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Using the Principles of the 'Hanen Programme for Parents' with Clients for Developing Early Alternative and Augmentative Communication

by Chris Sherlock

This paper was presented at the CM2000 National Symposium, Lancaster University, September 2000

Introduction

The *Hanen Programme for Parents* is defined as "a family focused programme, in which Hanen Certified Speech-language therapists help parents learn to interact and communicate with their child during everyday activities and routines in ways that promote social interaction and language learning." (The Hanen Centre)

The programme is well founded theoretically and has a flexible structure. There are many supporting materials, which include guidebooks and videotapes. These enable therapists to work with children with a range of communication disabilities and levels. The work is through training and empowering parents/carers and educators.

The sound technique and principles make it applicable to many situations and allow it to be incorporated into work with those who are most likely to enhance communication for children who need to use AAC, their parents/carers.

Therapist's Background and Rationale

I completed a Hanen Certification course (1998) and jointly ran 'It takes two to talk' courses in a child development centre setting. I then moved to Access to Communication and Technology (ACT), which is the West Midlands Regional assistive technology and AAC centre. We carry out assessments and make provisions for people who are developmentally or chronologically very young. It is imperative for us to have the client's local team, including their parents, more skilled in promoting the child's early interaction. Such preverbal skills are precursors to symbolic based communication systems. Only with more awareness of how to help the child to communicate in any way will parents and local teams be able to facilitate the use of AAC to communicative effect. All communications must be noticed, used and enhanced, whether for the clients who will achieve limited/early language, or those clients who may become fully linguistically and communicatively competent. This is particularly important where carers may be hoping for a technological solution to their child's difficulty, when their child is actually already communicating in many ways that may not be being valued or capitalised upon. These skills will be foundations for AAC and no system will work well without them or at all without sensitivity to attempts to use them by those who interact with AAC users.

Hanen: an Introduction

Hanen was developed in Canada by Ayla Manolson, a Speech and Language Pathologist, and it was named in memory of her parents. It now has a dedicated centre in Toronto (see below).

The *Hanen Programme for Parents* is increasingly available through trained speech and language therapists increasingly in the UK and world-wide. The supplementary specialist courses are also becoming more available.

A *Hanen Programme for Parents,* usually entitled 'It Takes Two to Talk' (Manolson 1992), is presented by at least one trained speech and language therapist (with assistance) who has completed a three day 'Involving Parents as Language Facilitators' training course and who keeps up their certification with the Hanen organisation. The parents' course, to qualify as a 'Hanen', must include 17 hours of group training with the parents, an assessment of the child, goals for the child that are set and modified as required and three video sessions with immediate feedback for the parents. The courses are aimed at parents/carers of children who are developing communication skills from a level of pre-intentional/reflexive responses through to a 2-4 word level (expression and comprehension).

The main practical features of the Hanen approach are:

- The '3a way':
    allow your child to lead
    adapt to share the moment
    add language and experience
- Use of videoing of the parents with their child and giving feedback to develop their '3a way' skills
- Group teaching
- Support and feedback of the group.

The length of the course allows parents to begin to really alter their own interactive behaviour and begin to alter that of their children by their own skill. The course is not a substitute for speech and language therapy but it can enhance the results of direct professional input. The course is demanding of therapists' and parents' time but there are rewards and clinical benefits for both.

Hanen Adaptations

It is important to understand that the process used in the work presented here is not a Hanen course and is only an application of the principles. The Hanen Centre is willing for their principles to be used in this way by trained therapists but are insistent that only a full course as described above constitutes a complete package for parents and can, therefore, use the name 'The Hanen Programme'.

Supplementary/alternative courses formally recognised and produced by Hanen are for:

- Parents of children on the autistic spectrum: 'More Than Words' (Sussman 1999)
- Parents who have limited literacy or English as a second language: 'You Make the Difference'(Manolson et al1995)

- Educators of young children: ‘Learning Language and Loving It’ (Weitzman 1992)
- Parents of children who are late talkers: ‘Target Word programme’ (Watson 1998)

In September 2000 the Hanen organisation will produce a guidebook called ‘Allow Me’ (Ruiter 2000) which is for workers with adults with developmental delays to enable them to promote interaction and language learning. This book includes a section on AAC use.

Why use Hanen?

Early Communication Skills

Infants and young children developing communication only fully develop their skills in the context of shared interaction with others (Trevarthen 1979; Stern 1977). Because of this need for shared interaction, partner interaction with an AAC user can make differences to how successful they are and how they progress (Blackstone 1997). The Hanen model can help us develop interaction that is child centred, naturalistic, culturally relevant and family based. It has an interactive and developmental model and promotes equal partnership in communication with genuine information transfer. Hanen involves parents/carers to optimise the child’s interaction, to promote early communication, and we hope on to AAC.

Changing Interaction

As AAC professionals we hope that carers and professionals will gain these skills from watching other professionals, from direct teaching and from experience. But we also know that self-monitoring and changes to habits are extremely difficult. Even greater difficulty occurs when one tries to alter behaviour of which we are only dimly aware. These behaviours may also be affected by our emotional reactions to the child’s disability, and other factors. The Hanen programmes offer us a way to constructively seek to alter the patterns of interaction of workers and parents. We can take care to be sensitive to the demands on parents (Goldbart 1999) and the group can support each other.

How Hanen is taught?

The course teaching style of the Hanen approach fits well with a diverse local team containing professionals, parents/carers and assistant/ancillary staff. The techniques take account of the needs of adult learners by using the *4P cycle* (Watson 1993):

- Prepare (start the learner thinking what a particular topic means for them)
- Present (present facts and information)
- Practice (hands-on experience and opportunities for problem solving)
- Personalise (opportunities to integrate with real life)

We can incorporate these features into the short intervention at ACT so that we make it accessible to all the participants.

What can be learned?

Using the *4P* techniques I can begin to introduce participants to the *3a way*. It enables us to address those particular skills which we want communication partners to employ with a child who is developing AAC.

- ♦ **Allow** is achieved by developing the skills of the parent/carer to ‘OWL’ their child, i.e. Observing, Waiting and Listening thus being a ‘Responsive Partner’ (Manolson 1992). The outcomes are to:
  - give the partner information about the child’s interests
  - provide opportunities for the child to express themselves
  - motivate the child to communicate in an environment that is secure and encouraging

  These are very relevant to the above aims of child centredness.
- ♦ **Adapt** is achieved by being face to face and letting the child know you are listening, for example by imitating them. The outcomes can include:
  - extending the number of conversational turns a child has so that the power of repetition can be harnessed.

  This is relevant to the AAC aims of Social Competency (Light 1989).
- ♦ **Add** is achieved by expanding on what the child says for example by adding a word, action or facial expression and gestures. These outcomes are particularly suitable
  - for focusing work on the modelling of new vocabulary on an AAC system
  - for building message length and complexity
  - for increasing the rate and efficiency of communication

  These are relevant to the AAC aims of Linguistic and Strategic Competency (Light 1989).

The Model of a Short Intervention using Hanen Principles at ACT

Access to Communication and Technology

The intervention model of ACT is mainly assessment, review, consultation and supportive working. This does not lend itself to the intense model of a whole ‘Hanen’ with parents joining forces as members of a group. But we do have assessment slots that last up to 2 days and during which many of the client’s local team are assembled and committed to spend the time on one child with each other (even if they are not all committed to the same outcomes!).

Including Hanen in the Assessment

The implementation of a Hanen type approach is with the permission of the local team who will take part. It is particularly discussed with the local speech and language therapist, so that we can work together during the assessment. It is particularly helpful if the therapist is also Hanen trained as their expertise can be highlighted and the message conveyed that their contribution is very much what we are recommending.

The approach does allow for all to participate a little as the group of parents might, supporting and encouraging each other. They may see each other work with the child and discuss this with a shared basis of information and observations, which we have on video to review during the process.

The aim is to lay down a shared understanding and basic skill awareness. We can begin change that will be a foundation for future work with that client and their local team. There may be carry-over to the skills being used with other students and

family members. When the local team and client return to ACT we hope for increased child centred interaction that we can then use to move on to specific AAC systems used in the same interactive ways, as recommended by Goldbart (1999).

Choice of Clients

I have chosen the assessment clients with whom I have worked in this way, on the basis of their level of communication development and the receptiveness of the local team and parents to spend the time looking at their own interaction skills, including giving permission for video. We are only just beginning to trial this change in practice, but I consider it to be good paediatric Speech and Language Therapy practice and a foundation for future work, with individual teams and more widely. This work is also relevant to the current emphasis in AAC and beyond, on interaction and service user empowerment

The Method

During the assessment we agree to use most of the second day to carry out training adapted from the Hanen model. We can not call it a Hanen course as it in no way reflects the full implementation.

So far, I have been able to carry out this type of short intervention with three children in the setting of their ACT assessment.

Using the second day gives me time to set the scene and expectations, to prepare and personalise the programme around the handouts and the video clips I will use and the aims I have for the session. I can also find out what Hanen services there are available in their local area that may be accessible for the family.

It is important to note that families do find accessing courses difficult for many reasons including childcare and transport. Seizing the moment to spend time on this topic when they are at ACT, and have overcome some of the problems can be a valuable opportunity.

The session lasts about two to three hours and involves various stages tailored to suit the particular client and team.

The Stages

1. Introducing the idea of the training and the differences from a Hanen course.
2. Using the Checklist from 'It takes two to Talk' we look at the child's communication and get an idea of their level. This allows us to review what we have already talked about in the assessment and try to reach some consensus about what we are seeing. It also gives some thing of a subjective baseline.
3. We then take the ideas of 'how and why' (Manolson 1992) the child is communicating and perhaps 'what' about. We end up with a pooled and personalised list of communicative behaviours that is fairly comprehensive. Often this is the first time that the whole current local team will have had the time to do this.
4. The next stage is to formulate some agreed aims, which are relatively short term. The aims need to be attainable by interacting with the child as a Responsive Partner.
5. We discuss how we can help the child move toward the aims, e.g. gradually adding to the number of turns they can take in conversation like games. We discuss the need to change what we do to achieve this rather than expecting the child to change as a result of more directive/taught input. i.e. being more like a communication partner than a teacher, a role that is more appropriate parents or carers.
6. I show a video clip of the Hanen Teaching Tape (Manolson 1984) choosing a child that is interacting at a similar level to the client. The clip shows the effect of 'Allowing the child to lead' and further introduces the approach. I provide handouts that summarise the points, reinforcing why I think that this will work for the child, for example by encouraging them to take another turn.
7. Then we 'have a go'. At this stage some people are keen to try and others prefer not to be videoed. As this is often not what parents are expecting when they come for the assessment and may not have been videoed before, especially with their child and in front of others, I do not insist that they take part. They will gain from watching and joining in the discussions. If they are willing to be filmed then I concentrate on them.

We make a video of about 3-5 minutes of interaction using favourite activities e.g. finger games. The parent trying to apply the things we have discussed. We then watch the video and discuss what we have seen and how the interaction can be adapted to 'Allow' the child more etc. The principles of Hanen apply to the adult learners in this situation. I guide the work to using the techniques of 'active listening, describing and making inferences and asking leading questions' (Watson 1993) to bring the adult to more awareness of their interaction while allowing for personal differences.

8. Then we try again, perhaps with some specific buzz-words for the parent to keep in mind to support the interaction. I may also give some quiet coaching and encouragement to help them to make a difference.
9. We may repeat this process for other members of the team depending on the time and then we round off by a review of what we have done. We may amend the aims in the light of how the child responds to the different type of interaction. They may have surprised us with their ability when facilitated in this way. We also set goals specific to ACT's involvement (Brewster 2000).
10. The local team has copies of all the working documents and the memory jogging handouts. The local team receive a copy of the video and one is kept at ACT

Case Studies

Case studies of two children were presented at the CM2000 Symposium:

- Sunnah had a traumatic brain injury. She is interacting at level I-II; 'Child responds primarily on reflex basis' (Manolson 1992).
- Chantelle has Rett's Syndrome (see below). She is interacting at Level II-III ' Child begins to explore the environment and starts to imitate actions and sounds' (Manolson 1992).

Video of their local team or parents 'Allowing them to lead' and taking turns with them was shown, and the girls' emerging communication and the changes in the adults discussed. The baseline checklists and the aims that were set and adapted were

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presented. In addition, individual examples of the work on video extracts were shown, and some early outcomes including parental satisfaction and staff changes and opinions were discussed.

Discussion

Initial follow up indicates that:

- Parents/staff have taken away skills that they have been able to use with the girls.
- Specific changes have been seen in classroom staff e.g. valuing students' communication more.
- There has been change in one child's communication in the way that we had identified in our aims.
- Local speech and language therapists have given helpful feedback about their inclusion they have been positive about (a) optimising their role in the work at the assessment, (b) emphasising how they are also skilled to support similar work back in the child's home area, especially if they are Hanen or similarly trained (Suphi 2000), (c) being backed up about interaction style in a situation where the parents perceive that this is an 'expert' view (Taylor 2000), (d) helping local teams reflect on what the speech and language therapist does with the client and understand this better (Suphi 2000).
- Local teams are glad of the time to spend on one child in a supportive environment and have commented that it will change their practice with other children in their class who are similar.

