


COMMUNICATION MATTERS

INTERNATIONAL SOCIETY FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

UK CHAPTER

FEBRUARY 2002 Volume 16 Number 1



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The Communication Matters Journal is the official publication of
Communication Matters / ISAAC-UK, and is an ISAAC affiliated publication

Front Cover: Sam (left) and Ben Miller at the One Voice Weekend in
December 2001 (page 23)

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CM Website: www.communicationmatters.org.uk

Registered Charity No. 327500

Company Registered in England No. 01965474

Printers: Crowes of Norwich

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The Personal Touch

by Mandy Brown and Joan Murphy

In 1995 a brain stem stroke left Mandy Brown with no speech and no useful movements from her neck down. When I first became her speech and language therapist I assumed she was the perfect candidate for a scanning voice output communication aid - she was intelligent, had no language disorder, was literate and was motivated. However, despite my efforts to encourage Mandy to use a Scanning Lightwriter she persistently refused a high tech device for her daily communication preferring to use an alphabet chart which is folded in a small square and stuffed down the side of her wheelchair. I respect Mandy greatly and wanted to know what she really felt about her communication and what was so important to her about her way of communicating. She uses a computer for her written thoughts and with a little bit of initial persuasion wrote this article via a series of E-mails...

"It's been several years since I took my stroke and ever since I could communicate again I have used a low tech aid. To me it is great but don't get me wrong - I still find it frustrating. Some people are better than others. Some put words in your mouth. People have tried to change me to a high-tech aid but they're too slow.

With my chart I know I have somebody's attention. Some people are better than others are but most people pick it up very quick. To others that use a communication aid it probably looks slow and difficult. You would be amazed - when you are out - the friends who want to try. I have a niece aged seven who is starting to be able to spell wee words. Also I have a friend who is dyslexic and she uses it with me. Sometimes it only takes a few letters for people to guess what I'm saying and sometimes I have to spell out the whole sentence or word.

People guessing can be more annoying and frustrating than anything. I know it saves time but if it's wrong not only the person guessing but also myself gets confused and we have to start from the beginning again, so it does not really save time. People should have some consideration and allow for some spelling mistakes. I feel that communication with some persons on a daily or weekly basis allows communication to become easier as each person begins to understand the other's methods of spelling and talking through the board.

Eye contact is important as you are able to see if a person is being honest or not, able to understand you or just saying they do, if they are happy or sad. These things can all be seen in the eyes and also by facial expressions. People say my eyes talk for me, they know when I am getting frustrated or not and what sort of mood swing I may be having. The only thing they can't read in my eyes are the words I am trying to communicate to them. My eyes probably tell too much. Ha, ha, ha.

Facial expressions could probably say more than eyes in some people as there are millions of facial expressions and if you know a person quite well you can read a face like a book without turning a page. Strangers' faces can also be read, maybe not as accurately as people you know but it can clearly be seen if someone is disgusted at the looks of some disabled persons or if they feel sorry for them. We do not need these looks of disgust or pity - we need to be looked at as human beings or just another person doing their shopping, college work, etc., and be treated as an equal.

I can have an argument as well as anybody else and you would be amazed at how and where I use the board. The board



Mandy conversing with a friend holding a letter board

goes everywhere with me, even the loo. I have two boards that I use, a solid board and a compact board that I carry with me when I am out. Due to the layout of the board, communication is a lot easier for myself and others (even strangers) as letters can be picked out easier than by going through the whole alphabet.

Some high tech communication aids can be big and clumsy. They can bring undue attention to one. I therefore think my wee board is small and compact it also fits into my bag if I don't want to draw attention to myself in a public place. I also feel my board gives me the more personal touch with whomever I am communicating, as they have to look at my facial expression and follow my eyes. I definitely feel it has the personal touch. Another definite with my board is that I can express my words in exactly the way I want and it also lets me have control of my conversation."

A final thought: Is there a danger that the technology is getting too clever for us? Clients may feel diminished by the impersonality of technology and therapists may feel overwhelmed by the time and patience and technical skills required to help someone use a high-tech device.

John Locke (1998) describes human language as having two main purposes. The first he calls 'propositional speaking' or the transmission of impersonal facts. The other he calls 'intimate talking' which involves developing and enjoying relationships with others. With 'intimate talking' we reveal personal thoughts, we engage in small talk, we gossip, we create reactions in others - we interact. Intimate talking does not depend on words - it requires pauses, eye contact, knowing looks, raised eyebrows, sneers, innuendoes, shrugs, murmurs of agreement or disagreement, giving and taking hints... All of these are inefficient in terms of transmitting facts but as Locke says, "the inefficiency of talk is a product of its intimacy."

So far, technology has focused on reproducing propositional speaking but as yet cannot provide a substitute for intimate talking. Albert Einstein said, "It has become appallingly obvious that our technology has exceeded our humanity." Was this what Mandy knew all along? It seems to me that by using 'intimate talking' she has succeeded in maintaining and developing her humanity.

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Motor Neurone Disease: AAC and Everyday Conversation

by Joan Murphy and Steven Bloch

This paper was presented at the CM2001 National Symposium, Lancaster University, September 2001

The authors are Speech and Language Therapists working with people with acquired communication disabilities. They both have a particular interest in Motor Neurone Disease (MND) and are currently carrying out separate research projects into the interaction between couples whose communication is affected by MND. The aim of this paper is to tentatively present some of the issues emerging from their studies and to illustrate them with examples from their data.

Introduction

MND is a terminal demyelinating disease affecting upper and lower motor neurones and producing muscular weakness resulting in a characteristic spastic-flaccid dysarthria of speech. Seikel, Wilcox et al, 1990

We believe that there are wider issues relating to the communication difficulties experienced by people with MND than simply the physical problems caused by diminished oral control. We believe that communication difficulties must be seen as a shared problem between the person with MND and his/her communication partner. In addition, a diagnosis of MND may lead to an alteration in the roles and relationships between partners that inevitably affects interaction.

It is acknowledged that Augmentative and Alternative Communication (AAC) can preserve communicative function even in the face of profound motor deterioration (Mathy, Yorkston et al. 2000). However we observe AAC devices failing for many people with MND and wish to challenge the reasons for this. We also believe that AAC must encompass a wider context than simply high or low tech aids. We are concerned that, in our observations so far, communication in its widest sense, including different methods and strategies for both the person diagnosed with MND and his/her partner, is overlooked. Although the importance of the communication partner has been noted it is often only as an *influence* and intervention almost always focuses on the person with MND.

Why everyday conversation?

We are interested in observing the interaction of people in their own homes engaging in everyday conversation with those most familiar to them. No matter how empathetic the practitioner is we would argue that the communication of people in a speech and language therapy clinic differs in quality, quantity and content from that of familiar people in their own living room. Our early observations indicate that the main intervention by Speech and Language Therapists with people with MND is to advise about dysphagia, assess for dysarthria and prescribe a high tech communication aid.

We hope that, by bringing a research perspective that studies in depth what is happening in the interaction of people, we can offer implications of our findings to the therapy situation.

Assumptions

We started our respective research studies with a number of assumptions about the communication of people with MND which we hope will be challenged:

1. Communication of people with MND gets worse with time – it is generally assumed that as the disease progresses, the speech and therefore the communication of people with MND gets worse.

We suggest that for some people, although their speech may deteriorate their communication may become richer and more meaningful.

2. All people with MND are similar in that the disease follows a similar pattern, albeit at a different pace, progressing from communication via speech which becomes gradually less intelligible, to communicating through the use of an AAC system (Doyle and Phillips 2001).

We have not observed this pattern – for some people speech has not altered and few people use AAC systems.

3. MND is hard to cope with and the people we see will be distressed.

People react in different ways and several of the families we are involved with are 'just getting on with their lives' and do not dwell on their illness.

4. AAC systems will help and people with MND will be using the technology that is now available.

A number of the people in our studies have rejected AAC as they feel it detracts from social closeness.

5. Speech and Language Therapists are experts in helping people with MND to communicate.

There appears to be a focus on dysphagia and dysarthria and little work being done on the interaction of people with MND and their partners.

6. People with MND need Speech and Language Therapists. (Yorkston, Strand et al. 1996)

Many of the people in our studies have worked out ways of managing their misunderstandings and have developed their own ways of enriching their communication. The need for appropriate support and advice for communication disability is not disputed. However, the assumption that the Speech & Language Therapist is the expert in managing a couple's communication may need examining.

Literature

Much is already known about the effects of MND upon speech function (see Yorkston et al. 1995 for a useful summary of MND-speech studies). Classic descriptions (Darley, Aronson et al. 1975) as well as contemporary accounts (Klasner, Yorkston et al. 1999) show that differences in voice quality, nasality and pressure consonants are found to be the most



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prominent. Work has also addressed intelligibility of MND speech as well as perceptual parameters (Kent, Kent et al. 1990; Kent, Kent et al. 1992) These latter studies show that an overall decline in intelligibility often arises for different reasons across people with MND. It is also noted that there is considerable dysarthric variability between people with MND (Yorkston, Strand et al. 1993). One of the difficulties with much previous work is that it studies subjects over a relatively short period of time and in highly controlled environments – restricting speech to single words or phrases. Thus, whilst we know from experience that many people do have deteriorating speech function there are few detailed reports of this change over the lifetime of the disease process (Dworkin and Hartman, 1979).

The function of AAC for people with MND has also been addressed. (Beukelman and Yorkston, 1980) stress the need for both capability *and* performance assessment, whilst (Zeitlin, Abrams et al. 1995) attempt to identify those factors which may be relevant to the appropriate prescription of AAC systems. (Mathy, Yorkston et al. 2000) do report on patterns of AAC use by people with MND. They point out that people with initial spinal symptoms tend to use more partner dependent AAC techniques and that familiarity with a communication partner has a distinct influence upon the selection of any augmentative communication method. The predominant model followed by the work presented above views the person with MND (with or without an AAC system) as an individual agent who either succeeds or fails in communication depending on their own (dis)abilities. Given this, we may know how speech deteriorates and what AAC systems are used, but we do not really know how people with MND and their partners are actually interacting at an everyday level.

Whilst an understanding of speech deterioration and AAC use is important, it is the consequences of any change to function which should be of greater significance to clinicians. There is no single psychological experience common to all people with MND (McDonald, 1994). Ways of coping may not necessarily relate to the severity of the symptoms (Hogg et al. 1994), and although technical solutions to physical problems are available, psychological solutions such as preparation for change are of greater importance (Carroll-Thomas, 1995). The reports of people with MND and their partners reveal a wide range of experiences and feelings (Robillard, 1999; Mowat, 2000). They tell us how these individuals experience MND as people and how they view the world around them with a degenerative disease.

Overall, there is a wealth of literature describing speech pathology in MND, and also individual accounts of living with MND. We know that MND is not a standardised experience and that different people cope in different ways. What remains to be reported are detailed descriptions and analysis of the everyday conversations between people with MND and their partners in natural (i.e. non clinical) settings. Many are aware of how time consuming and socially awkward communication can be in the presence of severe dysarthria, but we still need to investigate the effects this has upon interaction and consider *how* couples manage to maintain relationships in the light of significant changes in physical function.

Our Research

There are a number of commonalities in the two research projects. We are both working for one day per week on our

respective studies as well as working as AAC specialists in community rehabilitation settings with adults with acquired communication difficulties. The data for both projects are video recordings of people in their own homes talking about any topic of interest to them. Both studies view communication as a collaborative effort between two or more people and emphasise the importance of close communication partners as joint participants in the research. Both studies are gathering data over several months to observe changes in communication as the disease progresses and plan to extract common themes from their data relating to the interaction of the participants. Finally, both studies are concerned with the ethical implications of this type of research, particularly with the intrusion in people's homes, fatigue and emotional reactions and the importance of informed consent, confidentiality and the right to withdraw from the studies at any time.

The studies also differ in a number of ways. The number of couples participating in each study varies as does the period of study for the two subject groups. The most significant difference regards the data analysis – for the Murphy study, communicative behaviours are coded and analysed to create a picture of common strategies employed. For the Bloch study, Conversation Analysis is used to describe and analyse joint action between couples in depth – exploring themes which demonstrate how the couples manage the consequences of increasing speech impairment. As a result of these differences in methodology it is predicted that the outcomes of each study will be have a different perspective. Murphy's study will report the strategies couples use to overcome speech difficulties and will use these findings to make clinical recommendations for assisting the management of other couples with MND. Bloch's study will concentrate on the minutiae of conversation between couples and will aim to encourage a greater reflection upon clinical decision making regarding the role of AAC and the importance of 'interaction therapy'.

Issues emerging from data

Natural Environment and Conversation: For many people with MND their most important communication is with close family members and friends – especially as the illness progresses and they go out less. It is therefore crucial that speech and language therapists are aware of the difference between communication in the clinic setting and communication in people's own homes where there are all the additional factors such as surroundings and interruptions. An initial look at our data shows that factors such as the topics of conversation, the purpose of interaction, the physical positioning and fatigue level may well be different in people's own homes. We also believe that it is important to understand that there may be crucial differences between the talk that couples engage in at an everyday level (e.g. story telling, reminiscing, daily planning) and the talk that is commonly found at an institutional level (e.g. interview between client and therapist).

