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Party Time: A Party for Youngsters who use AAC

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One Saturday in March 2006, eight young AAC users, plus parents, a few siblings, and plenty of helpers, came to a party. This article explains what made it an AAC party, describes some of the fun that went on, and reports the planning, preparation and programming that made it work. We will also look at the positive outcomes; both expected and unforeseen.

The idea of a party came after holding a couple of traditional children's parties at home. The children and I had such a good time playing old-fashioned party games, I thought it would be fun to organize something similar for young AAC users. We envisaged a homely, low-tech event; something families could potentially reproduce themselves at home. There would be party games, songs, an interactive puppet show, a fine party tea; and all the activities would be set up so that children could participate using their AAC systems.

When *Augmentative Communication in Practice: Scotland* kindly approved our grant application, we invited SLT and teacher colleagues to meet and think about what the party should be like. The planning group were selected for a variety of reasons; some were already AAC enthusiasts, some were 'apprentices', some were people we wanted to influence, some were simply 'party people'.

We soon agreed the broad program; greeting and closing routines, a visual timetable, familiar games adapted to be inclusive for AAC users (and to create

many opportunities for communicating) and a sit-down party tea in the middle. We decided to use 'party bags' as a vehicle for collecting mementos of the afternoon. As each activity ended, each child would be given an associated item to put in their party bag. Some items would be just tokens, some would have inherent interest.

THE GAMES

The games took more planning than we had imagined. The aim was to have the 'feel' of ordinary children's party games. Of course there would have to be modifications to make the games meaningful and physically accessible, (and provide reasons/opportunities for using AAC). However we realised that even seemingly simple games could present significant challenges. Take 'Pass the Parcel' for example. Originally, we thought this was the definitive party game, and even used 'would enjoy playing pass the parcel' as the basis for selecting which children to invite. On reflection we found drawbacks with the familiar version; physically passing the parcel to the next child, or removing a single layer of wrapping could be difficult for some children; tracking the parcel might be difficult for others; AAC users might have difficulty handling both the AAC system and the parcel; there are long waits; and in the end there is only one winner. A further disadvantage was that the game did not actually require any communication at all!

The party helpers had three planning meetings. From a long list of favourite games and an over-optimistic estimate of how many could be included, we gradually cut back and prioritised, leaving a couple of extra activities in reserve. Different helpers each took responsibility for thinking through the practicalities of each game, and bringing all the necessary equipment.

Initially we considered inviting every child with an AAC system in Aberdeen and Aberdeenshire, but that would have been a huge event and we wanted a more intimate scale. A party for all would also mean a wide range of ages and abilities, requiring different activities on offer at the same time. Our aim was to bring people together. We settled for inviting all the children we thought could enjoy traditional-style games. Broadly, this meant ages from nursery to primary. A couple of older children that we knew would enjoy the day were invited as 'assistants'. On the day they would wear special badges and receive special 'thank you's', but would really just join in like the others.

We invited parents to attend with the children. However, we recognised that parents might not know how to facilitate their child to participate via their AAC system so each child was matched with a helper to model/provide support to the parents.

The children we invited were either using, or preparing to use AAC. The youngest was rising three; the oldest was fourteen. Their

AAC systems included: Makaton signing, ETRAN, symbol charts, Big Mac, Techtalk 8, Techtalk 32, Alphatalker, Future Pad, DynaMyte, Norand with The Grid. Several of the children used more than one system. For each activity it was necessary to identify key vocabulary, identify best AAC system(s) for that activity for each child, record/program new vocabulary (in a child's voice), make new pages/ overlays, make new low tech materials, and work out when it would be possible to re-record any single message devices.

One of the schools generously loaned a box of Big Macs, so we could record messages for a couple of activities ahead. We also brought a couple of spare Talkers and overlays. All the Talkers were charged before the party, and in fact only one ran down. However, the spare devices proved useful for brothers and sisters to join in.

Some of the children needed to be introduced to new vocabulary in preparation for the party. Some children also needed to be introduced to the games in advance.

Setting up Talkers and symbol materials took Lesley, speech and language therapy assistant, a couple of days. This time was well invested, though, because new vocabulary and overlays would be useful in everyday situations, too, for example words for clothes, food, and animals, and interjections such as "Look!" and "That's silly!"

The party venue was a city centre community centre, chosen because it was friendly, wheelchair accessible and affordable. There were two large rooms plus a café area. As they arrived, the children were introduced to their helper, and the parents were shown the *Welcome Pack*, which explained how their child would be joining in (see Appendix 1.)

We began with a *Hello Song*; the simplest and most repetitive possible, with expectant pauses for the child to tell everyone their name, and then say it again. Next, the visual timetable was introduced, showing the first game: *Pass the Clothes Basket*.

This game was our final modification of 'Pass the Parcel'. The basket contained an assortment of colourful dressing up items including a rainbow wig, Wellington boots and a feather boa (Figure 1). When the music started, a helper carried the basket from child to child around the circle. Two adult 'volunteers' stood in the middle. The music was timed discreetly so that the basket stopped in front of each child just once, in a pre-arranged order. Children whose AAC systems offered a choice of dressing up items had their turns first. They used their Talker to select an item, and which 'volunteer' had to wear it.

For later turns, items were held up so the child could point, reach or eye point, and

then use a Talker to say who should put it on (see Figure 2). The two volunteers looked wonderfully ridiculous, and the children were encouraged to call out 'that's silly' and 'that's funny' with their Talkers. We marked the end of the game by showing that the basket was empty. The feather boa was cut up into lengths, and each child took a piece to go in their party bag as a memento.

Next came an active game, *Corners*. This game, too, had been modified slightly to meet our goals. In the standard version the corners of the room are given names; the children run and stand in a corner; an adult calls out the name of one of the corners; and all the children in that corner are out. This is repeated until only one child is left. We modified the game so the children had to declare which corner they were going to. We named the corners Bear, Rabbit, Mouse and Bird in order to introduce vocabulary needed later for the puppet play. Children with pages or overlays prepared for the play could use the same page for *Corners*, thus getting familiar with the layout, and avoiding the need for another change. Children who were 'out' took turns to call the next corner to be out, using Talkers. The last two children playing were declared winners. The party bag memento was a colouring sheet picturing the four animals.

Now we moved through to the café area for *Tea*. The tables seated 4 or 5 people, which made it very natural for different families to sit together and get to know each other. It was lovely to hear and see the AAC chat, as parents found out how other children used AAC to communicate. We had made sure that each child's favourite food was there, but on another table, so they had to request it. To signal the end of tea, each child chose a chocolate bar to go in the party bag.

We returned to the big room for the *Play* which was based on 'The Bear Snores On' by Karma Wilson and Jane Chapman. Most of the children had been prepared for the play by hearing the story from the picture book during the previous week.

At the start of the Play, the narrator held up the



Figure 1 'Pass the Clothes Basket' Game

picture book to cue the children in, but the story unfolded by a combination of commentary from the narrator, actions by toys and puppets, and (most importantly) by the children shouting out. The style was unsophisticated, partly to reduce distractions and partly so parents might feel inspired to try something similar at home. The stage was just a couple of tables pushed together; there was no set; the 'curtain' was a cloth whirled off the tables to announce the start, and spread back over everything to mark the end. Props were kept to a minimum, and were brought on as required, in order to keep the stage uncluttered. We had also simplified the cast; Hare was re-named Rabbit, and less familiar animals, such as Gopher, were left out. The sleeping brown bear and the mouse were cuddly toys; the other characters were puppets.

Each child's helper had a copy of the script (see Appendix 2), which highlighted lines that child would be able to say using their AAC system. Time dependent lines, such as "It's a bear!" were allocated to children with more complex systems. Children who would probably activate their Talker constantly were given lines which were needed constantly, for example snoring bear noises, or "Shhh, don't wake the bear!" helpers were encouraged to use the script to keep track, and help the child find the marked message at the appropriate time,



Figure 2 'Party Tea' Game

but we did not pause overlong for interjections. Overall, we were looking for a pantomime atmosphere; the more the audience shouted out, the better. There were no really wrong messages, and if something got missed, the story could carry on regardless. Children using AAC systems so rarely use them to interrupt or comment spontaneously. It was great to see the excitement of the children calling "Look! Look!", whilst the narrator wilfully looked in the wrong direction.

Each child received a copy of the original picture book for their party bag. The children took their overlays, symbols and scripts home from the party. We hoped they would join in when the book was read at home, and maybe act out a different version, using their own toys.

Time was running on, and we had to skip our next activity, and get into a circle for singing time. The helpers just had time to get the right pages and overlays before *Old MacDonald* strode in wearing overalls and a straw hat! We quickly re-recorded the spare BIGMacks with "ee-i-ee-i-o" and handed them round to everyone who might like to use them; including parents and siblings.

The party bag item to mark the end of the song was a little Easter chick; so we included a verse with a "Cheep Cheep here, and a Cheep Cheep there!"

Now it was time to end with the *Goodbye Song*. After the singing, came one last item for the party bag; a CD made up individually for each child with video highlights from the afternoon.



WHAT DID WE LEARN?

The party felt great, and has had many positive outcomes. There are a few things we might do differently another time.

For one thing, despite the months of discussion, there was still too much to do in the week before, so ideally we would start planning earlier, start building up vocabulary earlier, and allow longer for preparing the children. And next time, we would like to find better ways of managing lengthy turn-taking and transitions.

If we were to use the same venue again, we would use the rooms differently. We

had assigned the smaller, carpeted room as a quiet room, for any child who needed 'time out'. In fact, no one needed this. The big room was noisy and echoing, so it would have been better to play in the carpeted room where everyone could hear each other.

An unexpected positive outcome was the way the helpers all learned together through the process of planning activities. None of us had ever prepared anything like it. There was a much discussion and food for thought, which will not only influence TASSCC's next event, but also how teachers and therapists plan for including AAC into regular activities. Working together on an out-of-school project developed new partnerships with the AAC team, and seemed to create a new energy and vision about AAC.

For parents, the event was accessible and informal. They could relax and enjoy their child's participating in his own way. Meeting other families with an AAC using child, changed some parents' perceptions of AAC and their attitude to their child's use of AAC.

Most important were the benefits for the children. It was fantastic to see their excitement and to hear them calling out, and chipping in. Everyone was included, and the party gave adults ideas about how to improve inclusion for AAC users in other situations. For some children, the party gave a boost to their enthusiasm about their Talker; one girl carried the overlays everywhere she went for the next couple of weeks!

We are making plans for our next event, a pantomime for children who use AAC: "Oh yes we can!" *

Pamela Cornwallis & Dithe Fisher
Specialist Speech and Language Therapists

APPENDIX 1: SAMPLE 'WELCOME PACK'

Note: all necessary overlays/ symbols/ pictures/ mini ETRAN frames were cut out ready and enclosed in the welcome pack in order of use.

This child's brief was the most complicated because she used so many different AAC systems...

Welcome to the party, Jenny. (Not real name.)

Your helper is Barbara.

This is how you will be joining in the games:

Hello Song:

- Techtalk 8 overlay 1 (just 3 messages, widely spaced).

Pass the Clothes Basket:

- Techtalk 8 overlay 2 to make comments (2 messages, widely spaced).
 - Mini ETRAN to choose clothes item.
- Two Big Macs brought round to choose between volunteers.

Corners:

- 4 Big Macs on centre table.

Party Tea:

- Eye-point to food and drink items.
- Symbols on tray for Yes and No.
- Symbols on table for adults to make comments.

The Play:

- BIGMacks with "Shhh" and "Look!" (The script suggests which to say when, but any time will be fine!)

Bears Gold:

- BIGMack with rhyme for all to chant together.
- BIGMack with "RUN!" to press when someone is being chased.

Old MacDonald:

- Mini ETRAN to choose animal.

When another child has chosen, show Jenny the chosen animal symbol and record the appropriate sound onto the Big Mac.

Goodbye song:

- Techtalk overlay 1.

APPENDIX 2: EXTRACT FROM 'THE BEAR SNORES ON' PUPPET PLAY

Note: Lines delivered using AAC devices are in upper case. Stage directions are in brackets.

(Narrator pulls cloth off the stage. Bear lying down at the back.)

(Sprinkle paper snowflakes, some on helpers; some on children if they like.)

LOOK!
ITS SNOWING
SNORE SNORE SNORE

Narrator: *What's that? I can hear something.*

SNORE SNORE SNORE

Narrator: *Can anyone hear something?*

SNORE SNORE SNORE

Narrator: *I can definitely hear something. Where's that noise coming from?*

(Bear rolls over, still sleeping. Narrator is looking the wrong way)

LOOK! LOOK!

Narrator: *Oh here's an animal. Oh My, it's big; Oh My, its furry. What is it?*

(IT'S A) BEAR!
SNORE SNORE SNORE

Narrator: *Oh I see, it's the bear snoring (stage whisper) he's asleep.*

BUT THE BEAR SNORES ON

Narrator: *Yes, that's right, it's daytime, but the bear snores on.*

DON'T WAKE THE BEAR
SHHH!
WHOOO WHEEEE
TO-WHIT TO-WHOO

(These messages are on STEP BY STEP to pass round the audience.)

A Survey of AAC Need in a Children's Hospital

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INTRODUCTION

When a child or young person is admitted to hospital ill or badly injured, communication can be severely affected. The child, their family and those who look after them may need effective and timely AAC intervention but little is known about what is appropriate. The provision of Augmentative and Alternative Communication (AAC) is known to be an important aspect of care for adults in hospital who have lost speech as a result of the illness or injury. But the literature shows little that looks at the AAC needs of children and young people in acute hospital settings.

The Birmingham Children's Hospital (BCH) in-patient Speech and Language Therapy (SLT) team sensed that we had a growing case load of children with AAC needs. We knew we had to find out more about what was appropriate for these children and analyse what we were currently offering. The increased incidence of children needing AAC appeared to be related to growth in:

- Our skill in identifying their needs;
- The severity of the illnesses and injuries survived;
- Colleagues' awareness of what we could offer.

This combination was leading to the referral of children with very significant communication needs at a very critical time in their life.

We had many questions about the AAC service we were providing. Were we:

- Offering the most appropriate approach(es)?
- Meeting the differing needs of children referred from a wide range of specialities?
- Meeting the needs with the resources we had?

THE LITERATURE ON THE AAC NEEDS OF PEOPLE IN ACUTE MEDICAL SETTINGS

Adults who are taken acutely ill and admitted to Intensive Care Unit (ICU) and other hospital wards are acknowledged to be at a critical time when they may need urgently to communicate, but when they might be least able to talk (MacAulay et al 2003 & Costello 2000). The stress placed on them, their families and those who care for them professionally by communication needs, is understood, as is the help provided by AAC.

Work has been done by Costello (2000) in Boston USA with adults and children for whom the admission to ICU is planned, and for whom there is time to get AAC systems ready: systems are personalised and their use has been practised. The act of preparing for the temporary loss of speech enabled patients and families to ready themselves for the actual immediate results of surgery. Professionals found

it easier to communicate with their patients as people with lives outside of the immediate medical need, as well as appreciating the improved efficiency of communication.

The Dundee ICU team, while developing and using their ICU-Talk (MacAulay et al 2003), found that nurses can identify breakdowns in communication with intubated patients (receiving help for their breathing and unable to speak) and that having an electronic system of spoken phrases accessed by the patient can help. These patients had not necessarily been able to input to the preparation of their vocabulary and phrases, which led to difficulties with the use of the aid while they learned.

Cockerill and Burgul (2006) have described the AAC journeys of children in their hospital in the UK. This work showed the need for consistency of approach to communication for children and families at such a critical time, as well as the swiftness of the changes in the needs and skills of the children during acute illness.

A team at Bristol Children's Hospital looked at the needs of children admitted to hospital with long standing disability affecting their communication. Their solution to the immediate needs of the children, their families and the hospital staff was to produce 'All about me' (Cook et al 2006) booklets that could be person-

Liberator-14

formerly known as the ECO-14

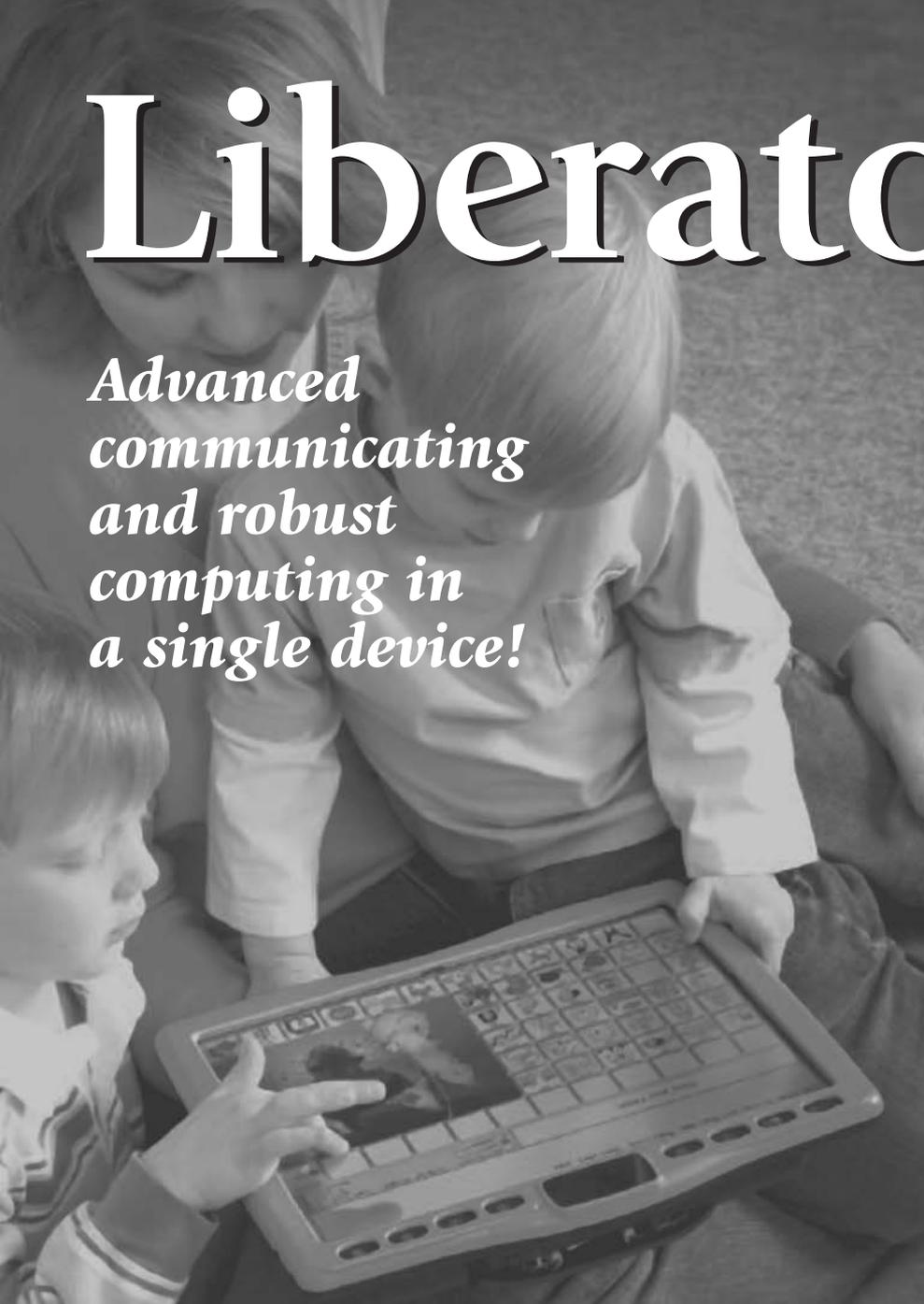
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alised to produce personal communication passports (Millar & Aitken 2003). This pragmatic approach to communication difficulties of children outside their usual environments, interacting with staff that are unused to them has resonance with our own findings.

