COMMUNICATION MATTERS

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REGULAR COLUMNS

COMMUNICATION MATTERS

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The Communication Matters Journal is the official publication of
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The CM Achievement Awards 2002

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

Jessica Herbert

Jessica is an 11 year old girl who has very complex needs as a result of her disabilities from cerebral palsy. She has severe athetosis and is unable to sit unaided/unsupported. She is unable to speak and uses a PCS book for all her communication needs.

Jessica is fairly reliant on the listener filling in the gaps for her once she has given a key word. This has also meant she has not been as independent as she could be on her school work, again relying on someone to assist her.

During the past year there has been a tremendous change in Jessica. She has matured considerably which has given her a new outlook. Jessica has realised that she can do things and that she wants to do them.

It started with Buddy Buttons to reinforce her yes/no responses. Jessica would try very hard to control the severe 'over movements' of her arms to activate these switches. She was pleased with her success with using the Buddy Buttons and was able to take her place far more obviously (and vocally) in the class discussions.

Her skills in using them led her to being an 'effects girl' for the group's Christmas play where she was able to use the switches to operate lighting and sound effects. As the play hinged around the knocking of the inn keeper's door, she was delighted to have such an important role.

Whilst using the Buddy switches, Jessica was also trying to access her Cameleon and computer with varying degrees of success. The problem continued to be that her switching was not consistently accurate, and it took quite a bit of time and effort to find a site where she was able to operate the switch comfortably and reliably. Since then she has made incredible progress. Being able to switch accurately has made an enormous difference to Jessica in a variety of ways. Not only has it opened up so many areas of curriculum for her, but it has also increased her confidence and self esteem.

Becoming more independent has enabled her to:

- have a go at doing something even though she may not get it right
- work with several different members of staff,where previously she felt secure working only with one or two
- explain what she finds difficult about a concept or what she doesn't understand
- work alone with no-one assisting her (eg. comprehension activities, spellings, news, story writing)

Most importantly, becoming more independent in her communication skills has enabled Jessica to blossom. She is ready to take her rightful place in the class, she is keen to participate in class discussions, she is always ready to share a joke and have a laugh.

And this is all due to Jessica's perseverance, her determination to master control over using the switch, her desire to open up a whole new world of greater independence despite her difficulties.

Jessica is a delightful girl whose pluck and perseverance will get her through the ups and downs of every day life and bring much happiness to those who are lucky enough to meet her.

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Laura Bird

Laura is eight years old. She has attended Ingfield Manor School for over three years, and our School for Parents before that. It is her dogged determination, as well as what she has achieved, which has resulted in this nomination.

When Laura first started using a communication book, she was presented with relatively few symbols per page, and eye-pointing was encouraged.

However, Laura had other ideas. She wanted to point with her hand. She also needed more symbols-loads more! Now, she has a book with 100 pages of 35 symbols per page. She knows her way around the book really well and she uses it constantly,

efficiently and creatively. She is, in every sense of the word, an active communicator. Furthermore, Laura has her symbols in an A5 folder as she was determined to use her hand when I had predicted that eye-pointing would be the efficient way forward. This means that the cells are very small, but she is able to target these symbols accurately. Achievement of this level of fine motor control is set against a background of hard work and determination in gaining postural control.

Determination has also been a key factor in high-tech skill development. When she was six years old, Laura came to her first session for introduction to IDV. She was new to row-column scanning, and new to dynamic screens. Experience with many children has taught me not to introduce all these things at once, and how important it is to work on accessing skills first. Laura, however, is not one of those children! By the end of the first session, she knew how to scan with two switches and understood page navigation. This was helped by the fact that she knew how to navigate her communication book so well, and the structure of each reflects the other. In the ensuing months, she worked quickly through levels A and B, and she now uses IDV-C.

In true Laura fashion, access is 'under negotiation'. She became frustrated with scanning. It was too slow, and her motivation dwindled. She became adept with a joystick, which was, I felt the way forward. Laura, however, does not see this as the way forward! She wants the immediacy of touch screen use. I'm concerned that direct selection errors will slow her down, frustrate her, and limit the number of cells she can have on one screen.

However, Laura has proved me wrong many times before! When I set her work, she is likely to take a line of passive resistance, until I respect her wishes. It's a path we've trodden before and I'm glad to say she has proved me wrong every time so far. We are currently compromising; joystick practice to humour me (and, in fairness to me, it is still the most efficient method), and touch screen practice so that Laura can, once again prove me wrong!

At the moment, Laura is learning her way around dynamic screens on school equipment. Accessing issues are likely to be a major part of the decision about the device she eventually owns. I do so hope we shall eventually be looking for something with a good touch screen. Knowing Laura as I do, I think we shall.

Whether using her symbol book, a VOCA or Clicker Grids, Laura uses her symbols effectively throughout her day. She loves to use her voice as well. Once again, being Laura, she has surpassed my expectations in this area. She uses her voice when she knows it is expedient to do so, and readily transfers to symbol use to augment her limited speech.

In order to achieve what she has done in communication, Laura has had to work so hard at improving her posture, as well as her fine motor control. She has worked hard every day to achieve these improvements. This is why she has been able to surpass my expectations in terms of accessing and speech sound development. As I hope you realise by now, her stubborn determination to do things her way makes her a very special communicator.

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Ben Gillard

Ben is a cheerful, sociable 16 year old boy who uses a communication book consisting of an A4 ring binder. He has six symbols to a page and he accesses this with his left hand. The book has many categories including days of the week, daily routine, rooms, shops, places, weather, clothes, colours and feelings. Ben has also recently been introduced to a 'Go Talk' communication device.

Ben has the characteristic signs of spastic quadriplegia. His activities are seriously restricted by the spasticity of his four limbs. His left side is stronger than his right. Ben has severe learning difficulties.

When Ben first came to the school in Summer 1999 he didn't have a reliable yes/no response. He had a very simple symbol book which he just turned the pages of and showed no recognition or interest in the symbols. Ben could vocalise just a few words; "yes", "no", "mum" and a few names. He would permanently touch a voice output device that was put on his tray.

Ben has received twice weekly speech and language therapy as well as working on his communication in class. Ben commenced work on PECS in September 1999 and within six months Ben was 100% accurate with all exchanges. Ben began to find symbols in his book and it became apparent that he was taking a real interest in the symbols and could distinguish between them. In March 2001 Ben commenced using a communication book in addition to his PECS book as many things we felt that Ben wanted to choose or select could not be exchanged for objects. In September 2001 we decided that PECS was no longer appropriate for Ben and he now uses his communication book in all situations.

Ben turns the pages of his communication book himself, he can find a named category and will also find an individual symbol that he wants. He makes relevant and appropriate choices and will offer information and answer questions.

Ben uses his Go Talk in different situations to make requests and greet people.

Ben's vocalisations have also now increased. For example, he has just returned from a trip to the States and when asked where he went he said "disney" and that he got there by "plane". He now attempts to name things with some good success. He will greet people with a sign.

In three years I feel that Ben has made excellent progress and that he shows great potential with his communication.

Dee Burgess, Senior Speech and Language Therapist
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Lightwriters

- Small, compact and portable
- Wide range of acceleration techniques
- Adapts to scanning for progressive conditions
- Direct selection and scanning models
- Designed to accommodate the wide range of other disabilities which may accompany loss of speech

SL87 – direct selection and switch access

Introducing a Lightwriter Communication Aid

by Catherine Harris

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

Introduction

In April 2001 the Adult Speech and Language Therapy Service in Portsmouth received funding from the three Primary Care Trusts to provide communication aids for adults as required. This was part of the overall package for Community Rehabilitation and was an exciting new development for the service. Previously, a very small bank of 'high tech' communication aids had been available for assessment purposes but any purchase of aids had been mainly dependent on self or charitable funding. (For people diagnosed with M.N.D. equipment was loaned through the M.N.D. Association.) This new resource was obviously going to have an impact on our ability as a department to give clients improved opportunities to trial an aid as a basis for decisions around longer-term provision.

The necessary local policy documents and standards were produced. A system of assessment and trial, before an aid was purchased for long-term loan, was developed. Any client who might benefit from using a higher tech communication aid would have the opportunity of:

- Assessment
- Period of trial on identified aid
- Training
- Loan of aid
- Review within three months and every three months in the first year
- Annual review and maintenance check

(Taken from *Communication Aids Standards,* SLT Dept, Portsmouth City Primary Care Trust; audited on an annual basis)

Training Issues

As 'high tech' communication aids have been supplied, issues were raised about what constitutes an appropriate level of training and support. It is a challenge to those working within adult services to ensure that there is adequate and appropriate input so that the use of "an AAC system can become an integral part of the individual's daily programme" (RCSLT 1996). The type of input will be influenced by whatever aid is provided and the needs of the user. Training should involve 'significant others' (e.g. partners, relatives, friends, enablers). This is all the more important when a high tech aid is introduced as initially there may be issues around the knowledge base of the therapist as well as the initial anxieties of the potential user and carer. "It is known that the success in delivery of AAC services still depends largely on the experience of individual SLTs and the significant others who are involved with the AAC user" (Murphy et al 2000). Although the AAC Centres are a valuable resource, the follow up and day-to-day support of the client will fall to the local therapy service.
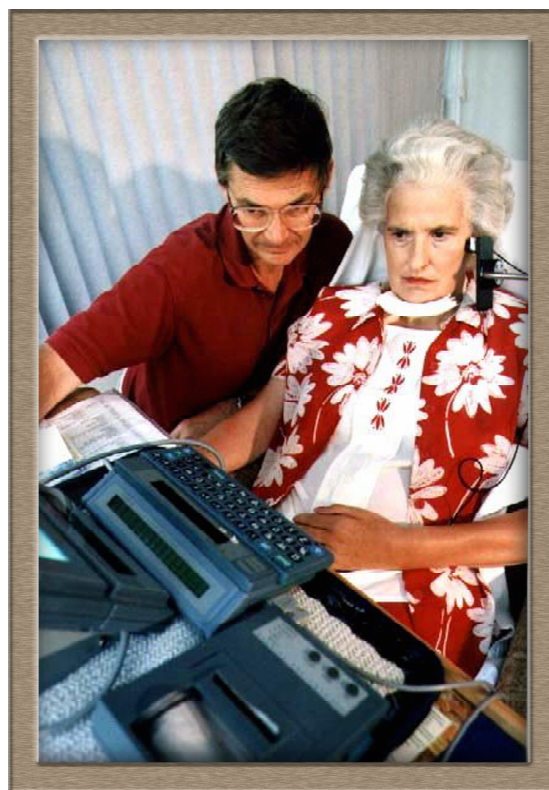

Figure 1 Using the Lightwriter with a head switch

Experientially, it seems that most manuals associated with communication aids are time consuming to read, learn and sometimes difficult to digest! This is a problem recognised to varying degrees by the manufacturers and suppliers. Opportunities for training are available in a variety of forms. The difficulty for the therapist then may be a lack of opportunity to apply the knowledge on a regular basis. In adult services, therapists may have diverse caseloads and there is the need for information to be easily processed, clearly presented and quick to reference.

