COMMUNICATION MATTERS

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COMMUNICATION

MATTERS

Editorial

Welcome to this issue of *Communication Matters* which leads with two Scottish articles - not inappropriate in the year Scotland's first Parliament since 1707 was inaugurated - from Murphy and Jans, both relating to adults requiring AAC. There is also an item from Glaswegian AAC users Canavan, Smith & Devlin (page 19), which was originally presented 'live' at an AAC SIG day in Scotland (participants were impressed by the competence and composure of the young presenters).

We are delighted to continue the special page dedicated to Parents and Carers issues (page 11) with another article by Katie Clarke; hopefully many other families with AAC users will soon start to contribute to this forum. Families should also note the forthcoming **CM'99 National Sympo**sium (page 13) at which there will be a Workshop on user and family issues. Given the risk of isolation that AAC users may suffer, families and professionals will be interested in Ramchandran's article on *Write Away* (page 22), which could help to provide on-going social contact as well as a means of developing and practising communication skills.

Ferguson's update on new procedures for funding is of vital relevance to the AAC community in the UK (page 12). Churchill updates readers on how the Communication Aid Suppliers Consortium, CASC, is developing (page 15). Netcott's article (page 17) on 'Whisper Voice' illuminates a little discussed aspect of AAC, and provides useful technical and practical information. Hawes takes a new look at how off-the-shelf computers can be used for AAC (page 25).

We look forward to seeing CM members and other friends at Carol Goossens' **AAC Study Day** on 17th (Scotland) or 29th (Lancaster) September, and at the annual *Communication Matters* **CM'99 National Symposium** in Lancaster on 26-28 September 1999 (see page 13). Starting on a Sunday, this is a new Symposium format which should give participants more time to enjoy the informal, as well as the academic and professional, benefits of this epic AAC get-together. There are top class Keynote speakers - Juliette Goldbart from the UK and Carol Goossens' from the USA - and a huge range of different presentations and workshops of varying lengths and topic areas. For those of you who are unable to get to the Symposium or to certain concurrent sessions, papers from the Symposium will be published in future issues of this Journal.

In addition to these papers, we are, as usual, looking for articles, photos, letters or new book/product reviews for future issues. So please send in your contribution!

Front cover: Stuart Devlin, Tracy Canavan and Iain Smith (left to right), senior pupils from Ashcraig School, at a Chatterbox Day at Motherwell College in Scotland (see page 19)

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Journal Editors, Artwork & Desktop Publishing:
Sally Millar & Patrick Poon
The CALL Centre, University of Edinburgh
Paterson's Land, Holyrood Road, Edinburgh EH8 8AQ
Tel: 0131 661 6235 Fax: 0131 651 6234 Email: sally.millar@ed.ac.uk
CM Enquiries, Advertising and Overseas Subscriptions:
Tel: 0870 606 5463 Email: admin@communicationmatters.org.uk
CM Website: www.communicationmatters.org.uk
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Enabling People with Motor Neurone Disease To Discuss their Quality of Life

by Joan Murphy

This study, funded by the Scottish Motor Neurone Disease Association, examined the effectiveness of a low-tech communication framework titled **Talking Mats** (Murphy 1998), as a way of allowing people with motor neurone disease / amyotrophic lateral sclerosis (MND/ALS) to discuss issues concerning the quality of their lives. The study involved five people with MND at varying stages of the illness. They all gave insightful comments about the use of the **Talking Mats** and the framework was modified as a result of their involvement. Overall their views of the **Talking Mats** were very positive and the final framework has the potential to be used with a whole range of people with communication difficulties.

Background

Deteriorating communication is one of the most distressing aspects of motor neurone disease/amyotrophic lateral sclerosis (MND/ ALS). As the disease progresses, the patient's lifestyle undergoes devastating changes including problems with mobility, activities of daily living, communication and relationships. It is at this very time, when the person's communication may fail, that important decisions have to be made.

GENDER	AGE	DATE OF DIAGNOSIS	MOBILITY	HAND CONTROL	SPEECH	HOME SITUATION	WORK SITUATION
Male	57	May 1998	Severely limited	Severely limited	No useful speech (Lightwriter™)	At home with family	Retired Plasterer
Male	49	1980	No useful mobility	No useful ability	Severely impaired (Lightwriter™)	At home with family	Retired Architect
Male	78	Jan. 1999	Slightly limited	Not affected	Slightly impaired	At home with family	Retired Foundry Worker
Male	50	Aug. 1997	Mod. limited	Severely limited	Severely impaired (Computer)	At home with family	Farmer
Female	58	Jan. 1997	Mod. limited	Mod. limited	Slightly impaired	At home with family	Housewife

An examination of relevant literature showed

that there are no measures that allow people with com-

munication difficulties to express their point of view. Bowling (1998) describes a wide range of health measures, but none of them take into account the specific difficulties people with communication difficulties have in completing any of these measures.

In addition many existing measures are based on medical, not on social criteria and do not take into account issues such as difficulties with speech, language, fatigue, poor hand control and literacy while the patient is completing the measure.

It was with these difficulties in mind that this project was undertaken. Its aim was to examine the effectiveness and **adapt** *Talking Mats* (Murphy 1998) for adults with MND. The *Talking Mats* framework is based on three sets of picture symbols, which are presented to the person with the communication difficulty. The symbols are used to:

- 1. Illustrate the **issues** that are important for inclusion in the subsequent interview.
- 2. Depict different **emotions** in order to allow participants to indicate their feelings.
- 3. Represent possible positive and negative **factors** relating to each issue.

Participants

Ethical permission was obtained from the relevant bodies. Five people with MND were approached and all consented to be involved. They were all from different backgrounds and the illness was at different stages and showed different symptoms for each of them. The following table summarises this. Table 1 Participants in Study

Method

Initial Visit

On the first visit to each participant the researcher explained the project, showed the format of the interview and emphasised that comments and criticisms would be particularly welcome. This initial visit also gave the researcher and the participants the opportunity to get to know each other a little.

Preparation of Pictures

Following this visit, the researcher prepared the issues, emotions and factors to be considered in the study. The six main issues were as follows: *people, home, health, work, indoor interests, outdoor interests* - within each a variety of different factors were displayed.

It was emphasised that these were not in any order of importance and new factors could be added at any time throughout the interview. Similarly if any factors were not relevant to the participant they simply did not select them. Seven emotions were used ranging from 'very happy' to 'very angry'. The pictures used were the Picture Communication Symbols¹ which were produced using the software package BoardmakerTM.

Selection of Pictures

For each of the six issues in turn, the participants were invited to select the factors that they considered affected their quality of life. They then placed each one, depending on how that factor helped or hindered their quality of life, under the relevant emotion on a second mat. Each participant selected the pictures in whichever way was most convenient for them: two named the pictures, and three indicated with a head nod while the researcher scanned through them. Blank squares were always presented in order that the participants could add any other factors that were relevant to them. In this way the participants built up a picture of their views on how various factors affected their quality of life for each issue.

Scoring Results

Once the participants were satisfied that the composite picture was a true representation of their views, the researcher recorded their responses on a scoring grid, adding any additional comments. She also took a digital photograph of each completed mat.

Results

All five participants completed the interview and all felt it was a useful and innovative way of allowing them to consider issues relating to their quality of life.

The interview lasted approximately one hour with each person. No one indicated that they found it tiring or irrelevant. The following photographs of some of the completed mats illustrate the views and reflect the individual circumstances of each person.

Participant B had, with time, come to accept many of the limitations which the illness had imposed on him and identified many positive factors in relation to his quality of life:



Figure 1 Participant B - Health

In contrast, Participant A was still very angry about how the restrictions on his mobility, speech and swallowing had damaged his quality of life:



Figure 2 Participant A - Health

For participant C, being able to continue a life long hobby to a modified degree greatly contributed to the quality of his life:



Figure 3 Participant C- Indoor Activities

While for one person the church was a great source of strength, for participant C the Minister (Figure 4, last picture on second row) was an irritation:



Figure 4 Participant C - People

Gardens were a mixed blessing – some people enjoyed sitting in their garden whereas for Participant E, no longer being able to look after the garden was a source of stress:



Figure 5 Participant E - Home

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The car greatly improved the quality of life for one participant but was a source of frustration for Participant D who could no longer drive:



Figure 6 Participant D - Outdoor Activities

For Participant B, although he missed his colleagues and found it hard to keep in touch with them, having no work related stress improved his quality of life:



Figure 7 Participant B - Work

There are many more specific points relating to each person but the most significant aspect of these findings is how personal each set of mats is and how clearly they represent the participants' feelings.

The following generalisations can be made. Some participants realised that, despite their illness, there were a number of positive factors in their lives and those relating to the issue of health did not necessarily overwhelm them. The use of the *Talking Mats* confirmed that most had come to accept many of the changes and limitations in their life as a result of the illness. Relationships and support from family were crucial for people's quality of life and having an interest or hobby that could be continued, even in a limited way, was important in maintaining quality of life.