One extract from video data shows a couple chatting about buying a new headboard for their bed. While the husband flicks through an Argos catalogue their dog wanders in and makes a series of strange noises, which causes them both to smile at each other and share the joke before resuming the discussion about headboards. From observing the video it is clear that the



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intimate exchange about the dog is the most meaningful part of this interaction. This supports Locke (1998) who defines two main purposes of human language – ‘*propositional speaking*’ or the transmission of impersonal facts and ‘*intimate talking*’ or which involves construction and enjoyment of relationships with others. He argues that “*if co-operative activity is to maximally benefit participants they need to know not just what others choose to tell them but what’s on their minds.*”

Joint Action and Strategies

One of the main issues underlying this research relates to the ways in which everyday conversation actually works between two people. It is important that speech and language therapists understand how each couple manage their own conversation rather than assuming that there is a professional answer which will ‘solve’ the problem. ‘Joint action’ emerges very clearly from all of the data as a method through which couples manage to achieve the ‘business’ of talking. Of particular interest is the way in which joint activity operates around the use of an AAC system. In one extract, a couple (Peter and Mary) are talking about DIY. Peter has severe dysarthria and introduces the word ‘shelf’ into the conversation. However, rather than producing the whole word in this sequence he says one phoneme at a time which Mary then repeats. By taking short turns each they build up the word together until Mary shows she has understood the meaning and is then able to comment upon what he is saying. This joint action is shown to be an agreed system which Peter and Mary have established – and results in a highly effective way of dealing with impaired speech – but without either person ‘owning’ the problem. It is the joint action between Peter and Mary that enable this process to work so well. There is very little attention paid to Peter’s (un)intelligibility in the video – through their joint action – the couple ‘simply’ get on with the activity of talk.

The initial data analysis reveals a wide range of strategies and techniques that couples are employing during conversation. One couple (Collette and Bill) employ a number of strategies throughout their talk. In a particular sequence, Collette is attempting to say the name ‘Gladys’ as part of a conversation about new patents at a day centre. Initially, she says the name, but Bill clearly states he doesn’t understand. Collette then repeats the name more loudly, but Bill still has problems. Collette then uses her LightWriter to produce the word. Bill has ongoing problems despite Collette’s use of her natural speech and the communication aid. Eventually, Collette points to herself and says, “like my mum!” At this point Bill displays his understanding, saying “Oh Gladys.”

This sequence is of interest not only because of the range of strategies they employ, but also because the difficulty is ultimately resolved through Collette’s use of shared knowledge – i.e. the life information they both share as a couple.

Each couple in these studies has their own way of dealing with speech intelligibility problems. It is through the close examination of these strategies that we are beginning to understand how conversations work between them and to make suggestions as to what might be useful when things become difficult.

Change

As well as observing change in speech over months as experienced by some people with MND, the participants involved in our

projects have described significant changes in their speech in the space of one day. They therefore require a range of communication strategies which they can call on from hour to hour.

Another issue emerging from our data is the variance in communication between different partners. Firstly there are striking differences both in intelligibility and content in the communication between the familiar partners and between the person with MND and the researcher. Also there are wide variations between family members. In one family the grand daughter understands her grandmother whereas the husband does not.

For many couples the change in role between them as the illness progresses causes difficulties. One couple described this:

Husband: I always thought I was in control with things like my driving, my ability to do things and I do get very anxious. Either I can’t do something or it doesn’t work out for me and that even has a knock on effect when (my wife) tries to do something for me and although she’s trying her best to do it – she’s not actually doing it wrong – but its not as easy as I would have done it.

Wife: Because there were things that you were doing before and I’m having to - it annoys and frustrates you. It makes you more anxious and irritable.

Husband: But we are learning to cope with it – I mean I don’t think I’m showing as much frustration now

Wife: Well when you get annoyed now, you get it over quicker, where before it just exasperated you totally.

Conclusion

There are six issues we wish to raise at this early stage in our work:

- AAC must be seen as part of a wider package of communication strategies which need to be examined and made available to people
- Partners should be seen as an integral part of communication – not just an influence
- Speech and language therapy intervention needs to address communication within the context of people’s natural environment
- Is it possible that communication between some couples with MND gets more meaningful as speech deteriorates and if so, why?
- For some couples high tech AAC detracts from social closeness
- AAC needs much more examination both as an interactive process and its role in supporting communication. We are only just beginning to consider the role AAC plays in couples with MND and the effects it has upon joint action.

We leave the final word to one of our participants:

“A lot of our communication is not verbal ...it could be important not to let these non verbal communications stop.”

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The CM Achievement Awards 2001

The Communication Matters Achievement Awards are made every year to acknowledge the achievements of people who have recently made a major breakthrough in learning to use a communication system other than speech. Eleven Achievement Awards were made in 2001. Here are the stories of five of the winners (the other six were published in the previous issue).

Ben Robertson

Ben is 16 years old with Angelman's syndrome and attends Watling View School in St Albans. It was when I started working at the school that I had the opportunity to work with Ben and his parents. For many years his parents had consistently approached professionals to help develop Ben's expressive skills. Ben had shown good understanding of language but was increasingly getting frustrated at not being able to communicate his needs and ideas. As he was approaching teenage years one growing concern was his difficulty in communicating his feeling and emotions. His parents spent hours making and developing creative ways of helping Ben to communicate his needs and ideas about events away from his immediate environment. Ben was using video diaries to tell his friends what he has done at the weekend. He would communicate basic choices and answer cued questions in class based activities using the ORAC and a symbol based communication book. But this was not efficient for Ben. Ben was initially so enthusiastic and motivated to use his ORAC that joint efforts from home and school could not keep up with his continual need for increasing number of overlays. He soon became reluctant to use the aid spontaneously for social communication or for structured class based activities. Ben needed a communication aid that would give him access to a wider vocabulary, an aid that would make it possible for him to express his needs and ideas spontaneously, to maintain conversations which were not reliant on flicking through pages or waiting for the overlays to be changed. But Ben had to prove to his local education authority that he had the required understanding to use a more complex communication aid.



I started to gather evidence by observing him in the classroom. One day, Ben pointed to a symbol of a 'breadroll' and immediately we assumed he was hungry and was requesting for a bread roll. He shook his head and then tried to find the symbol for 'physical education'. We still continued to assume that Ben was hungry because he had done exercises in the gym for PE. At which point he took us to the gym and showed us the mat to tell us that he had been rolling on the mat. It was then we all realised that Ben did indeed have excellent semantic knowledge of words and was able to link the symbols i.e. 'bread roll' to indicate rolling on the mat as he did not have a symbol for rolling on the mat. His parents at home frequently related these sorts of frustrating episodes. Based on my observations, I decided to make a new communication book similar to a PECS

book. Vocabulary was organised in categories. His teacher was advised to teach Ben new vocabulary in categories and to follow exercises to link meaning of words. He was encouraged to use a sentence strip to link words together. One of difficulties for children with Angelman's syndrome is maintaining attention. Ben would often find the word he was looking for but he would not be able to retain the word to search for the next word. He therefore, had to rely on his listeners asking lots of 'yes/no' questions and of course making wrong assumptions if he pointed or showed a symbol nearest in meaning to the word he wanted, if it was not there.

Ben very quickly started to link words together and was able to express his emotions in the classroom by selecting appropriate symbols e.g. 'I feel disappointed', 'I feel tired'. Ben was then introduced to a 'MessageMate' with 20 words. He very quickly, within two weeks, moved to one with 40 words. Ben started to communicate using the MessageMate in combination with his Velcro based symbol communication book. Endless hours were spent by his parents and school in maintaining overlays to meet Ben's needs. He continued to tell us and give us plenty of opportunities through frustrated conversations when he would try to flick through his pages to look for a symbol which was closest in meaning to convey his idea. But Ben was persistent. We approached the local Local Education Authority to purchase a dynamic screen communication aid that would be portable and would have a large vocabulary. They wanted more evidence and suggested he went to a school for children with physical difficulties for assessment. We suggested that Ben would benefit from trialing an aid such as the DynaVox. We would prepare video evidence to show that Ben was able to communicate spontaneously in variety of everyday situations at home, school and in varied social activities in the evenings and at the weekends.

Ben was given a DynaVox on trial for 8 weeks. He immediately started to show greater confidence in initiating conversations with both his peers and with adults. He would now use the DynaVox to greet someone instead of coming up close to the person or pushing the person. He was able to develop a more contributing role in social tasks such as when entertaining at home, ask his friends and relations what they would like to drink, and whether they would prefer ice or soda or sugar in their tea/coffee etc. He started to comment and ask questions e.g. "What do you like?", "Look at that", etc. He was able to have a conversation with his mother in the dark from the back of the car to describe his weekend when he had spent two days away from home at the respite care centre. For the first time Ben had the opportunity to communicate without having to rely on an adult to interpret his vocabulary needs. With the success of the DynaVox, we asked if Ben could trial a DynaMyte as it was smaller and easier to carry. His ability to express ideas and needs became more spontaneous.

During the trial, Ben was able to demonstrate his communication skills when he was filmed by an American film crew in variety of situations by spontaneously initiating, asking questions, commenting about past, present and future events, clarifying misunderstandings and also telling his mother and professionals to go away or shut up.

Ben has now got his own DynaMyte, he has been developing into a more and more competent as well as confident communicator who enjoys interacting and communicating with his peers and adults. He is now able to remind his mother for his treats. He continues to use the MessageMate and the DynaMyte to talk on the phone to his grandmother to remind her of his requests for treats or to find out when she is visiting him. He will call his friends from round the corner to see if he could meet up with them. Ben has also shared his communication aid with his friend Luke to show me that Luke could also communicate. Ben and his friend can now be observed making conversations, helping each other and at the same time helping us professionals to listen and learn.

We would like to nominate Ben for an award in recognition of his amazing achievement. We feel that Ben has not only progressed personally with his communication skills but he has helped to shape the future of children at Watling View School in how we listen and help develop their communication needs. We acknowledge that the coming years are very challenging for Ben and for us as he approaches adulthood. I am delighted that his efforts and achievements have been recognised by Communication Matters.

Mayuri Dave

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Luke Gordon

Luke is 16 years old and attends Further Education class at Watling View School in St Albans. I started to work with Luke in 1998 when I commenced work at the school. At the time, Luke was communicating using the ORAC in the classroom and some Makaton signing and natural gestures to communicate his basic needs and ideas. He was beginning to show a lot of frustration when he was not understood. The teacher was finding it difficult to maintain the ORAC and his behaviours were getting difficult. Around the same time, Luke's friend Ben was being introduced to the MessageMate in the classroom and at home. Luke would go over to Ben to help him access the MessageMate. They would share the device regularly at home when they would meet for tea. In school, Luke was given a 40 overlay MessageMate and



soon was using it spontaneously to answer questions, make comments and initiate interactions in various locations at school. There was increase in his use of the device to contribute choices and ideas in conversations with his friends and in class based activities. Luke was beginning to spontaneously share his friend's DynaMyte to supplement his vocabulary when the words he wanted were not available to him on the MessageMate.

We started to video Luke with his friend in school using the DynaMyte and the MessageMate to request items, to initiate and share news with their peers, to negotiate and comment in conversations. Luke took on the role of guiding the staff as to what vocabulary was needed on the DynaMyte by using gestures and pointing to objects. Based on this evidence, Luke was given a DynaMyte of his own and very quickly in school he started to have spontaneous conversations with his friends. Recently he was observed to share humour and to relate his experience of using a communication aid to visitors from the Mainstream school service. He was able to select appropriate vocabulary from various pages. He would from time to time request help from his communication assistant when he was unable to locate a word. However, with minimal guidance, Luke was able to answer the visitors' questions and later share the experience with his peers. On another occasion, Luke was able to direct his teacher to stop talking and to change the activity to one he was more interested in i.e. he wanted to stop reading and use the computer. He will remind his friends and adults what is for lunch and will bring messages to his Speech and Language Therapist and take back messages from various locations around the school.

From all these examples it is evident that Luke is now a confident communicator and will use his new communication skills to help others. I hope you will consider Luke to be a worthy candidate for the award. He has worked hard for himself and has guided the professionals in acquiring a suitable communication device for him. His behaviours and social use of language have become more appropriate as he has been able to contribute in spontaneous conversations. We know that there are many challenges ahead of Luke and hope that he will have continuing success in communicating his needs and ideas as he enters adulthood with an appropriate means of communication.

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Kwaga and Sam

Both Kwaga and Sam have been diagnosed with autistic spectrum disorder at the more severe end of the spectrum. Both have additional learning difficulties. Kwaga and Sam's difficulties impact on all aspects of their lives and have always been amplified by their associated communication and language difficulties.

When I first started to work with Sam in 1999, I found that Sam's main way of expressing himself was a range of vocalisations, screeches and screams which he was using to attract attention to himself and to try and communicate his wants, needs and emotions. He had no spoken language, but had learned to nod his head for yes. Sam had limited access to

continued on page 38...

Auditory Scanning a Large Word List for Communication

by Stephanie Brewster and Neil Gregory

This paper was presented at the CM2001 National Symposium, Lancaster University, September 2001

Introduction

In the spring of 2001 we met a young man (MW) who had been hit on the back of his head with a bottle; six months down the line, he remained in intensive care with his head injury. He was still unable to talk, had very little physical movement, and was prone to severe headaches brought on by using his impaired vision. He had little or no apparent cognitive impairment.

MW was able to mouth words, but his level of intelligibility was very low, particularly for unfamiliar communication partners, and those without the time to decipher a message. As well as doctors and care staff, who needed to discuss care options with him, the police (Scott and Walker 2000) had a need to take a statement from MW. However, even with the most expert of partners (his sister), communication was slow and frustrating. He wanted us to enable him to communicate quickly and clearly, and to begin to control equipment in his environment.

Here we will describe the rationale for the high tech (computer based) Alternative and Augmentative Communication (AAC) system we developed for MW and explore some of the implications arising from it. We will touch on what makes auditory scanning different from visual scanning. We will also discuss how we attempted to get round the problem of MW's limited spelling skills. Factors involved in the choice of vocabulary will also be commented upon. Our work is of relevance to anyone working with clients whose communication needs are extensive but constrained by factors such as visual impairment and access methods restricted to scanning.

The Combination of Difficulties

We immediately instigated a low-tech system of 'manual auditory scanning', using words and phrases spoken to MW from a structured list from which he would choose; MW's family helped him compile categorised lists of phrases and topics, covering most frequently occurring subjects of conversation. In addition, this list gave him access to a spelling option. With an actively participating and knowledgeable partner, many messages were soon being communicated using the low-tech system.