Conclusion

The features of the *Hanen Programme for Parents* seems (on early experimental and very adapted usage) to answer some of the needs that professionals in AAC have identified i.e. helping parents/carers and non specialist staff working with developmentally delayed clients to facilitate the development of communication skills and AAC. The use of such techniques also helps to address the requirements of users, including parents, to be highly involved and empowered. It is hoped that we may also see carry over into the use of later AAC provisions.

In the future I would hope to see 'Hanens' or similar for parents/carers of AAC users so that the others advantages of the programme such as the group support can be used.

Similar Programmes

There are a range of papers in the literature that address similar needs to alter the interaction of communication partners and thus the client's communication, with different client groups. Such work includes programmes for those working with people with intellectual disabilities (Purcell et al 2000) (Money 1997) and carers of adults with aphasia (Booth & Swabey 1999) (Kagan & Gailey 1993) (Lyon et al 1997).

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To purchase Hanen materials in the UK contact: Winslow Press Tel: 0800 243755

Rett's Association, 113 Friern Barnet Road London N113EU Tel: 020 8361 5161 Email: info@rettsyndrome.org.uk

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Getting Started with a Core Low Technology Augmentative & Alternative Communication (AAC) Vocabulary

by Judy Robertson

This paper was presented at the CM2000 National Symposium, Lancaster University, September 2000

Introduction

The impetus for this paper and document has come from three sides. The first has been listening to and observing my daughter Amy's language development. Like many speech and language therapists who are parents, I was amazed at the rate and range of vocabulary learned in the first two years of speaking. Language development in action is very different to a text book or listening to a lecture!

The second has been from my experience of setting up two children's AAC starting from 'scratch' in the light of my new awareness of language development. And the third comes from continuing to do assessments and chatting to speech and language therapists, parents, carers and teachers who all ask, "Where do we start?" and "What actual symbols do we introduce first, and what next?".

Working at Nash Further Education Centre in Bromley from 1990 to 1996 setting up an intensive AAC Curriculum and having worked intensively in the field of AAC for 10 years, has demonstrated the need for clear goal setting and then very structured programmes for teaching, learning and practising AAC. The 'Liberator Lesson Plans' provide a structured programme of teaching learning and practising high tech AAC (Minspeak Application Programmes) which complements the structured 'Core AAC Curriculum' and City & Guilds 'Certificate in Effective AAC'. However a similar structured programme is required for teaching, learning and practising to use low tech (i.e. symbols/words) AAC.

Background

Before Amy was born, I started working with 4 year old Sarah who has cerebral palsy and required AAC. She was attending a mainstream nursery, had no AAC and was receiving one session of speech and language therapy per half term. She is now seven and attends our local mainstream primary village school. When Amy was 1.5 years old I started working with Jordan who was 2.5 years old, had cerebral palsy and also required AAC. Sarah and Jordan started with an 8 symbol per page layout in their symbol books. Sarah had many nursery and home activity pages, while Jordan's were people, toys, games, songs and favourite places. At this time I was very 'tuned in' to a toddlers' vocabulary and attention span! Sarah and Jordan both had/have Big Macks which were/are used for messages, repeated texts in stories, songs and games.

The next stage of development for Sarah's book was to add a row of 'grammatical' symbols above the 8 symbols to allow some simple sentence building without the need to turn pages. These included I/me, you, did/was/had (past), not, like, want, go and look/see. At the same time Sarah started to use an Alpha Talker, initially on 8 location with many different icon themes and overlays to use in different situations and for different activities and games.

As Sarah's hand control improved, she was able to use her thumb to point to smaller squares and the symbol book was developed to 16 symbols per page plus the 8 grammar symbols. Where possible two of the 8 symbol pages were combined to keep the location of symbols the same. Sarah was then also able to access the 32 location keyboard of the Alpha Talker. Initially 16 messages were stored in every other location and then the other 16 were filled in with single-hit messages, and the messages were represented by Rebus symbols. However, the aim was for Sarah to use Stepping Stones and eventually LLL, so the Rebus symbols were organised approximately following the structure of Stepping Stones. Later on the Rebus symbols were replaced one by one with the Minspeak icons and sequences were introduced.

Sarah is now working towards LLL and awaiting funding for the Pathfinder. She is continuing to develop her symbol book and every half term or more new topic charts are introduced to follow the National Curriculum class topics.

At the same time as starting to work with Jordan, the need for a structured programme of introducing low tech AAC became highlighted and so I started to work on the project.

Getting Started with a Core Low Technology AAC Vocabulary

The aim of 'Getting Started with a Core Low Technology AAC Vocabulary' is to provide a core vocabulary of approximately 1000 words and phrases in very structured, manageable amounts for introducing, teaching and learning. The very structured format of Getting Started also aims to reduce the workload of speech and language therapists, teachers, parents, carers, etc. by providing a framework on which to build a person's AAC.

The Vocabulary is set into 25 topics, three of which are simple sentence building. Each topic has a quiz to pass before moving on to the next topic.

Originally the vocabulary in each topic was aimed to be grouped in eights which can easily be presented in symbol books or broken down into fours or twos or combined. However this proved difficult with the amount of vocabulary. The vocabulary was selected from many sources including the many personalised word/symbol boards, word frequency lists, Amy's expressive language and children's 'first word books'.

Each topic has four groups of vocabulary which may be nouns, adjectives, verbs, adverbs, etc. On each page it is possible to record the date of introduction and used in context. There is

GETTING STARTED TOPICS

1. People & Interests
1a. Let's Play
2. Going Places
3. Food & Drink
3a. Going Out to Eat
4. Body & Clothes
5. Animals & Nature
6. At Home
6a In The Garden / Park
7. At School / College
7a. Story Book Words
8. More People & Interests
9a/b. Going to More Places
10a/b. More Food & Drink
11a/b. More Body, Clothes & Medical
12a/b. More Animals & Nature
13. Going Shopping
14. Going on Holiday
14a. Sports
15. Let's Chat!
16. Special Days
17. Days & Months
18. Number, Time & Money
19. Describing
20. Let's Chat Some More!
21. Not!
22. Future Questions
23. Past Questions
24. Conversations
24a. Giving Instructions
25. Go For It!!!

also space to record personalisations. The topics are interesting and motivating and the person developing their AAC can see their progression through the programme as each quiz is passed. Throughout the programme there are suggestions for applying AAC and topics 15, 20 and 25 are designed to develop symbol combination and phrase and sentence building.

There are sections of vocabulary which may not be appropriate or of personal interest to individuals and this is where the programme must be personalised. However by making the vocabulary available allows the speech and language therapist, teacher, parents, carers and user to decide whether to include it or not. As with all AAC systems and programmes personalisation is essential.

The aim of the 'Getting Started' programme is to provide an end goal of a full core low tech AAC system that the person can use flexibly in different situations to independently communicate their personal thoughts and ideas, and essentially to have the small steps of development and progress clearly stated and recorded to maintain motivation and interest from all concerned.

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PUBLICATIONS

Liberator Lesson Plans available from Liberator Ltd, Whitegates, Swinstead, Lincs NG33 4PA Tel: 01476 550391

The Core AAC Curriculum available from SCOPE, The Library, 6, Market Road, London N7 9PW Tel: 020 7619 7100

City & Guilds The Certificate in Effective AAC available from City & Guilds, 1, Giltspur Street, London EC1A 9DD Tel: 020 7294 2800

Getting Started with a Core Low Tech AAC Vocabulary available from Independent Expressions, 54 Pondcroft Road, Knebworth, Hertforshire SG3 6DE Tel/Fax: 01438 813658 Email: independent.expressions@btinternet.com

Working in Partnership - Communication Book Workshops

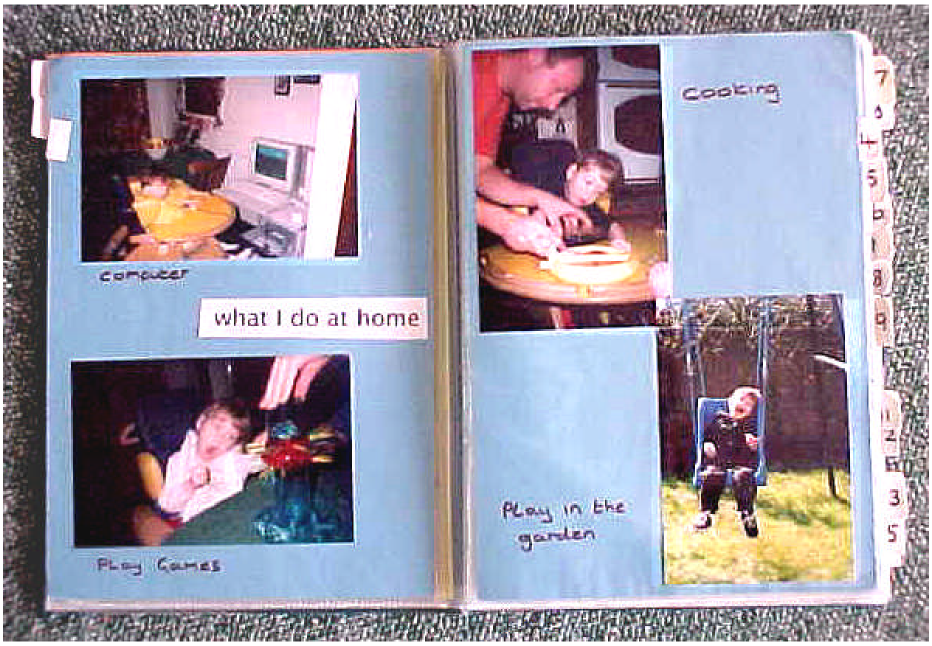
by Hannah Curry, Liz Parker & Sally Chan

This paper was presented at the CM2000 National Symposium, Lancaster University, September 2000

Introduction

At the beginning of every school year, there is always a flurry of activity, as speech and language therapists gather new photographs and symbols together in an attempt to update each child's communication/talking book. As children progress through the school, new staff photographs need to be added, and relevant topic vocabulary included.

At Claremont School in Bristol, we have a Speech and Language Therapy Department of 3 speech and language therapists, equating to 1.1 w.t.e.. There are currently 72 children within the school, which is a LEA primary school for children with physical difficulties. Historically, it has been the speech and language therapists who have taken overall responsibility for the development of communication books and other low-tech systems. The Department recognised that there was a need to work jointly with parents and the class team to develop communication books. It was also recognised that to involve parents and families, joint working needed to be nurtured, and so the communication book workshops were developed.



A Communication Book

The workshops were initially for children within the nursery department, and then extended to children in the primary and junior departments. The Paediatric Communication Aids Service (PCAS) is based at the school, and has a regional remit to assess children for AAC systems within the South-West. Hence the workshops extended to those families who had already been assessed by the Service, as well as to others in the region working or caring for children with AAC needs.

Aims

Murphy et al (1996) stated that for AAC to be maximised there needs to be more co-ordination within the team of carers, with someone adopting a clearly identified role as coordinator. The workshops aim to create such co-ordination.

The involvement of the family is crucial to implementation of any AAC system, and that involvement can be enhanced by empowering and giving responsibility to the family for developing the use of the AAC system(s). Functional communication and the use of AAC systems during the child's routine are important for effective use.

Communication/talking books are files or books of symbols arranged in categories. The children should have access to their own personalised communication book all the time, be encouraged to indicate their needs, and to express themselves, through regular use of the books. The workshop specifically focuses on the development of these books to:

- promote collaborative working
- further develop joint planning, decision-making and implementation
- share responsibility
- share ideas for implementation and use of books
- inform parents and families of other low-tech systems (e.g. Talking Mats, PECS)

The overriding aim is to nurture partnership between the school and family environments. Those who attend are encouraged to have a particular child in mind, and so the ideal scenario is when parent, teacher/LSA, and the speech and language therapist are able to attend and jointly plan the AAC system for their child.

The workshops include information on facilitating communication with the child using AAC systems. Hoge & Parette (1995) stated that "Language development in young children with disabilities is frequently an important focus of early intervention strategies used by caregivers and professionals. All adults having contact with the child are presented with opportunities to facilitate communicative development. When these facilitation strategies are used, communicative intervention is more functional, and generalization of language skills in natural settings may be achieved".

Workshop Format

1. Introduction

> "In this country we are justly proud of the freedom of speech, that we can say what we want. But I think there is a more basic right than freedom of speech and that is the freedom to speak". *Professor Stephen Hawking*

Following on from this quote, members of staff are introduced and the agenda presented.

2. Aims of communication books

Why do our non-verbal/unintelligible children need communication books?

