas we'd be very happy to hear from you!



Being part of a bigger organisation obviously also has its responsibilities. Currently US\$25 of your individual membership fee to Communication Matters goes as a membership fee to ISAAC (there is a sliding scale for different categories of membership). Traditionally people from the UK have played a prominent role in the governance of ISAAC. Prue Fuller was the ISAAC President between 1998-2000 and Janet Larcher was Chair of the Board of Directors between 1998-2002. Anthony Robertson (2000-2004) and Katie Price (2002-2004) are currently on the EC. As Chair of CM, I am a Board member – and Pat Thomas has now joined me as the other representative from the UK. Also, Janice Murray takes over as Editor of the ISAAC Bulletin in January 2003.

Be Involved in your AAC Community

At this year's Board meeting several issues were discussed that need further work. *You could influence what happens with ISAAC over the next few years!*

Fee Structure: For the first time this year the fees we pay to ISAAC were to have been set by the Board rather than by the EC. However, the Board rejected the proposal put forward and there is to be a working party looking at the fee structure. If you have any ideas, concerns, suggestions or questions about this, please contact me.

Facilitated Communication: In some countries the terms FC and AAC are used synonymously: FC=AAC and vice versa. Sometimes AAC is discarded once FC is introduced. Some members of the Board wondered whether ISAAC should have a 'view' on FC, or produce a position paper on this topic. There is to be a working party looking at the need for this - and again, if you have views on this matter please contact me and I will forward them to the working group.

Awards and Fellowships: ISAAC has various awards it gives to people who have made an outstanding contribution to the world of AAC. Do you know of anyone who deserves to be recognised in this way?

And Finally...

Something to think about for the future: would you be interested in serving on the ISAAC EC or Board? Let me know.

Don't forget to start saving now for the next ISAAC biennial conference in Natal, Brazil (4-10 October 2004). The conference venue looks spectacular (so does the beach!), and everywhere (including the beach) is reported to be fully accessible. In 2006 the conference will be nearer - in Germany.

Further Information

For more information about CM or ISAAC, please contact:

- *Janet Scott*, Chair of Communication Matters, SCTCI, WESTMARC, Southern General Hospital, 1345 Govan Road, Glasgow G51 4TF Tel: 0141 201 2619 Fax: 0141 201 2618 Email: sctci@sgh.scot.nhs.uk
- *Anthony Robertson* (Executive Committee member with special responsibility for people who use AAC) Email: independent.expressions@btinternet.com
- *Katie Price* (EC member) Email: k.price@ich.ucl.ac.uk
- *ISAAC website:* www.isaac-online.org

News from CASC

Communication Aid Suppliers Consortium

by Dave Morgan

New Chair of CASC

You may be wondering why this column is being written by me and not by Simon Churchill. The simple reason is that at CM2002 in September, Simon reminded us that he had completed four years as the Chair of CASC (and the appointment was in theory for three years!). Simon decided he wanted to make way for 'new blood', so an election was held in November with the result that I was elected as the new Chair.

The first thing I would like to do is to thank Simon for all his hard work over the past four years. During that time, CASC has grown dramatically, has produced a Code of Practice for members, has continued to provide excellent CASC Road Shows (with much assistance from Patrick Poon), and has continued to be the voice of the supplier network in discussions with various bodies, including the government.

So, where to from here? The first thing is to say that the CASC Road Shows must continue, as must all negotiations and lobbying for better funding and support for the AAC industry. We must also continue the excellent working relationships with Communication Matters. However, it is always good to look at how we do things from time to time, and to consider whether we can do them better. Equally, it is wise to consider whether there are other things we could be doing which, at the moment, we are not. This does not mean the 'new broom' syndrome. Rather we need to identify what the major objectives are over the next three years for CASC. To this end, I will be producing two questionnaires over the next few weeks: one for CASC members and the other for AAC professionals, people who use AAC and family members. This will provide us with a view, both from within CASC and from outside, about what we are getting right and what we are not. If nothing needs changing, then why try and fix something that isn't broke? However, if we can identify areas for change or improvement, then let's try and achieve what is needed.

I look forward to the next three years in office and to working with many of you personally.

CASC Road Shows

CASC has held five Road Shows in the last three months of 2002, including three Road Shows for CAP contacts held in conjunction with ACE Centre Oxford and ACE Centre North, as well Road Shows at Rookwood Hospital in Cardiff and at the Institute of Child Health in London (hosted by the Wolfson Centre) where over 100 delegates attended. There are already a number of CASC Road Shows scheduled for 2003 - these are listed on the next page. More are planned for the second half of the year - watch this space and the CM website!

Further details and the latest news on the Road Shows are available at www.communicationmatters.org.uk. To book a place please email admin@communicationmatters.org.uk, or tel/fax 0845 456 8211.



