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Editorial

Welcome to this historic issue of the ***Communication Matters* Journal** - the last issue of this Millennium.

Following a very successful **CM'99 National Symposium** in September (page 16), we have received many interesting papers from Symposium presenters for publication. This issue contains several papers on the theme of adults and communication.

Fitzgerald and Reeves kick off with a paper on why a multi-disciplinary approach is essential to enable people with MND to continue to communicate (page 2). Armstrong, Jans and MacDonald describe a study in Scotland on the effectiveness of AAC use by people with Parkinson's Disease (page 5). A European Union funded project to design and evaluate a portable communication aid for people with dysphasia is detailed by Tippell et al (page 7). And on page 11, Reeves presents her work on AAC with the over 65's.

If you are interested in dynamic screen communication systems, turn to page 27 for the first part of Millar, Larcher and Robinson's paper of the workshop they gave at the CM'99 National Symposium.

Following an introductory article in an earlier issue (Vol.13 No.1) on the City & Guilds Certificate in Effective AAC, Rappell shares her experiences and provides practical tips on how to get the course off the ground (page 23).

On page 14, Mitchell describes the aims and work of the Foundation for the Advancement of Assistive Technology.

We are delighted to announce the start of a regular *Service Delivery Forum* section in the Journal. Katie Price starts the ball rolling with a very interesting article on issues around motivation for communication for children with cerebral palsy (page 19).

For parents and enablers, Katie Clarke brings readers more news and views, and Barry Gilbert lists some websites of particular interest to parents (page 13).

To mark the new Millennium, the next issue of the CM Journal will highlight two themes: AAC users' experiences and AAC internationally. Please contribute by sending in articles, photos or personal accounts. Articles by AAC users, readers from around the world, and people from the UK who have worked or visited abroad or have links with other countries are all welcome. So put pen to paper or fingers on keyboard and send us your contribution by the end of January!

Front cover: Mo McCarthy, Nicole Rappell and Andrea (left to right) from Lord Mayor Treloar College (see page 23)

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Maintaining Communication for People with Motor Neurone Disease

by Val Fitzgerald and Jackie Reeves

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

Introduction

Motor Neurone Disease (ALS) is a neurological degenerative disease causing muscle weakness. Any of the muscles can be affected. The life of a person with MND, and equally that of their carers, is one of constant readjustment to a changing level of ability as the function of one group of muscles after another is lost.

Motor Neurone Disease is so called because it is characterised by a selective degeneration of the motor neurones involving both the corticospinal pathways and those, which originate in the motor nuclei of the brainstem and the anterior horn cells of the spinal cord. The autonomic nervous system and the sensory nerves are not affected. Intellect and memory remain intact in the vast majority of cases.

The course from diagnosis to death is infinitely variable. Average age of onset is 56 years and most people can expect to live between 2 and 5 years after diagnosis. Men are affected more than women in a ratio of 2 to 1.5 to 10 percent of cases are familial. It occurs in about 1 in a 100,000 people. Common first signs are stumbling, weakened grip, cramps or a speech problem.

To date there is no known cure for MND. However this does not mean the situation is hopeless as we can, in part, alleviate symptoms, give support and compensate for, at least in part, for disability.

Communication problems almost inevitably occur. A multi-disciplinary approach, including regular review is needed. We believe that communication needs to be maintained in two ways. Firstly, to enable the client to convey wishes, needs and feelings as fully as possible, for as long as possible. Secondly, maintaining an ongoing dialogue between the client, their family and all the professionals involved.

AAC and Motor Neurone Disease is being considered more, for instance in Beukelman and Mirenda's book *Augmentative and Alternative Communication, Management of Severe Communication Disorders in Children and Adults.* But in Leigh and Swash's *Motor Neurone Disease, Biology and Management*, the section on communication aids is very small compared to that on swallowing problems. We can see how the situation in relation to AAC has changed since 1987, from the book *Assistive Communication Aids for the Speech Impaired.*

Mary Marlborough Disability Services

An average of 10 patients per month, with Motor Neurone Disease, has been referred to the Mary Marlborough Disability Services (MMDS) over the past year. Most are referred because of lack of arm function or head control; some for an AAC assessment only.

Most people have already been seen by local professionals but are referred to MMDS for specialist advice. Referrals often arrive with scant information. It is therefore important to contact local services to gain more information and avoid duplicity of work. From this information can be determined which members of the Team would be most appropriate to see the client at the initial assessment.

At MMDS the Speech and Language Therapist and Occupational Therapists as well as other members of the multi-disciplinary team work closely together and take a holistic, client centered approach. There are many links and overlap in our work.

Clients can be seen as outpatients at MMDS or on an outreach visit anywhere in the country. Clients who live a considerable distance away or who have a multiplicity of problems to address can be admitted for a week's team assessment.

The clients when they are first seen can be broadly divided into three groups:

Group 1 - People with no significant speech problems but other physical problems.

Group 2 - People with mainly bulbar symptoms resulting in speech and swallowing problems. They are often still mobile.

Group 3 - People with combined problems and late stage referrals.

Group 1

Usually present with severe weakness in arm, trunk and neck muscles but without speech, voice or resonance problems. They are usually referred for provision of mobile arm supports because of an inability to feed themselves. The arms hang limply by the side of the trunk. The weight of the arms combined with the effects of gravity on weak trunk and neck muscles tends to pull the trunk and head forward so the person id looking at the floor. The resulting posture, head position and inability to use body language can have a profound effect on communication, namely: (i) inability to make eye contact; (ii) give or receive facial expression or body language; (iii) difficulties in joining in group conversations and social isolation.

The role of the Occupational Therapist and Physiotherapist, as well as providing equipment for eating, is to give advice on posture in both standing and sitting and provide postural support as necessary, which might include:

- shoulder braces
- collars
- beanbag cushions
- riser recliner chairs
- Or, at a later stage, tilt-in-space wheelchairs

Appropriate advice and support results in improved comfort as well as the means to communicate more effectively.

The Speech and Language Therapist will be introduced and will monitor swallowing and communication locally, on ideally a monthly basis. Clients have different preferences. Some people will want to familiarise themselves with communication aids whilst others prefer to wait until it is absolutely necessary. Advice on telephones and computer access may be needed. Clients may be referred on to organisations such as AbilityNet. It is useful at this stage to begin to consider what sort of AAC devices may be necessary and how these can be obtained. Some of these people may still be working and need support to continue this for as long as possible.

Group 2

These are the group of clients that are usually seen initially by the SLT and have sometimes been mis-diagnosed. In Oxfordshire, the local SLT continues to monitor swallowing and refers on to MMDS for an AAC Assessment. The initial interview will include the completion of a personal profile. Problems identified, which need input from other team members, will be passed on to the appropriate professionals.

Common first symptoms include slurred speech (dysarthria), reduction in volume of the voice (dysphonia) and/or hypernasality. Swallowing problems also occur. Clients will often be using writing to supplement speech.

AAC equipment often considered:

- voice amplifiers
- Lightwriters
- laptop computers
- personal organisers
- small digitised aids for backup
- alphabets for spelling key words

Monthly monitoring and the help of an SLT Assistant are considered essential. Nearly everyone will need help and support. A plan should be made for future communication needs and discussed with the other professionals involved. The Motor Neurone Disease Association's Loans Bank and their support in purchasing equipment are invaluable. Professionals who do not see so many clients with MND often under-estimate the speed at which the illness can proceed.

Group 3

Clients from Groups 1 and 2 as they deteriorate may develop a range of different symptoms becoming gradually more and more dependent. Other clients come as a new referral, at a very advanced stage, when local services cannot find solutions. The main problem will be how to manage a rapidly changing situation where many professionals are involved. Families and clients, in their highly charged emotional state, sometimes have unrealistic expectations of what can be achieved, in terms of communication, where there is often very little bodily movement remaining. The client and his family may also need to consider options of PEG feeding and ventilation at this late stage of the disease.

The OT and PT in conjunction with other members of the team will be considering all the issues outlined in Group 1 but they may also need to consider: (i) the use of mobile arm supports for accessing a communication aid or computer; (ii) special controls for wheelchairs; (iii) provision of environmental controls; (iv) switch access; (iv) integrated systems.

The SLT will often be overseeing the change to a switch activated communication aid (in conjunction with other switch operated equipment) such as a scanning Lightwriter, or in helping to prolong computer use.

Discussion with the client and family will address what high and low tech systems are needed. Communication books, alphabets, E-Tran boards, eye blink codes may all be used. Switches sometimes need to be changed on a monthly basis.

The communication aid may need to be mounted on a wheelchair. Ongoing support to programme aids, choose vocabulary and suggest ways of communicating is essential.

The client is usually seen in their own home at this stage, as travel has often become impossible because of very high fatigue levels and the practicalities of transporting a highly dependent person.

By this stage there may be an unwieldy group of people involved but it is very important that everyone knows what is happening.

Conclusion

The client and family should be offered a multi-disciplinary approach when MND is diagnosed. All the team should work closely together and make every effort to enable the individual to continue to communicate and to convey his wishes for as long as possible.

It is also essential that the lines of communication are kept open between all the professionals involved as well as with the client and his family.

To ensure this happens and to prevent duplication of help a Key Worker should be appointed to take responsibility for keeping everyone informed and to call in the appropriate help at the appropriate time.

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Parkinson's Disease and the Use of AAC: Looking for some evidence

by Linda Armstrong, Deborah Jans & Alison MacDonald

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

Introduction

There is little evidence in the literature on the effectiveness (or lack of effectiveness) of augmentative and alternative communication (AAC) use by people who have Parkinson's Disease (PD). This paper focuses on the results of a project undertaken to gather some information in this area. First the background to the project, its structure and relevant (but scarce) knowledge and clinical experience in this area are outlined. Then the results from a survey of speech and language therapists (SLTs) are presented with results from a questionnaire completed by people with PD and their carers about their attitudes towards and/or experiences with aided AAC. Key issues for practice and future research are highlighted.

Project Background

The Scottish Centre for Research into Speech Disability clinic based at Queen Margaret University College (QMUC) has for some years been interested in issues concerning group support for adult clients using communication technology. At the international conference in Dublin 1998, findings from two quite distinct client-groups were reported. That paper emphasised the differing support needs of different clients: people with intact cognition and language but severe physical disability and people with fairly functional motor skills but more marked linguistic and/or cognitive deficits.

Among other observations, it was noted that in one group, in comparison with other group members, a client with PD made slower progress and continued to require direct prompts to use his machine, had more difficulty in retaining message codes and was more easily confused and distracted by typing errors.

Initial reference to the literature yielded very little on the topic of the use of aided AAC by people with PD. Discussion with colleagues tended to indicate that speech and language therapists (SLTs) had little experience in this area. However many commented on the need to investigate it in more depth.

One of the issues noted in this earlier project was the importance of carer involvement in order to promote more effective use and hopefully to reduce the reliance on direct prompting in the client with PD. It seemed that it was not enough for the SLT to visit and explain the workings of the device to carers but that sessions exploring its use and practising interactive communication through the device might be required.

The lack of efficacy data to support the use of AAC with people with PD led two of the investigators (AM and DJ) to develop an initial project to survey the literature more systematically and to examine the experiences, opinions and concerns of SLTs in the field and those of people with PD and their carers. The third (LA) was employed to carry out this pilot work.

Evidence Already Available

Motor speech difficulties associated with Parkinson's disease (PD) are well documented and thought to occur in up to 50% or more of cases. Although most people with PD will be retired, there are also a number who will be diagnosed earlier in life.