Reviewing practice between authors and institutions (Blackstone 2007) shows that low tech (paper based) approaches might be the most useful in acute settings perhaps because of flexibility and immediacy and that electronic communication aids while used and appreciated may have more of a secondary role to play.

Little work is available that looks specifically at the AAC needs of children and those around them in acute/ICU settings. This applies to children who have become suddenly ill/injured as well as those with long term neuro-developmental conditions.

The final group of children for whom there is little information about their AAC or pre-AAC needs are those very sick and very young children and babies who are likely to have had all, or most, of their lives so far in hospital and who are likely to have long term communication needs. Our study looked least at this group.

THE HOSPITAL AND THE SLT DEPARTMENT

Birmingham Children’s Hospital is a large regional teaching hospital with Foundation Trust Status. The hospital serves the West Midlands and beyond with specialist and general services. The hospital has 220 beds: 18 of these are Paediatric Intensive Care.

During the period of our study, November 2004-6, the hospital admitted 37,200 children for stays of more than 1 day.

SLT services to In Patient children during the period of the survey were 2.5 whole time equivalent (WTE) SLTs and 1 WTE SLT Assistant. During the period of the study we received 348 referrals: 0.9% of the hospital’s admissions, 26 of these children proved to need AAC. The majority of referrals are actually for extremely unwell infants and children for whom eating and drinking needs are the main focus.

CARRYING OUT THE SURVEY

To find answers to our questions about our AAC service we retrospectively surveyed the notes of all the children to whom we had offered AAC over two year period. We chose the start (November 2004) to coincide with the discharge from hospital of a long standing patient who had taught us a lot about AAC, but whose discharge freed time to look at the needs of other children.

We took our definition of AAC to be very broad covering the use of sign, symbols and a wide range of techniques and tech-

nologies. We expanded this definition pragmatically to include the counting of speaking valves for those children with tracheostomies. The option of speech using the valves made the difference in terms of our ultimate ability to meet the needs of the children. 40% of the children had tracheostomies (a surgically created breathing hole in the neck) that can prevent speech.

Trawling of the case list for the two year period yielded the 26 children to whom we had offered AAC. The 26 children were 7.4% of the referrals to SLT over the two years.

A survey sheet was devised that allowed us to examine the SLT notes and extract similar information for each case. Each set of notes was read, the sheet filled in and the data added to an electronic database.

CHARACTERISTICS OF THE CHILDREN WHO NEEDED AAC

We collected basic information about the children and their admission (Table 1). The age range was 1;11 to 15;06.

Age	Number of Children
Less than 3 years old	4
3 to 5 years old	4
5 to 11 years old	7
11 years+	11

Table 1 Age & Number of children

Most (18) of the children spent under six months in hospital, the longest stays were Two children staying more than 18 months. Twenty five of the children came from within the West Midlands NHS region.

Referrals came from the medical and surgical teams at the hospital. The primary referring team were Neurosurgery (14). However many of the children were known to two or more teams up to a maximum of five. This pattern led to the children having a range of pathways through the wards and departments of the hospital. These pathways impacted on how effectively consistent AAC approaches can be implemented. In 64% of cases the children had time on Paediatric Intensive Care Unit (PICU). Most of the stays on PICU were 3-6 weeks.

The children had a range of underlying conditions and diagnoses that brought them to the hospital (Table 2). Usually these were the reason for them needing AAC, but not always. These figures are for the conditions that drove the need for AAC.

All the children were referred on to other SLT departments when they left the hospital. Four were also referred to the regional AAC service for further assessment and provision.

Condition	Number of Children
Posterior Fossa Tumour PTF(a brain tumour)	6
Traumatic Brain Injury (e.g. a road accident)	5
Acquired Brain Injury (e.g. near drowning accident)	4
CVA (stroke)	4
High Spinal Injury	2
Cerebral Palsy	1
Chorea (movement problem)	1
Down Syndrome	1
Head and Neck Cancer	1
Peripheral Neuropathy (damaged nerves)	1

Table 2 Condition & Number of children

When the children left the hospital the majority were using speech as their main means of communication. This included those who were able to speak because they were using a speaking valve. Of those who were using AAC four unfortunately could not take with them when they left the hospital the AAC system they had been using while in-patients.

THE ‘USEFULNESS’ OF THE AAC APPROACHES

For the 26 children, 80 examples of use of AAC techniques and technologies were identified from the notes. The range was 1-9 per child. The most frequent (mode) number of approaches was 1 which accounted for 8 of the children, but for 6 of the children we used 5 AAC techniques and technologies. Overall the average (mean) was just over 3 AAC techniques and technologies per child. This includes the speaking valve, which made such a difference to the number of children who could return to speech (5).

We graded the outcomes for the techniques and technologies as ‘not useful’, ‘partially useful’ and ‘useful’. We did this subjectively but on the basis of how the case notes described the use and value placed on the approach by the child/family/staff including SLTs and on more than one comment in the notes.

Not useful: not taken up by the child or family or actively rejected by them (e.g. a communication book that was too detailed and not used).

Partially Useful: the approach was taken up and used/valued by the child and family/other communication partners in:

- Some situations;
- For direct SLT activities;
- Led on to ultimate system;
- Full usefulness may be unclear.

Example: An aided language display for games, where the child was able to use the display with the SLT, but family and other staff did not make use of the display.

Useful: Used consistently and over time by the child in more than one situation. Valued by the child, family and other communication partners, and/or supported a significant move to ultimate system/speech.. Example: Communication passport that was lost and family immediately asked for another.

We divided the techniques and technologies we used into the following categories:

- Advice (e.g. what is AAC and what can it offer?)
- High Tech AAC (e.g. Lightwriter)
- Low Tech AAC (e.g. ALD)
- Low Tech : Alphabet based spelling charts
- Low Tech: Symbol communication book
- Low Tech: Communication Passport
- Low tech: Symbol timetable
- Medium Tech AAC (e.g. Step by Step or BIGMack VOCAs)
- No Tech AAC (e.g. yes/no eye blink system tried by ward staff)
- Sign (Makaton)
- Speaking Valve (Passy Muir swallowing and speaking valve)
- Speech

RESULTS

There was no clear relationship between the child's duration of stay or condition and the number of approaches that we used:

Medium Tech

We found 13 examples of Medium tech AAC use and 53% of these were coded as 'useful'.

High Tech

There were only 7 examples of high tech AAC use but 57% of these were coded as 'useful'. These figures are very small but we are working on adding more cases from November 2006 onwards.

Low Tech

Low tech AAC approaches, were coded 'useful' on slightly over 50% of the occasions they were used. These were our most frequent type of intervention for example we offered 8 communication passports, and 5 of these were coded as 'useful' or 'partially useful'.

Signing (Makaton) was only used 3 times but on 2 of these occasions it was coded 'useful'. Makaton was used for children with developmental needs, rather than because of the reason for their hospitali-

sation e.g. a toddler with Down syndrome and leukaemia. Children with brain injuries, etc. may not have the dexterity to sign which is why signing is apparently under-represented.

The speaking valves were used by five children, allowing them to return to speech when otherwise AAC would have been the only option.

No Tech

The least success lay with No tech AAC approaches. We had 15 examples of use but only 26% coded as 'useful'. However 60% are coded as 'partially useful'. This category includes all the 'eye blink' and 'mouthing words' systems evolving with the child's medical situation. Whilst not really AAC, these approaches were often used before referral to SLT - frequently when the child was still in PICU and at their most unwell. Clearly at this time any approach might be relatively difficult because stress levels and illness are at their greatest. However, we were able to introduce more useful approaches while children were in PICU.

CONCLUSIONS

This is a difficult patient group to study, as there is such diversity of need.

We have shown that we need to continue to offer a range of AAC techniques and technologies that are flexible and responsive overtime, as the child and their circumstances change. These changes are in the child's stage of illness or recovery and in their pathway through the hospital.

We are able to show that overall we are offering AAC perceived as useful or partially useful in the majority of cases. Particularly useful are the Communication Passports produced by our invaluable SLTA, reflecting the intuition of the Bristol team.

'Non-useful' approaches seem to occur more frequently in situations where the child is so ill that any approach will be a challenge and/or where we have not yet had a chance to offer our input. Indicating that AAC and SLT can offer significantly to the care of a child in that situation.

Currently medical colleagues do not always refer all the children with whom we might intervene at a time when we might begin to be useful. This is something we are addressing by raising awareness of AAC and our service. We want to establish a picture of the numbers of children who are not being referred and who we could assist and link this to the ongoing analysis of cases we do see.

As an SLT team we appear, on current information, to be almost meeting needs at

the referral rate we have. We are able to offer the range of AAC approaches that are needed: there is no evidence in the notes of a child having to wait to use a piece of equipment e.g. a BIGMack because another child was using it. But some children (16%) cannot take home what they need to continue to communicate as they have been doing in hospital. This relates directly to our very limited resources of high tech AAC equipment (i.e. 2 Lightwriters) - devices that we cannot afford to send out of hospital with a child on discharge. These children took low-tech alternatives with them and were supported by their local SLT teams when they returned home. With a struggle, local services were able to provide replacement high tech aids. If we had not had the speaking valve option we would have met this challenge significantly more.

THE FUTURE

We continue to gather more data and will analyse this to learn more about what is successful and appropriate and plan to tease out some patterns and guidance. A part of this is the possibility of studying in more detail one diagnostic group and their needs. This should enable us to develop audit standards and then test these.

We should continue work on training and awareness raising with colleagues. If this process increases referrals we need to check that we can still meet the need: standards and audit work should help with this.

We should work with the wider hospital and beyond to explore how we can ensure that children who need to do so can go home with high tech AAC. *

Chris Sherlock
Speech & Language Therapist

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Identity in Teenagers who use AAC

Report and Consultation on a Project in Progress

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“ *Not saying anything...
 is not the same as...
 not having anything to say.* ”



photo © ISAAC (adapted from website)

This article describes the aims, theoretical background, methodology and progress to date of a research project in progress. A small sample of preliminary data and of the views of the participants about taking part is presented.

INTRODUCTION

The research sets aims to explore issues of identity and the life worlds of a group of 10 teenagers in England who use AAC. This study is unusual because it focuses on the young people's own perspectives and how they see themselves, rather than those of people around them such as parents, teachers and therapists. It is unique in using anthropological methods which are designed to look in depth at a situation over a long period, rather than relying

RESEARCH QUESTIONS

- How do young AAC users construct their sense of self and identity?
- What kinds of social relationships do young people who use AAC have?
- How are young AAC users seen by others?

on a snapshot, which might be obtained using more common qualitative techniques such as one-off interviews or focus group discussions.

THEORETICAL BACKGROUND

The study draws on theory from anthropology and from the newer disciplines of

childhood studies and disability studies. All these approaches tend towards looking at people as part of society rather as a 'clinical population'. Anthropology typically uses qualitative methods of enquiry, the main one being ethnography. This involves the researcher being a 'participant observer' in the situation they are researching. Thus I have spent time with the 10 young AAC users in their real settings of school, home and out of school clubs and activities. This means that I have tried to learn first hand about what happens in their real worlds and understand their perspectives, rather than looking in from the outside or from other people's viewpoints.

Anthropological approaches aim to 'make the familiar strange'. In other words they

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set out to view situations with open minds, in order to find out what is going on and why. The idea is to look for the meanings behind the situations they observe or participate in (Geertz 1993, Hammersley and Atkinson 1995). Social scientists see identity as made up of 'selfhood'; how the person sees themselves, and 'personhood'; how other people see them. I aimed to investigate both of these during the project (Goffman 1963, Jenkins 2004, Cohen 1994). In looking at the young peoples' own perceptions, those of others and their social interactions, new conceptualisations of the way in which identity works, especially which language is not easily expressed through speech may emerge.

The way that concepts of the body and the mind are related is also of interest to social scientists, as ideas that individuals have about themselves will be linked to how society sees them (Csordas 1994). I am interested in how the young people in the study see themselves, in the light of the very strong messages which our society projects about both our bodies and minds. Anthropology is of course very concerned with aspects of culture and in this study the culture around disability is also a focus. Meredith Allan (2006) has asked whether there is an AAC culture, and this is a question underlying this study too. The ways in which language, thought and meaning are related, especially for young AAC users as people using different ways of expressing their ideas is a core focus of the research (Geertz 1993). I aimed to use narrative (storytelling) approaches to talking to the participants, as many authors have suggested that hearing people's own stories is an excellent way of gaining a rounded view of their lives and concerns (Occhs and Capps 1994).

The new discipline of Childhood Studies has also informed the project. A growing number of researchers are recognizing that children and young people have been a neglected group in sociological research, and have generally been viewed as 'objects' of research through an adult lens, rather than as active participants whose perspectives might be valuable. Ways of doing research *with* instead of *on* children are now developing fast, and these aim to shift the focus to the children's own views (Christensen and James 2000, Garth B & Aroni R 2003, James 1995). Thus the adult researcher's role is to facilitate the presenting of children's accounts of the world.

Thus methods used in childhood studies suggest:

- Treating children as people who have something to say in their own right;
- Changing ideas about what children and young people (YP) are competent to do and think;

- Seeing children and YP as people now, not as people in the process of becoming someone.

However, this does also pose some questions for the adult researcher, such as:

- What is the nature of the adult researcher's role and relationship with the children s/he researches with?
- Should you use the same methodologies as for children as for adults or different ones?

Although my study will be addressing these questions, they will not be discussed in depth in this article.

The discipline of Disability Studies also has key concepts to contribute to this project. This expanding group of researchers has amongst other topics, been concerned about the ways in which research in disability is conducted and produced. In parallel with the concerns about research with children described above, research in disability has tended to be *on* disabled people rather than *with* them, and not necessarily focused on their concerns. There has also tended to be a focus either on specific impairment groups (e.g. clinical research) or social research, but arguably with a rather narrow range of methods and types of participants. Thus there has been work exploring the perceptions of adults with disabilities, but less with disabled children and particularly little with those with learning or communication impairments (Davis, Watson et al 2003). Socially focused disability research is often informed by 'hard-line' versions of the 'social model' of disability and thus does not include any focus on people's experience of impairment at all. Thus the very real and important concerns that disabled people may have arising directly from their impairment have often been under-represented in the disability studies literature (Murphy 1987, Priestley 1998, Shakespeare 1994, Zola 1993). Contemporary approaches are now beginning to bring 'the body' back into the picture, as well as aiming to use emancipatory and participatory approaches which foreground the real experiences of disabled people themselves. Disability research now therefore aims to:

- focus on participants as people not as 'medical subjects';
- increase involvement of disabled people actively in all aspects of the research process;

ETHICAL ISSUES

All the young people and families opted to be involved in the project after being given verbal, pictorial and written information and an opportunity to ask questions.

A small number of possible participants or their parents (3) decided they did not want to join the project for a variety of reasons. The young people are involved in ongoing verbal consent at each stage of the project and parents signed a comprehensive written consent form.

Every effort will be made to ensure confidentiality by anonymising school and participants' names and specific permission is sought for the use of photos. The project had ethics clearance from Sheffield University and I have CRB clearance and appropriate professional experience of working young and vulnerable people.

- reflect carefully on whose voice is represented and who determines what kind of research is done?

- recognise the importance of personal stories and disabled people's own perspectives.

STUDY PARTICIPANTS

The key participants in the study are 10 teenagers who use AAC, and who attend a range of different types of schools. All use at least one VOCA accessed either directly, or via head switches. These are used in addition to an individually variable range of low tech methods, including signing, picture and symbol books, alphabet boards, e-Tran frame and their own speech and gestures. All have broadly normal cognitive skills, although some have additional impairments or medical needs such as hearing impairment, epilepsy, and tube feeding.

- 4 boys (ages 12, 14, 14, 16)
- 6 girls (ages 10, 13, 13, 13, 15, 15)
- 7 at special schools (4+1+1+1)
- 2 split placements at mainstream + special
- 1 at mainstream school

Additional contributors to the study are family members, friends and a range of school and healthcare staff. Some data was also collected from teenage members of the 1Voice group during their DVD project and from a group of 7 older teenage AAC users attending a specialist college.

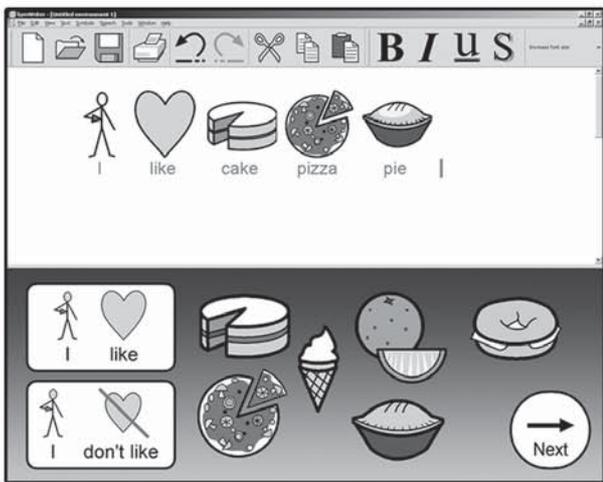
In addition to these participants and informants I have also had the invaluable support and resource of four adult AAC users who have acted as research advisors. I have been in regular contact with them and have used them as a sounding board for ideas about methods and concepts during the project.

RESEARCH METHODS ETHNOGRAPHY: WHAT'S THAT?

This is a qualitative research project using ethnographic methods. The main

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DISCUSSION TOPICS

- My important people
- My day
- My treasure box (favourite things)
- This is me (self description)
- Things I like, Things I hate
- How people help me
- Tips for talking to me
- My life story
- My dreams
- What's important when making friends
- My communication
- Vignettes – (sample stories about young people to discuss)

activity has been participant observation, in the young people's schools, homes and other places where they go (e.g. activity and sports clubs, field trips, etc.) over a one year period. As the participants are in a number of different schools and geographical locations, this meant that although I was a regular visitor in all their lives, I was not with any one individual for intrusive lengths of time. In their schools, I negotiated a role roughly equivalent to a classroom assistant and so joined in with a range activities during and after the school day. In homes and community settings I was welcomed as a regular visitor by all the families, as an interested and friendly adult 'doing a project'. In all the settings my focus was on being with the young AAC users during whatever they were doing and additionally talking informally to other young people and adults around them. In addition to the participant observation which took up the vast majority of my fieldwork time, I also negotiated with the teenagers to have regular individual conversation sessions in a quiet and private space (either at home or at school). During these sessions I used a narrative interview approach to ask them about a range of aspects of themselves and their lives. We used drawings, symbols, photos and mindmaps produced during conversations to record their ideas. In each case I was guided by them as to both their preferred modes of communication and topics of conversation. Below is a sample of some of the discussion topics used. Participants always had a choice about whether and which of these to do on a particular day.