The issues and factors selected appeared to be relevant to all five participants irrespective of their backgrounds and they all found the use of the Picture Communication SymbolsTM both helpful and enjoyable.

The following comments made by the participants illustrate their views of the *Talking Mats:*

- "A very clever idea"
- "It lets you get behind the disability""
- "The pictures are interesting and fun"
- "The control is with the person with MND"
- "The pictures help me think about the issues"
- "It's like looking in a mirror"
- "It's made me think"

"I said more than I would normally say and I suppose that's good"

- "It's given me food for thought"
- "It's very good"
- "It's easy to do and could be done by anyone"
- "It covers just about everything"

The spouse of one participant commented "*That's the most he's talked for a long time*", and another spouse said, "*It's let him express his feelings*."

During discussions with the participants about how the results from the *Talking Mats* could be used the following suggestions were made:

- To give feedback to individuals.
- To compare how people's views changed with time.
- To allow people to think about their lives.
- To give feedback to carers, MND clinical specialists, Rehabilitation Teams etc. about how the person with MND feels about things.
- To compare patterns of views across a large number of participants from different situations and at different stages of the illness.
- To be used initially to 'take the temperature of an individual' but also allowing the opportunity to come back and explore some issues in more detail

This study has confirmed that the following features of the *Talking Mats* are relevant for people with communication difficulties when considering quality of life issues:

- The *Talking Mats* are simple and enjoyable to use.
- Using *Talking Mats* is non-threatening in that there are no right or wrong answers.
- The factors which influence the quality of life issues can be easily personalised for individuals.
- People with limited hand control and/or those who fatigue easily can use the *Talking Mats* instrument simply by eye pointing or using listener scanning.
- The participants can take as long as they require to consider the pictures, select them, move them around and change them until they are happy that the final composite picture truly represents what they mean.
- The final pictorial representation can be photographed as a permanent record of the participant's views and used in order to bring about change.
- The results can be compared by carrying out the interview on different occasions with the same person.

Four alterations to the original tool were made as a result of comments made by participants and the observations of the researcher:

- 1. Some of the emotion pictures were altered e.g. *frustration* was added.
- 2. Instead of each emotion having a descriptive label it was felt it would be simpler and more relevant to give each emotion a grading from 1 (very positive) to 7 (very negative).
- 3. The development of a coding grid with a space for comments allowed for a more detailed summary of the person's views than simply having a photograph of each mat.
- 4. Some new pictures were added e.g. hospice, family mealtimes.

Feedback to Participants

An essential part of research is feedback to the participants. As well as producing materials and reports the actual process of research should provide direct benefits to participants. Each participant in this study appeared to find the actual involvement in the research enjoyable and interesting and several commented that it gave them considerable food for thought. No one found it distressing or negative. In two instances their spouses were present and they too found it a useful exercise. All participants have been given a copy of the photographs of their completed mats and the option of receiving a copy of the final report.

Conclusion

This adapted tool appears to be an effective way of allowing people with MND, both with and without a communication

difficulty, to consider their quality of life and express their views on what factors improve and what factors hinder their lives. The real value of the tool will depend on how a person's quality of life is improved by patients, carers and staff making appropriate changes as a result of the views expressed on the mats.

Joan Murphy Research Speech and Language Therapist AAC Research Unit, Department of Psychology University of Stirling, Stirling, FK9 4LA, Scotland Tel: 01786 467645 Fax: 01786 467641 Email: joan.murphy@stir.ac.uk

Joan Murphy has produced a training package 'Have I got Views for You!' based on this study. Please contact the above address for further details.

¹ The Picture Communication Symbols (PCS) are ©1981-1997 Mayer Johnson Co. and are used with permission - Mayer-Johnson Co., P.O. Box 1579, Solana Beach, CA 92075, USA

REFERENCES

Bowling, A.(1998) Measuring Health Open University Press Murphy, J. (1998). Talking Mats: Speech and language research in practice. *Speech and Language Therapy in Practice*, Autumn 1998, 11-14.

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Supporting Adults with Learning Difficulties: Integrating Communication Technology into their Daily Environment

by Deborah Jans

This paper was first presented as a series of training seminars for staff and carers working within group homes for people with learning difficulties. It may be found useful as the basis for an introductory presentation on AAC to similar groups, that readers might be asked to do.

Introduction

Within the present social climate, many long-stay institutions are closing and individuals with learning difficulties of varying degrees are now living within the community. The communication needs and expectations of these individuals has changed. Furthermore, the needs and expectations of their carers and facilitators has also changed. This paper will discuss how communication technology can influence and benefit the daily lives of individuals with varying degrees of learning difficulties.

What is Communication?

Communication can mean different things to different people. It can be a simple gesture, a smile, words, pictures or a set of isolated movements. Whatever your mode of communication is, having a communication system can influence your life.

Communication is:

- about being given opportunities
- about choices and decisions
- participation and being included
- having one's say
- about having control
- identifying and voicing one's own views
- about being with other people and contributing

Communication can be very powerful. But what if an individual does not have conventional or 'natural speech'?

What Communication Technology Can Offer

Communication technology can offer individuals with learning difficulties a chance to participate in daily activities. This can lead to varying degrees of independence and participation. Figure 1 illustrates a step-wise progression toward independence taking the user through a variety of stages.



it may not be reasonable or realistic to expect a young person to cook the entire meal for a group of five residents and staff in his/her house. However, he/she may be able to participate in the activity by helping to mix one portion of the meal through using a switch and a switch latching box to operate an electric blender. Another request which is often made of individuals with learning difficulties is to take part in Members' Councils in day centres or in their homes. Again, it may be unrealistic for these individuals to be able to take part independently in these activities, but they may be able to participate in other related activities which involve choices and decisions, such as planning daily menus for their house. The issue here is to provide communication technology that will allow individuals to progress through different stages of participation on their way to independence. We will return to this idea on graded steps through participation later in this article.

Types of Communication Technology

There are different types of communication technology within the field of AAC: **Low Tech, Light Tech** and **High Tech**.

Low Tech

Low tech communication systems come in a variety of sizes, shapes and for a variety of purposes. A low tech augmentative communication system might take the form of simple picture cards, menus, diaries, passports, books, boards, place mats, and so on. Good design and layout are important for both aesthetic and functional use. A clear well organised and attractive layout is more likely to encourage accurate and enthusiastic use than one which is boring or cluttered.

Colour can also be a powerful element of designing low tech boards, etc. For example, topical vocabulary can be colour coded. This may be particularly helpful for visually impaired users. Colour can also be used to highlight specific areas of a board. For example, vocabulary to identify feelings, if this is seen as a priority for communication at any given time.

Consideration must also be given to what the individual will use to retrieve vocabulary. This can vary from photographs, digital images, symbols, text or a mixture of text and symbols. There are a number of recognised symbol systems which are now in electronic format. The main aim is to identify which symbol system the user is able to identify and use and then use this consistently. Additional factors will be identifying the communication partners which will probably be other resiMacaw / Spokesman (Toby Churchill) Advertisement dents with learning difficulties as well. This needs to be taken into account. We want to promote communication between residents not just carers and staff.

It is also important to decide what you are going to put on your low tech aid. Appropriate vocabulary needs to be identified by staff, family and the user themselves. Vocabulary should provide a variety of uses not just to request basic needs but also to comment on other people's communication, to negate what someone has said or maybe just to introduce humour into the conversation.

Low tech systems can be static or dynamic. Traditionally, low tech communication systems have been boards or books which have a finite set of vocabulary. A new technique developed at the AAC Unit, University of Stirling, **Talking Mats**, is a low tech framework which is dynamic in nature. This framework can be used with any symbol system or written text. Individual symbols or words can be individually mounted with Velcro on a mat. Users can eye point or finger point to the desired response which then can be transferred to a blank mat. At the end of the discussion or conversation, the facilitator and user will have built up a talking mat which represents the individual's views on a given subject. This can then be photographed to keep a record of the outcome of the conversation.

We have found this framework very useful for encouraging an individual to express feelings and ideas at any given time in a conversation. It can also be used to encourage discussion between individuals in a group situation and then expanded to produce a consensus talking mat that the group can agree on. For example, all residents in a house can compile on a mat which house rules they may want to implement. These can then be discussed with the whole group and one 'master' group talking mat can be produced which takes into account all the residents concerns and ideas.

Light Tech and High Tech Aids

There are many different voice output communication aids now available. There are single message devices which will allow the individual to lead an activity, or comment on what is going on around them. These can be linked with battery operated devices to link communication and cause and effect. For example, we have adapted a battery operated pencil sharpener which can be activated through a Big Mack which may provide a message such as, "I will make sure your pencil is sharp." This message would serve as an introductory message to the action of sharpening pencils.