In the first year of the newly funded Portsmouth service, the most frequently provided aid was found to be the Lightwriter. The demand reflected the local caseload of people with dysarthria secondary to progressive neurological conditions, oral surgery and stroke. As the Lightwriter was introduced, simplified diagrams and a summary were often needed to reinforce a training session. The manual provided by Toby Churchill Ltd encourages therapists to "draw some simple diagrams, write a few notes and explain through conversation".
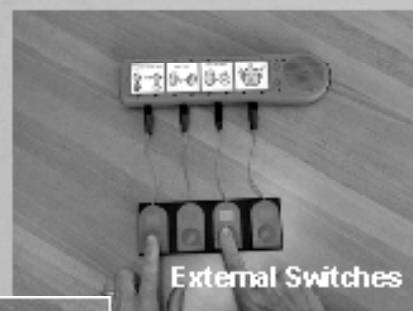
A New Resource

As the specialist therapist working in AAC, it seemed that the next logical and useful step would be to produce simplified

adVOCAte
a new dimension in digital recording communication aids

advocate (ad-vŏ-kăt)
someone that speaks on behalf of another

user-friendly information to reinforce learning. This could be given to a client during the session. The ultimate aim was to create a flexible tool, which would have benefits, not only for the potential user, carer/care staff but also for the therapist or trainer introducing the Lightwriter.

After two months, a pilot package was developed. The resulting pack was designed to be a training and reference tool.

The format of the document is now described. Ten functions are identified as being the most appropriate to introduce through an initial training package. These include:

- Using the 'Set-Up' menu.
- Storing and deleting memories
- Storing and deleting abbreviations
- Calculations
- Editing
- Printing

A section is included to enable the therapist and client to plan and record dates of training and to monitor progress. Each section has a defined aim and a diagram of the keyboard is provided for easy reference. The instructions are presented in bullet points. Some sections have practice exercise sheets to build confidence. After a session the appropriate sections can be left with the user for reference and practice.

The Lightwriter is a text-to-speech aid, which can be used at the very simplest level i.e. press 'ON' and start typing. It is recognised that while a 'normal' speaker will communicate around 150 words a minute, the average Lightwriter user will be communicating at 12 to 20 words a minute. This reduction in rate of communication emphasises the need to ensure that all the potential time saving methods are explored to maximise potential interaction.

It is important, however, to remember that a communication aid will only be part of the whole communication system and that a holistic approach is imperative.

Trialling the Package

The pack was initially trialled with 12 Lightwriter users and their carers in the Portsmouth area. This took place over a period of six months in 2001.

The pack was found to be most useful when used over 3-6 sessions. The intention was not to replace the manual but to help the therapist introduce the Lightwriter in a planned and systematic way. The user will have increased confidence and therefore gain maximum benefit from the aid.

The following case study outlines how the pack can be used.

Case Study

Mr M is a 67 year old man, married with 3 children. He took early retirement from the police force and then worked as a museum assistant. Diagnosed with Parkinson's Disease in 1995, symptoms first presented in 1991.

He was referred for Speech and Language Therapy assessment by his GP in March 2002. At that time, he presented with a severe hypokinetic dysarthria, which resulted in significant problems with intelligibility. Active on several committees, he was also due to travel to Australia to see his daughter in April 2002.

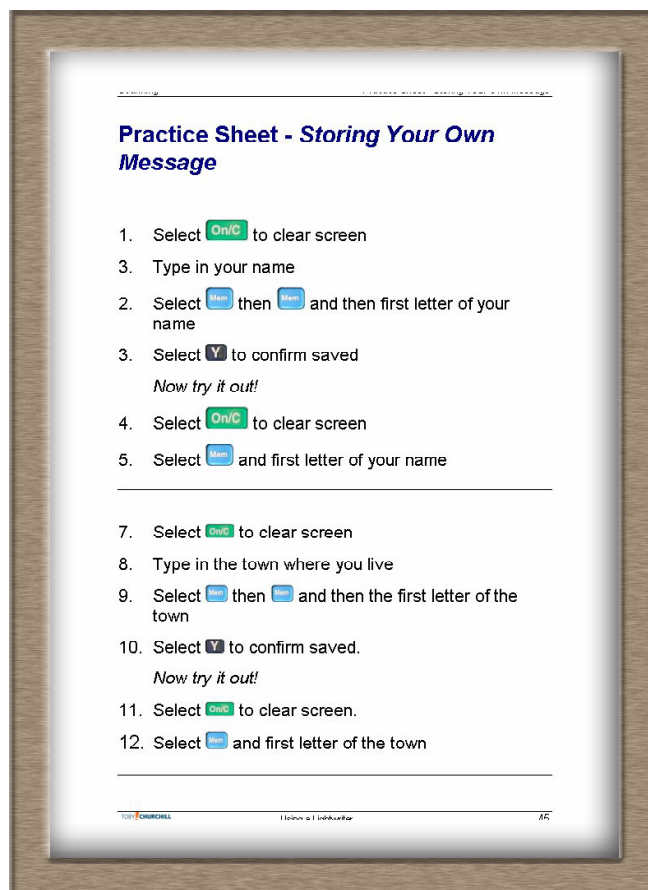Figure 1 Introducing the Lightwriter functions

Figure 2 A Practice Sheet

Management

Session 1: Informal assessment. Good insight into difficulties. Discussed principle of AAC and possible use of speech output aid. Demonstrated SL35 Lightwriter QWERTY layout with Dec Talk. Higher level of accuracy was achieved with deep keyguard fitted. Introduced first handouts on basic functions and memory use. Loan of aid for trial at home for a week.

Session 2: Discussion on use of Lightwriter at home and in other situations. Positive feedback from Mr and Mrs M. Had not used manual but had referred to handouts. Introduced sections on Abbreviations and Calculations. Demonstrated print function with mini printer. Order put in for Lightwriter for long-term loan.

Session 3: Mr M. using Lightwriter both at home and in other settings. Had used in committee with pre-programmed phrases on memory. Positive about using Lightwriter with own computer printer as finding keyguard helpful. Training on Printing and Editing. Order put in for link cable. Encouraged to use manual if other functions required.

Session 4: Feedback on use and now confident on all functions. Review session booked after return from trip.

Session 5: Lightwriter being used effectively. Printer useful. Ongoing monitoring.

Case Study Summary

This method of training was satisfying for the client and the therapist. A structured, reinforced approach resulted in an effective outcome within a relatively short time-scale.

Training the Therapists

Following the initial piloting of the pack with users and carers, two separate training workshops were run in Portsmouth for 18 local therapists working in the adult service. These were two hours in duration, systematically working through the pack, teaching each function followed by an opportunity to practise at each stage.

A follow-up questionnaire was sent out to all therapists working with adults in the Portsmouth area. The results were as follows:

- Questionnaires returned: 18 out of 20
- Training extremely useful or very helpful (16 therapists)
- Training pack extremely or very helpful (16 therapists)
- Training pack extremely or very helpful (10 users)
- Training pack extremely or very helpful (9 carers)
- Since the training the pack had been used with 12 clients
- Four therapists used the pack only
- Five therapists used the pack alongside the manual

Feedback included recognising the value of dedicated time for hands- on training, the benefit of user-friendly handouts, and a more systematic way of introducing a Lightwriter.

Availability of the Pack

Following discussions with Toby Churchill Ltd, the pack 'Introducing a Lightwriter' is now available on CD-ROM (for
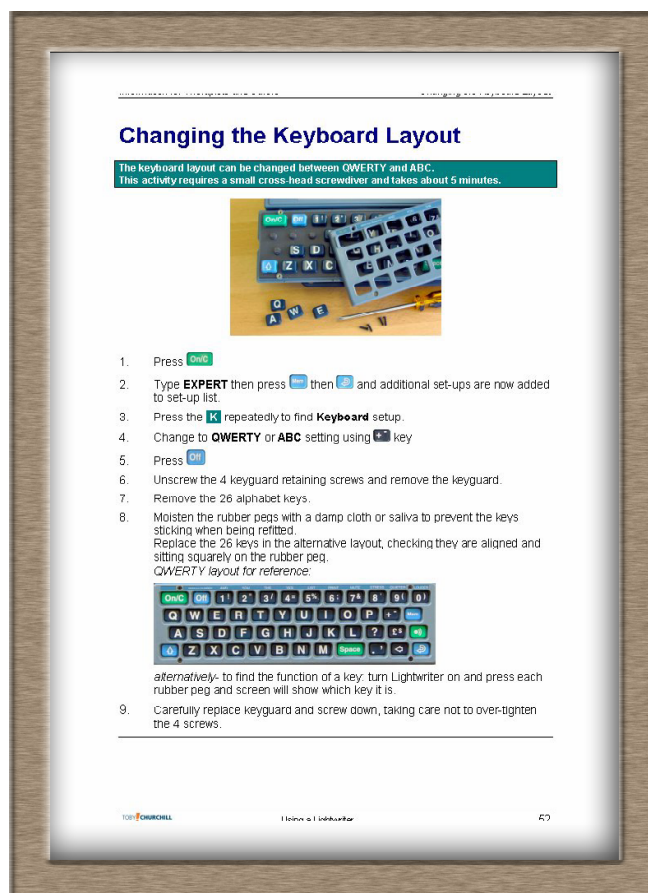

Figure 3 Changing to QWERTY or Alphabetic layout

PC and Mac) at £20 (excluding VAT). The Site Licence limits the training pack for use on a single site, but it may be used to support multiple users of Lightwriters on the same site, or used on more than one computer and by more than one person within that site. For more information please contact Toby Churchill Ltd on Tel: 01223 576117 Email: sales@toby-churchill.com.

