

# COMMUNICATION *MATTERS*

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Cover: Three year old boy, who uses an eye pointing board, decorates 1Voice's 10th birthday cake (page 29)

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# Visiting Alien Planets

## Taking AAC outside of the usual environments



### SOPHIE SCOTT

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### IT'S SAFER TO STAY AT HOME

There is something very comfortable about staying at home, in your local area, or even in your home country rather than travelling away from home. Everyone speaks the same language and you are used to the food! There is also an unspoken understanding about rules and social etiquette that means you do not have to explain who you are and the people around you understand how you like to function.

In terms of people who use AAC, their normal environments are well set up to support their identified communication needs. This means that in the familiar environments (i.e. home, school, care settings) they have:

- identified support systems;
- been issued with specific AAC equipment that everyone is familiar with;
- staff trained in supporting their specific communication needs (e.g. responding to VOCAs, facilitating use of partner assisted communication books);
- familiar, controlled environments (e.g. school, college, home).

Unfortunately we all move between different worlds in our lives and often encounter alien places, where the use

of the system can break down for a variety of reasons. This can be due to encountering different people who are often unaware that a communication system is in use, or if they do know of it, may have no knowledge of how to support the use of a system or respond to communication attempts.

Moving to a new place can mean that a communication system may not be available, as it may have been left behind, or tidied away or just out of reach, because the importance of a communication system is not realised or recognised. The other difficulty is that moving into a new world often means new demands on vocabulary, as there may be different topics of conversation (e.g. moving into a hospital setting from the community).

### PREPARATION, PREPARATION, PREPARATION...

Usually when we go on a trip, there is a huge amount of planning and preparation. For most people who use AAC there are clear times of change that are planned for, where communication systems may be adapted or the new people in that environment will have time to learn about systems and strategies (e.g. school transfer, transfer into adult services). Unfortunately, not all

trips are predictable and so the planning may not have happened. Often people end up in situations they did not anticipate (e.g. admissions to hospital, changes in staff due to illnesses or personal reasons, communication aids breaking down or going missing).

The key therefore is planning for the expected and unexpected...

- What do you usually pack? Make sure that when moving environments, the communication system is on your packing list. You may also want to pack a spare (i.e. low tech system if you use voice output) in case of missing luggage, or in case the system does not work for some reason.
- Do you need to make any adaptations? Think about the adaptations you usually make for a trip (e.g. packing a phrase book, taking different money, packing beach clothes for a different climate). The usual system may not work in the new environment (e.g. you may not be able to take a system into that environment or access issues such as positioning in hospital may affect access). You may need to think about changes that you need to make be-



fore you go (e.g. different vocabulary for a different environment and for different conversation topics).

- What do you want people to know about you? Some of us take family photos or information on trips with us to explain who we are. Even if we do not pack something so concrete, we often spend a lot of time telling new people about ourselves, explaining who we are, what we do and what we like or do not like.

Sometimes everyone has a bit of an unexpected trip! It may be a sudden change in circumstances or to support someone who needs help. Some trips you know will happen, but you just are not sure when, so you may need to have a plan in place that you can action when the moment comes. Think back to your usual packing list and take the things you would usually take.

Although some journeys may not leave much time, you may have time to chuck the essentials in a bag, and if you have a standard list it will be easier. Think about the different needs of the environment - you may be able to predict that this trip will need waterproofs whereas another one needs sunglasses. Even if the trip is to somewhere you have not visited before, you may be able to predict some of the needs.



#### NEVER GO ANYWHERE WITHOUT YOUR PASSPORT!

You need your passport to travel outside of the country. It allows you to be recognised and gives other people some understanding about where you are coming from and who you might be. You usually keep it somewhere safe, but find it quickly when they are needed. Communication passports (Millar & Aitken, 2003) are a well used tool that can easily be transported to help explain who you are. While they need updating every now and again, the majority of the information in them will remain relevant and even if slightly out of date, will give a new friend or acquaintance an idea of who you are, and are often a starting point for conversation.



Sometimes, when travelling, we are asked to provide information about health or other issues, such as insurance or next of kin. For those with communication impairments, it is likely that the information that professionals have access to may be difficult to interpret, or it may be difficult to find the relevant information (e.g. bulky medical notes). For staff working in

non-medical settings, the information may just not be available. Therefore, we need to consider the possible use of a patient-held record (e.g. Early Support family file) that can travel with an individual to provide important and relevant information for those who meet an individual who uses AAC.

#### ALWAYS READ THE SMALL PRINT

No-one goes off travelling without checking the terms and conditions of their trip, and without a certain agreement about what to expect and what the tour company will provide. We have an expectation that while we are away, the people employed to facilitate a trip will have an understanding of our needs and expectations. A travel company will actively advertise the support mechanisms you can expect while you are in a strange place.

In terms of facilitating communication, there is a range of legislation stating that individuals who use AAC should have access to their systems and their use should be supported in the environments they move through (i.e. UN Convention on the Rights of the Child, Disability Discrimination Act, Every Child Matters, National Service Framework for Children). We are also all aware of the importance of individuals being able to ask questions and contribute to decision making, whether that is about what to have for breakfast, or to express an opinion when in hospital and discussing plans for surgery.

Therefore, the expectation could be that people supporting those with communication needs will have knowledge and experience of types of communication system and strategies to support their use. However in reality this is not always the case, as the importance of communication is often overlooked or it is assumed that individuals who do not speak verbally cannot communicate successfully.

#### WELL TRAINED TOUR REPS

When we go on holiday, we expect to have competent tour reps who know we are coming and who are there to pick us up at the airport. There is also an expectation that they will be able to predict some of our needs, offer different options during our trip and meet our basic requirements. In reality this is not always the case, and when dealing with communication impairment, staff who may encounter individuals who use AAC may have little or no experience of communication systems or of working with people with communication impairments.

While it is unrealistic to train everyone, there is a need for generic training in specific areas (e.g. hospitals, care homes, etc). Certain groups of people can be identified as likely to come into contact with people who use AAC and could access training courses / general information about communication impairment. This means that professionals working in these or with these settings need to ensure that basic training is available and accessed to ensure that an underlying knowledge is achieved.

It is also essential that where possible, information and training is provided in relation to each individual's specific AAC needs. Again, this is easier in situations where this is predictable, as there is time to make contact and to provide suitable training and information. However, in the unpredictable situation, it is still possible to provide information and possible brief training around an individual's specific needs, particularly if a link can be made with a key person within the new environment.

#### SUMMARY

While families, professionals and those who use AAC themselves try to ensure that communication needs are met in the usual environments, it is not always easy to meet these needs in new and unfamiliar places. If a transition is predictable, then it is possible to plan to ensure training, information-sharing and where necessary, adaptation of a communication system to ensure it continues to meet an individual's needs in the new environment. However, in unexpected changes, it is not as easy to meet these needs in advance, and may not be the priority at the time of transfer. Preparing for the unexpected is always difficult. Some forethought and prediction of what could happen allows us to manage unexpected change more successfully.

In summary (i) have a list of what you may need to facilitate communication in a different environment; (ii) try to predict for possible changes and make sure you have back-up systems in place; and (iii) make sure you have accessible information about the individual and the system in use that can be provided at the time of change to facilitate the transfer and on-going successful communication. \*

Sophie Scott  
Principal Speech and Language Therapist

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# The Lancasterian Pupils' Press

## Developing a symbolised newspaper

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This article will explore ways in which *The Lancasterian Pupils' Press* – a symbolised newspaper developed by secondary pupils at Lancasterian School – has evolved.

It originated from a weekly Social Communication Group led by the speech & language therapist and has subsequently grown into a cross-curricular initiative involving therapy and teaching staff.

The article will discuss ways in which the newspaper has been developed and how it incorporates a range of AAC strategies and assistive technology solutions to support the development of both spoken and written language skills.

### BACKGROUND INFORMATION

The newspaper, was first introduced by the speech & language therapist in September 2006.

The need had been identified for a Social Communication Group within the Senior Department at Lancasterian School. This group was subsequently established to focus on developing social communication skills, including:

- Basic social interactional skills: eye-contact, turn-taking, listening & attention skills.
- Conversational skills: initiating a topic of conversation, topic main-

tenance, ways of switching a topic appropriately, closing a conversation and communication repair strategies.

The news was considered to be a good way of generating discussion within the group, with a view to creating a symbolised newspaper to provide pupils with a tangible outcome for developing expressive language skills.

### RESEARCH

The therapist had previously explored other symbolised publications available, including the US newspaper *News-To-You*. This is a symbolised paper for “beginning readers and individuals with special needs”. This was, however, not always appropriate for a UK audience given that the vocabulary and topics covered were often not relevant within the UK.

*E-Live* is another newspaper available online within the UK; this is more accessible for many of the pupils at Lancasterian School and does cover many relevant topics with appropriate vocabulary, however, it was recognised that providing pupils an opportunity to create their own news reports could be an effective and more motivating means of developing their spoken and written communication skills.

### DEVELOPING SKILLS


Since 2007, *The Lancasterian Pupils' Press* newspaper has become embedded within the curriculum to promote the development of both spoken and written communication skills for pupils requiring speech & language support. Pupils have also been able to develop their skills for using voice output, switch access and environmental control.

The Lancasterian Pupils' Press has been integrated into a weekly English lesson and is now jointly coordinated between the speech & language therapist and a teacher. Sessions are jointly planned following both Speech & Language Therapy and teaching objectives.

Sessions add a cross-curricular dimension to pupil learning encompassing different aspects of the curriculum including English, ICT and Design & Technology.

Table 1 below shows how some of these areas are addressed and how Speech & Language Therapy objectives are incorporated.

Pupils discuss a range of topics divided into specific news categories such as World, UK, School, Entertainment, Weird and Sport News. They create a review of issues that they are interested in.

Curriculum Area: English	
<i>Speaking &amp; Listening Objectives</i>	<i>Pupils' Press sessions</i>
Pupils are encouraged to contribute effectively with increased confidence in a variety of settings.	Discussion time at the start of each session allows pupils to give information about their chosen topic of news. Pupils take on the role of news reporter in the development of The Lancasterian Newsround. More recently, pupils have the opportunity to give their news reports via School Radio.
Pupils will participate, contribute and respond appropriately to others in discussion.	Discussion time focuses on use of good interactional skills and conversational skills, as identified by the speech & language therapist.
Pupils will take varied roles in group work	Pupils take turns in being news reporters and listeners.
<i>The Speaking &amp; Listening aspects of the English curriculum complement those identified by the speech &amp; language therapist for social communication skill development.</i>	
<i>Reading Objectives</i>	<i>Pupils' Press sessions</i>
Pupils will have access to a wide range of texts.	Pupils are shown a variety of local and national newspapers and magazines to research their news reports.
Pupils can reflect on the meaning of what they have read and provide reasons for their choices or preferences.	Pupils are encouraged to interpret meaning from the different articles they read and give their opinions regarding the news topics they discuss and write about.
<i>Writing Objectives</i>	<i>Pupils' Press sessions</i>
Pupils will use planning, drafting and editing processes to improve their writing.	Narrative strategies introduced by the speech & language therapist, help pupils structure their ideas. Word maps are also used to help pupils organise vocabulary.
Pupils will communicate their ideas, thoughts and feelings through writing.	Pupils are encouraged to interpret meaning and give their opinions as above. Some pupils chose <i>drawing</i> as a means of recording their ideas, as this image shows – it represents a Chelsea footballer injuring an Arsenal player with his studs! 
Pupils will use their recording and writing skills with increased confidence for a range of purposes and styles.	Pupils are provided with a range of specialist software to make the writing process easier.

