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AAC – the ongoing perspective

Sally Boa

In November 1996, two multidisciplinary team's were commissioned in Glasgow to serve the physically disabled population living in the community. The team in the North of Glasgow operates within a social model. Many of the people who are referred to the team have long term, very complex needs, and a significant proportion of those that require Speech and Language Therapy intervention use or require assessment for some form of AAC.

Over the past decade it has become increasingly apparent that ongoing support is required if AAC users are going to learn and continue to use their AAC systems successfully. Generally, AAC intervention (for "lo-tech" or "hi-tech" systems) progresses through a number of stages, as follows:

- Assessment for AAC system
- "Learning to use the system"
- Provision of AAC system
- Use of AAC system
- Discharge from the service / Ongoing monitoring

The amount of time spent on each stage depends very much on the individual AAC user.

For many people, particularly those who have acquired conditions, the amount of time spent "learning the system" can often be underestimated. (MacDonald 1997). It is often assumed that people who can read and whose language is intact can just pick up and use spelling based AAC systems. My own experience with individual AAC users and evidence from the literature indicates that the use of AAC rarely comes naturally to anyone. One particular case study by Glennen et al (1991) which described the difficulties that MH, a 34 year old man with an acquired condition had in learning to use his new modes of communication, demonstrates that any AAC intervention is time consuming and is, for most people at least, very long term.

This has obvious implications for service providers and raises questions about how the need for sometimes very intensive input and long-term support can be met.

Within the North Glasgow Community Physical Disability Team, attempts have been made to address this question, and this paper aims to describe how this is being done.

Background to the Community Physical Disability Team (CPDT)

When fully staffed, the Team comprises the following (WTE posts):

1	Team Leader	2	Occupational Therapists
2	Physiotherapists	1	Speech and Language Therapist
1	Dietician	1	Nurse
0.4	Psychologist	5	Generic Team Assistants
1	Secretary		

The Team has finite resources, a large geographical area and population (530,000 approx.). The key to being able to provide intensive input when required and ongoing support and monitoring for individuals who are using AAC is in part dependent on the work of the 5 Generic Assistants within the team.

When a client is accepted for input by the Community Physical Disability team, they are allocated a key worker whose role is to co-ordinate Team interventions and liase with other professionals and agencies. Each professional within the Team works closely with a particular Team Assistant who has a generic role, that is that they carry out interventions on behalf of the range of professional staff within the Team. This helps to keep the number of people going into an individuals home to a minimum, and also means that a consistent monitoring role can be easily taken on.

Case Studies

During the presentation, 2 case studies were described which demonstrated how generic team assistants can be utilised and can provide support for individual AAC users as well as helping to influence the person's environment to promote maximum use of a system or systems.

... it has become increasingly apparent that ongoing support is required if AAC users are going to learn and continue to use their AAC systems successfully.

Case Study 1

The first case study described a lady (KL) who has Multiple Sclerosis, and examined how instrumental the generic assistant was in ensuring that the client was given enough time and support to learn how to use the AAC systems being introduced. Because the Team Assistant was seeing KL on behalf of other professionals on the CPDT, she was able to monitor and give feedback about how useful and effective the various systems were whilst working with the client for other reasons (eg Carrying out passive movements). The fact that the Team Assistant was not seeing KL specifically to work on her communication, meant that an honest picture of KL's communication could be built up. A description of the various systems, which were tried with the client, was given.

Case Study 2

The second case study described a young woman (LT) who is in a minimally responsive state following a severe brain injury. Initially, Team input involved the introduction of a sensory stimulation programme which was carried out largely by a Team assistant and LT's relatives. The benefits (or not) of this input were regularly reviewed by professionals on the Team. At a later date, a programme of passive movements was put into place. Again, this was largely carried out by a Team Assistant. Each time LT's passive movement routine was being carried out, it became apparent that LT became significantly more responsive, and a consistent movement was identified that could be used to develop a "yes/no" response. Progress to date with LT will be described, and the positive aspects of a holistic approach will be commented on.

Summary

Given the finite resources that are available, it is important that a mechanism can be put into place that can ensure that AAC users can be monitored and supported. This needs to be done on an individual basis, taking into account the person's circumstances, their own abilities and wishes. It must also consider how formal and informal carers can be enabled to help in this process without becoming overwhelmed or overburdened.

References

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Telephone use by people with communication difficulties: an overview

Joan Murphy

Background

Using the telephone is now a part of everyday life. Very few homes are without a telephone and many have more than one. We see the growth of mobile phones all around as people communicate via technology in all sorts of unlikely places. It is hard to imagine not having access to the telephone – it is difficult to be part of today's world without using the telephone. However, for people with a disability this everyday way of communicating is often denied.

People with a disability who may have restricted mobility and fewer opportunities for meeting people have a particularly strong reason for using the telephone. It can allow them to have access to emergency help, information, family and friends without leaving their homes.

“Being able to use basic telephone services means having to be able to reach the telephone, hold it, find the relevant number in a directory, dial the number, speak into the mouthpiece, hear the voice at the other end of the line and read the bill when it arrives. There are many people in the UK for whom one or more of these activities may be impossible or very difficult”

OFTEL Consultative Document 1998.

Study

The Scottish Office funded a study carried out by the AAC Research Unit at the University of Stirling to examine the use of the telephone by adults receiving speech and language therapy within Forth Valley Health Board. The project obtained demographic information, identified the main obstacles to telephone use, investigated the views of carers and finally examined how speech and language therapy is provided in the use of the telephone.

Information was obtained via postal questionnaires and semi-structured interviews from the following three groups of people:

- * adults known to the speech and language therapy service within Forth Valley Health Board.
- * the main carer of the adults receiving speech and language therapy.
- * ten speech and language therapists who work with adults living within the area covered by Forth Valley Health Board.

People with communication difficulties

A large amount of data was gathered about the difficulties experienced by people with communication difficulties and the full study will break down the results according to diagnosis of the 88 participants who responded. The main difficulties described by the 7 AAC users who replied were –

- * not being allowed enough time to speak/respond
- * people not understanding the voice of the communication aid
- * difficulty with hand control
- * telephone badly positioned
- * a lack of information about what is available.

Carers

From comments from carers the three most important advantages of the telephone for people with communication difficulty were:

- * being able to keep in touch with family and friends. Many carers described the use of the telephone as an important factor in preventing isolation and helping people keep in touch with the outside world.
- * maintaining independence and not having to rely on carers to speak on their behalf – e.g. making appointments and getting information by telephone.
- * safety and security by being able to call for help whether it be to family, friends or the emergency services. Several carers described the importance to them of knowing that they could get in touch with the person with a communication difficulty to check they were OK.

Speech and language therapists

All of the speech and language therapists interviewed commented that it was an area that was often neglected in therapy and several said they had not really considered telephone work for patients other than stammerers. However, they all thought it was an issue that needs to be given greater thought and should be included in assessing patients' needs. Two therapists who had done group work with people with dysphasia had had a lot of success, so much so that by the end of the course some patients were phoning the therapist to rearrange appointments and phoning each other for a chat. The speech and language therapists discussed a number of adaptations and strategies they felt would be useful in helping people with communication difficulties to use the telephone more effectively.

Conclusion

This study confirmed that telephone use is an under-used and overlooked resource for people with communication difficulties and their carers. The findings formed the basis of a workshop held at the Scottish Study day in Augmentative Communication in Cumbernauld in October 1998. In addition an information booklet for therapists, carers and users is planned.

Reference

OFTEL: Consultative Document February 1998 – *Telecommunications for people with disabilities*

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Group intervention with AAC users

Alison MacDonald

Introduction

What do we mean by 'group intervention'?

One definition of a group:

'Two or more people interacting with one another so that one influences the other' (Pauline Maskell, *Working in Groups*, 1996)

A group therefore should be composed not just of a few people who are sharing individual access to a therapist, teacher or other support person because time is short but must have goals and an underlying purpose which sees specific benefits from grouping individuals together and from the interactive possibilities offered by the group.

Communication groups usually have either an educational, facilitatory or socio-interactive focus or possibly a combination of these and a major function of a communication intervention group is to provide practice and experience in some of the skills identified as important to eventual communicative competence. Joan Murphy's research (Murphy 1997) emphasises the importance of bridging the gap between speech and language therapy sessions and more natural settings. Group intervention might be seen as one way of bridging this gap.

Intervention implies that there is someone whose role is to shape and guide the group work and to ensure that the underlying aims of the group sessions are met. These groups will therefore need to have some form and direction which is usually undertaken by a speech and language therapist, teacher or other designated group leader. The role of leader may at times be fairly directive but at other times may be one of supporting and facilitating in a more low key way. It is important therefore, for a group leader to be clear at the outset of a group session what form the leadership is going to take.