A pilot study is also under way to train volunteers in using the pack to support people in using a lightwriter. Initial feedback has been positive.

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ICU-Talk: An AAC Device for Intubated Patients in Intensive Care

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Abstract

A multi-disciplinary project involving nursing, computer science and speech and language therapy developed a computer based communication aid called ICU-Talk. This device has been designed specifically for intubated patients in an intensive care unit (ICU). The ICU-Talk device was trialled with ICU patients. This paper reports the development of ICU-Talk along with results from the trials.

Background

The use of AAC with intubated patients in ICU is not well documented in the literature. There are reports of systems developed for individual patients but these tend to be low-tech [3, 7]. Studies which have used high-tech AAC involve devices which were not specifically designed with this patient group in mind [4, 5]. The ICU patient and the ICU environment provide many challenges when trying to address communication.

Patients who find themselves in ICU are acutely ill. The effects of the drug treatments along with the acute nature of their medical condition often mean that patients are unable to breathe for themselves, and they may have a degree of physical weakness. Although this is a temporary situation and many patients make a good recovery, the psychological effects can be long lasting [8]. One of the most difficult things for the patient to cope with while they are in ICU is the inability to communicate [8].

Most patients in an ICU require mechanical ventilation to assist with breathing. While patients require help with their breathing, they are unable to communicate using speech. This is because they are intubated. Intubation involves either a plastic tube being inserted into the patient's throat via their mouth or a tube in their neck (referred to as a tracheostomy). Using an alternative method of communication can be very difficult for an intubated ICU patient. Many patients attempt to mouth words, but if they are intubated orally, lip reading becomes very difficult. Weakness can affect the movement of their hands and arms making writing or gesturing difficult, and hands or arms may also be attached to drips or monitors. Some patients in this situation have reduced ability to learn new information, impaired memory, visual disturbances and reduced attention and concentration [1]. Nursing staff who work in intensive care units are highly skilled at anticipating the communication needs of patients who are trying to communicate but find interpreting their communication attempts time consuming and difficult [2].

One of the major problems when working with this patient group is the temporary nature of the patient's condition. Many patients will only be ventilated and require a communication aid for a very short length of time, perhaps one or two days. Costello [4] reported success with children who have planned admissions to ICU following surgery. Prior to admission, users were trained and the children pre-stored phrases into an AAC device using their own voice. This AAC device is commercially available but has not been developed specifically for ICU patients.

The ICU-Talk project was a three-year multi-disciplinary research project. The aims of the project were to develop and evaluate a computer based communication aid specifically designed for intubated adult patients in ICU.

Development

ICU-Talk has been designed to be quick to learn and easy to use. It comprises a choice of two interfaces, both of which support interaction via touch screen, mouse emulation or a single switch. There is a database of pre-stored phrases, which can be personalised through the completion of a computer-based interview.

Database Development

The vocabulary for the database was collected in two stages. Stage One involved asking nursing staff from ICU to give examples of communication attempts made by intubated patients. 34 nurses from a possible 44 gave over 200 examples. For Stage Two an observation tool was developed using the examples given by the nurses. These were used to compare actual communication attempts by intubated patients with those recalled by the nursing staff. 12 patients were observed for a total of 30 hours. 53% of patients' communication attempts were examples that the nursing staff had suggested. The remainder of the communication attempts were patient specific. This finding suggested that the database for each patient should be individualised.

The results from stages one and two were collated and a total of 190 phrases and questions were found to represent commu-
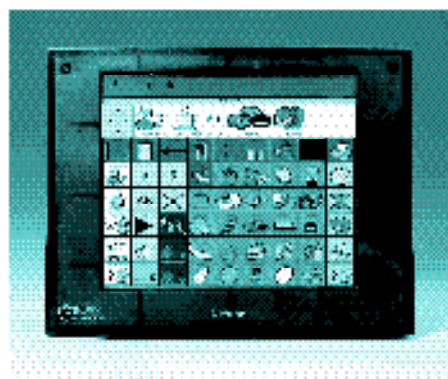
nication attempts by ICU patients. The phrases were organised into eight different conversation topics and formed the core database for the ICU-Talk device. All patients who used ICU-Talk received the same core database.

Collecting a set of personalised phrases for ICU patients is very challenging, as patients only require the AAC system for a short length of time so traditional methods of data collection were not suitable. A fast method of turning information about the patient into phrases for inclusion in the database was required.

A computer interview was developed which asked specific questions about the patient. Answers to the questions took the form of real names or were chosen from multiple-choice lists. Answers were then automatically incorporated into phrases by the computer to form the database of personalised phrases. The interview was designed to be completed by a close friend or relative as they are an available and reliable source of information about the patient (6). There were 13 computer interview questions in total which, if fully completed, automatically generated 80 personal phrases and questions. These were the added to the patient's core database.

Interface Design

Design considerations for the interface had to address several issues. These included the user's lack of concentration, their restricted physical access and their reduced ability to learn and remember. Two ICU-Talk interfaces were developed with the guidance of a computer games company and were designed to be visually stimulating but not distracting. This allowed the patient a choice of styles. Both styles had a main page where eight topics were displayed. The topics and their related phrases and questions were colour coded to assist the patient with navigation through the system. Each topic contained a different number of phrases and questions. With the Boxes design up to 10 phrases or questions were displayed on the screen at any time and with the Bubbles design only 6 could be displayed. The patient navigated through a topic to find the phrase or question they wanted.

The two styles support the use of touch screen, mouse emulation (trackball or joystick) and single switch scanning. These different access methods ensured that patients at different stages in recovery and those with severe physical impairment could still access the ICU-Talk device.

Equipment Constraints

ICU patients are very vulnerable to infections. To prevent the possible cross infection amongst patients using ICU-Talk, the ICU-Talk device had to be waterproof and able to withstand thorough cleaning.

In an emergency gaining access to the patient to deliver life-saving treatments is critical. Staff must therefore be able to easily move the ICU-Talk device out of the way to gain fast access to the patient.

The patient must be able to access the ICU-Talk device from a number of different positions e.g. sitting, lying flat, lying on their side. To meet all these requirements a rugged flat-panel screen was selected for use along with a standard personal computer. A special mounting system was specifically de-

signed to allow the patient to safely access the device when lying or sitting.

Methodology

In May 2001, the ICU-Talk device was introduced into the Intensive Care Unit at Ninewells Hospital, Dundee. Evaluating the effectiveness of the device in use with real patients was complicated. Each patient was unique presenting with different medical diagnoses, treatments and because of the acute nature of their illness their condition could change rapidly [7]. Experimental conditions cannot be controlled and post-trial feedback from patients was unreliable because surviving patients who have been in intensive care rarely remember anything of their visit [6].

Patients were referred to the ICU-Talk project by the nursing staff in ICU. Nurses used a referral checklist to ensure that the patient met the required criteria. A member of the project team then visited the patient to explain what was involved and demonstrate ICU-Talk. If the patient agreed to participate in the project then the ICU-Talk device was set-up. Their preferred interface and an appropriate input method were selected. Following a brief training and practice session, patients were encouraged to use the ICU-Talk device to assist in their communication attempts.

Results were collected using an automated collection mechanism and three paper-based questionnaires. The automated collection system was an event recorder that tracked all use by the patient. To gather expert opinion and anecdotal evidence from the nurses, a one-page nursing questionnaire was completed by nurses caring for patients who were using ICU-Talk, at the end of each shift. To collate the opinions of patient's relatives on ICU-Talk a two-page relative questionnaire was completed by the relative once the patient was discharged from ICU. General feedback from the nurses giving their opinions of the project and the ICU-Talk device were gathered via a questionnaire issued half-way through the evaluation period.

Results

During the one year evaluation period, 21 patients were given ICU-Talk. The first two patients' data was excluded as nurses and other staff members also used their ICU-Talk device. This meant that data collected by the computer about the patients use was invalidated as the computer was unable to distinguish between use by the patient and use by someone else. To overcome this difficulty a practice mode was developed for other users to explore ICU-Talk. This meant, for example, that relatives could have ICU-Talk demonstrated to them without the patient's program being interrupted and without corrupting the patient's data.

Details of the remaining 19 patients can be found in table 1. The age range of patients was 36 to 76 years old, with a mean age of 57 years. 10 patients were female and 9 were male and they used ICU-Talk for up to 6 days with a mean length of use of 2 days. Apache II scores ranged from 12 to 29 with a mean score of 19. The length of stay varied from 2 to 127.2 days. From this group the mean number of days that ICU-Talk was used by intubated patients was 2.

The event recorder recorded all the selections made by a patient when using the ICU-Talk device. This allowed the researcher to examine the conversation patterns of the patient and view the most frequently used phrases. Unfortunately, some patients have repeatedly selected the same phrase within a very short time frame either accidentally or due to tremor or perhaps because their communication partner did not hear the phrase the first time. Therefore, summary statistics such as the most frequently used phrase may not accurately describe the phrases the patient found most useful.