There are also mini message devices which allow individuals to make choices within their daily lives. Facilitators and carers must allow individuals the opportunity to make choices in their lives. It may be a choice between sitting on a bean bag or a mat or having a hot or cold drink. Choices must be real choices that are appropriate to the environment and situation. When identifying appropriate choices for an individual, it is best to identify graded steps through which the individual can progress over a period of time. When discussing choices and graded progression, a useful resource is the **Speaking Up**, **Speaking Out** Advocacy pack published by *Communication Matters*. Within the Practical Guide part of this pack, there are worksheets to follow to allow facilitators and individuals to identify appropriate and realistic choices. Many individuals may start out using simple gestures, facial expressions and body language to communicate. The individual may then progress through different types of AAC. The main aim is to build on skills from previous levels and experiences to achieve the maximum potential for each individual.

Many individuals with learning difficulties will benefit from the use of a variety of different types of technology in different environments. For example, an individual may use a low tech place mat during meal times and a high tech aid for taking part in discussions. In this way, the user is using different skills and different technology to meet the demands of the situation. Another example of this might be a young adult with severe dyspraxia who may use his verbal speech for a few single words. For longer utterances, such as relaying information about a family holiday, they may require a voice output communication aid. Appropriate communication (using whatever method) is always the primary goal (not the use of technology for its own sake).

Another way people are beginning to use communication technology is to enhance language and/or memory skills. Some simple communication aids can be useful as aids to memory for individuals with poor attention span and/or limited memory skills. For example, one young man living in a group home found it difficult to remember what activity he was going to take part in on a particular day. The staff in his house programmed a One Step communicator with a message to remind him that Monday was swimming and not to forget his swimming pack. This message was available to the individual when he woke up in the morning.

Communication technology can also be used during small group activities. Many of the aids allow for a variety of switch inputs to allow different group members to access different messages during one activity. In addition, individuals can use the aid to lead a group activity. The main objective for each user is for the individual to feel **integrated** into his environment not **isolated**.

Implementation

Careful thought needs to be given to how to implement a communication system with an individual or group. It may be best to consult other members of the team and outline a written plan for implementation. The written plan can be as simple or as complex as is necessary. A plan should include what is to be implemented, how implementation should go forward and who is responsible for carrying the plan out. Consideration should also be given to the type and amount of communication opportunities and appropriate vocabulary. This allows for all individuals to understand and use the system which has been agreed as well as providing for a record keeping system to be established. This allows progress to be charted.

Another way to aid the implementation process is to construct a diary or Passport for the individual. This will allow the user to explain how to use the system to others. This can be particularly helpful when there is a change of staff or carer, or when there is a change of living conditions.

Another implementation idea is to have a set space on a wall or door which has information about how communication systems are used within a house or centre. Be careful, though, that any confidential information is removed.

continued on next page...



A Message to All Readers of the CM Journal from Prue Fuller, ISAAC President

In 1989 the Governor of West Bengal T.V.Rajeswar, sent his best wishes to a very special gathering of people from all over India. It was the occasion of the 'The Sounds of Silence' Conference, the first regional ISAAC Conference held in Calcutta. Those of us not from India who were fortunate enough to be there quickly learned that many of the speakers from different parts of India were deeply committed to AAC and determined to ensure that people who needed AAC could have access to it. It was one of those conferences you never forget. We learned a great deal and came away buzzing with excitement and admiration for new found friends who were achieving so much, often in unbelievably difficult circumstances.

The Spastic Society of Eastern India, which hosted the '89 conference, was started by two parents who wanted their children with cerebral palsy to have a chance to learn. The Society (now the Indian Institute of Cerebral Palsy) has grown exponentially from those early days when people met, I'm told, in a hut with a tin roof. The Institute now has its own custom built building and numerous outreach groups across India. AAC, however, was always recognised as important and Bliss Symbols were used with the children who came to school way back in the 1970s. Since that time the Centre has embraced different AAC systems including technology. But only a few have access to high tech systems. I remember heated discussions in 1989 about the ethical puzzle, 'How right is it to spend money (for high-tech) on a tiny minority of children with disabilities when the vast majority have nothing at all?' Wisely, the Centre has continued to carefully explore the potential of high-tech but at the same time has concentrated on training parents, communication partners and professionals and on the dissemination of information so that people all over India can learn about AAC. Anne Warrick's ISAAC Press

book, *Communication Without Speech*, features, among others, augmented communicators from Calcutta.

It is about Anne's book that I am writing to you. With their intensive training programmes, the Indian Institute of Cerebral Palsy needs training materials that are relevant to the conditions not only in vast cities like Calcutta, but also in isolated rural areas. Anne's book with it's breadth of knowledge and practical information about using effectively a range of AAC systems is just the sort of material needed. What is more, it now has additional questions attached to each chapter that Anne has written especially for Poland where it is to be used as part of a distance learning pack. The United Nations Umbrella Project has funded the translation of Communication Without Speech into Polish, but no one will fund the translation into Indian languages. Some children in India (often the most wealthy) are taught in English, but most of course speak their own language, as do their family, friends and teachers. ISAAC has been asked if Communication Without Speech can be made available in Bengali and Hindi. We are trying to raise the money. Thanks to one of the CM trustees we have found an organisation in Manchester that would be prepared to do the translation and we are also looking at costs of the translation if it were done in Calcutta. We need to raise £3,700 for the translation into Bengali and the same amount for Hindi. Then we have the cost of printing. We've already raised over a thousand with local fund-raising efforts. But there is some way to go. It would be wonderful if Communication Matters members could help get this project off the ground. Anything you could send, however small, would be wonderful. It all adds up and we can start with one language.

So I'm throwing down the gauntlet! If we really want AAC to be effective across the world, we have to be active. *Please send contributions, made payable to ISAAC, to 4 Benson Place, Oxford OX2 6QH, UK.*

Supporting Adults...continued from previous page

No matter what strategy you adopt to implement a communication system, consideration needs to be given to the availability of equipment, involvement of the user in all planning and decision making, a commitment from all concerned, and identified procedures and a time scale for review and updating of communication needs.

Advocacy

Advocacy is another area that is increasingly coming to the forefront. Advocacy allows an individual to have his/her views heard. In order for an individual with a learning difficulty to take part in the advocacy process, a clear and effective communication system needs to be in place. Establishing a consistent communication system might be the first step towards initiating the advocacy process. Here again, we now have a resource pack which addresses this issue; *Speaking Up and Speaking Out* contains a handbook and practical guide to help facilitators communicate with individuals with severe communication impairments.

It is clear that we are living and working in a society where individuals with learning difficulties will be participating in community life. The use of communication technology can certainly make this participation possible.

Deborah Jans, Coordinator & Specialist Speech and Language Therapist, KEYCOMM St Giles Centre, 40 Broomhouse Crescent Edinburgh EH11 3UB Tel: 0131 443 6775

HELPFUL RESOURCES

- Speaking Up, Speaking Out: Pathways to Self Advocacy, Handbook and Practical Guide, available from Communication Matters, c/o ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR Tel: 0870 6065463 Email:admin@communicationmatters.org.uk.
- Personal Communication Passports, available from CALL Centre, University of Edinburgh, Paterson's Land, Holyrood Road, Edinburgh, EH8 8AQ Tel:0131 651 6236 Fax: 0131 651 6234 Email: call.centre@ed.ac.uk
- Talking Mats, A Low Tech Framework to Help People with Severe Communication Difficulties Express their Views, available from the AAC Research Team, Dept. of Psychology, University of Stirling, FK9 4LA Tel:01786 467645 Fax: 01786 467641 Email: joan.murphy@stir.ac.uk

Parents and Carers Page

by Katie Clarke

ast year I ran an informal workshop at *Communication Matters* National Symposium. The idea was for us to get together in groups to look at ways in which we could improve communication support services in their links with parents, carers and users.

We had a good turnout and a real mixture of professionals, carers and users in each group - all sharing their wide range of experiences and invaluable ideas.

On of the first things we talked about together was ways we could improve resources for carers and users. I do feel that if we can empower parents and carers then they in turn will feel better and cope better and therefore this will be more beneficial for the user they are supporting. After a great deal of discussion we came up with the following 'wish list':

- 1. Involving parents from the word 'go'
- 2. Lots of sensitive, early communication by professionals
- 3. More information for parents
- 4. Meetings with 'everyone', 'anywhere' every 6 months
- 5. Informal get togethers for parents/carers
- 6. SLT meetings with parents to discuss how child is communicating at home/other contexts
- 7. Questionnaire to parents regarding AAC devices
- 8. Parents to help with appropriate vocabulary for AAC high and low tech devices
- 9. Child introduced to AAC as early as possible
- 10. User to be encouraged to choose own vocabulary and to programme devices
- 11. Peer support
- 12. User groups more organisations needed to set up groups
- 13. Internet access and support

We also felt that it was important to support those professionals working in the field of AAC and ways of doing this included:

- High levels of inter-disciplinary and multidisciplinary support
- Support of other professionals
- Must be a two-way process
- Staff training and awareness
- More peripatetic teachers

The workshop finished with a brainstorm of ideas for *Communication Matters* to work towards that would be of benefit to parents/carers of users with AAC:

- More handouts for everybody at conferences
- Journal to have a news/suggestion/open forum page

- Newsgroup set up on the Internet and a be-friending scheme
- Summer school for young users
- Facilities for young users at conference

The two hours past far too quickly - the groups could have done with at least half a day as there was a wealth of ideas and discussion in the air.