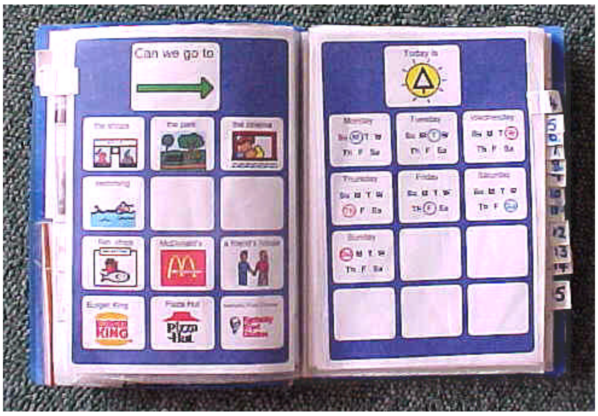
- Choice-making
- Greetings and conversation
- Sharing news
- Message-giving
- Making requests
- Interacting with less familiar people
- Expressing feelings and emotions
- Expressing likes and dislikes
- Interacting in class
- Responding to questions
- Using language for pretend play
- Teasing

Each aim is discussed and examples invited from the participants.

3. Sequence of Symbolic Representation

The choice of symbol system will depend on various factors, particularly the child's developmental level and visual skills:

- Objects
- Photographs
- Colour pictures
- Black and white line drawings
- Symbols – Bliss
  - Makaton
  - Picture Communication Symbols (PCS)
  - Picsyms/Dynasyms
  - Minspeak icons
  - Rebus
- Written word/letters/numbers



Using Symbols

4. Access

A brief description of the different means of accessing communication books is given, with an explanation of the advantages and disadvantages of each method.

This is then followed by a discussion regarding the most appropriate method for each child represented. Parents/carers are encouraged to consider the abilities of their own child with respect to the following:

- Finger/hand pointing – the accuracy, strength and consistency of movement.
- Eye-pointing – the accuracy, reliability, a communicative partner willing/able to interpret the response.
- Scanning – the child's visual skills, head control, cognitive level.
- Coded – the child's number/colour recognition, cognitive level.

Parents/carers whose children have more advanced cognitive skills need to access more vocabulary at one time. When physical difficulties prevent direct selection using finger/hand/eye-pointing, the use of a coding system is encouraged, e.g. using symbols which are colour/number/letter coded.

Then other forms of low-tech communication systems are demonstrated and discussed:

5a. Communication Boards

Examples of communication boards used in the nursery department are distributed:

- Meal-time mats
- Drinks choice boards
- Toy choice boards
- Colour-coded eye-pointing symbol boards
- Individual symbol boards

5b. Talking Mats

Talking Mats were originally developed by Joan Murphy as a low-tech framework to help people with severe communication difficulties express their views (1997). The Mats are carpet tiles (available at carpet shops and scrap-stores at a low cost) with symbols/photographs attached. We tend to use PCS symbols with Velcro (hook) attached to the back, enabling the two surfaces to stick together.

A description of the use of Talking Mats as a classroom resource, and for use at home is then given. Several parents have asked for their own Mats at home with a range of relevant symbols.

Talking Mats can be used alongside communication books and communication aids, and can be used in a variety of ways:

- Expression of feelings (emotion symbols)
- Choices (food/drink symbols)
- Sequencing (symbols depicting the daily routine)
- Making-up stories, using a limited range of symbols
- Curriculum vocabulary – numbers/letters/colours

Talking Mats are very flexible, allowing only a few symbols to be displayed at one time rather than the whole set. Symbols can be easily positioned to allow for optimum access.

During the workshop we show a video, produced by the University of Stirling illustrating the use of Talking Mats with a child with cerebral palsy, using eye-pointing as a means of access.

Talking Mats

5c. Picture Exchange Communication System

The Picture Exchange Communication System is well documented and known to be an effective communication system for many children with autistic spectrum or specific language disorders. More recently it has been used for children with other difficulties, with some success.

Janice Light's criteria for effective communication, includes the aspect of "social competence". PECS addresses this by promoting the skill of initiating interaction with others through exchange of pictures, with no direct prompting from another person. However, PECS is dependent on certain motor skills and not appropriate for those children with severe physical difficulties.

As some parents/carers on the workshop have children on the autistic spectrum, it was felt appropriate to include the system here.

6. Personal Communication Passports

> "Passports are a positive way of supporting people with sensory and communication disabilities who cannot speak for themselves, by collecting together important information about them and making this accessible to others with whom they may interact".
>
> *Sally Millar, CALL Centre (1997)*

Passports were developed by the CALL Centre, and the use of the Passports was pioneered by Sense Scotland, for children and adults attending respite and holiday placements. Personal Communication Passports are described and demonstrated during the workshop, as a means of relaying relevant information concerning the child to all carers.

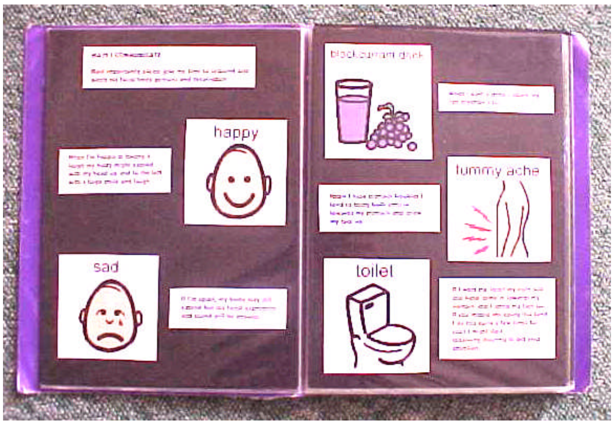
Personal Communication Passports are recognised as a valuable medium of information sharing, particularly for children and adults with severe or profound difficulties. This client group has a range of difficulties, which hinder development, communication, interaction and mobility. Their skills are often obscured by these difficulties and are only recognised by those carers with whom they are familiar. The Passport includes relevant information about the child, which enables others to gain an insight into the child's strengths and weaknesses.

Passports are particularly useful for children moving into different environments, so increasing the number of possible communicative partners.

Passports involve a tremendous amount of input and work, necessitating the involvement of a team, rather than an individual. The team may be the child's 1:1 helper and parents, or everyone working with that child.

The CALL Centre's leaflet on Personal Communication Passports (available from the CALL Centre) includes a list of possible page topics; below are just a few of those topics:

- Important people in my life
- How I work best
- Eating and drinking
- My communication system
- Things I like/dislike
- Things I can do by myself
- My sight/hearing



Personal Communication Passport

7. Paired Activity

The participants are encouraged to discuss and consider the situations in which their child would most want to communicate, and the vocabulary they would need to make five basic choices e.g. which toys to play with, which person to read the nightly story etc.

- Divide into pairs to discuss five examples of choice-making
- Feedback, what vocabulary you would need to include in the communication books
- Write up ideas on the flipchart

The pairs share their ideas, and others can select the choices they feel are the most appropriate for their child.

8. Decision-Making Time

Parents and carers continue to work together to consider various options with their own child in mind. Decisions should be reached in the following areas:

- type and size of book
- symbol system to be used
- size of symbol and number of symbols on each page
- accessing method

- how to facilitate constant availability e.g. loop to hang on chair
- introductory page
- photos to be taken and by whom
- individual roles – who does what?
- When will the book be used? Specific times to get people started.

9. Boardmaker

The Boardmaker software programme is available throughout the workshops, and participants are invited to request specific Picture Communication Symbols to be included in their child's communication books.

10. Concluding Comments

The ethos of joint responsibility and partnership is emphasised. Feedback forms are distributed for participants to complete.

Feedback Comments

The feedback questionnaires are distributed at the end of the workshop to gauge the response of the participants. Below are some of the comments relating to what the participants particularly liked about the workshop:

- "The variety of ideas and sharing of many different people's experience."
- "Practical ideas, good range of strategies."
- "not too many people – able to ask questions and share information."
- "Good use of overheads, video, actual examples of books, boards, mats etc.".
- "Lively delivery, friendly approach. Welcomed ideas and discussion."
- "Very useful to take back to colleagues."

Conclusion

The workshops have generally been well received by parents and school staff. As with any course, the enthusiasm is there initially but needs to be maintained if the course is to be productive long-term.

For the participants within our school it has highlighted the need to have regular review workshops, a chance to feedback problems and concerns, as well as successful development and implementation.

For participants from neighbouring Trusts/schools within the region, it has been an opportunity for parents and class teams, including speech and language therapists, to learn about low-tech ideas and strategies, and to jointly plan low-tech provision for their children.

In describing the workshop here, it is hoped that others may feel empowered to run similar workshops, as a means of nurturing collaborative working with parents, with the emphasis on shared responsibility.

Hannah Curry, Liz Parker & Sally Chan
Speech & Language Therapists
Paediatric Communication Aids Service, Claremont School,
Henleaze Park, Westbury on Trym, Bristol BS9 1DR

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Joan Murphy (1997) Talking Mats: A low-tech framework to help people with severe communication difficulties express their views. Produced at the University of Stirling and funded by the Gannochy Trust.

Do You Need a Small Grant?

Communication Matters welcome applications for small grants. Consideration will be given to applications for projects or activities that further the aims of Communication Matters. Examples include:

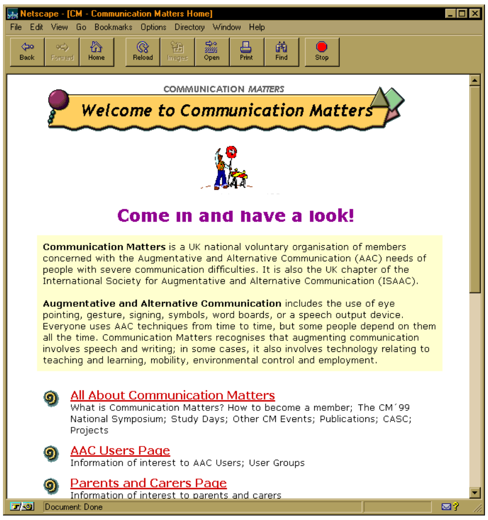
- organising or travel to an **AAC User event**
- the costs of publishing an **information leaflet**
- the costs of a **social research project**

The applications will be reviewed by the Small Grants Committee and an external reviewer in March, June and September.

For an application form, Tel: 0870 606 5463
Email: admin@communicationmatters.org.uk

Visit the Communication Matters Website

www.communicationmatters.org.uk



Come in and have a look!

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

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

All About Communication Matters
What is Communication Matters? How to become a member; The CM´99 National Symposium; Study Days; Other CM Events; Publications; CASC; Projects

AAC Users Page
Information of interest to AAC Users; User Groups

Parents and Carers Page
Information of interest to parents and carers

Parents and Enablers Page

The last parents' page was written at 11pm the night before our first *One Voice Family Weekend,* in between madly packing stuff for the eight of us to go away and collecting all the files and paperwork for the Blackpool family weekend.

That was three months ago and we are now planning the next one! It was a great success and was as every bit as good as we had hoped for. Many thanks to all the families who came to make it such a worthwhile occasion; to our group of fantastic volunteers who came with endless energy and enthusiasm; and to the five AAC users who were an inspiration to all who were there.

The biggest 'boob' on the organisation front was that half way to Blackpool I realised that I had forgotten Nadia's pole to fix on to her electric wheelchair to mount the Dynavox. This goes between home and school and is quite easy to leave behind as it is not the sort of thing you can just pack into the school bag. Anyway, I felt I had really let Nadia down so blamed my husband Andy as of course it was his fault entirely! The Dynavox then had to be balanced on her slightly cracked tray which made it not particularly accessible.

The best part of the weekend for me was seeing all the kids together in the soft play area and bumping into other mums and dads on the way round. It is only parents of disabled kids who have the joys of crawling around Whacky Warehouse or Charlie Chalk's soft play areas. Plus it was wonderful seeing the kids put on their puppet shows on the Saturday afternoon - most professional! From a personal point it was so positive to see Nadia chatting to Gerald Masterson on the Friday evening, the first time Nadia had interacted with an adult user.

Since then though we have had lots of equipment setbacks which seems to happen far too often. These all result in lots and lots of phone calls, letters of suggestion/complaint, more phone calls and plenty of stress. Nadia's file was 'corrupted' on her Dynavox over Christmas, which was two years of hard labour and was most frustrating. There was, however, a back up but it has taken nearly two months to get it all sorted out. During this time the keyguard broke (the little flimsy bit at the top had broken before and superglued together - like the wheelchair tray) so we decided to try a joystick instead as Nadia's means of access. That was OK until it broke (trodden on we think by some clumsy builder whilst doing our extension) and was sent back to SEMERC who then send it to Penny and Giles and who say it may take anything from two to six weeks to fix.

"BUT it is for my daughter's voice," I pleaded down the phone in the same frantic tone I had used five minutes previously on the phone to the wheelchair people: "BUT it is for my daughter's mobility - she cannot get around without it. It is half term and I have to carry her around the house the whole time."