From the ICU-Talk Project Nurse Questionnaires, which were completed at the end of each 12 hour shift:

- 68% of staff found that they needed to remind the patient to use ICU-Talk
- 44% said that patients used ICU-Talk with someone other than themselves

- 12% said that the patient used ICU-Talk as a first means of communication
- 44% said that ICU-Talk assisted with patient care
- 4% said that patients used it to start conversations
- 84% said that ICU-Talk did not obstruct their observation or care of the patient
- 72% said that the patient did stop using ICU-Talk and resort to others forms of communication
- 76% said that it was not harder to understand the patient when they used ICU-Talk

The relative questionnaire response was poor but revealed comments ranging from "My mother found it a little big and a little scary", to "I felt ICU-Talk was wonderful!"

The midpoint questionnaire was answered by 35 of a possible 38 nursing staff. There was an even split between experienced

PATIENT	AGE	GENDER	MEDICAL DIAGNOSIS	APACHE II SCORE	INTUBATION T=Tracheostomy O=Oral intubation	LENGTH OF STAY	NO. OF DAYS ICU-TALK USED
1	65	F	Severe burns	12	T	18.3	6
2	39	M	RTA, rib fractures	12	T	26.1	2
3	54	M	Aspiration pneumonia	19	O	2.0	2
4	43	F	Septicaemia	15	T	57.9	3
5	69	F	Septicaemia	23	O	24.9	3
6	50	F	Poisoning	23	T	36.2	2
7	52	M	Peritonitis	26	O	127.2	3
8	75	M	Empyema	29	T	14.8	3
9	76	M	Necrotic gall bladder	25	T	43.5	1
10	74	M	Cardiogenic shock	26	O	12.6	1
11	76	F	Cholycystect- omy	20	O	17.9	1
12	48	F	Colectomy	13	O	15.4	1
13	52	F	Oesophagec- tomy	13	O	13.3	2
14	68	M	Respiratory arrest	16	O	3.7	2
15	75	F	RTA, multiple fractures	20	O	36.9	1
16	74	F	Ischaemic bowel resection	14	O	14.8	2
17	36	F	Splenectomy	24	O	11.8	1
18	63	M	Whipples procedure	14	O	5.1	1
19	65	M	Pancreatitis	22	O	7.3	1

Table 1 Information about patients who used ICU-Talk

(more than 5 years in ICU) and less experienced nurses. The results were summarised as follows:

- 97% felt nurses should be involved with using ICU-Talk with patients
- 90% felt patients in intensive care need a computer based communication aid
- 89% felt a patient's well-being is affected by their ability to communicate
- 71% felt in their experience patients fail to communicate effectively using mouthing and/or gesture
- 68% felt ICU-Talk obstructs their view of the patient
- 53% felt the ICU-Talk device is difficult to manoeuvre

Discussion

The ICU-Talk project aimed to develop an augmentative and alternative communication (AAC) system for intubated patients in a hospital intensive care unit (ICU). The results collated so far have confirmed that ICU-Talk can be used by intubated patients in ICU and requires very little training. The evaluations have highlighted problems with the software and the current equipment.

The most significant problem with the software concerns the organisation and the navigation of the database of phrases. The current approach uses a hierarchy of topics and approximately 270 phrases. When the patient first uses the device they do not know what phrases are available or where they are stored. Thus, patients may try to find a phrase that does not exist, and if it does, they still have to correctly identify the appropriate topic. The issue of organisation and retrieval of large quantities of data has been ongoing in the field of AAC. The next stage of the ICU-Talk project will address this issue.

The project has overwhelming support from the nursing staff and they agree on the need for a computer based communication aid, though their concerns regarding access to the patient need to be addressed and an investigation into other possibilities is underway. A tablet PC has been purchased and funding is being sought to trial this smaller computer but there are concerns about its ability to withstand the rigours of the ICU environment.

A future project is planned to address the issues discussed above and to trial an improved device in a multi-centre trial involving several intensive care units in the United Kingdom.

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Email: fmacaulay@computing.dundee.ac.uk
Website: www.computing.dundee.ac.uk/projects/icutalk

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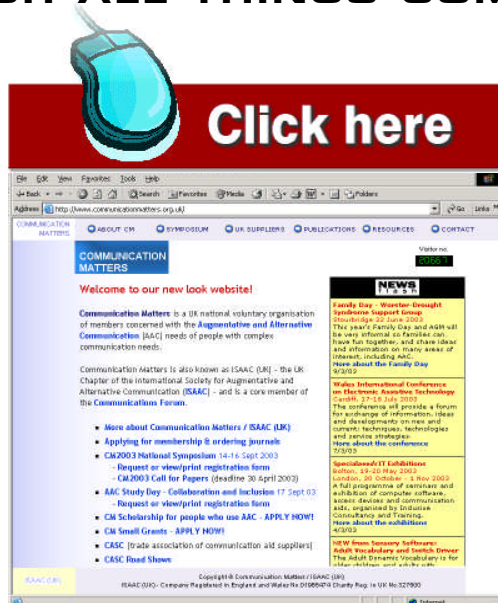
Trustees News

from Janet Scott, CM Chair

Spring is here again and I am looking at a gorgeous big bunch of daffodils sitting on the table, wondering what to write! This seems to have been a time of people quietly getting on with the work of running *Communication Matters*.

The CM Website

We have totally revamped the website and it is now easier to navigate around, and is packed full of useful information and links. Three of the leaflets: *What is AAC, First Steps* and *How to be a Good Listener* are available on-line. So make *www.communicationmatters.org.uk* your first port of call when looking for information about AAC, suppliers, assessment services, conferences etc.

New CM Publication

The *Safety in Numbers* pack, a photographic telephone directory, is now available from *Communication Matters*. This simple pack was the brainwave of Rosaleen Cudmore who worked with Tina Detheridge (CM's publications co-ordinator) to bring it to fruition – please see page 27 for more details.

Communication Matters is keen to help with the publication of AAC related materials. So, if you have an idea but have no idea how to take it forward, or if you've got something already written and are looking for a publisher then it might be worthwhile discussing it with Tina or one of the other Trustees. The *Communication Matters* Publications Policy will also help – please contact us for a copy.

On-going Work

Work on revising the Constitution is ongoing, and hopefully we will have the new document available for your approval at the AGM in September. The Trustees are grateful to Janet Larcher for her 'external' review of our work to date.

Some of the Trustees are busy working on the development of an *Introduction to AAC Training Pack*.

CM2003 Symposium & AAC Study Day

The Trustees are all gearing up for *CM2003* National Symposium in Lancaster. This will begin with a plenary session and the *Communication Matters* AGM on the afternoon of Sunday 14 September 2003, and presentations will be held on 15 and 16 September at Lancaster University. On 17 September, there will be a special AAC Study Day on *'Collaboration for Inclusion: The AAC Context'* presented by Dr Carol Miller from the University of Birmingham.

Put these dates in your diary now! Have you thought about submitting a paper for *CM2003?* Go on – you can do it!

New Arrivals

Since I wrote this column for the last Journal we now have two new 'Trustee babies'. Congratulations to Helen Whittle and Sally Townend – and their partners of course!

News from CASC

Communication Aid Suppliers Consortium

by Dave Morgan, CASC Chair

Survey Results

In the last issue of this Journal, I said that we would be sending out questionnaires to all members of Communication Matters. The aim was to see how our 'customers' (for want of a better word) saw the CASC organisation now and in the future. I am pleased to announce the questionnaires have been sent and that we had 161 replies (40% response rate).

Most of the statistical results were, perhaps, fairly predictable. For example, about three out of every four respondents felt that the main thing that CASC did now was to organise Road Shows and/or act as a supplier body to liaise with *Communication Matters*. But there were some surprises. For instance, about 50% of respondents said that CASC was an organisation that could be approached by people (e.g. those who use AAC, enablers, family members or professionals) who are encountering severe problems with AAC suppliers who are also members of CASC. In addition 77% of those responding stated that CASC should act as a 'policing' organisation for communication aid suppliers.

Although CASC has a Code of Practice, acting as a policing organisation has never been one of its aims. This is obviously an issue that would need very careful consideration by CASC members, especially with regard to who would make decisions about taking any action against a member. In addition, over 12% of respondents had either never heard of CASC or didn't know what they did, and 19% said they did not know the aims and objectives of CASC. There is obviously a need to better promote and inform people about CASC. So, allow me to restate the aims of CASC:

- Create an improved awareness of the state of the art of AAC.
- Advance the knowledge of AAC.
- Manifest support for organisations in the field of AAC.
- Act in the best interests of customers.
- Promote a professional approach to the development, manufacture and service of augmentative communication systems with the emphasis on quality assurance.
- Maintain a Code of Practice.

These and other aspects of CASC (including a list of CASC members and the Code of Practice) can be found on the *Communication Matters* website.

Finally, 40% of respondents had other suggestions for how CASC could further assist or support the AAC industry. The list of suggestions is quite comprehensive ranging from general comments to some practical ideas which perhaps should be implemented.

CASC members will meet to discuss the results of this questionnaire, together with the results of a separate but similar questionnaire completed by members of CASC to try and ascertain what they think their organisation should do. I will bring you some of the first results from that meeting in the next edition of this Journal. If that meeting decides any changes to

the operation of CASC (e.g. changes to the Code of Practice or Objectives), they will also be added to the CM web site.

For the moment, it is clear from all these surveys that:

1. The Road Shows should and will continue.
2. The liaison between CM and CASC is an important aspect of the work, and that too must remain.
3. There are many other things that CASC could be doing, given the time and the resource.

May I take this opportunity to thank all of you who took the time and trouble to complete and return the questionnaire.

New CASC Member

CASC would like to welcome a new member: *Hearing Products International Ltd* of Echo House, 26, Haigh Park, Haigh Avenue, Stockport SK4 1QR.

If you want to get in touch with them their telephone number is 0161 480 8003 and the contact name is Chris Rohde.

STOP...PRESS...STOP...PRESS...

1-Voice Family Network Day

This 1-Voice family day will be held on 29 June 2003 at the Earth Centre, Doncaster, to bring together families and anyone interested in AAC.

Find out more about this event from: *www.1voice.info*

STOP...PRESS...STOP...PRESS...