If anyone feels like writing in to *Communication Matters* on ways they have improved links with families then it would be interesting to read about positive practice in this area.

At the next CM Conference in September, I would like to run another workshop in a similar way. This year we want to look at 'AAC in the Home v AAC in a Structured Environment'. We do hope that as many if not more of you can meet us to exchange views and ideas in an informal way.

In the meantime life with the Clarke family has become slightly more chaotic with the arrival of our twins Jake and Samara in April. Hopefully, I will be bringing them along to Lancaster so you will get to meet them then! So I am now going to go and add their names onto Nadia's Family Page of her Dynavox...

> Katie Clarke (CM Trustee) Communication Matters c/o ACE Centre 92 Windmill Road Headington, Oxford OX3 7DR

AAC in the Home: Is it Possible?

Katie will be leading another workshop at this year's **CM'99 National Symposium** at Lancaster University. Her session on Tuesday 28 September will explore some of the day-to-day practical issues of using AAC systems in the home. Details of CM'99 and how to register are on page 13.

Helping our Children Communicate

Katie will also be presenting a workshop at The *Challenge of Communication* on 6 October in Harrogate, where she will be talking about the range of aids and equipment she uses with her daughter. More details of this event can be found in Diary Dates on page 16.

Contributions Welcomed

We need your news, views, comments, articles, etc. for this page...

Come on, send something to the Editor today!

Purchasing Communication Aids for the UK National Health Service: The Role of NHS Supplies by Mike Ferguson

Inlike environmental assistance devices, communication aids have been largely regarded as ad hoc puchases within the UK's National Health Service and as such, have not been included in national purchasing contracts. Availability was dependent on a variety of factors and trusts arranged the provision of communication aids without the benefit of a structured national framework.

However, in July 1998, NHS Supplies (a department of the UK's National Health Service) was instrumental in setting up the *Electronic Assistive Technology* (EAT) Group — which was specifically aimed at influencing the national supply chain, at strategic level, to take a holistic view in providing electronic assistance for a more comprehensive range of requirements. Included in the group were purchasing experts from NHS Supplies, together with clinical staff, therapists, consultants in rehabilitation medicine and representatives from the *Medical Devices Agency* (MDA).

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At the group's second meeting, in September 1998, amongst the topics under discussion was the renewal of the national contract for environmental control devices, which have featured in NHS contracts for many years. When group members discovered that communication aids were not covered by the existing contract, it became apparent that they considered these 'Cinderella' items of the electronic assistive technology world were long overdue for inclusion in NHS contracts.

Historically, provision of communications aids had been fragmented, with products and services funded via a number of complicated routes, including education and social services, charities and the health service, with no standardised approach and wide geographical variance as to which users received what level of equipment and services. As with most innovations, deciding what to do was the easy part. Because communication aids had not previously featured in NHS contracts, the marketplace was a relatively unknown quantity.

NHS Supplies conducts extensive analysis and research into new product markets when renegotiating or setting up contracts, but consultants and clinical scientists in the EAT group were unwilling to see any delay in incorporating communication aids into electronic assistive technology contracts. In order to prevent any unnecessary delays, NHS Supplies' buyers took on the challenge, undertaking an intensive market research programme to a shortened timescale, evaluating the optimum method of establishing and influencing an entire new supply network.

It was decided that the best way forward was to develop a more holistic approach to the new contract, aiming to offer integrated solutions, both for users with multiple assistive technology needs and their clinical and professional advisors. This would mean that trusts would have easy access to a structured market, with clearly defined pricing and monitored service delivery. This meant easier budgeting and enabled planned purchasing for the trusts. In addition, if a user required a combination of devices to assist them, the contract provided for liaison between providers of the technology to iron out any technical queries relating to the compatibility of the devices.

With an NHS yearly spend of around £5.5 million for environmental control equipment coupled with an estimated annual value for the communications aid supplies market of approximately £4 million annually, both suppliers and customers had a lot to gain by working together to develop this untapped potential.

Prior to drawing up any tender documentation, NHS Supplies consulted the industry, including the *Communications Aids Suppliers Committee* (CASC), communication centres and clinical professionals such as speech and language therapists. With the very small number of British manufacturers supplying this technology, it was crucial that enough were included to assure price competitiveness and prevent destabilisation of the market and users waiting in vain for equipment if one manufacturer happened to cease or vary production.

As part of NHS Supplies development of the new contract process, applicants will be required to undergo rigorous laboratory assessments of their equipment together with stringent analysis of the service levels they were offering. Only when these standards have been attained will companies be eligible for inclusion in the contract. This evaluation programme is funded by NHS Supplies, explained Mike Ferguson, senior buyer in the rehabilitation team at NHS Supplies. The process is ongoing so that as new products are made available

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Th	e health service contract will cover all the key
cor	nmunication and environmental assistance aids
• • •	

they in turn undergo the same tests to ensure uniformity in quality, service delivery and effective performance.

The health service contract will cover all the key communication and environmental assistance aids from the major suppliers and manufacturers. Those that are currently undergoing the evaluation process will be on line later this year. As Mike Ferguson explained, the main benefits of the new contract, which started in April this year, are that everyone has been involved in making it as effective as possible. "We consulted everybody – users, suppliers, manufacturers, clinicians, therapists. It highlights the benefits of working in partnership. Environmental control systems suppliers have forged links with communications aids suppliers. This has made it possible to provide integrated solutions for user's particular needs. There is access to expertise, interfacing between all those involved - there is a real sense of working together."

> Mike Ferguson Senior Buyer, NHS Supplies Premier House, 60 Caversham Road Reading RG1 7EB Tel: 0118 980 8819



Trade Exhibition

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Distinguished AAC User Award

AAC users, parents and professionals

from all disciplines (including

education, healthcare, and engineering) will be present.

Guest Speakers

subsidised places (£50) for AAC users

plus their parent or personal assistant

RING NOW

.....

For a CM'99 booking form, ring

Communication Matters

0870 606 5463

Email: admin@communicationmatters.org.uk

Vol. 13 No. 2



Trustees News

Announcing Communication Matters' New Website

The Trustees are very pleased to announce that Communication Matters' new Website is now open for visitors to learn more about the work of CM and to find out about CM's publications and events. Visitors can also join Communication Matters on-line, or order journals, newsletters and books.



In designing the look and feel of the Website, Patrick Poon and Simon Churchill consulted an array of guidelines for making Websites more accessible to people with a range of sensory and physical disabilities. Due to limited resources, it was decided to concentrate the effort on making the CM Website more easily accessible to users of AAC systems, and to make the layout as clear, simple and attractive as possible.

Please do browse the CM Website and tell us what you think by leaving your comments on the Bulletin Board or Guestbook, or you can send them to the CM's new email address: admin@communicationmatters.org.uk

isit



There are pages containing news and issues relevant to AAC Users and parents and carers. There is also information about CASC, its Road Shows and brief details of the products and services offered by each CASC member.



News from CASC

Communication Aid Suppliers Consortium

by Simon Churchill, Chair of CASC

CASC has now been in existence for 10 years and has grown considerably during this period. For the past five years Ken Pennington has chaired CASC until he retired from this position in April this year and I have now succeeded him as Chairman. On behalf of all CASC members I would like to thank Ken for all the hard work he put into this activity, and in particular for initiating and developing the CASC Link Days/Road Shows which have proved an enormous success for both participating members and delegates. The Road Shows allow the members to explain and demonstrate their products in far more detail than they can at an exhibition, and the small groups format encourages questions from the delegates, making them interactive and informative sessions. Another key activity over the past few years for CASC members has been detailed understanding the Medical Devices Directive and CE marking with all the ramifications that this has entailed, and gaining clarification on the changes from the old NHS Environmental Control Contract to the new Electronic Assistive Technology Contract which now incorporates communication aids.