Speech and language therapy for motor speech difficulties in people with PD has become recognised as an appropriate and effective intervention. However the usefulness of aided AAC in association with this medical diagnosis is not well recognised, despite augmentation and alternative means of communication being widely used with people who have other progressive neurological conditions such as motor neurone disease. Voluntary organisations involved with people who have PD advocate the potential benefit and use of AAC for people with PD yet we lack evidence that AAC can be effective for this population.

Several interacting factors which may influence the effectiveness of AAC for people with PD have been identified via clinical practice and in the literature, i.e. motor symptoms, cognitive changes, drug side-effects, language problems (word finding difficulties), age-related unfamiliarity with technology, spouse/carer attitude and support and training (or lack of it).

Some studies which demonstrated the effectiveness of low-tech AAC with people with PD were published in the 1960s to mid 1980s. These involved single cases or under-defined groups of people whose improvement in communication is noted usually anecdotally following introduction of an amplifier, pacing board or alphabet board. No more recent or rigorous research has been located in the literature.

Aim and Method

The main aim of our study was to summarise the experiences and attitudes of some Scottish SLTs (a) as a preliminary investigation with a view to developing a research project to measure the effectiveness of aided AAC for people with PD and (b) to provide SLTs with some clinical evidence on which to base their practice. 30 experienced SLTs working in a range of settings completed the questionnaire in face-to-face discussion or by telephone. Questionnaires were also completed with a small group of people with PD and their carers.

Results

All SLTs reported that they would consider or had considered offering AAC to a person with PD. 27 had used low-tech AAC with people with PD (usually amplifiers and alphabet boards). 11 SLTs (58%), who felt able to comment on overall success, felt that they had generally a poor level of success in introducing low-tech AAC, two felt this type of intervention had been very successful, three moderately successful and three unsuccessful. Success was reported to be related to a wide range of factors.

25 SLTs had offered high-tech AAC devices to clients with PD. All who had used these kinds of devices with this client-group had used a Lightwriter. Other devices were used very rarely and reflect the time of referral of the person for AAC assessment, i.e. often very late into their disease when general motor as well as motor speech ability are notably reduced and cognitive impairment may be significant. Therapists perceived that they had a greater level of success with high-tech AAC than with low-tech. The SLTs were asked to give factors which would help them to decide whether or not to introduce aided AAC to a person with PD. Some of these were related to the medical condition. Others were more general factors to be considered when introducing AAC to anyone with communication difficulties. 23 interviewees rated their attitude towards aided AAC for people with PD as positive or very positive.

Four people with PD who were using Lightwriters were also interviewed. All reported they were more likely to use their Lightwriter outwith their home and with strangers rather than with family. Two felt that aided AAC should be introduced to people with PD when they had to repeat themselves occasionally and two felt when they had to repeat themselves often.

Five carers of people with PD who had used aided AAC were also interviewed. None of these people had received training nor had they been put in touch with another carer in a similar position. Three felt that aided AAC should be introduced when the person had to repeat occasionally and two when they had to repeat often.

Issues for Research and Practice

This survey has confirmed several already formed impressions and highlighted some issues that require further investigation.

It has confirmed the belief that so far AAC with this client group is perceived as being generally less successful than with some other client groups. One reason for this may be that it is often not possible to offer AAC until late into the disease process because of the pattern of referral. However, it has also shown that, in principle, SLTs feel there is a need for augmentative support of some form for people with PD. There appears to have been more success reported using high tech devices, i.e. voice output communication aids rather than low tech boards etc. This needs to be explored in more detail. Is it to do with the timing at which these are typically introduced or possibly that high tech devices impact more on the communicative patterns of the users? Are there ways in which AAC use can be introduced to, supported in and eventually used more effectively by people with PD? Research to look at providing guidelines for therapists on the introduction and training in AAC use with people with PD is required.

Many reasons for lack of success were suggested both by therapists and carers. While the limiting factors imposed by the disease itself are fairly well recognised there is clearly a need to look at extrinsic factors such as attitudes, interaction patterns and lack of familiarity with the QWERTY keyboard layout, or technology in general, that is a particular difficulty for people in this relatively non-computer literate age group. Research is needed to look at the training needs of both the clients themselves and also for the best ways in which to support and train carers.

All groups surveyed, SLTs, carers and clients themselves, felt that earlier referral and introduction to AAC, before motor control and the ability to learn new skills were too severely affected, would be beneficial. It is perhaps easy to come to this conclusion in retrospect. There are obvious implications for service delivery and also concerning the actual attitudes and motivational responses of clients in the early stages of coming to terms with their probable deterioration in speech production. There is a need therefore for research to identify both the most appropriate time to commence intervention and also to look at the most supportive way in which to introduce the concept of AAC and the possibility of its increasing need as the disease progresses.

Many of the subjects surveyed reported limited or moderate success only, however, even limited success may be significant for the person with PD in maintaining effective communication for a longer time or in particular situations. How, therefore, can success be measured? How can small but significant gains become meaningful to a person who has known flexible, fast and fulfilling communication for most of his/her life and finds it difficult to perceive the limited gains offered by AAC as worthwhile? Here again appropriate training programmes need to address this. There is also clearly a need to devise relevant outcome measures or to look at appropriate adaptations to existing tools to measure communicative effectiveness.

The major research issues therefore appear to be:

- to produce guidelines for the introduction of AAC to people with PD and
- appropriate training in use of above guidelines
- to look at the best ways to motivate, support and train carers/ communication partners
- to investigate the stage in the progression of the disease at which AAC might best be introduced
- to look at and develop ways of measuring the outcomes of the use of AAC by people with PD

Funding is currently being sought to follow up some of these issues. If this is forthcoming a two to three year research project will be carried out at QMUC that will aim to produce a training package for use by SLTs which will suggest guidelines for assessment for AAC introduction, training programmes for both patients and carers and will also provide outcome measures for this client group.

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A more detailed paper describing our project has been submitted to the International Journal of Language and Communication Disorders. A full bibliography is available from the authors.

Trials and Triumphs:
Investigating the Use of a Portable Communication Aid with People with Dysphasia

by Paul Tippell, Stuart Whitehouse, Antonio Parolini
Alexandra Davies, Philippa Hardy
Andrew Lysley & Rachel Moore

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

The PCAD project is a European project funded by the Telematics Applications Programme which was initiated and co-ordinated by Thames Valley University, London. It was set up to address the needs of the dysphasic population by designing a portable communication aid specifically for clients with dysphasia. In order to achieve this objective, interdisciplinary work has involved users and professionals (clinicians, engineers, teachers, aphasiologists, linguists, AAC specialists) from several European countries: United Kingdom, The Netherlands, Portugal, Germany, Sweden.

The key to success of aphasia and AAC is perhaps dependent upon the interaction of the following factors: comprehensive assessment of user requirements and clients, the overall acceptance or "openess" to augmentative communication strategies, and the compatibility of the hardware and software in terms of the client's cognitive, linguistic, and physical skills.

Assessment

Analysis of User Requirements

Initial work within the project involved assessing the user requirements for this client group. Interviews were conducted with speech & language therapists in both the AAC and dysphasia fields, and with clients and their carers; coupled with drawing on the professional experience of the project team. Interview topics covered AAC currently and previously used with the dysphasic client group, the perceived role of AAC with people with dysphasia, training and vocabulary requirements and compiling a future "wish-list" of what they would like to see in a communication aid specifically for people with dysphasia. Main themes identified revealed little use of communication aids (particularly high tech) with this client group, an overall desire to work on speech, and good use of other natural strategies. This led us to emphasise the augmentative value of a communication aid with this client group, respecting a client's residual communication skills and aiming to integrate them into an aid rather than assuming that a communication aid will replace the user's communication.

Assessment for Client Selection

Many factors have been outlined in the AAC literature as perhaps contributing to either the success or failure of AAC intervention. User-specific variables such as cognitive and language deficits, lack of communicative need, lack of opportunities for interaction, lack of ongoing support, and poor motivation may be just some of the factors contributing to ineffective use of communication aids with the dysphasic client group. In order to try and select the most suitable clients for the PCAD clinical trials we have designed a screening tool to be completed with information from speech & language assessments, informal observation, and a video of structured conversation. The screening tool is chiefly based on the ideas presented in the assessment and referral form used at the Communication Aid Centre, Frenchay Hospital in Bristol. It is intended to assist the clinician by building up a profile of the client's skills and difficulties (1-3 scoring), covering eight main sections: cognitive skills, language skills, current communication methods, communicative need, physical skills, visual skills, environmental factors, psychosocial factors.

Why PCAD?

In order to tailor PCAD specifically to the dysphasic population we have tried to focus on why dysphasia presents a different challenge to other client groups. Clients with dysphasia may present with very specific language deficits, but may have useful skills that they can draw on, such as self-phonemic cueing and drawing. They may have other associated deficits such as hemianopia and hemiplegia which need to be accommodated. We have therefore developed a device that is:

- Portable (a large number of people with dysphasia are ambulant)
- Professional-looking and businesslike to recognise our clients' experiences of "normal" communication
- Integrates natural strategies and focuses on an augmentative rather than an alternative role
- Encourages therapeutic as well as functional use of the device

Portable communication aid for clients with dysphasia

The majority of the clinical trials used an off-the-shelf Hewlett Packard palmtop computer with a colour touchscreen, a keyboard and digitised sound/speech. In addition, special software, has been designed and developed by the project consortium to work within microsoft's Windows & CE operating environments. PCAD's software system is modular and can be configured to the individual need and capabilities of the dysphasic users. The software is very flexible and incorporates:

- Hierarchically structured multimedia user vocabularies
- Word and picture galleries
- Phonemic cueing allowing sound to be broken down into individual phonemes

- A communicative drawing module - enabling the user to draw and store their own drawings and also allow the user to create their own personalised communication system
- An Integrator Editor - including an innovative end user simulator, a centralised resource database, a categorisation editor, and a versatile hierarchy generator.
- A Facilitator Editor - a simplified editor for use by carers to directly configure the CE devices, and modify and update user vocabulary.

Figure 1 Portable Communication Aid for people with dysphasia

Clinical Trials - Single Case Studies

Clinical trials have been undertaken at various stages of the project. The results of these trials have been fed into the iterative development of the device. They have helped us establish which clients may benefit from using PCAD, and have helped us to identify training and support strategies that may be useful for clients, carers and therapists. A single case study methodology was designed to evaluate the use and benefits of PCAD.

Types of Trials	No. of clients assessed using screen	No. of clients taken on for trial	No. of successful trials	No. of unsuccessful trials
"Wizard of Oz" trials (Stage 1)	2	2	1	1
Alpha trials (Stage 2)	14	8	6	2
Beta trials (Stage 3)	16 (to date)	15 (to date)	not yet known	not yet known

Table 1 Breakdown of clinical trials undertaken using PCAD

Issues of Effective Use

Technical

- Changing technology - one risk of using off-the-shelf technology is that it may become obsolete, therefore as the project has progressed the software development team has designed the software so that it will work on a number of hardware platforms
- Inevitable technical hitches - as software is continually being tried and tested
- Translating clinical ideas into technical terms required detailed storyboarding and regular meetings between technical and clinical terms to develop concepts
- Too many 'wish-list' ideas - not enough time to implement all of the ideas!