Nadia and friends at the One Voice Family Weekend

Nadia's 'barbie-pink' wheelchair broke two weeks after our extension and through-floor lift had been completed to aid her independence. It also was a week after the warranty had expired and does anyone advise you a month before on strongly suggesting that it is such an important piece of equipment that you should definitely extend it? No, it is only when it breaks down and you have a £300 bill that you find out about the warranty. "Parents have enough to think about without having to remember the date the wheelchair was purchased," I said to the lady at *Whizz Kidz* who was pleading innocent. These phone calls are all made around wiping up spilt juice, splitting the kids up before they kill each other, cleaning up yet another poo the new arrival has made - oh no, not another baby but just Spike Clarke our five month old puppy - and making the tea.

Ah, and then the manual wheelchair broke on a walk two days ago about a mile from the car, down a muddy track of course. Luckily I had Jake (now 22 months) in a back pack so we wrenched him out and somehow stuffed Nadia in (now nearly 9 years) and made our way back to the car. What a motley crew - 11 children, 1 puppy, 4 adults, with one pushing a three-wheeler wheelchair and one heavily laden with large, floppy child in backpack. Somehow we managed to get to the car and drive home in time for another phone call regarding a broken piece of vital equipment.

Anyone know of a nice quiet nine-to-five office job going?

Katie Clarke
Email: andykatie@btinternet.com

Sensory Software Advertisement

COMMUNICATION *MATTERS*

CM2001 NATIONAL SYMPOSIUM

A Two and a Half Day Residential Symposium on

Augmentative and Alternative Communication

Sunday to Tuesday

16 to 18 September 2001

University of Lancaster

PROGRAMME

- *Practical Workshops*
- *Short Platform Presentations*
- *Video Presentations*
- *Case Studies*
- *Trade Exhibition*
- *Guest Speakers*
- *CyberCafe*
- *Hands-on Demonstrations*
- *Distinguished AAC User Award*

AAC users, parents and professionals from all disciplines (including education, healthcare, and engineering) will be present.

PAY EARLY FOR DISCOUNTS

CM Members Full Package Cost: including 2 nights accommodation, registration & all meals only £290 ***(£245 for early bookings)***

There are a limited number of subsidised places (£50) for AAC users, including their parent or personal assistant

For a CM2001 booking form, ring Communication Matters

0870 606 5463

Email: admin@communicationmatters.org.uk

More information on website:

www.communicationmatters.org.uk

A Unique AAC Study Day

GIVING AUGMENTED LANGUAGE TO INDIVIDUALS WITH COGNITIVE DISABILITIES

Presented by

Gail Van Tatenhove PA, MS, CCC-SLP

This Study Day is intended for teachers, SLTs, OTs, classroom assistants, parents and anyone with an interest in augmentative communication for children, young people and adults with learning disabilities.

Gail Van Tatenhove will give you lots of concrete and practical ways of using augmentative communication with people who have learning disabilities. She will make extensive use of video examples and demonstrate a variety of useful teaching/ communication material on the following topics:

- Language content and structure
- Matching communication displays and approaches to language goals
- AAC teaching approaches
- Social and community-based strategies

Now at two UK venues in 2001

Dunfermline Conference Centre, Scotland
13 September 2001

University of Lancaster, England
19 September 2001

Delegate Rate: £75 (**£65** if paying before 1 July); Parent & AAC User Rate: £50 (**£40** if paying before 1 July)

For a Registration Form or further information, please contact:

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

This AAC Study Day is organised jointly by *Communication Matters* and *Augmentative Communication in Practice: Scotland*

News from CASC

Communication Aid Suppliers Consortium

Industry News

Liberator

Liberator have announced changes effective from 1st January whereby Liberator will no longer sell new Prentke Romich equipment. Liberator will continue to be responsible for maintenance of all Prentke Romich equipment sold before 1st January 2001, and will continue to sell refurbished Prentke Romich equipment, as well as the new VOCAB+ system. Liberator's contact details remain the same. Both Liberator and Prentke Romich International (see below) will sell the Ablenet range of equipment and also the Saltillo communication aid.

Prentke Romich International

A new company called *Prentke Romich International (PRI)* has been formed to handle sales of Prentke Romich equipment. PRI will sell all new Prentke Romich equipment (e.g. Pathfinder), and will be responsible for servicing any of this equipment sold since 1st January 2001. PRI's telephone number is 01733 370470.

RSL Steeper

Following the sudden death of David Hawkins, RSL Steeper have announced a re-organisation of their Assistive Technology Division which is responsible for all of their environmental control equipment and the IconSpeak communication aid, and have appointed John Fuller as Director of this Division.

Cambridge Adaptive Communication

Following the merger of Cambridge Adaptive with Possum Controls last summer, further re-organisations have taken place. Earlier this year it was decided to consolidate all Cambridge Adaptive operations at Possum's Aylesbury premises and as a result David Mason and Ian Foulger have left by mutual consent. Cambridge Adaptive has worked hard to re-engineer the Cameleon 3 to overcome the previous technical difficulties and are now starting to ship units against their back orders. Cambridge Adaptive's new contact details are: 8 Farmborough Close, Aylesbury Vale Industrial Estate, Stocklake, Aylesbury HP20 1DQ Tel: 01296 719736 Email: info@cameleon-web.com

CASC Road Shows

We have had to cancel the week long tour in the Irish Republic and Northern Ireland planned for March in view of the on-going Foot and Mouth epidemic in the UK and consequential movement restrictions in the Irish Republic. It is hoped to re-schedule these shows for later in the year. We do not anticipate the situation will impact any of the Road Shows in Great Britain unless movement restrictions are imposed in the future.

For the remainder of this year, the Road Shows will be going to some exciting venues old and new, including: London, Newcastle, Irvine (N. Ayrshire), Perth, Edinburgh, Malton (N. Yorks), Oldham, Leamington Spa, Westerham, Stourbridge, Portsmouth, Burton-on-Trent, Mirfield (W. Yorks) and Plymouth.Details of the spring/summer shows are on page 20. Further information at www.communicationmatters.org.uk

Simon Churchill, Chair of CASC

SCOPE Speaks Out to Members of Parliament at Westminster

Scope's ***Speak for Yourself*** campaign continues to grab people's attention.

Following publication of our campaign report, *Speak for Yourself,* we are publicising our recommendations to key decision makers to ensure people without speech get the equipment and training they need.

The Scope study identified that many communication aid users are footing the bill for their equipment themselves. We found that less than half of all respondents' equipment had been paid for by statutory services. Scope has major concerns that disabled people and their families who are unable to fundraise or who cannot afford to buy the equipment are being denied their rights. As one respondent to the survey commented, "Communication is everyone's right and everyone should be able to express their opinions in whatever way possible." Thousands of disabled people are being denied that right.

Taking the Campaign to Westminster

In February we launched the campaign at the very heart of British democracy: the House of Commons. As with any campaign, we need to convince politicians and decision-makers that the needs of people without speech are not just important, but are as important if not more so, than any of the other issues Governments are asked to address. To do this we are seeking the support of MPs in Westminster, they in turn can help us convince the Government to take action.

John Humphrys, of Radio 4's Today Programme, supports Scope's 'Speak for Yourself' campaign to ensure that all people who need communication aids in order to speak, get one.

We were delighted that 52 MPs and Members of the House of Lords attended the Scope reception. We also invited around 20 communication aid users to the reception so that they could mingle with MPs and use their aids to tell them first hand why this campaign should be top on their agenda. Communication aid users gave Scope terrific support to ensure politicians left the reception well informed about the issues. We were delighted that Anthony Robertson spoke about the positive effects his aid has had on his social and family and work life.

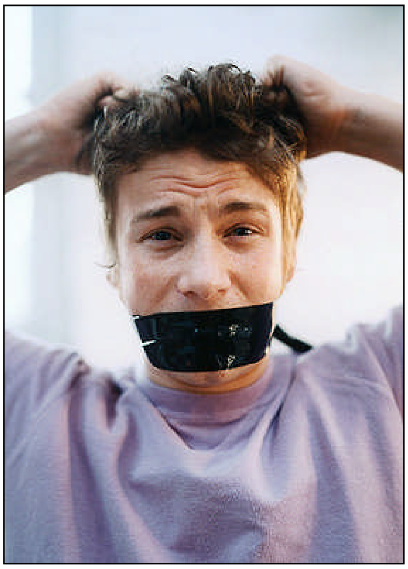
Political and Celebrity Support

Health Minister John Hutton MP, who is responsible for disability equipment, spoke at the reception and accepted that

Tony Parsons, Journalist & Broadcaster:
"Where would I be without my voice? Having a voice is essential to get on in life. The Government should ensure that anybody who needs a communication aid has access to one."
Also pictured is **Katie Caryer**:
"If you can't see properly, you get glasses, if you can't hear properly you get a hearing aid, if you can't speak, you get nothing."

the current situation is "intolerable." He went on to say that the Government would be acting on the findings of the Scope report and in an unusual move invited guests to come back in a couple of years time to hear about any progress. You will not be surprised to know that we are following up on his speech with officials at the Department of Health.

We also had celebrity support: Tom Paulin, poet and TV critic, delivered his specially commissioned poem about the communication experiences of his disabled brother. We also had support from stars like John Humphrys, Tony Parsons and TV's 'Naked Chef', Jamie Oliver. They agreed to lend their weight to the campaign by having their photos taken in a 'gagged' pose to illustrate the frustration of not being able to communicate. These pictures were enlarged and used at the reception to great effect.



Jamie Oliver, Naked Chef:
"I can't imagine not being able to speak for a day let alone months or years."

Celebrity involvement also helped us get media coverage for the campaign. The Sunday Times ran a personal story about Tom Paulin and his disabled brother's experiences. Scope's Press office also secured coverage in the Daily Express, and on regional TV. Local radio and newspapers have carried lots of stories and pictures featuring communication aid users.

Scope is pursuing the campaign with the Department of Health and we are suggesting ways of improving the service to them. We will be encouraging the Department of Health to commit some of the new resources announced in the budget to meet the needs of communication aid users. In Parliament Scope has tabled an 'early day motion' (EDM). The motion (EDM 342) calls on Government to take action in light of the report. We need your help to make this a success.

Make Communication Aids an Election Issue

As we are approaching an election most MPs will want to be seen to respond to the needs of their constituents and help deliver necessary change. If you have not already written to your MP, please do so and urge him or her to sign EDM 342. MPs can also be encouraged to write on your behalf to Ministers at the Department of Health on the issue. (All MPs can be contacted at the House of Commons, London, SW1A 0AA - you can also write to your Welsh Assembly Member or your Member of the Scottish Parliament if you have one). The more letters that are sent the greater chance we have of getting a good result. Please also write direct to John Hutton MP, Minister of State at the Department of Health, Richmond House, 79 Whitehall, London SW1. We still need to emphasise the importance of communication aids and training for those without speech. We wouldn't want politicians to forget - especially during a General Election.

Ordering the Report

Copies of Scope's *Speak for Yourself* report are available for £3.00 to individuals and communication aid users; £12.50 to professionals and organisations. Contact Tel: 020 7619 7341 Email:information@scope.org.uk.

James Ford, Campaigns Officer
Scope, 6 Market Rd, London N7 9PW
Email: james.ford@scope.org.uk

Pictures: Scope/Patrick Harrison

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

NORTHERN AAC SIG INAUGURAL MEETING

As we go to press, the Northern AAC Special Interest Group informed us that it is holding its inaugural meeting at 12pm on 29 March 2001 at Hexham Community Centre, Gilesgate, Hexham, Northumberland. It's for everyone with an interest in augmentative and alternative communication.