If the main purpose of AAC intervention is to achieve communicative competence then we need to look at the components of this. Janice Light has suggested four areas of communicative competence that need consideration if individuals are going to become competent in their AAC use. These would seem a good starting point when planning group AAC sessions.

These competencies were described by MacDonald and Rendle (in Watson 1994) as follows:

Linguistic competence – adequate mastery of the native language (vocabulary and grammar) plus the code (e.g. signs or symbols) required to operate the augmentative communication system;

Operational competence – mastery of technical skills required to operate the system, i.e. the motor and cognitive skills required to signal a message or to operate specific device features (pointing, signing, visual scanning, operating switches, controlling cursors, editing etc.);

Social competence – knowledge and skill in the social rules of communication (e.g. making appropriate eye-contact, sharing the balance of talking and listening) and using communication for a range of different purposes (social chat, making requests, responding to others, contradicting people, etc.);

Strategic competence – flexibility in order to adapt communicative style to suit the receiver (e.g. signing more slowly to strangers; turning up the volume on the communication aid in a noisy room), or learning how to correct misunderstanding or to extend the conversation (e.g. if a child cannot explain something clearly on his *TouchTalker* he might have a message that says, 'Please hold up my Bliss chart, I'd like to explain something').

Facilitating Competence in a Group Setting

When examining how these communicative goals might be facilitated in adult groups it is important to remember that adult AAC users fall into quite diverse subgroups. One consideration may be whether the individual members have a congenital or acquired communication difficulty. The level of previous experience brought to AAC use is often a major factor, e.g. literacy level, keyboard skills (familiarity with QWERTY layout), socio-interactive skills and previous opportunities for developing conversational proficiency and linguistic flexibility.

The role of leader may at times be fairly directive but at other times may be one of supporting and facilitating in a more low key way.

Linguistic Competence

A group setting can provide excellent opportunities for sign and symbol users to learn and consolidate new vocabulary items and to ensure that these are integrated into real conversational and information conveying situations from the start.

Most adults with acquired disability will have well developed orthographic skills so that while they may need to become familiar with the QWERTY layout there is less need to focus on linguistic or symbolic aspects. It may, however, still be important to build up skills in the selection and retention of stored message codes. Shared discussion on useful coding strategies and message selection can be very valuable. The group setting also allows more natural conversations to evolve which can then be analysed for high frequency phrases that might usefully be stored.

Operational Competence

There are times when learning to operate the mechanics of a communication aid or setting up good positions for chart pointing needs the undivided focus of a one-to-one situation. The slightly dyspraxic signer may, however, benefit from multiple examples of handshapes provided by their peers without too direct a focus on their own production. Equally some adult VOCA users have enjoyed making use of a group setting to compare voices and learn how to alter these and other parameters such as volume control.

Social Competence

Having worked with adults who have an acquired loss of speech it is evident that while most of these people may have been socially and linguistically competent before their loss of speech there are still many areas of social and strategic competence in which they may benefit from guidance and practice. In fact it might be argued that for some people it is more difficult to change from a long established and highly effective means of communication to using new and inevitably slower modes. An emphasis on social and interactive skills therefore may be as important as in groups for congenitally communication impaired people. The approach and slant may, however, be different. For many people who have never experienced easy communication it is well established practice for professionals to set up opportunities to develop and practice turn-taking and eye-contact skills. The adult who has lost speech, however, may also find it difficult to recognise the need to look up from a communication aid keyboard or to know at what point to press the speech output key in a group discussion without overriding their neighbour.

Strategic Competence

The group setting provides an excellent setting for looking at strategic competence and flexibility. Sign and symbol users may need to understand that they should slow down a sign for some conversation partners or back up a sign with a symbol for someone unfamiliar with their signs. Communication aid users, once they have mastered the operational features of their machine, need to practice altering the volume for different situations, and to learn to make use of a call buzzer or other 'Attention Getter' when in a voluble group discussion.

In conclusion there would appear to be very good arguments for focused group intervention work with AAC users both with developmental communication impairment and also for those with an acquired difficulty. The specific aims and activities undertaken may be different but in all cases it is important to consider all four of Janice Light's components of the ultimate goal of communicative competence.

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Social Competence

1. Role play to trigger different **communication acts** such as requesting, contradicting, asserting, e.g. returning goods to shop; ordering taxi.

2. **Turn taking and responsibility:** one member takes coffee / tea orders from others in turn and passes information on to leader.

Strategic Competence

1. Group exchange ideas on and practise **attention getting strategies** for VOCA use – e.g. in a discussion: compose contribution, wait for appropriate entry point then use call buzzer or phrase such as *‘Just one thing...’*, *‘Could I make a point...’*

2. Users are encouraged to **switch to alternative / back-up modality** if necessary. Leader sets up activity requiring vocabulary not stored in user’s communication aid – user is forced, prompted if necessary, to signal message such as *‘I’ll tell you on my chart – could you hold it up for me.’*

Students with an acquired brain injury in a college setting

Anne Chirnside and Alison Cox

Staff at Stevenson College have been interested in the challenge of working with students with acquired brain injury since the mid 1980s when an innovative pilot proposal for research was developed jointly by the college, Astley Ainslie Hospital and LEAD Scotland. It was not possible to attract funding at that time but over the intervening years a limited amount of work with head injured students was undertaken and staff expertise was gradually developed.

Building on this expertise, the first structured approach to developing provision began in 1994 largely through the personal interest of a member of staff, Anne Chirnside, who had a particular interest in communication and linguistic difficulties. The resulting IMPRINT programme was developed to offer an integrated approach to the educational needs of students with acquired brain injury. In 1996, Stevenson College was successful in obtaining research and development funding from the Further Education Funding Unit to take this work forward.

Work with students with acquired brain injury will continue to be challenging in an educational context. There is no doubt that further education can play an important part in enabling students to maximise their potential and provide an 'acceptable' environment in which to come to learn more about what can be achieved and how.

This abstract brings together the major strands of our work, providing a summary of the possible consequences of acquired brain injury; an overview of the College's provision for such students and a brief description of the research undertaken at the College. It reflects a full report produced by Anne Chirnside and Alison Cox.

Summary of possible effects after brain injury

Individuals are likely to experience a **combination** of different difficulties.

Although some difficulties tend to be common to many people, it is important to identify the individual's particular set of weaknesses, *as each person will experience different difficulties at different levels of severity.*

Cognitive and behavioural difficulties tend to be hardest to cope with, and hardest to deal with.

Social functioning

- * poor behavioural control
- * socially inappropriate behaviour
- * egocentricity
- * sexual disinhibition
- * lack of enthusiasm
- * verbal disinhibition

Cognitive competence

- * impaired short term memory
- * poor concentration
- * reduced information processing
- * poor problem solving skills
- * difficulty making decisions

Self direction

- * lack of initiative
- * difficulty sustaining an activity
- * inability to monitor own performance
- * difficulty prioritising
- * easily distracted
- * lack of insight into own competence
- * perseverance

Communication skills

- * impaired productive language skills
- * word finding difficulties
- * poor spelling
- * difficulty organising information
- * confuses listeners
- * slow delivery
- * difficulty sustaining conversations
- * digresses frequently
- * excess and redundant detail

Physical impairments

- * weakness or loss of function on one side
- * visual impairment
- * hearing loss
- * reduction in stamina
- * extreme fatigue

College provision For students with acquired brain injury

At Stevenson College there are basically two sorts of provision for students with acquired brain injury: individual support for those whose level of competence enables them to access mainstream courses; or a specifically designed programme which focuses on the needs of this group. Students sometimes begin on the special programme, then, after some time, add one or two mainstream classes, so that they continue to have the support and security of the special programme whilst adapting to the different environment of mainstream.

Personal support for those on mainstream courses

Individual support for those on mainstream courses is dependent on the particular needs of the person. However, in almost all cases it involves liaison with mainstream staff as we have found that background information, and some hints on management are extremely beneficial to everyone. In general, the mainstream environment is less directive than is helpful to many people with acquired brain injury, but if staff are aware of this, they can take a more directive approach, making instructions clearer and structuring choices. In addition, the slowed processing common to many of these students can mean they feel unable to participate fully or they miss information or they take longer to complete tasks. It is important that mainstream staff are alerted to this in advance.

Support provided in individual sessions may focus on study management issues, such as drawing up a structured work timetable; strategies to compensate for memory impairment; organising ideas and information as required by various assignments; or self management issues related to how the person interacts with others. Sometimes it is support of a more personal nature that is needed, as students may still be attempting to come to terms with the consequences of their injury.