Diary Dates

8-10 January 2003 Special Needs Fringe, Kensington Olympia Hotel Cost: FREE Contact: Inclusive Technology 01457 819790	London	7 March 2003 Play Through Technology Cost: £100+VAT Contact: ACE Centre-North 0161 627 1358	ACE Centre-North, Oldham
15 January 2003 Special Access to Computers (Mac & PC) Cost: £60 Contact: CALL Centre 0131 651 6236	CALL Centre, Edinburgh	12 March 2003 As Easy As AAC Cost: £100+VAT Contact: ACE Centre-North 0161 627 1358	ACE Centre-North, Oldham
from 23 January 2003 Communication Disability (module of 8 half-day sessions) Cost: £250+VAT Contact: ACE Centre-North 0161 627 1358	ACE Centre-North, Oldham	12 March 2003 Computers and Dyslexia (Mac & PC) Cost: £60 Contact: CALL Centre 0131 651 6236	CALL Centre, Edinburgh
24 January 2003 CASC Road Show at Redbrook Hotel, Shrewsbury Cost: FREE Contact: Com. Matters 0845 456 8211	Shrewsbury	17 April 2003 CASC Road Show at Holly Bank School Cost: FREE Contact: Com. Matters 0845 456 8211	Mirfield, W. Yorks
28 January 2003 Making Personal Passports (Mac & PC) Cost: £60 Contact: CALL Centre 0131 651 6236	CALL Centre, Edinburgh	29 April - 1 May 2003 (Provisional) ICT/SEN Update 2003 (Mac & PC) Contact: CALL Centre 0131 651 6236	Dundee, Edinburgh, Dumfries
31 January 2003 How to Decide on an AAC System Cost: £100+VAT Contact: ACE Centre-North 0161 627 1358	ACE Centre-North, Oldham	12-13 May 2003 Picture Exchange Communication System (PECS) Contact: CALL Centre 0131 651 6236	CALL Centre, Edinburgh
6 February 2003 Making Symbol Materials (Mac & PC) Cost: £60 Contact: CALL Centre 0131 651 6236	CALL Centre, Edinburgh	20 May 2003 CASC Road Show at Wycombe Hospital, Bucks Cost: FREE Contact: Com. Matters 0845 456 8211	Wycombe, Bucks
10-14 February 2003 CASC Road Show in Ireland Cost: FREE Contact: Com. Matters 0845 456 8211	Galway, Tralee, Limerick, Dublin, Belfast	25 June 2003 CASC Road Show at Sunfield School, Stourbridge Cost: £6.75 Contact: Com. Matters 0845 456 8211	Stourbridge
12 February 2003 Switched-On 2 Cost: £100+VAT Contact: ACE Centre-North 0161 627 1358	ACE Centre-North, Oldham	30 June 2003 CASC Road Show at The Futcher School Cost: FREE Contact: Com. Matters 0845 456 8211	Portsmouth
27 February 2003 CASC Road Show at Meldreth Manor School Cost: FREE Contact: Com. Matters 0845 456 8211	Meldreth, Herts	14-16 & 17 September 2003 CM2003 National Symposium (14-16th) & Study Day (17th) Contact: Communication Matters 0845 456 8211	Lancaster



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

For more information please contact:
1-Voice
PO Box 559, Halifax HX1 2XL
Tel: 0845 3307861
Email: info@1voice.info
www.1voice.info

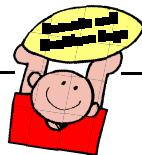
1-Voice UK Internet Support Group



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@yahooroups.com



Parents and Enablers Page

by Terry Gibson

CM2002, Communication Matters' Annual National Symposium, was the wonderful experience that I thought it would be and I'm so glad that I made it this year. It was good to meet friends from *I-Voice* and everyone else, share meals and go to workshops together. I can't put all my feelings about it in a nutshell and I hope this article reveals something of what I got out of it.

On Sunday evening I spoke with Dawn Seals and her family. I told her how much I had enjoyed her presentation at the *I-Voice* weekend last November and that I wished I had some video of her to show at my son's school. Dawn said she would like some video of herself and that she would love to come to Michael's school and talk to the children. Her mum offered to drive her up any time if I can arrange it. I've given the BECTa and *I-Voice* videos, Amanda Creely's presentation and other information to Michael's head teacher and she is showing it all to the other teachers before we get together about it.

I went to the following workshop sessions:

- *Personal Communication Passports for People who use AAC* by Sally Millar
- *Combining Literacy and Communication for People who use AAC* by Debi Taylor
- *Symbol Charts: Are we making it up as we go along?* by Katie Price
- *Dynamic Screen Vocabularies: Which, when, why, how?* by Janet Larcher
- *My Experience as an AAC Role-Model* by Amanda Creely
- *I-Voice Internet Support Group*

Personal Communication Passports

The Passports session was a godsend. Sally Millar taught us how to distil all of the most important information about a person, providing a most comprehensive introduction to him/her, written in the first person and presented in a pocket organiser or small booklet. The Passport, which is intended to be a collaborative effort between all of the key people in the persons daily life, opens up the whole world of its owner to any reader in a minute. I've made Michael a first draft as an example and took it into school with the CALL Centre information pack so the teachers can have a look at it before we discuss it formally. I really felt that I had come home with something special and that I could start to work on straight away.

Combining Literacy and Communication

We may have been a lot further on in all areas had we used such a structured approach to combining literacy and communication skills from the beginning. My son, Michael, is 13 now and we have missed the early stages of being able to include communication skills and semantics with his reading and phonics. I've ordered Debi Taylor's Language and Literacy Laddder training pack (see page 14) so that I can work with

Michael - and know when to give him his Rung-8 Certificate! Michael's English teacher does make every endeavour to include use of Michael's DeltaTalker in class.

She has a set of laminated and Velcroed labels for all the words from the three Wellington Square books that she is using this year, last year and next, hanging in clear pockets on the wall next to a big board with Velcro strips where the labels can be used in word sentence building. Labels for the letters of the alphabet and phonemes are Velcroed down each side of the board. The Makaton symbol for each word, where available, is included on the label. The teacher asked me recently for some spare copies of Michael's dictionary pages to cut up, so that she can add the Delta Talker symbols for each word to the labels. Michael knows where all of these words are in his talker and is happy to read aloud and sentence build.

Symbol Charts

Katie Price gave us lots of guidelines to designing symbol charts, and pointed out that they should promote child-child interaction and active participation in relationships. Michael is very dramatically expressive and sociable. His way of liking someone's coat or top is to charm it off the persons back for him to try on and be photographed doing it. He loves to zap our guests with static electric shocks - a special relationship he has with our settees - and enjoys reading about how electricity is made. He likes to feel a baby's heartbeat and see the colour of its eyes. He signs 'two', 'ten', 'where', 'bye-bye' and points at his own clothes and eyes to ask further questions and enquire about siblings/others not present. He uses the options pages on his PlayStation games to discuss particular weapons and levels of the game. He will scroll down the list of titles on the cheat disc and point to the one he wants to buy/rent/get back from someone he has loaned it to. He has no trouble using the uppercase onscreen keyboard on the cheat disc to type in the lowercase titles from the game covers. (Unfortunately this was not retrieving cheats from another folder but overwriting existing titles. Big brother put us right on this one.) He knows if we have time for a scooter ride to the swings before a favourite TV programme and he never misses Robot Wars. He's got lots of robots names and weapons in his Talker. He remembers these and his school words easily. Michael is quite happy for me to practise saying full sentences on his Talker but until a couple of weeks ago has shown no inclination to do so himself. In many instances, picking up his Talker would actually hinder his expression. The moment for action would pass.