TYPES OF DATA

A range of different types of qualitative data will be generated from the fieldwork, including photos (taken by me and by participants), mind maps of discussions,

schoolwork on relevant topics, fieldnotes, audio recordings of individual discussions, interviews with parents, and focus groups with older teenagers and school staff at two schools.

PRELIMINARY RESULTS: SOME INTERESTING QUOTES

As the project is still in the fieldwork phase, detailed results and analysis are not available yet. However, I have presented here some interesting quotes from participants so far, about a variety of aspects of their lives. These have been grouped broadly by the discussion topics from which they arose.

ANALYSIS AND VALIDATION

Once the fieldwork period is completed, analysis of visual material, fieldnotes and transcribed audio-recordings will begin. This material will be coded thematically using NVivo. Initial themes and linkages will be represented to the teenagers for their feedback and validation of my analysis. The four research advisors will also be invited to comment on the analysis.

PARTICIPANT FEEDBACK

About halfway through the year of fieldwork, I asked the teenagers for feedback about their experience of being involved in the project. Obviously there may have been constraints on them making negative comments directly to me, but given that they are regularly given the opportunity to withdraw from the project and none have done so, I feel that their generally positive comments may be representative.

POSSIBLE IMPLICATIONS AND APPLICATIONS

There are a number of possible theoretical and applied implications which may be outcomes of this kind of phenomenological research. Valuable insights into the lived worlds of a 'hard to reach' group of young people who are often excluded from research will be heard. From the theoretical point of view it will contribute to the emerging fields of both anthropology of childhood and of disability, and highlight the relative omission of disabled children and particularly AAC users from both arenas so far. Applications of this research might be to provide more particularised and 'real' information for professionals planning and providing services for young AAC users, and to inform pub-

Topics - Quotes	Gender & Age
<p>My life story</p> <ul style="list-style-type: none"> - Hospitals hospitals hospitals - I was very ill when I was born - I didn't breathe for 23 minutes - My life isn't easy 	girl 13 boy 11 boy 14 girl 10
<p>How I see myself</p> <ul style="list-style-type: none"> - My friends know me as a person - I'm sporty and mad - I have lovely long legs - I am beautiful - I'm good at ICT 	boy 14 boy 14 girl 13 girl 13 boy 14
<p>My dreams, My future</p> <ul style="list-style-type: none"> - I want to work with children to tell them about disability - I want to work in IT - I want to go to nightclubs - Job in wheelchair making technology - I want to go to university in Australia and run a health club - I want to live away from home and use a mobile phone - I want to be the England football coach - I want to live in a bungalow with my brother, he will look after me 	girl 15 girl 15 girl 15 boy 14 girl 13 girl 13 boy 14 boy 14
<p>Things I like, things I hate</p> <ul style="list-style-type: none"> - I like this school (special) because it helps me find things I can do well - I like food - I would like more friends at home - I like chilling out with my brother - I hate it when my mum runs out of chocolate - I like playing with my Xbox 360 - I don't like people who don't like me - I hate it when my wheelchair breaks down 	girl 15 girl 15, boy 14 girl 15 boy 14 boy 14 boy 14 boy 11 boy 14, girl 15
<p>About Communication</p> <ul style="list-style-type: none"> - My pathfinder is fantastic - I would like a comm aid that would fit in a handbag - I love my Dynavox and I hate my Dynavox - My dynavox works hard for me - I don't like the American voice - I hate it when my Dynavox breaks down - I always use the fastest method available, the VOCA is the slowest of my methods - The communication aid is too slow - I use 'facetalk' always - I can say what I want to - I get my point across somehow 	girl 13 girl 13 girl 10 girl 13 girl 13 boy 14, girl 13 girl 15 girl 15, boy 12 girl 15 girl 15
<p>Talking to other people</p> <ul style="list-style-type: none"> - Some people are good at listening and waiting and some people are awful - People need to listen more carefully to understand me - People should give us more time - I hate it when people don't talk to me directly - I would like to talk to my friends - I want to use my speech more 	girl 13 boy 14 boy 12, girl 13 girl 15 girl 13 girl 10

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lic awareness and policy initiatives related to this group. Indeed it is hoped that the results of the study will contribute to the current collation of views from disabled children and AAC users respectively (Office of Disability Issues 2006, SCOPE 2007, Bercow Review 2008). In addition it is hoped that the benefits of using long term and in-depth qualitative methods of enquiry may be seen and future researchers persuaded to use these approaches with other hard to reach or excluded groups.

FULL RESULTS AND REPORTS

The full results, analysis and reports of this study will be available in late 2009. A briefer summary of the results and conclusions will also be produced in an easy to read format and will be distributed to participants, schools and others. *

Mary Wickenden
Researcher

ACKNOWLEDGEMENTS

I would like to express my sincere thanks to all the young people and their families,

and to the schools and colleges, for welcoming me into their worlds, and to the research advisors for their interest and support.

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Tamsin Starts to Talk

CLARE LATHAM

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Tamsin and her mother took part in the ACE Centre project, *Look2Talk*. The project created a guide to developing a communication book for children whose only method of accessing communication is by eye pointing. This guide was then tried out with six families, one of whom was Tamsin. In the light of the findings, the guide is being revised and will be accompanied by a DVD of the families' interactions with their children. The guide will be available from the ACE Centre at the beginning of May 2008.

This article describes the inspiring journey Tamsin and her mother made as together they learned to talk through symbols.

Tamsin (born with cerebral palsy affecting all four limbs) is a bright four-year-old girl. She can vocalise but has not yet gained any recognisable spoken words. She is unable to point with her hand or finger. She has an eighteen month old brother and attends a nursery specialising in the needs of physically challenged children.

At the age of three Tamsin began to use two symbols "Yes" on her right wrist and "No" on her left wrist. She began to respond to simple questions by looking appropriately to either the "No" or "Yes" symbol. She also looked to things that she wanted around the room, or to a different room to indicate something out of sight.

When taken there, she looked to the item she wanted.

Tamsin's journey with symbols continued through the introduction of a simple communication book, containing pictures and symbols that she pointed to with her eyes. Initially, it was just her Mum who was shown how to use the book with her. To begin with, Mum only used symbols in play activities that they both enjoyed.

Quickly, Tamsin wanted to say:

"Stop feeding my doll."

"She needs changing."

"She needs more drink."



Figure 1 Tamsin plays with her doll

Before long, Tamsin and her Mum felt the need for more words as they played. They were introduced to the concept of encoded eye-pointing, with a two stage selection process. Here symbols are placed

in blocks of 2, 4, 6, or even 8. First the user eye-points to select a block. Then the user makes a second eye movement to select a colour on the outside of the page that indicates the colour of the symbol within the block.



Figure 2 Eye pointing strategy

In Figure 2, Mum is demonstrating that to say "train" you look first to the block of four symbols where she is pointing and then to the yellow dot at the top left of the book (to show it's the yellow edged symbol that is meant).

In this way, colour games were used to practise matching, grouping and identifying symbols enjoyably. Within six weeks, Tamsin began to encode and enjoy a richer vocabulary in her play.



Figure 3 Tamsin selects what she wants to draw

Tamsin then began to enjoy taking control of the book by looking to a symbol that said “go to my top page” (Figure 3). Instead of just responding to her Mum’s choice of play activities (e.g. “Do you want to play x or y?”) Tamsin was able to say “Go to my top page”, then “Go to play things” and, finally, “I want cooking games”.



Figure 4 Tamsin tells her Mum to put lemon curd on the toast for her brother

Tamsin and her Mum continued to enjoy a range of play activities. Visitors to the

house were also introduced to Tamsin’s method of communicating. Her Mum demonstrated how the system worked and how easy it was to read Tamsin’s eye-pointing. Before long, dad, granny, cousins and friends were happily listening to what Tamsin had to say as they played with her.



Figure 5 Tamsin plays with train set

But one day Tamsin seemed to lose interest in playing. What was wrong? Working on intuition, we decided Tamsin needed more of a challenge. We introduced her to more imaginative and challenging play with more extensive symbol vocabulary. Mum showed her the fun of hiding items in, on and under things; how to ask questions like “Where” and “Can I”; and how to chat about what had just happened in their play (recall and comment).

Tamsin soon took control and explored the new concepts repetitively, using her Mum’s hands to place items in trains, dolls’ houses, garages and parks. Their stories grew in richness, “climbing up again”, “hiding under - not found”.

Play, fun and chatting with others was growing but what happened to Tamsin’s original and spontaneous “talking”? To ensure that this continued and developed, Mum and Dad continued to respond to her facial expressions and general eye-pointing, but making sure the book was available if she required it.

One day it ‘just happened’. Whilst Mum was feeding her porridge, Tamsin looked to her book. Mum opened it and Tamsin said, using her symbols, “No more porridge”. Later, while Mum was feeding her little brother and making fun noises to encourage him to eat, Tamsin again asked for her book to say, “Mummy silly”. From these small beginnings Tamsin has continued to request her book to communicate many things that four year olds need to say. Things that are worrying her; things she wants to do and who she wants to do them with; things that happened sometime ago but have relevance now; questions she wants answered; and things she wants her brother to do - and *not* to do!

Tamsin faces many challenges ahead but at the age of three the most pressing challenge for her and her family was communication. En-skilling her mother in the use of symbol communication, how to use it and how to read Tamsin’s eyes confidently, has enabled Tamsin to “find her voice” - a voice, not just to be used with her Mum, but with all her family and friends. In short, Tamsin, with her mother’s skilful example and guidance, has begun to talk through symbols. *

Clare Latham
Speech and Language Therapist



Augmentative and Alternative Communication

This is the official journal of the International Society for Augmentative and Alternative Communication (ISAAC), published quarterly by Taylor & Francis Ltd, UK. AAC publishes original articles with direct application to the communication needs of persons with severe speech and/or communication impairments for whom augmentative and alternative communication techniques and systems may be of assistance.

CM Members rate (per year): £47 (£30 student/retired)
(£140 ISAAC Institutional/Corporate)

Unterstützte Kommunikation

This ISAAC affiliated publication is published four times a year in German by ISAAC-GSC. **CM Members rate (per year):** £36

Members of Communication Matters (ISAAC UK) must send their orders to CM (address at bottom of page)

Readers outside the UK can order in local currency from their local Chapter of ISAAC, or in dollars directly from ISAAC, 49 The Donway West, Suite 308, Toronto, ON M3C 3M9, Canada Tel: +1 416 385 0351 Email: info@isaac-online.org Website: www.isaac-online.org



c/o ACE Centre, 92 Windmill Road, Headington, Oxford OX3 7DR
CM Tel & Fax: 0845 456 8211 E: admin@communicationmatters.org.uk W: www.communicationmatters.org.uk

AGOSCI in Focus

AGOSCI in Focus (formerly AGOSCI News) is the newsletter of the Australian Group on Severe Communication Impairment. It is an ISAAC affiliated publication and is published twice a year. **CM Members rate (per year):** £21

ISAAC Israel Newsletter

ISAAC Israel Newsletter is an ISAAC affiliated publication. Published annually in the spring of each year, in Hebrew with a few English abstracts.

CM Members rate (per year): £19

What is Communication Matters?

Communication Matters is the UK Chapter of ISAAC (International Society for Augmentative and Alternative Communication), so members of Communication Matters are also members of ISAAC.

Our Vision: Communication Matters' vision is a world where speech, language and communication difficulties are not barriers to opportunity and fulfilment.

Our Mission: Communication Matters is all about enabling people to communicate. We value and promote the individual's right to participate in all aspects of life by using their most appropriate means of communication to express their thoughts, feelings, needs and desires.

What are the benefits of Membership?

Members of Communication Matters receive:

- The Communication Matters Journal three times a year.
- Reduced delegate rate at the Annual Communication Matters National Symposium.
- Regular electronic newsletters with the latest news in AAC developments, information about Communication Matters Road Shows, study days, other events, and more.
- All the benefits of ISAAC membership, including ISAAC publications at substantially reduced rates (AAC Journal, ISAAC-Israel Newsletter, AGOSCI News), and special delegate rates for the Biennial ISAAC International Conference. You can also access the member's area of the ISAAC website and, if you join early in the year, you will receive a Membership Directory.

How do I become a Member?

If you live in the UK, you can become a member of Communication Matters (and therefore of ISAAC) by contacting:
Tel: 0845 456 211 admin@communicationmatters.org.uk
www.communicationmatters.org.uk

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

What is ISAAC?

- ISAAC stands for International Society for Augmentative and Alternative Communication.
- ISAAC is a big international organisation that focuses on AAC.
- ISAAC was formed in 1983 and has over 3,700 members.
- ISAAC members live in more than 50 countries around the world.
- There are ISAAC Chapters in Australia, Canada, Denmark, Finland, French-speaking Countries, German-speaking Countries, Ireland, Israel, Italy, Netherlands-Flanders, Norway, Sweden, United Kingdom and United States of America.

ISAAC's Vision: AAC will be recognised, valued and used throughout the world.

ISAAC's Mission: To promote the best possible communication for people with complex communication needs.

What does ISAAC do?

- Advocates for augmented communicators & their families.
- Supports the use of AAC around the world. This includes countries that do not know about AAC.
- Has an exciting awards & scholarship program for members.
- Encourages the development of AAC products & services.
- Produces a series of books for people involved in AAC.
- Has an international conference every two years.
- Sponsors a peer-reviewed scientific journal – Augmentative and Alternative Communication (AAC). Peer-reviewed means that each article is anonymously reviewed by three people who are experts to see if it is suitable for publication. Visit the website at: www.isaac-online.org/en/publications/aac.html for more details.

What do ISAAC members receive?

- Full access to *ISAAC Information Exchange* the new web-based version of what was *The Bulletin*. *ISAAC Information Exchange* is a dynamic international resource for sharing knowledge, experiences and perspectives on AAC.
- Access to ISAAC website and past Bulletin articles
- An International Directory with a list of all ISAAC members. A new Directory is published every year.
- ISAAC members can buy the AAC Journal at a 54% discounted rate.
- ISAAC members can attend ISAAC conferences and meetings at 15% or more discounted rate.
- ISAAC members can buy other ISAAC products and resources at an average discounted rate of 25%.
- ISAAC members network with professionals & AAC users world-wide.



Click here



www.communicationmatters.org.uk

- Latest News...
- Publications...
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'Listen to Me' 1Voice DVD

KATIE CLARKE

1Voice, PO Box 559, Halifax HX1 2XL, UK
Tel: 0845 330 7862 Email: info@1voice.info www.1voice.info

The 1Voice Teenagers have been awarded

The Diana Award for their ability to improve and inspire the lives of others. 1Voice teenagers, parents and personal assistants will be heading to London again for the second time. The 1Voice Teenagers supported the recent No Voice, No Choice campaign and attended the Parliamentary reception in November. This time they are attending the Diana Award Holders Event on 19 March 2008 together with young people from all over the country at an exciting and interesting day.

Meanwhile, the 1Voice team are overwhelmed by the incredible response to requests for our 'Listen to Me' DVD. We were delighted to launch the DVD at the last Communication Matters CM2007 National Symposium, and since then we have been busy posting DVDs out all over the world. Thanks to the initial publicity and the promotion of the DVD on YouTube we have had interest from professionals living in India, Canada, USA and Australia. We have sent out press releases and articles in various journals and newsletters which has also gathered a remarkable response.

Comments include "your DVD is a wonderful source of inspiration for others", "I love it", "your DVD is an excellent resource", "Great DVD. I will be using the DVD for awareness training for parents, professionals and students who use AAC", "Awesome!".



Young people have told us "Cool people using talkers", "Great", "Good talking about talkers", "I want to show people out of college the DVD. I want to show schools", "I want to take home DVD and show mum and brother".

We have sent copies to all our membership and handed out DVDs at the Communication Matters CM2007 National Symposium. On top of this we have had over 150 requests from individuals ranging from those working in national charities, speech and language therapists, participation workers, social workers; trainers; special educational needs teachers, disabled children's teams, information officers, children's centres, etc. The DVD has also been used at conferences, workshops and seminars around the UK and USA.

Last week all the young people involved received a certificate from the Makin' It Real team at Youth Action Network. We have also entered the Project in for the Positive Images Award from Children Young People Now - so watch this space. What is great about these awards is that they are mainstream - and that the DVD is having a huge impact not just on the AAC world but also on the general public.

The Teenage Project 2008 will be held at Hothorpe Hall, Leicester on 18-20 July 2008. The theme will be 'Lost in Transition' and we will be working together with a team of role models; skilled facilitators and the Council of Disabled Children to put on what we are sure will be a thought provoking weekend. Anyone wishing to volunteer for the weekend please do get in touch. Volunteers gain a real insight into the world of AAC and what the issues are for those who use AAC and their families.

Our annual National Network Day will be held on 20 July 2008 for anyone using AAC and families from across the country at the beautiful Hothorpe Hall. Accommodation is available the night before at reduced rates for members.

For more information on our work with youngsters who use AAC and their families, the Teenage Project, Role Model Project or for a copy of the DVD, contact 0845 330 7862 or info@1voice.info *

Katie Clarke
Chair of 1Voice



isaac



MANY STORIES - ONE VOICE

INTERNATIONAL STORYWRITING CONTEST

The Trustees of Communication Matters are delighted to support the ISAAC international storywriting contest to promote literacy and the AAC Awareness Month

Our past, present and future will always be connected by the stories that are told – whether it was from the town crier, grandmothers passing along family tales, books, artwork, song, newspapers or now in the age of video and the internet – stories always have a place in society and impact all who hear them. No matter what your age is, what country you are from, what ethnicity or race you are, where you work or go to school, you have something to say, a story to tell, and the world is ready to listen!

As part of the 2008 International AAC Awareness Month, ISAAC invites you to have your voice heard around the world by entering the *Many Stories - One Voice* writing contest.

Who can enter the contest?

Anyone who uses AAC is welcome to send in a story, whatever their age or skill. The story can be written with or without help, by one author or by a team.

How do I submit a story?

You can submit your story in **words, artwork, cartoons, photographs or other written or visual medium**. Written stories should be up to 500 words and capable of being read at one sitting.

Your story can be written for children or adults, and must include AAC within it (such as a character who uses AAC, someone learning about AAC, or AAC in the storyline).

Read the submission guidelines and download the submission form from www.aacawareness.org. Then email your story and form to ISAAC at contest@aacawareness.org by **13 June 2008**.

For more information on how to enter the *Many Stories - One Voice* writing contest please visit: www.aacawareness.org or email: info@aacawareness.org

What will happen to my story?

ISAAC will compile all the entries into an online publication so they will be available to be read during 2008 International AAC Awareness Month events. Selected stories will be highlighted at ISAAC's 13th Biennial Conference in Montreal, Canada. All stories from the UK will be forwarded to Communication Matters (see below).