For further information or to be notified of future meetings, contact Liz Panton, Communicate, The Lodge, Regional Neurological Rehabilitation Centre, Hunters Road, Newcastle upon Tyne NE2 4NR Tel: 0191 219 5640 Fax: 0191 219 5647 Email: ask@communicate.totalserve.co.uk

Diary Dates

2-3 April 2001 CALL Centre, Edinburgh
Picture Exchange Communication System (PECS)
Two Day Workshop. Contact: CALL Centre 0131 651 6235

4 April 2001 ACE Centre North, Oldham
Getting Started with the IntelliTools Suite
Cost: £100 (full day) Contact: ACE North Tel: 0161 627 1358

25 April 2001 London
CASC Road Show in London
Cost: £5; Contact: Katie Price Tel: 020 7837 7618
[redacted]

27 April - 4 May 2001 Elveden Forest Center Parcs, Suffolk
Seven Day Intensive AAC Course for AAC System Users
Contact: Chatability/Independent Expressions 01438 813658

1 May 2001 Newcastle upon Tyne
CASC Road Show at The Holiday Inn
Cost: £5; Contact: Communicate Tel: 0191 219 5640
[redacted]

2 May 2001 Irvine, N. Ayrshire
CASC Road Show at Greenwood Teachers Centre
FREE; Contact: Com. Matters Tel: 0870 606 5463
[redacted]

3 May 2001 Perth
CASC Road Show at The Dewars Centre, Perth
FREE; Contact: Rhona Matthews Tel: 01738 473714
[redacted]

4 May 2001 CALL Centre, Edinburgh
CASC Road Show at CALL Centre
FREE; Contact: CALL Centre Tel: 0131 651 6235
[redacted]

12 May 2001 CALL Centre, Edinburgh
CALL Centre Family Open Saturday
(In partnership with KEYCOMM, Edinburgh)
FREE; Contact: CALL Centre Tel: 0131 651 6235

16 May 2001 ACE Centre North, Oldham
As Easy as AAC!
Cost: £100 (full day) Contact: ACE North Tel: 0161 627 1358

16 May 2001 Malton, N. Yorkshire
CASC Road Show at Cauwood Day Services
FREE; Contact: Jon Ainley Tel: 01653 696588
[redacted]

17 May 2001 Oldham
CASC Road Show at St. Anne's Rugby Club
FREE; Contact: ACE North Tel: 0161 627 1358
[redacted]

18 May 2001 Leamington Spa
CASC Road Show at Manor Hall, Leamington Spa
FREE; Contact: Helen Whittle Tel: 01926 317700
[redacted]

1-8 June 2001 Longleat Forest Center Parcs, Wilts
Seven Day Intensive AAC Course for AAC System Users
Contact: Chatability/Independent Expressions 01438 813658

4-5 June 2001 London
Picture Exchange Communication System (PECS)
Two Day Workshop. Contact: Beth Dumonteil 01273 728888

6 June 2001 ACE Centre North, Oldham
Boardmaker Basics
Cost: £50 (morning) Contact: ACE North Tel: 0161 627 1358

6 June 2001 ACE Centre North, Oldham
Advanced Boardmaker
Cost: £50 (afternoon) Contact: ACE North Tel: 0161 627 1358

6 June 2001 Westerham, Kent
CASC Road Show at Valence School
FREE; Contact: Pat Thomas Tel: 01959 562156
[redacted]

7 June 2001 ACE Centre North, Oldham
Clicker 4 Basics (Windows)
Cost: £100 (full day) Contact: ACE North Tel: 0161 627 1358

18-19 June 2001 Dublin
Picture Exchange Communication System (PECS)
Two Day Workshop. Contact: Beth Dumonteil 01273 728888

20 June 2001 ACE Centre North, Oldham
Network Day (presentations, demos, what's new)
Cost: £30 (full day) Contact: ACE North Tel: 0161 627 1358

28 June 2001 ACE Centre North, Oldham
Switched ON! Maximising Success for a Switch User
Cost: £100 (full day) Contact: ACE North Tel: 0161 627 1358

13 July 2001 Stourbridge, W. Midlands
CASC Road Show at Sunfield School
FREE; Contact: Sandra Allen Tel: 01562 882253
[redacted]

26 July 2001 Portsmouth
CASC Road Show at Futcher School
FREE; Contact: Rosie Lakin Tel: 01705 375318
[redacted]

3 August 2001 Burton-on-Trent
CASC Road Show at Bladon House School
Cost: £5; Contact: Christine Harcombe 01283 563787
[redacted]

The 'One Voice' Family Weekend

by Katie Clarke & Tamsin Crothers

The last weekend in November saw 12 families using AAC, 5 adult AAC role models and 15 volunteers meet up in the Norbreck Castle Hotel for the first *One Voice Family Weekend.*

This was a weekend that had grown from an idea spawned in the back of Katie Clarke's minibus, following the CM Symposium and much discussion about the importance of family involvement and support, and inspiring stories of group work and residential experiences. "What about if we had our own AAC residential weekend in England?" says Katie. "Yes, and wouldn't it be great to have role models so children can actually see what they're aiming for?" says Tamsin. So we looked at hotels and planned activities, and wrote letters and applications for funding. I'm sure someone said, "It'll be an awful lot of work" at one point. They were right, but has it been worth it?

The *One Voice Family Weekend* aimed to overcome the isolation that a communication disability can bring for children and their family. The weekend aimed to start up a support network for families and children, in a fun environment. We also wanted to include experienced AAC users to act as role models for the children and their family.

The weekend was advertised in the *Communication Matters Journal,* via flyers distributed at regional AAC assessment centres, and through personal and professional contacts. Application forms were sent out on a set date, and families accepted on a first come, first served basis. The age limit for children using AAC was 6-13 was to ensure that children were old enough to cope with a residential setting, and could participate independently in activities while their parents/ carers attended workshops. The upper age limit was 13 to make sure that whole group activities would be appropriate for everyone.

The Weekend

The families and volunteers (83 in total) arrived on Friday evening, and after dinner, played a 'getting to know you"' game, aiming to help everyone mix. Saturday included two parent workshops, discussing AAC at home and AAC in school, children participating in a boccia workshop, and a theatre workshop. The children put on a shadow puppet production, including the speaking children and AAC users. Saturday evening saw leisure activities (including ball pool and swimming) followed by dinner and after dinner speeches by the adult role models. The disco lasted until we all dropped!

On Sunday, the parent workshop focussed on an evaluation of the weekend, the future of *One Voice* and the part people would be willing to play in this. The children's session was an animated feedback session. Before lunch, the more stout of heart went on a trek along the sea front, and after lunch we had a whole group session to say goodbye and thank everyone for contributing so much to the weekend.

Having fun together and a chance to meet other children who share a common bond

Evaluation

All participants filled in application forms and evaluation forms, so that we could monitor the effectiveness of the weekend.

1. Children

The children at the weekend included AAC users, siblings and volunteers' children. The children's official feedback came through rating aspects of the weekend (such as food, friends, theatre, boccia, disco and the weekend as a whole) as "great", "ok" or "rubbish". Most aspects were rated as "great" or "ok", with a handful of "rubbish", that covered a range of topics. No particular area stood out.

2. Families

The most frequently mentioned reasons for wanting to attend the weekend were to have a good time, meet other families in a similar situation, for children to meet with other children using AAC, for children to use AAC socially, to share and gain information, and to meet AAC role-models.

"It felt good to know we are not alone"

The overriding feeling from the weekend was the positive experiences of meeting families who share similar

Parent Workshops: Sharing experiences and feelings

experiences (mentioned by 7 families), learning from others and sharing information, meeting AAC role models and seeing their children meet and interact with other AAC users. One family felt a residential setting was important to "...allow time to focus on AAC without distractions of homelife."

Children and Role Models chatting together

When asked, "Which was the best part of the weekend?" one family answered, "Just being here." Comments on the 'best part' of the weekend tended to focus on the support issues, motivation and overcoming the isolation a communication disability can bring to a family, "socialising with families in the same position as us, sharing advice and feelings". Others talked about their own child benefiting from being in a communicative environment. One family reported one of the best moments as being "the first time [my son] spoke to another AAC user to really have a laugh." In fact the bringing together of the *One Voice* families was an emotional experience at times.

Specific events mentioned were the theatre workshop, disco and "being in a hotel!" Parents valued their workshop time, although three families felt this time could be improved. One suggestion was to invite a guest speaker.

Most families indicated that we could not improve on the weekend. The suggestions we did have related to increasing the length (although most families felt a weekend was "just right"), centralising the venue to the middle of England, and reaching out to include children from a wider range of backgrounds (e.g. one parent families, families from ethnic minorities).

3. The Volunteers

Volunteers' reasons for attending included having fun, gaining experience, meeting people involved with AAC, and sharing ideas. The AAC users indicated a desire to meet other AAC users and offer their skills as role models.

In their evaluations, volunteers felt they had gained from the experience. One wrote they had gained "so much, I don't know where to start!" Positive feedback included meeting families, gaining insight into AAC with the family and seeing young AAC users interacting socially.

The main suggestions to improve the weekend for volunteers (and the organisers!) included delegating workshops/activities to volunteers before the weekend, assigning specific roles for people.

The Budget

We wanted the weekend to be accessible to everyone and therefore charged a nominal fee so as not to exclude anyone on financial grounds. Families who felt able, could make an additional voluntary contribution. We therefore charged £10 per child and £20 per adult. In the evaluation, families felt that this was about right. The total cost of the weekend was £8,550. The rest of the money was raised through the *Communication Matters* grant, events, donations and sponsorship.

"One Voice is a MUST" – The future

One parent summed it up, "The question isn't 'Should *One Voice* continue?' *One Voice* is a MUST". Families had many ideas as to other directions *One Voice* should take, including a more year round approach to families supporting each other, and involvement in policy, service provision and training from a parent point of view.

We'll know for next time!

Comments were positive about the fundamental ethos and layout of the weekend, and we have taken on board individual ideas to improve the weekend in the future. We will definitely keep the same basic layout of child/parent workshops, with whole group activities, and we have decided to keep the off-season weekend at the same venue, at least for the *One Voice Family Weekend 2001.*

The main thing that we will change comes from volunteer comments, and we intend to delegate jobs, which will not only decrease the workload on two people, but will also bring a wider variety of approaches to the experience.

Summary

We feel that the whole weekend was a success, achieving our aim of setting up a support network for families involved with AAC. The whole atmosphere of the weekend was warm and friendly, and the formal evaluation confirmed the general atmosphere and the value of meeting and mixing with people who have such fundamental common ground: communication. Most of the families indicated how important it was to meet others in the same situation as them, and for their children to meet other AAC using peers and the AAC role models.

Everyone indicated that there is a definite place for the *One Voice* weekend. Even more encouraging were the diverse ideas that came from the first weekend as to the other roles that *One Voice* should fulfil. We are currently in the process of applying for charitable status to stand *One Voice* in good stead to take all of these issues forward.

We are grateful to *Communication Matters* for the grant that made this weekend possible, and also for all the advice and support you offered from the hatching of the plan, to fully-fledged weekend.

Was it worth it? ***YOU BET!***

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Running AAC Groups on Themes at Primary and Secondary Level

by Alison Mackenzie & Elizabeth Holmes

This paper was presented at the CM2000 National Symposium, Lancaster University, September 2000

In this paper, we describe the approach Elizabeth and I, as speech and language assistant and therapist, have been using to work on development of AAC within Oakes Park School for children with physical disabilities in Sheffield. We are part of Sheffield Speech and Language Therapy Agency Schools team and carry responsibility for the work within this school and for assisting other SLTs in developing the work in low and high tech AAC across a range of schools in the city.

What we mean by themes

Themes are topics that can be developed over half a term or more. The topics aim to bring fun, success at communication and extra power from extended communication: ideas you may remember if you have read Crothers and John's article in CM March 2000 about their holiday groups.

For the younger children, it was agreed with the classteacher that the children would benefit from play based activities, allowing time for extra play opportunities not available for non verbal children in national curriculum lesson times or even at play times. We have used lists of word frequency and types of language use at particular ages to stimulate our imagination, whilst checking vocabulary was appropriate. For the older students, it was agreed with school that they needed work to practise communication for use at breaks, outside school and after school.

We felt that for all the adults in the pupils' environments, observing fun would motivate them to provide more repetition of the same or similar communication activities outside the groups. In running the groups, we videoed regularly so teachers, class assistants, parents and the pupils themselves could observe what was happening. Parents were encouraged to come when they could and were invited to come to an end of theme party. The senior group was set up more specifically to target the speech and language therapist skill sharing with a teacher and class assistants so sharing of planning, leading and observation was arranged.

Why we decided to work with themes

Over the years as AAC approaches have developed, different ways of supporting children with severe communication difficulties have been trialled by SLT and regularly reviewed with staff at Oakes Park School. From the speech and language therapy perspective, we were always short of time for individual work and preparation. We were very happy to run work in pairs and small groups to develop the children's communication skills and had also worked within the classroom, particularly on development of literacy hour. The difficulty had been, particularly before Elizabeth arrived, ensuring adequate preplanning. This meant liaison and information gathering taking place between SLT, home and school did not feel sufficient before, during or after a group. It also meant not enough time was allocated for our own thinking and training processes, organisation and management of preparation time. In the longer term, this was resulting in preparation of materials that were less effective in terms of cost, durability and breadth of use and limitations in the development of a progression of communication skills for the children.

AAC work within our service is still developing. Elizabeth was appointed in October 1998 to support SLTs with this. Alison, as specialist SLT in AAC and technology for assisting communication, has been providing some of Elizabeth's training and support and has needed to find ways to help her use her time efficiently.

In early 1999, we went to Crothers' and John's presentation of their work and we came away enthused with more ideas of how to support learning and carryover of AAC systems. They had worked with bigger groups of children, helped their families learn more about AAC and helped them support each other in a fun-based communication learning environment.

So…we started with a holiday group in June 1999, inviting five children and families from three different schools. Unfortunately, only two families eventually attended for the two sessions and it seemed the investment of time and planning was too great. However, in the following weeks, we realised how much we could capitalise on that preparation as we used the theme and materials in our work in two schools.

Themes used so far

Primary Group
- Percy the Parkkeeper / the park
- Getting a party ready
- Around the house
- Making friends
- Playing games

Secondary Group
- Packing to go away
- Shopping / getting a picnic ready
- Making up 'medical' stories - accidents and what to do
- Requesting and playing different types of games
- Getting the help you want in the kitchen (working with an enabler)

Developing the approach with one school

By September 1999, we decided we could offer the themed approach to Oakes Park School as a good way of planning the support for the children with high AAC needs.