Clinical

- Restraints on clinicians' time to programme device - has led to the development of a central multimedia resource database. This consists of a number of symbol and photo libraries (PCS, PICTO, Picture This) and sound files (synthesised and digitised).
- Iterative software development has meant that clients (and therapists!) are always involved but have to re-learn and make constant adjustments and accommodations. Iterative development is a two-edged sword from a clinical perspective.
- Differing training requirements of AAC and aphasia specialist therapists have been identified giving rise to the writing of a therapy-training manual

Triumphs and Achievements

- Use of PCAD in a number of specific functional situations, for example, at the library, at the bakers, eating out, at the post office, banking, at the doctors, buying clothes, making phone calls, ordering fish & chips
- Excellent use of communicative drawing to assist information transfer:

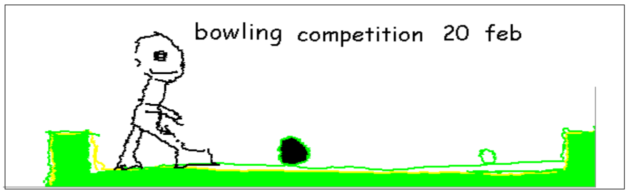

Figure 2 Example of a client's communicative drawing

- There has been some therapeutic use of device - to assist spelling, phonemic cueing, auditory feedback: *"He goes up to the study and is there for hours..." (carer)*
- Many users report on an increase in client confidence and self-esteem: *"He mixes better, confidence a bit more now." (carer)*
- The user and carer groups have enabled users and carers to practice with the device in a safe environment with peer support, and have consolidated training and helped generate ideas for other users

Figure 3 User group support and interaction

Conclusion

By focusing on a small group of pre-selected dysphasic clients, PCAD has been able to evaluate to some extent the effectiveness of an AAC device as an augmentative component of a total communication system. Much emphasis has been placed on client acceptability and compatibility. Both the hardware and software are professional in appearance, thereby enhancing the status and self-image of the client. Serious attention has been given to providing communication modules that can be seamlessly integrated with the users' natural communication strategies, for example, communicative drawing and writing. PCAD points towards a realisation that AAC technology in dysphasia has an important part to play but only where it is harnessed to specific communication scenarios or "events". It is also not surprisingly clear that effective use of AAC technology in dysphasia is inextricably linked to high quality training and support.

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AAC and the Over 65's

by Jackie Reeves

This paper was presented at the CM'99 National Symposium, Lancaster University, September 1999

Introduction

102 clients were referred to Mary Marlborough Specialist Disability for an AAC assessment between 1.4.1998 and 31.3.1999. Thirty-two were over 65. They came from Oxfordshire and the areas were covered by Mary Marlborough Centre's (MMC) block contracts. Eighteen were seen at home or in a nursing home as part of the outreach service, eleven were seen as outpatients at Mary Marlborough Centre and three were seen on the ward in hospital. It is more difficult to see these people at MMC (transport problems, fatigue, etc.) and it is felt to be more appropriate to introduce AAC into their home environment.

This is a significant group. It is felt that there are specific problems in introduction AAC to an older population. Gitlin, in *Designing and Using Assistive Technology* says, "Specifically, we know very little about experiences of older adults who initially confront the need for assistive devices late in life as the result of a first-time disabling condition." In conclusion, she says, "Reasons for use and non-use appear in these cases to be more complex than those previously discussed in the literature."

Referrals broken down by primary medical diagnosis

Cerebral vascular accident	11
Motor neurone disease	6
Query motor neurone disease	1
Parkinson's Disease	8
Cancer of the Larynx	2
Multi systems atrophy	1
P supranuclear palsy	1
Diagnosis unknown	1

Referrals broken down by primary speech and language diagnosis

Aphasia	5
Aphasia/dysarthria	2
Dysarthria/dysphonia	7
Voice problem	13
Dysarthria	5

Referrals of clients who have had a CVA are increasing. Traditionally they have been referred when traditional Speech and Language 'fails'. There is much more of a trend now to see AAC as a part of 'total communication'. Thirteen referrals were for a voice problem. When we consider AAC assessments, voice amplifiers are considered a relatively simple solution. In this group a careful provision and ongoing support can enhance quality of life.

What people feel about growing older

Dame Peggy Ashcroft in *Famous ways to grow old* says, "...but finally everyone suffers from growing dependence on other people. Anything that one can do to reverse that and give help I am sure is of enormous importance." This would seem to be a good maxim when working with AAC and the older person.

Mary Marlborough Centre

The person who refers the client (usually the SLT) is asked to fill in a detailed form. The local SLT and a carer be asked to be at the initial assessment. A personal profile is also completed so that other problems that arise can be passed on to the appropriate person. There is access to a loans bank of equipment from MMC and the local SLT service.

Reasons for Referral

Sometimes the reasons are not clear and the expectations of the client and family can be unrealistic. An increase in the use of technology by younger people often leads to inappropriate requests. Requests have included, "something so we know what he is thinking", and "to improve the communication between us in any way" or "please help him use a computer".

Problems Around Assessment

If an assessment takes place in a hospital, day hospital or nursing home, the lack of privacy, background noise, the client's general health, and medication levels are all factors that have to be taken into consideration. In other settings these also apply, but looking at more long term solutions we will consider the partner's health, hearing levels of the client and their carer, cognitive changes due to old age or dementia, vision, fatigue and lack of motivation.

The elderly seem to be more suspicious of new things. A surprising number however are anxious to embrace new technology particularly when family members live abroad. Russell and Mcallister say, "The client's perceived cognitive ability was a major factor for speech pathologists in determining whether they would use an AAC system".

AAC and Aphasia will not be discussed in detail as there are particular problems that may well be covered in other talks. However a large percentage of people with Aphasia are "verbal" and require an AAC package that may be part therapy and part functional communication tool. A combination of 'high' and 'low' tech solutions may be used.

AAC systems tried by clients after assessment

Lightwriter SL35 and Windbag software	1
Voice Amplifier	11
Communication charts and Alphabets	3
Voice amplifier and SL35	1
SL35 only	8
Alphatalker and Communication chart (Boardmaker)	1
Alphatalker and Winspeak software	1
No equipment considered suitable	1
Telephone with amplification	1
SL35, S4B, Consideration of a laptop with Windbag	1
Alphatalker and Chatbox	1
SL35, SL4B and voice Amplifier	1
Did not wish to try an AAC device	1

Voice Amplifiers

Eleven clients tried voice amplifiers. We have access to Voicettes, an Amplicord, a Freiburg, a Medella, Flexitals, Lions Club Amplifier, Stanton Advox, Easitalk, Ross Wireless Headset System and a Realistic Speaker using a headset microphone. Each varies in amplification and microphone quality and assessment for this is considered important. The client also needs to try out the piece of equipment in a variety of settings.

Funding

An AAC system or piece of equipment is not recommended until it has been tried out. Oxfordshire has no written agreement for funding of aids for adults and has not funded any in the last two years. Other areas have been able to lend or fund aids. Unfortunately there is a tendency to lend what is in the cupboard rather than try to get what is appropriate.

Final use of AAC by the 32 clients

The latest use of equipment by the clients will be discussed in more detail at the presentation.

Reasons for use and non use of equipment

This is of interest of everyone in the field of AAC. Beukelman and Mirenda says, "Numerous factors influence AAC interventions for people with severe communication disabilities due to acquired physical impairments" and "families of some older adults appear to have difficulty in accepting the use of electronic communication techniques for a spouse or parent because they struggle with accepting their loved one's loss of speech or writing ability." A final quote, "Another constraint involves the availability of facilitators".

With this selected group of referrals to MMC, there seems to have been an increase of use of AAC equipment, after the employment of an SLT Assistant. The assistant programmes aids, makes low tech. equipment, spends time at a person's home helping them to use for example a communication aid and reports back any changing needs. Data relating to the SLT assistant's involvement will be noted for future use.

Some factors that have been noticed, particularly in the older group, are:

- Lack of time by staff in the SLT service and outside
- The clients prefer to talk if at all possible
- Partners and professionals are not always supportive
- The hearing problems of the client and/or partner
- Physical difficulties in operating equipment
- Depression and the lack of opportunities to use a system

Case Histories

John 76 yrs. CVA, 1995. Aphasic, hearing aid in left ear, needs to lip read. Can read but not spell. Non verbal. Computer user through his previous work as a technical designer and has a computer at home. Has a manual wheelchair and about to purchase a powered chair. Lives at home with his wife. Right sided paralysis; was right handed. He was referred to "improve communication between him and his wife and help him use his computer again".

Kenneth 73 yrs. Parkinson's Disease, since 1984. Voice, articulation and cognitive problems. He is mobile with a typical Parkinsonian gait. He was a company director. He lives at home with his wife who has a hearing loss, 2 hearing aids and is a lip reading tutor. He was referred for a voice amplifier assessment.

Charles 84 yrs. Parkinson's Disease, since 1989. Variable voice volume, good articulation. Lives at home with his wife, sits mostly but can walk with a walking frame. His wife has diabetes and appears confused at times. Charles goes to a day hospital each week and would love to be able to talk to the other clients. He was referred for a voice amplifier assessment.

Douglas 81 yrs. CVA in 1996. Aphasic. Some previous medical history. Was a special needs teacher, his wife as well. Douglas has no spontaneous speech. Verbal Comprehension at a very low level. Cannot read but appears to recognise some key words. He does not spell, draw or initiate non verbal communication. He lives in a nursing home, his wife lives close by and visits every day. Douglas has a right sided paralysis. He was referred for an AAC Assessment when his wife told the local SLT that she was buying him a Lightwriter. He died in June 1999.

Lilian 86 yrs. CVA, 1995. Articulation, language and vision problems. She has been known to the local SLT service for many years. Husband has a heart condition. Very concerned about his wife and improving the communication between them. Their life was ballroom dancing for many years before they became ill. They live in sheltered housing with carers coming in. Lilian is unable to walk. Bill contacted a communication aids supplier with a view to purchasing an aid for his wife and applied for funding to the Sequel Trust. The company referred for an AAC assessment. Her husband has recently died and Lilian is in a nursing home.

Joan 83 yrs. CVA, approx. 1989. Articulation and voice problems. Her husband has a hearing loss but does not wear his hearing aid. They are both mobile and active and they live in a Cotswold town but appear to be rather isolated. Joan's mother had dementia and her husband wonders if she has similar problems and both very mobile. The local SLT requested an AAC Assessment.

Dorothy 85 yrs. MND diagnosed in 1996. A widow, she lives in a nursing home and has no speech. She has swallowing problems and is bothered by her dribbling. She has a peg. She is mobile and goes shopping. Her nephew works with computers and she has family all over the world. She was referred by the local SLT.

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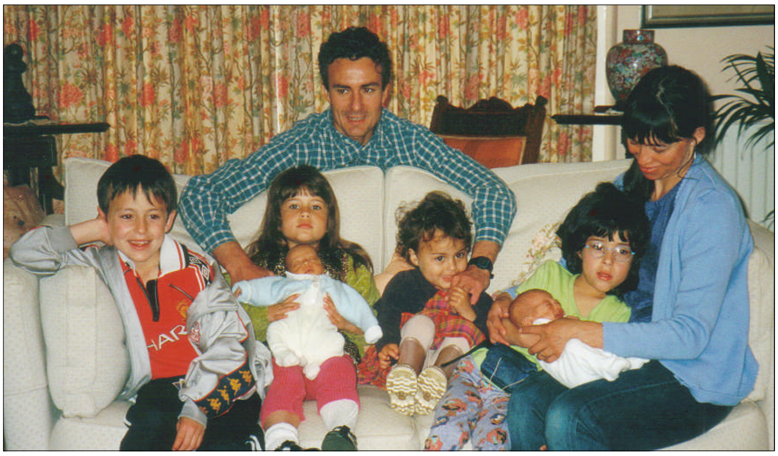
Parents and Enablers Page

by Katie Clarke

It has been a busy couple of months, what with helping run to our local playgroup, looking after all the children, going on holiday to Cyprus plus attending three national conferences.