Other strategies employed to assist students on mainstream classes include use of a Dictaphone to gather information; access to word processing facilities to make it easier to organise and present written work; use of electronic spellcheck and thesaurus to facilitate word finding; and strong encouragement and assistance in the use of a personal organiser – diary or electronic.

It has been our experience that there is increased likelihood of a positive outcome if students with acquired brain injury on mainstream courses have the advantage of a named person who can provide coordinated support. Such students can often perform tasks and exercises perfectly well, but for the total management of their studies they require some assistance.

A specially designed programme

For some years now Stevenson College has run the IMPRINT Programme. This programme has developed in response to the needs of students with acquired brain injury. It provides a secure, non threatening and supportive environment in which students can develop new skills or brush up existing ones. All classes are taught in small groups by experienced staff, and in most classes students work at their own pace on an individually negotiated agenda. In some classes the focus is on group work with the aim of promoting cooperation and interaction.

The programme is part time, with flexible components and can be suitable for those who may have been recently discharged from hospital out patient services, as well as people whose injury was some time ago, but who have had difficulty reintegrating into the community. It gives people a structure to their week, and aims to assist in rebuilding self-esteem within a stimulating and encouraging environment.

The programme components fall into two groups: technology skills and enabling skills. Technology classes offer a wide range of activities to suit the varying experience and abilities of students, including basic computing skills, the internet, and keyboarding skills. Over the years we have been increasingly well resourced in terms of equipment and aids to cater for a variety of physical needs, eg students with one-sided impairment can learn to use an ergonomic keyboard to enable them to access the computer with one hand.

Case Studies

Susan had just begun a degree course at university when she was involved in a car accident. When she first came to college to join a special course, she walked with a rollator (a walking aid), had hearing difficulties, spoke with a slight slurring and generally performed at quite a slow rate. She was unable to process information at anything like her previous level of competence. After some time she was walking unaided, she still had some hearing impairment but it was much less noticeable, and she was participating and initiating in group activities because her processing had speeded up. It is more than likely that S will progress on to mainstream modules.

Frank enrolled on an HNC course at college. He had hoped to go to university, but a car accident had intervened. He had difficulties retaining and organising information and his processing was also slow. Sometimes when he was tired, he was not really in touch with what was going on. He was able to achieve a few open book modules where he could work at home, at his own pace, but he still required extensions on the time allocated. He was not able to achieve modules which called for the retention of new information.

Jim had been a machine operator and then an administration assistant. He had a stroke which left him with communication impairment. His production of language, both written and spoken, was painfully slow. When tired or stressed he had great difficulty producing coherent language. He had no mobility problems, his memory was excellent and his concentration strong. A work placement was set up for him which required accurate data input, but no interaction with the public. This successful experience gave him a great sense of achievement and boosted his self esteem.

Harry had been a printer and his job with its socialising was very important to his identity. He had a cerebral haemorrhage. The main results of this were that his memory was affected and he was unable to problem solve and reason at his previous level. He was determined to return to work, and crushed to discover that he could not handle work demands that previously would have been easy for him.

Tom had worked in a shop, was immensely social and loved the outdoor life. He had a car accident. This left him with impaired function down one side. His memory was affected and when tired or stressed his memory was very poor indeed. He also had difficulty with concentration, but in any case he had always preferred practical activities. He was very quick and witty, giving a lot of pleasure to others in his group, but sometimes he was unable to see when his witty remarks might be hurtful.

The enabling skills offered tend to depend on the nature of the student group. Generally we run an investigations course which focuses on project planning, sequencing, prioritising and following through. It can be done at different levels. A supported open learning workshop allows each student to select a subject of their own choice from a range, and work towards a module in class. This provides study skills support; structure; sociability; and aims to increase concentration span.

The agenda of our communications groups depends very much on the needs of the students. In the past we have had groups with serious language difficulties where we have worked on such areas as simple sentence building or regaining an interest in reading through the identification of appropriate text material, and then working on those texts. We have also had groups in which the focus was more on pragmatics, where we have employed functional activities based on the appropriate use of language in a range of situations. Our current communications group operates as a workshop in order to cater to the very different needs of a wide range of language competence.

The benefits of a special programme

Whilst students undoubtedly benefits from the skills they develop in the various courses, it is important to recognise the very significant holistic benefits of the college experience: it allows students to begin again with people they did not know before their injury; they are no longer regarded as patients and are required to make choices and decisions which greatly enhances feelings of control; they can gain greater insight into their present strengths and weaknesses in a context which emphasises the positives. One of the best outcomes is when students begin to see a way forward that they find acceptable. It happens frequently, but unfortunately not always.

Measuring the impact of acquired brain injury

Each year about 300 per 100,000 of the British population sustain a head injury of sufficient severity to warrant hospitalisation. The majority are young men, with a peak between 15 and 25 years. Data gathered in 1987 indicates that head injury is the main cause of disability in men under the age of 60 in the UK.

The long term consequences for the survivors of acquired brain injury tend to be cognitive and neurobehavioural, rather than physical in nature. Lifespan is unaffected in the majority of survivors, with many facing 40 – 50 years of life post-injury. However, quality of life is usually severely affected. There is therefore a moral obligation, as well as an economic one, to address the long term needs and aspirations of those with head injuries and their families, on whom a heavy burden often rests.

During the last decade, the emphasis amongst those members of the 'research community' who are interested in post incident outcomes following acquired brain injury has started to move slowly but noticeably away from identifying and measuring only 'medical' progress, to a new level of awareness that life for the young person with an acquired brain injury usually extends well beyond the period when physical and medical stability has been achieved. The identification of ways in which to measure and evaluate ongoing change and longer term progress, and to develop educational and community services which accelerate or enhance that progress, is therefore a valid research activity. Indeed, referral sources, policy makers and funders will increasingly seek credible information on optimal interventions and their effectiveness.

It will become increasingly important to know whether 'education' makes a difference following acquired brain injury, and to establish whether there is clear justification for continuing to develop a comprehensive further education programme with its associated resource implications. Even those who are firmly convinced of the value of education following acquired brain injury would like a better understanding of what strategies and interactions are likely to be most effective.

The Research Focus

IMPRINT focuses on the provision of appropriate, accessible educational opportunities for young adults with acquired brain injury, maximising integration where possible – but acknowledging an ongoing need for separate, additional tutorial sessions for most participants and discrete provision for some students. The context for this research can be summarised as follows:

- ✱ It is not easy to provide for a group with such complex needs, making it all the more important that provision is targeted, where possible, at maximising benefits for the students.
- ✱ Progress of students with ABI is often slow and difficult to measure. Strategies for recording and demonstrating such progress would be valuable.
- ✱ Options for people with ABI, post-discharge from hospital, are limited and may not always be acceptable to the individuals themselves. Collection of data on the uptake of services could inform the wider evaluation of head injury provision.

The purpose of this research has therefore been threefold:

1. To extend our understanding of what can be achieved through further education generally, and IMPRINT specifically, by students with ABI.
2. To validate the approaches adopted by staff in supporting students with ABI.
3. To inform the future planning of provision for this client group.

In this abstract it is only possible to provide a flavour of the research activity, and to touch on a sample of the lines of enquiry. One such line of enquiry was associated with establishing how people with an acquired brain injury got to know about their options on discharge from hospital – and why they opted for IMPRINT.

At the time the study was undertaken, IMPRINT was in its third year of existence (including the first pilot programme which ran in 1994). It had been established in recognition of the complex needs of individuals with acquired brain injury who applied to become students, and the concomitant difficulties experienced by staff at Stevenson College in effectively meeting these students' support needs within the typical course timetable or framework. Staff acknowledged that the general educational trend towards mainstream integration could have made the establishment of a discrete programme for students with acquired brain injury seem inappropriate or unpopular. This proved not to be the case.

Those interviewed (both students and their 'significant others') expressed strong support for the development of a programme that catered specifically for people who had an acquired brain injury and allowed tutors to become experienced in offering a curriculum tailored to the participants' needs. Political correctness, and the persuasive lobby for integration, did not appear to affect their views of what was best for them.

Recording progress

When asked if they felt they were making progress as a result of being on IMPRINT, all the students felt that they were improving in a number of ways. 75% of the respondents had specific goals, and two thirds of those students assessed themselves as being closer to reaching those goals than they had been on commencing IMPRINT. All the significant others who were interviewed could identify ways in which their relative had

progressed, although two-thirds claimed to have resigned themselves to the fact that a 'return to normal' was out of the question and/or that progress would occur slowly. IMPRINT students had set themselves many varied goals:

- ✿ to get fitter/improve stamina
- ✿ to live independently
- ✿ to make friends
- ✿ to travel independently
- ✿ to get speech back
- ✿ to return to work/find a job
- ✿ to learn how to use a computer
- ✿ to enter a relationship / get married
- ✿ to calm down

The extent to which achievement of, or progression towards, these goals can be attributed to IMPRINT is difficult to assess. Other factors, including the site / severity of the original brain injury, the immediate post-incident circumstances, time period since injury, environmental factors and an individual's temperament / personality, can all have a bearing on outcome. Nevertheless, it is worth noting the progress that respondents have shown whilst on IMPRINT which they, and their significant others, attribute to the programme – particularly where this progress is substantiated by feedback from the lecturers with whom the students have been working.