How is Communication Matters supporting the contest?

Communication Matters will be showcasing some of the UK's homegrown literary talent:

- Copies of stories from the UK will be available at the Communication Matters CM2008 National Symposium in September.
- Three of the best UK entries will be chosen by the Trustees of Communication Matters, and the authors will be invited to read their stories to an audience at a London venue in October 2008.

More information about the UK events at: www.communicationmatters.org.uk/writingcontest or email: admin@communicationmatters.org.uk

What can I do to help?

- **Spread the word!** Copy the contest flier enclosed with this journal (or download a copy from www.communicationmatters.org.uk) and pin it up at your local school, library or other public place.
- **Start planning your own events for International AAC Awareness Month** - Be a leader in your community by organising a reading or other event during October to raise awareness of AAC.

Key Dates

- **13 June 2008** Closing date for submission of entries to ISAAC
- **2 August 2008** All stories presented to Sudha Kaul, ISAAC President
- **August 2008** Stories published on the ISAAC website
- **September 2008** UK entries chosen by Communication Matters for the public reading in October



TRUSTEES' NEWS

FROM LIZ MOULAM, CHAIR OF COMMUNICATION MATTERS

There is so much enthusiasm and positive action going on at the moment that it is hard to know where to start...

JOHN BERCOW REVIEW

The Trustees spent a great deal of time in December and January putting together the Communication Matters' submission for the Bercow Review of Services for Children and Young People (aged 0–19) with Speech, Language and Communication Needs in England. The interim report was published on 20 March 2008 for further consultation, with feedback due in by early June. The interim report summarises the position overall for all children with speech, language and communication needs (SLCN) including those who use AAC and fall into the low incidence but often high cost needs group. Please see the article in this edition of the Journal (page 25) with a summary of our submission and how we feel the interim report relates to our initial recommendations. At this early stage, the review team have not finalised the recommendations and solutions; these will feature in the final report due out in July 2008.

There is a link at www.communicationmatters.org.uk to download the Bercow interim report, along with a summary of CM's original submission. Please forward any further feedback to me lizcommatters@aol.com or to Patrick Poon at admin@communicationmatters.org.uk by 30 April 2008.

AAC CAMPAIGN IN SCOTLAND

Scotland is carrying on its own campaign about AAC provision, called 'Give us our right to communicate'. The campaign is led by a group that includes Augmentative Communication in Practice: Scotland (ACIP:S members are also associate members of Communication Matters), RCSLT, Capability Scotland and others. This has so far included a briefing for MSPs, letters to MSPs following an AAC Users' meeting in February, a motion on AAC to be debated in the Scottish Parliament, and a meeting with a Scottish Minister to be held in May 2008.

INDEPENDENT LIVING STRATEGY CONSULTATION

On 3 March 2008, the UK's Office for Disability Issues (ODI) launched a cross-government Independent Living Strategy, co-owned by the DCSF, DOH, DWP and other government departments. The focus is from age 14+ for the rest of life, and is a consultation about transition to adult services through to life long provision of equipment and services. AAC and specific communication equipment are mentioned, along with environmental controls/electronic assistive technology. The strategy document is available at: www.officefordisability.gov.uk/independent/strategy.asp Communication Matters will be making a submission to the ODI - we welcome any comments on the proposed strategy by 30 April 2008 either to me at email: lizcommatters@aol.com or to Patrick Poon at: admin@communicationmatters.org.uk

ON-LINE SURVEY

We had a fantastic response to the on-line survey in January as 438 people completed the questionnaire. The

Trustees have already started to make use of this valuable information to guide us in the way we take forward the business of the charity. A full report will appear in the next journal but it is good to know just what you feel we are doing well and where we can improve.

It was clear that you as respondents wanted us to focus on many things, the top three areas being:

- *Awareness raising* on the needs of people who use AAC and families and on what AAC is.
- *Education of all of the AAC community and others* through Conference, more study days, road shows and other media, such as the website
- *Providing expertise and advice about AAC* to government departments, advisory bodies, third sector organizations, etc.

In order to be able to do all this, the Trustees (who are volunteers and carry out their Communication Matters role in their 'spare' time) have decided that we need to investigate fundraising to take on staff to carry forward our development plans. This will enable us to maintain the momentum which has been achieved through the Bercow Review process including our representation at The Communications Consortium and associated activities and working with the consultants for QCA reviews. So, at the Communication Matters Annual Meeting in September 2008, we intend to discuss the 5-year strategy and the Communication Matters business plan, and to give feedback on progress towards making this a reality.

ISAAC GOVERNANCE AND AWARENESS RAISING

At the ISAAC Board meeting in Dusseldorf in August 2006, the Board made a commitment to review ISAAC's governance. Much work has been going on behind the scenes, and in the UK we are grateful to Janet Scott, Janet Larcher, Simon Churchill and Patrick Poon who have all provided excellent feedback to help in this process. The draft document is available at www.communicationmatters.org.uk for comment. The proposed changes will be voted on in August 2008 at the next ISAAC Board meeting in Montreal.

Please see the notice (page 20) and poster/flier in this copy of the Journal about the *Many Stories - One Voice* storywriting contest. This is an exciting opportunity to showcase the literacy talents of people who use AAC in the UK and we hope you will encourage everyone to enter.

BOARD OF TRUSTEES HEALTH CHECK

No, we didn't all rush down to the doctors, but following the governance review and acceptance of the new Memorandum and Articles of Association last September, we carried out our first review of Communication Matters Board performance. This involved every Trustee completing a questionnaire about how we work together and our effectiveness. These were then collated by Janet Larcher into one 'anonymous' document that highlighted where we think we do well, but more importantly what we think we need to improve in order to be more effective. The results were used at the recent strategy day, alongside the online survey results, to guide Communication Matters' Trustees in planning for the future.



TRUSTEES' NEWS

LEADERSHIP TRAINEE

As this goes to print we have just interviewed some fantastic candidates for the leadership position. All of the candidates could have taken on the role and we would have loved to work with each of them. We have had to make a decision as we can only offer one post and we hope that this person will take up the offer and work with the Board of Trustees from the summer. The trainee, and we as Trustees, are very fortunate in that Janice Murray has agreed to be the mentor and we look forward to working with them.

FINALLY

This report fails to do justice to the incredible amount of time and effort the Trustees and Friends of Communication Matters are putting into running the organisation. We now have associate members on all of our sub-groups and are finding their input invaluable. It is an exciting time for Communication Matters. Some members of the present Board are due to stand down in September and due the governance changes we need new people to come forward to join us. It is a rewarding role, so if you would like to consider applying and want more information, please contact Patrick Poon or myself.

Meanwhile, I look forward to seeing you all in September at the CM2008 National Symposium in Leicester, and/or in August, if you are fortunate enough to be able to attend the ISAAC Biennial Conference in Montreal.

Liz Moulam, Chair of Communication Matters
Email: lizcommatters@aol.com

eCAT NEWS

JOHN BERCOW REVIEW

Since the launch of the John Bercow review, BHTA eCAT members have felt that they could have valuable input to the review, from a general industry and business viewpoint. To that end we tried to arrange for John to meet the suppliers, together with the BHTA Director General to explain some of our thoughts and ideas. However an opportunity for this was not forthcoming and we were left with two of our members representing the whole group. Since then John has indicated his desire to meet the eCAT group and hear of our experiences from past Government funding schemes, after the interim report, planned for 19 May 2008.

At the same time I realised that probably no-one had thought to raise the issue of VAT on extended warranty, which is a true anomaly in the disability industry. In case you don't know, a person with a disability

eCAT NEWS

buying a product specifically designed to alleviate or help overcome a disability can claim VAT exemption on the purchase and/or repair of that product (and accessories) if using their own money. Equally, a registered charity buying or paying for the same items for a named user can also claim VAT exemption. However there is *no* VAT exemption allowed on extended warranty, regardless of who pays for it. I have spoken to John about this and suggested that he incorporate it in the final report (I was too late for the Interim Report) as the effect on income to Customs and Excise would be minimal, while the value to disabled people could be considerable. He has promised to give it careful consideration.

eCAT AND COMMUNICATION MATTERS

At the last eCAT meeting in February, Communication Matters' Chair Liz Moulam attended as an invited guest to discuss how Communication Matters and eCAT could work more closely together in the future. The discussion included such topics as the annual symposium and the value of suppliers at that event, Communication Matters Road Shows, clarification of the position of Commercial Members and Trusteeship, funding opportunities and how commercial members could help promote Communication Matters by including an A5 flier about Communication Matters in with every new product despatched.

Members agreed this was a very valuable contribution to the meeting and that it would be good for eCAT members to invite the Communication Matters' Chair to other meetings in the future when there were enough relevant topics for discussion.

THE FUTURE OF THE NHS EAT CONTRACT

The other major topic that is currently being discussed, but that did not appear before the last meeting (so is being discussed via email initially) is the future of the NHS EAT (Electronic Assistive Technology) contract, which is due to end in March 2009 and cannot be further extended. At a meeting I attended both as DynaVox Director and Chair of eCAT it was made clear that after March next year, communication aids will come under the Transforming Community Equipment Supplies system and NHS orders will be processed via Novation/DHL rather than direct between the NHS PCT and the supplier. We need to understand the implications of this, so I have invited the lead NHS individual to a future eCAT meeting to discuss it with us.

Finally, the eCAT sector was paid a high compliment by the BHTA Director General recently, when he said that although we are the newest of all the eighteen sectors of BHTA, he holds us up as a model section because of the way we work together, in spite of being competitors, and because of the amount of constructive and valuable dialogue that takes place, both eyeball-to-eyeball at meetings and via email. Just thought I would like to share that with you...

Dave Morgan, Chair of eCAT section, BHTA
Email: david.morgan@dynavox.co.uk



PRESS

RELEASES

New Lightwriter - New Management

Toby Churchill Ltd is celebrating its 35th year with the launch of their latest new generation Lightwriter - the SL40. As with all the range this is a dedicated communication aid but with a difference. Not only does the SL40 deliver text to speech communication it offers SMS texting facility, environmental control and many other exciting features. For more information or a demonstration from one of their product advisors contact them at sales@toby-churchill.com or call 01954 281210.

Toby Churchill Ltd is now under the ownership of David Collison, ex finance director. After 34 years, Toby decided to 'ease up a little' and has changed his role within the company to that of President. The change brings renewed vigour but does not alter the company commitment to bring dedicated communication aids to the market.

Sandra Hartley, speech and language therapist, has also come on board and is working with the research and development team to ensure a dialogue between users, professionals and researchers at all stages of design and development.

The dynamic changes will build on the recognised company ethos - 'Dedicated to Communication'.

AGOSCI 2009 Conference - Call for Papers

The AGOSCI 2009 Conference Committee is pleased to invite you to submit an abstract proposal for 'Communication FEEL THE POWER'. The closing date for abstracts is Friday 1 August 2008.

The conference will be held at the National Convention Centre, Canberra from 7-9 May 2009.

Information on abstract submission is available at: www.agosci.org.au

The MegaBee

The MegaBee is a new communication aid which aims to occupy a niche area in the provision of AAC for patients with extreme stroke, motor degenerative, or spinal trauma. The device is easy to learn, easy to use, and allows communication on a letter-by-letter basis with patients who are unable to speak and unable to write legibly. Originally it was developed for a locked-in syndrome patient at Stoke Mandeville and its use is extended to severe stroke victims and motor degeneration illnesses. Furthermore, one device can serve many people and thus it can be a general purpose tool, not a patient specific one. Further details about the MegaBee can be found at: www.megabee.co.uk

COMMUNICATION MATTERS



NATIONAL SYMPOSIUM

21-23 SEPTEMBER 2008 UNIVERSITY OF LEICESTER

The Communication Matters / ISAAC (UK) National Symposium is an annual event embracing a wide range of issues relating to augmentative and alternative communication. The two and a half day event provides a forum to meet and to exchange information with representatives from all disciplines associated with AAC, including people who use AAC and their family members.

SYMPOSIUM PROGRAMME

Platform Presentations
Practical Workshops
Case Studies & Research Papers
Seminars
Trade Exhibition
Guest Speakers
Social Events

REGISTRATION

All registrations allow full access to all the presentations and trade exhibition. The registration fee also includes refreshments, lunch and evening meals. Residential registration additionally covers accommodation in student halls (with breakfast). There is a substantial discount if you register and pay before 31 July. Prices from £345 for full residential registration.

There are a number of subsidised places for people who use AAC, and their family members.

BOOKING FORM & INFORMATION

For further information and a booking form, please visit www.communicationmatters.org.uk, or ring Communication Matters on 0845 456 8211 or email: admin@communicationmatters.org.uk





DIARY DATES

24 April 2008 PC-based Communication Devices and Software Contact ACE Centre: 01865 759800 www.ace-centre.org.uk	Oxford	18 June 2008 Developing and Using Low Tech Communication Contact ACE Centre: 01865 759800 www.ace-centre.org.uk	Oxford
24 April 2008 Software Awareness Day (Softease and TAG) CALL Centre: 0131 651 6235 www.callcentrescotland.org.uk	Edinburgh	19 June 2008 Kidz South Contact: 0161 214 5962 www.kidzsouth.co.uk	Reading
29 April - 1 May 2008 Naidex 2008 www.naidex.co.uk	Birmingham	3 July 2008 Recording in Mathematics for Students with Physical Disabilities Contact ACE Centre: 01865 759800 www.ace-centre.org.uk	Oxford
30 April 2008 Environmental Controls Contact PCAS: 0117 353 3613 www.pcas.claremont.bristol.sch.uk	Bristol	9 July 2008 Switches - Who, why and when? Contact ACE Centre: 01865 759800 www.ace-centre.org.uk	Oxford
6 May 2008 Low Tech AAC Contact ACE Centre North: 01457 829444 www.ace-centre.org.uk	Oldham	14 July 2008 Communicating with Children in Hospital: Study Day Contact: 0845 456 8211 www.communicationmatters.org.uk	London 
13, 14 & 15 May 2008 Communication Matters Road Shows: Ireland FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	Cork, Limerick, Dublin 	2-7 August 2008 13th ISAAC Biennial Conference Tel: +1 514-2871070 Email: isaac2008@jpd.com www.isaac2008.org	Montreal, Canada 
15 May 2008 Creating Motivational Activities for Users of AAC Contact ACE Centre: 01865 759800 www.ace-centre.org.uk	Oxford	21-23 September 2008 Communication Matters CM2008 National Symposium Contact Tel: 0845 456 8211 www.communicationmatters.org.uk	Leicester 
21 May 2008 The Grid 2 Contact ACE Centre North: 01457 829444 www.ace-centre.org.uk	Oldham	25 September 2008 An Introduction to Assistive Technology (AT) Contact ACE Centre: 01865 759800 www.ace-centre.org.uk	Oxford
28, 29 & 30 May 2008 Communication Matters Road Shows: Scotland FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	Glasgow, Edinburgh & Dundee 	October 2008 ISAAC International AAC Awareness Month Contact: info@aacawareness.org www.aacawareness.org	Worldwide 
29 May 2008 Software Awareness Day (Crick Software) CALL Centre: 0131 651 6235 www.callcentrescotland.org.uk	Edinburgh	16 October 2008 Boardmaker and its Application Contact ACE Centre: 01865 759800 www.ace-centre.org.uk	Oxford
4 June 2008 Communication Matters Road Show: Co. Durham FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	Murton, Co. Durham 	6 November 2008 Communication Matters Road Show: London FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	London 
10 June 2008 Introducing Clicker 5 Contact PCAS: 0117 353 3613 www.pcas.claremont.bristol.sch.uk	Bristol	12 November 2008 Communication Matters Road Show: Manchester FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	Manchester 
12 June 2008 Communication Matters Road Show in Ipswich FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	Ipswich 	26 November 2008 Communication Matters Road Show: Bristol FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	Bristol 
12 June 2008 AAC SIG Meeting: Advocacy and AAC Contact: 01216 278235 www.aacsig.org.uk	Oxford	11 November 2008 Aug. Comm. in Practice: Scotland - AAC & Autism Study Day CALL Centre: 0131 651 6235 www.callcentrescotland.org.uk	Fife, Scotland
12 June 2008 Speech Recognition Update CALL Centre: 0131 651 6235 www.callcentrescotland.org.uk	Edinburgh	20 November 2008 Kidz Up North Contact: 0161 214 5962 www.kidzupnorth.co.uk	Bolton
17 June 2008 Communication Matters Road Show: Oxford FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	Oxford 	<p style="text-align: center;">ACE CENTRE - ACCREDITED TRAINING MODULES</p> <p style="text-align: center;">Three accredited training modules are now available from the ACE Centre. For more details turn to page 30 or visit www.ace-centre.org.uk. Alternatively, ring the Training Coordinator at ACE Centre on 01865 759800</p>	
18 June 2008 Communication Matters Road Show: Worcester FREE Tel: 0845 456 8211 www.communicationmatters.org.uk	Worcester 		

Communication Matters' Submission to the Bercow Review

LIZ MOULAM

Communication Matters, c/o The ACE Centre, 92 Windmill Road, Oxford OX3 7DR, UK
Email: lizcommatters@aol.com

This is a two part report on Communication Matters' submission to the Bercow Review of Services for Children and Young People (aged 0–19) with Speech, Language and Communication Needs in England. The first part is a summary of the submission, with some background information. The second part is a comment on the interim report with respect to AAC; it is not summary of the entire report but highlights points relevant to associate members of Communication Matters and others.

SUMMARY OF COMMUNICATION MATTERS' SUBMISSION TO THE BERCOW REVIEW

In order to pull together the submission, the Board of Trustees consulted the associate membership of Communication Matters, the Friends of Communication Matters, the Communication Matters' Membership Guidance Group, together with the Trustees' own knowledge and experiences as parent, person who uses AAC, SLTs, teachers, suppliers, clinical scientist from diverse backgrounds and parts of the UK. We also included information from other ISAAC Chapters and from colleagues in Scotland, Ireland and Wales to add context to the overall picture. In addition, the Board of Trustees have worked with the following groups and individuals and this also informed the submission:

- Communications Consortium (third sector organizations that support the Communication Trust who have particular interest in AAC, including ACE Centre North and 1Voice).
- Scope
- Becta
- FAST (Foundation for Assistive Technology)

Communication Matters was represented at the AAC Focus Meeting hosted by Scope on 17 December 2007. The following groups were also present and worked collaboratively to plan and present evidence to Mr John Bercow MP and Anthony Thompson (Department for Children, Schools & Families). Attendees were:

Abigail Lock (Scope facilitator), Toby Hewson (AAC user), Dave Calvert (Park Lane School with specialist Communication and Interaction status), Hector Minto (Possum Controls), Chris Stevens (Becta), Nick Trapnell (Speech & Language Therapist), Liz Moulam (Communication Matters), Lalitha Iyer (1Voice), Anna Reeves (ACE Centre North), David Weatherburn (eCAT), Karen Fanthorpe (North Lincolnshire PCT), Ruth Scott (Scope), Marc Bush (Scope, note-taker).