Publishers invited to free inclusion on SwitchIndex.com

All publishers of switch accessible software are invited to register their software at *SwitchIndex.com*. This will enable their applications to work automatically with the *Crick* USB switch interface. The site is also growing into an index of switch accessible software.

The *Crick* USB switch interface works with most switch-accessible software on both Windows and Mac. It comes with a small application called USBKeys. This allows the user to set up each of the switches to send different keypresses or mouse clicks. Recently released is version 2 of *USBKeys,* which allows any key or key combination to be set up. It also includes a database of applications that it knows, and the keypresses or mouse clicks each application expects. When one of these applications is started up, *USBKeys2* recognises it automatically, and sets itself up to send the relevant key presses or mouse clicks when a switch is pressed.

Users can add their own database entries to their copy of *USBKeys2*. Crick Software is collecting as much information as we can about switch accessible applications to add to our master database at *www.SwitchIndex.com*. And *USBKeys2* updates itself automatically from this site. The aim is to make everything simple for the user. They simply plug in the interface and go - no setting up is required. The website includes everything that publishers require to get included on the database.

STOP...PRESS...STOP...PRESS...

Gus! Pocket Communicator

Gus Communications has recently released an updated version of the *Gus! Pocket Communicator* Pocket PC speech software (UK Version). This product is designed for people with communication or speech disorders who require a small, user friendly speech system and have the physical ability to use a hand held computer. It offers unlimited pages of words and phrases, along with the ability to create new words and phrases on-the-fly. This is the most portable and powerful speech solution available today and is compatible with *any* Pocket PC from any manufacturer (e.g. HP, Compaq, Dell). Available as software only or bundled with a Pocket PC. There are also on-line video tutorials available from the website.

Software available for download from *www.gusinc.com*

STOP...PRESS...STOP...PRESS...

Switch Play & Control from KEYCOMM

KEYCOMM have produced a new booklet called *SPLAT* Switch Play Learning and Technology: A Guide for parents and carers. It is aimed at giving to parents of young children using single switches to play with adapted toys. It is easy to read and full of digital camera photos to help families get the most out of play experiences with their child. It has also been useful for keyworkers in Child and Family Centres here in Edinburgh.

Another booklet *Switch Control for Young People* is also available in the same format for use with families and carers of young people ages 9-16 with severe to profound disability using simple switches to control t heir environment.

Each booklet is £3 per copy including p&p; both booklets can be purchased together for a discounted price of £5 including p&p within mainland UK. For further information or to obtain copies of the above booklets, please contact Deborah Jans at KEYCOMM, 40 Broomhouse Crescent, Edinburgh EH11 3UB, UK or Email *deborah.jans@educ.edin.gov.uk*

STOP...PRESS...STOP...PRESS...

New Training Resources for SENCOs

A new, free-of-charge information resource to support teachers dealing with special educational needs was launched at the Special Needs Fringe exhibition in January 2003.

The resources are training materials developed by the Inclusive Consultancy and Training Syndicate (ICTS) as part of their delivery of New Opportunities Fund (NOF) training.

Ralph Tabberer, Chief Executive of the Teacher Training Agency, pressed the switch that made these resources go live on Friday 10th January at the exhibition. Mr Tabberer said that: "We must remember that all teachers - not just those who have been specially trained - come into contact with pupils with special education needs and require easy access to resources to help them. These materials from ICTS have been used in training thousands of teachers already and are of proven quality and value. ICTS are the first of the major

training providers to make their materials freely available on the internet. It is a generous step and I hope others will follow their lead."

NOF training has had a considerable impact in the special needs sector. The programme delivered by the ICTS reached almost all of those working with pupils with severe and complex special needs in special schools in England, Wales, Northern Ireland and Scotland. However, Special Educational Needs Coordinators (SENCOs) in mainstream schools, and in special schools dealing with moderate learning difficulties or behavioural problems, do not always have detailed information about using technology to support pupils with low-incidence disabilities. Each year, and often unpredictably, they may need to know what approaches and resources are available for a particular learner.

"Because of the involvement of the centres of expertise in each field, and across all four countries, the ICTS training units online are probably the best resource yet created to show how new technology can help pupils with severe and complex special educational needs overcome the extra challenges they face," said Martin Littler, Chair of the ICTS Consortium.

"We are delighted to be able to donate these resources to help SENCOs, student teachers, NQTs and anyone who would like to use them in support of their learners."

Stephen Dunmore, Chief Executive of the New Opportunities Fund, welcomed the move to open resources to other teachers, saying: "The scheme, funded by the National Lottery, to train the nation's teachers in the use of ICT has an added bonus when resources developed for specialist training are now freely available to all. We hope as many teachers as possible will benefit, and in the long term that will benefit children with special needs."

"This is an exciting proposal from Martin Littler - these would be useful resources for schools which have a minority of pupils with special needs who did not take training from ICTS," said John Anderson, Education Technology Strategy Coordinator of the Department of Education in Northern Ireland.

The resources represent the combined knowledge and experience of the ACE Centre; ACE North; the Advisory Unit; the CALL Centre, Edinburgh University; CENMAC; the Down's Syndrome Association; Inclusive Technology; Janet Larcher Associates; the Manchester Metropolitan University and the Royal National Institute for the Blind, and others.

The free resources are now available from Inclusive Technology's website *www.inclusive.net*

There are also resources about AAC at: *www.inclusive.net/resources/units/unit3/unit3_contents.shtml*

STOP...PRESS...STOP...PRESS...

Adult Dynamic Vocabulary

Most pre-stored vocabularies are aimed at the younger user. For older children and adults with language difficulties, a larger vocabulary is required. The user may also need to use standard computer software, but lack the spelling ability to enter text from a keyboard.

The new *Adult Dynamic Vocabulary* from Sensory Software contains about 5,000 words in approximately 1000 grids. Despite its size, the logical layout makes it easy to find words. We would suggest it as a logical step up from *CALLtalk* for users who are not using text based input. Details on *www.sensorysoftware.com/resources/gridsets/adv.html*

STOP...PRESS...STOP...PRESS...

New Switch Driver

Sensory Software have released a new version of their free Switch Driver that allows either USB or serial switches to work with all switch software. A free download and explanation of USB switches is available from: *www.sensorysoftware.com/overload/overload0016.html*

All publishers of switch accessible software are invited to contact *info@sensorysoftware.com* to ensure that their software is supported.

STOP...PRESS...STOP...PRESS...

Electronic Assistive Technology Customer Consultation Group (EAT CCG)

The Communication Aid Service at Frenchay Hospital, Bristol has served on the Agency's EATCCG for three years. Their brief has been to contribute to the knowledge about AAC in general and electronic voice output communication aids in particular.

In collaboration with the NHS EATCCG, a unique opportunity to begin a database that will centralise information about how individuals of all ages have access to augmentative and alternative communication has been made possible. This involves the development of a *questionnaire* to be completed by those people in the UK who run recognisable *centres* specifically set up to assess individuals who need appropriate voice output communication aids. These can be run by either charitable, educational or NHS establishments.

A letter has been sent tto all the SLT Managers in the United Kingdom asking them to identify the most appropriate person in their trust, organisation, city or region who should be asked to complete the questionnaire.

Many services have people skilled in the area of AAC and that these people often have access to small banks of communication aids so that they can carry out assessments as part of their job description. We are not yet ready to include this detailed information but hope that the database can be developed over time to provide this richer national picture.

Please be aware that your Manager will be giving details so that the Questionnaire can be sent to the most appropriate person(s) by the NHS EATCCG. Remember, information is power! A national database would provide quality information to professional bodies and funding services. Don't forget to fill it in if you are one of the people nominated to receive it. We really need as many completed questionnaires as possible to make it all worthwhile!

For further information, contact Eileen Grist Tel: 0117 9753946 Email: *eileen.grist@north-bristol.swest.nhs.uk*

Diary Dates

9 May 2003   Cheadle, Cheshire
CASC Road Show at BGWS Conference Centre
Cost: FREE Contact: Com. Matters 0845 456 8211

12 May 2003   Charlton, London
Writing with Symbols Software
Contact: CENMAC 0208 854 1019

12-13 May 2003   CALL Centre, Edinburgh
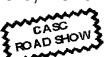**Picture Exchange Communication System (PECS)**
Contact: CALL Centre 0131 651 6236

13 May 2003   Ashford, Kent
CASC Road Show at The Stour Centre, Ashford
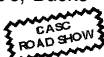Cost: £10 Contact: Com. Matters 0845 456 8211

19-20 May 2003   Bolton
SpecialneedsIT North
Contact: 0870 429 4302 Website: www.publishers.org.uk

20 May 2003   Wycombe, Bucks
CASC Road Show at Wycombe Hospital, Bucks
Cost: FREE Contact: Com. Matters 0845 456 8211

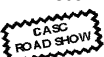**21 May 2003**   Bristol
CASC Road Show at Claremont School, Bristol
Cost: FREE Contact: Com. Matters 0845 456 8211

10 June 2003   Charlton, London
Access, ICT and Communication Aids
Contact: CENMAC 0208 854 1019

22 June 2003   Stourbridge
CASC Road Show at Sunfield School, Stourbridge
Cost: £5.00 Contact: Com. Matters 0845 456 8211

25 June 2003   Stourbridge
Family Day - Worster-Drought Syndrome Support Group
Contact: national.contact@wdssg.org.uk

25 June 2003   Charlton, London
Positioning Pupils and their Equipment
Contact: CENMAC 0208 854 1019

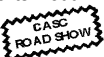**29 June 2003**   Doncaster
1-Voice Family Network Day
Contact: 0845 330 7862 info@1voice.info www.1voice.info

30 June 2003   Portsmouth
CASC Road Show at The Futcher School
Cost: FREE Contact: Com. Matters 0845 456 8211

10 July 2003   Charlton, London
Using ICT for Keeping Records
Contact: CENMAC 0208 854 1019

11 July 2003   Charlton, London
Helping the Child with Developmental Co-ordination Disorder (Dyspraxia)
Contact: CENMAC 0208 854 1019

17-18 July 2003   Cardiff
Wales International Conference on Electronic Assistive Technology
Contact: 029 2031 3931 Website: www.wiceat.org

14-16 September 2003   Lancaster
CM2003 National Symposium
Contact: Communication Matters 0845 456 8211

17 September 2003   Lancaster
Collaboration for Inclusion: The AAC Context
Contact: Communication Matters 0845 456 8211

30 October - 1 November 2003   Islington, London
SpecialneedsIT London
Contact: 01923 690620 www.specialneedsexhibition.co.uk

THE BOB BLACKBURN MEMORIAL BURSARY

By now many of you will have heard of Bob Blackburn's sudden and unexpected death earlier this year.