Michael Gibson

Although I have made picture dictionary pages of all the words Michael's teachers have given me, they are only lists of words and do not enable real communication between him and his teachers, most of whom have only known him for a year. My task now is to find the most useful phrases he needs in each class and for general communication, and make some symbol charts for quick access. We could use photos and short video clips of his signs and gestures and interpret them with his range of meanings on a symbol chart and a computer. Several video files can be displayed on one PowerPoint slide and played by clicking on them.

Dynamic Screen Vocabularies

Janet Larcher gave us a comprehensive look at dynamic screen vocabularies, at all the software, symbol sets and vocabularies currently in use; their suitability for clients according to age, needs and abilities; how to progress through levels and how to use test sentences when comparing one system with another. I wouldn't like to choose a communication system from such a wide range without much further study, but I love the facility of a grid system that can be dynamically navigated to provide easy access to any of its contents. I'd like Michael to have his own laptop and a hand-held computer. (The screen on our laptop died in July). I just don't know whether to introduce him to another communication system when he is just getting to grips with Minspeak/LLL, or whether we should just start off with a blank grid system to use for our own symbol charts and photo gallery at first while we learn more.

As Janet says, young adults like quick access to whole sentences and Michael certainly enjoyed having real photographs with messages on the ChatPC we borrowed from Liberator earlier this year. He has an extensive library of photos and video on our home computer of family and home activities, the weekly school trips, days out with all the groups we are involved with, people's coats Michael is a keen photographer and can download and save the pictures himself. His life could be in his pocket.

It was heartening to find out that there are only three basic methods of language representation - Single meaning pictures, Alphabet-based systems and Semantic compaction. I brought home a leaflet from www.aacinstitute.org which said that many people who rely on AAC choose to use multiple methods to communicate. Logged data of the most effective communicators indicates that they use semantic compaction for 90-95% of everything they say, the remaining 5-10% being split between spelling and word prediction. They use pre-stored utterances for less than 2% of communication. Knowing this has given me a greater appreciation of the power of Minspeak. I do feel though that Michael is still young enough to find value in pre-stored messages and not expert enough at using his VOCA to do without them.

Semantic compaction is based on hieroglyphics. A relatively small number of symbols (up to 128), each with multiple meanings, are used. It is the sequence in which the symbols are selected that defines which utterance is to be generated. Thousands of individual words and phrases can accessed from one page with (typically) two hits. It served the Egyptians well enough.

I was delighted to see that Tony Jones from Liberator is creating a software version of Minspeak/LLL.

I missed Judy Robertson's workshop on Dynamic Minspeak. Michael already uses a 128 icon overlay but I wanted to know if I could apply the Minspeak Application Programme, Stepping Stones, rationale in reverse order if I ever need to create smaller pages for him.

My Experience as an AAC Role-Model

I was so moved to tears during Amanda Creely's presentation (see page 9) that I couldn't ask any questions when she finished. The sheer effort that Amanda has to make to operate her VOCA must inspire anyone with similar difficulties to believe that they could access a VOCA themselves. Speaking from her own experience with AAC, Amanda said lots of things that she feels children new to AAC need to know, and that she would have liked to hear when she was just starting out herself. I did say hello and thanks to Amanda, and she kindly gave me some printouts of her speech.

1-Voice Internet Support Group

We really enjoyed our two weekends at Norbreck Castle and the Family Fun Day at Hothorpe Hall with 1-Voice. Michael is the only person who uses AAC we know at home and it was so good to be with others. Tamsin Crothers gave me some of copies of the 1-Voice video and I've sent one into school and one to Michael's surgeon, Steve Wall, along with Amanda's speech. I finally gained access to the 1-Voice Internet Support group late in September but was unable to post a message. I will try again soon.

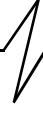
And More...

I had a chat with Alan Martin and he loaned me his video and his article 'Mouse on the Move'. His video is on VHS tape and he would like it to be digitised. He would also like to have a web page. Our common interest prompted me to do a Front Page tutorial, ask Jeeves how to transfer VHS to PC and try without much success to re-film his video from my TV with my web cam. I'll be able to do more about it now that I have dealt with some correspondence and completed building a computer at home. I had to do it last week, as it is part of my computer course assignment as well as being something that we needed to do anyway. Alan phoned to say he was going offline himself for a while to sort some problems out with his computer. Back soon, I hope.

I downloaded a copy of the Telenet Project Report from the ACE Centre's website. I would very much like to have some experience of video-conferencing and remote access to software. If Michael was to take a laptop or hand-held computer to school and he or the teachers ran into difficulties, or we just wanted to discuss something quickly, this would be the ideal solution. We may even be lucky enough to take part in some future project.

I have contacted many people whose sessions I missed to ask for information on their workshops and spoken to some CASC members, who have offered demonstrations and loan of equipment. I've sent Mr Wall some information on the BECTa CAP

continued on next page 23...



Review

CM2002 Communication Matters National Symposium

by Kate Williams

As a first time delegate, speaker and family member to the annual Communication Matters National Symposium, I was feeling a little apprehensive about what to expect, yet at the same time excited about attending the event. We arrived on Sunday and were greeted by the team from *Communicate* (the AAC Centre in Newcastle). They told us where we were staying and gave us our conference welcome packs. We were staying in the university halls of residence, which were fairly basic, but adequate.