Below is an abridged version of the Executive Summary of the Communication Matters' submission to the Bercow Review. A summarized version of the full submission is on the Communication Matters site: www.communicationmatters.org.uk

INTRODUCTION

The right of children and young people to be consulted as experts in their own lives and about services that are relevant to them is well documented throughout UK legislation and government guidance. Children and young people with SLCN and especially those who need AAC to convey their thoughts, feelings, wishes and opinions have the same rights to be consulted, to access education and communicate with their families, extended families and social networks as typically developing children and young people. Developing good communication skills is essential to developing self care and independence in adult life and early intervention and assessment is key to this. Communication Matters are delighted

that the Children's Plan demonstrates the government commitment to UK and international legislation. Whilst there are numerous recommendations within this submission we urged the Bercow Review to adopt as a priority the following:

Recommendation 1

A National Service Framework for All Children with SLCN

'The joint submission by Afasic, Communication Matters, RSCLT and Scope on Commissioning Incentives, January 2008.'

The aim of this is to use the current legislation with some added measures and exemplars to ensure local Commissioners do not lose sight of the need to use devolved funding to support those with SLCN.

Recommendation 2

The Need for Funding

The low incidence but high cost of providing equipment and ongoing support services for children and young people who need AAC and eAT for Communication has led to sporadic funding for equipment and ongoing services as well as disparate professional expertise. It is important to protect the professional expertise that exists at Regional Centres and in pockets throughout England. In addition effective provision must recognise that:

- a. Ring fenced central government funding for the supply of equipment and replacement, etc. to be managed by a broker.

b. Regional Centres of Excellence to be funded either by central government or through joint commissioning of pooled funding streams from Local Authorities (Children's Trusts) and Health using a formula based on the population of each Local Authority and expected prevalence.

c. Local Authorities and Health to jointly fund multi-disciplinary local teams to ensure wraparound provision of ongoing support in both school and home/social environments.

Recommendation 3

The Need for a National Organization for AAC

The overall awareness of AAC and eAT is low due to the level of incidence. Consequently the level of awareness of people who use AAC and eAT and their families is also low. Local Authorities have not seen the provision of AAC or eAT as a priority and consequently the right of the individual to be heard and be empowered has been overlooked. *The Communication Matters' vision is to establish personal empowerment, local ownership of provision of equipment and services, regional support and expertise and a national framework supported by a national organization, The AAC Trust*, for all people who need AAC and eAT of all ages*, although the initial focus would be on establishing services for the provision of equipment and ongoing support of those under 19 years. The approach would be a phased implementation over a period of time.

Note: The Board of Trustees believe that the current Memorandum and Articles of Association of Communication Matters allows the charity to expand and take on this role. We are the only organisation which covers the needs of *all* people who need AAC, whether congenital or acquired. We represent all age groups and the associate membership spans every group within the AAC community from families, to professionals, to suppliers across the whole of the UK. We are currently working on plans to move towards this goal and details will be presented at the Annual Meeting of Associate Members in September 2008.

Other recommendations

Assessment and provision of AAC is paramount, by establishing commissioning incentives, ring fenced funding and a national body to oversee the process, it is believed that the other priorities and recommendations will be achieved as a by-product providing the recommended infrastructure is established. These are:

- Assessment of Need and Provision;
- Training and Support in Education;
- Training and Support for Families and Social Networks;

- Children and Young People as Achievers;
- Transition;
- Research relating to AAC and eAT.

Conclusion and next steps

It is clear that to fulfil its legal and statutory commitments the government of England must consider carefully its provision of equipment for children and young people who need AAC and ongoing support services.

Communication Matters hope that government will adopt the recommendations for the provision of equipment and ongoing support services for children and young people who need AAC. It is therefore with great interest we received the interim report and some of the highlights are below:

THE JOHN BERCOW INTERIM REPORT

Throughout all the meetings Trustees attended with John Bercow during the consultation period, he has consistently showed empathy for those children and young people who need AAC to communicate.

The 122 page report, published on 20 March 2008, includes many of the points Communication Matters made following our own consultation about the challenges faced by provision of AAC equipment and on-going services.

Within the report it is possible to identify the main challenges faced for children and young people requiring AAC in many of the points being made more generically for those with speech, language and communication needs (SLCN). The surprise, or maybe not, throughout the report is the lack of support for all SLCN especially in secondary school. There are some specific mentions of AAC, and these are no more or less than other named SLCN. Overall the report is a summary of the present day situation for those with SLCN and has not attempted to suggest solutions, particularly as this interim report is now out for further consultation.

Chapter 1 deals with comments made by families, the next steps includes several suggestions made within the Communication Matters' submission, although they might well have been made by many other people as the issues are common to all SLCN.

Chapter 2 covers commissioning incentives, the need for commissioners of services in Children's Trusts and PCTs, plus others, to work together and have good guidance on how SLCN should be met. The AAC Focus Group, which was facilitated by Scope and attended by mainly Communication Matters' associate members identified ways in which joint commissioning could be incentivised

across agencies. This was taken up by Scope and became a joint submission to the review from Scope, the RCLSLT, Communication Matters and Afasic.

Chapter 3 is about the right workforce, leadership and accountability. This highlights the need for skilled experts to be part of assessment and early intervention teams, but that emphasis must also be about developing the workforce to support older children and young people. It was noted that support should be extended to families and everyday activities taking place not just at school but at home also. This chapter highlights the need for Education and Health to work together, to establish accountability for SLCN, to review SLT resources and to reassess local authorities' accountability for provision on SLT for statemented pupils.

Examples of low incidence, high cost provision services included a case study of The Ace Centres. With the withdrawal of government funding and core funding from the Gatsby Charitable Foundation both centres have made some staff redundant and without new funding will continue to lose expertise. This situation is not unique to The ACE Centres and equally applies to many of the other specialist centres that are funded by PCTs.

Throughout the summary of responses to the on-line questionnaire, AAC gets a mention in nearly every relevant section, from the need for professionals with specialist training in AAC, to funding for AAC with no organisation (health or education) being responsible for AAC. Specifically the report mentions (p86) the responses received from young people who use 'VOCA and AAC equipment' who stated they were reliant on their communication aids to express themselves and make themselves understood. Our thanks go to all of them and to everyone who helped to make this happen - no other group of young people got this type of mention.

The Communication Matters submission was comprehensive, with recommendations in all the areas the review is looking at. We remain optimistic that these recommendations will be included when the final report is issued.

To further influence the final report, we need now to respond to the interim report with further evidence and comment. A link to the full copy of the Bercow interim report can be found at www.dcsf.gov.uk/bercowreview.

Please send all feedback to me at lizcommatters@aol.com by 30 April 2008.

*

Liz Moulam
Chair of Communication Matters

Keeping Pace with (Assistive) Technology

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INTRODUCTION

This paper presents an overview of a European Commission funded project researching the learning needs of professionals working with people who use assistive technology (AT). An introduction to the project is followed by an overview of its structure. Two main areas of the project have been selected for description: the training needs analysis and the development and provision of AT training guidelines.

The aim of the Keeping Pace with (Assistive) Technology (KPT) project was to understand and promote the life-long learning needs of professionals working across Europe with people with disabilities in health services, social services and vocational training/job orientation (doctors, physiotherapists, occupational therapists, speech and language therapists, social workers, educators, rehabilitation engineers, trainers, tutors, psychologists, etc.).

The project, running from 2004 to 2007, focused on the skills development associated with Assistive Technology applications, in particular in those areas where technology develops relatively rapidly: aids for communication, computer access, and environmental control. As professionals belonging to the target audience indicate, they often lack the specific competences needed to know how technological aids can support rehabilitation, independent living and social inclusion programmes, tailored to the individual needs of people with disabilities. One of the reasons is the rapid development of assistive technology that quickly outdates the initial training knowledge of the target audience. Another reason is a perceived lack of knowledge related to factors that can support AT intervention, such as methods of and benefits in interdisciplinary teamwork and appropriate timing of interventions. These professionals can make their interventions more effective and efficient if they have access to appropriate learning opportunities in a life long learning perspective.

Many professionals belonging to the target group have university qualifications but lack opportunities to update their knowledge or to find AT related support in managing cases. In

many parts of Europe there are a number of organisations in health, education and social services including Assistive Technology centres, that work in close contact with local services, normally in responding to the needs of AT users and contributing specific knowledge and skills related to inclusive technologies. Recognised as important resources by public authorities the number of independent AT Centres, and other organisations in the AT sector is rising in Europe, and providing training and support to professionals in the field is considered to be one of their main activities. Nevertheless not all these organisations have as yet optimised their training practice, although important initiatives that aim to respond to training needs of professionals are under way in Europe such as the European Qualifications Framework (EQF) website: ec.europa.eu/education/policies/educ/eqf/index_en.html. AT services in the UK are excellent in many instances but it is clear that there is much to be gained from understanding a wider European perspective and from reflecting on what it is that professionals actually need to support their ongoing professional learning beyond their initial training.

STRUCTURE OF THE PROJECT

This project was administered by research partners in Italy and comprised clinical/academic members from: Italy, Ireland, Belgium and the UK. The first phase of the KPT project compared the training practices of various European AT Centres and University initial training courses, linking those outcomes to changing social inclusion policies in the involved member states and regions. The AT training needs of the target audience were then analysed. During the second phase guidelines were developed to direct and support training provision to the target audience. The guidelines were developed to refer to the various learning opportunities a professional will come across during his/her career (initial training at University or vocational training, managed training programmes and informal learning through case management support). Finally, examples of training units that reflect these guidelines were developed. Target

audience representatives were involved in all phases of the project, as well as people who use AT, being direct stakeholders.

OVERVIEW OF TRAINING NEEDS ANALYSIS METHODS AND RESULTS

This training needs analysis investigated into the assistive technology training needs for professionals who work with people with disabilities but who do not necessarily classify themselves as AT specialists. Drawing on existing research and models (Heart Line E project, 1995; TELEMATE, 1999; EUSTAT, 1999), the analysis identified professionals within three key groups: clinical, technical and social/administrative. Professionals within these groups were selected to represent the areas of AAC, environmental control and computer access in the areas of home, work, vocational/educational, community/leisure and medical settings. Research participants were identified across the partner countries with reference to their use of AT centres and/or their known input to AAC services within each country.

A questionnaire was designed to explore participants' perceived training needs. The questionnaire design was informed by a combined model developed from the Heart Line E project (1995), WHO ICF classification (2001) and informed by work of the TELEMATE (1999) and EUSTAT (1999) projects. Information about, and links to, all of these models and references can be found on the Keeping Pace with Technology website (see below). The questionnaire sought to identify: information about the respondent, formal experiences of education and perceived training need for formal education, work focused training experiences and perceived needs and preferred learning styles and experiences. It is possible that the participants selected for this type of task may have lacked a comprehensive understanding of their own training needs, that is, knowing what it is they need to know. Therefore the questionnaire was designed to represent a menu of training possibilities from which the participants might choose. Opportunities to provide qualitative comments were included. A small pilot study was conducted by the English partners and the questionnaire design was validated by peer review within the KPT consortium. In total 135 questionnaires were completed for this study.

The proportion of respondents reporting that they studied aspects of AT as part of a professional training programme was relatively low (20% n=27/135). The remaining 80% reported no experience of AT related training as part of formal education. Of those receiving AT focused education, SLTs made up the greatest proportion (see Table 1).

Profession	Frequency	Percent
Physiotherapist	1	3.7
Doctor	2	7.4
Teacher / educationalist	4	14.8
OT	7	25.9
SLT	13	48.1
Total	27	100

Table 1 Professions studying aspects of AT as part of formal education

Of this sample, 81.6% (n=22/27) reported favourably (defined as fairly useful or useful or very useful) on their AT related education in terms of its preparation for working in the AT field. The remainder (26% n=5/27) reported that their AT education had not been useful.

A high proportion of respondents reported no pre-qualification learning in AT but also indicated a desire to develop knowledge

and skills in this area. Respondents identified that keeping pace with new developments in AT technology and increased demand for AT were the most significant challenges to their current work that may imply a training need.

Of the sample of respondents that had received post-qualifying AT training (n=83), 79 answered the question concerning the usefulness of their training. 49.4% (n=39/79) reported that it had been 'very useful', 40.5% (n=32/79) reported that it had been 'useful' and 10.1% (n=8/79) said it had been less useful, categorising it as 'fairly useful'. Across the sample, working with a colleague and face-to-face training were perceived to be the most effective way of delivering training (mean score 1.5). Private research and distance learning and study for formal qualifications were less well viewed as effective methods of training delivery (see Table 2).

Training Method	Mean Score*
Working with a colleague	1.5
Face-to-face	2.4
Secondment	3.9
Visiting good practice	4.2
Private research	6.0
Distance learning	6.3
Study for formal qualification	6.4

Table 2 Mean score of effectiveness of training method

* Participants rated methods from 1 to 7, with a score of 1 representing the most effective method and 7 the least effective method

Respondents choosing to provide qualitative information about training and learning in AT commonly reported that they had developed skills and knowledge through everyday work experience with support from colleagues some of whom may have a specific role as an AT advisor. A selection of comments received included:

"Learning from others."

"(I) learned by experience and from other team members - asking colleagues with experience."

"Although we had a full course on AAC in my SLT program, most of us (including myself) never had a placement or any practical experience with people who use assistive technology until after we had graduated... when I got my current job... in which I deal mainly with people who use AAC and other forms of assistive technology, I had forgotten most of what I had learned about this area in university, and I had to re-learn it on the job."

"(I) have learnt on the job with advice from AT advisor."

"On the job with help from AT advisor."

Interestingly topic areas highlighted as high areas of need for training included: (1) identifying clients' levels of functioning, in particular cognitive skills, (2) assessment for AT, (3) outcome measurement, and (4) functional use of AT.

The training needs analysis revealed many interesting issues (see KPT website for full report), and similarities in training needs were seen across the European partners. The training needs analysis also confirmed the likely benefit of guidelines for those delivering training and for professionals working in multiple environments; in multi-professional teams, and across national boundaries.

The Guidelines themselves were subsequently developed through working parties and discussion amongst all members of the research project team. Consultation with validation panels, including experts in the AT and related fields, and users of AAC, were held in each participating county. The result was a draft Guidelines document that was then reviewed and modified over a series of stages to produce the final version.

OVERVIEW OF THE KPT TRAINING GUIDELINES

In this section an overview of the training Guidelines is presented together with recommended core principles for all AT training that are outlined in the guidelines, and a brief description of guidelines for structuring a learning programme. A full description of these guidelines and principles can be found on the KPT website (see below). It is recommended that readers do refer to the full Guidelines for information and ideas on developing their own learning programmes.

A BRIEF OVERVIEW

The Guidelines were developed for trainers involved in delivering AT learning programmes in communication, computer access and environmental control, at undergraduate or postgraduate level, or outside formal education and training. They presuppose that trainers have effective knowledge and skills in AT and are likely to have already been involved in delivering learning programmes for those working (or who will be working) in this field. Training providers would also have the appropriate knowledge and competence in basic training procedures, interaction with learners and methods of supporting learners throughout the learning process. That said, these Guidelines should also be useful for people intending to begin training delivery and well as professional organisations, national accreditation bodies and industrial federations. The Guidelines could also be used to influence the writing of policy documents, including government policy documents that highlight the need for AT Training. The Guidelines aim to provide a flexible framework for designing learning programmes. A learning programme may be defined as:

'An inventory of activities, learning content and/or methods implemented to achieve education or training objectives (acquiring knowledge, skills or competencies), organised in a logical sequence over a specified period of time.'

Commission of the European Communities, *Towards a European Qualifications Framework for Lifelong Learning* [Commission Staff Working Document] (SEC (2005) 957, July 2005), p. 46.

The learning programmes might take place in a variety of settings including for example, an AT Centre, a university (or other types of educational establishment), a workplace specialising in one or more AT fields, or a client's home etc., and embraces a wide variety of different ways of learning.

The framework (Figure 1) for the Guidelines is based around a number of processes that programme designers consider throughout planning and delivery (see Figure 1). The Guidelines begin with an analysis of training needs. They then move on to consideration of the learning level (foundation, intermediate, advanced and mixed levels), aim, objectives and the learning outcomes. Development of content detail and the choice of method or methods of delivery are then considered. Finally, the learning programme can be matched against the original findings from the analysis of training needs.

It is expected that users of the Guidelines are likely to move flexibly between its elements as the learning programme is developed and refined. Flexibility and adaptability are important in programme design, as the past experience and current needs of those involved in the learning programme may be very variable.

AT CORE PRINCIPLES

The Guidelines advocate a set of core principles relating to AT which need to be considered to ensure that AT achieves its optimum potential. All trainers will need to be aware of these principles when designing and delivering any learning programme. The Guidelines also recommend that consideration should be given as to whether there will be a specific learning outcome, or learning outcomes, written for one or more of the principles. A learning outcome is a statement of what it is the learners will or should be able to understand or do following completion of a learning programme. Ideally then, learn-

ing outcomes should be measurable. As an alternative, the core principles may underpin the course content without a specific learning outcome relating to them. This depends on the learning needs of the participants and the specific course being designed. The Guidelines propose that the following principles should form the basis of any learning programme related to AT:

- The client and people significant to the client (family, friends, carers and supporting professionals) must be at the centre of all assessments, support and training with the aim of maximising autonomy and participation for the client.
- A range of people (including the client and people significant to the client) should be involved in finding an appropriate solution. This range will be dependent on the needs of the client.
- The needs of the client, the context, and the client's environments within which technology will be used must be taken into account (i.e. the adoption of a holistic approach).
- The attitudes and expectations of the client and people significant to the client must be taken into account during assessment and support.
- Assessments, support and training for clients with complex needs should be carried out by a multi-professional team.
- AT should be seen as a tool, not an end in itself. How the technology is used is more important than the technology itself. In some situations AT may not be the solution.
- Learners should be aware of the importance of lifelong learning for themselves and for the users of AT and people significant to them.
- The AT assessor/support worker has a clear responsibility in managing the expectations of the client and in promoting independence, not the development of dependency.