Curriculum Area: ICT	
<i>Objectives</i>	<i>Pupils' Press sessions</i>
Understanding information around us	Pupils are encouraged to interpret information from a range of sources, including newspapers, TV and the internet.
Representing information graphically	Pupils are encouraged to find relevant pictures to support the information they are writing about.
Finding/collecting information	Pupils are encouraged to use a range of sources to find their information, including BBC News, CBBC Newsround, Google etc.
Creating pictures	Pupils find pictures using Google images.
Collecting & presenting information	Pupils are encouraged to organise their writing and insert pictures as required. They are encouraged to alter the layout according to need. They are encouraged to use specialist software programs.

Table 1 Curriculum areas and related Speech &amp; Language Therapy objectives

### COMMUNICATION STRATEGIES

Pupils are encouraged to use a range of communication strategies within sessions, including AAC strategies to support both receptive and expressive language skill development. Some of the strategies used are outlined below:

#### Use of symbols related to news topics

Figure 1 is the News Category prompt board used to encourage pupils to initiate their chosen topic for discussion and relate to a specific type of news.

#### Use of symbol prompt boards

To generate ideas for expressive language output & encourage initiating topic of conversation (see Figure 2 overleaf).

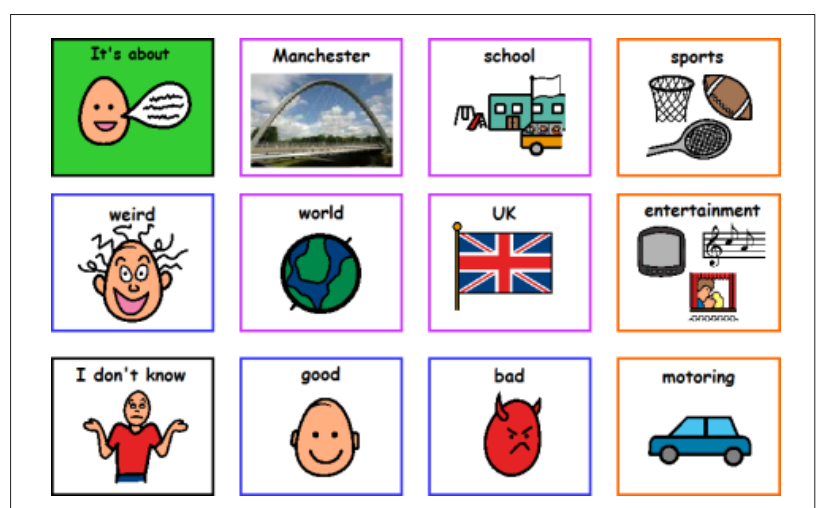


Figure 1 News Category prompt board

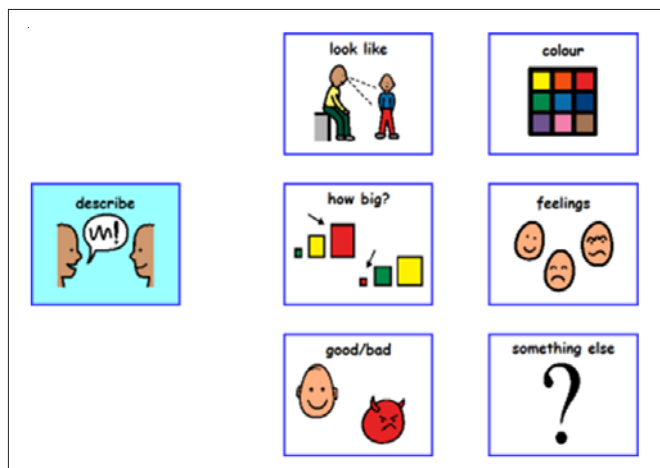


Figure 3 Adjectives grid

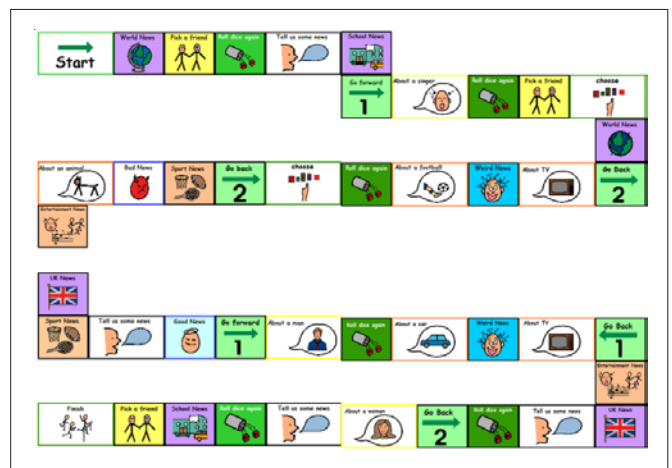


Figure 4 Board game

### Use of symbols/pictures/key words

To prompt use of specific vocabulary. Figure 3 is the symbol prompt board to encourage use of adjectives within expressive language output.

### Use of a customized board game

To generate topics of discussion. Figure 4 shows the Pupils' Press Board Game.

### Use of narrative strategies

To structure their ideas, i.e. Who? What? Where? When? Why?

## USE OF ASSISTIVE TECHNOLOGY

Pupils take responsibility for specific news reports using specialist equipment and software to facilitate their spoken and written communication. Some pupils use voice output communication aids (VOCA), including Pathfinder, Vanguard & Palmtop devices. Figure 5 shows one of our pupil's Vanguard page specifically programmed for Pupils' Press information. This page allows him to introduce the topic of conversation within group sessions.



Figure 5 Vanguard showing programmed page

Some pupils use their VOCA for written communication as well as spoken; others use specialist software to support their writing such as Clicker 5, ClozePro, (Crick Software) Symwriter, Communicate InPrint and Communicate ByChoice (Widgit Software).

SPEECH & LANGUAGE THERAPY			
Language Sample			
<u>Pupil:</u>		<u>Date:</u>	
<u>Topic:</u>			
WHO?	WHAT?	WHERE?	WHEN?
<u>Comments:</u>			

Figure 6 Structured recording chart

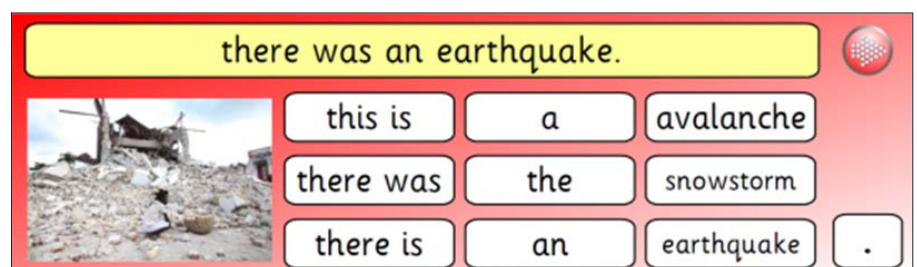


Figure 7 Interactive word map in Clicker 5

In all situations, pupils are encouraged to give information verbally to form the content of their news report. Support staff transcribe pupil comments, some using structured recording charts as shown in Figure 6.

The relevant vocabulary is then transposed into the relevant software to enable the pupil to write their news story. Often a simple written word list/word map will

provide sufficient support for a pupil to write their news story.

Clicker 5 is a useful tool for developing interactive word maps for pupils to support their writing.

An example of how Clicker 5 has been used is shown in Figure 7. This grid relates to the Haiti earthquake. Information was gathered through discussion and then vocabulary was put into a series of linking Clicker 5 grids.



The grid in Figure 8 relates to an article about pupil fun during 'snow days' off school at the beginning of the year! The pupil collated the information through questioning and the responses were placed in the grid. The pupil was required to use the correct word order and record accurate responses.

As these grids show, the software is used at different levels according to the needs of the pupils. Some pupils use the word maps within the grids to create their own sentences, focusing on appropriate word order and meaning. Others, as demonstrated by the Haiti grid, use modelled sentences to create their report. In this situation, the information has still been collated with the pupil, but they need a sentence prompt to create their detailed written article. Pupils are again encouraged to follow the meaning of what they have written and monitor errors.

Figure 9 shows an article about last year's Dancing on Ice competition. A Communicate ByChoice page was created to allow the pupil to record who was still in the competition.

Pupils are encouraged to use appropriate word order within their writing and monitor their written information for appropriate meaning. They are encouraged to use narrative strategies to sequence their written ideas in a structured way as with their expressive communication.

Some pupils have used Lancasterian School's multi-media Studio to create their own newsroom. The Studio has a range of equipment which can be controlled through infrared and switch access. Pupils have been able to use switches and voice output communication aids to control lighting, sound and images within The Studio. They have created their own video footage as news reporters. These videos have provided an invaluable means for pupils to monitor their expressive language skills. It has also been a useful assessment tool. A combination of Possum and SpaceKraft's ShowMagic software has been used within the Studio.

## OUTCOME

Pupils have concentrated on their spoken language skills to generate information for their news reports. This information has then formed the basis for written news reports within English lessons. The range of specialist software available enables pupils to produce more comprehensive written reports. Word maps provide a visual prompt for content but the pupil has to monitor appropriate word order and meaning. These reports are collated to produce The Lancasterian Pupils' Press newspaper.

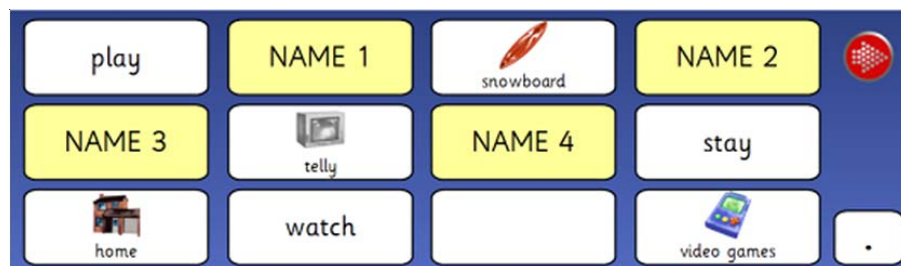


Figure 8 'Snowed-in' grid



Figure 9 'Dancing on Ice' article

Pupils have been more motivated to record their ideas using a variety of computer programs according to their language levels and have often produced more comprehensive information as a result.

Pupils' awareness of the world around them has increased since starting The Pupils' Press. Pupils will independently watch news programmes and often explore newspapers too. They are more likely to initiate a topic without staff prompting and have developed an understanding of different types of news. They can quickly associate a news story with its relevant category, i.e. world, UK, Manchester, weird, etc.