At 4pm the conference opened with an inspiring session called 'Storytracks of AAC' delivered by Keith Park. He was full of energy and enthusiasm, and really gave the conference a good start. Having read all about the Trustees of Communication Matters, the AGM was a good opportunity for me to finally put faces to names. All first-time delegates were then invited to have a free glass of wine or two and the opportunity to have a look around the trade exhibition. The trade exhibition was smaller than I had expected but still packed with lots of variety.

Later that evening we had a buffet dinner and then got into teams for the pub quiz. Our team was appropriately called 'Not a brain cell between us'. Dave Morgan was the quiz master and his team from DynaVox at Sunrise Medical Ltd put our brains to the test. I've still not managed to work out where he dreams up his questions! Having the pub quiz on the first night was great because it gave you an opportunity to get to know people.

In the morning we all joined together again for a very passionate speech from Professor Pam Enderby. Her speech was entitled 'Sometimes it Works', and it highlighted some of the random variables surrounding AAC provision and support. For the rest of the conference we had the choice of which session we wanted to attend. There was a wide variety of sessions to suit a wide variety of interests. Personally I found it hard to choose which to go to, because many of the sessions I wanted to attend clashed. However, all of the sessions that I attended were delivered in an informative yet friendly manner, and I feel I gained a lot from them all.

Monday evening started with an enjoyable dinner and a fantastic pudding, followed by entertainment from a local band, Striding Edge. This was an opportunity to let your hair down have a dance, a drink and a good chat. Most people had a really good time and many partied into the night.

The morning after the night before started with a choice of six, two-hour long sessions. I chose 'Dynamic Screen Vocabularies' by Janet Larcher. It was a great opportunity to see a person I had heard so much about. Later there was a further opportunity to look around the trade exhibition or to drop into the CyberCafé.

Then came a session that I had been waiting for. It was the Communication Matters Distinguished AAC User Award

Presentation. Karl Parrish, the winner, delivered a speech called 'The Secret life of an AAC User'. This was of particular interest to me because I have a family member who uses an AAC device. Karl's speech was excellent, filled with humour, and I thoroughly enjoyed it. The winners of the CM Achievement Awards were also announced and I was sad to hear that this year may be the last year of these awards.

After lunch there were further sessions, then a plenary session which was an update on the Communication Aids Project (CAP) in England. Because I'm from Scotland, where CAP does not apply, this became a very interesting session for me looking at the way England is going about funding communication aids and other specialist equipment.

To sum up, the Communication Matters Symposium for me was excellent. There was lots to see and do, and I would highly recommend it to anyone who has an interest in AAC.

*Kate Williams, speech and language therapy assistant
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Parents and Enablers...continued from page 22

project and passed on Mark Saville's invitation for him to get in touch with the ACE Centre.

A couple of weeks ago Michael dearly wanted to visit one of his classmates at home. We must try a speakerphone again soon. He was keen to learn how to say "Whats your phone number?" "Where do you live?" "Can I come to your house and take some pictures of your coats?" "It won't take long. Just a short visit." "I like your blue coat. Can I try it on?" "My phone number is..." "Will you call me?"

I wrote a letter in icons so Michael could talk to his friend. She gave him her phone number and we visited her last week. She modelled seven coats for him and let him try on his favourite blue one. I took some photos and we have photographed Michael in many coats this week. The need to get results has finally motivated him to use phrases and full sentences on his Talker. This is quite a leap in progress for us. We're going to buy a few metres of Velcro and make some labels to play with.

As predicted we spent a chunk of our savings on computer parts and gatherings, but we just can't lose. Thanks to a good cash injection from family and friends we made it to Rome and Pompeii!

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Interactive Storytelling and AAC with People with High Support Needs

by Alice Gallimore, Marie Savill and Keith Park

This paper was presented at the CM2002 National Symposium, Lancaster University, September 2002

Introduction

Interactive Storytelling is based upon three principles: firstly that apprehension precedes comprehension; secondly, that affect and engagement are central to responses to literature; and thirdly that recital and performance are valid means of experiencing of stories, drama and poetry.

The story material that we have been using with children and adults in Lewisham and Greenwich is varied: Red Riding Hood and Shakespeare's Macbeth; Goldilocks and Oliver Twist; Jack and The Beanstalk and My Fair Lady. We have also been using a wide selection of poetry, from T.S.Eliot and Seamus Heaney to Beowulf and the book of Genesis from the King James Bible of 1623.

Emphasis is put upon the intrinsically aesthetic or sensory quality of storytelling. Nicola Grove (1998) argues that: "Considering literature as an art form suggests that it can be experienced at a physical level, just like a painting, a piece of music, a film or dance. In the context of a curriculum which consistently emphasises the exercise of cognition over feeling and imagination, to speak of the physicality of text strikes a radical note. Yet...the appeal of a poem or a story lies in its ability to excite the audience in a way which is first and foremost sensory." (Grove, 1998). What follows are some examples of storytelling activities that include AAC users.

Use of voice output communication aids within interactive storytelling

The value of voice output communication aids (VOCAs) to support clients to make choices or requests (e.g. "I want crisps") has long been acknowledged and is indeed a common practice in most establishments. In our experience there are also many examples of switches being used to support clients to understand how they can cause change in their environment (e.g. to turn on a fan).

The challenge for practitioners in education and adult services is to provide opportunities for people to use their VOCAs to fulfil the most basic function of having a voice. Moreover that people will consistently listen to this voice and respond accordingly. Once this sentiment is shared and understood by everyone involved, VOCAs are more likely to be successfully implemented in a range of settings.

Interactive storytelling groups can be a powerful showcase for VOCAs, as they provide an excellent forum for competent AAC users. Furthermore they offer a supportive context for staff and clients for whom AAC is a novel concept. The groups achieve this by being organised so that they run over a set

number of weeks with the same staff, clients and storytelling material. This ensures that staff have numerous opportunities to learn how to record messages, how to operate the switch to play the message, how best to support their client to play the message, and the type of feedback the client needs following the message.