Recognising that communication aids and environmental control systems are increasingly becoming interconnected and integrated, CASC decided to expand its membership a few years ago to include environmental control companies and invited Possum and Hugh Steeper to join. It was also decided last autumn to allow commercial service providers as well as equipment suppliers to become members, and Vocation have now joined the organisation. Current CASC Members are: *AbilityNet, Cambridge Adaptive Communication, Crick Software, Easiaids, Don Johnston, GEWA UK, RSL Steeper, Liberator, MARDIS, Morphonics, Possum Controls, Ritchie Electronics, Sunrise Medical (Dynavox), Techcess, Toby Churchill, and Vocation.*

CASC recently also decided that in order to move forward as an organisation it was essential to have a written constitution and we have now formulated and agreed a Constitution and Code of Practice. The key elements are described below.

Principal Activities

- Organisation of and participation in Road Shows in the UK to demonstrate the members' products.
- Forum to discuss areas of common interest and to address issues relating to the Communication Aid industry.
- Liaison with Communication Matters:
 - The Chair of CASC is automatically a co-opted Trustee of CM if they are not already elected by CM as a full Trustee.
 - Any CM Trustee can attend a CASC meeting, but will not have voting rights unless they are also a member of CASC.
 - CASC can report their activities and give details of Road Shows in a special CASC section in the CM Journal.
 - CASC will provide CM Trustees and members with an annual report of activities (to be published in the CM Journal).
 - All information and documents issued by CASC will incorporate the CM logo/wording, i.e. CASC is a subgroup of *Communication Matters*.

Aims of CASC

- 1. To create an improved awareness of the state of the art of AAC.
- 2. To advance the knowledge of AAC.
- 3. To manifest support for organisations in the field of AAC.
- 4. To act in the best interests of customers.
- 5. To promote a professional approach to the development, manufacture and service of augmentative communication systems with the emphasis on quality assurance.
- 6. To maintain a code of practice.

CASC Membership

A commercial supplier of AAC products and/or services who is also a Commercial Member of *CM* is automatically eligible to become a Member of CASC if they so wish.

Code of Practice

The following is not a legal definition, but a spirit to be followed:

- 1. CASC members will provide an honest presentation of the products and services they offer.
- 2. CASC members will not misrepresent their competitors' products or services.
- 3. Members will not misrepresent their demonstrations or consultations as Clinical Assessments.
- 4. Recognising that no individual product meets everyone's needs, CASC members will freely recommend alternative Communication Aids or products to clients if they believe these alternative technologies might be more appropriate to meet the clients needs. Our goal is always to find the most suitable solution for the client.
- 5. CASC will supply information to members to keep them abreast of regulatory requirements.

Change of Name & CASC Road Shows

At the same time, we decided to change our name from the *Communication Aid Suppliers Committee*, as it had been called, to the *Communication Aid Suppliers* **Consortium** since it reflects our membership and organisation more accurately.

In order to accommodate the larger membership, we have had to make slight modifications to the **CASC Road Show** format to accommodate more members participating than the previous format permitted. We have also decided to strengthen our links to *Communication Matters*, of which we are a sub-group, and the Road Shows are now being organised by Patrick Poon who now also handles our accounts. Patrick is currently planning CASC Road Show tours in Scotland and Ireland. The next Roads Shows in 1999 are on: **21 October** at ACE Centre Oxford, and **15 November** at ACE Centre North. If anybody is interested in hosting a CASC Road Show and would like to know more about the requirements, please contact Patrick on Tel: 08706065463 Email: admin@communicationmatters.org.uk

Web Site

You can find out more about CASC and the Road Shows by browsing the new *Communication Matters* Website at www.communicationmatters.org.uk (see opposite page). You will also find a brief description of the products and services offered by each CASC member and a link to their Website.

> Simon Churchill CAS C Toby Churchill Ltd, 10 City Business Centre Hyde Street, Winchester SO23 7TA Tel: 01962 842792 Email: simon_churchill@compuserve.com

Diary Dates

Dunfermline

17 September 1999

Creating A Communicative Classroom

This Study Day is a unique opportunity to learn from a leading expert on how to encourage language and communication in the classrooms of children requiring augmentative communication support. (This Study Day is repeated on 29 September 1999 at Lancaster University.)

Venue: Dunfermline Conference Centre Cost: from £75 (subsidised places from £40 for AAC Users and parents)

Contact: SCTCI, Westmarc, Southern General Hospital, 1345 Govan Road, Glasgow G51 4SF Tel: 0141 201 2619 Email: sctci@waacis.edex.co.uk

23 & 24 September 1999

University College London

Language, Reasoning and Early Mathematical Development International Conference with presentations and workshops. Contact: University College London Tel: 0171 504 4204

26-28 September 1999 CM'99 National Symposium



Lancaster

A Three Day residential symposium on augmentative and alternative communication, with practical workshops, platform and video presentations, case studies & research papers, poster displays, guest speakers, and trade exhibition.

Venue: Lancaster University Cost: from £210 (also subsided places of £50 for AAC Users, parents and carers)

Contact: Communication Matters, c/o ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR Tel: 0870 6065463 Email: admin@communicationmatters.org.uk

29 September 1999



This Study Day is a unique opportunity to learn from a leading expert on how to encourage language and communication in the classrooms of children requiring augmentative communication support. (This Study Day also held on 17 September in Dunfermline.)

Venue: Lancaster University Cost: from £75 (subsidised places from £40 for AAC Users and parents)

Contact: Communication Matters, c/o ACE Centre, 92 Windmill Road, Headington Oxford OX3 7DR Tel: 0870 6065463 Email: admin@communicationmatters.org.uk

6 October 1999

Harrogate

A one-day conference with exhibitions and workshops on ways of meeting the needs of people with communication difficulties. Open to delegates from statutory authorities, industry, voluntary organisations, users and carers.

Venue: Pavilions of Harrogate Cost: £65 professionals;

£25 voluntary organisation; £15 users/carers

The Challenge of Communication

Contact: Ann Morris, Crimple Lodge, Fullwith Mill Lane, Harrogate HG2 8HJ Tel: 01423 871713

7 October 1999

ACE Centre, Oxford

Technology for Learners with Physical and/or **Communication Impairments: Assessment Issues** Contact: ACE Centre Tel: 01865 759800

21 October 1999



CASC Road Show at ACE Centre Oxford Contact: Gillian Nelms, ACE Centre Tel: 01865 759800

28 October 1999

CALL Centre, Edinburgh Voice Recognition in Education: Introduction

An introduction to the use of voice recognition systems, aimed at people with little or no experience of the systems, and who are considering their use in an educational context. Cost: £40

Contact: CALL Centre, University of Edinburgh, Paterson's Land, Holyrood Road, Edinburgh EH8 8AQ Tel: 0131-651 6235/6 Fax: 0131 651 6234 Email: call.centre@ed.ac.uk

30 October 1999

University of York

Special Needs Technology 2000

A one day conference & exhibition with workshops and discussion sessions on special needs education, music therapy and assistive technology.

Contact: Judy Parker, Dept of Electronics, University of York, Heslington, York YO10 5DD Tel: 01904 432319

4 November 1999

CALL Centre, Edinburgh

Symbol Software for the PC

This course is for people who work with adults or children using symbols for communication or to support literacy. Cost: £40 Contact: CALL Centre Tel: 0131 651 6235/6

10 November 1999

Birmingham

RARE: Recent Advances in Rehabilitation Engineering

The programme comprises presentations on service issues, practical experience and research; and a commercial exhibition. Venue: Birmingham Botanical Gardens Cost: £85

Contact: Centre of Rehabilitation Engineering, King's Healthcare Rehabilitation Centre, Bowley Close, London SE19 1SZ Tel: 0171 346 4274

13 November 1999

University of York

Oldham

Afasic Parents' Conference 1999

Workshops will include Social Communication Skills, Statementing, Problem Solving, Tribunals. Venue: Univ. of York Contact: Afasic, PO Box 2320, Hove BN3 6RS Tel: 01273 381009 Email: carol.afasic@lingwoods.demon.co.uk

15 November 1999

CASC Road Show at ACE Centre North Contact: ACE Centre North Tel: 0161 627 1358

18 November 1999

Making Use of Computers for Early Literacy

This hands-on course will focus on developing early literacy skills through manageable computer-based tasks. It is aimed at teachers or support staff wishing to create a varied working environment for all pupils, including those with SEN. Cost: £40 Contact: CALL Centre Tel: 0131 651 6235/6

19 November 1999

Tools to Support Writing

This is an introduction to technology for people with physical writing problems, or difficulties with spelling or composing text. It will cover laptop computers and the use of spellcheckers, talking wordprocessors and word predictors. Cost: £40 Contact: CALL Centre Tel: 0131 651 6235/6

1 December 1999

ACE Centre, Oxford **Creating and Implementing Communication Systems** Contact: ACE Centre Tel: 01865 759800

17



CALL Centre, Edinburgh

CALL Centre, Edinburgh

`Whisper Voice' Enhancement Aids

by Dennis Netcott

This article looks at the range of voice enhancement aids available for people with 'Whisper Voice' difficulties

Introduction

The communication difficulties experienced by people with 'Whisper Voices', for example due to laryngectomy, has never been easy to solve, partly because of the variable frequency loss in each person, and limited technology. The existing range of commercially available aids fall into two main categories, those for **Group** and those **One-to-One** situations:

Group Situations - Voice enhancement aids for use in group situations (e.g. in a conference room or classroom) are readily available in the form of standard power amplifiers and radio microphones, for example, the AN-100 (£500 plus VAT)², WA 100 (£440 including VAT)³. Where more amplification is required, a bespoke system might be necessary, e.g. a combination of the *Fostex SPA 12* amplifier and *Audio-Technica* radio microphone (£700)⁴. However, portability is an issue where greater amplification power output is required: the size and weight of the equipment usually increase with power output.