Over the years Bob has rescued many of us (including me!) from that desperate feeling of "Oh no! What have I done?", "Can't stand these machines! It's hung up again!". His quiet, calm manner talking you through what to do with a recalcitrant communication aid (while managing to not make you feel totally stupid) has been much appreciated and will be very much missed.

Bob and his team somehow always managed to fix things. Bob's technical knowledge with a range of different communication aids spans many years – his depth of wisdom will be hard to replace. I frequently used to phone him up with a "I used to know what to do with this – but I just can't remember!" type of query – and he was always able to come up trumps.

Communication Matters would like to show our appreciation of Bob's support to individuals who use AAC and their families by offering a free place at the CM2003 Symposium this September at Lancaster University. This place is for someone who uses AAC (aged 16 years or over) and up to two PAs/family members. Reasonable travel expenses will be provided. Names will be drawn from a hat. This bursary is open to people using any form of aided AAC, whether low-tech or high-tech.

To apply, please provide the following information:

- **Your Name,** address, contact phone number and/or email of the person using AAC. **All entries will be put in the hat for the draw.**
- Name of AAC system used. (This information is for administrative purposes only to confirm that the person actually does use AAC; there will be no preference shown to people who use an aid from Liberator Ltd.)
- An indication of your method of travel to Lancaster e.g. train, car. (This information is for administrative purposes only to enable us to make appropriate budgetary arrangements.)

Please send in your application by **1 June 2003** on a postcard or by email to:

The Bob Blackburn Memorial Bursary, Communication Matters, c/o ACE Centre, 92 Windmill Road, Oxford OX3 7DR Tel: 0845 456 8211 Email: admin@communicationmatters.org.uk

Sensory Software International Ltd

Adult Dynamic Vocabulary for The Grid

New pre-stored vocabulary for older children and adults

The Grid combines a powerful on screen keyboard with a symbol communication system that is so easy to use. The Adult Dynamic Vocabulary (ADV) is the latest addition to our large range of materials for The Grid, Pocket Grid and WordWall.

The main vocabulary is arranged in grids of 48 cells (like IDV level C)

A large vocabulary

Most pre-stored vocabularies are aimed at the younger user. For older children and adults with language difficulties, a larger vocabulary is required.

The user may also need to use standard computer software, but lack the spelling ability to enter text from a keyboard.

ADV contains about 5,000 words in approximately 1000 grids. Despite its size, the logical layout makes it easy to find words. We would suggest it as a logical step up from CALLtalk for users who are not using text based input.

Like all our grids, ADV can be used in many ways:

✓ Communication on a desktop, laptop or tablet PC
✓ As a powerful on-screen keyboard on a PC
✓ Print overlays for other communication aids
✓ Export the grids to a palmtop or tablet CE computer

ADV on a palmtop computer

The ADV Quick Talk grids are designed to speak instant messages, and have only 24 cells. This allows the whole vocabulary to be used on a laptop or tablet, with instant messages in a smaller format on a palmtop.

Used as an on-screen keyboard

Use ADV to create emails, Word documents, or to use any other text based Windows software. Here it is in use with Writing with Symbols.

ADV was compiled using the new Widgit Rebus symbol set.
ADV and symbols for use with The Grid or WordWall - £200
A special pack with ADV, WordWall and Writing with Symbols - special price of £272.

Switching to Communication

by Tony Jones and Martyn Maltby

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

Introduction

This paper deals with practical issues surrounding the use and development of switching skills with individuals (children and adults) experiencing profound and multiple/complex learning difficulties (PMLD). Both authors are practicing special needs teachers still actively working with individuals experiencing PMLD - Tony Jones in a college and Martyn Maltby in a school.

This paper is *not* about the ergonomics of switch use; this has been well documented (e.g. *www.ace-north.org.uk/resources/resq.htm)*. Nor is this paper about extolling the virtues of one piece of hardware or software over another. If we were to recommend anything it would be PowerPoint, a piece of software that most establishments will have and yet, often, underused and undeveloped.

This paper *is* about the everyday reality of life in a classroom with individuals for whom real progression is challenging.

The Needs of Learners Experiencing PMLD

It is our belief that individuals experiencing PMLD have a need and a right to develop communication skills. We believe this need outweighs all other educational needs and indeed, we would argue that other needs are likely to be dependent upon the ability to communicate. While we cannot fault a philosophy that supports an individual's right to have access to a national curriculum, we believe that 'right' and 'rite'are not one and the same thing. We all have a right to study astrophysics at Cambridge University under Stephen Hawking. However, Cambridge would make just claim that there are certain pre-requisites to this study and that for the individual sitting in, without such pre-requisites, such a session would be meaningless. The 'rite' of putting severely cognitively challenged individuals into (to pick one at random) a session on the 'impact of Romans on Britain' seems to us a little questionable to say the least unless this is simply a vehicle for more important targets (for example communication). Furthermore, we would be tempted to call an infringement of human rights, any situation that allowed an individual to leave school without an effective means of communication because energies were deployed in other directions citing political or philosophical rhetoric.

The Importance of ICT and Switching

While some might claim that the use of ICT in support of emergent communication skills is overvalued (See for example Cockerill 2002) we would make no such claim. However, no one is claiming that ICT (assistive or adaptive technologies) alone are the answer. ICT is a tool, a means to an end and, with this group of people especially, rarely end in itself (although some may need technology to augment their existing commu-

nicative abilities). As with any tool, it is as good as the craftsperson that uses it -although the quality of the tool itself does have some part to play. The craftsperson, one of those dedicated folk in the average classroom, has a number of tools at his/her disposal, if these tools are chosen wisely and used well then they can and do make a difference (here we speak from experience). They must be a part of a more global strategy (strategies?) for the amelioration of the condition and all who work with and in some way impinge on the lives of the individuals concerned (significant others) must play their part. Techniques and strategies such as Multi-Sensory Referencing (Jones and Galway 2002), Intensive Interaction (Nind and Hewett 1994*www.intensiveinteraction.co.uk/index.asp*), Non Directive Therapy (Cockerill 1990) all have major parts to play (the list is not exhaustive) in the equation that helps an individual make sense of his/her world and move forward, albeit slowly, towards emergent interpersonal communicative behaviours. The reader will note that these techniques are primarily based on human-human interactions and not technology-human interactions supporting Cockerill's (2002 op.cit.) motion that we need to put the emphasis back on face-to-face, human-human interactions.

How does the master craftsperson make best use of his/her tools? First the master chooses with care – there will be those tools s/he uses the most, the favoured tools, and a few peripheral tools that are used for that very special purpose. The master knows that a few tools used well are better than a whole galaxy used badly. Second, the craftsperson knows which tool to use and when and how to wield it to get the best results. Third, the craftsperson does not start the polishing process before the material has been prepared and worked. S/he would probably consider ludicrous the notion of adapting the polishing process to make it more suitable for the unprepared material.

This paper is about the use of switches. A switch is simply a tool that may be used in conjunction with other tools to help the craftsperson develop his/material towards a desired goal. Switches can help an individual reach many goals including those involving communication, cognition, and control. Indeed, for some individuals, a switch or switches may be one of the essential pre-requisites. A switch is fairly useless on its own, by definition, a switch operates something else - activating a switch enables something else to happen. Providing the master chooses and prepares wisely, the switch will tirelessly and objectively perform its given duty. That is not to say that the material will always be compliant. Indeed, the material may be resistant. In real terms, there are many individuals for whom the switch is an inappropriate starting point. This is where the parallel techniques take centre stage. That is not to say that we give up on the introduction of a switch as a means

to help establish, let's say, cause and effect. How do we introduce a switch to the individual (let's call him Adam, we'll introduce Eve later) who ignores our presence and sits and rocks in his chair?

Problems and Some Ideas for Solutions

We've already stated that we would be using other techniques to help Adam move from his state of isolation towards more social interactions. However, we wouldn't necessarily wait until this was achieved before introducing a switch. We would:

1. Try to discover something that Adam finds stimulating (a motivator or motivators).

2. Provide the motivator(s) through the activation of a switch.

3. Help Adam 'discover' the switch.

There are three basic rules for switch use that have served us well. There are always exceptions to rules and the switch rules are no exception! However, we recommend them for your consideration:

1. Never use the word 'switch' when talking to the learner. Never say "Hit the switch Adam", rather say "Adam, turn on the fan". Keep the phrase simple, consistent and put the keyword (in this case 'fan') last.

2. Label the switch with a symbol. The individual experiencing PMLD must encounter many switches during the average day – how is Adam to discriminate between one switch and another? In one session the switch turns on some music and in another it activates a foot-spa. On one day the red switch turns on a fan and on another day the same switch makes a dog move and yap. How is Adam ever to learn that the switch is doing this? It hardly has the same result every time it is activated. It is not predictable. It is not consistent. The label helps to build in the consistency. We know that Adam may not be consciously attending to the label (at first) but good practice dictates that, nevertheless, switches should be labelled (unless there is a good reason for not labelling!).

3. Do not hold the switch rather mount the switch. There are good reasons for holding a switch and we'll deal with some later but, unless there is a good reason, don't hold the switch. Holding the switch can lead to unconscious 'cueing'. Furthermore, your switch positioning will likely be inconsistent.

We also have Eve in our group. Eve is more social than Adam. However, when we put a switch in front of Eve she first tries to put it in her mouth and, when she finds she cannot do that (it is firmly mounted) she repeatedly hits the switch over and over!