The following information is a breakdown of the ways in which we have used VOCAs in our groups.

Single message VOCAs (e.g. BIGMacks)

These enable approximately twenty seconds of sound to be recorded and replayed at the press of a switch to fulfil the following functions:

1. To play a word/phrase or sound effect that complements the story but is separate to its progression...

'My Fair Lady' was adapted for a group of adults in Lewisham, the second episode of which lends itself to this type of VOCA use:

Episode 2 – The Entertainment

"I'm off to Catford to tell stories
Cor Guv we'll have a smashing time!
(Name) is quite a talker
OOH wot a corker
So get me to Catford on time"

"Cor Blimey" was recorded onto the VOCAs as a tribute to the cockney theme running through the musical and also because it is part of the local culture. It was voiced many times without disrupting the flow of the story.

This type of VOCA use is key in teaching clients about cause and effect (i.e. 'if I press the switch I hear a voice').

2. To initiate each episode in the story...

'A Midsummer Night's Dream' was adapted with AAC users in mind, for example in the first episode, Titania's snoring can initiate the first exchange, and if repeated can contribute to the comic effect of the activity:

Titania (11, ii)

Zzzzzzzzzzzzzzzzz.....
What thou seest when thou dost wake,
Do it for thy true-love take:
When thou wakest, it is thy dear:
Wake when some vile thing is near.
Eee-Eee-Eee- orr!!
I pray thee, gentle mortal, sing again
Eee orr!! Eee orr!! Eee Orr!!

Helping clients to initiate the story can alter the power balance considerably and give them the opportunity to control others!

3. To voice the final line of the episode...

'Orpheus and Eurydice' was adapted for adults with complex needs by Penny Fenn Clark, (physiotherapist for adults with learning disabilities in Lewisham). The material supports AAC users who are developing skills in time dependent switching:

Act 2, Scene 2 – The Realms of the Blessed Departed

"Oh! What joy and peace and light!
Heavenly beauty, pure and bright!
Blessed spirits bow to greet me.
Will my Eurydice meet me?
In this afterward of bliss
All I want to know is this –
Tell me shadows, where is she?
Where is my Eurydice?
Is she here? Don't make me guess!
She is here? Oh Yes, OH YES!!!"

The client can be encouraged to voice the final line through their VOCA as Eurydice (aka another group member) emerges from under a glittery blanket!

Multiple message voice output communication aids (e.g. Step by Step, Sequencer)

These enable you to play a series of messages in the order that you recorded them. They are invaluable to AAC users as they empower them in the following ways:

1. To lead a whole episode...

The VOCAs can be used with any storytelling episode adapted into call and response format. The switch is pressed and the rest of the group echo the line back, the switch is then pressed again. The process is repeated until the whole episode is completed.

An example from Oliver Twist used at Charlton School with a mixed ability class.

"The Artful Dodger was:

Snub-nosed, *snub-nosed*
Flat-browned, *flat-browned*
Common-faced, *common faced*
Bow legs, *bow-legs*
Sharp eyes, *sharp eyes*
Man's coat, *man's coat*
Cuffs back, *cuffs back*
Artful Dodger?, *Artful Dodger?*
E's a geezer!"

The experience of leading the group using a VOCA was observed to be very powerful for class members who were non-verbal. Faces lit up as pupils realised that both their more verbal peers and all the adults in the room were waiting and responding to them. The power balance was shifted! This idea of leading the story was also used with a ten year old boy who is registered blind. When given the opportunity to lead the first verse of the Jabberwocky poem in assembly he pressed the VOCA twice for the first two lines then paused, smiled and giggled as the hall was silent waiting for him to continue. He then continued with the rest of the poem with a broad smile on his face. He was in control!

2. To introduce all the members of the group...

Each group member's name can be recorded onto the VOCA in turn. As the client shouts out the names of the

clients using their VOCA the named person can be supported, for example, to stand up or raise their hands in the air for an added visual effect. This has been used effectively with a group including people with visual impairment to introduce who was in the room before the storytelling began.

Supporting people with high support needs to access the story

Storytelling has been used with groups of students with mixed ability or groups where all the students have a diagnosis of profound and multiple learning disability and some may have additional sensory impairments. The forum of storytelling allows the people leading the group to tailor the session so all students are given opportunities to access the story in a way felt to be meaningful to them. A variety of strategies have been used with different stories and different pupils. These include:

1. *Use of vibration:* Various drums, gongs, resonance board (or the stage at the Globe Theatre!)
2. *Use of props:* These can be big, such as a large purple flag used in Hark the Herald Angels Sing. They can also be individual such as a prop used for each of the episodes on Oliver Twist. For example, a particular hat for the Artful Dodger or a row of hankies for the verse about Fagin.
3. *Use of signs:* Signing in white gloves with a dark T-shirt.
4. *Positioning of group members:* The positioning of all students and helper needs to be considered so all can see, hear, be comfortable and can access a VOCA.
5. *Movement and Stillness:* This can represent changes in the story. For example, in A Christmas Carol, Mr Fezziwig's party can be done in a circle dance, or a Mexican wave can be done to welcome the raven in The Raven.

To illustrate the use of some of the above strategies, let's take the case study of Nicole, a 12 year old girl with striking good looks. She has a medical diagnosis of profound and multiple learning disabilities, epilepsy and dual sensory impairment. For the Midsummer Night's Dream story we used a variety of strategies to ensure Nicole was able to access the story. We placed Nicole in the centre of our group and we all sat in a circle around her. We took her out of her wheelchair and lay her on a resonance board. This was one of Nicole's preferred positions and also enabled her to feel the vibration of the beat of the story as the leader tapped the edge of the board with our feet. We noticed that after several weeks Nicole would move herself so her head was directly by the foot of person tapping on the board. We also used a glittery blanket, a known favourite of Nicole's, in the episode on Pyramus and Thisbe. We covered Nicole at the end of this episode with the blanket. Nicole responded with vocalisations and smiles. In a different episode (Oberon's speech that releases Titania from the magic spell) we used a parachute. Again Nicole enjoyed being under the parachute smiling, vocalising and appearing to look.