## SUMMARY

There have now been 17 editions of The Lancasterian Pupils' Press. It has grown from a Speech & Language Therapy led Social Communication group to become a cross curricular initiative which the Qualifications and Curriculum Authority (QCA) highlights as important towards "unifying areas of learning that help young people to make

sense of the world and give education relevance and authenticity".

The Pupils' Press English sessions provide the tangible outcome of a half-termly newspaper and a Newsround video. Pupils enjoy opportunities to discuss current events with various levels of AAC support and are highly motivated by the chance to control their environment within the multi-media studio.

Lancasterian School has recently purchased a School Radio system which will provide an added dimension to The Lancasterian Pupils' Press. \*

Alli Gaskin  
Specialist Speech & Language Therapist

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- Plain English, MENCAP: [www.mencap.org](http://www.mencap.org)
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# Head Switches to Eye Gaze

## A bumpy journey!

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### INTRODUCTION

This is the story of a pupil's progression from head switches at age three to the successful use of eye gaze technology at the age of eight.

### THE PUPIL

Katherine has a diagnosis of athetoid cerebral palsy affecting all four limbs. Her speech is unaffected except for her limited breath control.

She is a cognitively able pupil who transferred to main stream junior school in September 2008. Until then the school had limited experience of pupils with physical disabilities and no experience of pupils with major mobility and personal care issues, but they were eager to meet Katherine's needs.

### ICT HISTORY

Katherine was first referred to the SEN-ICT team when she was about to start nursery school at which time she trialled two Buddy Button switches initially positioned to allow her to access them with her hands.

She demonstrated that she could press the switch at the appropriate time, though she had a ballistic movement regardless of which hand/arm she used and of the position of the switch.

When the switches were positioned one to each side of her head she used them with greater control in her movements. Katherine used her left head switch to scan and her right to select. She had a more control with her head than with her hands. Even at this early stage it could be predicted that Katherine was going to have to do a lot of scanning in order to select letters, words, numbers, activities etc and with the head switches she would be more in control, less tired and possibly able to develop a faster scan rate.

Initially the switches were secured with universal arms but these were time consuming to position. Katherine was provided with a headrest by her OT, which would be interchangeable with her existing head rest, to which the switches could be attached. Katherine's computer had a standard mouse and keyboard to ensure other children could join in with her ICT activities.

Katherine continued using this equipment when she transferred to Infant School. Additionally she was provided with 'Clicker 5'. At the end of her reception year the switches were replaced with radio switches – these removed the need for wires trailing between laptop and chair. Very quickly Katherine's crea-

tive and imaginative writing skills progressed and 'Clicker 5' alone was no longer sufficient to meet her writing needs. She moved on to use simultaneously both a Clicker grid and a prediction grid from 'Penfriend XL'. She was soon able to start writing complex sentences. At this time she began to use 'ClozePro'. Katherine was often at a disadvantage in information-giving lessons such as geography and history; 'ClozePro' was used to help her process all the information given, without the need to write many sentences.

Through Foundation and Key Stage 1, Katherine developed some excellent ICT skills which would give her a solid base for the future. Alongside the skills she developed with her specialist programs she gained knowledge of some of the applications within MS Office including Word and Excel.

### ASSESSMENT

At Katherine's transition review in June 2007 a decision was taken to re-assess her ICT needs ahead of her transfer to Junior School in 15 months time.

*"Joint working is critical to deliver services that provide effective support"* (Bercow, 2008). Joint working was exactly what Katherine needed and it was



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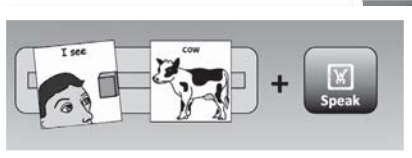
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important to look at all her ICT needs within this one assessment. There is no permanent assessment team in the local authority. It was, however, possible to gain advice from a multi-professional team including:

- Mum, teacher and teaching assistant, all of whom know Katherine really well;
- SENCo from the junior school, familiar with the curriculum requirements;
- Occupational therapist, knowledgeable about Katherine's motor skills;
- Independent ICT Consultant;
- Advisory teacher for SEN-ICT who holds the equipment and training budget.

This team had four of the five components the WATI Assessment Package (2004) describes as being essential when making decisions about assistive technology. The fifth is someone skilled in the area of language development but Katherine does not currently have input from a Speech and Language Therapist.

Donegan (2000) suggests that *"there seems to be reluctance amongst some professionals to acknowledge the potential benefits of collaborating with other professionals or specialists"*.

However, this was not the case for this assessment. Almost everyone who had been asked to support the assessment knew that eye-gaze was one of the options being considered and as, at this time, most of the team had not seen this technology in action, they were keen to be involved.

Although Katherine had been successful in recording and retrieving whilst controlling the computer with two head switches, the OT argued this could not be a long term solution and therefore raised the question "did Katherine have the visual skills to use eye-gaze technology?"

Sargent (2009) discusses the importance of normal visual behaviours when considering eye gaze technology for a pupil with motor impairment:

- Steady, direct gaze;
- Evidence of visual recognition;
- Eye contact;
- Visual searching: looking for...
- Control of eye movements/visual attention.

Katherine displays all of these visual behaviours and, following much discussion and consideration of other possible options, it was agreed to consider an eye-gaze device.

## DECISIONS

Initially a bolt-on device was considered. This would allow Katherine to continue using her current laptop and would be practical within the classroom allowing her to use her eye-gaze anywhere she used her laptop.

The Cogain Project (Communication by Gaze Intervention) looks at a range of devices in their eye tracker catalogue. The Eye Tech TM3 (bolt-on device) is described as targeting users with disabilities including cerebral palsy, anyone who cannot use a standard mouse. The device shows "tolerance to involuntary head movements" and allows for moderate head movement. The TM3 weighs only 3.6Kg (8lbs), easy for teaching assistants to manoeuvre. The suggested battery life of over five hours, more than adequate for a pupil at the beginning of Key Stage 2.

Katherine's head movements were thought to be moderate, however, when recorded on video on two separate mornings (at the beginning and end of the week) it became apparent that the TM3 was not a viable option; her head movement, especially when she was concentrating, was too great for this device.

The second device to be considered was the MyTobii P10 (stand alone device). Cogain lists pupils with cerebral palsy as one of the target users. This device requires the user to have an "Ability to focus gaze on objects on screen for a short duration. The system operates well even if the user has some eye tremor or spasmodic head movements." Weighing almost 9Kg (20lbs) the MyTobii is much heavier than the TM3. This device needed to be positioned close to a power socket and had to be positioned at right angles to light sources, avoiding excess glare. In many ways this makes it less flexible than the TM3; however it was decided that the MyTobii could meet more of Katherine's needs and it was agreed that this is what she would trial.

## FUNDING

Currently there is no joint funding arrangement with the PCT or Social Care and Katherine's Local Authority - and as eye-gaze was being considered purely for recording and retrieval the device would have to be funded by education. To allow discussion on funding, and even before a trial was arranged to determine if Katherine was able to use the eye-gaze, it was important to establish the cost of the whole package (including extended warranty), which totalled £17,500. The authority

had never spent this amount of money on a single item of equipment for any pupil before.

One Monday morning, towards the end of the financial year the SEN-ICT team received an e-mail: "Can you spend £10k before Friday?" A huge sum, but not enough to fund the MyTobii package. Had other teams received a similar e-mail? A flurry of phone calls later and the extra money was provided from teams within the Physical and Sensory Support Service, all of whom support Katherine in school.

At the end of March 2008 it was possible to place an order with SmartBox for a MyTobii P10. A scary decision as Katherine had not yet trialled the device, but as this level of funding might not be available again it was necessary to take this gamble.

## MYTOBII IN THE CLASSROOM

The Quality Indicators for Assistive Technology Implementation Consortium (2005) comments that teams often focus on acquiring equipment and not on classroom implementation. In February 2009 Katherine finally received her MyTobii. It had taken almost two years of hard work to organise the assessment and the funding for the Katherine's eye gaze system. It would have been easy to hand over the equipment to her school and step back, however it was important that the effort did not stop there.

Initially there were lots of problems. Katherine, like many eye gaze users, found controlling the computer with her eyes extremely tiring. It was suggested that she worked for two short sessions each day, one in the morning and one in the afternoon. However, even so she tired very quickly and she hated this. This was the first time she had encountered something she found so difficult. Frequently she went home in tears saying she could not do it and that she wanted to go back to her head switches. In a bid to boost her confidence she was encouraged to 'train' other people. One teacher was unable to write her name; she and Katherine were able to laugh at this. Katherine could cope with other people not being able to do a task but was miserable when she could not do it herself.

Staff supporting Katherine in school found the move from head switches to eye gaze very difficult. Initially using the MyTobii was slower than using switches and staff needed lots of reassurance that it was acceptable for her recording to be slower at the beginning. We are all slower with a new skill, especially when



it is something that is very tiring. Some school staff thought that Katherine was too young to be using this technology. They had looked at the MyTobii community.com website and felt that most other users were older than Katherine when they had first tried eye gaze, but of course the technology was not available when they were seven.

Katherine had no difficulty with the basic calibration. She was able to fix on the five calibration points, with both eyes together and with each eye separately, however it was not the one-time calibration that the brochure suggested. Investigation showed that Katherine sat upright in her chair when calibrating the device, but tended to sit forward when accessing the on-screen keyboard and therefore was not in the same position and often mis-selecting.

She was shown how to use the 'Track Status' window - this shows her if her eyes are registering with the system (see Figure 1). The (yellow) triangle at the top of the Track Status box should be in the middle - this shows that Katherine is at the ideal distance for eye control. Two white circles representing her eyes should be as close to the center of the box as possible. An indicator bar at the bottom of the Track Status box will turn green if it is able to track Katherine's eyes.

Katherine was encouraged to use this every time she started work and after a few weeks she needed the track box less often.

Once her positioning was more settled it was important to recalibrate the device. Within the advance settings it was possible to check the calibration points and then improve individual points as necessary. Katherine improved each point with both her right and left eye and since then has had no further problems.

One early major customisation was to set up the program to make an audible 'click' when a letter/word was successfully selected. Before this Katherine was locating the letter she wanted then looking to the workspace to see if it was there, however if she looked up too soon her letter would not have been selected and she would have to start again. By knowing that she has to listen for the click she stopped looking too early.

It was important to remember this was a totally new way of recording. Katherine's peers began to develop their handwriting skills four years ago - they had developed their visual discrimination and memory, and had the strength and endurance to create the quality and quantity of work demanded of a Year 3

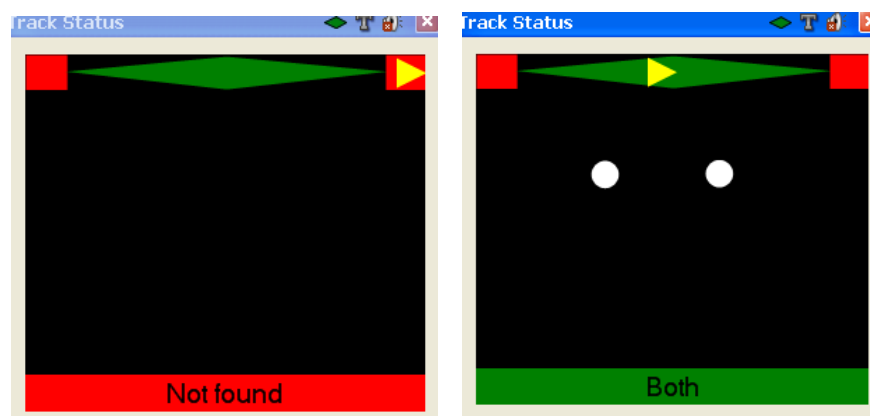


Figure 1 The 'Track Status' window



Figure 2 Standard Star Talker Chat Keyboard

pupil, however in many ways Katherine was only developing her recording system now.