Adam & Eve

We are informed that Adam sits and rocks. How does he sit and rock? This is not such a silly question – does he walk into the room and find a seat in the corner away from others or is he non-ambulant and pushed into the room? What does he do if a member of staff sits near by and if that member of staff offers an object? Does he glance at the person or the object? Does he alter his rocking pattern? Does he shift his motion so as to move away from the proffered item? If he does then we know he is aware of our presence and consciously choosing not to become involved.

With an individual at this stage of development, the aforementioned techniques of Intensive Interaction (op cit) and non-directive therapy (op cit) have proved useful. The aim, in the former, is to try to make oneself more interesting than the individual's self-stimulatory behaviours using actions based on early mother child exchanges.

While all of this is proceeding, the individual can be introduced to the switch or perhaps we should say the switch is introduced to the individual. The switch is positioned so that the learner will access it perhaps accidentally at first. This is one situation in which holding the switch becomes more acceptable. With accidental activation comes a reward – the motivator – this could be favourite music, wind in his face (from a fan), going out for a walk if in a wheelchair (the switch is attached to a BigMack that says "walk please"), etc. When accidental activation has been successful on (what you consider to be) sufficient occasions, move the switch so that the learner has to make a little more effort to achieve the reward. If Adam is now given some space and time does he activate the switch? If not, we continue on course with the suggested strategies and re-introduce the accidental switching procedure. It is, however, rare in our experience for learners not to interact with the switch after the initial phase.

Eve's behaviour is somewhat different to Adam's. She is repeatedly activating the switch over and over without stopping. In this situation there are at least four things we recommend that you try 'ABCD':

>'A' is for *Accessibility*
>
>'B' is for *Blocking*
>
>'C' is for *Change*
>
>'D' is for *Differential Reinforcement*

Accessibility means that you make the switch a little less accessible. Move it further away slightly; change the angle; put it on the learner's non-preferred side. Does any of this have any effect on the rate of switching?

Blocking means that you block the learner's access to the switch until it is once again appropriate to allow activations. This, once again, could mean holding the switch! Alternatively, one may remove the switch or physically block the learner's access.

Change refers to the notion that there may be something about the switch itself that is acting as a motivator for the learner: its colour, its click, its shape, and so on (e.g. swapping from an AbleNet Jelly Bean switch with an audible click to an ERI Matrix switch which has a different shape and no audible click. In each instance we make a change and note any corresponding change in learner behaviour.

Differential reinforcement makes use of the potential of switch-operated software/ hardware to differentially reinforce correct switch activations. Consider a simple PowerPoint presentation that puts an image of Robbie Williams (for example) on the computer screen and plays a (part of a) Robbie Williams track. The program is
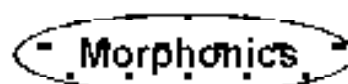
looped to make it continually respond to the switch. There is only one slide in the show: the active slide. When the switch is activated the active slide is selected and automatically begins to play the music. However, if the switch is selected again, the slide loops on itself, the music stops and tries to restart. This continues for as long as the learner continues to hit the switch. The music never gets chance to play and the image (if we time it in) never really appears on the screen. It is only when the learner tires of repeatedly activating the switch that things happen – the image appears and music plays. The computer will not tire before the learner and reinforces the desired behaviour!

The Next Stage

So s/he can activate a switch and turn on that yapping dog? For how long will that remain motivating? The same old things happening in each session is stagnation and not progression but, sometimes, moving the person forward is both daunting and difficult. For us, the next stage is to introduce another switch – the 'Null Switch'. The null switch does nothing, it is a bit of a distraction, it is not plugged into anything. The null switch looks different to the active switch. The active switch is labelled, is a different colour and may be a different size. The null switch initially has no label and is not connected to any motivator. Only when the learner activates the active switch is there a reward. Does the learner discriminate? If yes then make the null switch easier to target and the active switch less easy. Does the learner still continue to discriminate the active switch? How far can we take this? The learner who ignores the null switch placed conveniently in front of his/her body and turns and stretches to access the active switch in order to (for example) turn on a TV for 20 seconds is not only demonstrating active discrimination between switches but also cause and effect. This should be recorded as evidence!

When the learner is discriminating (note that we are not claiming that the learner is reading the symbol on the active switch) then we introduce a label to the null switch. The null symbol should be something that is consistently used for this purpose throughout your school or college and only for this purpose. We use a red cross on a white background. Be wary of making claims on success at this point: the learner may not be discriminating between symbols. S/he may be discriminating between some other attribute of the two switches (we should eventually ensure that both switches, the null and the active switch, are identical). S/he may have tried both and then remembered and stuck with the switch that works. S/he may have figured out the 'game'… go with the one that is a little more difficult to reach. However, all of these demonstrate learning! We advise caution on the claim that the learner can discriminate between symbols until you are sure that is exactly what is happening.

Multi-Switching versus Scanning

When we have achieved success with symbol discrimination, and we should emphasise that this can take many days, weeks, months (or even years) of work, then we can begin to introduce
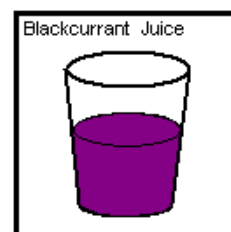
choices with two or more (four is a practical maximum) switches operating two or more items. Once again, we urge caution about what can be claimed from the success of this venture. Is Adam making a choice if he selects one of two switches that are attached to (for example) a Partner Two and says 'Orange Juice' as his preferred choice of drink? No! He could have randomly hit either switch and be rewarded with a favoured drink (Orange or Blackcurrant). However, when he activates the switch with the blackcurrant symbol he gets blackcurrant and when he actives the switch with the Orange Juice symbol he gets orange. How can we be certain that Adam knows one from the other? Ask him! Hold up Orange and say 'What is this? Adam can use the same switches to name the item. Ah but Adam doesn't realise that is what you are asking. He thinks that you are offering him a choice of drinks again and that is why he chose the blackcurrant! To be more certain we could introduce a symbol for something that is not a drink and ask again. Even here we can only be reasonably certain that Adam has discriminated the drink symbol from a symbol that is not a drink (We say reasonably because Adam may be selecting on the basis of the most familiar symbol!).

If Adam is still at a pre-intentional stage at this time – the continual linking of the two 'choices' with the drink given will, it is hoped, over a period of time, help Adam to realise that the Orange symbol is associated with the Orange Drink and the Blackcurrant symbol with the blackcurrant.

When we move beyond two or three switches, we begin to use the Intellikeyboard from IntelliTools *(www.intellitools.com)*. This hardware and software system allows learners to choose from a range of options (from 1 to over 100) and can provide
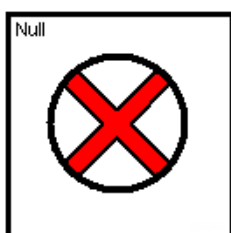
The Intellikeyboard

voice output feedback as well as other auditory stimulation.

The Intellikeyboard can also be operated with one of two switches for learners experiencing greater physical difficulties. A further piece of software from the IntelliTools range, Intellipics (and now Intellipics Studio), provides a means to set up training activities for such things as symbol recognition. Furthermore, this program works in conjunction with Overlay Maker to create the overlay for the Intellikeyboard.

For some multi-switches may not be an option and the individual may need to use single or dual switch scanning. It is not the intention of this paper to explore this area of development other than to suggest that, if you are unsure about which is the best route to follow for an individual then you should follow both until it becomes clear which is the best solution.

Communication

The Intellikeyboard overlay eventually can be removed, laminated and given to the learner as a simple communication board. The learner no longer needs the feedback from the computer system provided that staff encourage, pick up on, and respond to, the use of the board.

Summary

It is possible with consistent effort to help an individual experiencing profound and multiple/complex learning difficulties to succeed with switches. Success is measured ipsatively, that is, measuring from a baseline (present position) to point along a line drawn as directly as possible to a future (SMART) goal. For some such work can take weeks for others it may take years of effort. We do not wish to lead anyone into believing that such progress happens overnight.

We wish you every success. Liberator can provide in-service training into your place of work in this area (please refer our website *www.liberator.co.uk*)

Tony Jones & Martyn Maltby
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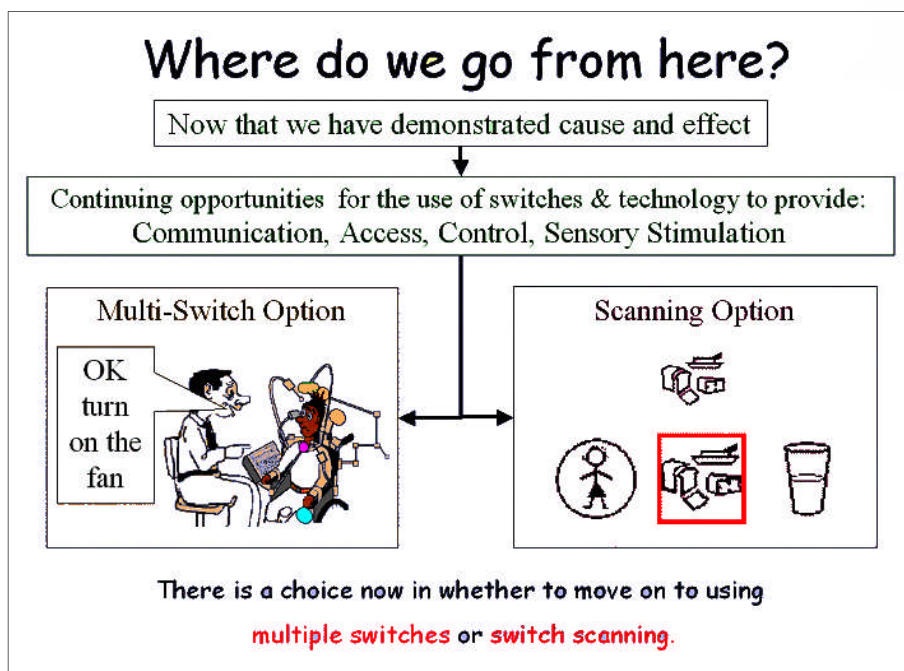
New Publications

## SAFETY IN NUMBERS: A Photographic Phone book

Devised by Rosaleen Cudmore
Published by Communication Matters

Communication Matters is delighted to announce the publication of *Safety in Numbers,* a photographic phone book for people who find reading difficult.