As a staff group working with Nicole, people felt that she was both accessing and, most importantly, enjoying the storytelling experience. When we went to the Globe she was able to take centre stage and lay on the stage with the group around her as the stage acted as a huge resonance board! The process of adapting the story for Nicole involved drawing on staff and her family's knowledge of Nicole and much trial and error. We would brainstorm with the whole staff group at the end of

each session about what we could do differently or keep the same to enable Nicole and her classmates to access the story more fully.

Interactive storytelling for young people with complex needs in transition

In July 2002 four young people with complex needs left the familiar environment of Greenvale School to embark on a new life in adult services. All those involved in the transition recognised the importance of maintaining some familiar elements in a process fraught with change. Their new service aptly named 'New Beginnings' was to start in September 2002 with the opportunity of taster sessions through the summer to give the young people and their new staff team further opportunities to get to know each other.

All of the young adults had expressed enjoyment within school based storytelling groups. With this in mind a weekly Interactive Storytelling group was set up through the summer. This involved the four school leavers and three young people who had left school within the previous three years and who were supported by Nexus's outreach service. The aim is for this group to continue to meet regularly for interactive storytelling sessions once the full service has commenced in September.

As an additional support to this process of change, some storytelling sessions were also arranged to give leavers opportunities to meet up with former school staff and friends but now with the support of their new staff team. This group would take place initially at the Queen's House, Greenwich Maritime Museum for four weeks before moving to the Globe Theatre for a further four weeks.

Enhancing Quality of Life (EQOL)¹ produced a quality of life manual describing a set of indicators that can be used by service providers during periods of transition to monitor and evaluate the quality of services they are providing for people with profound and complex needs.

The quality of life manual (Dee, Byers, Hayhoe and Maudsley, 2002) identified five domains: respect, choice, change, feelings and relationships, as being particularly important during transition. Each domain has a series of associated indicators, an example of an indicator from three of the domains: respect, relationships and change, and how they relate to the storytelling experience in transition are described below:

Respect

People's adult status is respected: Storytelling is a universal activity. It has occurred in all human cultures and societies, and can be enjoyed and appreciated at all sorts of levels. Perhaps because its roots are in community storytelling, stories appeal to people of all ages, from different backgrounds and with all levels of ability. As adults we can enjoy stories through a range of different media such as reading books and going to the theatre. We can enable adults with learning disabilities to access stories in way that is meaningful to them through interactive storytelling.

Relationships

People have opportunities to share experiences with others: Interactive storytelling is set up to facilitate interaction from

peer to peer as well as with staff. The story provides the group with a shared activity in a supportive and friendly atmosphere. The groups take place in a variety of community based settings (e.g. the Globe Theatre) which ensure that the group encounters members of the community on a regular basis.

Change

People have many opportunities to learn about change in safe and supported circumstances: In our transition storytelling groups young adults are able to meet up with old friends and be introduced gently to new people who will be significant in their adult lives. This gives new staff a chance to understand how these young people communicate and participate within the group.

It is clear from the examples discussed that storytelling can provide a useful support at times of transition for people with complex needs. In order to develop this further we would hope that future school leavers in their final year with complex needs will be able to take part in a weekly transition link to an established storytelling group in adult services.

Outcomes

There is an unresolved dilemma about measuring outcomes for aesthetic experiences such as storytelling activities. We may like going to a concert, listening to a piece of music at home, visiting an art gallery and so on, not to gain skills but because we think we may enjoy it. The parents of one child recently asked a school for more storytelling activities because they had observed one of the sessions and seen their child laugh. A laugh, three times out of three on three consecutive occasions, does not sound too convincing as an outcome. The issue remains how - or if - we can realistically measure the outcome of what is not a didactic activity: a story that is performed for its own sake. As a teacher recently said, "Let's write the targets at the end when we know what they have achieved!"

The types of outcome we are still trying to evaluate realistically have included the following: giving participants opportunities to respond; the empowerment of AAC users; learning outcomes for staff; the extent to which multidisciplinary goals can be combined; records of achievement, and parents' views.

As professionals, whilst we have tried using various forms to set targets and predict outcomes we have often felt that they have not reflected the progress made. For example a pupil with a target of hitting a BIGmack to initiate an episode of storytelling had by the end of term not achieved this target but had instead learnt to initiate an episode by vocalising. Photographs and video have been used effectively to show progress of pupils' ability to respond to stories and develop basic communication skills. We have also found that Interactive

¹ Enhancing Quality of Life (EQOL) is a three-year research project managed by Skill: National Bureau for students with Disabilities, and the University of Cambridge faculty of education. The project team sought to investigate the transitions made by young people with profound and complex needs. As a result of their findings they produced a series of publications. (Dee, Byers, Hayhoe and Maudsley, 2002).

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Storytelling can be a forum in which a person use skills that they may not be able to show in other settings. It can therefore be useful to assess a person's communication skills in this setting and to build targets around the transferring of these skills to other settings.

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STORYTELLING RESOURCES

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Foundation for Assistive Technology

The idea behind **FAST** is very simple. FAST's aim is solely to seek to advance assistive technology by bringing together the needs of disabled people for assistive technology and designers, engineers, developers so that future designs are needs based (what users really want).