<i>Progress made by students while attending IMPRINT</i>		
Progress with ...	% of respondents	Additional comments
Writing	33	"I think people can read what I've written these days."
Word finding	33	"He was always stuck for words, now we have real conversations"
Speech	50	"I'm no longer scared to pick up the telephone when it rings!"
Confidence	33	"Now I can go into a classroom of people without feeling sick"
IT skills/computing	50	"A good thing since the head injury is ... I've learned computing"
Memory/organisation	66	"She won't leave the house without her diary organiser"
Concentration	25	"These days he can watch a TV documentary and not doze off!"
Self control	33	"I've calmed down a lot – mind you, I needed to!"

Research Summary

Head injury is the main cause of acquired disability in young men. Typically, survivors of head injury face more than forty years of life following injury – but the quality of that life (and the lives of family and carers) usually changes dramatically – with loss of work, severe strain on relationships, detachment from friends and social isolation being commonplace.

The attempt to rebuild one's life following an acquired brain injury is really just beginning at the point of discharge from hospital. Yet, this is the time when access to rehabilitation and support services generally diminishes or becomes more fragmented.

Strategies for the inclusion and re-integration of adults with acquired brain injury into the education community are yet both novel and experimental. IMPRINT offers an example of what can be achieved within the further education sector, but also provides evidence of the resource implications associated with developing such provision properly.

Despite often looking fit and well, those with acquired brain injury more than any other students can find the demands, the pace and the practicalities of 'unsupported' mainstream study to be beyond them. Yet many seek further education as a means of 'returning to a normal life'. It is therefore important that staff have an awareness of the impact of acquired brain injury, and an understanding of appropriate teaching and support strategies.

For students with acquired brain injury, access to support and the option to seek assistance is easier when class sizes are small and when the mode of delivery is flexible, varied and paced according to student need. The majority of lecturing staff interviewed for this research study were aware of using particular strategies and approaches when teaching students with acquired brain injury.

One of the intentions of this study was to enable the student voice to be heard and acknowledged. For this reason, many of the respondents important and revealing comments have been retained in the report.

Those interviewed clearly attribute aspects of their progress to participation in the IMPRINT programme. In the majority of cases, that progress can be substantiated by feedback from lecturers and students' families. An opportunity for further work in the area would enable the existing criteria to be refined into a more objective set of measures (or progress indicators) to determine the relationship between education and quality of life following acquired brain injury.

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Footnote

There are three sections to the full report on the IMPRINT project:

Section One brings together our experience of working with students with acquired brain injury in college. It is produced as a guide for teachers and lecturers in FE and HE on the range of difficulties which students might experience and ways of minimising the effects. This section has been produced by Anne Chirnside. Readers are also referred to the research in section three which looks at both student and lecturer viewpoint.

Section Two is an account of the work placement project involving students with acquired brain injury, supported in placement by a job coach. For many individuals who have had a brain injury, returning to work remains a priority – although not always a realistic option. The pilot project offered supported and carefully matched placements, aimed at helping individuals assess the feasibility of sustaining work. This experience was then the focus for guidance about future options, including alternatives to paid employment. Co-ordinated by Anne Chirnside, the project also involved a specialist careers adviser, Dave MacKay and a job coach, Mark Smith.

Section Three is an account of a small scale research study into the benefits of the college experience for adults with acquired brain injury. The research was undertaken by Alison Cox and provides an interesting insight into the views of students and lecturers about the impact of acquired brain injury in the learning environment. The study also explores the expectations of students and their families, and the extent to which the FE sector can rise to the challenges of including and supporting students with acquired brain injury.

Copies of the full publication, priced at £7.50, may be obtained from Stevenson College by contacting Angela Garvin via telephone: (0131) 535 4800 or email: agarvin@stevenson.ac.uk

AAC in the hospital setting

Joyce Seaward

Stirling Royal Infirmary is a 443-bed District General Hospital. The Speech and Language Therapy Service to all in-patients comprises 0.5 wte with a further 1.3 wte for out-patients and community referrals and 0.6 wte for the Area Rehabilitation Service. There are good links between the clinicians working across the service encouraging a ready flow of ideas and developments in AAC between hospital and community.

The hospital Speech and Language Therapy caseload is predominantly made up of referrals from the medical, rehab and care of the elderly wards. However ENT, ICU and orthopaedics also refer regularly. Stroke accounts for the largest group by aetiology and so a high proportion of clients suffer from dysphasia, dysarthria and dyspraxia.

High-tech aids for example *Lightwriters* or *MessageMates* are available for short-term loan via the Area Rehab Service. Applications for long-term loans are assessed by a loans panel and submitted to the Health Board for purchase.

The main aim of this paper is to discuss the range of low-tech aids used on a daily basis in the acute setting. Individuals in the acute stages of recovery after stroke often require very simple direct images to help comprehension – even the most considered chart can be too complicated. A bold black marker pen and plenty of plain paper are the best tools to prepare dynamic and often ephemeral support at that stage. It does not matter if it is quick and rough – getting the message across at the time when it is needed is the main aim. A clear image perhaps a single word or two and hopefully some humour can prove invaluable. Ward staff and family members can be reluctant to try this approach, scared in case their drawing “isn’t good enough”. The process of encouraging them to have a go can provide a useful opportunity to highlight how hard it can be to communicate in a different way than normal and to encourage them to look carefully at how hard it is for the client to say even the simplest things.

Large coloured YES/NO cards (green or yellow for YES and red for NO) are easily pre-prepared and are always useful in the early stages.

As recovery progresses a mix of free hand and computer generated symbols can be introduced.

Symbol charts¹, Written-choice technique², *Talking Mats*³, Letter Tiles and a written/drawn record of a session, all have their place on a daily basis. As always, equipment or an approach that has been explained and / or demonstrated to carers and staff has more benefit. An ongoing tension exists between the need for ready prepared materials and more time consuming customised equipment.

In the long term, Communication Books and Communication Passports may be crucial elements in an individual’s progress towards independent living. It is therefore very useful to develop the link between symbol and message as early as possible.

AAC can help the severely language impaired individual to understand the issues and choices which sometimes arise at the time of discharge. Careful preparation involving familiarisation of symbols, explanation of possible routes and potential difficulties using the techniques developed in the *Talking Mats* package is very constructive. In this way a well-supported client can make his wishes known quite unequivocally to his advocate and family alike.

It is very satisfying to be able to support less common situations with an AAC solution, for example preparing simple line drawings and simplified instructions for an individual with acquired brain damage beginning to learn how to manage a colostomy.

The work shop sessions gave participants an opportunity to try out several of the techniques discussed above with a particular focus on selecting vocabulary items.

Joyce Seaward
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Stirling.

References

¹Mayer-Johnson Co, *Boardmaker* Picture Communication Symbols (PCS)

²Garrett, Kathryn L and Beukelman, David R *Augmentative Communication Approaches with Severe Aphasia*, Chapter 4, *Augmentative Communication in the Medical Setting* (Editor Kathryn M Yorkston)

³Murphy, Joan *Talking Mats- a low tech frame work to help people with severe difficulties express their views*

First into the future with MND and a stroke

Spencer Houston

Background, Education, Social and Medical History

I'll begin with my background and education, social and medical history. My name is Spencer. I am 53 years old. I have three grown up children and live independently. I started my career as an electronic engineer, later switching to the more exciting option of teaching mathematics in Special Education. I was a senior instructor in sea kayaking and roamed mountain and sea, summer and winter.

In 1989 I was diagnosed with atypical MND and in 1996 suffered a stroke which left me with dysphasic difficulties.

For the past 30 years I have been computer orientated, having worked for a military avionics company. Technology held no fears for me.

Over the last 25 years I have taught children with social, emotional, behavioural and educational difficulties, and the determination of some of these children to become integrated affected me long-term. Immediately following my stroke, I imagined that, like them, I would become as normal as I wanted to be. Watching their determination to overcome their problems inspired me.

Speech and language history

Pre-stroke my speech was okay. A speech and language therapist had warned of speech deterioration, and explained that artificial voices were available. At this stage I had not personally owned the phrases “*MND resulting in loss of speech*”, and “*technology can be used to speak*”, but I appreciated the frank and open approach of those around me. In the two years before retiring from education I used a computer to assist me with administration, social work and teaching .