I went, of course, to the *CM'99 National Symposium* in Lancaster and was pleased to meet up with some of the other parents who attended. There were even two mothers with their young sons who had come all the way from Italy just to attend the conference for the three days in order to gain as much information as was possible. I had a lot of admiration for them in their quest to know and understand more about AAC so they could help further with their children's communication. Parents can gain a lot of information from the exhibitions, from meeting Users, attending workshops and meeting each other. If anyone has any ideas as to how to make the next CM Symposium more 'accessible' for parents, carers and personal assistants, or how to make it more family-friendly, please let CM know.



The twins with the rest of the Clarke Clan

Looking back at the CM'99 Symposium, the highlights for me were hearing the Users' presentations and I was very moved by their honesty, openess, and feelings on being an AAC User. I would like to thank them for sharing their experiences with us. Alan Martin made a powerful and political Distinguished AAC User Award Presentation and motivated me into writing to my local MP on communication aids being a civil rights issue. Communication aids need to be given priority by the government - **so, contact your local MP and be a voice!**

> *She looked extremely worried and signed, "Fighting Dangerous."*

Talking of the government I heard Margaret Hodge, the Minister for Disabled People, talking at *The Challenge of Communication*, which was a very well organised and interesting conference in Harrogate on 6th Oct. Unfortunately, although she was supposed to be talking on Communication she rattled on about the Disability Discrimination Act and briefly mentioned communication aids without very much knowledge or thought. She left very quickly after only answering one question on plans for regional assessment centres which she fumbled over.

The third conference the babies and I went to was the *Scope Annual Conference* in Blackpool. There was nothing on Communication or at least, if there was, I missed it. Having a disabled child has made me passionate about equality and civil rights. Communication is vital, it is our children's birthright; without communication our children can become locked in their isolation and excluded. I told Nadia that I went to Conferences to fight for equal rights. She looked extremely worried and signed, "Fighting Dangerous." She must now think I am a conference thug or hooligan. I'm not - honest!

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Interesting Websites for Parents & Enablers

Recommended by Barry Gilbert

www.access-ability.co.uk/index.html	Excellent site dedicated to people with disabilities
www.cafamily.org.uk	Contact-a-Family's site
www.conductive-ed.org.uk	All about Conductive Education
www.cpaction.org.uk	Cerebral Palsy Action's site
www.disabilitynow.org.uk/links.htm	Great links
www.disabilitynow.org.uk/search/16_voice.htm	Good articles from parents
www.disabilitynow.org.uk/search/index.htm	Search for articles on disability

Get on the *FAST* Track

by Moira Mitchell

This article describes the resources and services offered by the Foundation for the Advancement of Assistive Technology

The Foundation for the Advancement of Assistive Technology (*FAST*) is a UK national charity funded primarily by the Department of Health. *FAST* was conceived by the Royal Association for Disability and Rehabilitation (RADAR) to address the need for cohesion in the development of assistive technology (AT) for disabled people in the UK. *FAST* aims to facilitate the advancement of assistive technology by liaising between research and development institutions, manufacturers, service providers and end-users. The trustees of *FAST* have in-depth personal and professional knowledge of the application of new disability technologies.

Following research *FAST* has ascertained that there are a number of factors which serve to limit the impact of AT research and development in the UK. There is a lack of collaboration and information sharing amongst researchers and developers leading to duplication and wasted resources. Consultation with broader industry is limited and there is poor communication between stakeholders about new developments. Research is not always sufficiently needs driven and a lot of disabled people remain unaware of potentially beneficial initiatives.

To address this situation *FAST* is developing an information resource dedicated to AT and its applications. *FAST*'s initial brief is to create a comprehensive on-line database which will comprise:

- ⇨ Research and development projects
- ⇨ Project outcomes
- ⇨ Assistive technology events and publications
- ⇨ Invitations for input from people with disabilities
- ⇨ Training initiatives (currently very limited)
- ⇨ Funding opportunities
- ⇨ Innovative practice in models of provision and ongoing support

This information resource will:

- ✓ Inform professionals and users
- ✓ Enable cross fertilisation of ideas
- ✓ Eliminate duplication and wastage of resources
- ✓ Improve communication and collaboration
- ✓ Encourage progress in provision training and support
- ✓ Be a point of contact for information sharing between the UK and the rest of the world

Information about research and development funded by statutory and charitable organisations is in the public domain. However *FAST* recognises that in many cases, particularly in the commercial sector, there may be a reluctance to share information about research projects until they are approaching completion. Protection of intellectual property is very important in the process of technology transfer and we would not expect people to divulge information which would affect their commercial rights. Commercial organisations will therefore be invited to contribute as much or as little information to the database as they see fit.

The database will be searchable from many different perspectives, i.e. it will be designed with the full spectrum of users in mind. The website will also invite input from disabled people or other interested parties from which *FAST* will compile data on user needs. Alongside this project *FAST* will facilitate focus groups of users, professionals and technology providers to investigate specific areas for future research and development. The outcomes of these groups will be combined with input from the website and the information made available to professionals in the field and broader industry where relevant.

If you would like to contribute to the database or the work of *FAST* in any way please do not hesitate to contact us.

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Email: moira@fastuk.org Website: www.fastuk.org

Joining COMMUNICATION *MATTERS* and ISAAC

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

What are the benefits of Membership?

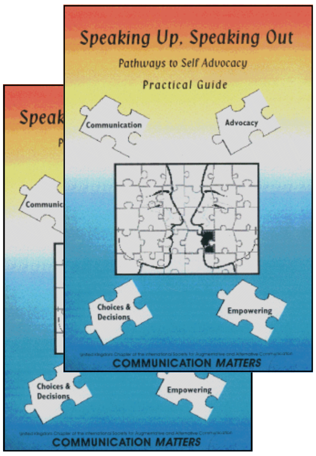
Members of Communication Matters receive this Journal three times a year, reduced delegate rate at the Annual CM National Symposium, and all the benefits of ISAAC membership. ISAAC membership entitles you to order ISAAC publications at reduced rates (AAC Journal, Communicating Together, ISAAC-Israel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

How do I become a Member?

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

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

Essential Publications from Communication Matters

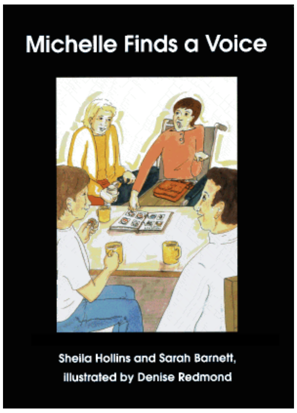


Speaking Up and Speaking Out! Pathways to Self-Advocacy

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

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

Michelle Finds a Voice



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

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

Alternatively Speaking

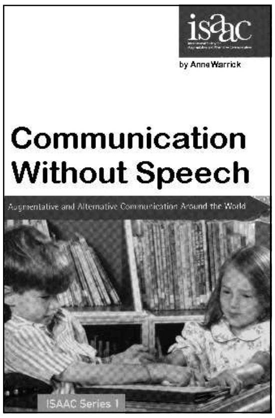
Published three times a year, this eight page newsletter, from Augmentative Communication Inc. in the USA, contains AAC issues and in-depth reports on topics vital to the AAC community. It is written by Michael Williams, who is an AAC user and serves on ISAAC's executive committee.

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

Augmentative Communication News

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

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

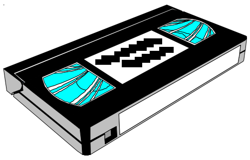


Communication Without Speech: Augmentative and Alternative Communication Around the World

This ISAAC book, written by Anne Warrick, is a highly accessible but very comprehensive introduction to augmentative and alternative communication. It contains lots of questions and practical tips such as vocabulary selection, assessment, education and vocational considerations, making communication boards, and includes excellent photographs and illustrations.

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

In Other Words (ISAAC video)



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

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

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

COMMUNICATION MATTERS
c/o ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR
CM Enquiries: 0870 606 5463 Fax: 0131 555 3279
Email: admin@communicationmatters.org.uk Website: www.communicationmatters.org.uk

Trustees News

CM'99 National Symposium & Study Day

Thank you to everyone who came to this year's *CM'99 National Symposium* and *AAC Study Day* in September at Lancaster University, and for making the two events such a resounding success. This was a bumper year, with 315 delegates attending the two and a half day Symposium. The trade exhibition was extremely popular with over 20 company stands and the launch of new products by three companies. There were inspiring keynote addresses from Dr Carol Goossens' (speech pathologist from New York), and Dr Juliet Goldbart from Manchester Metropolitan University.

The Symposium was followed by a one day intensive AAC Study Day on *Creating a Communicative Classroom* which was presented by Carol Goossens'. The Study Day attracted more than 210 participants at Lancaster, and there was a similar number in Dunfermline a week previously when the Study Day was hosted by *Augmentative Communication in Practice: Scotland.* Many participants praised Carol's dynamic style of presentation and the extensive use of video clips to show the practical application of her many ideas and methods.

The CM Distinguished AAC User Award 1999

Congratulations to Alan Martin who is this year's winner of the CM Distinguished AAC User Award. Alan presented his rousing paper 'Fight for your Rights' at the CM'99 National Symposium. The judges had great difficulty choosing from the five entries submitted this year as they were all of a high standard. Be sure to read Alan's winning paper, as well as the other entries, in the next issue of the CM Journal.

New UK Representative for the ISAAC Board

A Call for Nominations (sent to all CM members in October) to fill a vacancy on the ISAAC Board of Directors produced one nomination, for Gerald Masterson. Gerald is therefore the new UK representative for two years. The other UK representative is Janet Scott; the Chair of the Board is Janet Larcher.

New CM Chair and Trustees

At the Communication Matters AGM on 26 September at Lancaster University, we said goodbye to CM Chair *Janet Larcher,* and welcomed *Janet Scott* as the new Chair. We thanked *Liz Panton,* who resigned as a Trustee, for her work as Secretary, and welcomed onto the Board of Trustees *Sally Townend* (from ACE Centre North, Oldham) and *John Angel* who has been a co-opted Trustee during the past year.

A Message from Janet Scott, the New Chair of Communication Matters

It is a great honour (and rather scarey!) to be stepping into Janet Larcher's shoes as Chair of *Communication Matters.* As you know Janet has been active in Communication Matters for many years. She has been a Trustee for ten years, nine of which as either Treasurer or Chair! During that time Janet has facilitated Communication Matters' development as the positive, active organisation it is now. However, it is now time for her to enjoy just being a member of CM (without any of the extra hassle!) and we look forward to seeing her, looking relaxed, at many future CM Conferences. Actually, Janet has to wait a little before she can truly relax as she has agreed to be a co-opted Trustee for a year.

For those of you who don't know me, I should introduce myself. I am a Speech and Language Therapist, and for the past 13 years I have worked at SCTCI. SCTCI is the Scottish National AAC resource and assessment facility funded within the Health Service in Scotland. Although I am based in Glasgow I spend a lot of time 'on the road' - providing an AAC service throughout Scotland means that I get to see some spectacular scenery, not always in the best of weather! Before working at SCTCI, I worked as a Speech and Language Therapist with people with learning difficulties and people with physical disabilities, and have been involved in AAC for the past 22 years (that makes me feel old!).

AAC is an exciting and changing field whether your contact with it is personal, professional, formal or informal. I remember and cringe at my early (and very much more recent!) mistakes and hope that I will continue to learn from meeting other people, reading about other people's experiences, attending workshops, etc. I wish to ensure that *Communication Matters* will continue to provide the forum for exchanging ideas, for debate, for raising awareness of AAC - that, as an organisation, we will continue to work towards inclusion and equality of all our various members.

Being the Chair of *Communication Matters* is meaningless without all of you, the membership, and without the hard work of the other Trustees and the Administrator. Together we can do great things! I could not even contemplate being Chair were it not also for the support of my long-suffering colleagues here at SCTCI, so thank you Wilma, Rosemary and Bob!