While we were aware that MW struggled to spell out more than the first two letters of most words (this level of literacy was the same as pre-morbidly) MW showed both the desire and the potential to use spelling where possible. He could also read simple text, but assessment indicated that MW would not be willing or able to use his vision.

We needed a system to contain a large set of pre-stored words from which MW would choose, given that spelling alone would be inadequate. Our hope was to give MW a system he would be able to use independently. This would enable him to

compile messages in preparation for the visit of the doctor, family members and others. This is not possible with a low-tech system, because there is no way of storing messages and presenting the correct message at the right time.

Why did we need a novel solution?

If you have ever looked at a typically organised communication array and tried to use it for scanning, you will know that to optimise the scanning, then huge modifications need to be made to the layout of the items, (Treviranus and McFadden 1986). This is because frequently used items are often located at the parts of the screen or keyboard, which are reached late in the scan pattern. Furthermore, time saving patterns such as row-column scanning, are often rendered inappropriate for a visually impaired user because the user will not know all the items within each row. We wanted a system designed specifically for MW's access method of auditory scanning.

Several potential switch sites were fairly readily identified, but clearly direct selection was not an option at this stage.

We gave MW the chance to try several methods of vocabulary organisation: semantic categories (e.g. parts of the body, feelings), grammatical organisation (e.g. by noun, verb), topic-based systems (e.g. family, court case, greetings) and alphabetically arranged items. MW's preference was a method of organisation based mostly on alphabetically organised words. A phrase bank also seemed appropriate although it appeared that the majority of MW's utterances would be novel. This word list would need to be large enough for effective, if basic, communication. Yorkston *et al* (1988) reported that "normal adolescents may use as many as three to five thousand different words in a single day".

The combination of the need for an auditory based system, accessible by scanning, and prestored vocabulary led to believe that only specially designed software would do what MW needed. Since he would not be looking at the screen, a laptop was most convenient, for the Intensive Treatment environment.

Use of a 'Standard' Word List

Three competing aims were identified for MW's system. These were *speed*, *simplicity* and *breadth of vocabulary*. There is generally a trade off between the first two: increased speed results in greater complexity. This is of particular relevance to a person who is not using vision, because of the extra concentration needed to follow the process with no visual display to follow. (We tried this out for ourselves with our colleagues and found it a lot harder to rely on the auditory channel alone).

isaac

Wonderful Communication

Fantasy and Fairytales are the themes of the
ISAAC 2002 International Conference
 to be held in Odense, Denmark 10-15 August 2002

isaac

Once upon a time, there was a group of people - about 10 per cent of the world's population - who had disabilities. About 25 per cent of them were unable to communicate because of the disabilities.

Then the good fairy waved her wand, and suddenly most of them could speak, read and write.

That more and more people can function at a much higher level in their everyday lives despite having severe impairments is really a fairytale come true. And where could it be more relevant to discuss this, and the many possibilities that the future will bring, than in Odense in the heart of Denmark - the hometown of the famous Danish author of fairytales, Hans Christian Andersen.

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It's 'Wonderful Communication' when children with communication impairments now have the opportunity to play and go to school instead of living isolated.

It's 'Wonderful Communication' when youths with communication impairments are able to get an education, and adults can be a part of the work force.

It's 'Wonderful Communication' when the right to influence one's own life via communication becomes a reality.

It isn't only in fairytales that the ugly duckling becomes a beautiful swan.

A greater focus on the needs of users of AAC means that individuals with disabilities will experience very few situations in which they feel disabled.

Then we will no longer talk about "Karen who can't speak" or "Peter who can't write". Because they can, in their own way.

Now that's a real fairytale.

The conference committee looks forward to giving you a warm welcome at ISAAC 2002, which will be held in a modern, accessible centre near the home of H.C. Andersen.

For further information about ISAAC 2002:

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We aimed for a relatively comprehensive word set, which could also take advantage of the speed enhancement afforded by sequencing according to frequency. According to Vanderheiden and Kelso (1987) “a relatively small number of words account for a relatively large portion of the communication”, and we wanted these to be accessed quickly. We used a published corpus of words, which enhanced the process of vocabulary selection significantly (Yorkston *et al* 1989). As our starting point the 1000 most frequently spoken words were put into the system. These words were digitally recorded, since intelligibility and ease on the ear was better than with a synthetic voice speaking the words. This arbitrary figure of 1000 seemed to offer a compromise between speed of access and breadth of vocabulary. It also gave word lists of manageable lengths for auditory scanning.

As a way of organising a word list, ‘frequency only’ is in effect a single level structure in which each item can be scanned through. There is no way of knowing when the desired word will appear other than learning all the lists! However the words most often used are offered early in the sequence.

Alphabetical organisation, on the other hand, enables a multi-level structure, grouping words according to initial letter (and in our system, second letter too). This results in significant time savings.

A combination of these two approaches was therefore used. This provided the benefits of getting at the most frequently used words quickly and alphabetic sequencing provided predictability and time saving associated with ‘levels’.

Figure 1 shows the number of steps that need to be scanned reach the desired word. It illustrates how, for three different words (‘the’, ‘family’ and ‘television’), two methods of organisation result in differing speed of access. For example ‘the’ is a high frequency word which would come first in a list of words organised by frequency. ‘Television’, however, falls 968th, but could be reached in only 15 steps by our method.

Similar savings could be made for ‘family’, needing only 10 items to be listened to. So the majority of the words in the 1000 word sample we provided MW, would be reached more quickly by our combination method.

There are some important points that need to be made about standard word lists:

- Word frequency lists may be drawn from many different sources, such as written or spoken samples. These may not be representative of the linguistic needs of an individual (Yorkston *et al* 1988). For example, the word ‘pain’ is of high importance to MW who frequently needs to draw a nurse’s attention to it. In our word list, ‘pain’ appeared at number 1612, i.e. outside the top 1000. On their own, such lists are not sufficient, (Yorkston *et al* 1989 and Marvin *et al* 1994). We therefore involved many people in compiling lists of additional words specific to MW to be added.
- Two general categories of words appear in frequency based word lists: structure and content words (Yorkston *et al* 1988). These are also known as “core” and “fringe” words. Structure words number about 200 in all and occur very frequently, consisting of pronouns (like “me”, “you”) conjunctions (e.g. “and”, “because”), and many other ‘little’ words. They enable grammatically correct sentences to be created. Content words occur more rarely and form a virtually open-ended class. The use of content words varies more between individuals, and yet is vital for effective communication (Marvin *et al* 1994).

Organisation of the Solution

We were aware of the typically slow speeds associated with scanning and with building up messages word by word. We envisaged MW might use the system to compile messages for later use especially as he was left alone for periods of time. However, we were not certain that the system we came up with would fall within his level of tolerance.

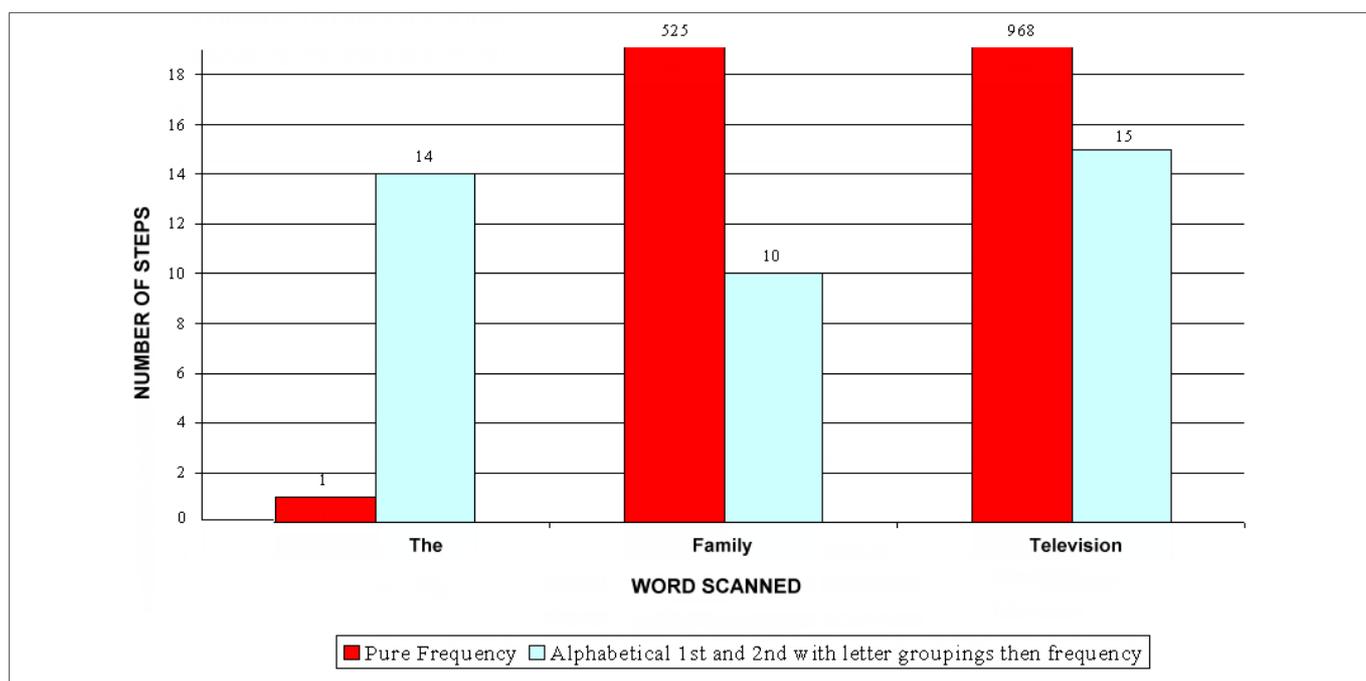


Figure 1 Number of scan steps to reach each of three words

In summary, the system:

- Scanned aloud through the alphabet, until MW pressed his switch to select the first letter of his desired word.
- It would continue to scan for him to choose the second letter.
- Finally it would scan through frequency ordered words beginning with those two letters.

In order to optimise speed we incorporated the following modifications:

- Initial letters were grouped 'ABCDE', 'FGHIJ', 'KLMNO', 'PQRST' and 'UVWXY' (Figure 2). This gave the time saving associated with row column scanning. Once the group in which the first letter was identified, the individual letters would then be scanned for selection (Figure 3). Note that 'Z' was omitted to keep the groups the same size and no Z words appeared in this word list.

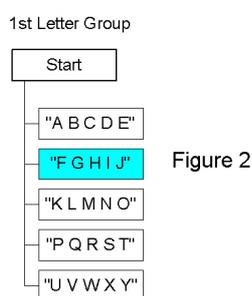


Figure 2

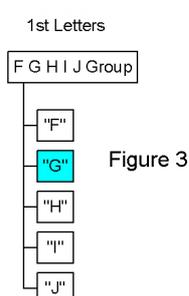


Figure 3

- Only viable second letters were offered; for example, if 'G' was chosen as initial letter, the only second letter options offered were A, E, I, O and R, from the 1000 words (Figure 4). They were presented in groups of up to five starting with the vowels, e.g. 'AEIO', followed by each letter individually.

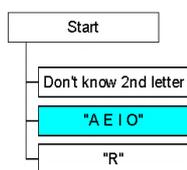


Figure 4

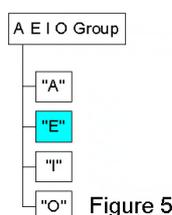


Figure 5



Figure 6

- Once the first two letters were identified (Figure 5), words were then offered in frequency order (Figure 6). The longest of these lists contained over thirty words: there were 33 words beginning with 'th'. (On average just over 6 words per list were presented.) We were unsure whether MW could tolerate scanning through this number of words individually. With short word lists, we would hope for some degree of familiarity to develop, and hence some predictability for MW.
- Phrases were also included separately, previously chosen by MW his family and care staff.
- To begin with we omitted many 'structure' words which did not contain meaning (e.g. the, and); we also left out suffixes (e.g. works and working were omitted leaving only 'work'). We hoped that this strategy would enable MW to get to keywords quickly, from which his listener would then derive meaning. In practice, MW would tend to search for the word he wanted. When it was not available to him, this resulted in time wasting and frustration. Additional training might have helped MW to adopt a more economic and strategic approach to constructing messages.

The Need for Safety Nets

Accidental switch presses or missed switch presses were certain to happen. To minimise the impact of these we included:

- 'Don't know second letter' option.
- 'Word not here' option, displayed with the letters selected so that the listener can interpret the word that is missing (e.g. I am in pa**).
- Second switch to stop the scan cycle and start again.
- A long switch press to speak out the currently chosen built phrase.

Conclusion

MW continues to be frustrated by his difficulties and we have yet to achieve the desired situation of the benefits of high-tech communication outweighing the effort he needs to put in. Much of the problem appears to be associated with the low speed of the access method and its relatively high 'risk' (e.g. if you miss your target item, you have to start that part of the scan cycle again); modifications are still needed. We are aiming for increased independence for MW, both in terms of communication and environmental control and continuing to work with MW, supporting both low and high tech communication methods.

Stephanie Brewster, Chief Speech and Language Therapist

Neil Gregory, Clinical Engineer

Access to Communication and Technology

91 Oak Tree Lane, Selly Oak, Birmingham B29 6JA

Tel. 0121- 27 8235 Fax. 0121 627 8892

APPENDIX

Development solution used: Microsoft Access 97, Microsoft Visual Basic 6 (SP4). Microsoft Windows '98 on a Toshiba 4090 CDS PII400 laptop

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Snapshots of a Trip to India

by Janet Scott

In November 2002 eight members of *Communication Matters* were privileged to be able to attend the first international conference focusing on AAC in the Indian subcontinent. The conference, *Silent Voices: International Conference on Augmentative and Alternative Communication, Disability and Human Rights*, was organised by the Indian Institute of Cerebral Palsy (IICP). It was held in the luxurious setting of the Taj Bengal Hotel in Kolkata, West Bengal.