I understood the availability of technology; but whilst I used it, had made no personal connection. I had been provided with a computer to assist me at work by the Dept. of Employment, the contracting technician dumped the machine on me and left. I had no say on the specification. The technology did not daunt me, but a programme of familiarisation would have benefited me practically and emotionally. As computers are normalised in society, the back-up should be commensurate with the user's knowledge and skill.

Communication status post C.V.A.

The stroke had forced me to face up to the reality of the stroke and the MND. One of my first requests in hospital was my computer. I could not speak. Requesting my computer was my way of attempting to get back to normal and to send a message to those around me both literally and metaphorically.

Shortly after hospital I had a meeting with my lawyer, and took my sister. To my amazement they were discussing my future. I signalled, and interjected, stating my wishes, and whilst not fluent, left them in no doubt. Even with significantly impaired speech, I realised that I could still communicate in a real-life situation – that I could cope.

The four months after discharge were traumatic – sorting out somewhere to live, renting then buying; signing papers for my legal separation; and knowing there were aspects of MND which my S & L Therapist had alerted me to and not fully discussed. As things settled, however, it became appropriate to tackle them. Generally, it was crucial that she was prepared to be challenged, allowing me to question her methodology while we worked on the rapport between ourselves.

Current communication status

My speech is still clear and fully intelligible, although sometimes when I think of what I am going to say I have difficulty fishing out the right words. Other times I know the meaning of the word but can't find the word. I also have difficulty planning and constructing a sentence.

You have to listen carefully – the vocabulary is at times surprising and unusually complicated. Listening sometimes involves asking the speaker to slow down or repeat what they have said. About 5% of the time I struggle to fully understand them, depending upon the speaker, situation, etc.

Reading is now quicker, and comprehension better. Silent reading has become more expansive, as I understand not just the words and difficult grammar, but also the ideas behind them .

My writing is improving. Words flow more easily, especially on computer. I use my predictor and spell-check on *E-Z Keys* supplied by Scottish Motor Neurone Disease Association. I can write formal letters, but always have them checked to prevent major problems.

I never forget my disability, and sometimes have difficulty expressing something I assumed was automatic. It trips me up and I think about the thoughts themselves. However, I believe that technology will eventually meet most of the needs I have been experiencing. If I had not had this practical input I would not be so well adapted to my disabilities. Also, I used to be very talkative, and there I can see a change. I listen more and am getting more out of life by listening.

Whilst facing up to the advances in my deterioration, I have found difficulty in accepting the practicalities of introducing switch access. I can still laboriously use a keyboard, and fell back on this. My Speech and Language Therapist suggested acquiring a keyguard as an interim.

My computer is:

- ✿ a writing system
- ✿ a communication system (e-mail, fax) especially family further away
- ✿ an information system
- ✿ a data base – addresses etc.
- ✿ a financial and legal organiser
- ✿ an entertainment system
- ✿ a speech system

Uses of technology

I am imagining a person with little or no technical information and I think it is a “suck-it-and-see” type of activity. That is, you only stop at the technology that you are interested in. Information needs to be simple and succinct, especially for stroke victims, with time allowed for assimilation.

It is important not only to talk about technology in advance, but to see that technology in operation.

I have been provided Internet software by the Wigram A.A.C. Internet Surfers (WAACIS) project. This includes both the E-Mail and WWW. E-Mail is something I access frequently. However the WWW presents me with problems. It has been difficult for me to know whether the fault has lain with my computer or the servers, and the way my disability has restricted my competence in describing the problems has exasperated me to the point of giving up.

One of the difficulties of WAACIS has been the lack of information provided on the website by individual users. It is difficult to engage in dialogue when you know so very little about someone.

Technology – current issues

Purchasing a computer for disabled people presents many problems. It is difficult for the supplier to understand the complexities of matching not only the computer to the client, but also trolley and seat. The experience of having my first computer delivered without a programme of familiarisation has led me to realise how important this is. The commercial aspects of buying a computer and trolley have badly frustrated me. It was difficult to know if I am getting “my value for money”.

With the new computer I have first hand knowledge of what I would like, and I am so much further down the road of MND that the increased specification of the computer will see me out.

I am of the opinion that at present disabled people who need a computer will find that professionals with the necessary skills are in very short supply, and therefore a heavy reliance will be placed on ‘computer’ friends.

Apart from WAACIS project, there has been no professional with relevant training background to do this. There needs to be an identifiable role within NHS and Social Work. Their computing departments are not accessible presently. The nearest AAC centre is 200 miles and three hours drive away where there is good support but it needs to be closer. I can hear the professionals think “On top of all I have to do – computers and the Internet!!!”

Discussion

Here are some of my current thoughts. Often I am aware of my thinking strategies – and they seem to be improving.

When I was diagnosed MND, prognosis was very important. Now I take each day at a time and right from the beginning of the stroke I never expected things to return to normal.

The point needs making that success is down to the patient as much as the Speech & Language Therapist. It is by rising to the challenges set by the Speech & Language Therapist and the challenges that I introduce to the sessions myself that have ensured any success I have made.

Amateur Speech & Language Therapists have augmented my professional Speech & Language Therapists regime – I have benefited from this voluntary help immensely.

Sharing jokes is very much part of the normalising process. On the other hand, peace and tranquillity are very much a feature of my future. That is not to say it is silence, which is not something that I am afraid of. In the past, I was very verbose and always contributed at meetings. It is remarkable that I am so composed about this.

Future communication

I'll finish by telling you what I think about my future communication. My experience of the "living will" issue has changed. Initially I thought that it had to be definitive about the way I wanted the final stages of my life to be lived. Although part of this remains, it is insignificant. I will not call it a living will but my wishes at the terminal stages of my earthly life. These wishes are not morally or legally binding on those who treat me. My psychologist is also my advocate. Until recently I thought that I would only be able to communicate with high-tech devices. Now I realise through experimentation with family and friends that smiles/frowns etc. can convey a lot and they are in tune with me so that I have no qualms about future communication.

I submit that this is just one more contribution to the hearts, souls and minds of those, like me, who you are trying to help communicate.

*Spencer Houston,
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The cunning plan!

John Angel

John Angel gave the following slide presentation using *Powerpoint*.

John Angel

- **Joan Murphy's cunning plan**
- **Getting to use the *Lightwriter* – my self-esteem**
- **Using the *Lightwriter***

What's the matter – he can read the manual, can't he?

- **With a stroke, self-esteem is lowered**
- **Simple tasks require effort and take time**
- **Your speech therapist may have a 'cunning plan' to get you to do things**

The *Lightwriter* and the telephone – 1

- **Pre-stored phrases – all you can find**
- **Try using them, remembering them**
- **Keep the ones you use**
- **Have a 'scratch pad'**

The *Lightwriter* and the telephone – 2

- **try it out with a friendly subject**
- **getting through**
 - **getting the other party on your side**
- **taking control**
 - **getting your message across**
 - **the importance of small talk**
 - **control is necessary because an unexpected interruption requires unexpected messages on the Lightwriter**
- **using space–?. using ‘over’**
- **goodbye**
 - **leaving the other person with a warm glow**

The telephone isn't so bad

- **Comments please to**
- **John Angel**
Tower House
10 Main Street
Clackmannan
FK10 4JA
email jangel@iee.org

Using Augmentative and Alternative Communication (AAC)

Scott Barbour

My name is Scott Barbour and I'd like to write about my use of AAC. My twin sister and I were born in hospital in Dundee on November 8th 1959. It was six months before my Mom and Dad discovered I had cerebral palsy. This was due to lack of oxygen when I was being delivered. My twin Lesley was slightly affected but I was confined to a wheelchair and unable to use my arms or legs properly. When some people meet me they think that I am mentally as well as physically disabled. That is not the case and I am not long in letting them know I can understand everything that is said to me. I'm not stupid.

I started school in Lanark when I was eight years old. I would communicate by looking upwards with my eyes when I was saying "yes" and down when I meant "no". I used this method of communication until I was 22. By this time I realised there was a lot I wanted to say and needed to find some method of doing this. My speech therapist came up with a Bliss Board with different symbols on it for different things. The things I may need to say in everyday conversation were drawn on to it in separate boxes and I would indicate with my eyes to the left or right and up and down until the box I needed was reached. This depended on people programming the right messages in for me but it opened up a new world of communication for me and gave me a chance to say what I wanted.

At the day centre that I went to at this time, I used a BBC computer with *BeebBliss* for one hour a day but not for every day. The rest of the time I used yes/no which was very frustrating.