Janet Scott in training for new Chair of CM, walking The Great Wall of China in aid of the British Heart Foundation

News from CASC

Communication Aid Suppliers Consortium

Since the previous issue of the Journal, there have been three well attended and stimulating **CASC Road Shows,** hosted by the ACE Centre in Oxford, the ACE Centre North in Oldham, and The Wolfson Centre in London. Each Road Show featured 10 to 12 CASC members presenting their latest products. Participants were able to attend eight presentations during the day, with lunch and refreshments provided by CASC.

Conditions for CASC Membership

At a meeting of CASC members during the CM'99 Symposium in September, it was agreed that, from January 2000, a company must meet the following requirements in order to become a member of CASC and to participate in Road Shows:

- the company must be a commercial supplier of AAC products and/or services
- the company must be a Commercial Member of *Communication Matters*
- the company must have signed up to the CASC Constitution (including the Code of Practice) and the Roadshow format

Can you help host a CASC Road Show in your area?

We are always looking for new venues, so if you would like to host a Road Show (or know a local centre which might be interested), please contact Patrick Poon, the Road Show Organiser (Tel: 0870 606 5463) who would be delighted to discuss this further. Remember, CASC will pay for hiring a suitable venue, lunch and refreshments, and help to draw up a programme and draft publicity material.

CASC Road Shows - January to May 2000

Please make a note of any CASC Road Shows coming to your area - do contact Patrick Poon if you need further information.

Jan 26	**Chorley** - Woodlands Conference Centre, Lancashire
Jan 27	**South Sefton -** Crosby Hall, Merseyside
Feb 21-25	**Ireland -** Galway, Limerick, Tralee, Dublin & Belfast
Mar 10	**Shrewsbury -** Disability Resource Centre
Mar 30	**Cambridge -** Professional Development Centre
Apr 5	**Loughborough** - Beaumanor Hall Conference Centre
May 3	**Salford -** Neurocare Centre
May 24	**Inverness**
May 25	**Edinburgh -** CALL Centre
May 26	**Glasgow -** Walton Conference Centre, Southern General Hospital

Web Site & Contact

To get an up-to-date list of the CASC Road Shows and brief information on each CASC member and a link to their Website, please visit the *Communication Matters* Website at *www.communicationmatters.org.uk*

For more information about CASC, ring Patrick Poon on Tel. 0870 606 5463 or Email: admin@communicationmatters.org.uk, or ring Simon Churchill (Chair of CASC) on Tel. 01962 842792 or Email: simon_churchill@compuserve.com

News about CASSIG

At the recent **CASSIG** meeting (the Communication Aid Services Special Interest Group), held during the *Communication Matters* Symposium in September, there was a general view that people working within an AAC 'service delivery' framework needed an opportunity for sharing information, concerns, ideas, etc. However, the consensus was that CASSIG as it currently exists did not seem to have been very productive in recent years and a decision was taken at this meeting to disband the group.

It was felt that there were other ways of providing a forum for opening up debate, sharing ideas etc. Three ways of encouraging this were agreed:

- There should be a CM Trustee with special responsibility for Service Delivery issues. Sally Townend, who works at the ACE Centre North in Oldham, has taken on this role. She will promote service delivery issues within CM and will be very happy to bring any related concerns/comments to future Trustees' meetings.
- People working within service delivery settings could schedule a meeting to be held during the annual *Communication Matters* Symposium for face-to-face sharing of ideas and views, etc. This is something which has always been possible, and is available to any other interested groups who might want to make use of the opportunity of having lots of people involved with AAC under the same roof at the same time. All that is needed is a telephone call to Patrick Poon, the CM Administrator, so that a time slot within the overall programme can be arranged.
- There should be a *Service Delivery Forum* section in the CM Journal and on the CM Website with a focus on service delivery issues. In this issue of the Journal, Katie Price from the Wolfson Centre in London kicks off the *Service Delivery Forum* with an article on issues around motivation for communication for children with cerebral palsy (see page 19).

Come in and have a look!

Communication Matters is a UK national voluntary organisation of members concerned with the Augmentative and Alternative Communication (AAC) needs of people with severe communication difficulties. It is also the UK chapter of the International Society for Augmentative and Alternative Communication (ISAAC).

Augmentative and Alternative Communication includes the use of eye pointing, gesture, signing, symbols, word boards, or a speech output device. Everyone uses AAC techniques from time to time, but some people depend on them all the time. Communication Matters recognises that augmenting communication involves speech and writing; in some cases, it also involves technology relating to teaching and learning, mobility, environmental control and employment.

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Information of interest to AAC Users; User Groups

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Diary Dates

20 January 2000 CALL Centre, Edinburgh

Voice Recognition in Education 2: Implementation Strategies

This is follow-up to Voice Recognition 1 and is aimed at identifying successful strategies for the use of systems in schools and other educational establishments. Cost: £40
Contact: CALL Centre Tel: 0131 651 6235/6

26 January 2000 Chorley, Lancs

CASC Road Show at Woodlands Conf. Centre, Chorley

Contact: Hazel Roddam Tel: 01253 763232 x233

27 January 2000 Merseyside

CASC Road Show at Crosby Hall, South Sefton

Contact: Rachel Scragg Tel: 0151 487 8000

27 January 2000 CALL Centre, Edinburgh

Special Access 1: Keyboards, Mice

This seminar is aimed at teachers and other working with children and adults with disabilities who cannot use a standard keyboard or mouse for computer activities. Cost: £40
Contact: CALL Centre Tel: 0131 651 6235/6

1 February 2000 CALL Centre, Edinburgh

Using Clicker

This twilight course (4.30-6.30pm) focuses on the use of the Clicker range of software. Cost: £20
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2 February 2000 CENMAC, London

Including ICT in the Numeracy Hour

This Day Seminar will explore how ICT can be used to support the activities of the numeracy hour. It will address the needs of teachers in special and ordinary schools, and will include the opportunity to see demonstrations of software that might be useful. Target Audience: SENCOs, ISTs. Cost: £55
Contact: CENMAC, Eltham Green Complex, London SE9 5HL
Tel: 020 8850 9229 Email: cenmac@cenmac.demon.co.uk

10 February 2000 ACE Centre North, Oldham

Getting to Grips with Boardmaker

Boardmaker is a fantastic software program that is invaluable for creating communication resources primarily with PCS symbols e.g. communication boards and overlays for communication aids. This half-day seminar will familiarise participants with the standard features of Boardmaker so that they feel confident creating their own resources. There will be opportunities to create resources of their own. Suitable for: Teachers; NNEBs; Classroom Support Assistants; SLTs; Support Services Staff.
Cost: £50 Contact: ACE Centre North Tel: 0161 627 1358

21-25 February 2000 Ireland

CASC Road Show Ireland: Dublin, Limerick, Tralee, Belfast

Contact: Patrick Poon Tel: 0870 606 5463

24 February 2000 CALL Centre, Edinburgh

ICT and Special Educational Needs Update

A number of the UK's leading suppliers of hardware and software will be demonstrating their latest products. Suppliers (provisionally) will include: Crick Software, Don Johnston Special Needs, Design Concept, iANSYST, Inclusive Technology, KCS, Resource, SCET, SEMERC, Tag, Techcess, Widgit Software.
Cost: FREE Contact: CALL Centre Tel: 0131 651 6235/6

10 March 2000 Shrewsbury

CASC Road Show, Disability Resource Centre, Shrewsbury

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21 March 2000 ACE Centre North, Oldham

Switched On! Maximising Success for Switch Users

For some learners with severe physical disabilities switches can provide the most effective way of giving control. However it is important that an appropriate type of switch and switch method is identified and that the individual is given time to develop their skills. This day is intended to give participants an understanding of switch use, a progression of skills using switches, identifying an effective switch access method and assessment issues connected with switch use. Suitable for: Teachers; NNEB's Classroom Support Assistants; OTs; SLTs; Support Services Staff.
Cost: £115 Venue: ACE Centre North
Contact: Denise Swann at CENTRA Tel. 01257 241428

18 May 2000 CENMAC, London

Getting to Know the Classroom Computer

How to turn it on, plug in the peripherals and find your way around a 'Windows' environment. A brief look at the software already available, how to access it and why some programs may be especially useful for children with special needs in your class. This will be a practical 'hands on' day! Target Audience: ISIs and Support Staff. Cost: £55 (including lunch and refreshments)
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Service Delivery Forum

Communicating in Good Health:

Issues around motivation for communication for children with cerebral palsy

by Katie Price

Introduction

Holistic appraisal of children's needs

There is a growing acceptance that any intervention aimed to support children and their families should consider the child *in total*. Developing knowledge of child development, and a recognition of the psycho-social aspects of impairment and disability have better equipped professionals to make a comprehensive appraisal of a child's needs.

This need for 'holistic' assessment is clearest, perhaps, for those children with multiple disabilities. Many children referred to an Augmentative Communication Service have both physical and intellectual difficulties, often in the context of a sensory deficit such as visual impairment. It is apparent that the influences on development in this group of children must be complex. Hogg and Sebba (1986)[1] have described how motor impairment impedes perceptual and cognitive development: similarly, we know that visual impairment can lead to different and often delayed acquisition patterns of other skills, including communication.

Furthermore, there is an increasing recognition that any appraisal of need must look beyond the *child* alone to the *child in context*[2]: in context in their family, their school and other wider communities.

Appraisal for communication aid provision

For those clinicians involved in the management of children using augmentative communication equipment, this makes appropriate assessment of need a formidable task. One important tool in this work will be the use of a *multi-disciplinary team*. We are better able to assess a full range of need in an integrated way if there is available a range of skills and approaches, and a model for cohesive working which allow the team members to collate their individual perspectives.

Our own work is as part of a tertiary Health Service provision, offering support to local Child Health teams in their management of children with severe communication disabilities. 70-80% of the children referred have cerebral palsy, and their motor disorders often preclude the use of speech as a communication channel.

The team at the Augmentative Communication Service comprises a speech and language therapist, occupational therapist, clinical psychologist, clinical engineer and a paediatrician, often a neurologist. We try, therefore, to work within the framework described above, providing a wide-reaching assessment profile of children for their families and local teams, and setting this profile into the wider contexts of the children's communication needs. The contributions of a classteacher, social worker, physiotherapist, classmate, IT co-ordinator are sought from the child's own team as appropriate, and the discussion for goal-setting and evaluation can involve 6-8 contributors.

In our attempts to provide a picture of the child's current functioning, we have developed a model for assessment that looks at several areas believed to be crucial for the appropriate recommendation of communication equipment or strategies.[3] At this time, the team documented the importance of careful assessment of visual skills, positioning and seating, cognition, language understanding, and motivation for communication.

Further work has led to us to believe that we must also consider, in the appraisal of communication needs, some more, somehow 'basic' areas of development, and the discussion that follows will outline these.

Fundamental to the approaches now taken by our team was the search for the answer to the question "Why isn't this communication aid as useful as we thought it might be?" Expectations from the provision of equipment are notoriously underachieved[4]: clinicians and researchers are constantly reviewing their appraisal procedures to identify influential factors in the successful/unsuccessful implementation of communication aid equipment.[5]

DISCUSSION

In best health?

It was becoming clear from some of our referrals, and from the insights of the paediatrician and speech and language therapist's contribution to our assessments, that some of the children we were seeing were simply not in best health. Under the assessment heading 'motivation to communicate' these aspects of the child's development were clearly affecting their ability to attend, to learn, to play and to communicate.