There were over 300 delegates from 12 countries in total. The majority of delegates were from India, Bangladesh and Sri Lanka, however there were representatives from Australia, Canada, Japan, Poland, South Africa, Sweden, Switzerland the UK and the United States. We met up with a fellow UK delegate, Anna, a student at Glasgow University who had funded herself to attend the conference!



The IICP choir at the opening ceremony

The three-day programme was very full – with plenary and concurrent sessions, a poster session, and an exhibition of current technology and display/sale of materials developed by the IICP.

As well as papers from professionals working in the AAC (speech and language therapy, special education, occupational and physiotherapy, software and hardware developers, researchers and academics), there were presentations from people



Prue Fuller, a past President of ISAAC, lighting the lamp on behalf of the UK delegates

using AAC and from parents. The IICP also launched three films during the conference: *Touching Lives*, *Silent Voices* and *Count Me In* – a film on inclusive education. Before the conference there were two days of instructional courses in aspects of AAC, organised by the IICP.

There was also a large post-conference meeting of people interested in networking and developing concrete ideas for ‘growing’ AAC throughout India and the subcontinent.

From the start the conference was a wonderful experience – full of colour, enthusiasm, music, poetry and life. The conference opened with a lamp lighting ceremony, a welcome song by IICP students and performance by Mallika Sarabhai, a professional dancer, who illustrated a poem written by a young woman who attends the IICP and uses AAC.

Her dance was entirely unrehearsed and was a spontaneous expression of the young woman’s words. This was balanced by a formal presentation by the Minister-in-Charge, Information Technology and Environment of the Government of West Bengal who highlighted the importance of technological advances to support people with disabilities.



A typically busy scene – delegates arriving for a plenary session

What about the conference?

Listening to the presentations I was struck by how much the similarities outweighed the differences in what might be perceived as current practice in the UK and in India. Sudha Kaul presented a survey she had carried out to find out the current status of AAC in India. Forms were sent out to all NGOs working with children with disabilities and to all Speech and Language Therapy training establishments. She received no replies from the SLT training establishments – but identified a Post Graduate Diploma in Special education with 50 hours on AAC. AAC systems in use identified by this survey are:

- Indian manual signs
- Low-tech systems – cue cards, communication boards, etc.
- Computer software
- Some imported high-tech aids and some indigenous high-tech communication aids



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Although there are obvious differences in scale and in resources available, many of the techniques used and the fundamental issues would seem to be the same. The scale of problem in providing a service where demand outstrips supply is obviously far greater in India, but at a basic level the problems are the same. I am sure that we in the West can learn from the successful community based rehabilitation programmes, screening and prioritisation procedures, etc.

- The debate on human rights and inclusion of people with disabilities in mainstream activities created a lot of discussion throughout the conference. The problems in finding meaningful post-school employment/education for people with significant physical/learning difficulties are an issue both in the UK and in the Indian sub-continent. The case for inclusion was clearly represented in the film 'Count me in' made by the IICP which showed some lovely examples of children with disabilities integrated in mainstream schools in Kolkata. However, in contrast, one of the speakers from the west described very movingly the problems encountered by her son in striving for equal rights as an adult in the able bodied world. She highlighted a need to develop a positive sense of identity within the world of people with disabilities. In contrast with western societies, where there is a drive towards independence, Indian society acknowledges interdependence and the belief that we all need each other in different ways:
- Fostering literacy development in non-speaking children is a topical issue in both the UK and in India – although with 723 different language spoken in India the problem must be much greater!
- Just as in the UK, advocacy is seen as an important vehicle for empowering people to have their voices and opinions heard.
- PECS and TEACCH (and adaptations of both systems) are used with children with autism.

Of course, it is impossible to visit India without becoming aware of the sheer *size* of the country (some delegates had travelled for more than two days by train to attend) and by the numbers of people. Of the one billion people now living in India, 90 million have some form of disability.

Sultana Zaman, (the 'mother' of AAC in Bangladesh) introduced AAC in 1991. Since then more than one million children have been introduced to AAC approaches, many through the Distance Training Package and Programme. This package contains printed materials for introducing AAC children and for training them in its use is explained through pictures, illustrations and simple text. A total communication approach is used with low-tech communication boards and Bangladeshi adapted Makaton signs.

I found Dr Zaman's presentation really interesting because as she was speaking I realised that I had heard the other side of this project – at a Communication Matters conference when Nicola Jolleff (Wolfson Centre) talked about her visits to Bangladesh in 1997 and 1998.

My main feeling from the conference is what a lot we have to learn from them, particularly about outreach services and creative use of limited resources. It really brought home to me that money is something but not everything. I was hugely impressed with the standard of poetry and writing and the artistic and aesthetic qualities of the young people's use of language. I am sure all the UK delegates would agree that we have a lot to learn from Indian society and in particular in the way the IICP organise their services for people with disabilities. (Nicola Grove)

Erna Alant, from South Africa, presented two papers both of which I found very thought provoking. She spoke from the perspective of a country where there is almost 34% unemployment, where 15% of the population have some form of disability – 4% have a severe disability – and where 1 in 8 people have HIV or AIDS, disproportionately affecting the economically active age group. The prediction is that there will be 40 million children orphaned to AIDS in developing countries by 2010.

I found this conference an incredibly positive experience. The enthusiasm of the delegates was almost tangible. The poster session was packed with people wanting to discuss each presentation. I wish I was back there again! (Joan Murphy)

Dr Alant highlighted the need to train *sufficient* numbers of people (in fields such as medicine, nursing, education, speech and language therapy etc) to compensate for these trends. She acknowledged that the role of AAC within these overpowering social and health problems is tenuous – but stressed that AAC cannot be put on hold until these problems are resolved. (Dr Mendes, from Sri Lanka, echoes this when she said that 93% of people with disabilities live below the poverty line and that 50% of children with disabilities receive no education.)

Dr Alant also questioned simple acceptance of the use of low-tech in developing countries because it is all that can be afforded and challenged people really to look at how effectively it is being used.



Simon Churchill working hard during the exhibition

Quotes from the Presentations

Mrs Merry Barua who spoke on behalf of the Action for Autism and who herself has a son with autism:

“There are enough kids around for us all to work together and lots left over – let’s not compete with each other.”

Sudha Kaul:

“Central to AAC is a belief in communication. Things like high-tech, funding etc are barriers which we professionals have created. Communication will happen if there are communication partners who are willing to give you time.”

Mallika Sarabhai, dancer:

“There are no silent voices. There are voices we don’t want to hear; there are voices we find difficult to hear; there are voices we are too lazy to hear.”

Those of us who were lucky enough to have been able to attend this conference had plenty of opportunity and time to listen and learn from each other in a very special place.

The Indian Institute for Cerebral Palsy

The IICP was the first non-governmental organisation dedicated to meeting the needs of people with cerebral palsy in eastern India. It was set up in 1974 by two parents who were frustrated at the lack of services for their young children with cerebral palsy. From a small school with two children it now supports over 3,000 families. They have 19 affiliates spread over north-east and other parts of India. It has initiated services

Undoubtedly one of the best AAC conferences I have ever attended, from the packed out pre-conference workshops, to the large post-conference meeting of people interested in networking together to ensure that AAC continues to grow throughout India. All through the conference and at this Sunday meeting, it was really refreshing to see AAC users take a strong lead. The theme of the conference AAC, Disability and Human Rights gave the presentations and posters a real urgency and relevance. There is a custom in Bengal (and especially in Kolkata) of holding ‘Addas’ when people come together just to talk and discuss things they are interested in. This conference was one big Adda! Our hosts somehow managed not only to run a fabulous conference (without the help of an official conference organiser) they also looked after us all with such kindness as if they had nothing else to do in the world! (Prue Fuller)

in all of the 17 districts of West Bengal and has 25 partner organisations. One of these parents was Sudha Kaul who had the vision and the determination to push IICP to where it is now – in purpose built premises providing school, community, residential, family, adult and communication services.

IICP also carries out research and is a nationally accepted training institute providing innovative and high quality training to professionals and parents in both urban and rural settings.

Some of us were able to visit the IICP before the conference started. The dedication of the highly trained staff (many have a PhD, MSc or MPhil – I felt distinctly uneducated!) and the students’ pride at their very real achievements were obvious. We were able to chat with some of the students and see some of the materials used, which included Objects of Reference, Picture Communication Symbols™, Clicker™ with Bengali script in the grids. Children were being taught in Hindi, Bengali and English.

Anne Warrick, author of the ISAAC book ‘Communication Without Speech: AAC Around the World’, sums it up beautifully:

“I have had the privilege to know the excellent AAC programmes and personal expertise and dedication of the IICP staff for so many years. Although I have tried to talk about it I now know that I am no longer a voice in the wilderness! They are a truly remarkable group. I shall never forget the day (many years ago now) that I found out in the military camp on Ballygunge Road (the original school) that children of six years who used AAC could read! And they didn’t know that our Canadian children couldn’t!”

*Janet Scott, Chair of Communication Matters
with contributions from:*

*Tricia & Simon Churchill, Prue Fuller, Caroline Gray,
Juliet Goldbart, Nicola Grove, Joan Murphy*

Photographs by Simon Churchill



Above: Three new outfits!

Left: Sudha Kaul and Joan Murphy sharing a joke

Below: Sue Balandin, President of ISAAC, shows off her new Henna hands



For further information about IICP, contact:

Indian Institute of Cerebral Palsy
35/1 Taratala Road, Kolkata 700 088
West Bengal
India

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COMMUNICATION MATTERS

AAC Study Day

AAC and Aphasia: New Ideas and Creativity

27 June 2002

Birmingham City Hospital

This study day is designed for speech and language therapists working with people with dysphasia.

It aims to provide an overview of current AAC systems and to develop participants' awareness of key clinical intervention issues.

The day will be an opportunity for participants to learn about different AAC options and to hear from specialist clinicians on how these systems can be used. There will also be opportunities to share experiences and discuss real life problems in AAC management.

There will be a session on managing expectations and the (non) acceptance of AAC. This day aims to be practical, stimulating and interactive.

Please note that extensive knowledge or experience of AAC is **not** essential.

Speakers include:

- ◆ Steven Bloch, University of London
- ◆ Joan Murphy, AAC Research Unit, Univ of Stirling
- ◆ Katherine Black, Communication Aids Centre, Frenchay Hospital

Delegate Rate: £75 (only **£65** if paying before 1 June)

For a Registration Form or further information, please contact Communication Matters:

Study Day Helpline: 0870 606 5463 Email: admin@communicationmatters.org.uk



Trustees News

from Janet Scott, CM Chair

By the time you read this it will be spring and hopefully the storms and bugs of January will be over. It's time to be thinking about this year's CM National Symposium at Lancaster University on 15-17 September...

- Why not submit a paper about something you're doing? For a copy of the Guidelines for Submission or for further information, please ring 0870 606 5463.
- We will be looking for new Trustees again, could you be a Trustee?
- What about the User awards? Could someone you know be eligible for an Achievement Award ... or might they want to apply for the Distinguished User Award?

Make sure that you have the dates in your diary, and try to come along (15-17 September). Last year, 93% of those of you who completed the membership survey at the CM2001 conference stated that what you liked most about being a member of *Communication Matters* was the opportunity to meet other people involved in AAC. The annual conference is the main place for meeting like-minded people.

Also, this year *Communication Matters* has organised an exciting Study Day on *AAC and Aphasia: New Ideas and Creativity* on 27 June at Birmingham City Hospital (see page 19 for more details). The speakers will be Joan Murphy, Katherine Black and Stephen Bloch. Thanks are due to Julie Atkinson and Helen Whittle for their help in finding a suitable venue for this Study Day.

Why not think about attending the international ISAAC conference too? This year it is in Denmark on 10-15 August. The international conference is a superb way to make contact with people from different countries and cultures who all have an interest in AAC – maybe I'm still in the post-India doldrums! Of course, the conferences are about providing you with opportunities to hear about current research, to learn from practitioners and people who use AAC, to see new communication aids and other AAC products – as well as being a good social occasion!

The membership survey also gave the Trustees useful feedback about what you'd like to see happening in terms of developing training and information packs, of extending the use of the CM web site. There were more ideas than we could cope with in one year – but we're working on it. It's worthwhile checking out the web site on a regular basis – it's full of useful information that is added to on a regular basis. Why not join in one of the discussion forums as well?

This year we have also been reviewing the Constitution with the aim of making it more 'user friendly' and more in line with what is currently happening in *Communication Matters* in the 21st century. As part of that exercise we are developing an Equal Opportunities policy – and hope to be able to share these with you at the AGM in September.

Have a good Spring!

The Communication Aids Project

Are you in contact with pupils who would benefit from using technology to support their spoken or written communication? If so, the Communication Aids Project (CAP) may be able to help. Funded by the DfES, this project is seeking to help pupils who have communication difficulties by providing technology to help them access the curriculum and interact with others, and to support their transition to post-school provision.

This project is designed to help pupils who have difficulty in understanding language, communicating verbally, developing reading skills and developing recording skills. The CAP Project only applies in England.

Who can apply?

The Communication Aids Project will run over two years and involves £10 million. It is intended to augment LEA and school funding by providing *additional* equipment and technology for pupils who have significant communication difficulties. LEAs and schools will still have obligations to identify and meet individual needs but where a pupil's communication needs have been identified, CAP funding can be provided to cover extra resources and the training needed in how to use them.

Funding covers assessment of the pupil's needs, provision of hardware and software, training for teaching staff, the pupil and his or her parents, and ongoing review. What's more, resources funded by this project are provided on long-term loan: the pupil can use them both at home and school and take equipment with them when they move from, say, primary school to secondary. CAP provides funding for assessment, equipment (hardware, software and peripherals) and training. The LEA, school or another agency provides or negotiates funding for technical support, maintenance of equipment and insurance.

How do I apply?