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Dynamic Minspeak!

by Judy Robertson

This paper was presented at the CM2002 National Symposium, Lancaster University, September 2002

Minspeak™ devices have more recently been developed to include a dynamic display as well as maintaining a fixed set of multi-meaning icons. The Minspeak Application Programme (MAP) *Stepping Stones* has been enhanced by embellished icons, activity rows and dynamic pages. This has allowed for the addition of fringe vocabulary and topic/subject specific vocabulary (both words and phrases) to make sentence construction and communication easier. Core vocabulary is still maintained within Minspeak™ sequences for the speed of accessing vocabulary. However the dynamic display system now allows for a progression from an easily accessible message system through to a complex, sophisticated language.

Many people using Augmentative and Alternative Communication (AAC) find Minspeak™ a fast means of accessing vocabulary to build grammatically complex sentences. Minspeak™ is the method of storing and selecting vocabulary using sequences of multi-meaning icons. The Minspeak Application Programme (MAP) *Stepping Stones* was devised in 1994 on the Intro Talker (the pre-cursor to the Alpha Talker and now, the Springboard™) and then on the Touch Talker and Liberator, as a 32 location programme which combined icons and rationales from the full 128 location MAP *Language, Learning and Living*™. The aim of *Stepping Stones* was to allow a progression from a 32 location device through to the full 128 location MAP Language, *Learning and Living* (LLL)™. The 32 icons were selected from those most frequently used in LLL™ and organised so that they reflected the LLL™ architecture. *Stepping Stones* was designed to be suitable for people who require a simpler system at present for developmental reasons or because they needed assistance with accessing skills, visual acuity or cognition.

Pathway to Stepping Stones was also written where each of the 32 icons had a 'single hit' word or message stored under it reflecting the word category stored in the full *Stepping Stones*.

A Progression of Overlays

However, many people being introduced to high technology AAC have found the 32 location MAP too complex to start with. The Vanguard, Vantage™ and now the Springboard™ software allows for the progression from a 4 location overlay with simple choices, through to 8 and 15 locations before moving onto *Stepping Stones* or *Unity* (another 32 location MAP).

The 4 location overlay (Figure 1) introduces the concept of communication, making choices, initiating and responding to conversations. The new dynamic software allows for pages to be made, to make vocabulary more easily accessible while the concept of Minspeak™ is being taught.

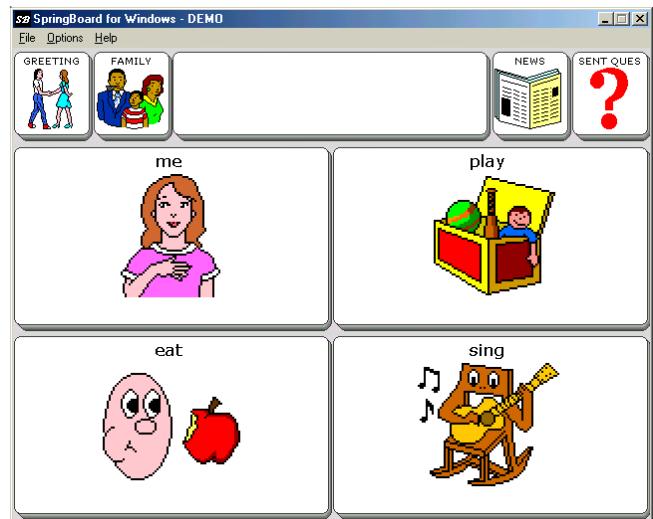


Figure 1 The 4 location Springboard overlay

The 8 location overlay (Figure 2) also allows for basic choice making, initiating and responding to conversations, while further word/activity categories are introduced. Using single words and phrases, the person using the device can build simple sentences via pages. Minspeak™ sequences can then be introduced at 8 and 15 location overlays in readiness for learning a MAP. The eight key locations can be more easily accessed by people with limited physical or visual skills or at the beginning stages of switch access and AAC.

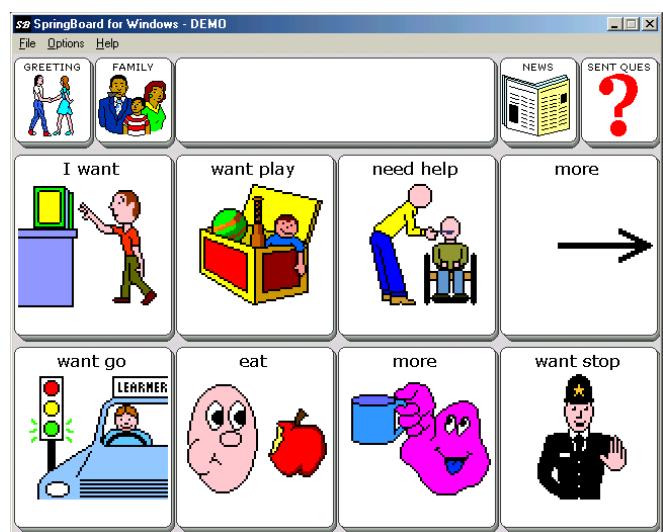


Figure 2 The 8 location Springboard overlay

The 15 location overlay (Figure 3) icons are taken from *Stepping Stones* and again reflect the *Stepping Stones / LLL*™ architecture. The icons when selected then access pages or icon sequences to allow choice making, initiating and re-



Figure 3 The 15 location Springboard overlay

sponding to conversations, information giving and questioning. The vocabulary system provides a core of frequently used words along with special pages of less frequently used words which can be strung together to build sentences.

Pathway to Stepping Stones has now been enhanced for the Springboard™. It combines some of the previous 'single hit' words and messages, with activity rows, a few Minspeak™ sequences and 'single hit' access to pages of topic vocabulary including places, art, body parts, days, weather, people, rooms, food, clothes, drinks, telephoning and shopping. Once a page has been accessed, items of vocabulary can be chosen by single selections before closing the page. This allows for a vast increase in vocabulary from the original 32 words and messages (Figure 4).