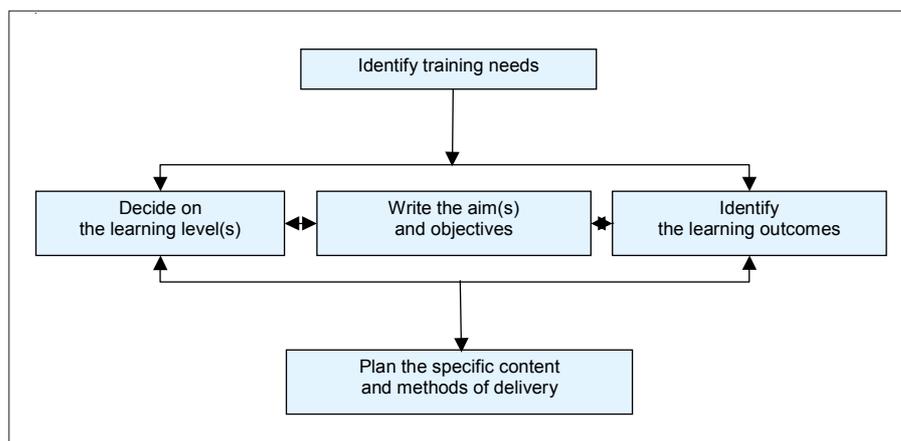


Figure 1 Framework for designing learning programmes

• Ethical issues are of extreme importance in any service-related profession and reference should be made to these issues in all learning programmes. *Towards a European Qualifications Framework for Lifelong Learning* states that these ethical competencies involve 'the possession of certain personal and professional values.' Examples of relevant ethical issues are: maintaining the confidentiality of privileged information and not using photographs or videos of clients in learning programmes without their permission. The Rehabilitation Engineering and AT Society of North America gives a comprehensive list of ethical issues in its Code of Ethics (see www.resna.org/AboutRESNA/CodeEthics/Ethics.html)

STRUCTURING A LEARNING PROGRAMME

Guidance is also given on structuring a learning programme including for example, deciding on learning levels relating to the experiences of the learners involved, designing aims, objectives and learning outcomes, as well as methods for achieving learning outcomes. For instance, the Guidelines relate to the design of training at three broad levels that are related to the EQF. Such levels can refer to entire learning programme or to single learning outcomes:

FOUNDATION LEVEL

This level is intended for those new to the field of AT. Learning programmes at this level would typically introduce general and basic concepts related to AT and/or provide an overview of an area of AT.

Intermediate Level

This level is intended for those who already have some basic knowledge and experience in a relevant field. Learning programmes at this level would typically provide a comprehensive study of an area of AT.

Advanced Level

This level is intended for those with a good working knowledge of and a variety of experiences in a relevant professional field. Learning programmes at this level would typically provide an in-depth study of one or more areas of AT.

So for example, a foundation level learning event might also aim to prepare students or professionals with a general interest in AT, but no expectations about direct involvement in 'hands on' service delivery to people with disabilities, or those with an interest in AT at this level, though in their professional field they may be working at a different professional level, for example a consultant paediatrician who wishes to know about AT, so he/

she can refer clients to the relevant service.

As a practical resource the Guidelines also provide useful materials including for example, checklists for planning a learning event, a template for designing learning programmes, and examples of learning programmes illustrating the guidelines in use.

Overall, the Guidelines represent a practical outcome informed by current research, existing models/frameworks in the fields of disability, AT and learning and expert consultation with specific reference to AT learning. The Guidelines themselves are intended to be used by trainers to facilitate the development of high quality and responsive AT learning programmes.

CONCLUSIONS

The KPT project has provided its researchers with an opportunity to learn from each other at a European level and also to reflect more locally. In appreciating the needs of learners and the fact that AT learning needs inevitably change throughout an individual's career, the project findings remind us that training and learning are complex issues. This complexity arises in part from the interplay between learning needs, preferred styles and the different demands of each professional's role. It is hoped that the project outcomes will be useful to individual professionals, AT Centres responsible for training and support, university teachers, employers in health, social services and vocational training. The outcomes are available through the project web site while a brochure in English, Italian and Dutch, summarising the project outcomes and referring to the website (see below), has been published and disseminated directly by the partners through conferences and direct mail.

As noted, this article only provides a flavour of the project and the guidelines. We strongly recommend that readers visit the project website for references and many more details of this project, including downloadable guidelines and sample learning programmes.

FURTHER INFORMATION

For further information, please visit the Keeping Pace with (Assistive) Technology website: www.at4inclusion.org/kpt/kpt_project.php

Steven Bloch
Speech & Language Therapist & Lecturer
Michael Clarke
Speech & Language Therapist & Lecturer
Ann Gresswell
Teacher & Physiotherapist

DVDS AVAILABLE

The Power of Communication

This film by Communication Matters delivers a powerful message that communication really does matter. The DVD is an introduction to AAC, and celebrates and promotes communication in all its forms. It is of general interest, and in particular to service managers and purchasers who have responsibility for AAC services.

Preview it online:

www.communicationmatters.org.uk

DVD available (£8) from:

Communication Matters
c/o The ACE Centre, 92 Windmill Rd,
Oxford OX3 7DR Tel: 0845 456 8211
admin@communicationmatters.org.uk

Listen to Me

A new DVD from a group of young people who use alternative ways of communicating. These disabled teenagers, who have severe communication impairments, have come up with their Top Tips on how to make sure they are listened to and consulted with.

DVD available (£8) from:

1 Voice, PO Box 559, Halifax HX1 2XL
Tel: 0845 330 7862 info@1voice.info
www.1voice.info

ACE CENTRE ACCREDITED TRAINING

- **Augmentative & Alternative Communication (AAC)**
- **Access & Control**
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These three training modules, developed by ACE Centre Oxford and ACE Centre North, can be completed as standalone courses which will be valuable CPD for anyone working with people with communication difficulties (spoken or written) or with physical and coordination. The modules can be accredited and may be combined to accrue the required number of CAT points to obtain a qualification at graduate or postgraduate level.

For further information about accreditation and costs for combined modules please contact the Training Coordinator at ACE Centre Oxford on 01865 759800 or email: training@ace-centre.org.uk

The Politics of High-Tech AAC in England and Wales

MARC BUSH & RUTH SCOTT

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SETTING THE SCENE

The past eleven months has seen a renewed political awareness of children and young people's issues surrounding the provision, use and support of Alternative & Augmentative Communication (AAC) in England & Wales. In September 2007 the government asked John Bercow MP to lead a review¹ into Speech, Language & Communication Needs (SLCN) in children (0-19 years of age) in England². The review is currently underway, with the Interim report published in March 2008 and the final report due in June 2008.

The Review was seen by the AAC community at large as an opportunity to bring AAC back to the table and raise awareness about the current crisis in the funding and support of AAC. The national disability charity, Scope in collaboration with others in the third sector (including the ACE Centres, Communication Matters, IVoice and The Communication Trust) has been working hard to ensure that the outcomes of the Bercow Review are meaningful for the whole AAC community.

PROGRESS TO DATE

Over the past seven years there have been a number of government initiatives to address the provision of communication equipment; but few localities have managed to build lasting capacity in the system. In 2001 the Department of Health announced £105 million funding for Integrating Community Equipment Services (ICES). Communication aids were included on the list of *disability-related community equipment*. The guidance explicitly stated that 'the government's intention [was] that some of the additional funding for equipment services should be directed to improving provision of communication aids'³. However, when surveyed in 2004, a year before the funding came to an end, 81% of ICES services had not yet begun work on AAC provision, maintenance or support⁴.

Similarly, in a more recent review of community equipment services (*Transforming Community Equipment Review*) in 2006, the Department of

Health proposed a new model of community equipment provision⁵. The proposed *Retail Model* has not addressed the specific issues associated with providing specialist AAC equipment, assessment or on-going support. Scope and others have raised these issues with the Department of Health, along with concerns about the continuing funding crisis for AAC.

Scope has told the Department that the *Retail Model* needs to be reassessing to establish how it will effectively provide AAC. We have also said that if it is concluded that the model cannot meet the needs of AAC users and those who support them in doing so, alternative provision must be made.

The government initiative with the most impact on the current state of communication equipment provision in England & Wales was the government funded Communication Aids Project (CAP)⁶. In 2002 the then Department for Education and Skills (DfES) provided, through CAP, £5 million per year for three years for expert assessment, communication

equipment and training for *school-aged* children, as a complement to local provision. Equipment was provided to more than 4,100 children, who could not get their needs met locally. Funding for CAP ran out in March 2005 and approximately 180 children on the CAP waiting list were left without equipment.

Whilst CAP provided much needed ring-fenced funding over the lifetime of the project, resulting in more children getting the equipment they need, it was always designed as a short-term, education-focused programme. The end of the ring-fenced funding highlighted the problems associated with devolving responsibility for funding high-cost equipment for low incidence impairment groups to local authorities and primary care trusts. The low incidence of people of all ages with complex Speech, Language & Communication Needs (SLCN) and the high cost of providing expert assessment, expensive equipment and on-going support, means that local health and equipment service providers do not prioritise the needs of this group of disabled people.

The government's intention was that CAP would build capacity in local authorities to provide and support communication aid use once CAP closed. Though some areas did build up considerable expertise, partnerships and infrastructure, most local authorities did not manage to create a viable, local or regional model of provision. Consequently the postcode lottery of provision in England & Wales remains.

Those children who received equipment through CAP had their expectations and life chances significantly increased. Three years on however, many face significant difficulty in getting their equipment upgraded, replaced or repaired. Withdrawing CAP funding and not replacing it with a broader, all-age, initiative has served to undermine the very positive achievements that the project made in some localities.

NO VOICE, NO CHOICE

In 2000 Scope launched a campaign called *Speak for Yourself*⁷ aiming to establish a statutory right to communication equipment. The *Speak for Yourself* campaign which ran from 2000 until 2001 and contributed to the establishment of CAP. At the first year anniversary of the closure of CAP in March 2006, Scope held a lobby of parliament to highlight how the lack of a statutory right to communication aid provision and support negatively impacted on those individuals who could benefit from the use of AAC. This lobby of parliament culminated in a petition signed by thousands of individuals being delivered to Number 10 Downing Street.

No Voice, No Choice: Disabled people's experiences of accessing communication aids

Research Highlights:

- Almost a third of survey respondents did not get their equipment funded by a statutory agency.
- The average cost of a communication aid in 2007 was £5,800.
- Only 65% were able to try out different communication systems.
- 19% of respondents had not received any training on how to use their communication aid and 14% of people taught themselves how to use their aid.
- 64% of respondents using high-tech communication equipment needed someone else to program their device for them.
- 44% of respondents said that people closest to them had not been trained or did not know how to use their communication equipment.
- 66% of respondents were not provided with a replacement communication aid when theirs broke down.
- A third of respondents did not have an effective back-up communication system for when their communication aid was unusable.
- Only 60% of respondents' communication aids came with a warranty or guarantee and 43% of these guarantees or warranties were valid for less than one year.

The full report and analysis can be found at: www.scope.org.uk/disablism/downloads/scope-no-voice-no-choice_report07.pdf

In April 2007 Scope and BT launched a partnership to research and actively campaign on the provision and support of AAC. This campaign is called No Voice, No Choice. Scope has published a number of reports and briefings from this campaign which can be found at www.scope.org.uk/disablism/communication.aids.shtml

Between July and September 2007 Scope conducted a survey into the experiences of people who use AAC: the Scope Communication Aids Survey 2007⁸. The results of this research were published in November 2007 in the report 'No Voice, No Choice: disabled people's experiences of accessing communication aids'⁹ and was launched in parliament. This report highlights the current state of provision and support in England & Wales of communication aids for people who use AAC.

FUTURE OPPORTUNITIES

Whilst the account given above may seem pessimistic, more recent opportunities and initiatives could go some way to resolving the current disparity in provision and support.

THE COMMUNICATION TRUST

In June 2007 Scope welcomed the establishment of the Communication Trust¹⁰ by Lord Adonis, and alongside it the establishment of the Communication Consortium; the third sector reference group for the Trust. The purpose of The

Communication Trust is to raise awareness of the importance of speech, language and communication across the children's workforce and to enable practitioners to access the best training and expertise to support the communication needs of all children. The Trust was founded by Afasic, BT Better World Campaign, Council for Disabled Children and I CAN. This small core group is supported by a number of partners and stakeholders.

The Trust is supported by over 20 voluntary and community groups who deliver services and support to children with Speech, Language & Communication Needs (SLCN). The Communication Trust is also working closely with a number of lead bodies in the field of workforce development including the Children's Workforce Development Council (CWDC) and the Training and Development Agency for Schools (TDA) and with professional groups in the field of speech, language and communication including Royal College of Speech and Language Therapists (RCSLT) and National Association of Professionals concerned with Language Impairment in Children (NAPLIC). The Trust's work is been supported by the Department for Children, Schools and Families and other funders. The Trust is hosted by I CAN and works to a representative board.

There has been an increasingly strong representation of organisations representing AAC issues on the Communication Con-

sortium; including Scope, Communication Matters, ACE Centre North and IVoice – Communicating Together. Scope, with its partners, is supporting the work of the Communication Trust and the Communication Consortium in its development of resources for workforces. An illustration of the initial work being done in collaboration is the Communication Trust's publication 'Explaining Speech, Language & Communication Needs' authored by Scope, I CAN & Treehouse¹¹. This document sets out a definition of SLCN which has been endorsed by the 25 organisations represented on the Communication Consortium and is a real achievement in getting, for the first time, a sector-wide agreed definition.

THE SPEECH, LANGUAGE AND COMMUNICATION FRAMEWORK (SLCF)

The Communication Trust is currently working on a pilot Speech, Language and Communication Framework (SLCF)¹². This will identify the skills and knowledge necessary for the children's workforce to support children's communication effectively, support the inclusion of children with SLCN and create the best outcomes for children mapped against the Every Child Matters agenda. The Framework aims to support managers in assessing the skills and knowledge of their staff and to identifying staff training and development programmes that help staff develop appropriate skills. The SLCF is being developed as an online audit tool that individuals and institutions can use to consider what areas of speech language and communication they may need to develop skills and knowledge in. The framework updates the Joint Professional Development Framework (JPDF), which set out joint training requirements for education and speech and language therapy colleagues working with children and young people with speech, language and communication needs. Scope, Communication Matters and ACE Centre North have been feeding into the development of this framework and influencing how AAC is conceptualised within the framework-in-progress.

INCLUSION DEVELOPMENT PROGRAMME

In October 2007, the Department for Children, Schools and Families launched the Inclusion Development Program (IDP)¹³, which takes forward the commitments made in the government strategy for Special Educational Needs (SEN) *Removing Barriers to Achievement*¹⁴. Over four years, the IDP will develop and deliver a programme of Continuing Professional Development (CPD) designed to strengthen the confidence and expertise of mainstream staff in Early Years settings

Executive Summary of Scope's Recommendations to the Bercow Review

- Acknowledge that communication is a basic human right and the right to communicate should include the right to the necessary equipment and support across all age groups.
- Collect national statistical data on the number of people in the UK with speech, language and communication needs as well as the numbers who would benefit from AAC across all age groups, including under-fives and people over 65.
- Collect national statistical data on the numbers of people of all ages in the UK who would benefit from AAC who are not getting their needs met.
- Implement recommendation 5.6 of the Improving the Life Chances of Disabled People report as a matter of urgency.
- Establish performance indicators for provision of AAC equipment, including guaranteed minimum standards and timescales for provision and a guarantee that equipment can be used anywhere.
- Clarify which local agencies are responsible for funding AAC equipment and clarify circumstances in which agencies should pool funding.
- Implement the recommendations made by Scope, Afasic, Communication Matters and the RCSLT on commissioning incentives at the Regional/Local Level (LAs & PCTs), practice-based commissioning and on joint-Commissioning.
- Ensure that the Department of Health's Community Equipment Review and the Communication, Speech and Language Review being led by John Bercow MP specifically address the needs of those who use AAC.
- Commission the development of a range of possible service models that can meet the needs of people who use AAC, address the current postcode lottery of provision and enable economies of scale through bulk purchasing.
- Establish minimum training standards on AAC use for SLTs, OTs and GPs and access to a specialist resource and information portal.
- Establish a 'core offer' for all children, young people and adults with a Speech, Language & Communication Need (SLCN).
- Support further research and development into AAC technology to improve the functionality, ease of use, design and reliability of AAC equipment and reduce the unit cost.
- Take action to prevent the loss of skills and knowledge around AAC by ensuring that existing centres of excellence on AAC assessment and provision do not fold due to lack of resources.

and in primary and secondary schools in ensuring the progress and achievement of pupils with Special Educational Needs (SEN). The focus of the IDP during the first year is on Speech, Language & Communication Needs and dyslexia. Throughout the remaining three years of the programme, the focus will be on autistic spectrum disorders (ASDs), behavioural, emotional & social difficulties (BESD) and moderate learning difficulties (MLD).

THE BERCOW REVIEW

As mentioned previously, one of the key political interventions currently being undertaken in England in terms of AAC is the Bercow Review of Children, Young People and SLCN. Whilst this review is only focused on children and young people in England; it does offer an opportunity to not only raise political awareness of AAC,

but also provides a forum for collaboration and innovation in terms of policy development. Scope, with other organisations, has been working closely with those supporting the Review to ensure that AAC provision is meaningfully included in the review and its recommendations.

In December 2007, Scope facilitated a focus group on AAC for the Bercow Review which explored the themes of: experiences of the use AAC, identification and awareness, commissioning, training and support, equipment, and models of provision. The focus group was made up from representatives from organisations working in the field of AAC, including people who use AAC and their families, commissioners of services, health and education professionals, assessment centres, speech and language professionals, and manufacturers of communication equipment.

continued on page 37...

AAC – More Than Just Speech Therapy

KAREN SHEFFIELD¹ & HELEN MILLWARD²

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In our presentation 'AAC - More Than Just Speech Therapy' given at the Communication Matters National Symposium in September 2007, we highlighted how developing an AAC system for children with complex needs depends on more than just having access to a speech and language therapist.

We suggested that having access to other professionals is often dependent on developing local and regional services across disciplines which could mean moving away from a *multi-disciplinary model*, where each discipline is independent and do not necessarily consult or interact with each other, to a *trans-disciplinary model* where professionals collaborate closely in order to problem solve and share expertise.

What do different professionals bring to the process for children who might benefit from developing AAC skills?

The speech and language therapist (SLT) is often the professional who starts the process, although in our experience there is an increasing number of situations where the process begins with someone else who makes a referral to the SLT. Within the SLT profession, AAC is often seen as a specialist area, but again our experience has shown that across departments, knowledge of AAC is increasing at

a generalist level so that local therapists may meet the AAC needs of their clients. Occupational therapists (OTs) are trained to assess a child's posture in different seating systems and will be able to advise about which system enables the child to make the most useful movements. They also have skills needed to identify and consider how equipment can be used functionally, and how to break tasks down into different aspects, for example, the interplay of cognitive and motor components. Some OTs will have experience of looking at the use of switches for different activities and identify a suitable switch site.

There are situations where the Physiotherapist will hold the major role in looking at an individual's posture and they will be able to advise on the suitability of a movement being identified for switch operation. Physiotherapists have specialist knowledge about how a child's muscle tone impacts on what the child is doing and they will be able to help the team consider the long term impact that a repeated movement may have on an individual's posture and long term function.

Special Advisory Teachers, for example, Teacher for the Visually Impaired, are the professionals who can help provide information about specific impairments and

how this may impact on the proposed system. They can help the assessment process by sharing specific information about the individual's level of functioning and can suggest different techniques and equipment that can assist in overcoming some of these difficulties.

Class Teachers are important, not only because they are the ones with the child throughout the school day but because they will be able to help the team identify situations in the classroom environment in which an AAC system may help the child's communication. What can be quite challenging is identifying ways in which the AAC system can help the child access the curriculum whilst helping them become more effective communicators in social situations.