This project is managed by the BECTa. The project applies only to pupils of school age in England who have significant communication difficulties. Applications to the Communication Aids Project should be made to BECTa, who will arrange for pupils to be assessed in conjunction with one of six CAP Centres in England.

To find out more about the project and the application process, visit www.becta.org.uk/cap, ring 024 7641 6994 or write to The CAP Administrator, BECTa, Milburn Hill Road, Science Park, Coventry CV4 7JJ.

News from CASC

Communication Aid Suppliers Consortium

CASC Road Shows

The CASC Road Shows will be visiting these exciting venues in 2002: Bristol, Leamington Spa, Wirral, Cheadle (Cheshire), Portsmouth and London - please refer to page 22 for dates. Other venues planned for this year include Newcastle, Birmingham and the Irish Republic.

Further details and the latest news on the Road Shows are available at www.communicationmatters.org.uk.



Need funding for an AAC user event or project?

Hurry and apply for a Communication Matters Small Grants Award

Closing date 1st May 2002

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 AAC User event, or travel expenses to get to one. In order to provide this type of funding, *Communication Matters* would expect the recipient to write an article for *Communication Matters Journal*, and for *Communication Matters* to be acknowledged in any literature you produce. If you are organising an event, especially one involving children, please consider and tell us about any insurance cover that may be needed and any legal responsibilities you might have (e.g. with regard to the Children's Act).
- The costs of publishing an information leaflet. In order to provide this type of funding, we would require *Communication Matters* to be acknowledged in any publications that are produced.
- The costs of a social research project. In order to provide this type of funding, *Communication Matters* would require a report at the end of the project (and six-monthly updates for longer projects) as well as a presentation at the *Communication Matters National Symposium*. We would require *Communication Matters* to be acknowledged in any publications that are produced.

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 1st May. Applicants will be informed of the result by 30th June.

For an application form, please contact *Communications Matters*:

Tel & Fax: 0870 606 5463
admin@communicationmatters.org.uk





Diary Dates

- 17 April 2002 ACE Centre-North, Oldham
ACE Centre-North Information Day
 Contact Tel: 0161 627 1358
- 24 April 2002 Derby
International Conference on Assistive Technology (ICAT)
 Contact: BCS Disability Group 01245 242 950
- 24 April 2002 Inverness
ICT / SEN Update 2002 (Inverness)
 Cost: FREE Contact: CALL Centre 0131 651 6236
- 25 April 2002 Jordanhill, Glasgow
ICT / SEN Update 2002 (Glasgow)
 Cost: FREE Contact: CALL Centre 0131 651 6236
- 26 April 2002 CALL Centre, Edinburgh
ICT / SEN Update 2002 (Edinburgh)
 Cost: FREE Contact: CALL Centre 0131 651 6236
- 13-14 May 2002 CALL Centre, Edinburgh
PECS Course
 Contact CALL Centre: 0131 651 6236
- 14 May 2002 Leamington Spa
CASC Road Show at Manor Hall, Leamington Spa 
 Cost: FREE Contact: Com. Matters 0870 606 5463
- 14 May 2002 ACE Centre-North, Oldham
Framework Software to Create Age-Appropriate Activities
 Contact: ACE Centre-North 0161 627 1358
- 15 May 2002 CALL Centre, Edinburgh
PECS Follow-up Course
 Contact CALL Centre: 0131 651 6236
- 17 May 2002 ACE Centre-North, Oldham
How to Decide on an AAC System
 Contact: ACE Centre-North 0161 627 1358
- 29 May 2002 Cheadle, Cheshire
CASC Road Show at BGWS Conference Centre 
 Cost: FREE Contact: Com. Matters 0870 606 5463
- 5-6 June 2002 Wirral
CASC Road Show at Foxfield School, Wirral 
 Cost: FREE Contact: Com. Matters 0870 606 5463
- 12 June 2002 ACE Centre-North, Oldham
Switched On 1
 Contact: ACE Centre-North 0161 627 1358
- 13 June 2002 Conference CALL Centre, Edinburgh
Introducing and Using Speech Recognition in Schools
 Cost: FREE Contact CALL Centre: 0131 651 6236
- 21 June 2002 ACE Centre-North, Oldham
As Easy as AAC
 Contact: ACE Centre-North 0161 627 1358
- 24 June 2002 Portsmouth
CASC Road Show at Futcher School, Portsmouth 
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- 27 June 2002 Study Day Birmingham
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- July 2002 Minnesota, USA
Seminar on Literacy and AAC
 Email: dkoppenh@gac.edu (David Koppenhaver)
- 9 July 2002 ACE Centre-North, Oldham
Choices Through Technology
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- 12 July 2002 ACE Centre-North, Oldham
Switched On 2
 Contact: ACE Centre-North 0161 627 1358
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ISAAC 2002 International Conference, Denmark
 For further information: www.isaac2002.dk
- 16-17 August 2002 Odense, Denmark
ISAAC Research Symposium
 For further information: www.isaac2002.dk
- 15-17 September 2002 Lancaster
CM2002 National Symposium 
 Contact: Communication Matters 0870 606 5463
- 30 September 2002 ACE Centre-North, Oldham
How to Decide on an AAC System
 Contact: ACE Centre-North 0161 627 1358
- 2 October 2002 ACE Centre-North, Oldham
As Easy as AAC
 Contact: ACE Centre-North 0161 627 1358
- 31 October 2002 Oxford
Visual Perception Difficulties in Children
 Contact: ACE Centre 01865 759800
- 18 November 2002 Stirling
Augmentative Communication in Practice: Scotland
 For more information on this Inclusion and AAC Study Day at the University of Stirling, contact SCTCI 0141 201 2619
- 18-19 November 2002 Birmingham
RAATE 2002 - Recent Advances in Assistive Technology and Engineering
 Contact: CoRE, King's College London 020 7346 1650
- 25 November 2002 London
CASC Road Show at Institute of Child Health 
 Cost: FREE Contact: Com. Matters 0870 606 5463

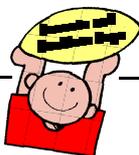
One Voice UK Internet Support Group



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@yahoogroups.com



Parents and Enablers Page

by Katie Clarke

Time flies as the Clarke children look forward to a busy month of birthdays. We have seven out of eight birthdays in the space of 28 days, which works out at a party every four days! A fun but expensive time of year and when you find out who your real friends are.

The kids are also excited about going away again to warmer climes - last October we went to Turkey and this Easter we are celebrating Grandpa's 70th birthday with a trip to Israel and a reunion with seven of the cousins that live over there.

Everything is still going extremely well with Nadia's mainstream education. She has just learnt her seven times table and is able to use one hand to sign the numbers quickly. In fact, is really good at mental arithmetic and is able to keep up with her classmates thanks to her signing skills. Again she uses sign language with literacy and although her signs are not always clear to those who do not know her well (especially as she has difficulty using two hands), she signs her reading books and mouths the key words.

Everyday words such as 'it', 'is', 'for', 'of' and 'the' are not used in BSL, which, of course, makes reading for deaf children particularly difficult. Also, BSL has its own grammar which has little similarity to English. We are working hard to expand Nadia's language because it is easy to fall in a trap with deaf children and to limit the vocabulary that we use everyday. For instance we might sign 'great' but unless we specifically teach Nadia words like 'fabulous', 'wonderful', 'fantastic', 'cool' and 'terrific', because she has limited hearing she would be unable to pick those words up through conversation. We are constantly challenging her language and delving beyond the sign.

This is vital if Nadia is ever going to be a good reader, as even now she comes across vocabulary at Level 6 that she has not encountered before. It requires constant patience and energy on her behalf and ours, as having a child that does not speak and is deaf is very complex.

Since our last successful Blackpool weekend (which I will tell you about later) Nadia's motivation has greatly increased in her use of her DynaVox. I am finding that as her language increases it is more difficult to understand her sign and so she is using her aid more and more. Another huge difference is that, *lo and behold*, we have finally got the aid mounted onto her electric wheelchair at home and at school. What an unbelievable difference! So, now whilst she is waiting for me to finish dressing the other kids in the morning, Nadia is able to sit in her electric wheelchair, use her DynaVox, go down in the lift on her own and choose her breakfast cereal. It is lovely to see her really communicating now at home and school; asking questions and initiating conversation.

Our biggest hassle (for the last 14 months) is that we have no AAC Specialist in Calderdale and it has taken numerous letters, phone calls and meetings, until finally the Speech and

Language Therapy Department is not taking this criticism personally, and the Education Authority are looking at AAC provision as a Calderdale issue.

But, as you know, all these things take forever. Even if it is stated in Nadia's statement that she needs a specialist, where is that expert going to be found? If any other parents have got similar issues then I would be very interested in how they have got on.

One Voice held their second family weekend at the Norbreck Castle Hotel at the beginning of December. We had a total of 89 people including 12 families, volunteers, adult role models and extra children. This year we had a Harry Potter theme throughout with everyone being sorted into the various four houses and gaining points for their house through games and good communication skills throughout the weekend. The children were so well looked after by the volunteers and the crèche workers, that the parents were able to disappear throughout the Saturday and then the Sunday morning to attend workshops. The workshops (led by parents and users) were most motivating and the parents could totally focus on them, knowing that their children were in the best of hands.

A big thank you to everyone that attended: to the families, volunteers, workshop leaders, our terrific role models (who play the most important part) and to all at the Norbreck Castle. Plus, thanks to *Communication Matters*, BECTa, Calderdale Community Foundation, Newcastle Building Society, and the many trusts we approached for funding to make the weekend possible.

ONE VOICE COMMUNICATING TOGETHER



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AAC Service Developments: The West Sussex Experience

by Steven Bloch and Sally Conner

Identifying the Challenge

The county of West Sussex lies along the south coast of England. It contains a combination of large towns (e.g. Chichester, Crawley and Worthing) as well as smaller rural communities. With an estimated population of 760,652, West Sussex has a higher than average percentage of people over 65 (33.3% compared with a national average of 25.1%).

The services within Education, Employment, Health, Social Services and Voluntary provision have developed to meet the needs of local populations with minimal structured coordination across agencies. Like many areas across the UK there has been no central funding for AAC equipment provision and no commissioning protocols for AAC service delivery. Other assistive technology services e.g. environmental control, wheelchair and computer access, have developed independently.

Generally, any AAC work that has been provided in the county has come from individual Speech and Language Therapists. This work has focused upon the needs of the individual users within each clinician's caseload. At a clinical level a range of AAC systems are utilised. Some high tech equipment is held by individual services within Trusts and many therapists have access to symbol software. Informal liaison between clinicians has taken place but there has been little collaborative forward planning or strategic thinking around AAC service provision and delivery.

Moving Forward

In 1997 the Speech & Language Therapy Service in Worthing was successful in bidding for Joint Finance Monies for a three year project to develop an Assistive Communication Service in the Worthing Area. The philosophy behind this project was not to duplicate the services provided by existing regional AAC equipment assessment centres, but rather to consider ways of supporting clinicians and others in long term AAC implementation and support. One of the initial outcomes of this work was the realisation that AAC services could only ever 'work' with the full support of the key agencies involved both at a grass roots and service commissioning level.

In November 1999 a one-day Conference for West Sussex was held, enabling AAC stakeholders to 'have their say'. This brought together approximately 50 key representatives from Education (including Further Education and Universities), Employment (Disability Teams), Health, Social Services, the Voluntary Sector, and users. The two aims being: to raise awareness and understanding of the main factors in local AAC Service delivery, and to begin to develop a framework for multi-agency service provision. The conference was facilitated by an independent management consultant and consisted of invited speakers providing national, regional, local and user perspectives. In the light of this information, delegates were

then asked to develop an 'ideal' AAC Service model for West Sussex, as well as barriers preventing the delivery of such a goal. The final task was to establish ways of overcoming these hurdles.

What emerged was a surprisingly high level of agreement amongst delegates regarding the most realistic model and how to move towards achieving it. Naturally, the multi-disciplinary team approach was favoured, but more specifically the following four issues were highlighted:

- AAC assessment/equipment provision is only the first step - long term support and training in AAC use and interaction is essential - especially for professionals and carers. This was seen as relevant for low/light tech solutions as well as high-tech equipment.
- 'Ownership' of AAC service provision must extend beyond Speech & Language Therapy - there are vital contributions from many agencies (especially the voluntary sector) which need to be recognised formally.
- Other forms of Electronic Assistive Technology (EAT) are developing rapidly - and any AAC service developments must recognise the need for integration with, for example: wheelchair control, environmental control and computer access.
- Access to services and information about AAC needs to be equitable and easy.

The day ended positively with suggestions for future service developments, including the call for more information about AAC use and need throughout West Sussex.

It was agreed that to move forward a core group of members was required to ensure that a range of issues and needs could be addressed. This led to the creation of the 'Forum for Assistive Communication' in West Sussex. The remit of this group was to bring together representatives from different agencies to begin the process of data collection, establishment of shared protocols, service standard development, user involvement etc. The idea was to create a truly collaborative and effective decision making group which could influence service provision throughout the county across all the key agencies.

Local information for local decision making

The first action of this group was to map a picture of what was actually happening in West Sussex regarding AAC. There was some idea of the number of agencies involved but no knowledge of what they were doing or more importantly how many AAC users were out there.

Given the number of different services involved it was decided to design a survey which could be distributed to as many services which might have contact with AAC users in West Sussex as possible. The questionnaire itself consisted of two

sections: one addressing user details and the other service provision. Once designed, the survey was distributed in June 2000 with an aim of launching the findings in a full report in April 2001.

Each survey pack included an introduction to AAC and guidance notes regarding the remit of the study (e.g. hearing aids and computers for education were not considered aids to communication in this study itself).

Survey Findings

The survey identified 303 people living in West Sussex who used of some form of assistive communication during June 2000. The age of users ranged from 14 months to 87 years, with 64% aged 19 or under, and 11% over 65.