One-to-One Situations - Equipment that is worn on the neck or body is limited both in aesthetic and technical specifications: the weight of the equipment restricts what is both practical and acceptable to the wearer. The choice of microphone, for example, a headband or collar style, can be a problem because of technical difficulties in matching such standard professional microphones to the limited number of body-worn voice amplifiers; prices often become unrealistic,

Microphones

For 'Whisper Voice' sound enhancement, it is **essential** that any microphone can be positioned as close to the mouth as possible (preferably to the side) in order to gain maximum benefit. Windshields, usually made of foam rubber, are necessary but this can often act as a deterrent for the user due to their bulbous shape and size. The latest *Beyerdynamic¹* microphone does not require a conventional windshield as one is incorporated in the head of its slim-line design. Many variations of microphones are made by major Audio manufacturers, including Collar, Headband, Lapel, Tie-clip and Behind the Neck styles. Suppliers such as *RWSalt*⁹ of Birmingham are able to provide an extensive range of amplifiers and microphones, but it must be noted that this company, like others in the field, are dealing with the professional sound industry. However, they have been most helpful in providing information and advice when requested.

Manufacturers' Influence

Microphone manufacturer, *Beyerdynamic*, would be prepared to consider adapting the specification for their latest 'minimic', if necessary and if approached. One major specialist company thought that they may have to re-design their equipment to permit compatibility with other commercial microphones, but this may not be a commercially viable proposition. One-toone communication system suppliers, like *Easiaids*⁵ and *Kapitex*⁶ serve a 'niche' market and are not currently able to consider any research and development programmes. Universities local to the Bristol area (where the author is based) have been approached, but the limited demand for this type of communication aid is insufficient to warrant the expenditure into research.

Ergonomics and Developments

The aesthetic qualities of the body-worn equipment is a difficult area; a large rectangular box at chest level is not acceptable to many! Mr J Berman⁷ of *iDC*, a design consultant in Bristol, has stated that he would be able to improve the aesthetics, technical specifications and the ergonomics of existing products. Unfortunately, there is a high price to pay as consultancy fees would be in the order of £250 to £300 per day. For those who have the electronics expertise, a cheaper alternative would be to design and build a Do-It-Yourself battery powered voice enhancer using readily available electronic components. For example, all the necessary parts can be obtained from *Maplin Electronics*⁸ for about £50: small loud-speaker slightly bigger than a 50p coin, pre-amp, potentiometer, etc. The cosmetics would then be a matter of opinion for the user.

Conclusion

Further research and development is necessary to improve voice enhancers, but progress is likely to be minimal and slow without a cash injection. For potential users of such equipment, they need to be as **forceful** and as **specific** as possible about their individual needs when talking with manufacturers and suppliers – remember it is a supply and demand 'market place'. For those with some technical expertise and time, the fact that improved designs can be made using relatively simple and readily available electronic components has to be a positive step forward.

Dennis C Netcott, Dip. OLD. MIPD Regional Disability Service, 19 Eagleswood Business Park, Woodlands Lane, Bradley Stoke, Bristol BS32 4EU Tel: 01454 848512

Editor's note: Would any readers who has any further advice on this subject please contact the author or this Journal.

REFERENCES

- 1 Beyerdynamic Ltd (Microphones), 17 Albert Drive, Burgess Hill, West Sussex RH15 9TN Tel: 01444 258258
- 2 BioAccoustics Ltd, (Powered Amplifiers, etc.) 26 Guildford Street, Luton LU1 2NR Tel: 01582 431000
- 3 Bristol Sound Systems (Powered Amplifiers etc.), 186 Kellaway Avenue, Horfield, Bristol 7 Tel 0117 9247771
- 4 Cheltenham Stage Services (Fostex Powered Amplifier/Audio-Technica/TOA Microphones), Unit 31, Ullenwood Court, Nr Cheltenham. Glos. GL53 9QS Tel: 01242 244978
- 5 Easiaids Ltd (Freiburg), 5 Woodcote Avenue, Purley, Surrey CR8 3NH Tel: 0181 7630203
- 6 Kapitex Healthcare Ltd, Kapitex House, 1 Sandbeck Way, Wetherby, West Yorks LS22 7GH Tel: 01937 580211
- 7 iDC (Mr J Berman, Consultant), 58 Northcote Road, Bristol B55 8EW Tel: 0117 9396688
- 8 Maplin Electronics, 302-306 Gloucester Road, Horfield, Bristol 7 Tel: 0117 9232014
- 9 R W Salt, Unit 2 Oak Court, Sandwell Business Park, Crystal Drive, Smethwick, West Midlands B66 IQG Tel: 0121 5443323

Talk:About (Don Johnston) Advertisement

Chatterbox Day at Motherwell College

by Tracy Canavan, Iain Smith and Stuart Devlin

t the recent **Chatterbox Day** at Motherwell College College in June 1999, three senior pupils from Ashcraig School gave short presentations about their lives. This was the first time that they had given a talk in public and they were all very nervous beforehand – however, on the day, they performed superbly with word perfect performances! Ashcraig School is a Secondary school run by Glasgow City Council for children with physical disabilities. There are a number of children at the school using high-tech augmentative and alternative communication aids: Lightwriters, DeltaTalkers and TouchTalkers. Tracy, Iain and Stuart all use LLL. Tracy and Iain have DeltaTalkers and Stuart has a TouchTalker as well as a WalkerTalker. Jean Morrison, learning support teacher, and Liz Hutt, speech and language therapist, helped Iain, Tracy and Stuart to prepare their talks.

Tracy Canavan

I'm Tracy Canavan. I'm 15 and I am in Fifth Year at Ashcraig School. I enjoy coming to Chatterbox meetings. Last time I was at a Chatterbox meeting I was just about to leave for a holiday in Australia with my family. Well, I left in November and came back in January. I liked it there and would love to go back.

The weather was good and we visited lots of places. In Canberra I visited the Parliament Buildings including Parliament House. The Sydney Opera House was wonderful but I was really excited when I went on a boat trip around the harbour where I had a great view of Sydney Harbour Bridge.

We were staying with relatives and had lots of barbecues. We also spent time at Bondi beach in Sydney. The whole family went to a nice hotel for a weekend and really enjoyed it. I saw a dead kangaroo lying on the road. The trip went very smoothly apart from a delay at Heathrow airport on the way out. Our plane was delayed so we left a day late. We had to stay at a hotel at the airport.

I visited Hill End and Sofala, Australia's Gold Mine towns. It was as though they were stuck in a time warp. The flights were long and I was tired and sore by the end of them. However it was all worth it. Our luggage was lost on the way home but eventually it arrived at our house. If anyone ever has a chance to do something similar, I would say "Go for it"! I would do it all again.

Other than fancy holidays, I am quite a busy girl. Most nights I go for a walk with my Granda. On Thursdays I go to the club at school. I'm a girl for socialising and parties. I enjoy 10-pin bowling, swimming and other outdoor activities.

I am doing the Caledonian Award at school and for part of it I have to improve on my DeltaTalker skills. I am making progress with headpointing and LLL and I hope to be a Motherwell College student in the near future.



left to right: Stuart Devlin, Tracy Canavan, Iain Smith

Iain Smith

My name is Iain Smith. I am 17 and in the Sixth Year at Ashcraig School. I would like to tell you a little bit about myself.

I have an older brother Calum, married to Sarah and they live in Perth. They are having a baby in November and I will be an uncle for the first time. My sister Christina is a teacher in the Isle of Lewis. She is getting married to Murdo in July in Glasgow and I will be wearing my kilt outfit for the wedding.

I like to see my favourite football team. They have won three cups this year. Can you guess who they are? I also like watching other teams on TV.

I go to Venture Scouts on Monday nights and enjoy weekends away at Scout camp. The Ashcraig club on Thursday nights is fun and I really enjoy going horse riding on Saturday mornings.

I am doing a leisure module in school and part of it was going to the ice rink for 10 weeks. I had never been on ice before but had confidence to go off on my own from the start. I am a whizz kid on ice and I am also good on roller blades. For my 17th birthday I got a mountain bike and I love it but I always wear a crash helmet.