In 1987, I was seen by Fife Assessment Centre for Communication through Technology (FACCT) and provided with a scanning *Lightwriter*. I was one of their first clients and this machine gave me my first voice. I started using a 32 overlay and moved to using a larger 132 overlay. I use a switch to access the machine. At the beginning I thought that I would never be able to use my communication aid but the use of the *LLL* package overcame this problem. Now I could not function without it.

In 1992, I got a machine called a *Liberator*. This used icon prediction which speeds up how fast I can use it and it had a printer.

In 1994, I became one of six full-time students at Motherwell College, learning about using communication aids. I also learnt cooking, painting and gardening which I did not like. I finished the course in 1996. I use my communication aid a lot better after being at college.

I recently changed to using a *DeltaTalker* which is quicker to use and allows me to change channels on my television and now I can watch what I want. I can also use my computer linked to my *DeltaTalker*.

Having a *DeltaTalker* means I can say what I want now to my family and friends and not what people think I'm saying. I still have problems with some people but I just say that I understand everything that is said to me and that I will respond if they give me time. Sometimes people see a wheelchair and they think I'm stupid or they only talk to the person that I'm with. I do not like that.

Having a voice makes it easier for people to get to know me and I like talking to people. However it is more difficult to start a conversation with strangers because I do not know what to say and that is something I need to work on.

The only problem I have with the machine is when it is in strong sunshine and I can't see the screen. Also when it breaks down but I have a rescue package that replaces my machine within 24 hours and I get support from FACCT. I also think it would sound better if it had a Scottish accent.

I have recently got a computer and I intend to use it to write a book about my life.

Recently I went on a *Liberator* Ambassadors' course and now I am a Silver Grade Ambassador. I hope to work sometime and show the *DeltaTalker* to people.

Scott Barbour
Fife

“My son is my son ’til he gets him a wife, but my daughter’s my daughter for all of her life” AAC: issues for users, families and partners

Liz Panton

Introduction

This paper aims to explore some family relationship issues for adult AAC users. Some issues will be the same whether a person has been an AAC user since childhood or whether they started to use AAC when they were adult. Others will be different. There can be some very special and difficult issues when someone in the family loses their speech suddenly or finds that they have a medical condition that means that they do not have long to live.

However, we first need to define what we will include when we talk about “AAC” and who we will include when we talk about “families” and “partners”.

Talking About AAC

The term Augmentative and Alternative Communication, or “AAC” for short, can include a wide range of communication methods and devices. Today we are thinking primarily about people who do not use “natural language” – speech or deaf sign language – as their main means of communication. When other people might use speech or deaf sign language in conversation, they will use communication aids, gesture, pointing and some signs or “hand talk”. We will be thinking about AAC mainly in connection with conversation rather than in connection with writing. For example, AAC can be used in conversations when:

- ✱ there are just two people talking to each other
- ✱ there is a group of people who are all talking to each other
- ✱ one person is talking to a whole group of people
- ✱ people are talking face-to-face
- ✱ people are talking over the phone

“You can choose your friends, but you can’t choose your family”

This saying suggests that when we talk about “family” we are only talking about “blood relatives” and that husbands and wives are not included. We are going to use the word “partners” to include husbands and wives.

However, who else *you* count as part of *your* “family” might be different to who I count as part of my “family”. Who we count as part of *our* families might even be different to who our partners count as part of *their* families. From time to time we may also change our minds and feelings about who counts as “family”.

The ties that bind us together in relationships that we call “kith and kin”, or “friends and family”, vary in length and strength and they can change over time. They can also pull tighter and closer in one direction than another. For example, we might be especially close to particular “in-laws”, a favourite brother, or a parent and feel that they are very much part of “our family”. At another time we might feel less close to them. Or we might feel that although they are part of “our family” we are not part of “their family”.

We could talk all day and still not find a definition of “family” with which we all agree. So, for the purposes of thinking about AAC and “family issues”, everyone can decide who *they* want to include when they think of *their* family. This means that if you think of a carer, or a Godchild, or a best friend, or a neighbour’s child as being part of your family, then they are part of your family.

Now, think about which of these people are important to you in terms of *communication*. Who do you *want* to talk to and who do you *need* to talk to? These are not necessarily the same people of course. What would you *want* to be talking to them about, and what would you *actually* be talking to them about?

Next, we will consider family relationships and communication, and how they might be affected when an adult in the family uses an AAC system.

“My wife doesn’t understand me”

This sad “pick-up” line says it all – communication break-down equals relationship break-down. Families are called “dysfunctional” when family relationships are very troubled, family members are unhappy and their behaviour causes other people problems or concern. Other families are more or less “functional” in

providing an emotionally and physically safe and supportive environment that helps individual members to reach their full potential.

The fact that an adult member of the family has a severe speech problem might or might not be a factor in determining how well the family functions. The fact that the adult member is an AAC user might alleviate some communication problems within the family. However, an AAC system or learning to use an AAC system might also impact negatively on some family relationships.

Introducing AAC into a Family

Families are always changing and adapting and are more or less functional from one time to the next. However, some factors that are always important to good family relationships and are a sign of a well-functioning family are respect, understanding, appropriate discipline, healthy interdependence and healthy boundaries.

If a severe speech problem is acquired in adult life by a family member then family relationships will be affected. In most cases acquired speech problems will also be accompanied by other impairments. What effect might these issues and the introduction of AAC have on the positive factors for functional families? We will consider two “relationship” factors: respect and maintaining healthy boundaries.

Respect

The person who has acquired a severe speech problem, often along with other disabilities, may be deeply affected in terms of their own self-respect. They will feel a strong sense of loss and grief for their former self. They might feel very ashamed and withdraw into their immediate family, avoiding meetings with their wider circle of “family and friends”. They might not be able to contribute to family life physically or economically and be so demoralised that they cannot contribute emotionally either. If they come to depend more and more on other family members for emotional support this can further undermine self-respect.

Introducing an AAC system might provide a practical solution to some communication problems. However, it might sometimes be a mixed blessing or the family might not be ready to accept such a solution. Negative consequences of introducing the idea of AAC will depend to a large extent on whether this is achieved as “breaking the bad news” (that speech is not an option) or “giving the good news” (that a means of communication has been found). This factor is not related to the AAC system and it is under the control of the person introducing the idea of AAC.

- ✱ Speech and Language Therapists and other professionals need to take care to introduce the idea of AAC in a way that does not undermine self-respect.

A factor affecting self-respect that *is* related to the type of AAC system is whether the user feels that the system is “socially acceptable” and appropriate to his/her age and intelligence. For example, it is often difficult for an adult with an acquired problem to accept use of a system with a picture display, even if an alphabet-based system would be impossible. Similarly, some people who have had a laryngectomy find it very embarrassing to use an electronic larynx and prefer to write messages.

One man gained confidence using a communication aid with his wife and later felt happy to use it with his grown-up children. However, an elderly woman who was happy to use her artificial larynx talking to her daughter and grand-children never felt comfortable or confident talking to her husband and son-in-law. She could not forget feeling ridiculed and humiliated when they joked about the sound of her voice.

Most people are heavily influenced by how their families, and specific family members, feel about their AAC systems. If the husband or wife is embarrassed by the idea of their partner using a communication aid this may cause further loss of self-respect for the partner, who might then feel that it is less trouble to reject the aid.

- ✱ It is important for Speech and Language Therapists and others to prepare the family as well as the potential user for the introduction of the idea of using AAC.

Maintaining healthy family boundaries

Think how many couples come nearly or actually to blows when one attempts to teach the other to drive? Or when one returns from the flat-pack furniture store with a surprise purchase that they then attempt to assemble together? Think how many parent-child spats are provoked by the seeming impossibility of a grown adult learning how to programme a video recorder in less than fifty attempts.

“Healthy boundaries” can be disturbed when partners or children are recruited to supervise “speech therapy homework” and as “tutors” for AAC users. This is another factor that can undermine self-respect as well as distorting family relationships. Failure of adult users, their partners or their children to cooperate with carrying

out AAC implementation programmes does not necessarily indicate obstructiveness or a failure to “prioritise” communication. It might indicate an attempt to preserve normal boundaries – and the peace.

- ✱ A family might have the time and skills to carry out “AAC training” with an adult family member but might find it hard to cope with or accommodate an “inappropriate” tutoring relationship between particular family members.

Recognise and respect family priorities

Professionals in the field of AAC, including myself, can be very utilitarian and concerned with the tasks that can be achieved if communication is improved, or the extent to which a person can become more “independent”. However, quality of family life depends just as much on healthy *interdependence*. AAC users are as interested as anyone else in maintaining, improving and enjoying relationships and “their place” in their family. We need to remember to ask about priorities for improving functional communication within the family. Then, when we identify AAC solutions, we need to try to make sure that they make a positive contribution to family relationships, interactions and family life. For example,

A young woman with young children who had had a stroke was capable of learning to use a complex communication aid. However, her main worry was that she could not call her children in from the street – she found that a whistle was far more use than a Voice Output Communication Aid (VOCA) for summoning her brood. She was also upset that she could not discipline her children in the house – her sister recorded a few choice phrases into a simple VOCA and she was able to shout at her kids and reestablishing her authority. She enrolled herself, her partner and her children in British Sign Language (BSL) classes. She felt that her shopping was enough to carry without adding a communication aid. She also revelled in the fact that she could flirt with her husband in public using BSL and no one would know.