Of the users identified, 74% used light technology systems as their predominant form of assistive communication, 22% used high technology systems, and 4% used a combination of both. These figures are represented in Figure 1.

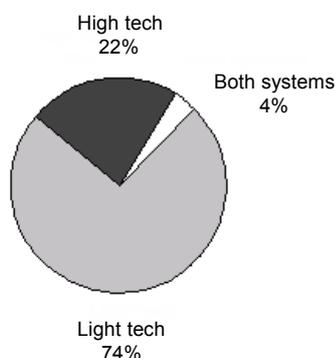


Figure 1 Percentage breakdown of system use by type in West Sussex

The majority of high tech aids used (51%) were symbol based aids. These were divided equally between static and dynamic systems. Spelling based systems were used by 38% of the high technology survey population.

Respondents were also asked to provide information regarding the source of funding for the high technology equipment currently used (see Figure 2).

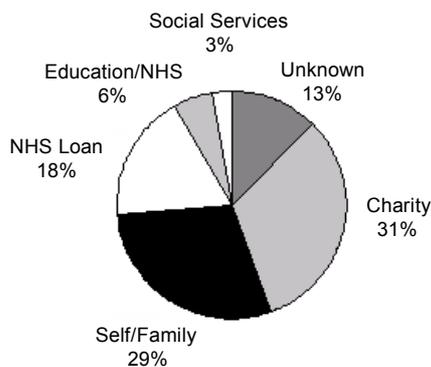


Figure 2 Funding sources for high technology systems in West Sussex

The largest groups identified were people with learning disabilities, followed by those with autistic spectrum disorder and then cerebral palsy. Those with acquired neurological disabilities (CVA, MND, MS, etc.) made up just over 20% of the user population.

Specific data was also gathered regarding geographical distribution of users – revealing local patterns which potentially reflect the different service provision of Speech & Language Therapy across the county.

Service Provision

From the data provided, the National Health Service is the lead agency in light and high technology assistive communication provision throughout West Sussex. Speech and Language Therapy Services are identified as the primary source for information, equipment prescription, assessment and advice.

Of the 48 organisations that have contact with assistive communication users, 33% offer some form of assessment, and 73% offer advice. Finance of high technology equipment is provided by 8% of organisations, whilst loans are offered by 21%. Information relating to assistive communication is available from 38% of organisations. Advocacy is available from 10% of services.

Implications for Current Service Provision and Delivery in West Sussex

The results from this study indicate that there is a wide range of assistive communication use in West Sussex and that a number of agencies are involved in ongoing service provision. Whilst many organisations provide advice and information, there is limited coordination or monitoring in this area. There are no national standards for the assessment and subsequent prescription of equipment and this is reflected at a county level. Funding and loans provision is spread over a number of organisations with no common pathways or audit procedures.

The implications of these findings on the key stakeholders are as follows:

Service users

- Variable local information available
- Inequity of funding opportunities
- Inconsistent access to assessment available across the county
- Variable support and follow up regarding high technology equipment provision
- Variable signing/symbols implementation and support
- Concentration of equipment resources in one area only

Professionals

- Limited coordination between services
- Inconsistent training resources
- Variable information re: equipment available
- Variable access to high technology equipment
- No framework for funding sources/requests
- No agreed equipment prescription criteria
- No audit of equipment use or follow up

Voluntary sector

- Variable information re: equipment available
- No clear pathways re: funding criteria

Commissioners

- Variable information re: service delivery and standards
- Inequity of service provision and equipment across West Sussex
- Ad hoc requests for funding with no explicit frameworks
- Limited feedback regarding efficacy of current service provision

The Way Ahead

The survey report was launched in April 2001. Service commissioners and providers were informed of the results of this work and then asked to contribute to plans for future collaborative working. The report made a number of key recommendations based upon a number of recent national reports and upon clinical need to ensure that light tech AAC system work was not neglected.

It was recommended that an Assistive Communication Service in West Sussex should be based upon agreed multi-agency standards and equity of access with a joint commissioning framework established across all the agencies and the voluntary sector. Such a service should be based upon recommendations in national audit reports, feedback from local stakeholder consultation and the findings from the survey itself. It was also recommended that the commissioning process should encompass a range of features relating to both service and equipment provision. It should reflect the finding that much assistive communication work does not involve high technology equipment, but that where it does it should be incorporated into clear packages of service delivery and care. In summary it was recommended that the key features for the provision of an Assistive Communication Service in West Sussex should include:

- Equity of access across West Sussex
- Agreed standards for prescription and support of all high technology systems
- Agreed standards for implementation and support of all signing/symbols use
- Consistent eligibility criteria and assessment procedures
- Agreed integration policies with other forms of assistive electronic technology (electric wheelchairs, environmental control and access to computers)
- Use of valid outcome measures for equipment use
- User involvement to monitor and advise service development and delivery

The Next Steps

The AAC work described above is not an end point. At this stage there are now two main strands of development:

1. Clinical

Therapists from each of the three existing Health Trusts and from specialist schools in the county are now meeting to

develop clinical standards and training protocols. This work will aim to provide local information for local professionals and service managers.

2. Service Provision

Following the recent 'Community Equipment Services' Department of Health Circular (March 2001, England and Wales) – the Forum is to become a subgroup of a Joint West Sussex Integrated Steering Group for Community Equipment Services. This will ensure that both AAC equipment and service provision part of the on-going collaborative work to integrate the provision of equipment in the community.

These two strands are closely related. At a service level it is important to provide senior managers and commissioners with information about local AAC needs. Also, service providers must demonstrate a commitment to service audit and 'value for money'. However, at a clinical level, clinicians also need to be working towards common standards of service delivery - ensuring that all potential service users have access to the best possible services.

There is still some way to go. User and carer representation needs to develop, and the main commissioning groups behind Health, Education and Social Services still need to be convinced that investment in AAC services can make a difference. The experience in West Sussex to date has shown that working together is the first step towards an improved AAC service for all.

*Steven Bloch & Sally Conner
representing the Forum for
Assistive Communication in W. Sussex*

*Further information is available from: Margaret Stinton, Chair,
West Sussex Assistive Communication Forum Tel: 01903 843143,
Worthing Priority Care NHS Trust, Trust Headquarters, Arundel
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Editor: Teresa Iacono, Victoria, Australia

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Reading with Symbols at Frederick Holmes School

by Nick Trapnell and Judith Chapman

This paper was presented at the CM2001 National Symposium, Lancaster University, September 2001

Frederick Holmes is an LEA school which caters for pupils with physical disabilities from Hull, the East Riding of Yorkshire and North and North East Lincolnshire. It has 84 pupils aged from 2 to 19 years.

This paper aims to outline our use of symbols to teach reading to pupils with little or no natural speech. The work was based on the 'look and say' approach to reading and aimed to provide a solution for individual pupils who had difficulties with speech intelligibility. Initially it was a problem solving exercise and has now been adopted from the Foundation Stage to Key Stage 3. We are currently supporting reading with symbols with 22 pupils aged from 4 to 14 years in Frederick Holmes school and six pupils in mainstream schools.

Reasons for Introducing Symbols

Pupils at Frederick Holmes school present with a wide range of physical impairments and associated communication disabilities. Approximately two thirds of the pupils use some form of augmentative communication with 21 using voice output communication aids. The school follows the national curriculum and, where appropriate, this is differentiated for individual pupils. Consequently there are some pupils who are following a curriculum equivalent to that of their mainstream peers and others who require a high degree of differentiation.

In 1995, therapists working alongside teaching colleagues in classrooms identified the need for a system to enable non-speaking pupils to access a reading scheme. A number of Key Stage 1 and 2 pupils were already reading using Makaton signs, but there were an increasing number of pupils who were not able to sign because of difficulties with fine motor skills and therefore symbols were required. Concerns about reading with pupils with little natural speech were twofold:

1. Teachers were concerned that the lack of objective measurements about a child's word recognition could mean that pupils were being introduced to new vocabulary and books before they were ready.
2. Conversely there were also concerns that some pupils who were ready to progress might be held back because staff were not sure that the pupil could demonstrate their understanding of the printed word.

It was decided that selecting a symbol would provide evidence of a pupil's ability to look at a printed word and recognise and encode this in the same way that naturally speaking children are able to utilise a 'look and say' method. It was acknowledged that this would involve an extra stage i.e. ensuring a pupil could recognise the symbols before written words were introduced.

Development

There were several reading schemes in use at Frederick Holmes School. The *Ginn 360 Reading Scheme* was selected for this

work as the vocabulary was cumulative and it was the most widely used within the school's primary department.

The decision was taken that a 'core reading vocabulary' would be developed, in which a single symbol matched an individual word, however, a total word/symbol match was not feasible and that some word endings and grammatical markers had to be included, consequently a small number of written words required a two symbol selection e.g. regular past tense forms.

This work took place over several terms, it started at the beginning of the reading scheme and stayed a few steps ahead of the pupils. However, with the benefit of hindsight, if we were to start again we would now consider the scheme as a whole and some things would be done differently.

The symbols selected were already in use within school and were drawn from a variety of symbol schemes and, in some instances, devised for inclusion in the reading scheme. The intention was to ensure that once a pupil had matched a symbol to a word within the context of reading this correspondence would always exist. Thus avoiding a scenario in which pupils could be presented with different symbols for the same word by different members of staff. This contrasts with the school's use of symbols for communication which includes a core vocabulary but also accommodates some variations e.g. the use of coloured PCS symbols in the nursery, with a gradual transition to black and white. We currently have a complete set of word/symbol matches for the main books for Ginn levels 1 to 4 and are in process of compiling matches for level 5.

Materials

All pupils who begin reading with symbols have:

- two sets of matching symbols printed on individual Flash cards
- words on Flash cards
- the symbols on a board (format of the board differs according to their method of access)

The materials have all been produced by the speech and language therapy team at Frederick Holmes School. Developing these materials has been a time consuming process because of the need to create a range of boards to suit different access methods e.g. direct selection using hands, encoded eye-pointing, direct selection using a laser pointer etc. This has only been possible because of the acknowledgement, from both speech and language therapy and school's senior management team, that this falls within the role of the speech and language therapy service in school which should not be measured only in terms of face-to-face contacts.

Access/Encoding

Approximately half of the pupils currently reading with symbols are able to directly access their boards by finger-pointing



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or fist-pointing with an encoding system. The remaining pupils are using eye-pointing and a small number are directly accessing using a laser pointer worn on a hat or helmet.

We have a number of different boards to accommodate different modes of access. Direct selectors have all their boards with cell borders colour coded for word categories, for example verbs are green, nouns are orange. For pupils using eye-pointing the situation is more complex. For level 1 of Ginn a simple colour coding system, using four colours, is used, however colour and position encoding does not provide sufficient scope for the range of vocabulary from level 2 onwards. Therefore a co-ordinate encoding system is introduced, allowing the introduction of colour-coding for word categories.

Identification of Pupils

No formal system of identifying pupils who will use this approach to reading is in place although pupils who have no natural speech are usually identified at an early stage, with consensus amongst all the professionals involved. The picture is less clear for pupils who have some natural speech. The speech and language therapy team advocate this approach for most pupils presenting with severe phonological or articulation problems in an attempt to avoid the scenario in which reading with symbols is introduced only when the pupil is perceived as having failed with an oral approach. It is felt that if the pupil's sound system develops adequately symbols can be dropped from the reading process more easily than they can be introduced at a later stage.

If appropriate, the speech and language therapy team will complete an assessment of a pupil's sound system, and on the basis of this will advise that reading with symbols is appropriate. There is not always agreement between therapist and teachers, especially where a pupil is able to signal all of the sound contrasts necessary for the first stage of the reading scheme. Consideration should be given to whether the pupil's sound system is likely to allow them to signal the differences required for level 2 and beyond e.g. 'like' versus 'likes', past tense markers, plurals, etc.

For only three pupils has there been a lack of consensus between the teaching and speech and language therapy teams. It should be noted that all three have severe motor speech difficulties and two of them prefer to use their natural voice despite significant difficulties in communicating without the support of an AAC system. For two of the pupils these issues have been resolved, they are successfully using symbols to support their natural speech for reading, for the third there is no longer any debate and it is accepted that symbols are an important part of his approach to reading.

Where there was a discrepancy between the views of the therapists and/or teachers and parents then an assessment of the pupil's intelligibility for reading aloud was attempted in the following way. The pupil was presented with individual words from the reading scheme. The words were visible only to the pupil and the adult presenting them. The pupil read the word aloud and two other familiar adults recorded what they thought they heard. This provided an opportunity to compare the target word with the perceived word enabling us to note whether the pupil was able to signal differences such as 'my' and 'mine'. For one pupil the success rate was less than 28 percent, even

within the context of the adults knowing that the words were taken from a possible list of only sixty two.

Staff Training

Initially reading with symbols was being developed within a Year 5 classroom as a collaboration between speech and language therapy and the classroom team. After some success, it was shared with the other teachers during a training session. Formal training has also been offered to both teachers and teachers' aides. The variety of pupils' access methods has necessitated individual support and demonstration for classroom teams, particularly as pupils move through school and as new staff join the school.

Home/School Liaison

Reading with symbols requires a high level of input from teachers, classroom staff and parents/carers to facilitate individual support for pupils. Reading with a symbol board does not always lend itself to some of the strategies advocated in the National Literacy Strategy and Frederick Holmes School is committed to the implementation of the literacy framework, e.g. group guided reading. However, as pupils have been successful using this method of reading with symbols, school staff have been very supportive in trying to meet these challenges.

Pupils' Individual Education Plans (IEPs) include objectives related to reading with symbols. Many pupils benefit from daily individual practice with the support of an adult within school and families who read with their children at home.

As pupils begin reading with symbols their parents or carers are invited to visit school and talk through the stages involved. When possible they are offered an opportunity to observe others reading with similar materials.

The Way Forward?

We are currently working on Level 5 of the Ginn scheme and are discussing with teaching colleagues where to go from here.