Classroom assistants or Learning Support Practitioners are vital members of the team as they are the ones who will be providing most of the daily support within the school environment and will often take on the majority of the programming. They are often the people who will have to set up the equipment for the child to use and transfer it between the different environments that the child is in.

This article discusses the roles of the different professionals involved in the process of looking at AAC but it must be remem-

bered that families too have a vital role to play in this process and can share information about the child that nobody will have.

IDENTIFYING STRATEGIES TO ENCOURAGE OTHER PROFESSIONALS TO PARTICIPATE IN ASSISTING CLIENTS TO DEVELOP AAC SKILLS

In the West Midlands, a Multi-Disciplinary Working Party developed an AAC Care Pathway with the aim that its use will ensure an improved level of service for those clients who need alternative/augmentative methods of communication. The Care Pathway enables professionals, and in some situations the client and their families, to highlight the information that is needed at different stages of the assessment process and the ways in which this is obtained. Using the care pathway also helps the co-ordinator of the team know how far the local team can get in the process and when they need to enlist support from other services. (For further information about the AAC Care Pathway please see our website www.actwmids.nhs.uk/AAC/care-pathway)

The following case study will show how a local therapist working within a Special School was able to access regional specialist services for specific support and timely intervention.

THE SCHOOL

The Orchard School is a day school, which provides education for children of primary age (2 - 11 years) with complex and severe learning difficulties and/or physical difficulties. It takes children from across the borough of Sandwell in the West Midlands and has a high proportion of pupils from different ethnic backgrounds. All the children have a Statement of Educational Need, or are undergoing an assessment for a Statement. Formed in 2000, following a reorganisation of the local education authority's Special Needs provision, the school has adopted the vision of being a Total Communication Environment. There is a long history of collaborative working within the school and the Head Teacher, supported by the members of the Senior Management Team, actively supports team-working across professions and the moving of boundaries. Developing the pupils' communication skills is always a priority for the school and this commitment is in part, demonstrated by the school having employed its own speech and language therapist since 2002.

THE CLIENTS

When this process started, three children on my (Karen's) caseload had been referred for a high tech AAC assessment system. All three had different physical difficulties and therefore different AAC needs.

Jessica was four years old, non-ambulant and has cerebral palsy with athetoid movements and additional learning difficulties. She was very motivated to communicate, and when she was referred for the assessment, she was just beginning to demonstrate understanding of spoken language at a two key word level. Jessica was easily distracted in the busy classroom environment, but had already shown that she had the cognitive ability to understand the concept of two-switch scanning.

Phoebe was also four years old, had cerebral palsy with additional learning difficulties but was extremely sociable and keen to interact with everyone around her. Again, she was just beginning to understand spoken language at a two key word level, was recognising symbols and using them expressively but we weren't sure about whether to keep encouraging her to reach out and touch the symbols or to encourage her eye-pointing.

Natalie was slightly older, six years old, when referred. She also had cerebral palsy but presented very differently. She could clearly understand language at a single word level but it was proving very difficult to assess the range of vocabulary she understood, due to her difficulties with planning her motor movements.

All three children had developed understanding of cause and effect using a switch, and used a single message voice output communication aid, a Big Mack, in lots of ways, including: joining in greeting routines, repeated phrases in stories and nursery rhymes. All three children were being exposed to a range of symbols in their low tech systems and were using them expressively to make choices and in other structured language activities.

Two of the girls clearly had the potential to use and benefit from a more complex communication aid whereas I needed advice about Natalie because her difficulties were more complex. Planning any sort of motor movement was so difficult for Natalie that we were never sure whether she was not motivated enough by the things we were asking her to do, or whether she didn't understand them. Another scenario was that it was just so difficult for Natalie to move that by the time she had planned and carried out the movement, any sort of opportunity for effective communication had largely gone. The local team included each child's physiotherapist who had carried out an assessment of possible switch sites and scanning systems, but it was becoming clear that we were both working beyond our own knowledge base and that we needed specialist advice. The school's Occupational Therapist was also keen to be

involved in the assessment process but did not have much experience of switching and was very limited in the time she had available to look at this aspect of the children's needs. All the children's class teachers were keen to support any programmes and their parents were supportive.

The local education authority were willing to buy equipment for the children but as money is a precious resource it could not be wasted buying equipment that was unsuitable and would end up in a cupboard!

WHERE TO GO NEXT?

Within the West Midlands, there is a regional specialist service, Access to Communication Technology (ACT), which amongst other things provides electronic assistive technology for children and adults who have difficulties communicating using speech.

Following phone calls to Helen Millward, Occupational Therapist at ACT, it was becoming clear that we did not need to refer these children for a complete assessment of their AAC needs because in terms of their communication skills, I had an idea of where to take them next, but what we did need was a 'switching clinic'.

The Specialist Therapists within ACT had not been used in this way before but were able to accept the referral partly because the all the members of the local team agreed to take part in the clinic and had expressed an interest in developing their own skills in assessing children's access methods. In addition, ACT, itself, was looking at how they could extend their Outreach Service.

The clinic took place at the Orchard School during a school day and the outcome for each child was very positive but different:

- Jessica needed a bespoke switch tray making which allowed the small switches to be recessed allowing the surface of the switches to be flush with the tray surface. This gave Jessica a stable surface to rest her hands on and make smaller movements to activate the switches, decreasing the level of uncontrolled movements she had been using to access the switches.
- Phoebe showed us that she had enough head control to be able to use a head mouse and had the understanding that the movement of her head was moving the cursor around the screen. The next stage of intervention was to identify whether she could develop the high degree of accuracy needed to use this access method in a communicative situation.
- Natalie responded to activities that had an instant response to the switch activation and therefore some very basic environmental controls were set up at home, allowing Natalie to change channels

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and turn her television on and off. The switches were also set up to work with some simple 'cause and effect' computer programs at both home and school. Natalie required the time to develop her ability to use the switches accurately before increasing the complexity of the tasks.

ACT provided us with a head mouse for Phoebe, their technicians made the mounting for Jessica's switches and two therapists made a home visit for Natalie to adapt some equipment for environmental control. Equally as important, they were able to advise us about the complexity of combining a child's functional movements

with other aspects of accessing a communication system including learning scanning skills. This was invaluable, as I have found that managing everyone's expectations about high tech AAC equipment and what it can and cannot provide is a tricky business at times. All the members of the local team have increased their knowledge about AAC and have since used some of the skills learnt when assessing other children within the school.

CONCLUSION

All the therapists involved in above case study were able to demonstrate what they

have learnt from the whole process including gaining more information about what different local teams are already providing for clients with AAC needs and how Specialist Services can be responsive to local needs and provide training to meet some of those needs.

We all found or had reinforced the fact that effective AAC needs to be more than just Speech Therapy. *

Karen Sheffield

Speech and Language Therapist

Helen Millward

Occupational Therapist

...continued from page 33 *The Politics of High-tech AAC in England and Wales*

In addition to this Scope submitted written evidence to the Review team on the experiences of people who use AAC, incentives for commissioners to fund services for SLCN and communication equipment. We also submitted a joint-submission on commissioning incentives authored by Scope, Afasic, Communication Matters and the Royal College of Speech & Language Therapists (RCSLT) and supported by I CAN, ACE Centre North, 1Voice Communicating Together and The British Stammering Association.

NO VOICE, NO CHOICE IN 2008/9

The above discussion illustrates that whilst ground has been made it is important that work continues to ensure that all those who could benefit from communication equipment, irrespective of their stage of the lifecourse, have access to the equipment and support they will need to communicate effectively.

Following on from the first year of our No Voice, No Choice research, Scope will be researching into professionals and statutory agents experiences of the provision and support of AAC. We will be publishing this research in the summer of 2008 and look forward to hearing from those of you who have experience in this area.

On 21 April 2008 Scope are holding a Scoping Event to explore the second year of our No Voice, No Choice research and to give participants an insight to the technological element of Scope and BT's partnership.

If you are a professional or statutory agent who is in one of the posts listed below and would like to attend the event or would like further information about it, please send your name, position, organisation and contact information to communication.aids@scope.org.uk or ring 02076197254 by 26 March 2008.

This event has a limited number of places and we are looking to get representatives

from all the professional and statutory areas and therefore will be restricting our invitations. If you are interested in attending, but we already have individuals representing your area of work we will keep your details and ensure that we include you in the later stages of the research. The day will be facilitated by Scope and the No Voice, No Choice Steering Group.

We are looking for professionals and statutory agents who are in the following posts (or equivalent):

- Local Authorities Managers
- Primary Care Trusts Managers
- Managerial Social Service staff
- Social Workers
- Key Workers
- Support Staff / Carers / Enablers
- Lead Commissioners
- GPs
- Speech & Language Therapists (SLTs)
- Therapists
- AAC Consultants
- Headteachers
- SENCOs
- Teachers, Teaching Support
- Communication Aid Centre Staff
- Speech, Language & Communication training staff
- Residential (managerial) service staff

Marc Bush & Ruth Scott

Policy & Government Affairs, Scope

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A Literature Review

The Possible Role of the Speech and Language Therapist in Facilitating Successful Vocational Participation for People who use AAC

VICKI ALLAN

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Vicki Allan, a newly qualified speech and language therapist, wrote this paper as an assignment for an AAC module while training at Strathclyde University.

Employment is a clear but often elusive objective of individuals who use augmentative or alternative communication (AAC). It provides opportunities for financial and residential independence, social interaction, community integration, a sense of self worth and a chance to improve quality of life (McNaughton, Light & Gulla, 2003). Furthermore, unemployed individuals generally report more depression, anxiety, social isolation, and low self-esteem than employed individuals (Blalock, McDaniel & Farber, 2002).

Communication has a significant effect on employment for disabled people and communication impairment reduces (by ten per cent) the likelihood of gaining employment (Berthoud, 2006). This paper discusses the role of the speech and language therapist (SLT) in facilitating successful vocational participation for people who use AAC.

IMPORTANCE OF EMPLOYMENT

For people who use AAC

For many people who use AAC, employment may represent a higher quality of life through offering the individual positive

social interaction with a variety of people in a range of contexts (McNaughton et al., 2003).

Furthermore, many people who use AAC are ambitious individuals who desire to achieve success and have an impact on the lives of others with disabilities. The fulfillment of personal goals will impact on self esteem as the individual feels like an active and valued member of society. This feeling is strongly expressed by an individual who uses AAC and has struggled to achieve employment:

"People often say, "Why bother to try to get into work?" I answer that I want to work for my money for the same reasons that anybody else does. I want the self-esteem of knowing that I am a productive member of society... I want to increase the quality of my life. I want to be able to afford to travel. I want to be able to buy all the equipment that could help me, which I can't get from statutory bodies. I want to go to the theatre and do all the things that everyone else aspires to." (Martin, 2002, p.1)

The importance of employment to individuals with degenerative conditions

cannot be underestimated. Contrary to the belief that individuals with life threatening illnesses do not pursue employment, studies have reported that pursuing professional goals may promote psychological wellbeing, quality of life and overall adjustment to disease progression (Westaby, Versenyi & Hausmann, 2005). Employment also often defines the individual's socioeconomic status and may be a necessity rather than a luxury, in order to fund the cost of living in society (McNaughton, Light & Arnold, 2002).

For wider society

The benefits of employing a person who uses AAC include the positive and inspirational effect the employment situation may have on other employees, the impressive work performance and loyalty of the individual who uses AAC and their ability to succeed in an often "hard-to-fill" job position (McNaughton et al., 2003). Furthermore, organisations often benefit financially by employing workers diagnosed with chronic or life threatening conditions (Westaby et al., 2005).

Although colleagues may appear positive and the person who uses AAC may be well

qualified, it may be some time before employers fully recognise their capabilities. Condescension is often subtly expressed through comments such as:

"I think it made the company feel good as a whole to know that they had given this guy a chance and he was doing a decent job." (McNaughton et al., 2003)

McNaughton et al. (2003) also report benefits for society through the employment of individuals who use AAC, specifically in the abandonment of stereotypes, increased awareness of AAC, and visible positive role models for other individuals who use AAC. One respondent stated:

"Employing an AAC user sends a strong, positive message that people with severe disabilities can function and contribute to the workplace. I think it has opened many people's eyes to what technology can do to improve life for people who have a disability." (McNaughton et al., 2003, p.241)

Furthermore, many people who use AAC become advocates for disability rights and through their employment, can act as an interface between the speaking and non speaking worlds. For example, an organisation, 'Just Different' employs disabled people, a large proportion of whom use AAC, to visit schools, educating staff and pupils on disability and difference and promoting the *properly supported and resourced inclusion* of disabled children into mainstream education (Just Different, 2008).

THE SLT ROLE

In order to assist individuals with disabilities to achieve and maintain employment, it is critical to develop a thorough understanding of the demands of the workplace and effective strategies for meeting those challenges. The SLT is likely to have a role in facilitating vocational participation through early intervention, providing the person who uses AAC with effective language and communication and ensuring the individual has an effective educational experience. The SLT will also have a role working collaboratively with other professionals and in changing attitudes and raising awareness of people who use AAC.

EARLY INTERVENTION

According to Downing (2005), what students are taught while they are in school provides a critical foundation for successful transition to the adult world. In order to successfully transition people who use AAC into an inclusive educational context, the SLT should provide AAC services as early as possible as, "this early attention allows children to develop linguistic, operational and social competencies

necessary to support participation in a mainstream environment" (Beukelman & Mirenda, 1992 p. 204). It should be equally important therefore, to start providing young people who use AAC with vocational support and ensure they are equipped with the necessary skills before they leave school in order to prepare them for the transition to successful participation in employment.

LANGUAGE AND COMMUNICATION

Language Development

The individual's ability to manage their AAC device and communicate effectively is critical for successful employment. The SLT, therefore, has a role in the facilitation and development of spoken communication and language skills through AAC. According to Beukelman and Mirenda (1992), many children who use AAC have both expressive and receptive language impairments and the language difficulties experienced by these children are influenced by the uniqueness of their language learning experience. As a result, "strategies specifically aimed at language development need to be an integral part of every communication intervention" (Beukelman & Mirenda, 1992, p333). The SLT may provide direct intervention through teaching and facilitating the individual's expressive and receptive language or indirectly through providing training programmes that are designed to enable parents to develop and promote their child's language development (Beukelman & Mirenda, 1992). In the same way, SLTs may be involved in training communication partners in how to provide an optimal communication environment for the person who uses AAC.

Managing AAC device

The SLT also has a role in ensuring the AAC device is organised and applied in such a way as to promote and develop effective communication skills. This includes the selection and organisation of symbols to facilitate language development and the length of the message units ranging from single morpheme markers to longer sentences and paragraphs (Beukelman & Mirenda, 1992). The SLT will be involved in the decision making processes relating to these issues and how the device can be tailored to suit the needs of the individual. Furthermore the SLT can enable the individual to use their AAC device effectively to help them cope with the demands of the workplace. This may include utilising a variety of AAC techniques, enabling the individual to develop their pragmatic skills through communicating with many individuals, for varied reasons, and about varied topics (Soto et

al., 2001). SLTs can help people who use AAC appropriately coordinate a variety of AAC techniques in order to meet the many communication demands of the workplace, for example, requesting help and giving instructions.

Beukelman and Mirenda (1992) also suggest advance preparation is required to compensate for reduced communication rates. The SLT can help the person using AAC develop automaticity in the use of pre-programmed workplace vocabulary and phrases to address these concerns including vocational and business vocabulary and phrases for using the telephone. According to McNaughton, Light and Groszyk (2001), intervention for people who use AAC should also include computer literacy and Internet training. This will provide individuals with a means of furthering their employment options and present them with easy access to a range of support networks.

CREATING AN EFFECTIVE LEARNING CONTEXT

Access to Curriculum

Beukelman and Mirenda (1992) discuss the importance of ensuring young people who use AAC have access to the "regular" curriculum. Failure to participate successfully in this way can have negative consequences for social interaction with peers and shape the student and teacher's perceptions about what the AAC user can achieve. However most importantly, the authors state that:

"Early curricular failure can lead to the child receiving a personalised curriculum whose content depends on the preferences and philosophies of staff. Inadequate longitudinal management of a personalised curriculum combined with staff turnover can often result in a splintered educational program, replete with gaps, redundancies and oversights."

Downing (2005 p 134) states that the fast pace of most high school classes, as well as the highly abstract curriculum and emphasis on complex verbal skills, can create learning environments that, initially, may appear at odds with the learning skills and styles of AAC students.

However, even the most abstract of course content can provide learning opportunities through careful modifications and accommodations. Many opportunities to learn communication skills exist within academic lessons, as the student responds to questions using a variety of AAC modes. In order to achieve such inclusive, but varied, educational goals, individuals on the IEP team should ensure there is consistently meaningful curricular content (Downing, 2005).

Literacy Development

The development of adequate literacy skills is viewed as an important factor in educational and vocational success however Light et al. (1996) found only 52% of people who used AAC had functional literacy. According to Beukelman and Mirenda (1992), exposure to a wide range of literacy experiences at home provides children with a solid foundation for successful literacy learning at school. This includes providing the student with extensive access to printed materials and media resources and playing with reading and writing materials. As children enter school, it is important that they are exposed to a literacy rich environment to facilitate emergent literacy development. This may include opportunities to actively participate in reading, opportunities to write about important events, and encouraging children to manipulate letters and phonemes to facilitate phonemic awareness and letter knowledge (Beukelman and Mirenda, 1992). Many children who use AAC are not exposed to this literacy rich environment to the same degree as their peers and the SLT may have an important role in educating the parents and school in the importance of this. Furthermore, the SLT may be involved in providing AAC tools to help the child develop emergent literacy for example, programming new vocabulary or symbols to help them participate in storytelling. As young people who use AAC seek vocational participation, greater attention should be focused on the literacy requirements of various jobs so that people who use AAC are better prepared for employment.

Vocational Programmes

The American literature concerned with the employment of people who use AAC tends to focus on specific vocational programmes and counsellors. The Augmentative Communication Employment Training and Supports (ACETS) programme aims to support people in reaching their employment goals by providing training and follow-up supports designed to increase their skills, experiences, and social networks related to employment. Foley and Staples (2003) describe an integrated AAC and literacy intervention programme developed for autistic adults within a supported employment setting. This Communication and Literacy Intervention (CALI) was created on the premise that AAC users with literacy skills have a wider range of social and vocational opportunities (Foley & Staples, 2003). The primary goals of the two year programme were to promote participants' community access, independence, personal empowerment and vocational preparedness through the development

and generalisation of functional communication and literacy skills to real world situations. Positive outcomes were achieved by all participants with some more likely to be considered for job placements. This result highlights the importance of literacy to obtaining employment for people who use AAC, however, the time frame and workload of the study, limits its universal use.

There have been few such vocational programmes or counsellors within the UK. According to Roland and Belin (1993), therapists must individually establish vocational evaluation programmes, taking into account various elements of the patient's particular context. However, there would be concerns that it is not realistic or feasible to expect SLTs to undertake this role on top of their caseload requirements and it is likely that working collaboratively with other professionals would be a more effective means of managing these individuals.