An elderly man with MND was uninterested in being shown a VOCA for general use, and indicated that he was damned if he would ever use something so stupid in public. However, he was reminded that he had said that he was very upset that he could not read to his young grandchildren or talk to them on the ‘phone. He took to it enthusiastically.

*Liz Panton
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The voluntary sector

Marie McGill, Rhona Currie and Elaine C. Burt

A panel of presenters from the voluntary sector outlined the services provided by their organisations.

Scottish Huntington's Association

My name is Marie McGill. My background is in nursing, essentially in the neurosciences and oncology. The latter seven years, prior to taking up my present post, were principally spent working in the research field. I have been employed by the Scottish Huntington's Association since June 1995 as the Huntington's Advisor/Project Manager for Fife, a primarily rural area (population approx. 350,000) situated on the East coast of Scotland.

Huntington's disease is a devastating neurodegenerative disorder of the central nervous system. Tragically it is also an inherent disorder, each child of an affected adult carries a 50% chance of inheriting the gene and consequently developing the disorder. Huntington's is often referred to as a triad of symptoms, the motor disorder, the cognitive disorder and the emotional disorder. It is these three symptoms with regard to speech and language difficulties that I would like to discuss with you today. Our service attempts to respond to the needs of people with communication problems through education, research update and multi-disciplinary working.

*Marie McGill
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MS Society

As MS Specialist Nurse, based in the Southern General Hospital NHS Trust, I am in contact with many people who have MS both in the hospital and in the community.

I try to ensure that the client group are referred, when appropriate, as early as possible to the Speech and Language Therapist. Many of my client group use computers, either for work, pleasure, or to 'surf' the Internet. Access may become a problem and referral to SCTCI may be appropriate and helpful.

The MS Society local Branch Network may help with purchase of equipment [although not usually for equipment which should be provided through the statutory services].

*Rhona Currie
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Institute of Neurological Sciences
Southern General Hospital NHS Trust
1345 Govan Road
Glasgow G51 4TF*

Head Injuries Trust for Scotland

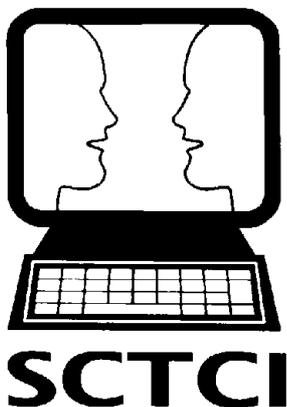
The object of the presentation was to look at the social communication skill deficits occurring following traumatic brain injury and to share the HITS experience of working with this client group.

The session covered client selection procedures, interventions and evaluation techniques which aim to improve skills within the social context and aid community reintegration for many clients.

*Elaine C. Burt
Project Manager
Head Injuries Trust for Scotland: Glasgow Centre
7 Queens Crescent
Glasgow G4 9BW*

Useful organisations

Organisations whose services include the provision of assistance for people with severe communication difficulties were invited to describe some of their services. These are the responses from the organisations that replied.



SCOTTISH CENTRE OF TECHNOLOGY FOR THE COMMUNICATION IMPAIRED

SCTCI specialises in working with people with severe speech and communication difficulties who may benefit from using some form of augmentative and alternative communication (AAC) technique. We aim to help people achieve functional improvements in communication in daily life by helping them to get the most out of the opportunities offered by AAC approaches and new technologies. SCTCI is funded on a contractual basis with most of the Health Boards in Scotland and staff are able to see both children and adults either on an outreach basis (in the person's own environment) or in SCTCI itself. SCTCI is based within the West of Scotland Mobility and Rehabilitation Centre at the Southern General Hospital in Glasgow. SCTCI offers:

- **Assessment:** An objective, independent assessment to determine whether an individual may benefit from some form of AAC approach and to make a personalised recommendation of what is required. The assessment may involve more than one visit and the subsequent recommendation will include details of specific equipment required by the individual, ideas for working with that person, and suggestions for improving communication between that person and significant others in his/her environment. Follow-up and support is provided, as required, to both the individual, his/her family and to key professionals involved.
- **Education and Training:** Training for people working with individuals who have severe communication difficulties and who may use AAC can be arranged on request. SCTCI has an ongoing programme of workshops and seminars and organises twice yearly training courses for Link Therapists (contact SCTCI for more details). SCTCI contributes to the national conferences on AAC held in Scotland on a yearly basis.
- **Telephone Help Line:** SCTCI deals with many enquiries each year, providing information and advice to professionals, individuals with communication difficulties, their families and other carers.
- **Specialist Library:** We use our library and information bank to answer queries. These resources are available for other people to use (*by appointment only*). SCTCI has some videos which are available for loan, for training, etc.

SCTCI staff are also involved in research and development in issues relating to AAC.

SCTCI
WESTMARC
Southern General Hospital
1345 Govan Road
Glasgow G51 4TF
Tel. 0141-201-2619
Fax. 0141-201-2649
Email:
sctci@waacis.edex.co.uk

AGE CONCERN SCOTLAND

AGE CONCERN SCOTLAND

Age Concern is a national voluntary organisation with the primary aim of improving the quality of life for older people in Scotland.

Age Concern is committed to working throughout Scotland to ensure that all older people have their rights upheld, their voices heard and have choice and control over all aspects of their lives.

Age Concern Scotland
Leonard Small House
113 Rose Street
Edinburgh EH2 3DT
Tel: 0131 220 3345
Fax: 0131 220 2779



AAC RESEARCH UNIT UNIVERSITY OF STIRLING

In 1989 an Augmentative and Alternative Communication (AAC) Research Unit was established at the University of Stirling. Since then a number of research projects studying the communication of people with impaired speech and their communication partners have been carried out. The AAC research unit is made up of an interdisciplinary team involving speech and language therapists, psychologists, sociologists and linguists. Our research has been supported by research grants from various funding bodies. Although our work was originally concerned with the communication of people with cerebral palsy, we are now involved with people with different disabilities, both congenital and acquired.

During the last decade we have explored a number of issues including:

- Interactive strategies of users of AAC systems and their partners
- Factors facilitating and hindering alternative communication
- The integration of different channels of communication (speech, verbal and non-verbal modes of communication, AAC systems)
- Good practice in the provision of AAC services
- Training and communication support networks
- Peer interaction in a residential setting
- Development of *Talking Mats* – a low tech communication framework
- Telephone use by people with impaired speech

AAC Research Unit
Dept. of Psychology
University of Stirling
Stirling FK9 4LA
Tel: 01786 467645
Fax: 01786 467641
Email:
joan.murphy@stir.ac.uk

We are presently looking at the communication of people with progressive illnesses.

We place a great deal of emphasis on producing practical outcomes from our projects. We have developed a series of posters entitled Freedom of Speech and a series of training packages with accompanying videos which have now been marketed. The training packages are all based on the philosophy that people with communication difficulties should play an active part in training others how to communicate with them and should have a determining role in their communication intervention.



SCOTTISH HUNTINGTON'S ASSOCIATION

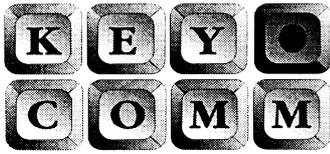
Scottish Huntington's Association
Thistle House
Main Street
Elderslie
Johnstone PA5 9BA
Tel: 01505 322245
Fax: 01505 382980

Scottish Huntington's Association

The Scottish Huntington's Association's service responds to the needs of people with communication problems through education, research updates and interdisciplinary working. It offers:

- local self-help groups throughout Scotland
- support and help for families
- professional advisory services in various areas of Scotland

There is an annual Family Conference and a number of professional study days and conferences are also organised.



Lothian Communication Technology Service

KEYCOMM

Lothian Communication Technology Service

KEYCOMM is a regional communication aid centre providing a service to individuals, schools, centres and institutions located within the City of Edinburgh and surrounding districts. KEYCOMM exists to help people of all ages with communication impairments make use of technology to contribute to and control their environments. The service is multi-agency funded (Health, Social Work and Education) and also has partnerships with Stevenson College and the Bioengineering Centre.

KEYCOMM's aims are to provide:

- * a Regional Multi-disciplinary service for people with communication disorders with a view to recommending appropriate equipment.
- * training and information to professionals, carers, and users about the use and application of technology.
- * a long term, support service for all those involved with communication technology.