It was important that the software packages provided for Katherine offered her appropriate applications with the opportunity to customise grids to meet her specific needs.

Katherine started off using the standard Star Talker Chat Keyboard from within The Grid 2 (see Figure 2). This was a busy grid and many of the cells are fairly small and difficult for Katherine to select.

Katherine was using her MyTobii for recording and did not require the program to talk, so the speak option was immediately removed from all grids. As Katherine found eye gaze control extremely tiring she needed a rest cell on every page. Consistency was essential e.g. 'rest' and 'home' must always be in the same location.

Katherine explained that she found it difficult to select cells on the right side of the page. A left keyboard was considered, however she was not familiar

with the ABC layout and it was too much for her to learn yet another keyboard, especially as her e-mail, web browser and contact list grids also have QWERTY keyboards. Katherine's difficulties accessing the right of the screen continue to be monitored and where possible cells placed on the right were made larger and therefore easier for her to access.

After four months, Katherine had a clear and uncluttered Home page (Figure 3) and her standard keyboard looked very different. Reducing the work space and moving the prediction cells allowed the letter keys to be larger and easier for Katherine to locate.



Figure 3 A clear, uncluttered Home page



Figure 4 A grid for using MS Office

It was important to ensure that all the cells from the computer control grids were incorporated in Katherine's main grid. She is familiar with many of the applications from MS Office and she needs to be able to access her documents, open and save new documents etc. It was also important that she could format her own documents. The format grid does have some small cells, however this is not a grid she uses everyday. Some of the font sizes have been removed but she still has lots of choice. Word prediction is vital for Katherine as she will never be able to record as fast as her peers. Prediction reduces the number of key selections needed to write, and as her skills develop it will allow her to produce a greater quantity of work in the given timescale. Katherine benefits from being able to use abbreviation expansion. Nisbet (1999) describes this as "a technique whereby long words or phrases (expansions) are stored in the computer and given a short abbreviation. When the abbreviation is typed, the program 'expands' it and types in the full word or phrase."

If Katherine selects her initials her full name is inserted; 'CJS' inserts the name of her school; typing single words inserts the whole phrases used in science experiments.

Katherine is able to access her word bank from her standard keyboard. The map pin in Figure 5 allows Katherine to stay on this self-closing grid, so that she is able to use a word from this page and then another or move on to 'more words'.

On some days, when she is very tired, Katherine struggles to use the QWERTY style keyboard and on these occasions she uses a Key 8 keyboard. She needs to select twice for each letter. For example, in Figure 6, to select the 'K', she first selects the GHIJKL cell (grid on left) and then the K cell (grid on right).

The appropriate cells from her Key8 keyboard link to exactly the same

wordbank and punctuation grids as from her usual keyboard. When these grids were introduced support staff commented that Katherine was not a baby and that she was used to a qwerty keyboard, but after a few weeks Katherine understood that when she was tired her standard keyboard was too difficult to use. She called this her 'Friday afternoon' grid.

#### EYE GAZE IN PRACTICE

Nisbet (1997) comments that "Choosing and setting up the equipment is an easy task compared to using it for day to day activities." When becoming familiar with her MyTobii and all the applications it was appropriate for Katherine to spend some one-to-one sessions working with her teaching assistant. Once that the initial learning time was over it was vital for her to work in class alongside her peers. A balance had to be maintained between allowing Katherine to create her own work and expressing everything that was within her head. It has been necessary for her



Figure 5 A word bank

teacher to identify the primary objectives for each piece of written work and based on that objective a decision needed to be made between:

- recording her work using her eye gaze technology;
- using head switches with her laptop to record using a combination of a Clicker grid with Topic words and her word prediction grid;
- Katherine and her Teaching Assistant (TA) alternating in recording sentences on laptop;
- Katherine starting recording and when she gets tired her Teaching Assistant finishing;
- Teaching Assistant starts recording and then Katherine takes over;
- Teaching Assistant scribing everything.

#### NEW IN YEAR 4

When Katherine's grids were initially customised the theme was clear, bold and uncluttered. The rest cell was 'double size' and positioned to the top right

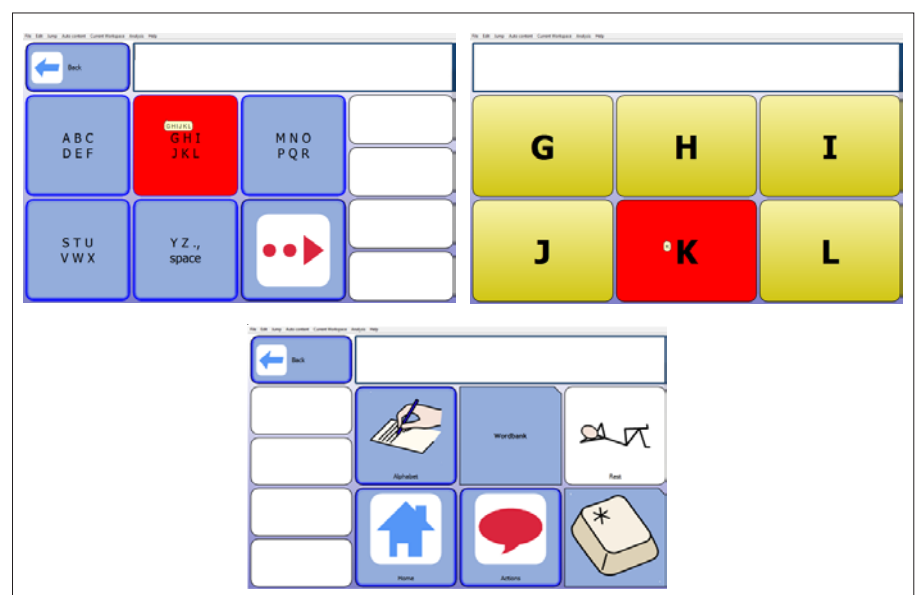


Figure 6 The Key 8 keyboard

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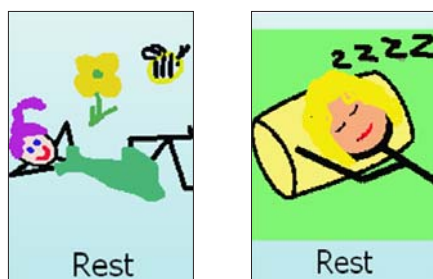


Figure 7 Customised rest cells

of every grid. At the beginning of Year 4 there were some variations as Katherine's friends had customised the rest cells! (Figure 7)

Katherine is a keen reader. She always reads with a partner who turns the page for her. While Katherine likes to work with a friend she always wants to do things for herself. During the autumn term two possible solutions were considered: accessing digital books and using her eye gaze to navigate through the pages. Accessing digital books may be useful in the future, however, currently it continues to be difficult to source electronic versions of the books Katherine likes to read and the text books she uses in school. So Katherine has been provided with a Readable2 page turner which she operates using her page turning grid (Figure 8).

This grid has very few cells and as they are quite large and easy for Katherine to select and she has been able to choose her own background using characters from one of her favourite stories. Katherine chose the fairy from *Sleeping Beauty* as her rest cell because there is lots of sleeping in that story.

#### THE FUTURE

Targets for the immediate future must be for successful implementation of the eye gaze technology. The school SENCo, teacher and teaching assistants have worked alongside SEN-ICT to cre-



Figure 8 Grid for page turning

ate an action plan including targets that form part of Katherine's Individual Education Plan. Currently she is working on transferring work from The Grid 2 into Word and developing her computer control skills within Windows.

Katherine was our first, and for some time only, pupil to use eye gaze and it has been difficult for the service to develop the skills needed to support her. Katherine has benefited greatly from termly input from a consistent member of the SmartBox team. He has been able to share tips from other eye gaze users and as Katherine's skills have grown she is now confident enough to e-mail him with her queries (and demands!). In 1999 Donegan commented that:

*"Technology is moving on at an increasing rapid pace. It is essential that users are able to benefit from the latest developments to make sure that they are making the most of what technology can offer at every stage of their development."*

#### CONCLUSION

It has been a bumpy road and no doubt there will be further humps and bumps

ahead. Katherine and her staff are now, however, enthusiastic and Katherine is producing the quantity and the quality of work which genuinely represents her potential. The time and money were well spent. \*

Ruth McMorran, *Specialist Teacher*

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- The costs of a social research project.

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The closing date for application is **30 June 2010**. Applicants will be informed of the result of their application by 30 September.



# The National AAC Coordinator for England

## Anna Reeves interviewed by Dithe Fisher

**Anna Reeves is the manager of ACE Centre North.** She is also a Communication Matters Trustee. Now she has taken on a third role, seconded to Becta for three days a week as National AAC Coordinator for England. Fellow Trustee, Dithe Fisher, caught her in a rare quiet moment to find out about the new role.

### So, what does the National AAC coordinator do?

Well, I do have an official job description [see Appendix], which is published on the Communication Council website. But from my point of view I think my job is to understand what is achievable in the current climate. Obviously thinking ambitiously about developing AAC provision, but also trying to be realistic. I see it as very much about coordination; pulling together different agencies and departments and individuals to work together. I think that collectively the answers are out there; we just need ways of coordinating solutions to some of the current challenges around AAC provision.

### Who are the agencies?

Obviously all the members of Communication Matters are stakeholders. Dare I say, I think that historically we have been a bit introspective as a community. Now there are opportunities to engage with bigger and wider agendas, such as the agenda around SLCN. So there are opportunities to work with other organisations like the Communication Trust and other organisations involved in the Communication Consortium. Key government departments



would be the Department of Health and DCSF.

There are other organisations and agencies as well; for me one of the most important areas to develop is around what is happening about the children's workforce. There is a Workforce Development Council and other key organisations. It would be really good to try to influence them, and raise awareness about AAC to get it onto their agendas as well.

### That sounds like an enormous task! How have you decided where to start?

Well there are certain things that I have to do, identified in the Better Communication Action Plan, such as setting up the AAC subgroup and defining the terms of reference for that group. That has now been established and has met once. Then there is work around influencing what's happening around the AAC grants programme. And of course supporting the work of the Communication Champion.

These are all clear starting points. But in my mind, and through emerging dis-

cussion with stakeholders, developing the children's workforce to have a better understanding of AAC is a key issue.

One of the challenges at the moment is that, outside our little AAC community, nobody really knows what AAC means. We need to raise awareness with the general workforce about what AAC is, and what it can offer.