Figure 4 The 32 location Springboard overlay

Stepping Stones for the Springboard™ has been designed to incorporate the speed of Minspeak™ with the ability to access topic vocabulary in dynamic pages and activity rows. One of the many changes of *Stepping Stones* on the Springboard™ was to remove the BOTTOM icon, move the top now icons along and put in the EYE icon to allow "I + verb" phrases to be easily accessed. Some of the 'rude words' have been stored under the SUN icon as 'social' vocabulary.



Figure 5 Stepping Stones for the Springboard

Pages

Dynamic pages have been introduced and designed to include phrases and words useful to the topics of eating out, shopping, telephoning, art, games, cooking, food, drinks (Figure 6), phone (Figure 9), about me, jokes, clothes, body, people, etc. Pages allow for the selection of vocabulary within a topic or activity, that can be strung together to build sentences without the need to close the page. The top row of every page is the same providing Minspeak tools, following the LLL architecture.



Figure 6 The Drinks page

Activity Rows

The Activity Row appears on top of the main 32 location MAP. It allows extra tools, vocabulary or page access to be available while using the MAP. Dynamic Activities are activity rows that appear when an icon has been selected in the MAP. Dynamic Activities are linked to the category of vocabulary that has been stored under that icon. Additional high frequency usage verbs and nouns have also been added as Dynamic Activity rows.



Figure 7 Tools Activity row

Keys have been colour coded to assist in recognition of:

- Tools (purple)
- Pages (red)
- Phrases (yellow)
- Verbs (green)
- Adjectives (blue)
- Nouns (white)



Figure 8 Pages Activity row

DAN words (adjectives) have also been restored so that high frequency adjectives (e.g. happy, sad, good, bad, hot, cold) are stored under 2 icon sequences. The NOSMOKE + DAN + icon sequences (i.e. 3 hit) are now alternative or additional adjectives rather than opposite ones as before.

Stepping Stones was originally designed as a key word communication system. Now, *Stepping Stones* for the Springboard™ allows for fully grammatical and complex sentences to be constructed. The aim of *Stepping Stones* has remained the same; to allow a progression from a 32 MAP to the full 128 MAP *Language, Learning and Living*™.

Having become confident with *Stepping Stones* and Minspeak sequences, a person using the Springboard™ then has the option of moving onto *LLL*™ on the Vantage™ with 45 icons or the full 128 MAP, *LLL*™ on the Pathfinder™, where many icon sequences are the same. This can build a person's



Figure 9 The Phone page

confidence with a new device while new sequences, icons, tools and language skills can gradually be introduced.

This combination of Minspeak™ and a dynamic display system allows a progression starting from an easily accessible message system of 4 keys through to a fully complex sophisticated language using 45 or 128 keys.

Judy Robertson

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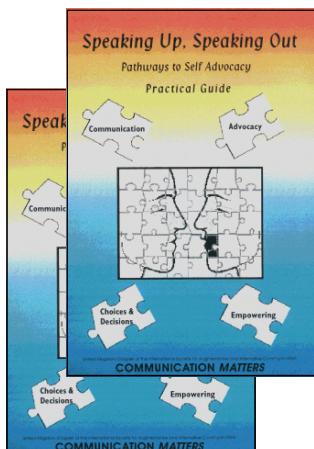
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The collage consists of nine screenshots from the Communication Matters website, arranged in a grid-like pattern. The top row shows the 'Joining' page, the 'Welcome' page, and the 'Journals and Newsletters' page. The bottom row shows the 'CASC Road Shows' page, the 'Communication Matters - BULLETIN BOARD' page, and the 'WHEELCHAIR MOUNTING FORUM - Communication Matters' page. Each screenshot displays different content such as membership forms, news articles, and forum posts.

Essential Publications from Communication Matters



Speaking Up and Speaking Out! Pathways to Self-Advocacy

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Michelle Finds a Voice

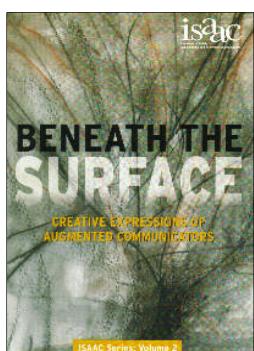
This book is a story about Michelle, a young adult with disabilities who is unable to speak or communicate effectively. A number of events cause her to feel unhappy and isolated until she and her carers are helped to overcome the communication difficulties. Michelle's story is told through pictures alone to allow each reader to make his or her own interpretation, but there is also text at the back of the book to provide one possible narrative for the pictures. The book was created by Sarah Barnett and Sheila Hollins and published by the Royal College of Psychiatrists, with financial support from Communication Matters.

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

Michelle Finds a Voice



Sheila Hollins and Sarah Barnett,
Illustrated by Denise Redmond



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. This book contains 63 paintings, drawings, poetry, stories, plays and essays – many in full-colour – from 51 artists and authors living in 12 countries. Published by ISAAC.

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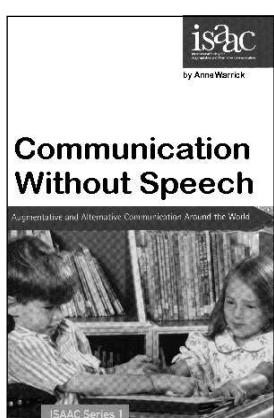
Alternatively Speaking

Published three times a year, this eight page newsletter, from Augmentative Communication Inc. in the USA, contains AAC issues and in-depth reports on topics vital to the AAC community. It is written by Michael Williams who uses AAC and serves on ISAAC's executive committee.

Augmentative Communication News

Published six times a year by Augmentative Communication Inc. in the USA, each issue contains eight pages of in-depth information on particular topics researched and written by Sarah Blackstone.

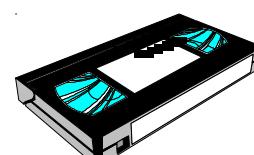
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Communication Without Speech: Augmentative and Alternative Communication Around the World

This ISAAC book, written by Anne Warrick, is a highly accessible but very comprehensive introduction to augmentative and alternative communication. 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.

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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.

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