Common health problems in children with cerebral palsy

The general health of children with cerebral palsy is monitored by their family, their general practitioner and through their school and Community Paediatrician. However, this group of children are prone to a range of health issues as a result of their neurological condition, and the effects of some of these conditions are subtle, and are often poorly understood. As a result, some health concerns may go undetected,

even with the monitoring in place as described above. This can be true for such issues as epilepsy, where brief or nocturnal seizures may not be easily detected, but may, untreated, have effects on the child's ability to attend and learn.

This discussion will look in particular, however, at the effects of under-acknowledgement of nutritional issues.

1. Feeding and nutrition

Approximately 40-50% of children with cerebral palsy are thought to have feeding problems: in those children who have spastic cerebral palsy affecting their whole body, the prevalence is thought to be as high as 85%[6]. Furthermore, problems in childhood appear to persist into adulthood: a survey of young adults with cerebral palsy showed that 56% of the sample had significant feeding problems.[7]

There are several identifiable causes for nutritional difficulties in this group of children: their communication difficulties, oro-motor impairment for chewing and swallowing, pharyngeal and oesophageal dysfunction make this group vulnerable to a range of conditions which will, in their mildest form, give rise to discomfort and distress[8]. In more severe forms; for example, the repeated inhalation of food and drink particles in the airway which can lead to repeated chest infections including pneumonia, or the continuing reflux of acid stomach contents into the oesophagus, these conditions will give rise to extremely painful and even life-threatening conditions.

Identifying all significant aspiration and gastro-oesophageal reflux from history and presentation can be difficult, and it is really only through pH probes and videofluoroscopic techniques with speech and language therapy/radiology interpretation that these conditions can be shown. Once identified, the conditions' management can be discussed, again in consultation with all involved.

Children with cerebral palsy have been known to be small relative to age standard norms, and this may account for the under-recognition of the difficulties associated with severe low weight-gain. The failure to gain weight will also compromise the child's ability to maintain an efficient immune system: it is easy to see how a child who is 'failing to thrive' becomes prone to infection, and hence less motivated to eat, and so more prone to infection, and so on. For children's whose weight falls below the 3rd centile for their height and age, they can be considered to be at risk of the same effects on their development as those children seen as more typically 'malnourished'. In addition to reduced immune response, these children will be at risk of reduced muscle strength for breathing, low cardiac output, reduced attention span and learning ability, decreased motivation, and increased irritability. Improved nutrition in this group has noted the reversal of some of these symptoms[9], and this underlines the importance of appraisal of nutrition and appropriate management for this group of children.

2. Including discussion of nutrition into an assessment about communication

There are some times, then, where the ACS team will identify the symptoms/signs of significant nutritional compromise in their children for whom their opinion is being sought about communication. Such a discussion will involve both families and local teams. The issues may be perceived very differently by any or all of those people involved. Any discussion of the management of "basic health" issues obviously needs careful presentation in order not to undermine parental or local team confidence in the management of the child in their care.

In one case, the school staff were keen to continue their programme of behavioural management for a young woman of 14 (K) who had been refusing food. The ACS team felt that there were indications that she was, in fact, aspirating on her food and drink, and her food refusal arose from fear of aspiration, and was an attempt to protect her airway. This possibility was acknowledged by the Community Paediatrician, who had seen K. only at the parent's request since she was 11, and who spoke with the parents following the ACS assessment. Subsequent videofluroscopy examination showed that K did indeed have silent aspiration of any textures thinner than yoghurt consistency, and her diet was modified accordingly with good results.

In some cases, however, the family may be unwilling to proceed with investigations. This may be their stance for many reasons: parents can feel that any investigation of oral feeding is likely to lead straight to a recommendation by the medical team that their child must be fed non-orally: by naso-gastric or gastrostomy tube feeding. It is very challenging to be confronted with the idea that, as a parent, you have somehow 'failed' to notice such a significant aspect as under-nutrition. This is particularly so since the time and effort invested by families feeding their children with cerebral palsy can account for an extremely high proportion of their day and their resources: it is hard to think of this as misdirected effort.

Furthermore, in extreme cases, their may be medico-ethical aspects for the teams involved in the implementation of their recommendations. Children who are experiencing persistent chest infections, and the fears of aspirating food, or the ulcers associated with chronic and severe gastro-oesophageal reflux may, it is argued, need 'protection'. As part of their duty of care, paediatricians may feel that their recommendations need to be followed through in the best interests of the child. Such considerations would be analogous to the recent publication of the case of a five month old baby girl for whom HIV testing was recommended: in a High Court Ruling, it was decided that the testing should go ahead against the wishes of her parents, in the child's best interests.

Clearly all efforts need to be made in order for any team to avoid such discrepancy of views, but it is clear that this type of discussion is becoming more frequent for clinicians working with children with cerebral palsy. Speech and language therapists, particularly, are expected to consider both feeding and communication issues for the clients in their care[10]. There is some sense developing that any issues of feeding management should be addressed 'first' if communication issues are to be resolved. Papers and presentations are beginning to discuss these issues[11,12], and it is likely that individual team's policies and experiences will be the most valuable way forward to identify ways in which consensus views can be reached.

Conclusion

For those professionals involved in the management of children using augmentative communication equipment, the discussion of such issues should continue to inform our practice, if we are to ensure that the recommendations we make for promoting communication development are to be the most relevant and useful to the child, their family and their carers.

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The City & Guilds Certificate In Effective Augmentative and Alternative Communication:

Some Tips on Starting the Course

by Nicole Rappell

Let me begin by breaking down any false illusions. This is not going to be a highly theoretical article! It may not even answer all of the questions you might have regarding the City & Guilds Certificate in Effective Augmentative and Alternative Communication. My aim is more akin to 'the quick telephone call' variety of information spreading. I hope to let you know the most interesting aspects of why we decided to take on The City & Guilds Certificate and how we went about it over the past year. If I get up to full steam, I may even be able to fit in some evaluative thoughts, but no promises!

I work as a Speech and Language Therapist (SALT) at a specialist, residential, further education college. Our students are from 16 to 25 years of age with a wide range of physical and learning disabilities. Within my case load, I work with many students who use a variety of light and high tech augmentative and alternative communication (AAC) methods. Some arrive at 16 with no previous experience of high tech voice output communication aids (VOCA), whilst others arrive after having had years of intensive input to gain high levels of communicative competence (Light 1989). All students study recognized further education courses as required for funding.

I was overjoyed...when I found out about the AAC Curriculum and the City and Guilds Certificate...

I had always felt that the students who used AAC had it tough. Not only did they have to spend time in other therapies, complete units on their courses, socialise but also contend with their SALT constantly plugging them to do more practice! I was overjoyed when through a Centres of Regional Excellence (C.O.R.E.) meeting, I found out about the AAC Curriculum and The City and Guilds Certificate in Effective Augmentative and Alternative Communication (Robertson 1999). As we all know, gaining the skills and knowledge to communicate effectively with AAC is next to impossible without high levels of motivation and endurance. At last we have something that can both publically and personally provide a means to give credit where credit is due!

Getting the ball rolling!

Starting a new qualification in any environment can be a bit daunting. Liaison and planning is required to ensure that students aren't covering the same information too many times and that staffing is available. Our first term had just started when I approached one of our education programme managers about The City & Guilds Certificate. It was felt that the timetable was already full and possibly a small trial would be more appropriate.

It was difficult to estimate how much work would be required to collect the evidence. In the end we decided to a small trial of three students - Paul, Penny and Andrea. They all used either a Liberator or Delta Talker as their main form of communication, in a wide variety of situations. These students had not worked through the AAC Curriculum and had all gained their skills through a range of programmes and collaboration with many SALTs. I spoke with the students individually regarding the nature of The City & Guilds Certificate. It was when I stated that if they had been studying French rather than icon sequences, that we would have no difficulties finding qualifications to give them accreditation, that they all agreed to be involved. We agreed that almost anything that the student said could potentially be used for evidence, as long as they gave permission. The students also agreed to take on the responsibility for making sure evidence was collected outside of our normal session. In the end they were helped by a range of teaching and care staff and a volunteer. These links were not formally stated but worked very well, as they tended to be with people with whom the students spent a great deal of time with.

[the students] were helped by a range of teaching and care staff and a volunteer.

I will focus on one of the students involved with our trial. Andrea first came to the college in September 1996. When she arrived she used a hand written word board, with approximately 200 individual squares containing English words with their Greek translation underneath. In October 1996 she began to use a Delta Talker with the 128 overlay Language, Learning and Living Programme (LLL), using direct access with her hand. When I first met Andrea, she was struggling both emo-


Andrea

tionally and linguistically to adjust to her Delta Talker. I watched as she matured as an individual, found acceptance of her Delta Talker, conquered all kinds of language problems. At 19 ½ years of age Andrea was ready to move on. She has now gone on to an independent living flat, firmly clutching her Delta Talker and already given her new social worker wonderful insights into the needs of an individual who uses a communication aid. Despite the fact that Andrea was now speaking in complex sentences, we felt we would start with the Pre-Entry level as we only needed to collect two pieces of evidence. As Andrea was leaving we only had a year to complete the certificate! This was going to be easier for students who used Liberators, as they had the printer facility.

then...I had to face City & Guilds jargon...

Left to right: Mo, Nicole and Andrea

It was then that I had to face City & Guilds jargon. What was the difference between an Internal Verifier and an Assessor? Did I have a Form R? Luckily the college already had centre registration. In the end, my head of department became the Internal Verifier and I became the Assessor. My responsibility was to co-ordinate the collection of evidence and devise how we would do it. Set your fears aside. The representatives from City & Guilds have always been extremely helpful, and will talk you through the paperwork. As the course is in a pilot study phase, they are more than open to any suggestions that you have. We were shown some 'evidence sheets' on which information can be stuck or written. These gave us enough ideas to plough ahead and devise our own. Now that we had the ball rolling, it was time to get down to collecting the evidence.

How to create a mountain of paper

We did quite a lot of brainstorming to try to invent interesting ways of collecting evidence, for a wide variety of speech acts and communication skills. I must admit that in the end, we returned to all of the methods that you would traditionally use as an SALT or teacher - transcripts or printouts, audio tapes, and video. The most interesting factor was the human element. I can clearly recall one afternoon, drowning under a mountain of evidence sheets, glueing on printouts, matching statements to the requirements of the curriculum, only to have Andrea and Mo (her unit leader on the house) arrive with more transcripts, from the pub the previous night! I screamed 'No More!' but secretly loved seeing sides of Andrea that I had not previously really come in contact with. I can safely say that I got to know all of the students in more depth, through other people collecting evidence. I believe that they helped so much, because it was for 'the certificate'. Establishing one good link between the candidate and a peer, parent, carer, or any member of staff is crucial, and all the better if the candidate chooses who this person will be themselves. The students all had folders with them, into which evidence would be placed. It was a bit like an internal mailing system.

Initially I didn't really give any information about what part of the certificate we were focusing on. Copies of the requirements (what evidence we needed to collect) were circulated to as many people as I could think of who may help the students. Our Speech and Language Therapy sessions went on as normal. Whenever a student said something that could be slotted in, it was written down or printed out. This quickly became a bit of a running joke. This may seem slap dash but it was very revealing. We were quickly able to work out what were high frequency communication acts e.g. requesting help/object/action, compared to which areas were very rarely touched, for example, requesting an explanation. Having these pieces of the jigsaw in place we were able to begin to use the process of collecting evidence to focus learning.

[I] secretly loved seeing sides of Andrea that I had not previously really come in contact with.