I was on holiday in Canada last year with my Mum and Dad. I played mini golf when we were on Vancouver Island and we were on a glacier in Jasper National Park. Lightwriter (Toby Churchill) Advertisement

Chatterbox Day...continued from page 19

Stuart Devlin

I'm Stuart Devlin. I'm in S6 at Ashcraig School and I would like to tell you about myself.

I really love football and I like going to matches. In fact, I'm football crazy. I joined a football club and I train on a Sunday. Craig Brown came to coach us last year for 1 day. I've got so many football strips I've lost count.

My brother Derek is 18. My sister Shannon is 5. My dad plays in a band and they have made a CD and a tape. Mum works part time. She started a new job last year.

I'm very busy as I take part in lots of activities. Monday night it's Venture Scouts. Tuesday night it's horse riding. Wednesdays are now free but until recently I attended signing classes. Thursday is Ashcraig Big Club night and Friday nights are usually free. On Saturday I either go to Linn Park in the morning or to a football match in the afternoon.

I go out often with my shared carers, Rosemary and Andrew and they bring another girl called Gail. Recently I started going to respite and quite enjoy it.

Joining

COMMUNICATION MATTERS and ISAAC

Communication Matters is the UK Chapter of ISAAC (International Society for Augmentative and Alternative Communication), so members of Communication **Matters are automatically members of ISAAC**. ISAAC is an organization devoted to advancing the field of Augmentative and Alternative Communication (AAC). Formed in 1983, ISAAC now has over 2,800 members in more than 50 countries, including 11 national/regional Chapters.

What are the benefits of Membership?

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

How do I become a Member?

If you live in the UK, you can become a member of Communication Matters (and therefore of ISAAC) by contacting: Communication Matters, c/o The ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR Tel: 0870 606 5463 Email: admin@communicationmatters.org.uk Website: www.communicationmatters.org.uk

If you outside the UK, you can become a member of ISAAC or subscribe to this Journal by contacting ISAAC, 49 The Donway West, Suite 308, Toronto, Ontario, M3C 3M9, Canada Tel: +1 416 385-0351 Fax: +1 416 385-0352 Email: secretariat@isaac-online.org Website: www.isaaconline.org

I'm also busy at school. Next year I am sitting Standard Grade SVS and I spent a week at Kielder Adventure Centre with the Social and Vocational Skills Group. I've just finished a leisure module and for 10 weeks I went ice-skating. I surprised myself as I was very frightened at first but soon found confidence to go on my own.

I've got a girlfriend at school called Sarah and we've visited each other's houses. She lives in Troon.

I think we've said enough. I hope you've enjoyed reading Tracy's, lain's and my stories.

Tracy Canavan, Iain Smith and Stuart Devlin Ashcraig School, 100 Avenue End Road, Glasgow G33 3SW

Chatterbox is the Scottish AAC Users' Group which meets three times a year, usually either in Motherwell College in Motherwell or in Upper Springlands in Perth. The students and staff of the *Communication First* course at Motherwell College administer Chatterbox and organise the meetings. For more information about Chatterbox, contact Gail Dennett or Morveen Urquhart, Support for Learning, Motherwell College, Dalzell Drive, Motherwell ML1 2DD.

Can You Help?

INVESTIGATION of INHERITED SPEECH and LANGUAGE DISORDERS

In collaboration with Professor Anthony Monaco of the Wellcome Trust Centre for Human Genetics at the University of Oxford, a team of neuroscientists at the Institute of Child Health are investigating the brain abnormalities and the cognitive and behavioural impairments associated with an inherited form of speech and language disorder, characterised by **verbal and oro-facial dyspraxia.**

To this end, we are trying to recruit interested families with members who meet the following criteria:

- A *marked* speech (and language) disorder affecting intelligibility and, possibly, early or on-going feeding skills (chewing, sucking, drooling) or reading and spelling.
- An absence of other aetiologies:
 - hearing and IQ within normal limits
 - no structural abnormality of the articulators
 - no concomitant metabolic disorder or medical syndrome

Additionally, there must be:

• *More than one* affected family member - preferably over more than one generation (regardless of whether the speech disorder appears to have resolved in the adult members).

Family members would undergo neuropsychological assessment, give a small amount of blood for linkage analysis and have non-invasive brain imaging. All expenses would be paid. If anyone knows of such a family who might be interested in participating, we would be very grateful to hear about them.

Please contact Debbie King, Speech and Language Therapist, Institute of Child Health Tel: 0171 905 2972 Email: d.king@ich.ucl.ac.uk

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A Penfriend Club for Everyone

by Eileen Ramchandran

Communication Matters has been asked to encourage members to consider participation in Write Away, to enhance social and communication opportunties for AAC Users

rite Away is the only national penfriend scheme for people with disabilities—with separate clubs for children and adults. Penfriends can communicate with one another using whichever form of communication suits them best (video or audio tape, symbols, Braille, e-mail, or pen and paper). *Class Match* and *Group Match* schemes are also available for those who may find it difficult to communicate as individuals.

Write Away was launched in 1991 as an integrated penfriend scheme for children and young people ages 8 to 18. In 1998 *Write Away Adults* was launched, offering a similar service for people over 18. Both schemes are open to people with all types of disabilities (including learning difficulties), as well as to their non-disabled siblings, parents and carers, and people without disabilities who are interested in communicating with disabled people. For a small one-off fee members are matched with up to three penfriends.

All children who become members of *Write Away* receive a colourful letter writing pack that contains a pen, writing paper, envelopes, and other materials. Then, three times a year, they receive a newsletter (in print, Braille or on cassette) to which they can contribute jokes, poems, drawings, and letters. On occasion, members also receive tickets and invitations to special events for themselves and their families. These outings give the children the chance to meet their penfriends face to face.

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But the best benefit of *Write Away* membership is that the children develop special one-to-one friendships, which builds their self-confidence and helps them to feel less isolated and alone. Tracy and Daniel have been writing to each other steadily for over four years:

"Tracy just loves getting Daniel's letters," says Tracy's mother Marian. "She has built up quite a relationship with him."

"Daniel doesn't have many friends," notes Daniel's mother Pat. "He finds it hard to relate to other kids."

Members who join *Write Away Adults* receive a starter pack, containing a pen, writing paper, envelopes and helpful advice on how to get the most out of being a *Write Away* member, and a subscription to the **Keep in Touch** newsletter (in print, Braille or on cassette), which features member contributions and offers mutual support and advice. In addition, each issue of Keep in Touch features a different reader competition, worth up to £25 in prizes. *Write Away* secured funding from the National Year of Reading to produce the newsletter on a quarterly basis.



Since joining *Write Away Adults*, Andy Machin, who has a visual impairment, has corresponded with his penfriend every week. As a result, the pair has developed a good friendship in a short time.

"It's nice to write to someone who understands and who wants to hear about the highs and lows in your life," Andy says. "And, he has told me about his interests, hobbies, and family. I now have a picture in my own mind of what he may be doing on a specific day."

Write Away Adults aims to reach all of its members, no matter what the disability or circumstances. "Every single person has the power to communicate," states Jamie Renton, director of Write Away Adults. "It's our challenge here at Write Away Adults to be intelligent enough, and sensitive enough, to help each person find that way."

Class and Group Match

For individuals who may find it difficult to correspond on a one-to-one basis, *Write Away* offers two schemes: **Class Match** and **Group Match**. These programmes are particularly important since they offer an opportunity for communication to people who are often left out of such schemes.

Each pupil in the class or person in the group contributes to a letter that is then sent to a matched class/group in a different part of the UK. As with the individual schemes, class and group members can correspond with their peers using computer, pen and paper, audio or video cassette, symbols, or Braille.

The Class Match scheme has been running since 1993, with 223 classes (an estimated 2,000 individuals) currently enrolled, along with a number of committed teachers who are responsible for the programme's successful operation. According to one teacher, "We swap letters and photos with our matched class two to three times per term. The students genuinely enjoy receiving mail from their penfriends." Another teacher says, "The Class Match scheme is fun. And our students write for a purpose."

Group Match is at present being run as a pilot scheme with 14 groups matched and communicating with each other. Jamie Renton is at present seeking funding to develop the service further. "There's a tremendous need for a Group Match scheme for adults", he explains, "...but the staff who support the groups don't necessarily have the training or support to understand the communication needs of the people they work with. So we need to have an informative Starter Pack and other systems of support in place."

Nonetheless, the groups that have been matched up are happy with the early results. Sharon Smith, the spokesperson for *Bridging Four* at Evesham College, says, "This scheme will give the group the enjoyment of communicating with other individuals in a similar situation, and this will help to improve their communication skills. (The Reporter Group in Kent has sent *Bridging Four* an initial letter with photographs and a copy of their newsletter, and they eagerly await a reply.)