The pack includes:

- An information page with key information about the person.
- Several blank pages ready to add photographs or symbols.
- A space for additional notes for an enabler, babysitter or other adult.
- A tag to make the book easy to hold as well as identifying the owner.
- A page of symbols for common services printed on labels ready to stick in.
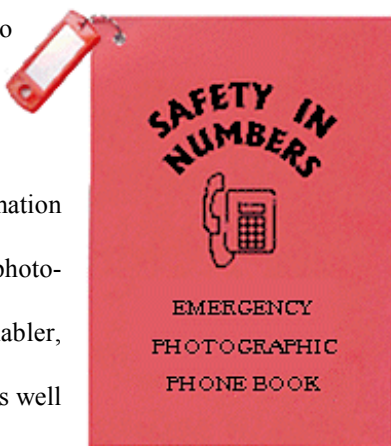
Price: £3.50 (inclusive of p&p in UK) Cheques must be made payable to 'Communication Matters'. Available from: Communication Matters, c/o ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR Tel: 0845 456 8211 Email: *admin@communicationmatters.org.uk*

This simple and practical resource is based on an idea by Rosaleen Cudmore:

"The idea came one day after having an incident that needed my son to help me. I was unable to communicate and needed urgent assistant. After a few moments I was able to get my son to fetch my handbag so that I could use my mobile and seek help.

After that incident, I devised this phone book so that even a toddler could use it. I decided upon photo identification. The people I chose where those who I trusted with my young family and also those with the same area code phone number. So that my child would not have to dial extra digits, he could recall three on the line and then three below, with the numbers big enough to not lose his place once started dialling. These people were safe and recognisable to him. Also this would be useful to emergency services if the situation warranted them to call somebody...hence, Safety in Numbers..."

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Augmentative and Alternative Communication

The Official Journal of ISAAC

Editor: Teresa Iacono, Victoria, Australia

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New Publications

Augmentative Communication and Inclusion: Children and Adults

Collected Papers from
Augmentative Communication in Practice:
Scotland's Twelfth Annual Study Day

Edited by Allan Wilson

Published by The CALL Centre, Edinburgh
51 pages ISBN 1 898042 24 1
£9.00 + £1.20 p&p

When I was asked to review this new publication, I was quick and eager to respond. This was an opportunity to read papers presented at the 12th Annual Study Day, organised by experts at the forefront of AAC research and development. Augmentative Communication in Practice: Scotland (ACPS) is an open group composed of people who use AAC, families, enablers and professionals.

The inaugural study day was in 1991, and this collection of papers is the eighth to be published, representing the presentations made in Stirling in November 2002. As Allan Wilson states in his editorial, "the theme for this year's Study Day was 'Augmentative Communication and Inclusion', a particularly relevant topic given recent legislation in Scotland and the United Kingdom".

ACPS has produced some extremely useful and practical publications which have proved to be very readable and reasonably priced. This collection is no exception. The book is well-written and clear, and at £9 (plus £1.50 p&p) is value for money, particularly for those who were unable to attend the Study Day but who would benefit from the information generated. It is hoped that attendance at conferences and study days will stimulate novel work practices and approaches. Having read these papers I was truly motivated to effect change in my work practice (as long as there are not too many barriers in place!).

The papers collectively covered many different areas – legislation, innovative work practices, whole school approach, classroom practices, children and adults, and feedback from the discussion session. The innovative approaches included the development of:

1. Inclusive playgroups as a result of collaboration between charity and statutory organisation (Playplus).
2. A service aimed at involving adults with learning difficulties in planning key issues (McFarlane, CLDT).
3. A group of adults with learning difficulties using high tech communication aids (Queen Margaret University College and Lothian Primary Care NHS Trust).

There was a good mix of pre-school issues, whole school approaches and specific classroom practices in those papers relating to children, and descriptions of issues around empowerment and specific high tech use for those relating to adults.

I was, however, disappointed to read three out of the eleven papers which made no reference to AAC. These included the "setting the scene" papers from Kay Tisdall (Director of Policy and Research, Children in Scotland) and Margery Browning (HM Inspector), where the emphasis was on inclusion for SEN children without regard for those who use AAC. The third paper was a transcript from a presentation made by a member of Speaking Forth (Forth Valley branch of Speakability) - though a personal account and compelling reading, the presenter with communication needs was not a user of AAC.

Speaking as a professional, it is always an illuminating experience to listen to personal accounts and case histories, and so this publication may have benefited from having less professional presentations and more accounts from people who use AAC, family members and enablers. A professional presentation, however, needs to draw on research and a review of the literature; evidence of this was lacking in some papers.

In conclusion, this collection of papers lived up to expectations. The book is very informative with a blend of relevant and current issues for both children and adults. Above all it is very easy to read, and will attract interest from many different groups involved in AAC.

So often we look to Scotland for relevant AAC research, statistics and forums. Perhaps we, south of the border, can be guided by the Scottish model and generate discussions concerning the development of similar study days in England and Wales.

Sally Chan
Paediatric Communication Aid Service
Claremont School, Henleaze Park,
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What is ISAAC?

Formed in 1983, ISAAC is a multidisciplinary organization devoted to advancing the field of augmentative and alternative communication. ISAAC has over 3,000 members in more than 50 countries, including 15 national chapters in Australia, Canada, Denmark, Finland, French speaking countries, German speaking countries, Ireland, Israel, Italy, Netherlands-Flanders, Norway, Spain, Sweden, United Kingdom and the USA.

The Mission of ISAAC is to promote the best possible communication for people with complex communication needs. The vision of ISAAC is that AAC will be recognized, valued and used throughout the world.

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

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FAST's User Forum members play an important part in this by giving us ideas via our 'I wish page' on equipment and services that needs designing so we can direct research and developers in areas where there is user need.

User Forum members are consulted on assistive technology projects that researchers and designers want user involvement on, in the form of consultation right at the design stage, and throughout the development. In this way the designs are user led, effective, affordable and needs based. Members are contacted only on projects, in areas of assistive technology they have expressed an interest in or meets their needs.

We are actively recruiting members for the User Forum and would really appreciate AAC users' involvement to create a large and credible force of opinion, advice and evaluation by people with disabilities. So tell your friends and contacts about FAST.

If you would like to join the User Forum, please contact Rosie Pocock by email: rosie@fastuk.org or by letter at the address below.

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FAST's on-line database (www.fastuk.org) provides the following information:
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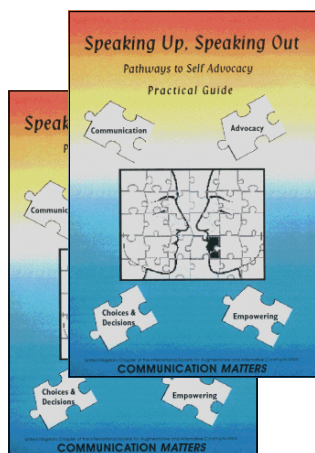
### Speaking Up and Speaking Out! Pathways to Self-Advocacy

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

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

Michelle Finds a Voice

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

Price: £10 plus £1.50 p&p from **Communication Matters**
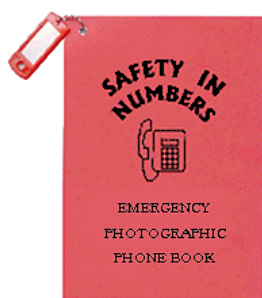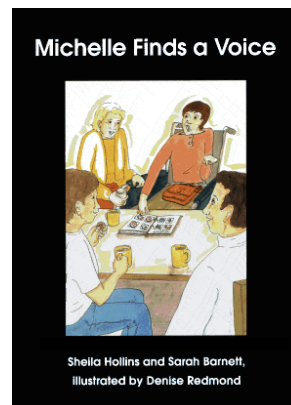
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This photographic phone book is for people who find reading difficult. The pack includes an information page with key information about the person, several blank pages ready to add photographs or symbols, space for additional notes for an enabler, babysitter or other adult, a tag to make the book easy to hold as well as identifying the owner, and a page of symbols for common services printed on labels ready to stick in.

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

Beneath the Surface

In August 2000, the creative works of 51 authors and artists from around the world were published in one book, Beneath the Surface. What these writers and artists have in common is that they are unable to speak and thus rely on assistive technology to communicate. Published by ISAAC.

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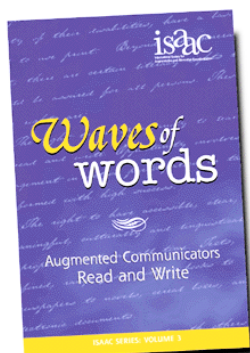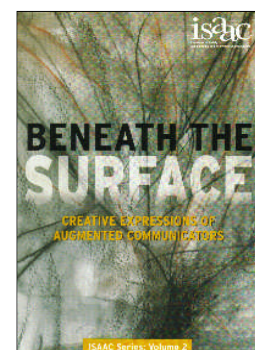
Waves of Words

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

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

Communication Without Speech:
AAC Around the World

This ISAAC book is a highly accessible introduction to AAC. It contains lots of questions and practical tips such as vocabulary selection, assessment, education and vocational considerations, making communication boards, and includes excellent photographs and illustrations.
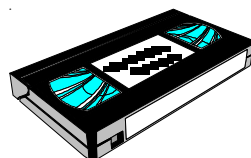
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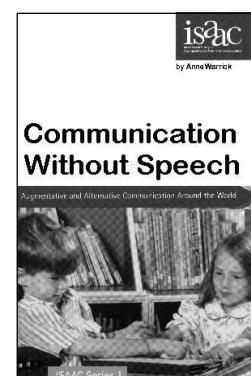
In Other Words (ISAAC video)

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

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

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