Many positive steps had already been taken in school to plan for this group of children:

- The school was already committed to AAC – it has had a total communication policy for a number of years, numerous INSET sessions have covered aspects of AAC work, such as supporting literacy, and PCs with WWS2000 and Clicker are available in every classroom.
- SLT and school have looked at the SCOPE AAC Core Curriculum and produced a shortened profile for use in the primary department to use for recording and monitoring AAC progress.

Recording progress

It was our aim to record progress carefully over the year to allow monitoring of the work, both in terms of pupils' progress and the use of themes. These were our methods:

- Written record sheet of each group session, with copies to class and home.
- A recording chart was used with the senior group, so all staff present were involved in reflecting on achievement. When possible, this was completed with the students at the end of the sessions.
- Video of sessions was done about twice a half term. These were sent to teacher and home.
- IEP targets – reviewing achievement and proposing future targets – were shared half-termly in primary.
- AAC Profile charts were completed at the beginning and end of the year by SLT.
- A discussion was held with the senior teacher involved, noting her views.
- A parental feedback questionnaire was sent out at the end of the year.

As well as these ways of monitoring the themes, we also kept a tick-list of frequency of occurrence of vocabulary in materials for each session, so that we could keep a check on what had been covered and what might need repetition.

What we have learned so far...

The Students

- ♦ are more confident in their use of syllabic vocalisation for greetings and reading symbols.
- ♦ are more spontaneously requesting and using their communication books and some signing.
- ♦ are more enthusiastic about using their communication aids in structured play/role play activities.
- ♦ There is more spontaneous use of non-verbal communication skills between the students and between students and adults.
- ♦ Increased expressivity from the students is guiding us in ways to evolve their communication books and overlays.

The Parents

- ♦ were supportive of the total communication approach.
- ♦ enjoyed the opportunity to attend, join in groups and/or see them on video.
- ♦ have so far responded positively to the questionnaire.

The Teachers

- ♦ The senior teacher found our recording system too detailed and complex for carryover into her own monitoring system. She felt this would be the same for any senior teacher. She was happy to take over use of a theme but simplifying it to a level of preparation she felt able to carry out.
- ♦ The primary teacher integrates details from our session notes and the AAC Profile into her own notes and planning.

SLT and SLT Assistant

- ♦ Improved consistency and progression within low and high tech materials.
- ♦ More joint working between SLT and assistant, enabling transfer of skills for use in other settings.
- ♦ Better continuity for the students in case of SLT staff absences.
- ♦ Better time management in SLT, as more materials are ready in advance, leaving time for preparation in other areas to be done from week to week.
- ♦ Prepared materials and approach able to be used across other settings in Sheffield for extension of AAC with support from the specialist SLT and SLT assistant.
- ♦ An enjoyable form of SLT delivery, which we feel, motivates the students and us.

What now?

We feel we still need to:

- Negotiate clearer understanding with school that it is a good use of our time to prepare a themed course, then deliver it.
- Continue joint working with school staff, running groups together to build communication awareness and transfer of skills.
- Continue discussion with school to devise a recording system that meets school and SLT criteria.
- Gather more information from parents for devising themes and extending carryover outside school.
- Find time to organise groups of AAC users together from several schools.
- Discuss holding more AAC Resources for the city centrally so all SLTs have access to running groups with themed materials and training others to do so.

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Keystage 1 wordlist for Literacy hour.

Case Study:

The Use of AAC to Promote Inclusion in a Secondary School

by Rosalind Bleach

This paper was presented at the CM2000 National Symposium, Lancaster University, September 2000

This study was funded by Oxfordshire County Council as part of its Special Educational Needs Standards Fund Inclusion Project. Professionals working with the special needs client group in educational settings were invited to undertake ‘action research’ studies in order to investigate best practice in promoting inclusion.

Our chosen project was to look into the effects of AAC, over a 7-month period, in developing social interaction between a secondary school pupil and his speaking peers, and also in his participation in targeted classes. We felt that by looking in detail at a particular pupil we would gain understanding that could be applied to other communication aid users in the future. The study gave mixed results as regards inclusion in class but suggested some clear benefits in the use of speech output aids in increasing social communication with the peer group.

Participants

The setting for the study was a Special Needs Base on the site of a mainstream secondary school in Oxfordshire. Pupils at the base integrate with the mainstream school at a level appropriate to their individual needs and abilities. The subject of our study (DT) was a 12year old lad with a degenerative neurological condition who entered the Base from a mainstream primary school in September 1999. He is a wheelchair user, and has significant learning difficulties, though his literacy skills are good. At the start of the study hand function was affected but was sufficient to allow direct access to both low- and high-tech AAC. Speech was his preferred mode of communication but intelligibility was impaired such that only single words and familiar phrases within a known context could be understood by those who did not know him well. He had a communication file but had not, up to this point, been willing to use it with his peers.

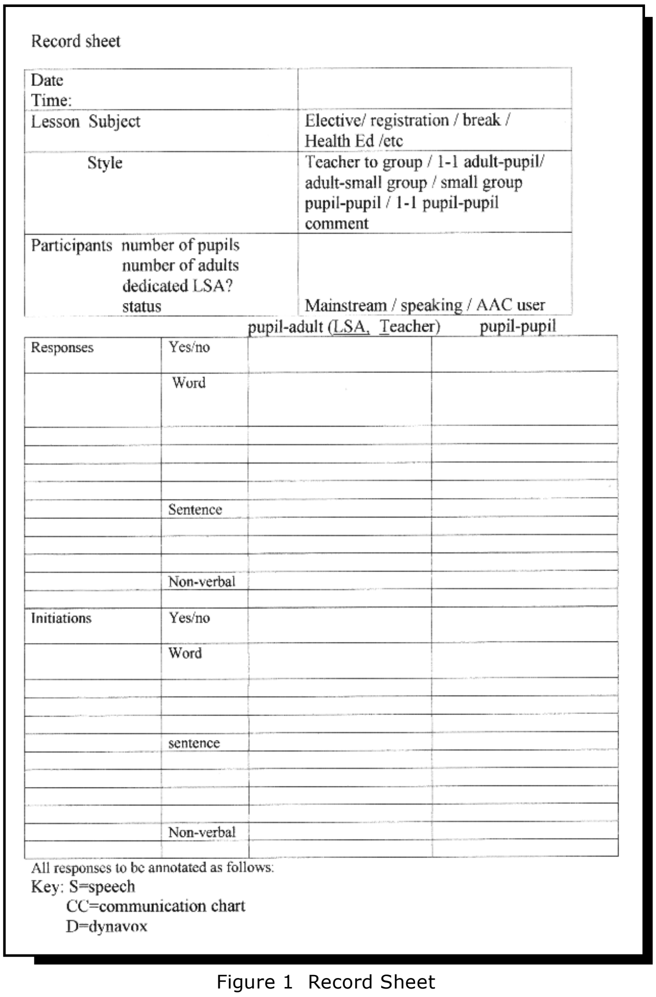
The Team

The project was lead by the SLT. It was planned in consultation with DT’s teacher and with the head teacher of the special needs unit. DT’s LSA was an integral part of the action research team.

Methods Used

Using a specifically designed Record Sheet (Figure 1) DT’s verbal interaction with teachers and peers was time sampled shortly after his arrival. A symbol/word chart (produced on BoardMaker) was introduced in early November. A VOCA (a Dynavox original, available within the unit as an assessment device) was introduced in late November. DT’s use of these was supported in a variety of non-clinical contexts. We continued to sample his verbal interaction at regular intervals over the period of the study.

Questionnaires were also used early in the project and again at the end to investigate attitudes his communication.



Record sheet

Date Time:	
Lesson Subject	Elective/ registration / break / Health Ed /etc
Style	Teacher to group / 1-1 adult-pupil/ adult-small group / small group pupil-pupil / 1-1 pupil-pupil comment
Participants number of pupils number of adults dedicated LSA? status	Mainstream / speaking / AAC user

		pupil-adult (LSA, Teacher)	pupil-pupil
Responses	Yes/no		
	Word		
	Sentence		
	Non-verbal		
Initiations	Yes/no		
	Word		
	sentence		
	Non-verbal		

All responses to be annotated as follows:

Key: S=speech
CC=communication chart
D=dynavox

Figure 1 Record Sheet

1. Observation, Recording and Support

The SLT on the team supported DT on a weekly basis in three main contexts:

- Registration / PSD with DT’s tutor group
- Class sessions both in the base and in mainstream
- Break-time at the base

Once a month the therapist’s role during each of these sessions was simply to observe DT, note his verbal output on the Record Sheet for a timed 20 minute period and take note of his communication needs.

During the remaining sessions she took a supportive part in facilitating interaction between DT, the class teacher and his peers, acting on information gained through observation. This was achieved in a number of ways during registration and class sessions:

- Direct work with the whole class, demonstrating (with DT's participation) the vocabulary available on his communication aids and inviting ideas for updating it.
- Alerting the teacher to opportunities for DT to communicate.
- Making informal contact with class members to encourage their involvement
- Alerting DT directly to communication opportunities and (where appropriate) helping him maximise use of his aids.

The SLT's role at break-time was to ensure the Dynavox was available and to alert DT and his peers to opportunities for interaction.

2. Questionnaires

These were given at the beginning and end of the project to 5 mainstream and Base staff, 15 mainstream pupils and to DT himself, to gain their views about achieving effective communication with him. Each of these client groups was given a specifically designed questionnaire. Questions to DT were administered in the form of an interview, using a series of communication mats so that he was able to take a more assertive role in giving his views and feelings. During the first interview he expressed a clear view that a 'computer' would help him talk. This, and other views proved very helpful when planning the introduction of his AAC.

3. Liaison and Training

Information gained in the above ways was shared with other support staff, who also added their own ideas and information. In particular regular dialogue was kept with DT's key LSA who took over programming of the device half way through the project having been trained along with his Base class teacher.

4. Vocabulary Development

DT's symbol chart and Dynavox were programmed in response to all information gained. The Dynavox vocabulary was developed gradually over the period and introduced to DT in individual therapy sessions in which he also made his own vocabulary requests. Particularly popular with DT and his friends were interactive jokes!

5. Video

A video was made of DT interacting with peers at break and registration.

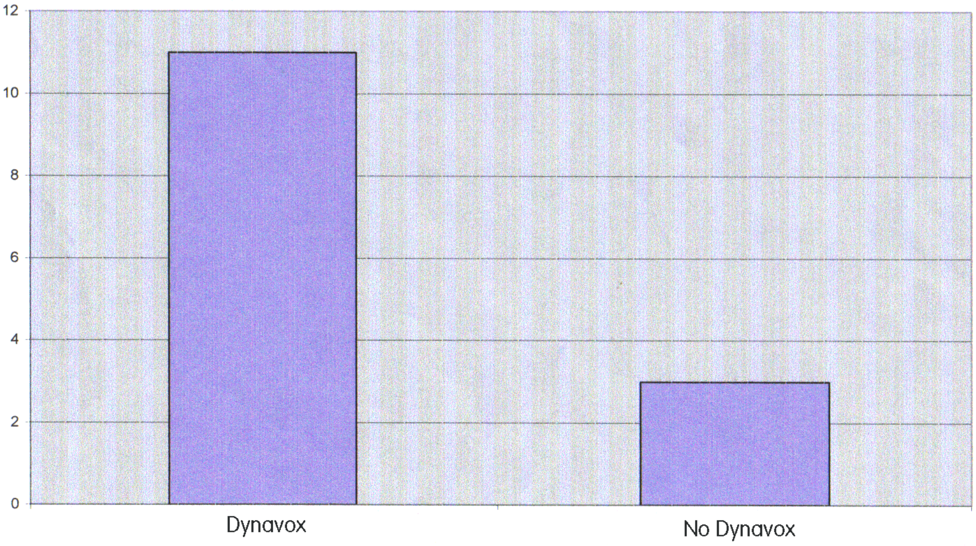


Figure 2 Initiated utterances, pupil to pupil, with and without Dynavox. Average per 20 minute period, break-time. April/May

Summary of Outcomes

1. Record of verbal Interaction

DT's verbal output was recorded under four headings:

- Communication *in response to staff*
- Communication *initiated by DT with staff*
- Communication *in response to other pupil*
- Communication *initiated by DT to other pupil*

It was also noted whether speech, the chart or the Dynavox were used for each utterance.

The number of utterances under each heading was counted for each targeted context and the results put on a graph to show changes over time (*yes* and *no* responses were not counted).

No consistent pattern of change was evident for the registration or class sessions, although there were some instances of valuable participation. Here there were a very large number of variables as to the style of teaching, (e.g. whole class or group-work), the subject matter, etc., and these affected DT's responses. The contexts in which the Dynavox was least effective were tightly structured classes where specific key-word responses were needed. Here speech or written words were the preferable medium. The Dynavox's efficacy was greatest in very small group classes where the response requirement was flexible. In large, whole class contexts self-consciousness often restricted DT's use of the device, (a problem that may well reduce with time).