We are aware that we have only symbolised the main books of the scheme and not the supplementary readers. In many schools different reading schemes are operated in conjunction with each other thus allowing pupils who need to consolidate their skills to branch sideways and explore a variety of material at a similar level. To facilitate this we are considering developing support materials for another reading scheme already in use in the school, possibly the Oxford Reading Tree. A policy also needs to be developed, with school staff, regarding the introduction of phonics to pupils with no natural speech as an aid to the development of both reading and spelling.

With the early stages of Ginn Level 5 boards under construction it has become obvious that it is not feasible to keep adding more and more symbols. Strategies need to be developed to promote independent reading and to look at ways of assessing pupil's reading comprehension.

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Training in Conversational Quality for an AAC User

by Audrey Syme and Alan Johnstone

This paper was presented at the CM2001 National Symposium, Lancaster University, September 2001

Introduction

This paper describes a training study carried out at Dundee University, as perceived by the trainer, Audrey Syme, and the AAC user, Alan Johnstone.

As an undergraduate in her final year, Audrey Syme was introduced to the field of augmentative and alternative communication, and specifically to a communication aid for non-speaking people developed at The University of Dundee, through her dissertation supervisor, Professor John Todman. Alan Johnstone had taken part in trials and evaluations with this communication system for a number of years and had become a regular visitor to Dundee University's Psychology Department. In October 2000, both trainer and trainee came together to carry out a 14 week training study in the use of TALK (Talking using Pre-Loaded Knowledge). Both training interventions will be described, the outcomes will be explained, and importantly, Alan's perspective of the study will be given.

The TALK System

The aim of TALK is to support social conversations for non-speaking people with familiar as well as unfamiliar partners. The system follows the utterance-based approach which relies largely on the storage of whole phrases on TALK screens, (See Figure 1) for later retrieval. The ability to store topic content in whole phrases allows a user to take control of topic development in social conversations. A conversation can be steered around a topic in which the user might have a lot of stored content. The system models pragmatic aspects of natural social conversation. This is achieved by the particular organization of topic content that models the way topics advance via small shifts of perspective (me/you; past/present/future; what/when/how/who/why/where. For example, "I went to Paris last year" would be stored under me/past/where. The user might want to ask their conversational partner if they were going on holiday this year, which would be stored under you/future/where. Thus, a movement from one screen to another is carried out with a maximum of three clicks of the mouse.

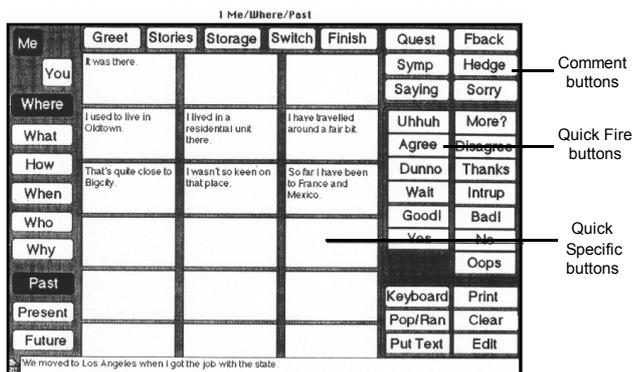


Figure 1 A TALK screen

Features of TALK

- The system utilizes TALK screens (or 'boards' as they are called in the commercial implementation) for the storage of phrases that can be retrieved at a later time.
- It has a greetings facility that can be customised to the idiosyncratic style of the TALK user, for example, "Hi, nice to meet you", "Hi, how are you".
- A range of recycled 'quick-fire' comments can be used, which serve an important role in social interaction. There are for example, feedback comments such as "Okay", agreements such as "Yes I agree" and repairs such as "That wasn't what I meant to say".
- There are also specific comments, such as ones expressing sympathy, such as "That's too bad" or turnaround questions, such as "How about you?"
- There are Storytelling directories which each contain 18 possible slots for stories and within each story board are 18 available slots for the input of phrases.
- There is an on-line input facility for a user to input novel phrases when a phrase has not been stored or if retrieval of a suitable response is proving difficult.

Alan's training programme focused on certain features of the TALK system.

Background to the Training Study

In recent years, the TALK system has proven successful in speeding up the rate of output by a user, achieving between 60-70 words per minute in social conversations (Todman, Rankin & File, 1999). Todman et al's 1999 study achieved this high level of output by limiting the number of words a TALK user could input on-line, making the TALK user more reliant on their pre-stored phrases. Additionally, Todman (2000) increased the rate of output of a TALK user by giving training on turnarounds, comments and quick fires.

Departing from this focus on speed, the issue in this study was whether training that took a more customized approach for a single user would be effective in improving the *quality* of this particular's user's social conversations.

Interventions

1. The first intervention, 'Pre-stored training', focused on improving the quality of Alan's pre-stored content, with the intention that this would encourage him to use his pre-stored phrases more and revert to on-line input less frequently.

The goal of this intervention was to enable Alan to take part in his favourite pastime, that is to debate without having his flow interrupted by delays for inputting novel phrases on-line.

Alan: "I get a buzz from debating controversial and current issues, like politics and disabled issues. I like to debate



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issues until I have exhausted them. There is nothing I like better than a good debating partner. Most of my conversations, even with people I have just met, involve a debate of some sort.”

2. The second training intervention ‘Narrative pause’ was intended to slow down the flow of Alan’s narrative content in an attempt to make his conversations more interactive.

The goal of this intervention was to allow Alan to engage in telling stories, which he enjoys, in a more interactive and interesting manner, through allowing his partner to participate in the story telling process.

Alan: “I like using the storyboards in TALK to tell stories as it gets me far deeper into a subject. It also lets people get to know me a lot better, by giving them an insight into my experiences. I also like it, as it lets me ‘take the floor’ for a good degree of the time during a conversation, which I must admit I enjoy.”

Participants

In addition to Alan as the TALK user in the study, 36 psychology undergraduates took part as conversational partners. Also, Alan’s employed assistant served as an unobtrusive observer.

Procedure

Each of the 36 conversational partners took part in a single conversation with Alan. Each conversation lasted around 20 minutes. The conversational partners were informed before each conversation that they would be talking to an individual who could not speak, but could communicate through a communication device, which utilized synthesized speech. The partner was asked to relax and have a ‘getting to know you chat’, where the TALK user would ask questions and they could also ask questions. The partners were informed that the conversations would be recorded. After each conversation ended, rating sheets were administered to Alan, his conversational partner and the observer.

Rating Sheets

The questions on the rating sheets were devised to tap into three aspects of Alan’s conversations. (See Figure 2)

1. Alan’s personal satisfaction
2. Alan’s communicative competence
3. The social interaction of the dyad

Judgements were made on a nine point rating scale.

Pre-stored Training

A list of commonly asked questions (43) were prepared. They were derived from the first 12 conversations that had taken place before training had been introduced. Both general and specific questions were included, such as:

1. Where are you from?
2. How are you?
3. What do you like to read?
4. Do you bet on anything else other than horses?

When Alan had responded to each question, a 5 point rating scale indicating ‘1’ definitely not satisfied to ‘5’ very satisfied was shown to Alan to indicate his rating of how satisfied he was with his response. Any judgements of responses below ‘3’ were noted and Alan was asked to construct a more satisfactory response at home.

The second pre-stored training session used a more structured approach. Three tree diagrams were prepared which focused on three general topics in which Alan had a lot of stored content, which were:

1. Sport
2. Home and Places
3. Hobbies

Under each of the general questions were three lines of related questioning. For example, under topic 1, were the questions:

1. What’s your favourite sport?
2. Did you watch the Olympics?
3. What about football?

Again, under each of the sub-topics was other related questioning. There were some suggestions as to how Alan could then bring in his debating issues. For example under the question “What’s your favourite Paralympic sport?” were suggestions, such as: “You could now move on to your friends taking part in the games”, “You could now move on to debate about hours of Paralympic coverage”, “You could move on to your questions about disabled issues on TV.” So, as well as rating these responses, these procedures also allowed Alan to fully cover topics he was well ‘versed in’ and to find ways to introduce his debating issues.

Alan: “The first session covered a lot of the predictable questions that might have arisen in conversations with new partners. It was useful to rate my present responses as, surprisingly, I found that a fair percentage of my stored responses were unsatisfactory. Therefore, revising these responses gave me a chance to provide better responses to certain questions. I think I used more of my stored phrases after training. I think if Audrey had reminded me before each conversation to use stored phrases as much as I could, I may have used them more often. There are always going to be new phrases I want or have to type in during a conversation, however, if I have a satisfactory response stored I will want to use it.”

Questions for TALK user

- Q1 How good do you feel about this conversation?
- Q2 How effective do you think you were in communicating what you wanted to?
- Q3 How well did you manage to interact with your conversational partner?

Questions for Partners

- Q1 How good do you think the TALK user feels about this conversation?
- Q2 How effective do you think the TALK user was in communicating?
- Q3 How well do you think the TALK user and yourself interacted?

Questions for Observer

- Q1 How good do you think the TALK user feels about this conversation?
- Q2 How effective do you think the TALK user was in communicating?
- Q3 How well do you think the TALK user interacted with his conversational partner?

Figure 2 Ratings Questions

Narrative pause Training

Alan trained with four of his stories: The Amsterdam story, The Paris story, The Betting story and The Cricket story. Attempts were made to train Alan in a 'narrative pause' technique. This procedure consisted of Alan choosing one of these stories and outputting the complete story from the start to the end of the story. Then he was asked to repeat the story, but pause and wait for a response from the trainer after each section of his story. The trainer would respond with either acknowledgements, such as "Uh-huh" or "Is that right?" which would mean he could move on to the next part of the story, or by asking him a question related to what he had just said. It would then be necessary for him to move out of the Story board to a Talk board to answer the question, then move back into the Story board to continue with the story. This training was intended to make the conversations more interactive, with the partner becoming more involved in the story telling process. This process was repeated with each of the four stories.

Alan: "I like the idea of making my story telling more interactive, with my partner being involved, however, this proved more difficult than we both expected, I think. During training I knew Audrey would make a response and she knew that she was supposed to make a response, however, in reality during the conversations, when I paused, the folk wouldn't respond. I think they may not want to have interrupted me. In the future, when telling stories with the TALK system, I might use the narrative pause at the beginning of the story, but if I feel the particular conversational partner doesn't know what is expected of them, that is, doesn't respond at these pauses, I would just output the story in the normal manner. In this type of training, I think a lot depends on the partner, which I can't control."

Predictions

1. The percentage of on-line input by Alan would decrease after both training interventions. Alan would use more of his newly constructed satisfactory pre-stored phrases and use less of the on-line facility to construct new phrases. Also, the training in narrative pause should motivate Alan to use the story telling facility more, therefore decreasing opportunities to input on-line.
2. The percentage of Alan's total word contribution in comparison to his conversational partners would increase after both training interventions. This and the previous prediction are interdependent. With the decreased use of the on-line input facility and associated increased use of pre-stored phrases, Alan would show an increased contribution to the conversation. Again, narrative pause training may encourage Alan to use the story telling facility, which will add to his contribution to the conversation.
3. Ratings of personal satisfaction, communicative competence and social interaction would increase with both training

interventions. Training should increase rates for the above ratings for Alan, his conversational partners and the observer.

4. The increased expertise gained in the use of this device (TALK) throughout the study should increase scores on the three subscales of Competence, Self-Esteem and Adaptability of the PIADS (The Psychosocial Impact of Assistive Devices Scale); a scale which assesses the situational aspect of Quality of Life. (Day and Jutai, 1996)

Summary of Outcomes

In relation to the first prediction that Alan's on-line input would decrease in favour of using his more satisfactory pre-stored phrases; Figure 3 shows an immediate decrease in on-line input after the pre-stored training. Subsequent conversations (excluding the 30th conversation) never reach the higher rate of on-line input in the first 12 pre-training conversations. Also the final 3 maintenance conversations, which occurred after a 5 week break maintained a low rate of use of the on-line facility. It would seem that the pre-stored training had a discernable effect, which had been maintained somewhat after the training had ended.

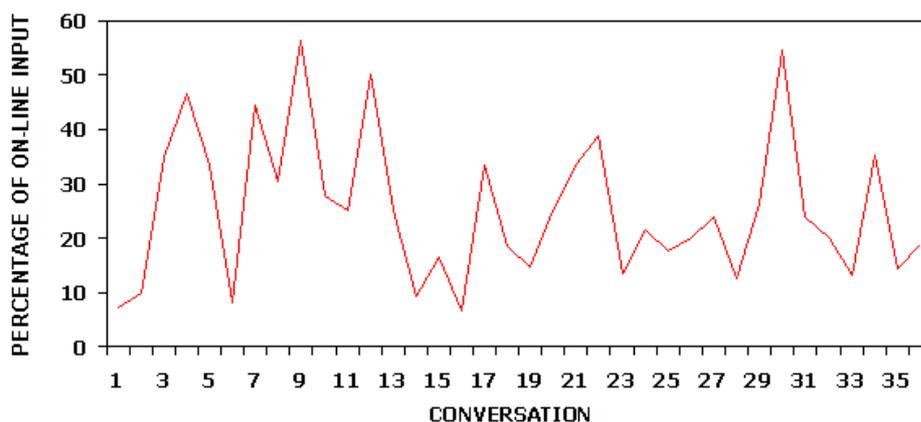


Figure 3 Percentage of On-line Input by the TALK user

There was evidence of an increase in the percentage of word contribution after the pre-stored training, with another gradual increase after narrative pause training. Interestingly, this percentage of contribution was maintained, and in fact increased, after the five week break, possibly showing Alan's increased ease at 'holding the floor', which may have been a result of the training given.