The terminology that's used is 'Universal, Targeted and Specialised' services. Raising general awareness about AAC will influence Universal services. Then the Targeted and Specialist workforces also need to have recognised competencies and standards in the delivery of their services.

This will lead to more parity at the national level of what services are available locally and also better understanding by commissioners of what good models of AAC service delivery actually look like.

### So is that another part of your role, liaising with commissioners?

That is a role that Jean Gross can have as Communication Champion.

She will have far more influence than I, or even Becta, because she is courting the media and has a remit from the Communication Council to go out and challenge directors of children services and PCTs around what they are doing about commissioning SLCN services for children generally. But I will be feeding in to her what is happening around AAC in particular.

### Have you met Jean Gross yet?

Actually, I have just got back from meeting her for the second time today. It was a very positive meeting, and I am extremely pleased that she has taken that post. Jean is clearly committed to AAC, and keen to be a champion for AAC as much as for anyone else with speech language and communication needs. She wants to meet once a month to discuss coordinating AAC service development. Part of my role is to provide her with information about existing services, so she can start making demands about filling the gaps.

### What have you enjoyed about it so far?

It's very different from anything I have done before. Unlike my other job, I have more opportunities to influence things at a national level because I am actually employed by the government with a specific remit to do it.

I have spent a long time lobbying and campaigning for better AAC provision. Having complained about it for such a long time, now I get an opportunity to actually do it. I am enjoying having the challenge of working out how to make that happen in reality. Working with big organisations, you have to work within their systems and in ways that they understand.

It is different to lobbying; you have to communicate with people in different ways. I am needing to learn a lot about bigger agendas; how AAC can fit into that so it is attractive to those decision makers and policy makers. I think it had to be someone from inside the AAC field to take on that role, knowing the context and history.

### How do you see the role developing over time?

There are a lot of unknowns. Officially the post runs for another two years from April, but that may depend on what happens at the general election. Looking ahead is a bit like looking at a magic eye picture; the longer you stare at it the more things appear, but a lot of things are still very blurred!

For example, the financial climate and the political climate will inevitably affect what is achievable over the next two and half years. With the Department of Health facing a £20 billion budget deficit, it is not the best time to be talking about better financial investment in AAC. That is not going to stop me asking the communication champion to seek better funding arrangements for AAC, but we have to be realistic about the pressures on existing budgets.

I am keen to be realistic about what is achievable, given this uncertainty, and

think about things that can really be done. If we aim for things that are too sophisticated and too high cost, without sufficient robust evidence to back up the case for it, we are on a hiding to nothing.

### If you could achieve one thing, what would it be?

Developing national standards for AAC services is really important. We have got specialist AAC services that have been vulnerable recently: without national standards it is very difficult for commissioners to fully appreciate the importance of those elements that we know are essential. Commissioners may be looking at cost efficiency without appreciating impact, and may see cost efficiency in the short rather than the long term.

In the field, we know that it is important to ensure that people are given the solutions they need. That may be expensive at times, or require significant support, but there is a cost involved in not investing in that kind of support and technology. Getting that message across to commissioners is very important.

We know what those standards need to be. There is a draft document already with Communication Matters that we need to develop and embed; get it understood and validated.

### How would it be validated?

It needs endorsement by the Communication Council through the Communication Champion; they are talking to commissioners all the time.

Alongside the standards we also need some sort of competency framework. I would like experts in the field to contribute to that. I am trying to get funding for a piece of work around developing a competency framework for the workforce. The National standards and the competency framework are things that don't necessarily cost a huge amount of money but would have a huge impact on improving provision.

People not familiar with AAC tend to see it as high cost, high tech provision, concerning a very low incidence population of people with complex disabilities. People think about Becta as 'education and high tech', and that reinforces that perception. We have to challenge that. The benefits of AAC are far wider and the definition of AAC is far wider than that.

Actually, in my experience, Becta have been very open to understanding that AAC is much more than just high tech. They also understand that the issues are much bigger than funding equipment. It's about having the workforce

and services to provide, not just assessment, but also ongoing support around AAC provision.

### I am sure CM members will be very interested in how this project develops. How can people find out what is happening?

Well, they can read about it on the Communication Council website, when this is launched.

I would also be happy for people to contact me at Becta if they want to be involved in any way. My email there is [anna.reeves@becta.org.uk](mailto:anna.reeves@becta.org.uk) \*

Anna Reeves interviewed by Dithe Fisher

## APPENDIX

### The National AAC Coordinator's job description:

- Work in close liaison with the Communication Champion and Communication Council, providing expert input and analysis and provide a link between the AAC communities and the broader SLCN agenda. The coordinator will chair the AAC subgroup.
- Bring specialist and educational technology expertise to the work of DH, DCSF and partners who are implementing key Government commitments, including:
  - linking with the 16 SLCN commissioning pathfinders (Bercow) to establish the existing scope of AAC and the potential for improving opportunities for those who need AAC;
  - support for development of models, including sub-regional and regional, to improve the effectiveness and efficiency of procurement of children's equipment, which will be piloted in 2009-10 (Child Health Strategy).
- Review, with others in the community, the AAC grants programme providing Becta and DCSF with expert analysis of how the programme can be developed and the knowledge base improved to support future provision.
- In light of the Workforce Strategy, review the existing position with regard to AAC and propose and support implementation of improvements so that the profession can support children with AAC more effectively.
- Contribute to the universality agenda for home access by representing the needs of those with SLCN and through analysis, identifying further opportunities for government and its agencies to address.

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PRESS

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# Naidex Communication Village



## See the latest innovations in Assistive Technology at the Communication Village, new for NAIDEX 2010.

Naidex 2010, the UK's longest established disability, homecare and rehabilitation show, returns to the **Birmingham NEC on 20th to 22nd April 2010** with added new and improved features, including the brand NEW **Communication Village** located in Hall 19 by the KideQuip feature.

Communication Matters will be giving a seminar on each of the three days in the Kidequip seminar theatre, where they will be discussing topical and relevant issues aimed at both healthcare professionals and parents of disabled children.

Following the appointment of Jean Gross as England's first Communication Champion, Naidex has launched a Communication Village which will be showcasing the latest developments in assistive technology for speech and language therapists, SEN teachers, parents and users of communication aids and assistive technologies.

The appointment of a Communication Champion was a recommendation in the 2008 *Bercow Report* on services for children with speech, language and communication needs, and forms part of the government's *Better Communication Action Plan* developed in response to the Bercow review.

The Communication Champion, funded jointly by the DCSF and Department of Health, will be responsible for working across Government, delivery partners and other stakeholders to co-ordinate and build on initiatives to improve services for children and young people with speech, language and communication needs.

The inclusion of the Communication Village at Naidex will support the government's drive to improve the lives of children and adults with communication difficulties. Key charities including the RNID and Communication Matters will be at the show as well as leading suppliers of assistive technology and communication aids including BT, Dynavox, Liberator Ltd and Toby Churchill.

BT has been working for the past 25 years to ensure that its communications products and services are ac-

cessible to the widest possible audience. And at Naidex 2010 visitors to BT on stand C17 will be able to see some of its leading products, such as Freestyle 700 and 750 and Big Button 100. The stand will also be displaying the new Converse 2200/2300. The Converse 2200/2300 is a practical and simple to use range of cored phones with features suitable for both the elderly and disabled.

On stand C18, Logan Technologies will be showcasing three 'new to Naidex' products which are easy to use mid-low tech devices which you can be used out of the box either as primary or secondary aids such as the ProxTalker communication device. The device contains 80 pre-recorded sound tags and 20 blank tags which can be pressed to help with verbal communication. Just pick a tag, place it on a button and press and the ProxTalker will say the appropriate sounds, word or sentence.

"The Communication Village is something Naidex has worked hard at introducing, as we believe everyone deserves to get the most out of the interactive communication solutions available. The purpose of the Village is to raise awareness and provide guidance to visitors who live with speech, language or communication difficulties and help promote services which will benefit them in their daily activities", commented Liz Virgo, Event Director.

With thousands of products being exhibited by over 360 companies, the event gives visitors, including trade representatives, healthcare professionals, parents, carers and teachers, the chance to test, touch and compare the most innovative new products to aid independent living. From wheelchairs to scooters, adapted vehicles to pressure relieving beds and much more, all under one roof.

**Naidex 2010 takes place at NEC, Birmingham on 20th - 22nd April 2010. Don't forget to visit Communication Matters on stand D6 in Hall 19.**

**Register now for free entry at [www.naidex.co.uk](http://www.naidex.co.uk) using priority code E316.**





## TRUSTEES' NEWS

### FROM JANICE MURRAY, CHAIR OF BOARD OF TRUSTEES

I would like to update you on a number of things that have been achieved since the last Trustees' News.

#### WEBSITE

The new website will be going live during April, and for a short while will run in parallel to the old version to facilitate the transition – look out for an announcement of the website launch in April's edition of our E-News. Thank you to Simon Judge and Patrick Poon for making it a reality and to Gillian Hazel, Dithe Fisher, Sandra Hartley and Janet Larcher for producing much of the current content. It has many new elements to it and continues to be a work in progress, so we welcome your feedback. One fairly recent addition is a database of AAC Assessment Services in the UK – do check it out and get in touch if you spot any services that are not listed.

#### PUBLICITY AND INFORMATION

In response to feedback from the Associate Membership, Sandra Hartley led on the development of a 'welcome flyer' for members that outlines the different activities of Communication Matters. If you would like copies to circulate, get in touch with Patrick Poon on [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)

#### SMALL GRANTS

We have had our first round of the popular, reinstated Small Grants scheme, co-ordinated by Gillian Hazell. We received several applications and have made one award and are in negotiation with a second. The next submission deadline is 30 June (see page 15); we will update you on the activities supported later in the year.

#### ORGANISATIONAL DEVELOPMENTS AND EVENTS

One less successful thing to report on is that our second re-submission of a bid for a fully funded Chief Executive Officer post has been unsuccessful. Whilst we continue to have these aspirations, in the short term at least, we remain an entirely voluntary organisation. We have therefore reconsidered the breadth of the current business plan and identify our core achievable activities. This has led us to focus on appointing a fundraiser/bidwriter to support us in awareness raising and education activities.

The AAC Assessment Services Forum had a very successful meeting in February, led by Sally Chan and Dithe Fisher, with Anna Reeves who was successful in obtaining financial support for the day from Becta. This work continues with a working party established from across the Associate Membership aiming to produce an updated document by the end of the year.

Development of the membership remains a priority and has us considering a number of things, including geographical distribution, user involvement and targeting less well represented groups, e.g. specialist teachers. This is being co-ordinated by Sandra Hartley and Janice Murray. Membership activity links with other marketing strategies that we are also re-visiting. And Simon Judge is updating our current branding of the organisation.

For the first time, we will have an exhibition stand at Naidex where we are launching some new publicity material. Thanks to the 'Friends of Communication Matters' and to ACT, Birmingham for supporting us at the event.

We continue to focus on delivery of our annual conference and a range of education orientated events. Toby Hewson has been trawling the country exploring potential venues for our annual conference. Specifically, we have been attempting to identify a location that could accommodate more people but not lose the flavour of a campus-style conference. Sadly, you will not be surprised to hear that one of the sticking points is the number of easy access bedrooms. If you know of any good venues we would welcome you getting in touch.