KEYCOMM offers core services including information on available equipment, extensive assessment, medium to long term loan of equipment, and inservice training and support. Our Regional Resource Centre has facilities for training, a library including books, journals and materials within the field of AAC, and a display of up to date electronic and non-electronic communication aids.

KEYCOMM runs regular training sessions on topics within the field of AAC and we have Open Afternoons on a monthly basis. We have recently established an information service: D.I.A.L.(Distributing Information to All Lothian). As part of this new service, KEYCOMM produces a newsletter twice a year. Additional projects are planned for the coming year.

KEYCOMM also has an extensive School Support Service which aims to support teachers and other staff in implementing communication technology systems into the classroom.

KEYCOMM's multi disciplinary team consists of a Coordinator and Specialist Speech and Language Therapist, an Occupational Therapist, a Development Officer in Special Education and a Clerical Assistant.

KEYCOMM Resource Centre
St. Giles Centre
40 Broomhouse Crescent
Edinburgh EH11 3UB
Tel: 0131 443 6775
Fax: 0131 443 5121
Email:
djans@keycomm.demon.co.uk.



Aberdeen City TASSCC

TASSCC offers technological support to those working with young people with special educational needs in both mainstream and special schools. It is funded by Aberdeen City Council, having evolved from the Scottish Office Education Department Microelectronic Technology for Special Educational Needs Project. We look after children and young people throughout the whole range of educational placements.

Teachers are usually the first to use TASSCC. However, parents and other professionals such as Physiotherapists, Speech and Language Therapists, Occupational Therapists, Educational Psychologists and School Doctors can make use of TASSCC's services to seek advice, try out equipment, look at software, etc..

Aberdeen City TASSCC
Summerhill Education Centre
Stronsay Drive
Aberdeen AB15 6JA
Tel: 01224 346127
Fax: 01224 346130
Email: tasscc@ifb.co.uk

H.I.T.S Head Injuries Trust for Scotland



Provides community based rehabilitation, support, advice and information to people with a head injury, families and carers.

HITS has three service areas throughout Scotland, each providing a range of group activities and support services. For further information on the types of groups available please contact your local office:

- Glasgow 0141 332 6104
- Grangemouth 01324 471311
- Galashiels 01896 751818

A monthly Information & Counselling service is available at the three service centres as well as in Broughty Ferry covering the Tayside Region. Please contact your local office for more information or Doris Raeburn, 01382 346659 ext 6351 for the Broughty Ferry service.

A programme of social events and information & social evenings runs throughout the year. A variety of speakers are invited along to the evenings. Please contact your local office for more information.

A volunteer programme with trained volunteers is available in Glasgow. The volunteers provide befriending services, tutoring services, travel coaching and a range of other services. For further information please contact 0141-332 6104.

Referral Procedures: An open referral procedure is operated, anyone with a head injury, family member, carer or friend can contact HITS for advice, support or information.

HITS
7 Queens Crescent
Glasgow G41 1BS
Tel: 0141 332 6104
Fax: 0141 353 2543

CALL Centre



CALL Centre, University of Edinburgh

The CALL Centre provides services and carries out research and development projects across Scotland for people with severe communication disabilities, their families and people who work with them in augmentative communication techniques and technology, and specialised computer use.

Assessment & Support Service – CALL offers a free assessment and support service for a very small number of children with complex communication, physical, sensory and learning needs who might benefit from microtechnology. Children are referred to CALL through education authority channels.

Consultancy & Service Level Agreements – If more than a single visit (+ report) is required, local authorities may wish to negotiate assessment, support and training packages, tailored to their needs. Contact CALL to discuss terms.

Information Services – CALL provides information and advice in response to general enquiries on communication technology for people with disabilities. CALL maintains an open-access reference library of books, journals videos and software which can be consulted by arrangement.

Loan Bank – CALL offers loans of specialist equipment for communication and learning, to allow for extended assessment and evaluation of a device or system before purchase. Technical support is available.

Training & Staff Development – CALL offers a range of training and staff development opportunities relevant to people working with children and adults. Contact CALL for a list of forthcoming events or to arrange training to meet your own particular requirements.

The CALL Centre is funded by the Scottish Office Education and Industry Department and Social Work Services Group.

CALL Centre
University of Edinburgh
4 Buccleuch Place
Edinburgh EH8 9LW
Tel: 0131 667 1438
Fax: 0131 668 4220
Email:
CALL.Centre@ed.ac.uk

**FIFE
ASSESSMENT
CENTRE FOR
COMMUNICATION THROUGH
TECHNOLOGY**

Fife Assessment Centre for Communication through Technology

The Centre provides a unique service in Fife to individuals with severe communication difficulty who may benefit from using an aid to communication.

What are the benefits? – Individuals who previously were frustrated and dependent on others for communicating have benefited from using communication aids by:

- speaking for themselves
- communicating by using the telephone
- chatting with friends at school

All of these benefits have led to a more independent and fuller life.

Who can FACCT help? – Children and adults who have no speech, little speech, or speech which is difficult to follow. They may be better at understanding a conversation than they are at taking part using their speech. This can be frustrating for everyone.

Their communication difficulty may have resulted from conditions such as:

- cerebral palsy
- multiple sclerosis
- head injury

How does FACCT help? – The Centre has a team of staff who select the most suitable communication aid and teach each individual how to use it. The team will also teach all supporting carers and staff how to make effective use of the aid.

This service is available to individuals in different locations throughout Fife including schools, centres, hospitals and people's own homes.

FACCT
ASDARC
Woodend Road
Cardenden
Fife KY5 0NE.
Tel: 01592 414730
Email:
facct@itasdarc.demon.co.uk

COMMUNICATION MATTERS

Communication Matters

Communication Matters is a national voluntary organisation concerned with the needs of people with severe communication difficulties. *Communication Matters* can provide information and support with augmentative or alternative communication systems, maximising communication opportunities for disabled people, and enhance their lives.

Communication Matters' members include AAC users, family members and carers of AAC users, speech and language therapists, teachers, social workers, occupational therapists, physiotherapists, rehabilitation engineers, computer programmers, lecturers, researchers, communication aid manufacturers and suppliers, psychologists and doctors. All are welcome and have experience and skills to offer.

The aims of Communication Matters are:

- to increase awareness, understanding and knowledge of good practice in the field of augmentative and alternative communication and technology.
- to provide a forum for the exchange of information and ideas between professional workers, AAC users and their families.
- to promote the positive role of AAC in the empowerment of people with severe communication difficulties in society.

Communication Matters is the UK branch of the International Society for Augmentative and Alternative Communication (*ISAAC*). Therefore membership of *Communication Matters* can lead to reduced fees at the International Biennial Conference, eligibility for study and travel scholarships and inclusion in the International *ISAAC* directory.

Tel: 0870 606 5463
Email:
cm@waacis.edex.co.uk



Motherwell College

Communication First

History – Since the early 1990s Motherwell College has been the only Scottish FE College to make provision for people with communication impairment who use Voice Output Communication Aids (VOCAs)

From 1994 to 1995 we offered a national pilot programme for users of VOCAs which was highly praised by both Scottish Office and users. This initiative led to the current range of courses, which were incorporated into our already extensive special needs provision.

The Current Situation – We are the only Scottish College and the only U.K. Further Education College to be awarded the ‘CORE Centre’ (Centre of Regional Excellence) title for our achievements in this field.

We are the Scottish focal point for developments in this area through our sponsoring of ‘Chatterbox’ users group, and our support for training and promotion of new developments.

The Promise – We offer VOCA users a guaranteed personal learning and support plan with individual programmes and tutorial support as agreed

We can provide a range of full and part time opportunities for day students and residents alike. We can offer you the chance of a lifetime.

Students benefit from a range of activities designed to develop personal effectiveness or vocational skills.

The Invitation – Invite us to your ‘Future Needs Meeting’ or your next ‘Review Meeting’ to hear more about what we can offer you.

Contact – Irvine Kinghorn Curriculum Leader
Gail Dennet Senior Lecturer
Morveen Urquhart Course Tutor



Motherwell College
Dalziel Drive
Motherwell
ML1 2BR
01698 232289



Highland Communities NHS Trust

Kingussie – Dingwall – Lochcarron – Ardnamurchan – Drumnadrochit

Specialist AAC Assessment and AAC Equipment Loan Bank

Speech & Language Therapy Dept.
Raigmore Hospital
Inverness IV2 3UJ
Tel: 01463 705424
Fax: 01463 711322
E-mail - hct.rni@virgin.net

Inverness – Skye – Fort William – Ullapool – Invergordon – Nairn – Aviemore