There was no clear pattern in any of the raters' (Alan, partners, observer) judgments of Alan's personal satisfaction, his communicative competence or social interaction. However, it was apparent that social interaction judgments by all raters dipped badly after the narrative pause training. As the aim of this training was to promote interaction, this was an unexpected outcome. This may have indicated a problem in the conversational partners' 'non-responsiveness' while Alan was in the story telling mode rather than a problem in the effectiveness of the training. As Alan himself had mentioned, conversational partners did not know that Alan was waiting for a response. When Alan was facing his computer, the partner may have tended to think he wanted to say something else and consequently refrained from responding. All that need be added to

SUBSCALE	First Presentation	Second Presentation	Third Presentation	Fourth Presentation
Competence	13	10	29	19
Adaptability	10	12	9	4
Self-esteem	4	5	8	9
TOTAL	27	27	46	32

Figure 4 Competence, Adaptability & Self-esteem Scores

would like to think that other training studies, would benefit other TALK users' in the same way. In relation to the TALK system, although it has some limitations, such as its lack of portability, I think it is great for someone who likes to talk a lot, like me."

Audrey Syme
& Alan Johnstone
csyme41415@aol.com

the present narrative pause training to make it effective may be an instruction to indicate to the partner by a head turn or eye contact that they have relinquished their turn and await a response. This is referred to by Duncan and Fiske (1977) as a 'turn-yielding signal'.

Figure 4 shows the scores on each subscale at each presentation of the PIADS scale, which was 1) before the study began 2) after the first 12 baseline conversations 3) at the end of the Treatment 1 (pre-stored training) conversations 4) after the maintenance conversations (5 weeks break). The aspect which appeared to gain the most benefit from the training study, was that of the competence subscale. A substantial increase in scores on the competence subscale came after the pre-stored training conversations.

Those items on the competence subscale that increased the most were competence, happiness and skillfulness. The greatest gains in the self-esteem subscale appeared to be in items such as increased self-confidence and decreased embarrassment. However, it was apparent that the Adaptability subscale scores decreased after the second presentation.

Alan: "I was surprised that there was not a larger difference in the data after the training. I definitely felt more into the conversations after training and I certainly enjoyed them more, especially the ones with the English students. In relation to the rating questionnaires, I must admit on the communicative competence question that I did not want to appear arrogant, by rating myself highly after the training. I was also surprised that the Adaptability subscale scores decreased after training. I was not surprised that the competence and self-esteem subscales increased; I did feel more competent in my communication and consequently more happy with myself."

Conclusion

After pre-stored training, as Alan himself has commented, perhaps basic reminders may have been necessary for any substantial change to occur in his use of pre-stored phrases. Also, in the narrative pause training, as mentioned, a head turn or eye gaze could be added to the training to encourage the partner to respond at the pauses. The increased scores in the PIADS questionnaire are encouraging. This suggests that the training programme in general has been beneficial to some aspects of Alan's quality of life.

Alan: "I think this training study did have an effect on the way I communicated, although it was not as apparent as I would have thought, and consequently how I felt about myself. I

ACKNOWLEDGEMENT

This research project was supported by a grant from The Rehabilitation and Medical Research Trust (Remedi).

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...continued from page 10

a small number of symbols for choice making (mainly during drinks time and a class room based toy choosing session) and had recently been introduced to a help symbol which he was learning to wear on a key ring. He also followed a symbol-based timetable both at school and in his residential unit.

As I got to know Sam, I found that he had excellent symbolic understanding and enjoyed activities involving symbols. He appeared to have no difficulties understanding new activities and seemed keen to have a go and learn any new tasks presented to him as long as he was able to take an active part in the activity. He also visibly enjoyed demonstrating his knowledge using symbols. It took Sam no time at all to learn to use a sentence strip to combine symbols into simple sentences and before I knew it he was able to use a sentence strip to request and comment during structured learning tasks. I was keen for Sam to start a personal communication book to enable him to use and generalise his communication skills both in a wider range of contexts and with different people as well outside structured learning or therapy sessions.

Because Sam was known to be very rigid in all aspects of his daily routines, there was an initial reluctance and a real fear amongst teaching and care staff that starting Sam on a personal symbol-based communication book might cause him to become more anxious and that as a result he might display more inappropriate anxiety-related behaviours. The feeling was that limited symbol vocabularies should be made available to him in the form of situation-specific key ring vocabularies. This would ensure that he knew what he could ask for during different activities and thus avoid any confusion or upsets. My view was that if we could provide Sam with a more general alternative/augmentative communication system, this might make him more flexible as he would be able to actively participate in an increased range of activities and learning tasks as well as be communicate about things that he wanted to communicate about rather than things that someone else had decided were OK for him to communicate in a particular context.

Sam started off with the key rings, while other children in his class moved on to communication books. It did not take long for Sam to decide that what he really wanted was a communication book and he simply started using other children's books. At the same time the key rings proved increasingly difficult to manage, especially as Sam kept hiding them because what he really wanted was a communication book. When he moved classes in September 1999, his new teacher was keen for him to start his own communication book and by Christmas Sam's book was the biggest in the school! At the same time, Sam's screaming behaviours were getting less and less and he was learning to tap people on the arm to get attention rather than screech continuously until someone responded. It was at this time that we first felt that Sam might benefit from being provided with a dynamic screen voice output communication aid (VOCA). This was new territory for all of us, as the use of VOCAs for children with autistic spectrum disorder is still in its infancy.

Sam tried out a couple of aids and immediately took to a DynaMyte. His parents decided to fund-raise the money for a new DynaMyte and Sam eventually took delivery of his personal VOCA in November 2000. Since then his progress has exceeded



Kwaga (left) and Sam with the DynaMyte

everybody's expectations and we all have difficulties keeping up with Sam's speed of learning. Sam spontaneously uses his DynaMyte during group activities such as 'Big Book' sessions and he has also discovered that 'chatting' might get him out of having to do work in lessons that he does not enjoy. In a recent art session, he was observed commenting on everything he saw in the art room without ever actually touching any of the papier maché materials he was supposed to use to make a volcano!

We have given up counting how many symbols Sam now uses on the DynaMyte as he confidently moves between screens at a speed that would put us adults to shame. Sam is beginning to use his DynaMyte to learn to communicate about feelings and is even tackling personal pronouns, an area which is notoriously difficult for children with autistic spectrum disorder. We will soon have to think about how to introduce Sam to grammatical markers and tenses. Sometimes I wonder who is on the steeper learning curve, us or Sam?

At the beginning, there was some fear that using the DynaMyte might not teach Sam the actual process of communication but might simply result in him using the VOCA as an electronic toy. Again, Sam quickly proved us wrong. He had no difficulties generalising his use of the DynaMyte to home and this has increased and created new opportunities for communication at home.

At school, Sam learned to use the DynaMyte to greet people in his classroom by moving the device towards the person he was saying hello or goodbye to and, to all our amazement, he started to generalise this greeting skill into unstructured contexts where he did not even have his DynaMyte. Sam will now approach familiar people, touch their arm, look at them and vocalise when he sees them in the playground or during assembly. He has also become much more aware of other people in his environment and will often spontaneously help out his teacher or try and talk for other children during snack time. On trips out Sam will tell the driver which way to go and he also likes talking about what the weather is like. He just really wants to talk!

Another big fear we had was that Sam would not be able to cope if the DynaMyte ever broke down. This inevitably happened and did indeed cause great upset. However, Sam calmed when he was presented with a paper-base social story explaining that the DynaMyte was broken but would come back repaired if he waited until a certain date. Sam accepted this and coped with

using his communication book while he was waiting for the DynaMyte to come back.

While the DynaMyte has not taken away Sam's autism, it has enabled him to be more flexible, participate and communicate in a wider range of classroom activities and has extended the reasons why Sam communicates, both at school and at home.

But what about Kwaga? Well, despite her many autistic features, Kwaga has always been more social and extrovert than Sam. She also has a communication book and over the last year has build up a huge personal symbol vocabulary. She is even trying to articulate the words represented by the symbols, but an element of dyspraxia makes it difficult for her to produce intelligible speech. Kwaga was intrigued when Sam first got his DynaMyte. She observed him and she tried to have a go herself whenever she was able to get near Sam's DynaMyte, which initially was an achievement in itself, because Sam was so protective of the device. As Sam got more confident and secure in the knowledge that the DynaMyte was his, he has become more flexible with regards to letting Kwaga have the occasional go. Kwaga and Sam now spontaneously run their own personal greeting exchange every morning sharing Sam's device!

Kwaga has learned to use Sam's DynaMyte by simply looking over his shoulder and having the occasional go herself. She will also try and say what she hears the DynaMyte say. She is now refusing to use her communication book whenever Sam and the DynaMyte are within reach. Kwaga's mum is now in the process of raising funds for Kwaga to have her very own DynaMyte. Kwaga and all of us can't wait for her to take ownership of the new device.

Radlett Lodge School, Sam's parents, Kwaga's mum and I are all extremely pleased with Sam and Kwaga's progress and are delighted that they are both CM Achievement Award winners.

*Lilo Seelos, Speech & Language Therapist
Radlett Lodge School, Harper Lane, Radlett WD7 9HW*

William Tennent

William is 11 years old, and has been in our school for almost two years. In that time he has made huge progress in his communication, and has impressed both pupils and staff throughout the school with his enthusiasm and good humour.

When we first met William, he could use some natural miming and gestures, and some approximations for words. Until he was nine years old he had been able to speak, but brain surgery had left him no longer able to communicate this way. Here is a picture of the William we now know...

He uses *Signalong* signs. He is still very good at natural mime and gesture, and will resort to that at times, but he has learned that it is useful to have consistent signs that most people around him recognise. He has had to adapt to using his left hand as the working hand for signing. It was not originally the dominant hand, so he has had to persevere and work hard. He has a wide variety of signs, and learns new ones as quickly as we can keep up with! He will invent new signs for himself; this week he worked out that 'P' plus a mime for 'camera' could mean 'photograph'. His family are learning signing, as are many staff members. William's example has inspired everyone who



William Tennent

meets him to want to communicate with him in this way. If he can do it, so can they! He is now using signs in many different settings, and learns new ones both at school and at home.

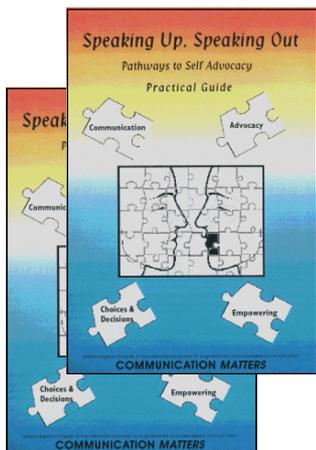
William is very keen to say as many words as he can. He finds the work tiring, but he is always willing to try. He never gives up, although he knows how difficult it is. He often practises at home. He uses symbols and our Speech Viewer software to help prompt him, and he has learned a small range of words using many different sounds. He is using his voice now in a variety of settings, not just within school and at home. He has had to learn *not* to use some of the less appropriate words in his vocabulary (at least in school, but maybe he uses them when he's out playing with friends!).

William began using a Dynamo in November 2000. Very quickly he mastered the technique of using the dynamic display system, and within 6 to 8 months he had used up virtually all of the memory in the machine. We have just borrowed a DynaMyte for him and transferred everything on to it from the Dynamo. There's a lot of work ahead for all of us, but William is, as usual, prepared to try and to use the machine in many settings. He takes responsibility for it in school, and makes sure his brother and sister and friends don't use it as a toy at home. He uses the basic 'Teen User' programme, and we are working on adapting it so that he has special pages for his own particular use. He was very excited recently when he learned and used a sequence of messages to use on the telephone - he phoned his mother using the DynaMyte. He is very keen to use the keyboard and will spell out at least part of a word if he can't get the message across any other way.

What impresses us most about William is his capacity for good humour and cheerfulness, even when he is working against the odds. (The humour of the average 12-year-old is not always appropriate in the classroom, but he's taken that on board too.) He shows a great talent for resourcefulness and will move through the differing communicative modes to suit each particular occasion. William is an active and positive communicator. He has worked hard and inspired us all.

*Anne Bruce
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Essential Publications from Communication Matters



Speaking Up and Speaking Out! Pathways to Self-Advocacy

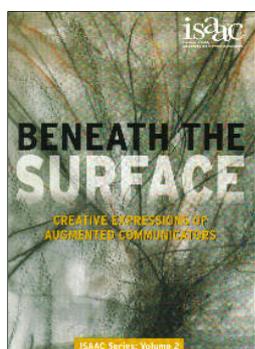
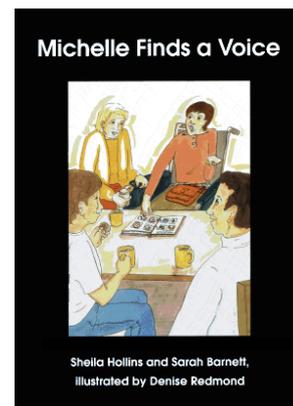
This pack is intended for carers, facilitators and others concerned with the advocacy needs of people with severe communication difficulties who need or use AAC. It is useful for staff development, especially for those working with adults. The pack comprises two books. One is a comprehensive and detailed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

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

Michelle Finds a Voice

This book is a story about 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**



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.

Price: £18 plus £1.50 p&p from **Communication Matters**

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 is an AAC user 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.

Ring **Communication Matters** for an order form.

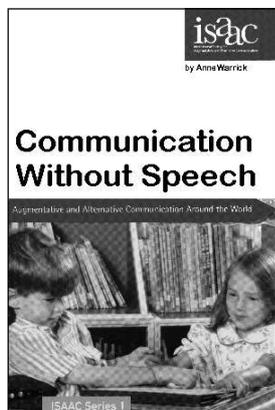


Communication Without Speech:

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.

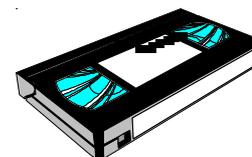
Price: £15 plus £1.50 p&p available from **Communication Matters**



In Other Words (ISAAC video)

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

Price: £10 to CM members (otherwise £15) including p&p **only available from ACE Centre (ring 01865 759800)**



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

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