A clear pattern did emerge for the break-time sessions (figure 2). Here there was a definite *increase* over time in the amount of initiated communication with other pupils. As it seemed possible that this effect was due more to increasing familiarity and friendship with his peers than to the Dynavox, we double-checked this by recording DT's verbal output again in social settings *without* making the Dynavox available. The result was a considerable drop in pupil to pupil interaction (figure 3). Analysis also showed that when the Dynavox *was* available DT's speech output increased as well. The aid appeared to have generally enabling effect on social 'chat' and to allow him to take a more active, rather than simply responsive, part in it.

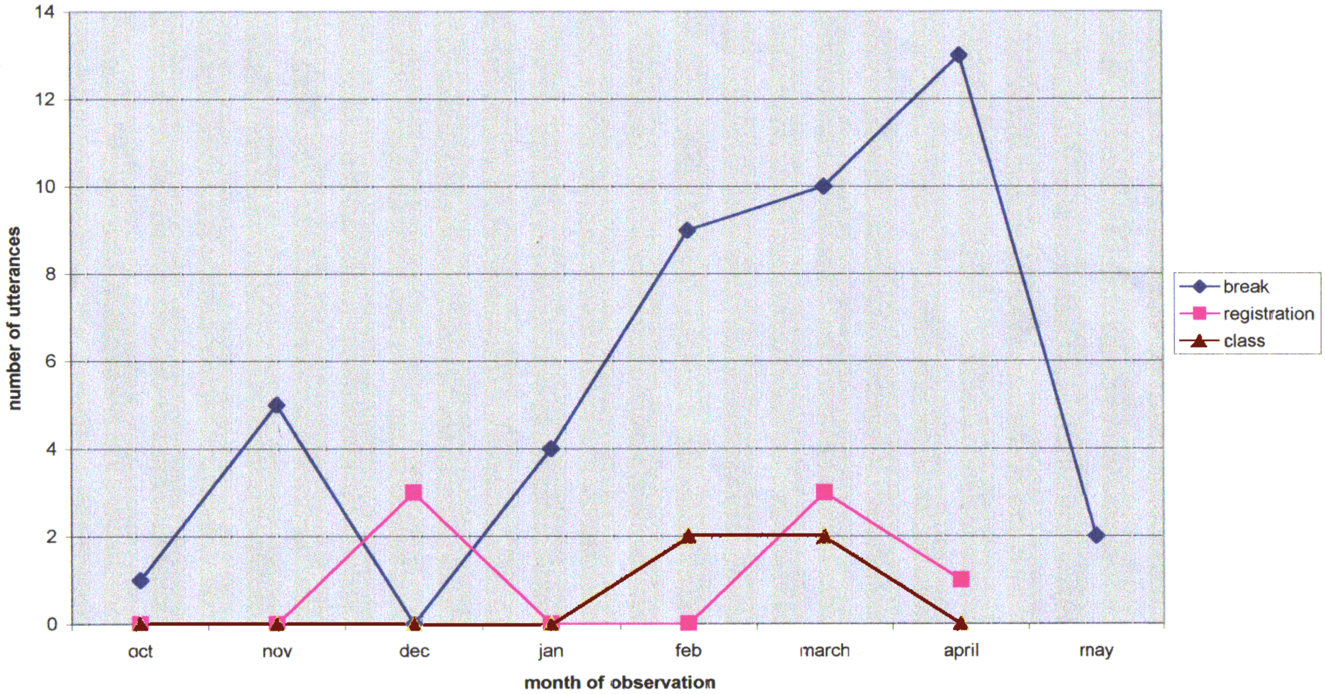


Figure 3 Initiated utterances, pupil to pupil

2. Questionnaires (End of Period)

Mainstream Pupils

Unfortunately, through a mis-understanding, only the 4 pupils with the clearest interest in DT were given the questionnaire again at the end of the period. Of the 4 who responded the second time all said that *talking to him* was now *easier* and that *getting to know him more*, his *chart*, his *Dynavox* and his *'helpers'* had all contributed to this.

Staff

Four of the five staff felt that both the chart and the Dynavox had helped DT's communication. The 2 mainstream staff also cited support staff's explanations and initiations as helpful as was also the other pupil's interest.

DT

DT continued to feel *sad* at not being understood and being unable to say everything he wanted. When asked (given open alternatives) what helped him say various types of utterances (ask questions, tell news etc) he chose *Dynavox* for everything except *'being rude'*, which he felt *talking* did better!

3. Liaison, Training and Vocabulary Development

The liaison and skill sharing with DT's key LSA was crucial in maximising understanding of D's communication needs and wishes and ensuring that the Dynavox vocabulary was kept up to date with these. This, in turn fired DT's enthusiasm to develop his skills and use them for genuine communication.

Conclusions

This proved a very useful study. DT made some real gains, particularly in the area of initiated social interaction with his peers. The speech output device helped to promote this. Another interesting finding was that the availability of the VOCA tended to increase, rather than impede, DT's use of speech. Much was learned can help us further develop his skills and also could be applied to a comparable pupil. Key factors were:

- A mix of observation and facilitation. Detailed observation and coded sampling of his utterances provided very useful data from which to plan intervention as DT's skills and needs developed.
- Direct SLT involvement in social and class contexts and with mainstream peers and staff. This raised DT's profile within the classes and was cited (unprompted) as helpful by both staff and other pupils.
- A sensitive response to requirements for communication in differing class contexts. Observation demonstrated that in some contexts use of a VOCA inhibited rather than promoted participation.
- Sharing programming and vocabulary development with a skilled support assistant. The high skill level of DT's LSA allowed dynamic carry over of the communication programme and ensured the vocabulary was always up to date and motivating to the user.

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Views of Young Adults at the Time of Transition

by Lois Cameron & Joan Murphy

This paper was presented at the CM2000 National Symposium, Lancaster University, September 2000

Background

> *"Young people often do not feel involved and informed in making choices"*
>
> *"Young people with severe learning disability need planning for what happens when they leave college"*
>
> *"Young people with communication difficulties have no independent voice in transition planning"*

These comments from the Young Adults Transition Project – (Optimum Health Services NHS Trust 1999) highlight that the time of transition for young people with a learning disability is particularly difficult. Moreover those young people who have an additional communication difficulty have a double burden in making their views and choices known. Their problems are compounded by the lack of appropriate interviewing tools and there is a very real risk of social exclusion. This is illustrated by the Beattie Report which states that, *"young people with learning disability are at risk of social exclusion and difficult transition on leaving school and during subsequent transitions"*.

This paper describes part of a research project funded by the Viscount Nuffield Auxiliary Fund which aimed to:

1. Identify the range of issues which are important to young people with a learning disability at the time of transition.
2. Identify the prerequisites needed to use the *Talking Mats* framework.

Talking Mats (Murphy 1998) is a pictorial[1] framework which was developed by Joan Murphy and has been used successfully with other client groups.

In this project the researchers used a three point scale to allow participants to express their views about six main issues, each one containing a range of factors. The issues were defined firstly by reviewing literature relating to transition for young people with a learning disability. Following this, discussions and workshops were held with Speech and Language Therapy staff, Further Education and Social Services staff.

A pilot study was carried out and the framework was adapted during the project in consultation with the participants.

The issues which formed the basis of the interview were:

- Accommodation
- Day activity-work/education
- Leisure- indoor interests
- Leisure -outdoor interests
- People
- Transport

Participants

Once ethical permission was obtained a considerable effort was spent in obtaining informed consent from the young people who were invited to take part in the project. Of the 17 who were approached, following discussion with their speech and language therapists, 12 agreed to be involved. Their ages ranged from 18 - 23 years and 9 were male and 3 female. All were in the process of transition either from school, college or day centre.

Aetiology	
5	Cerebral Palsy
2	Downs Syndrome
1	Autism
1	Foetal alcohol syndrome
1	Hydrocephalus
2	no known aetiology

Table 1 Aetiology

Table 1 shows the aetiology of the participants' disabilities. In addition, five of the participants had significant challenging behaviour.

Comprehension
2 - single key words + context
5 - 2 - 3 key words
2 - specific processing and sequencing difficulties
3 - mild difficulties
Expression
6 - speech
5 - low tech AAC
2 - high tech
4 - signing
(some used more than one method of expressive language)

Table 2 Communication Skills

Table 2 shows the communication skills of the participants.

Methods

Each participant was interviewed using the *Talking Mats* to allow them to build up a picture of their likes and dislikes relating to each issue presented. Each interview was video recorded and a digital camera was used to take a picture of each completed mat. Care was taken to obtain confirmation that the participant was sure that each 'mat' was a true picture of their views. A follow up visit was made to each participant to check they were still in broad agreement with their choices and to give them their own copy of their 'mats'.

The video recordings were analysed by three researchers to ascertain inter - judge reliability and to determine the prerequisites required in order to be able to use the 'mats' reliably and to determine the significant factors within each issue.

Results

All 12 were able to use *Talking Mats* to some extent to express choice and 10 completed all 6 'mats'. The two participants with the most severe difficulties were presented with the two most concrete issues only – indoor and outdoor interests.

The following 'mats' show the views expressed by two of the young people involved in this study.

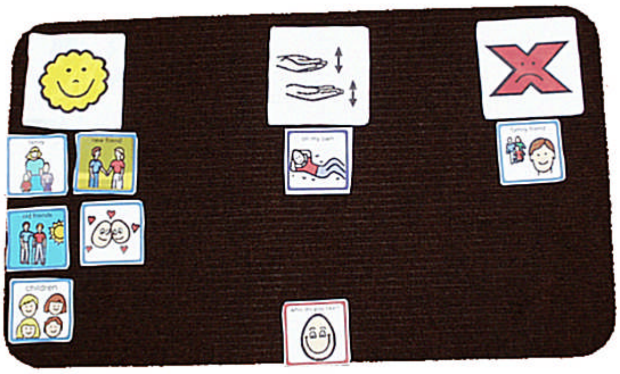

Figure 1 People

The above 'mat' shows what a young woman in the study feels about the people in her life. She is happy about spending time with her family, her old friends from school and her new friends at college, her young nieces and nephews and her boyfriend. She is unsure about spending time on her own and she is clear that she does not want to spend time with her parents' friends.

Figure 2 Leisure

The 'mat' in Figure 2 combines a young man's views about outdoor and indoor leisure interests – (he did not use the mid point). It shows that there are lots of activities he would like to do but the five things he does not like are – looking at newspapers, snooker, housework, watching TV and watching football. This 'mat' was particularly pertinent as the young man had significant challenging behaviour which staff attributed to him being bored and the main activities offered to him were snooker and watching TV!

Prerequisites

The prerequisites required in order to be able to use the *Talking Mats* successfully were split into physical and cognitive skills.

The physical skills required are enough vision to be able to see the picture symbols and some pointing method to indicate placement of the picture symbols on the 'mat' whether it be by hand or eye. The cognitive skills identified are the ability to make use of the combination of visual, verbal and tactile signifiers and the ability to indicate reliable Yes/No confirmation using any method.

Discussion

From studying the videos, we feel that in order to overcome the occasions where ambiguity occurs, the use of *sub-mats* to explore the question in more detail is advisable. For example, one participant placed *library* at the negative end of the mat which surprised his carer, as she thought he liked going to the library. By presenting him with a sub-mat of books, story tapes and videos the researchers established that it was books he did not like, but that he did enjoy going to get story tapes and videos.

We were surprised at how little the participants were distracted. Despite the interview lasting between 45 minutes and one hour and even when interrupted, we had no difficulty in bringing people back to the task. In fact many expressed how much they enjoyed it and some were keen to carry on for longer. Possible reasons for this are that it is not perceived as a test but more of a conversation; the participants seemed to be aware that they had ownership of the interview, and that it moved at their speed and that it was their views that were being expressed. The structure of the interview where participants could select or ignore pictures as they wished and the feeling that there were no right or wrong answers overcame the problem of acquiescence which is often a problem when interviewing people with learning disability.

The number of factors selected by participants as indoor and outdoor interests made us question why many young people with learning disability are classified as being bored. It appears that there are many activities they want to be involved in - none of them unreasonable, costly or impractical.

Uses

There a number of uses for the *Talking Mats* with young people with a learning disability such as involving them in developing Life plans, allowing them to be involved in service development, exploring differences of opinion, exploring sensitive issues.

Future

The authors are planning to offer training in the use of the *Talking Mats* with people with a learning disability and are applying for funding for further research in this area.

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[1] The Picture Communication Symbols (PCS) are ©1981-2000 Mayer Johnson Co. and are used with permission - Mayer-Johnson Co., P.O. Box 1579, Solana Beach, CA 92075, USA.