As many of you are aware in England, we are gearing up for the Year of Speech, Language and Communication (unconfirmed as yet to be re-named as the 'Year of Talk'). Given our national profile we aim to capitalise on this as much as possible across the UK with a number of fun, awareness raising, educational events. The events team on the Trustees, led by Dithe Fisher and Sally Chan are co-ordinating our efforts. We will be approaching some of you directly with ideas but do get in touch if you would like to know more or have a good idea that may need some financial backing.

Communication Matters continues to maintain its presence and contribution at a number of national and international activities including ACCE, the Adult Communication Coalition England (Gillian Hazell); Communication Forum Scotland (Dithe Fisher & Janet Scott), the AAC sub-committee of the Better Communication Action Plan (Toby Hewson); the Communication Consortium (Janice Murray, Toby Hewson & Sandra Hartley); ISAAC Council (Janice Murray & Liz Moulam); Becta Expert Reference Group (Janice Murray).

#### RESEARCH

Our research programme, co-ordinated by Mike Clarke with Liz Moulam in her role as Interim Research Lead, continues at a pace. We have appointed Katie Holmes as the Research Manager, and as I write this I am aware that the interviews for the Research Lead post are imminent. Through the website, we will provide all members with an opportunity to get to know both of these new Communication Matters employees very soon. Along with the collaboration partners (specifically Simon Judge and Janice Murray) we aim to provide an update and discussion forum at the conference later this year.

#### CONFERENCES

Whilst we are gearing up for our CM2010 conference in September (visit [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk) for more information and booking form), we are aware that preparations are well under way for the ISAAC International Conference in Barcelona in July. For those of us fortunate to be able to go to either of these events, we hope they prove to be an enjoyable and stimulating occasion for all.



## HOT NEWS

### RICHLY DESERVED AWARD FOR SUDHA KAUL



**Dr Sudha Kaul**, Executive Director of the Indian Institute of Cerebral Palsy, Kolkata and former President of ISAAC, is well known to many people in the UK. Recently, on India's Republic Day when national presidential awards are announced, Sudha was awarded a Padma Sri for her services to the country. In the UK, this is equivalent to the Queen's new year/birthday honours awards. This is a highly prestigious award; only six people in the whole of Bengal have been recipients.

Sudha has worked tirelessly since the mid 70s in her home city setting up services for children and adults with cerebral palsy. She established education and employment opportunities and has pioneered developments in her country in the field of AAC. Over the years, Sudha has also spent considerable time in the UK gaining her Masters qualification through City University, London and her PhD through Manchester Metropolitan University.

Communication Matters (ISAAC UK) send their warmest congratulations to her.

\*

### BETH MOULAM WINS ISAAC AWARD

Congratulations to Communication Matters member **Beth Moulam** for winning an ISAAC award for her multimedia entry in the 2009 AAC Awareness Story contest.

The entry was created jointly by Beth and her Australian friends Emma Green and Morgan Liddle-Webb. It tells the story of their friendship and their many methods of communicating in different situations and with different people. Their PowerPoint movie, 'AAC Around the Globe', features their writing, poetry and photos, as well as their own voices and voice output devices.

The movie can be viewed at [www.youtube.com/user/1voicemovies#p/a/u/1/JGQ7wCsT3AY](http://www.youtube.com/user/1voicemovies#p/a/u/1/JGQ7wCsT3AY)

You can also read/view the other entries received from all over the world at [www.aacawareness.org/2009stories.htm](http://www.aacawareness.org/2009stories.htm)

\*

### CORRECTION

In Communication Matters Journal Vol 23 No. 3 (November 2009) the article 'The Multi-Modal Nature of Communication Between Natural Speakers and Aided Speakers: A Pilot Study' was incorrectly attributed to Pippa Bailey alone; the correct authors are Pippa Bailey and Dr Karen Bunning.

## eCAT NEWS

### FROM DAVID WEATHERBURN

#### MEETING THE COMMUNICATION CHAMPION

Following our BHTA meeting in February, eCAT members were joined by other suppliers of AAC products and services for a meeting with Becta and **Jean Gross**, the new Communication Champion.

This was an important meeting in which Jean Gross outlined the objectives of her new role and her initial ideas for the proposed 2011 National Year of Speech, Language and Communication.

We brainstormed and discussed the many barriers to effective AAC provision, and suppliers expressed their support for implementation of the Better Communication Action Plan (BCAP).

#### SUPPORT FROM SUPPLIERS

Suppliers play a vital role in effective AAC provision, through product innovation and development, support for assessments and trials, training and ongoing product / customer support. eCAT suppliers account for almost all expenditure on high-tech AAC and are in a unique position in that a small number of organisations have access, either directly or indirectly, to the entire population of people who use AAC.

Suppliers potentially hold, or could gather, some useful information. So one of the ways we can help support the BCAP in the short term is through provision of data and other information that might help us understand:

- (a) how many of the people who need AAC are being served;
- (b) who funds those AAC products now;
- (c) any patterns or trends in that expenditure.

Such information could help inform better decision making in future. By contrast, the very large number of health, education, local authority, charity and private organisations that purchase AAC equipment are highly fragmented and it would much more difficult to first identify them and then gather useful data from them.

#### CASE STUDIES

The other request Jean Gross made is for examples of what has worked or not worked in the past. These case studies should mention the area concerned but not individuals' names. If you are able to help with case studies, or if you are familiar with other models of AAC provision (within the UK or internationally) that we may be able to learn from, please do contact Anna Reeves at [anna.reeves@becta.org.uk](mailto:anna.reeves@becta.org.uk)

**David Weatherburn**  
Chair of eCAT section, BHTA  
[david@ability-world.com](mailto:david@ability-world.com)



## DIARY DATES

20-22 April 2010 Birmingham

### **Naidex 2010 at the NEC Birmingham**

Visit Communication Matters in the 'Communication Village'

More information: [www.naidex.co.uk](http://www.naidex.co.uk)



27 April 2010 London

### **Clicker 5 Training**

Contact CENMAC: 020 8854 1019 [www.cenmac.com](http://www.cenmac.com)

6 May 2010 Oxford

### **Making Sense of Eye Gaze Technology**

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

10 May 2010 London

### **Clicker 5 Training**

Contact CENMAC: 020 8854 1019 [www.cenmac.com](http://www.cenmac.com)

12 May 2010 Worcester

### **Communication Matters Road Show in Worcester**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



13 May 2010 Edinburgh

### **Creating Accessible Resources for Glow**

Contact CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

15 May 2010 Exeter

### **1Voice Southwest – Fun Day**

Contact Anne Williams: [1voicesouthwest@1voice.info](mailto:1voicesouthwest@1voice.info)

21 May 2010 Bristol

### **BoardMaker Training**

Contact PCAS: 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

24 May 2010 Birmingham

### **Communication Matters Road Show in Birmingham**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



8 June 2010 Leeds

### **Communication Matters Road Show in Leeds**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



10 June 2010 Oxford

### **Communication Matters Road Show in Oxford**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



12-13 June 2010 Derbyshire

### **1Voice Family Network Day**

Contact 1Voice: 0845 330 7862 [www.1voice.info](http://www.1voice.info)

14 June 2010 Bristol

### **Communicate: In Print 2**

Contact PCAS: 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

15 June 2010 Oxford

### **AAC SIG Day – AAC & ASD**

Contact Julie Atkinson: 0121 627 8235 [julie.atkinson@sbpct.nhs.uk](mailto:julie.atkinson@sbpct.nhs.uk)

15-17 June 2010 Dundee, Edinburgh, East Kilbride

### **ICT and Inclusion Exhibition & Seminars**

FREE CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

24 June 2010 Basildon

### **Communication Matters Road Show in Basildon**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



24 June 2010 Oxford

### **AAC – What is there to say?**

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

## DIARY DATES

25 June 2010 Bristol

### **Clicker 5 Training**

Contact PCAS: 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

29 June 2010 Ipswich

### **Communication Matters Road Show in Ipswich**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



7 July 2010 Gateshead

### **Communication Matters Road Show in Gateshead**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



12 July 2010 London

### **Clicker 5 Training**

Contact CENMAC: 020 8854 1019 [www.cenmac.com](http://www.cenmac.com)

24-29 July 2010 Barcelona

### **ISAAC 14th Biennial International Conference: Communicating Worlds**

More information: [www.isaac2010.org](http://www.isaac2010.org)



2-4 August 2010 London

### **Pragmatic Organisation Dynamic Display (PODD)**

Contact Rosie Clarke: [rosie.clark@greenmead.wandsworth.sch.uk](mailto:rosie.clark@greenmead.wandsworth.sch.uk)

26-28 September 2010 Leicester

### **CM2010 National Symposium**

Contact: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



14 October 2010 Oxford

### **Control, Communication and Play**

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

4 November 2010 Barnsley

### **CM Study Day: Eye Gaze in Action**

Contact: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



9 November 2010 Oxford

### **AAC SIG Day**

Contact Julie Atkinson: 0121 627 8235 [julie.atkinson@sbpct.nhs.uk](mailto:julie.atkinson@sbpct.nhs.uk)

9 November 2010 Stirling

### **AAC Study Day: Eye Gaze**

Contact ACiP: Scotland 0141 201 2619 [www.acips.org.uk](http://www.acips.org.uk)

18 November 2010 Oxford

### **Developing & Supporting Low Tech Communication**

Contact ACE Centre: 01865 759800 [www.ace-centre.org.uk](http://www.ace-centre.org.uk)

22 November 2010 (TBC) Bristol

### **Communication Matters Road Show in Bristol (TBC)**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



November 2010 (TBC) Manchester

### **Communication Matters Road Show in Manchester (TBC)**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



30 November 2010 (TBC) Glasgow

### **Communication Matters Road Show in Glasgow (TBC)**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



1 December 2010 (TBC) Perth

### **Communication Matters Road Show in Perth (TBC)**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



8 December 2010 (TBC) London

### **Communication Matters Road Show in London (TBC)**

FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)



## Death, Loss and Grieving

# Supporting Children Who Use AAC to Talk About Bereavement or Loss

**SHELAGH CROSSLEY**

Lister Lane School, Lister Lane, Bradford BD2 4LL, UK

Email: shelagh.crossley@yahoo.co.uk

**Talking about death and loss is never easy,** nevertheless it is recognised as an important part of the coping and the healing process. In order to ensure and often to regain our mental health and well being, we all need a vehicle to 'get things straight in our minds' and thus re-establish the equilibrium. For many of us, this is to talk.

Historically, in our culture, there has been a habit of not talking, hoping it will all go away. Today we like to think we have moved on. But has it? For some of us yes it has, but consider what it is like for some one who needs to use AAC to talk about their feelings and thoughts. Does anyone take the time to offer the opportunity to talk? And even if they do, does that tend to be in the immediate time frame of the event?

Experience suggests that the need to talk or address these very personal issues can be, in fact, timeless. It may be weeks, months or even years before a bereaved person has worked through the emotions to achieve well being and a personal understanding. It may also take this time to actually be ready to talk.