When we came across an area that the student found difficult, we would usually dedicate our Speech and Language Therapy session to it. This may be then followed up with homework sheets, discussions with the person that they were working with outside of our sessions and even homework via e-mail. For example Andrea had difficulties with 'Directing others - giving encouragement'. She frequently used the phrases 'Well done' or 'Good luck', but appeared to have no other spontaneous way to offer encouragement. With a huge brainstorming pad, I would offer Andrea situations and ask what she might say. With each example I would either try to think of a situation that Andrea had gone through or could possibly go through, using names of her friends etc. If she could not think of anything, I would offer her a model. No matter how many times Andrea must have heard me say 'Go on, you can do it!' she could not think of this when trying to 'offer another student encouragement to use a new communication aid'. We would work through many types of offering encouragement and finally return to one. If Andrea could spontaneously generate an appropriate sentence, then we would accept this as a piece of evidence.

Almost without fail, at some stage I would end up with a piece of paper with something similar arriving from the house or classroom, as our second piece of evidence. Many times I felt I was just showing the students that they could say these things and that they were socially important things to say!


Left to right: Penny and Andrea

With telephoning we went through a similar process. Using handsfree phones and audio tapes, we were able to record many phone calls. Again transcripts of phone calls turned up, from situations when the tape recorder had not been available. The end of the Easter holidays provided a great opportunity to video a conversation, which had to be spontaneous as I didn't know what the students had been up to. Each student had a box in the therapy room that I use. As each item was added, the folders slowly started looking like books. In the end I was saved by our Speech and Language Therapy assistant. As our normal end of year reports loomed, she saved the day by typing, checking and collating all of the evidence to be sent away.

And now the evaluation bit...

What I discovered was that all of my traditional methods of working, found a use in setting up and supporting The City & Guilds Certificate. In busy education environments, it is extremely difficult to find the time to do language samples and analysis of them. This certificate provides you with a very good framework for working out what pockets of communication competence (Light 1999) need to be worked on. It helps you to find the gap and this makes trying to find out why infinitely easier.

We all hate additional paperwork. For each piece of evidence needed we had a different sheet with completed details. On the computer each Unit had a folder and each Evidence Sheet was a different document. In essence this meant that we could always find the right piece of paper, fill it in and transfer it to the student file. There is no getting around the fact that there is a lot of paperwork. I would always argue that with a clear system, the benefits outweigh the disadvantages. Just don't use super glue!

In retrospect these folders of evidence have a myriad of uses. Finding relevant outcomes measures when you are working in the field of AAC is difficult. I feel that collecting evidence of effective communication in this way provides a wealth of qualitative material to support the nature of our work. Additionally, these may be used in training or with parents to exemplify what 'effective augmentative and alternative communication' really means.

When asked what they thought about the course in the end, Penny commented, "I learnt how to give a warning. I was surprised at how much I knew." Whilst Andrea said, "I think good idea because I try more phrases." They both felt that they would recommend it to other individuals who use AAC.

In the next academic year we are going to try a group environment to work through the first stage of thinking about different ways to say things, with many more of the students. I feel sure that they will gain enormously from working through these specific issues together. Without these AAC skills many of our students would be unable to access their educational programmes. Hopefully this qualification will help work towards a recognition that funding cannot be provided for one but not the other.

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Further information on the course is available from: Customer Services Enquiry Unit, City & Guilds, 1 Giltspur Street, London EC1A 0DD Tel: 0171 294 2800 Fax: 0171 294 2405 Email: enquiry@city-and-guilds.co.uk Website: www.city-and-guilds.co.uk

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Dynamic Screen Communication Systems: Part 1

by Sally Millar, Janet Larcher & Philippa Robinson

This paper was presented at the CM'99 National Symposium, University of Lancaster, September 1999, as a workshop session, with discussion of examples, and demonstrations projected directly from dynamic screen systems running on Dynavox and Dynamyte devices, Cameleon II, and Freestyle, as well as standard PC and Mac G3 PowerBook laptop computers. This paper covers only the first part of the workshop; the second part, which is to do with the introduction and implementation of a dynamic screen communication system, will be published in a later issue of this journal.

Component Parts of a Dynamic Screen Communication System

Dynamic screen communication systems are proliferating, in the field of AAC, and growing in popularity (especially, perhaps, in the education sector and amongst parents, who find the visual aspect of these systems reassuring, and who like the way you can explore the system without needing any previously acquired specialist knowledge). However, as advertising materials abound and symbols and pages flash past, it is easy to become confused by dynamic screen communication systems. This workshop was an attempt to provide an overview.

To help to 'untangle' some of the complexities, it is firstly important to note that dynamic screen communication systems include four main components. It's important to distinguish between:

1. The symbol system used
2. The vocabulary (choice of symbols made available, and their organisation and layout)
3. The software program used to display the vocabulary
4. The hardware devices which can run the software which displays the vocabulary

Pre-stored Vocabularies

In our view, it is well worth considering using a pre-stored vocabulary, rather than starting to create one from scratch. (In the UK, we would suggest that it is only fairly recently, since there have been pre-stored vocabularies around, that the use of dynamic screen software has really taken off and become more widespread and successful.)

Some advantages of pre-stored vocabularies include:

- they save time (many hundreds of hours of planning and development work)
- they are highly cost effective (since development time is money)
- they capitalise on the skills and experience of experts (e.g. workers in specialist services who see lots of AAC users)
- they minimise technical hassle (allowing practitioners to concentrate on personalising the system to the needs of the user, and on teaching and using the system)
- potentially, they provide a ready-made low-tech system as well as high tech (using printouts of the screens)

Some possible disadvantages of pre-stored vocabularies might include:

- There may still not be a suitable vocabulary available for a particular type of user
- Practitioners may feel they are forcing the user to fit the available vocabulary, rather than tailoring the system to the client (although most people prefer to criticise and alter an existing system, rather than starting with a completely blank screen)
- Practitioners may feel that the documentation of existing vocabularies is inadequate for giving out to parents/ staff, and do not approve of simply leaving people to 'explore' an extensive and complex system on their own.
- Someone may *want* to design their own system
- A user may already have a well-used low tech system that needs to be mirrored on a high-tech system (rather than a completely different new one being introduced)

This last may be a false assumption - although theoretically you can create an electronic version of a paper-based symbol book, this may not be a sensible approach. It might end up being unnecessarily cumbersome and miss out on some of the attractive features of electronic implementation. It might turn out in practice to 'behave' differently from the paper version for the user (e.g. by having a different effect on listeners, and thus altering the kind of listener feedback that the user receives).

The following pre-stored vocabularies for dynamic screen communication aids are currently available in the UK:

Symbols	Vocabulary	Program	Device
PCS	IDV	Talking Screen, Winspeak	Cameleon, Norand Penkey or any PC
PCS	QuickFire	Clicker 3	PC with processor speed 200MHz or above
Rebus	IDV Chailey	Winspeak Talking Screen	Any PC
Dynasyms	Gateway Dynavox exemplars & cs user, wseadult, speller	Dynavox 3100	Dynavox/myte or any PC
PCS	SDPro exemplars & BeginIT Dynamically Speaking UP Dynamically	SDPro	Freestyle iBook/PowerBook Any Mac

IDV=Ingfield Dynamic Vocabularies
SDPro = Speaking Dynamically Pro

New Vocabularies in Development

The authors are currently developing new pre-stored vocabularies. Millar and Larcher are collaborating on a CALL Centre project in Edinburgh, funded by the Scottish Office Education Department, to develop a vocabulary suitable for use by a young but cognitively able child who would be following the 5-14 National Curriculum possibly in a mainstream Primary

Sensory Software Advertisement

school. This vocabulary, provisionally entitled ***CALLTalk,*** is currently in pilot use by one child with cerebral palsy in a Scottish school and is intended to be made available to other 'beta-tester' sites early in 2000, and made available for sale to others in due course after that. The current version is on two platforms, Mac and Dynavox, and is primarily designed for direct access, rather than switch and scan access. If further development is funded, this aspect may be considered, as well as a 'trainer' version for users at earlier cognitive levels.

Robinson has been developing a vocabulary for a particular client of the Communicate Centre in Newcastle, who is an ambulant teenager with moderate learning difficulties, using a Dynamyte communication aid. Again, this system is primarily designed for direct access. It has been in use by the client for some time now, and he has shown excellent progress in many areas. This vocabulary is referred to for the moment as the ***'Newcastle system'***, and is also due to be marketed, possibly later in 2000.

The details of implementation of both systems are outlined below:

Symbols	Vocabulary	Program	Device
PCS	CALLTalk	Speaking Dynamically Pro	Freestyle, PowerBook, iBook or any Mac
Dynasyms	CALLTalk	Dynavox 3100	Dynavox/myte or any PC
**** PCS***	*CALLTalk*	*Dynavox 3100*	*Dynavox/myte or any PC*
Dynasyms	Newcastle system	Dynavox 3100	Dynavox/myte or any PC

* Potential development

Comparing the different vocabularies

The following table is an overview of the kind of user these vocabularies were designed for:

Vocabulary	Age	No. of locations	Other
BeginIT	18-36 months	8 or 12	very young child or mild/moderate/severe delay
CALLTalk	4-12 years	30 or 35	cognitively able child, including text & prediction
Chailey	3-19 years	24	Severe physical disability plus visual/learning difficulties
Dynavox - csuser	teen/adult	70	symbols
Dynavox - speller	fully literate	70	spelling/word prediction
Dynavox - wseadult	adult	60	words - NO symbols
Gateway	7-11 years	54 or 72	good language learning & literacy potential
IDV (4 levels)	3-12 years	18-60	Key stages 1&2, physical disability
Newcastle	teenager	54	moderate/severe learning difficulties
Speaking Up	4-12 years	20 average	receptive language 4-12 years

We carried out a test, to see how some of these vocabularies compared (IDV, Chailey, CALLTalk, Gateway & Newcastle systems). With each, we generated a 'test sentence' (e.g. that a child might want to say at classroom 'News time). The test sentence was *"I am feeling sad, my guinea pig is dead."* Some issues that arise from this kind of exercise include:

- the number of keypresses required (important for users with severe physical disabilities and slow accessing)
- the availability (or not) of specific vocabulary, and room (or not) for the addition of personalised vocabulary
- the logic of where specific words are stored (relevant to the visual/cognitive/memory load on users, ease of navigation - i.e. whether you keep getting lost or not - and the overall speed of use)
- the number of page changes involved- and whether these were self closing popups or pages that required the user to hit a 'go back' key (relevant in terms of the overall speed of communication)

All of these factors interact with each other in complicated ways to make up 'ease of use' (which will be different for different types of user). There was little time for discussion of the results during the workshop; below we can speculate on some possible implications:

- **In IDV,** the system was extremely efficient (13 keypresses, six page changes) - though the word 'dead' was not available - we could only say *"my guinea pig is sick"*. If 'dead' was spelled out, the total was 15 keypresses). However, with a more complex sentence structure and/or more esoteric vocabulary, the user might find themself unable to proceed, or involved in a much longer series of keypresses and page changes.
- **In CALLTalk,** on both Mac and Dynavox, all the vocabulary was available, but it took more keypresses and page changes to get to it (20 keypresses and 11 page changes plus 3 automatic popup closures). However, because the grammatical 'little words' are stored in permanent popups (i.e. available from anywhere in the system), it is theoretically possible to access an almost infinitely wide range of sentence structures and vocabulary without unduly increasing this number of keypresses and page changes (i.e. there may be more 'room for growth' in CALLTalk design.) Another difference is that there are fewer symbols per page to scan: it might actually be quicker for a user, depending on accessing capability, to change page than to search through very large numbers of symbols on one page.
- **In the Newcastle system,** it took 18 keypresses and 13 page changes (some self-closing popups) to reach the sentence "I am feeling sad, my guinea pig died". (N.B. Dynasyms do not offer a symbol for 'guinea pig', so a modified 'anteater' had been pressed into service...)
- **In the Chailey communication system,** the test sentence took 32 keypresses, and 24 page changes. This is explained by the logic of the Chailey system, where emphasis is placed on absolute and utter consistency, requiring the user to go back up to the Top Page (category index) and back down through the entire hierarchical choice 'tree' for every single word,

giving 4 keypresses and 4 page changes per word, (whereas the other systems use a less precise logic, and either predict the sort of language likely to be used in association with certain vocabulary, or provide access through some kind of 'sideways' link (e.g. popups). In spite of being laborious, this may be an advantage to users who have learned to access words through this cast iron routine and structure. It may be an indication that the Chailey System supports users who function communicatively at the level of single key words, but does not facilitate the construction of sentences. (N.B. The Chailey system does not offer either 'dead' or 'sad'. If both words were spelt out, it would bring the total to 41 keypresses and 24 page changes, otherwise we can only say, "I am hurt, my guinea pig is hurt.")