Julie Rickett, a senior support worker in South Bucks whose group has been corresponding with one in Huddersfield, notes,

"So far, we and our matched group have exchanged letters and photographs of each other. My clients seem to be really enjoying receiving the letters and thinking about what they would like to tell their penfriends in return. It is proving to be a positive experience for all concerned."



Future Plans

So, what's on the horizon for *Write Away*? The organization has several big plans in progress. One development will be a mentoring scheme, through which young people with disabilities can be matched with a disabled adult role model who then acts as a mentor for a period of time. The organization is also researching the possibility of accreditation for people with disabilities to develop their communication skills.

Finally, *Write Away* is in the process of developing a network of regional officers around the country. These appointed officers will promote the work of *Write Away* and support members in their area to participate fully in the schemes. Since children and adults with disabilities can lack opportunities to connect to people, having a penfriend can provide the perfect opportunity to become a part of someone else's world, while boosting selfesteem and improving communication skills.

Eileen Ramchandran Write Away

To learn more about *Write Away*, contact: Jamie Renton (adults) or Kathryn Hick (children) Write Away, 1 Thorpe Close, London W10 5XL Tel: 0181 964 4225 Fax: 0181 964 353 Email: penfriends@writeaway.demon.co.uk

Editor's note: A Trustee of Communication Matters, Alison Futerman, is liaising with Write Away on various aspects of their Adult and Group Match schemes. Sensory Software Advertisement

Using Computers for AAC: A New Look at an Old Debate

by Paul Hawes

I can almost hear the groans. "What?", I hear you say. "Not this old discussion again."

Well, the computer industry does not stand still, and this discussion is constantly renewed in the light of these changes. In the last couple of years there have been a number of important developments in portable computing that have made the use of computers for AAC attractive to a far wider range of people than in the past.

Ultra-portable computers and off-the-shelf devices with built in sound and touch screens are now readily available. The features of such machines compare well with dedicated AAC devices.

Let us remind ourselves of the issues and ask ourselves why we should want to use a computer as a communication aid, why we did not do so more often in the past, and how recent changes have altered the balance.

Advantages of using a computer for AAC

- Less expensive scarce resources can help more people.
- More Uses many users need a computer anyway for writing, internet access and so on.
- Easy to re-configure many people need to change the system they use, either as a result of development or progression of an illness. A computer based system can keep up with the user's needs with little more than a change of software.
- More support available in the community I have not conducted a scientific study, but I would guess that the people who can operate Windows 95 outnumber those who are familiar with semantic compaction systems by several orders of magnitude!

Problems with using a computer for AAC

- Poor battery life
- Lack of robustness
- Doubts about effectiveness
- Lack of convenience
- Lack of portability

How computers have become more effective for communication

In recent times the design of portable computers has altered radically. A number of advances in both hardware and software have helped to improve their usefulness as AAC devices. Let us take a look at these traditional drawbacks of computers and see to what extent they have been lessened, or even overcome, with new developments.

Battery life

Early portable computers were power hungry and could not be used away from the mains for long. This remains an issue, but

batteries are better than they were, and the machines are far more sophisticated in the way that they use the battery.

Newer power management systems allow machines to work for longer on a charge. Smart power down modes allow the machine to conserve power when not in use, yet to be ready for action without the delay of rebooting. Also, automobile adapters allow the battery of a powered wheelchair to run a computer indefinitely with no danger of damaging the machine.

Battery life is not an issue for everyone and many wheelchair mounted systems can be powered from the wheelchair battery. One very popular device has no battery at all.

Robustness

Very few components were especially made for portable computers. Therefore items such as disk drives needed very careful handling, and often could not survive the harsh environment of an AAC machine.

Most portable machines are now far more durable as a result of the development of special components, notably small hard

drives with high shock ratings. Many machines are designed for vehicle mounting, and some are ruggedised to a military specification.

Naturally, the casing is also important and portables built to a military specification are available. However, it is by no



means clear that the extra cost of a full military casing is justified, as even ordinary cheap laptops come back broken surprisingly rarely. When allocating budgets, it may well be worth asking if you will really get three times the life if you pay three times a much.

Effectiveness

There has been a perception in some quarters that only dedicated systems could have the necessary functionality for effective AAC. This probably arose because pioneer workers in the field had no choice but to use dedicated systems, and much of the literature describes work done on these machines. However, software has been advancing as well as hardware and most new design of language systems is now done on a computer. An excellent example would be the Ingfield Dynamic Vocabularies.

Displays

The first portable computers were acceptable for text based systems, although early LCD screens were practically invisible in bright light. Colour screens did not exist, which limited the possibilities for symbol based systems. For text users, the newer TFT displays allow a system to be used in most lighting conditions. For those who need symbols, the availability of good quality colour means easier comprehension of the meaning of symbols and the function of cells.

Convenience

All systems required a separate speech synthesiser, and often other peripherals as well, resulting in too many wires and too much fiddling about to get a system started.

No longer is it necessary to use a separate (and expensive) hardware speech synthesiser. Most computers, including portables, now have integral sound. This, coupled with very high quality text to speech generated in software alone, allows the machine to



talk without the inconvenience and expense of a separate synthesiser. Newer models, like the touch screen PC illustrated, are far more compact, and easy to mount.

Portability

The definition of portable varies with the user. For some, it means that it can be carried in a pocket and be used standing up in a 'phone box. For others, portable simply means that it can be put in a box to accompany the user to respite care. However, the trend is to ever lighter and smaller devices. Mainstream manufacturers like Toshiba are showing the way with the Libretto and Portege ultra-portable PCs

The most dramatic development is the recent availability of touch screen portables with colour and sound. As well as offering a truly integrated touch panel at last, they are also useful to switch users, as they are easy to mount on wheelchairs.

Examples of recently implemented AAC systems using computers

These examples are intended to show cases where a computer was the obvious choice. This may have been because the user had a real need to integrate other computer functions, or because the specific problems of the user ruled out an off-the-peg device.

1. Text and Switches

The screen below was designed for a literate schoolboy. He has cerebral palsy and has acquired good switch skills. He is well supported at his school. He needs occasional AAC as his speech is not always intelligible.

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His system consists of a laptop computer which is set up for him in lessons by a helper. He uses an on-screen keyboard and a text based AAC program in class. At other times, he relies on his natural speech.

2. Symbols and Touch Screen

This screen is used by an adult stroke survivor with good language skills. However, his spelling and word recognition are poor. He is ambulant.



His system is a portable touch screen computer with the Chailey Communication System. As he can point rapidly, the large vocabulary of the Chailey system allows him to create well-structured sentences rapidly, while by-passing his difficulty with written language.

3. Visual and Motor Problems

The screen below is used by a lady with advanced MS. She has slow, ataxic hand movements, poor vision and no speech at all. She is not mobile.



Her system is a portable computer with a large screen and an Intellikeys keyboard. The text is set for very large characters.

4. Switches and Some Literacy

This screen was designed for a girl who uses Ingfield Dynamic Vocabularies for communication, and is likely to be dependent on symbols for some time. She has effective switch control.



Her system consists of a tablet PC with an on-screen keyboard that can use her AAC grids as well as a normal keyboard. She uses her grids as a word bank when the word processor is selected, and as a dynamic screen communicator when the Picture Communicator is selected. She is able to switch independently between the two.

Where Next?

Without doubt, the computer-based communication aid has finally come of age. Even a number of wellknown dedicated devices are really PCs under the lid. The question of whether a PC is a useful communica-



tion aid has been answered by the specialist manufacturers themselves. (The question is now whether you want a computer that has been specially designed so that it cannot be used for anything else.)

There is now a new standard for computers called Windows CE (Compact Edition). This is a cut-down version of Windows intended for use on palmtop computers, smart mobile

phones and the like. Work has already been done to provide software that turns pocket sized CE palmtop machines into text communicators and slightly larger touch panel devices into symbol-based dynamic screen systems.

All CE machines have touch screens, they become active as soon as they are switched on, and battery life of 12 hours is common. They are also lightweight, ranging from a few ounces to a couple of pounds. Sound promising?

Conclusion

Despite some remaining problems, computers are more suitable for use in AAC than ever before. In addition, more people wish to use computers for other purposes.

The combination of these two factors makes it probable that many more AAC systems will be based on mainstream hardware in the future.

> Paul Hawes AbilityNet, Hassel House Link Industrial Estate Malvern WR14 1UQ, UK Tel +44 (0)1684 563685 Fax +44 (0)1684 576188 E-mail paul@foundcom.org.uk

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Communicating Together is an ISAAC affliated quarterly magazine published by Sharing to Learn. It focuses on the sharing the life experiences and the communication systems of AAC users. An online version, ComTog, is also available.

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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. Developed by a special task force of Communication Matters members, 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. Various solutions are explored, including the use of signing, symbol charts and electronic communication. 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.





strated by Denise Redm

Price: £10 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.

Ring Communication Matters for an order form.

Augmentative Communication News

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

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Communication Without Speech



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)**



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