COLLABORATIVE WORKING

Educationally

For many students their school career is dependant on the attitudes of the professionals working in their academic environment. However, educators may have inappropriately low expectations, resulting in limited and inappropriate experiences (McNaughton et al., 2002). In order to ensure effective educational participation for children with AAC needs, SLTs should work collaboratively with educational staff and provide forums where team members can articulate their priorities and design pro-active solutions to resolve potential conflicts (Downing, 2005). These meetings can also enable the SLT to advocate on behalf of the person using AAC and encourage staff members to take ownership of the child through taking an active role in their management. The contribution of the teacher in this manner can be crucial to the success of inclusive schooling for the AAC student (Soto, Muller, Hunt & Goetz, 2001).

Beukelman and Mirenda (1992) believe the SLT should be the overall manager of AAC interventions for children with severe communication disorders in an educational context. However this is not a realistic statement in terms of service delivery in the UK as SLTs are likely to be visiting a number of schools delivering blocks of therapy. Educational staff may feel resentful rather than empowered if SLTs return to the school to take control away from the rest of the staff. SLTs should balance a consultative model of service delivery, training and equipping teachers with the necessary skills to take ownership of the child, with the provision

of direct intervention to children as they progress through the school.

Vocationally

The SLT is likely to be one member of a multi-disciplinary team who can provide support and opportunities for individuals who use AAC to start or return to some form of employment. Liaison between rehabilitation professionals and employers is an important factor in enabling people to access appropriate services and eventually return to work. Ideally, long term support which facilitates planning for return to work should be offered to all individuals who use AAC and SLTs should have a responsibility for this due to their ability to effect change. However, despite their best intentions, SLTs may be limited in the extent to which they can help patients participate successfully in vocational activities due to a lack of NHS funds and caseload demands. It may be more appropriate and effective for SLTs to offer indirect services through liaising with a number of professionals such as vocational counsellors or specialisms, training vocational staff and establishing links with services to support people who use AAC.

RAISING AWARENESS AND CHANGING ATTITUDES

According to Dickerson (1995) in Odon and Upthegrove (1997), society continues to perceive people with disabilities as less capable and is not ready to integrate them into the country's work force. AAC users have experienced negative attitudes in the workplace, for example, co-workers reluctant to interact with them and employers underestimating their capabilities (Light, Stoltz & McNaughton, 1996). According to individuals who use AAC, other people's attitudes are one of the biggest barriers to successful vocational participation.

"The REAL barrier, in my opinion, are [sic] people's stagnant and outdated attitudes toward people with speech disabilities... The biggest stigma is that other people perceive us as being retarded. This mentality held by employers in the "real world" has prevented us (people who use AAC) from showcasing our talents and abilities." (McNaughton et al., 2002 p66)

In order to change people's attitudes, SLTs need to raise awareness of AAC in the workplace through education and training. The SLT should work closely with vocational and rehabilitation staff members who are influential in the facilitation of employment for AAC users.

Employer and Colleagues

According to a report 'Ready, Willing and Disabled' by the charity organisation Scope, staff attitudes were the third big-

gest barrier to disabled people getting work. Furthermore, comments from respondents suggested that many employers thought disabled people would not pull their weight and would result in others having to work harder. Employers' negative attitudes, inflexibility and failure to implement adaptations to the work role, hours or equipment have also been perceived as barriers (Lock et al., 2005).

Where an individual who uses AAC has terminal illness, while there may be some positive impact on colleagues, employees may experience anxiety and discomfort around individuals with a terminal illness (Westaby et al., 2005). A lack of knowledge about conditions such as aphasia may also cause a barrier to individuals who wish to return to their previous employment. The SLT should direct employers and employees to organisations that can provide support and assistance. The Scope website includes recommendation reports for employers and the Jobcentre Plus 'Job introduction Scheme' pays a grant to employers to manage the costs relating to the disabled individual. Where possible, SLTs should liaise with employers and vocational agencies, offering training on different communication disorders and supporting AAC users in employment. Projects like these are currently being implemented in Edinburgh and Argyll and Clyde where speech and language therapists have been working with local employment services to provide training to job coaches and other workers who support people commencing or returning to work (Witcher, 2006).

People who use AAC

A key barrier to employment is information concerning employment and retraining (lock et al., 2005). An important aspect of intervention, therefore, is the provision of information to the person using AAC themselves. The SLT should help the client establish links with organisations that can facilitate access to employment. Charity based organisations such as Scope can offer employment and training services and provide reports such as 'Ready, Willing and Disabled' which discusses employment from the perspectives of individuals who use AAC, employers and colleagues. Jobcentre plus also provides services for disabled clients including Disability Employment Advisers, providing specialist support to people with acquired and degenerative disabilities including training advice and information, job introduction schemes and employment assessments. Access to Work Advisers also provide support to disabled individuals to help overcome work related obstacles. SLTs may also be in a position to alert the client to legislation that may

support their vocational efforts including the Disability Discrimination Act (2005) and Scottish Executive reviews relating to communication support services for individuals in Scotland (McPake & Johnstone, 2002).

In addition to sharing information with the person using AAC, the SLT may be involved in providing a supportive yet realistic picture of their vocational ability and ambitions. In acquired chronic cases such as aphasia, the SLT will have a role in helping the individual adjust to their new identity and their new communication mode. SLTs may also assist people who use AAC in the psychosocial adjustment of a degenerative illness. Participants with MND in McNaughton et al.'s (2001) study highlighted the struggle to accept the reality and overcome the frustrations associated with their condition and to be able to actively seek help from others as particular barriers in successful employment. SLTs may take on a supportive/counselling role with these individuals as well as helping them to adapt to progressively more complex AAC systems as their condition deteriorates.

CONCLUSION

Successful employment outcomes for individuals who use AAC have benefits for the individuals themselves, their employers, and society as a whole. The SLT has the potential to help facilitate successful vocational integration through working directly with the person who uses AAC, however must take care to balance this role with the complex demands of their caseload. As a result, it may be more realistic for the SLT to work indirectly through training and educating educational, rehabilitation and vocational staff and working collaboratively with a range of professionals to facilitate vocational participation for their client. Further investigation into the barriers that people who use AAC encounter in employment experiences is required in order to develop supports that will contribute to positive employment outcomes. Equally important, however, is the willingness of society as a whole to give individuals with disabilities an opportunity to demonstrate their skills and achieve their goal of successful vocational integration. *

Vicki Allan
Speech & Language Therapist

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Talking Mats and Dementia

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Caring for someone with Dementia is never easy. One of the most distressing aspects of the illness is the deterioration of communication between people with dementia and their caregivers. As dementia progresses, the person becomes harder to 'reach' and it becomes increasingly difficult to ensure that their views are listened to. The communication difficulties often experienced by people with dementia mean that a wide range of staff in different settings as well as family, friends and other relatives are keen to find ways to communicate with them more effectively.

Talking Mats is a low-tech communication framework, developed at the University of Stirling by a group of researchers grounded in clinical experience as Speech and Language Therapists. The Talking Mats framework was specifically created to help people with communication difficulties express their views. Using a simple system of picture symbols and a textured mat, people are able to indicate their feelings about various options within a topic by placing the relevant image below a visual scale. The whole system is inexpensive and accessible, and can be used in any setting. With application and research initially in the areas of cerebral palsy and motor neuron disease, the success of the Talking Mats framework has since been tried and tested, with research leading to specific packages created to improve communication with those with, for example, learning disabilities or aphasia.

Keen to examine whether Talking Mats might also help people with dementia, the Joseph Rowntree Foundation funded a 15-month research project to be carried out by the Talking Mats team at the University of Stirling. The project aimed firstly to establish whether Talking Mats could help people with dementia to communicate, and secondly to examine how effective Talking Mats might be for people at different stages of the illness. An example of a Talking Mat is shown in Figure 1.

The project involved 31 people with dementia - 10 with early stage, 11 with moderate stage and 10 with late stage dementia - and compared how well people at different stages of dementia could express their views. The research compared communication using Talking Mats, 'ordinary conversations', and 'structured conversations', and focused on four aspects of their well-being (Activities, People, Environment and Self).

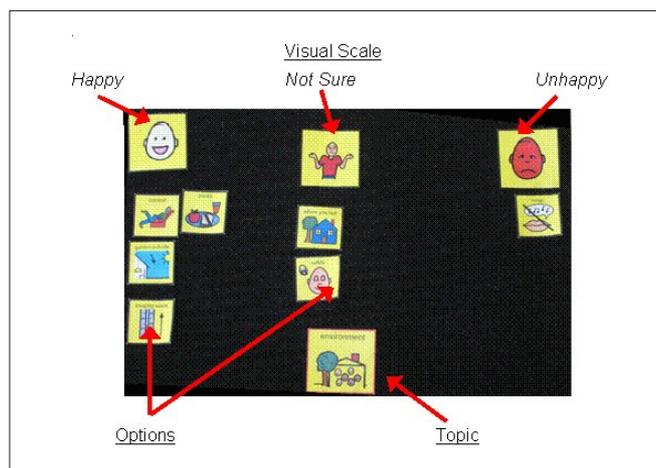


Figure 1 Example of a Talking Mat

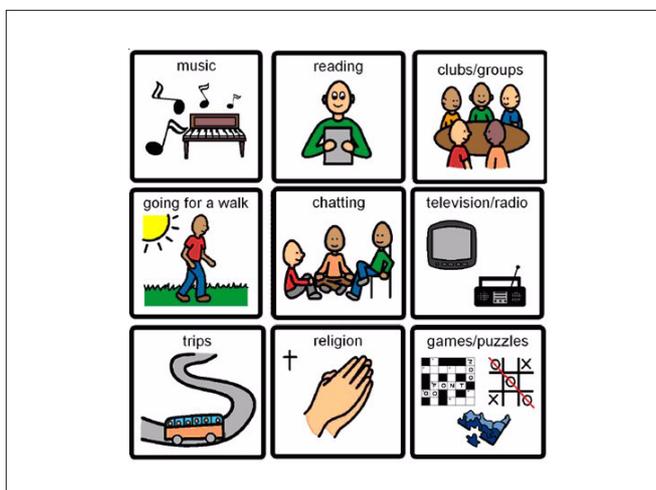


Figure 2 Picture symbols of the 4 main topics

RESULTS

The researchers videoed and then analysed the different 'conversations'. Quick digital photographs of individual 'mats' provide a 'snapshot' picture of the feelings or views of the person involved in the Talking Mats conversation. The video and photographic evidence were then reviewed to determine how effective the different types of conversation were.

The project found that conversations using Talking Mats were more effective for people with dementia than ordinary conversations. Using Talking Mats actually improved the quality of information that people with dementia were able to give: a crucial aspect in ensuring their views are heard. The conversations with the Mats were also proved to make the information more reliable, whilst during the actual conversations themselves, people with dementia were less likely to drift off the topic when 'talking' with a 'mat'.

Additionally, the researchers were able to conclude that whilst using Talking Mats as a tool in conversation, those with dementia were less inclined to repeat words or phrases, and their conversations also lasted longer.

So, were Talking Mats useful in communication with people at all stages of dementia? It was discovered that people with early and middle stage dementia certainly could use Talking Mats effectively. An interesting finding indicated that people with late stage dementia showed an improvement in their communication when chatting with Talking Mats, over structured and regular kinds of conversation. However, as expected, not everyone with late stage dementia was able to use Talking Mats effectively.

The researchers concluded that Talking Mats can be used by many people at all stages of dementia and that the framework improves their ability to communicate compared to ordinary conversations. Talking Mats can therefore play an important role in improving the quality of care by providing a simple, low-cost tool that family and staff can use to engage with people with dementia, helping them to express their views about a variety of topics.

PRACTICAL IMPLICATIONS

The researchers believe that the main results of the project mean that Talking Mats may be helpful in allowing people with dementia in a variety of situations to express their views about a wide range of topics. For example, Talking Mats could be used to:

- Allow people with dementia to choose what they want to do on a day-to-day basis;
- Help people with dementia remember what they have said;
- Provide a structure for conversation between a person with dementia and their friends or relatives during social visits;
- Provide an instant record (through a digital 'snapshot') of what people with dementia have said, to either put in their notes or simply to show to their families;
- In addition to being used to augment communication and decision making, Talking Mats may also simply be enjoyed as an activity, allowing people with dementia to occupy their time doing something that is personally meaningful.

They also have the potential to:

- Help people with dementia tell family and staff how they feel (e.g. how bad their pain is, or how much they enjoy the food);
- Provide information for medical and social work staff about the views of people with dementia in relation to health and social issues;
- Help people with early (and perhaps moderate) stage dementia when they face difficult decisions such as giving up driving or moving to different accommodation.

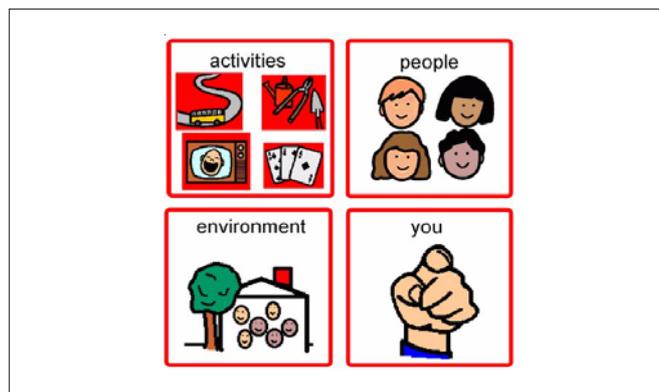


Figure 3 Picture symbols of options in the Activities topic

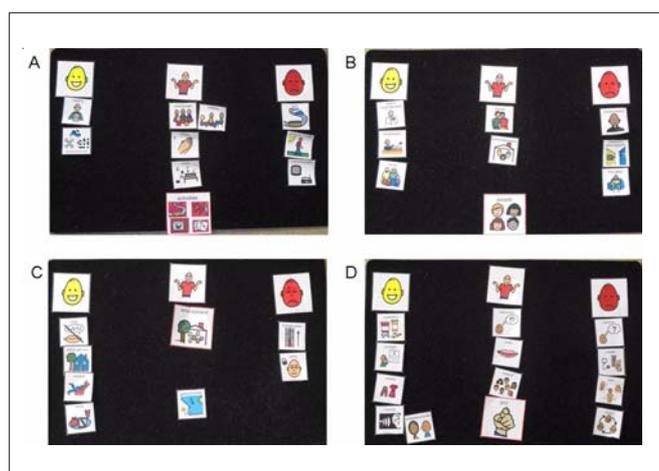


Figure 4 Examples of completed mats of individual views of each topic:
A - Activities; B - People; C - Environment; D - Self

This low-technology communication framework offers a valuable resource to people with dementia, their family, friends, care practitioners, service commissioners and all those who are interested in improving the quality of care delivered to people with dementia.

The full report, *Communication and Dementia: How Talking Mats can help people with dementia to express themselves* by Joan Murphy, Cindy Gray and Sylvia Cox is published by the Joseph Rowntree Foundation. It is available as a free download from www.jrf.org.uk

Joan Murphy has received further funding from Joseph Rowntree Foundation to carry out two additional studies. One will examine the use of Talking Mats as a decision making tool for people with dementia and their family. The other is looking at the best way to provide training that has a long term impact for care home staff.

The team at the University of Stirling run training courses in the use of Talking Mats which are open to all. They are also developing packages which contain mats, symbols and a booklet with guidelines for the use of the Talking Mats framework. For further information about Talking Mats and the training courses available please contact 01786 467645 or www.talkingmats.com.

*

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Cindy M Gray
Research Fellow
Sylvia Cox
Independent Consultant and Social Researcher



ESSENTIAL PUBLICATIONS

FROM COMMUNICATION MATTERS



The Power of Communication (DVD)

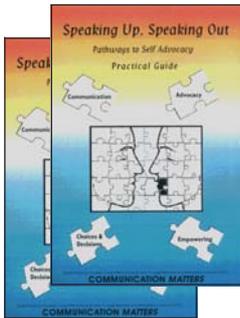
This DVD has been produced by Communication Matters to provide an introductory presentation on Augmentative and Alternative Communication (AAC). The film delivers a powerful message that communication really does matter. The DVD celebrates and promotes communication in all its forms - central to the values of Communication Matters, a UK charitable organisation concerned with the needs of people who use AAC.

Price: £8 each (£20 for three) including p&p

Speaking Up and Speaking Out! Pathways to Self-Advocacy

This pack is intended for carers, facilitators and others concerned with the advocacy needs of people with severe communication difficulties who need or use AAC. It is useful for staff development, especially for those working with adults. The pack comprises two books: a comprehensive Handbook and a Practical Guide.

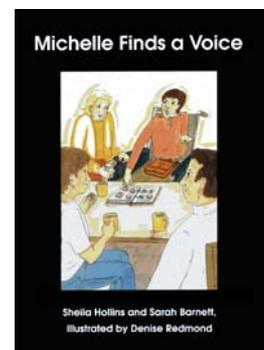
Price: £30 including p&p available from **Communication Matters**



Michelle Finds a Voice

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

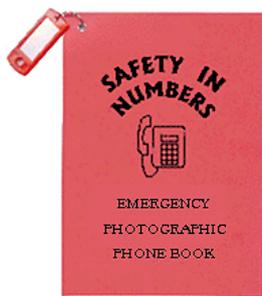
Price: £10 plus £1.50 p&p from **Communication Matters**



Safety in Numbers: A Photographic Phonebook

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

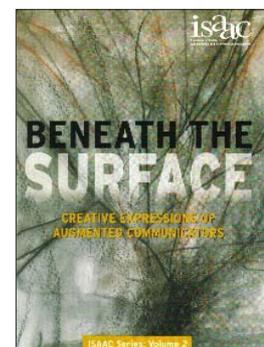
Price: £3.50 including p&p from **Communication Matters**



Beneath the Surface

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

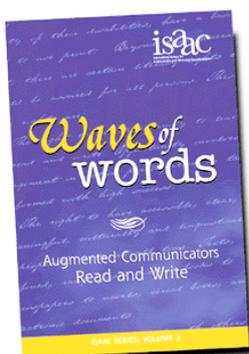
Price: £15 plus £1.50 p&p from **Communication Matters**



Waves of Words

The challenges confronting individuals with severe communication disabilities are chronicled in this ISAAC book. The focus is on the strategies that teachers, therapists and individuals who rely on augmentative communication from around the globe have used to produce ultimate success in the struggle to learn to read and write.

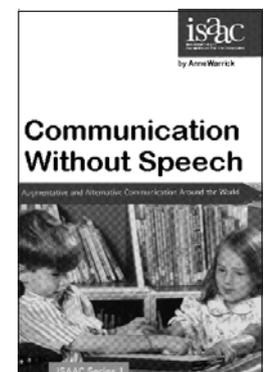
Price: £15 plus £1.50 p&p from **Communication Matters**



Communication Without Speech

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

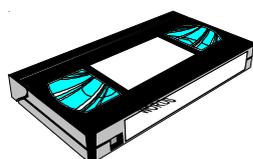
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In Other Words (ISAAC video)

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

Price: £12 to CM members (otherwise £17) including p&p
ONLY AVAILABLE FROM ACE CENTRE (Tel: 01865 759800)



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

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