A Personal Perspective: Employment Using Alternative and Augmentative Communication Systems

by Anthony Robertson

This paper was presented at the CM2000 National Symposium, Lancaster University, September 2000

In the UK, a person using alternative and augmentative communication (AAC) has many fences to climb over to become employed. Few colleges prepare students for employment. Users and their families have to find their own way forward. Those reaching the stage of employment face another challenge. Their salary must offset their loss in benefit.

This paper covers the following points and considers them from the perspective of both the user and the employer:

1. **Preparing Students**
   Should colleges and training establishments prepare their students for independent living and life in employment if this is a realistic goal for that person?
2. **Competent Facilitator**
   Does having a competent facilitator enhance the chance of a person using alternative and augmentative communication towards gaining employment?
3. **Effective Facilitation**
   When is a facilitator necessary to participate fully in work situations and to keep within acceptable time frames for completing work?
4. **Accessible Employment**
   What types of employment are accessible to people using Alternative and Augmentative Communication?
5. **Working Environment**
   What happens when access to a building is a problem? Is working from home the solution?
6. **Financial Challenges**
   It can be a challenge to balance the loss of benefits against the pay of a first job in employment, as many people would start on a lower sum than they previously received in benefits. Should a gradual reduction in benefits be introduced?

I have been working in the field of Alternative and Augmentative Communication for six years, gaining experience as an advisor and consultant. Having Cerebral Palsy, I use a variety of Alternative and Augmentative Communication methods including non-verbal communication, a Bliss-symbol board, a word board, and a head-pointing Liberator.

1 have presented at many conferences, including Communication Matters, Minspeak USA, Minspeak UK, Pittsburgh Employment Conference and ISAAC. In my role as Ambassador Co-ordinator with Liberator, I train other Alternative and Augmentative Communication users to give talks and demonstrations. As User Group Co-ordinator I plan and run most of the seven groups around the United Kingdom which support all people using Alternative and Augmentative Communication. I regularly visit people at home, in school and other institutions to give support and training, demonstrate Alternative and Augmentative Communication, and give advice where appropriate.

I now have my own Alternative and Augmentative Communication Consultancy business. Through my own work and life experiences, and through meeting many other people, I have gained a wide knowledge base of Alternative and Augmentative Communication issues. This professional knowledge combined with my personal perspective of Alternative and Augmentative Communication provides me with a fairly unique viewpoint of employment issues.

1. Preparing Students

In the United Kingdom specialist schools and colleges often make people see through a very narrow perspective and a limited viewpoint. This can leave students with the view that their only options are living in a residential home or moving back in with their parents, as living a more independent life is for more able-bodied people. It is frequently not presented as a viable option and is portrayed as an unrealistic goal. People using Alternative and Augmentative Communication who say that they want to live independently face a mountain of opposition.

This is probably because staff are unaware of current Alternative and Augmentative Communication issues and what is going on outside the residential home setting. With staffing problems and shortages it is commonplace that they just don't have the time to help the person follow through their goals. As long as a person's care needs are being met there is often someone else who needs staff time first. However, I feel that this isn't good enough now we are moving into the twenty-first century. It is better in the long run for all concerned to help and support a person towards independent living; even if their ultimate goal is not to become employed, at least they can live how they want.

2. Competent Facilitator

Having a good facilitator when you are trying to find your first place of employment is very important, I believe, to give a springboard for the person using Alternative and Augmentative Communication so that they can show their full potential. It is vital to demonstrate that you are in control of your needs, you can manage your time, and can cope with any tasks required of you. More able-bodied people using AAC may require only their communication aid to meet the demands of their job.

3. Effective Facilitation

When planning to work, or even after finding work, I think that it is important to be real with yourself with regards your disability. Sometimes you may be able to do a task but may need a facilitator to do it so that you can complete your jobs within an acceptable time frame.

People who use facilitators need to be able to manage them effectively. They must be aware of the needs of the facilitator as well as their own ideas. Sometimes it is hard to balance what is the role of the facilitator and what is your role. You need to be aware of what is an appropriate salary, and how to be clear about working hours, holidays, and what is expected of the facilitator.

4. Accessible Employment

There are certain jobs which I believe are more accessible to Alternative and Augmentative Communication users. For example, office jobs such as answering the telephone, typing, and computing tasks.

If the user is more able-bodied, it opens up more doors of opportunity such as shops and garden centres.

If a user has further education and relevant qualifications and is able to communicate fluently it opens up more doors.

The Ambassador Programme which I run for Liberator Ltd gives people 'work experience' and practice in giving talks and presentations. These are skills that will be very useful in later employment.

5. Working Environment

In the United Kingdom, and as far as I believe in the United States, making buildings accessible can be funded in most situations. In the United Kingdom 'Access to Work' will put in ramps and equipment required. However, with computers, e-mail, and telecommunications working from home is thought to be a good solution because you have all your own facilities 'on tap'.

I believe that to work from home is a lot to ask, for someone just starting in the employment sector. One reason is that you need to be very disciplined to know when to clock on and off. You can invariably find yourself working very little or too much without realising you are doing it. Also, when you are working from home you lose the friendships and social life that working in an office setting brings.

It is also much harder to get help and support from colleagues and managers when you are not in the building with them. Being in different buildings creates a big gap between you and your manager. My first office was in my bedroom at my flat. This was a crazy situation that needed to be rectified.

6. Financial Challenges

The financial challenges of working can be broken down into four points:

a. Being realistic about how much a job should pay you.
b. A job should pay you enough to match your benefits.
c. There should be a scaled reduction in benefits.
d. Do not upset your care funding.

If you went for a cleaners job, you should expect to get a cleaners salary. If you went for a secretarial role you will be paid more, according to the value of the job. This is an important point to remember. A job has a value in the workplace and this is not determined by anyone's personal financial needs, whoever they are.

Does a job pay enough to match the loss in benefits incurred? This is probably a deciding factor for anyone who uses Alternative and Augmentative Communication and is trying to decide whether to work. If they are losing money, or just getting the same amount as on benefit, many might argue against working. I believe that this is creating a culture where disabled people (including those who are using Alternative and Augmentative Communication) feel that they are better off on benefits. The pay they get from a job must therefore at least match their benefits so that there is some incentive to go out and gain employment.

I believe that the proposals that have been tabled here in the United Kingdom to enable benefits to be reduced in line with pay will be a must for the future in order to get Alternative and Augmentative Communication users out into employment. A scaled reduction would remove a lot of the financial challenges of starting employment.

There is a huge gap between having funded care and being paid enough to be able to afford to privately buy in care. It is sometimes difficult to enter paid employment and still be entitled to funded care. Funded care can be sharply reduced when a certain pay threshold is reached.

Conclusion

I have tried to outline the most important aspects of this big topic area. I believe that anything is possible if the will is there from both the Alternative and Augmentative Communication user and the employer.

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Useful Tips for Taking AAC Overseas

by Caroline Gray

I have been very fortunate in having been invited to visit a number of countries that are either 'emerging' in the United Nations definition, or where AAC is a new concept. I have met some wonderful children and very dedicated staff in countries as widely spaced as India, Poland, Greece, Romania and the Czech Republic. It was while I was sitting being eaten alive by a particularly virulent species of mosquito with Tricia Churchill in Romania last summer that the idea of a checklist came to mind.

There are one or two considerations to take into account before planning in great detail, booking tickets and packing your bags:

1. If you know you are going to be travelling some time in the future and feel moved to combine work with pleasure, then e-mail ISAAC on secretariat@isaac-online.org and get a brief mention in the Countries with Emerging AAC page of the ISAAC Bulletin. Give details of:
   - who you are
   - what AAC experience you have
   - where you plan to be when
   - an address for people to contact you before you leave the UK

   This gives people an opportunity to make contact with you. If you get more than one response, give the contacts each other's names. By putting interested parties in touch with each other, you are sowing the seeds of a self-help group that will outlive your visit and encourage on-going support. Sometimes those who contact you live far apart and so are going to find it difficult to meet up and share ideas and experience. But even so, the seeds of a support group are established.
2. If you are invited to visit a country as the guest of an organisation, find out as much as you can about the organisation and what they expect from you. Is the organisation bona fide and will it continue into the future? What are its aims? Who do they work with?
3. Ask for details about the people you are going to work with. Video is the ideal medium as it will give you a good idea about conditions generally. However, video is not always possible, in which ask for case notes on the people you are likely to be asked to work with. You may find yourself confronted with novel (to you) medical terminology and professional titles.
4. Allow at least four months from the original invitation to departure, more if possible. This gives you time to gather information. While e-mail is increasingly used, some places still depend on the postal service and this adds considerably to planning. If neither e-mail nor fax is available then allow a minimum of six months. Be aware that phone lines are not always reliable in remoter parts, and take time differences into account when faxing (some people switch off their fax machines at night).
5. If you want to know what diseases you might be in danger of contracting, phone *Masta* on 0891 224100. They will take you through a phone questionnaire (press '1' if you are staying in a city, '2' in rural areas, '3' if camping, etc.) and send you printed advice that you can then take to your GP. I have used this service a number of times - one pays for the cost of the call (and it is at those premium rates). On top of that, there will be the cost of the injections from your GP. Some courses of injections need to be started anything up to six months before you leave the UK.
6. Protocol. It is worth looking through the *Rough Guide* book on the country you are planning to visit in order to get some idea about cultural differences. For example, it might matter which hand you use for certain activities, or touching a head might be considered very rude, as might where you point your feet. You might not have ever thought of some of the accepted ways of doing things. A few minutes in a book shop or library can save some considerable embarrassment to both you and your hosts. It is a good idea to take some gifts. Here, advice from someone who knows the country would be the best guide.

Materials that could be useful and will take time to gather together

- *Ann Warrick's* book 'Communication Without Speech' available from Communication Matters or ISAAC.
- *ISAAC video* – In Other Words. Available from the ACE Centre, Oxford. Tel 01865 759800 or ISAAC.
- *Booklets produced by the Spastics Society of Eastern India.* These are a great set of books, comprising of the following titles (each one is written in clear English and accompanied by simple line drawings): *You and your baby; Toileting; Dressing; Physical Management for the cerebral palsied child; Cleanliness; Special furniture; Epilepsy.*
- *Low tech communication charts and books.* Take a range of these, and remember that access to symbols will be an issue - different vocabulary is needed for different religions, food, clothing, etc. Choose books that use different methods of access - direct access, colour encoding, auditory scanning, etc. Take a letter board.
- *For AAC workshops.* Take scissors, A4 and A3 paper, coloured pens and black felt tips, pencils, Blu tack, velcro, plastic wallets for putting charts into, a few small toys (beanbag babies; toy cars; face paints; simple picture books, text free if possible), a Big Mack, a switch and a battery-operated toy (remember batteries can be expensive to those you are working with), name badges.

Tips when running a workshop or assessing children

- If working with an interpreter, and you ask them to ask the child, make sure that they do. What often happens is someone else answers on behalf of the child. It is important to demonstrate that the child has something positive to contribute.

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- Before you do anything, explain what you are going to do and why, do it, then explain again.

Useful items for yourself

- **String** – for hanging washing, tying up posters that you can then hang off something, etc.
- **Wipes** – I have known the water to be cut off, and although I hate using wipes in the UK, they can be very welcome in extremis.
- **Water bottle** e.g. Evian, it won't last long once you arrive but can be filled up with boiled water if need be. When buying mineral water abroad, check that the seal is unbroken.
- **A plastic cup** is surprisingly useful.
- **A small back pack** is very helpful for carrying things around.
- **International power plugs** so that you can run a computer, if you take one, off the local electrical grid. Also on the electrical front **a four-way switch adapter** and some **fuses**.
- **A small torch** can come in very useful in the dark.
- **Loo roll** and **towel.**
- **Bug repellent**, spray, coils or tablets for a device you plug into the mains. Or better still all of them.
- **Basic medicine kit** – plasters, aspirin if you use them; if you are in a country where AIDS is prevalent and you are not sure how near you are likely to be to a good hospital then you can take sterilised injection kits, etc. from Boots. Immodium or equivalent for upset stomachs is a good idea, you are likely to have a change of diet.
- **Cosmetics** such as soap, shampoo, Tampons, sun cream are often expensive.
- **Things for cameras** – you can guarantee that your battery will run out if you have one of those classy automatic loading, automatic zoom, etc. Similarly you never take enough film.
- **Trainers** for walking.
- **A paperback book** for long journeys.

When you leave, it is sometimes helpful if you and your hosts can draw up an action plan of what might be helpful things to try with any children you have worked with and for those who are keen to take the AAC further.

Have a wonderful time. You will work hard but come back very stimulated and having learned a great deal from people you might have considered you were going to teach.

Caroline Gray
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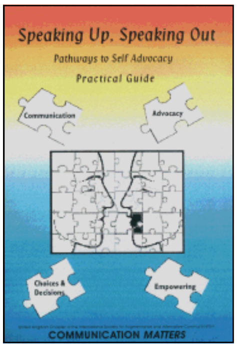
Essential Publications from Communication Matters



Speaking Up and Speaking Out! Pathways to Self-Advocacy

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

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

Alternatively Speaking

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

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

Augmentative Communication News

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

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