These are real issues for all of us. However it is especially difficult for people who use AAC and for the people who support them.

This paper will address some of these sensitive issues and generate discussion to enable both professionals and families to ensure AAC users have the vocabulary they need, when they need it. It draws on our experiences in a special school in West Yorkshire.

The school caters for pupils with physical difficulties, aged 2-13. The pupils have a wide range of physical and medi-

cal conditions including degenerative and life challenging disabilities. The majority of pupils require augmentative communication systems.

Coping with bereavement and loss has become increasingly part of our lives at school. This had been addressed for staff with bereavement training during the last academic year. Although this had raised the issue of how pupils with limited communication can express their feelings and thoughts following a loss, we had not really provided any solutions. As staff, we did what we as adults often do when the solutions are difficult: nothing. We thought of many excuses why that was OK, including:

- Protecting children: they are too young; they don't need to know; they wouldn't understand.
- Protecting parents: it will make them worry, it will be too painful.
- Protecting ourselves: I don't know how to do it; I don't know what to say; I might cry.
- Cultural issues: getting it right.
- Believing people, especially parents, didn't want to talk to pupils, rather than recognising that we didn't know how.

And the rest...

But it wasn't OK!

We then had a situation where, sadly, 2 pupils died in one week and the issue was back in the forefront of our minds. We had come a long way in our practice and protocol to support the family and staff and how we would respond as a school but we still had nothing in place to support the pupils to express their own emotions.

Around this time, I had been working with a brother and sister with a degenerative diagnosis. I knew they were very aware of their own deteriorating physical condition. The sister was very ill and was in hospital in London. Mum had expressed concerns about informing her son about the death of his friends as she knew how worried he was about his sister.

As caring human beings we were very aware that we needed to put something in place to allow this young man to talk about the emotions and fears he was feeling but As professional, we also knew we needed to get this right!

It seemed that there should already be some pages available for his device, but we couldn't find any and so set about creating our own (the young man uses a high tech device)

Although this young man is very cognitively able and alert, he is also very physically challenged. At the time he was using 2 switch scanning which required a great deal of effort. Some days he was unable to access his device at all. The pages needed to allow access to complex feelings and emotions but he could only cope with 12 - 16 buttons.

We considered the types of vocabulary he would need and also how this could be presented. We did not want to 'put words into his mouth' but we also needed to know we were providing him with enough vocabulary to meet his needs.

What do children say when they experience a loss, how do they feel? Cruse Bereavement Care and other sources cite things such as:

- Why did it have to happen?
- Was it my fault?



- Will you die too?
- Daddy didn't die; when is he coming back?
- Where has she gone?
- I wish I were dead.
- One minute I'm angry, the next I can't stop crying.
- What happens to the body?
- Will it hurt her when she is burned?
- Can you die standing up or do you have to lie down?
- When will I get a new grandma?

The emotions and thoughts of children are, it seems, as unique and varied as the children themselves. To provide pages and vocabulary to cover the endless possibilities is surely impossible.

We decided that to support this child and indeed other children in school now and in the future we needed to provide pages with general starting points. We could then be led by the child once we had a clue to where his thoughts were taking him. We also realised that the success of this approach would be very much down to the skill of the communication partner. How to ask the right questions, listening and giving time for a response, and then most importantly checking that we had understood the intended meaning, are all important skill when supporting and communicating with someone who uses AAC. In this context these skills are vital. For example, the comment "I need a hug". Could that be now from me or was it from someone else, perhaps Mum that evening, or was it about something that had already happened in the past?

The pages we started with (Figure 1) covered broad emotions and general vocabulary and came from our own experiences and from a professional and personal knowledge of the kinds of things children say.

The next step was to introduce the pages to some of our pupils. I found this a much harder task. Where was I to begin? As with any vocabulary set, the children cannot use it unless they know what is available to them and have knowledge of where it is stored.

Finally I decided to talk to some children and ask them what they thought. Were these the sorts of words that they might need in order to talk about their friends? Would they find them useful to have on their devices? After all they were the ones who would use the pages.

The initial trials allowed pupils to tell us things we would otherwise have had no idea about and quickly gave a very clear message about how important this



Figure 1 Initial vocabulary set

project was. One boy explained he was worried about his aunt but then couldn't talk about it any further, asking to play a game instead. Later that day he talked to another member of staff telling her his aunt had Cancer and he was worried. We had had no idea. Immediately this highlighted a number of things:

- Access to relevant vocabulary is vital.
- The importance of asking the right questions.
- The courage to ask the right questions.
- The child needed some ability to express who he would like to talk to (in this instance it had not been me).
- Our need to respect when a child has said as much as they want to, and to know when to back off.

This led to developments in the pages to include a talk page to enable requesting a listener, and an "I don't want to talk about it" button (Figure 2).

## CONCLUSION

This paper explains how this work developed from an initial urgent need in our school. However it soon became clear that this was a much bigger project than we initially dared to think.

Not all pupils use high tech devices. How were we going to support these pupils too? How are we going to maintain the pupil's knowledge and familiarity of the pages and vocabulary? They are not words or pages that are likely to be used in everyday conversation in the classroom or even at home.

To address some of these issues we have developed a set of symbols that could be used with talking mats to work with pupils who do not use high tech devices.

This is still very much 'a work in progress' and a great deal of work needs to be undertaken to ensure we can embed the vocabulary and opportunities to talk about these sensitive issues with the

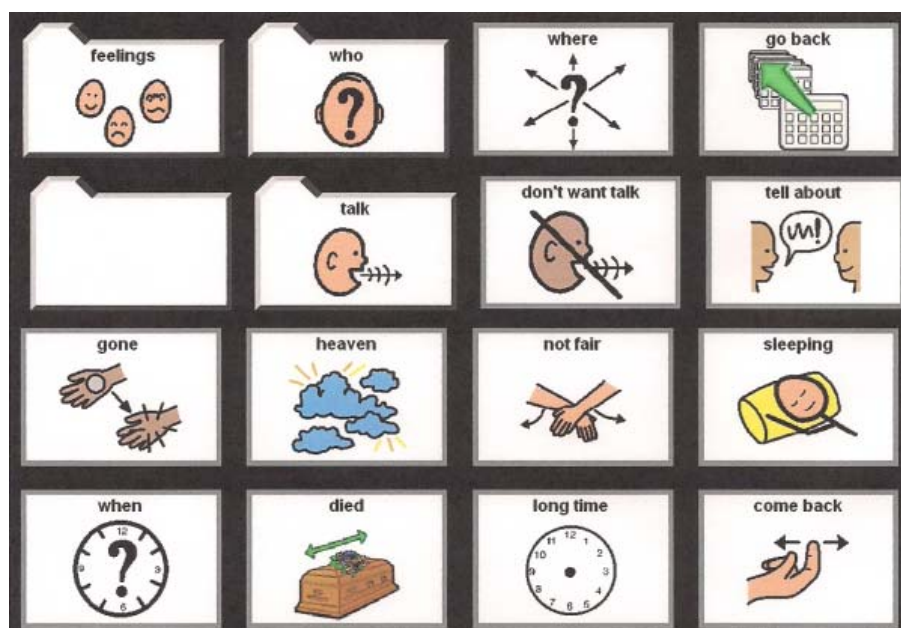


Figure 2 Addition of a 'Talk' page

pupils into the curriculum. A possible opportunity for this is included in the SEAL (Social and Emotional Aspects of Learning) curriculum, where the relationships module covers the subject of loss.

This is the work to date. Our initial research showed there is very little material readily available – yet this is such a vital subject for the well-being of so many AAC users. We are sure others have found themselves in similar situations and no doubt found their own solutions.

We hope that sharing our experiences has helped to raise awareness and to encourage a more proactive approach in other organisations.

Please feel free to email me to share ideas and experiences. There is still much to be achieved. \*

Shelagh Crossley, Assistant Headteacher

#### ACKNOWLEDGEMENTS

Special thanks to Jane Kitsen, colleague and friend, without her we may not have had the courage to undertake this work. And to the children themselves for guiding us through.

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## JOINING COMMUNICATION MATTERS & ISAAC

### 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:** A world where all individuals have a right to a 'voice' through the provision of equipment and ongoing support services.

**Our Mission:** Communication Matters values people who use any form of communication and promotes 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 rate at Communication Matters Study Days.
- 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.
- Access the members' area of the CM website.
- All the benefits of ISAAC membership, including ISAAC publications at substantially reduced rates (AAC Journal, ISAAC-Israel, AGOSCI News), and special delegate rates for the Biennial ISAAC International Conference. 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](mailto:admin@communicationmatters.org.uk)  
[www.communicationmatters.org.uk](http://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](mailto:info@isaac-online.org)  
[www.isaac-online.org](http://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](http://www.isaac-online.org/en/publications/aac.html) for more details.

#### What do ISAAC members receive?

- Full access to *ISAAC Information Exchange*, an 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.

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There are a number of subsidised places for people who use AAC, and their family members. Book early to avoid disappointment.

### BOOKING FORM & INFORMATION

For further information and a booking form, please visit [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk), or ring Communication Matters on 0845 456 8211 or email: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)





# Capturing the Code

## Making high street toys and home appliances accessible

### SALLY CHAN

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**Surfing the Internet for infrared remote control toys and playing with the toys is a worthwhile investment of time and work: it is all about giving the opportunities of play to our youngsters, and adults, who would normally be denied access to such fun and stimulating activities.**

One of the youngsters who had been referred to the Paediatric Communication Aids Service (PCAS) was very reluctant to use a voice output communication (VOCA). He was not keen to extend his communication beyond his limited vocalisations and gestures which had been his communication system most of his school life. Then he discovered that he could operate his DVD player and TV using a communication aid (MiniMo). He no longer had to rely on his mother to turn it on and off. His mother no longer had to stay up to all hours waiting until his DVD had finished, and then turning it off for him. He had found some level of independence. This led to using the same VOCA for communication.

Another young lad with cerebral palsy who attended Claremont school in Bristol, Steven, used to wake his parents up every Sunday morning so that his mother could turn on his television for his favourite TV programme at 7 am! This was not his parents' idea of a lie-in. Until that is, his father sawed off several centimetres from the legs of his bed, and positioned Steven's VOCA (Dynavox V) on the floor between his

bed and TV. Steven could then get out of bed safely, reach the VOCA, select the TV page and turn the TV himself. He then leapfrogged back to bed to watch TV in comfort. The benefit of such independence extended to the rest of the family.

There has been an exciting development in the use of infra-red (IR) equipment for disabled people. The use of IR equipment for children with physical impairment can motivate a child to use a switch or a voice-output communication aid (VOCA), and possibly lead to greater interaction. IR equipment such as toys, TVs, DVD players, and music systems can be made accessible using switches or communication aids. Easy if you know how!

IR codes on standard remote controls can be captured by these specialist equipment, so empowering the individual to be as independent as possible from an early age.

Switch-operated equipment has been limited in the past and dependent on specialist equipment being available – battery device adapters, soldering irons, specialist catalogues. The ability of using high tech communication aids to capture IR codes, and the provision of devices such as the BigJack to capture the codes for switch access, has opened up a whole new world.