Each system was tested by its author who knew it well, therefore there were no keypresses wasted through 'getting lost', or failing to find the required vocabulary in the expected place and having to go back up to the top page to try again. A proper test of the logic of the system design would really have looked at how easily a 'naive' user managed to generate the test sentence. It would also be interesting to see by how many keypresses and page changes their efforts differed from those of the experienced user.

(N.B. We did not time the overall speed of use with each vocabulary, as we were 'talking through' the process as we demonstrated, which took up additional time.)

Choosing a System

The informal 'test' above is only a rough indication of some of the relevant factors - it is far from being the whole story. A large number of interacting factors have to be weighed up in the process of selecting the most appropriate dynamic screen communication system for a specific user, in their own particular setting.

Hardware

- portability - size, weight
- screen angle, brightness, touch screen option?
- robustness
- battery life
- processor speed of processor (affects speed of page changes especially)
- specialist versus standard computer equipment
- availability and quality of technical support
- mounting options available
- cost

Discussion

Dynavox was chosen for the Newcastle teenager, as an established dedicated system that could make the transition with the user from school into adulthood. Freestyle, as a version of an Apple Mac based system was chosen for the Scottish Primary school child, as he is in a remote rural area where school staff have only difficult and occasional access to specialist AAC input, but are familiar and knowledgeable with Apple Mac.

In general, we find that a system that can be introduced and practised at first on a standard classroom Mac or PC is welcomed in school settings. Especially given the increasing awareness of under-use of AAC systems, education authorities are unlikely to sanction purchase of a communication aid costing several thousands of pounds without solid evidence that it will be of benefit to the pupil, and can be managed by staff in the classroom setting. If staff and user are introduced to the system and cover the early groundwork on a computer that they know, then a much more convincing case can be made for later purchase of expensive dedicated equipment such as Freestyle or Dynavox/myte.

Software

- robustness
- ease of programming
- range of features - access to other applications, e.g. a word processor
- quality of documentation
- staff familiarity
- availability of training
- availability and quality of support
- cost

Discussion

All of the main dynamic screen software applications are more or less robust, but there is variability in the documentation and training supplied with each. One major reason why the IDV vocabularies are proving popular, we believe, is the accompanying Workbook which provides a wealth of ideas for introduction, teaching and use of the system, in the form of a structured language/communication programme.

Environmental Factors - the support team around the user

- local team experience
- local team time availability
- specialist support available to local team
- training available to the local team
- attitude and motivation of local team
- number in the class (where the user is a child)

Discussion

In our view, there is no such thing as 'the right AAC system' for a communication individual, there is only a 'workable AAC system' within the user's particular context. The above factors will determine how workable any system is within a given context.

Environmental Factors - features of the individual user

- the match between user age and cognitive ability
- the need for:
  - access to curriculum software used by peers
  - development of literacy skills
  - printed output

Discussion

One of the key advantages for school use of the Speaking Dynamically Pro software for the Primary school user of CALLTalk is its flexible ability to launch other applications - e.g. a word processor, on-screen keyboards and wordbanks, 'My Diary' page, pre-prepared worksheets, MathPad - an on screen sum layout program - and so on - from within the communication aid (and to return to the heart of the communication aid automatically, when use of the other application is finished). In our view, a major disadvantage for school students of many AAC systems, is the difficulty of getting language work printed out.

Special Features of Particular Hardware and Software

Additionally, different devices and programs may have features which may be of particular interest to meet specific users' needs, such as visual difficulties. For example:

- search features (Dynavox)
- macros (Talking Screen)
- cell magnification (Talking Screen, SDP)
- word morphology (Dynavox)
- auditory scan
- possibility of and contrast between prompt voice and output voice

Issues in Designing a Dynamic Screen Vocabulary Structure

If you do decide to create your own vocabulary from scratch, instead of using an existing pre-stored system, the following factors will need to be considered:

Overarching issues

- The quantity (size) of vocabulary may conflict with speed of delivery. For example, the more words there are, the more pages and page changes there will be, therefore the slower communication will be.
- Speed of access can be affected by visual and cognitive factors as well as factors to do with physical difficulties. For example, it may be quicker for a user with limited visual scanning ability to scan through fewer symbols on different pages, than a large number of symbols on the same single page.

Visual Presentation

Try to evaluate the impact of :

- number of cells on the screen, and the size of each cell
- symbol size and text size within the cell
- the relative size of symbol and text
- cell shape and the relative position of symbol and text
- colour of symbol, background, text, border (if lots of different coloured backgrounds are used, it might be visually clearer to use black and white symbols rather than coloured symbols)
- highlight colour and style
- border colour & width
- spaces between cells
- regular or irregular cell size within pages and between pages

Cognitive Load

- Number, range, consistency, and presentation of navigational styles - page 1/page 2, branching tree structure, popups, use of index...
- consistency of location of key items - functions and vocabulary categories
- colour coding
- visual presentation
- auditory prompts

Consistency is the key to ease of use.

The use of colour coding is worthy of particular consideration. If this is used, it may be based on the grammatical function of each word (e.g. IDV, where living things are yellow, other nouns are red, verbs green, adjectives blue etc.) or designed to support navigation through the system (e.g. in CALLTalk, all permanent popups are yellow, pages are pale blue, computer application launchers are white, 'all on one page worksheets' are pale green and so on).

Access Factors

- speed of access
- scanning styles available - half, quarter, row/column
- number of adjustments available - touch screen /mouse settings, touch screen viewing angle, mounting etc.
- number of key presses
- number of page changes

If a user has severe physical accessing difficulties, consideration of these will take precedence over many others aspects of system design.

Teaching and Learning a Dynamic Screen System

The second part of the workshop focused on how a dynamic screen communication system might be introduced and taught to users, how the system can be supported, for school staff, parents and families, and how the system can be managed progressively over time. This will be written up in a future issue.

If anyone would like further information about either the CALLTalk or the Newcastle system, please contact the authors.

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Information about other vocabularies, software and hardware mentioned in this article can be obtained from these sources:

Cameleon, Chailey Communication System, IDV vocabularies and workbooks - from *Cambridge Adaptive Communication* (see inside back page)

Clicker 3, Quickfire - from *Crick Software,* Tel: 01604 671691 Email: info@cricksoft.com

Freestyle, Speaking Dynamically Pro & vocabulary exemplars - from *Don Johnston Special Needs* (see page 20)

Gateway, Dynavox, Dynamyte - *Sunrise Medical* (see page 4)

Winspeak - from *Sensory Systems* (see page 28)

New Books Review

Sensory Stimulation - Theory & Activity Ideas

Susan Fowler, Occupational Therapist, Spastics Society of Victoria, Australia (1999)
Published by Spastics Society of Victoria, Australia
ISBN 0 959 679472

This book contains a wealth of ideas for staff working with individuals with multiple disabilities. However, it is much more than just a list of useful ideas. It also puts sensory stimulation into a theoretical framework and provides some useful background to this area.

The book is divided into two sections: Section 1 explores the meaning of sensory stimulation and the details of a sensory programme. Section 2 includes a wide range of practical ideas to enable people to start running their own sensory stimulation programme.

The theoretical framework is useful as many people working in this area may feel they know about sensory stimulation but have little knowledge of the theory behind the ideas. The theory, which supports the use of sensory stimulation, could be useful in persuading managers that this is a valuable learning experience for participants, as well as a pleasant activity. This section also encourages readers to consider their aims for the clients involved in the programme. Assessment and recording Forms are included in the book and readers are encouraged to evaluate the programme. A useful section is the clearly presented idea of sensory banks. These are collections of items that are categorised according to the different senses.

The activity ideas are wide ranging and while they are aimed at adults would equally be useful to a younger age group. The activities are presented clearly with a number of aims, followed by the appropriate ingredients and equipment needed. There is then a full description of the method for each activity and the way each sensory experience can be enhanced for each participant. The activities are divided into a number of categories: Drinks, Food, Personal Care, Household Care, and Crafts. While this is, for some people, quite prescriptive; readers are also encouraged to analyse any tasks they are involved in and to present it to the participants in such a way as to make it a sensory experience.

This book is a useful resource for those professionals working with individuals with severe and multiple disabilities. The only section that will not be of use is the section containing Australian contacts and prices for the equipment that is mentioned in the book. The book ends with an appendix, which outlines the achievements and increase in skills that can be achieved by taking part in the programme. This summary of the benefits of using sensory stimulation techniques in the daily life of individuals with multiple disabilities is realistic and gives readers aims when implementing this uncomplicated but very worthwhile approach.

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The AD/HD Handbook

A Guide for Parents and Professionals on Attention Deficit/Hyperactivity Disorder

Alison Munden and Jon Arcelus (1999)
Published by Jessica Kingsley, London

This book sets out to provide a readable guide to ADHD for parent and professionals. As such it has several good qualities. It is short, attractively and accessibly laid out and is easy to read. The chapter structure moves from definitions and diagnoses to discussion of explanations and then moves into treatment and the roles of different agencies. It has a useful list of contacts and references.

The authors of this guide are child psychiatrists who are trying to provide a concise account of a condition around which there is an immense and complex research literature. My concern is that making this accessible for parents and teachers actually so oversimplifies it so that doubts and complexities are lost. The concept of ADHD is used in explanations of behaviour that tend to be tautological. Children have it because they show the behaviours which define it. They show the behaviours because they have ADHD. Despite a huge volume of research there is still no definite means of identifying this condition other than a subjectively based observation. This book does not question the validity of the concept.

Equally it does not recognise the controversies over the volume of drug prescription in the USA. The UN International Narcotics Control Board and the Federal Drug Agency in the USA itself have expressed grave concerns over both over-prescription and increasing illegal use of methylphenidate. This book simply suggests that we are under-prescribing in the UK. The increasing diagnosis of ADHD in the UK is clearly not unrelated to the decision in the early 1990s by Ciba Geigy to reintroduce and actively market Ritalin in the UK. Financial analysts point at the need for the large US drug companies to expand their sales beyond a nearly saturated US market.

The development of a social perspective on disability and criticism of medical models is currently challenged by the existence of a large group of parents asserting their rights and the right of their children to be classified as having a medically defined disorder and to be prescribed medication. This phenomenon needs to be understood and not simply disregarded by those writers committed to inclusion. It is clear that there are children in families and classrooms who are showing a high level of distressing and unmanageable behaviour. In my view it is essential that we support and understand families with children who display these kind of difficulties but we are not honest as professionals if we present an oversimplified view which denies the contested nature of some of the claims made about ADHD. This book does not acknowledge this. It can still be a useful resource for parents and teachers looking for information if they read it critically and remember that there are still controversies and disagreements over both the nature and explanations of ADHD and its treatment.

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(These views are expressed in more detail in Lloyd,G. and Norris,C. Including ADHD? *Disability and Society. July, 1999.)*