Families can purchase IR toys from high street shops, and using BigJacks or high

tech communication aids, can make these toys accessible to their disabled child. This could be the solution to the “what to buy for Christmas and birthdays?” problem.

### INFRARED EQUIPMENT

Infrared (IR) toy vehicles operate just like TV, VCR, DVD remote controls by sending commands from a transmitter (the remote control) through an infrared light beam. The IR receiver in the TV or infrared toy picks up these commands and performs the action given.

An Infrared transmitter sends out pulses of infrared light via an LED on the transmitter in a code that the IR receiver interprets and turns into specific commands such as Volume Up/Down (your TV) or Turn Left/Right (your remote controlled car).



Infrared tank and controller (no antenna)

The range of an IR signal is usually limited to around 30 feet or less. Infrared, also called optical control or opti-control, requires line-of-sight, that is, the



LED on the IR transmitter must be pointing at the IR receiver in order to work. It doesn't see through walls. Depending on the strength of the IR signal and interference from sunlight or other infrared-transmitting devices, the range may be shortened.

Do be careful: 'RC' can refer to radio controlled or remote controlled. Remote control covers both radio and infrared. When looking for toys and equipment for use with the VOCAs and BigJack, you need to have infrared control. Watch out for an antenna as this is a giveaway – it means that the toy is radio controlled. Radio-controlled toys are operated by a wireless, hand-held controller that sends radio signals to the vehicle. A specific radio signal or frequency is sent from the controller to a receiver inside the vehicle to tell it to go, stop, turn, and do other manoeuvres.



Radio-controlled car (has antenna)

The benefits of radio control are that the radio signal can go through walls and round corners. Infrared control is more limited in that the beam needs to be in line from the controller to the toy.

#### ENVIRONMENTAL CONTROLS

*"Interaction is a kind of activity that occurs as two or more objects have an effect on one another."* (Wikipedia)

Communication is a form of interaction; environmental control is another form of interaction, as the child effects change within their immediate environment. The control in being able to change TV channels, play your music, and stop the DVD when wanted, is very powerful and exciting for our children. Such control was previously only available following a visit by the Environmental Control Service. Children from a young age now can be introduced to environmental controls by using BigJacks and high tech communication aids.

Environmental Control Services (ECS) provide specialist equipment, such as the Gewa Prog and the Freeway, Primo and Vivo, to enable independence. Earlier independence can be introduced before you get to the ECS, using VOCAs or simple switch-operated devices. One such device is the BigJack from Possum. The black unit can learn infrared codes from another controller, such as TV/DVD remote control or a toy remote controller. All you need is the BigJack and the controller to learn the codes;

you do not even need the TV or toy when programming.

The BigJack is a robust switch accessible Infrared transmitter, which accepts up to 6 input switches. Each one of the 6 locations can learn an IR code from another controller such as: TV on/off, volume up/down, channel up/down; or if a toy: on/off, horn, forward, backwards. A single switch can be used to use a single function, or a second switch can be introduced to access two functions. During group work, several children can operate the TV/toy using different switches and functions.



BigJack (left) and Gewa Prog (right)

An alternative to the VOCAs and BigJack is the Domino Infrared Remote. Domino is a large button, switch adapted programmable infra-red (IR) device. Each Domino remote has four 'mode' buttons (yellow) and six 'action' buttons (white) that can be used to control any series of actions the user selects. The Domino can therefore store four devices – toys, DVD player, ipod, TV – at any one time. The six action buttons relate to the functions for that particular device. If bought through Dream Technology then the Domino is switch-adapted. The author has not used this device but would welcome any feedback from those who have.



Domino IR remote control with switch adaptation

#### HIGH STREET IR TOYS

Toys come and go; as soon as you find a robust IR toy that works with VOCAs and BigJack, it disappears off the market! Be prepared for head offices of high street shops not knowing the difference between radio and infrared controls; of course *you* know the difference now!

Below is a list of toys that have been tried and tested but that are not necessarily available now:

- Bio Train
- Ice-skating ballerina – John Lewis
- My first Infrared Race track – Toys R Us
- Police Car – Early Learning Centre
- Roary racing car – Argos
- Robosapien Robot, Homer & Spiderman
- Thomas the Tank Engine – Amazon.



Robosapien Robot

If you Google 'Infrared toys' then you should find quite a good selection, even on eBay. Some of the options are:

- [www.amazon.co.uk](http://www.amazon.co.uk) for Airhogs Micro Zero Gravity Infrared Control car
- [www.argos.co.uk](http://www.argos.co.uk)
- [www.elc.co.uk](http://www.elc.co.uk) for Meccano build and play infrared car. This is from the Early Learning Centre. A sibling could build the Meccano car and the child using a switch or VOCA could operate it – teamwork!
- [www.hurcotttoys.com](http://www.hurcotttoys.com)
- [www.iwantoneofthose.com](http://www.iwantoneofthose.com)
- [www.otherlandtoys.co.uk](http://www.otherlandtoys.co.uk) for Moon in my room and RC Infrared Abrahms Nato Tank.

The author has not trialled any of the above – not yet, that is! The above are only toys that she has found during her 'research', and so is not to be held liable if they do not work. Nothing ventured, nothing gained.

This is an exciting area of technology; opportunities for disabled children and adults to have fun and access mainstream toys and electrical equipment without having to knock down walls and install high tech environmental control systems.

Interaction is part of communication, and switch access can provide the means for independence; who knows where technology will take us in another twenty years. \*

Sally Chan  
Clinical Manager,  
Specialist Speech & Language Therapist

# 1Voice Role Models and Holistic Support

## KATIE CLARKE

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**1Voice is an award winning UK charity** that was established 11 years ago and has developed its activities to support young people who use AAC and their families in the complexities of their own worlds and that of the AAC world.

The organisation runs day and residential events to motivate and inspire all family members. Children leave more encouraged and committed to using their aids in their wider communities. Parents attend workshops to learn more about AAC and how to motivate their young people. Some of our teenagers from the successful Teenage Project will describe the difference the organisation has made to them and the creative and innovative methods that are used to inspire and raise aspirations.

Our teenagers using AAC are now used to presenting the work of 1Voice. They show a range of DVDs including *Listen to Me* (which has been shown all over the world), music and Powerpoint to describe the organisation and how it meets the needs of families across the UK whose children are AAC users.

## AN INNOVATIVE IDEA

'1Voice - Communicating Together' was the innovative idea of speech and language therapist Tamsin Crothers, who works with young AAC users in the north of England, and Katie Clarke, the mother of a young AAC user. The organisation was established to meet the needs of young disabled children who use a range of AAC methods and their families. It achieved charitable status

in 2001 and has since grown and developed its range of activities to include:

- Role Model training
- The award winning Teenage Project
- A young group's residential
- Family led workshops
- Volunteering and learning opportunities for student speech and language therapists
- Volunteer team to assist at events
- Branches across the UK

They have a website and regular newsletter. The organisation has national recognition and is a driving force at government level around ensuring that the needs of people who use AAC and their families influences the design of speech and language therapy provision.

## HOLISTIC SUPPORT

Holistic support makes a significant and positive difference to each member of the family. The organisation believes that without a whole family approach to AAC, young people are at risk of being unmotivated to become active AAC users. Many of our children who have grown up with 1Voice have been successful at mainstream schools; are included within their local communities; do voluntary work at strategic local



level as well as national; are in control of their own budgets to pay Support Workers; and are looking forward to becoming Role Models themselves and go into higher education.

The teenagers have been involved in different projects. They always stress the importance of peer support and how the volunteer team of Role Models has greatly influenced their own personal use of AAC.

## THE IMPORTANCE OF ROLE MODELS

At every residential event 1Voice has a team of disabled adult Role Models, who are in control of their own lives, and many of whom are studying at University or have jobs. Many families have not had the opportunity to meet successful disabled adults before coming to a 1Voice event.

Role Models work alongside the families, using a variety of AAC methods, to

encourage very young AAC users to interact proactively. Role Models are requested to attend training and to have the same roles and responsibilities as the volunteer team including non-disabled speech and language therapists, occupational therapists, students, and other professionals working in the field of disability.

Role Models run workshops for parents and for the young people. Certain Role Models are active Trustees of the organisation and give a great deal to ensure that they do make a difference to young people's lives. One is our Treasurer and another at present is our Role Model Co-ordinator.

#### BECOMING MORE INVOLVED

There is a defined progression route for young people to become more engaged within the charity.

After attending the Young AAC Users' weekend (for children aged under 13) children are able to attend the Teenage Weekend (for 13+ years). Once they reach approximately 16 years old, young



people are given training to become the next team of Role Models. We now have eight Role Models who have been part of 1Voice from being young users of AAC.

Some comments from participants:

*"B and N are still buzzing from the weekend. Thanks to everyone for making it, yet again, fun, inspirational, life affirming and so very, very uplifting. And, of course, congratulations to 1Voice, your work really does make a tangible difference to our lives and it's great that it is recognised and celebrated."*

*"Just to say well done to you and 1Voice. O had a fantastic time in Blackpool and*

*we definitely feel that the bottle is half full and not half empty. O loved everything but the best thing for him was meeting other AAC and power chair users. 1Voice is great and we cannot wait for next year's weekend."*

At the CM 2009 National Symposium in last September, our team of teenagers presented the history of 1Voice and how the organisation was established, their award winning project and the Listen to

Me DVD, what being a Role Model meant to them; and the importance of peer support and family support. Our Role Model Co-ordinator spoke of the impact of 1Voice and the difference it makes to young people's lives. Many thanks to Beth Moulam, Michael Reed, Jemima Hughes, Ruth Price, Nadia Clarke and Jodie Turner. Special thanks to Katie Caryer who was our anchor woman and to Terry Gibson for putting the Powerpoints together.

More information about 1Voice can be found at [www.1voice.info](http://www.1voice.info) \*

Katie Clarke

Chair, 1Voice - Communicating Together



#### 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): £61**

(£183 ISAAC Institutional/Corporate; (£37 people who use AAC)

#### Unterstützte Kommunikation

This ISAAC affiliated publication is published four times a year in German by ISAAC-GSC. **CM Members' rate (per year): £39**

#### 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): £23**

#### 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): £21**

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## Final Evaluation

# Leonard Cheshire Disability Communication Project

**STEVEN BLOCH & JANE MAXIM**

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### INTRODUCTION

When residents of long-term care homes are asked about what constitutes good quality care or quality of life one of the key constructs mentioned is the opportunity for social interaction [1, 2]. Staff working in long term care homes also cite interactions with residents as the most rewarding part of their work and that their relationships with residents are central to the quality of care they provide [3]. It is everyday communication between service users and staff that ensures care needs are met and that informed choices and decisions can be made in residential and health care environments [4, 5].

### THE LEONARD CHESHIRE DISABILITY (LCD) COMMUNICATION PROJECT AND ITS EVALUATION

In 2006 the LCD Communication Project was initiated. With significant funding from the Big National Lottery fund, the aim was to provide long-term communication benefits for service users and staff through a national staff training programme and the creation of regional Communication Support Officers (CSOs) responsible for communication service developments within individual homes.

The project arose from an identified need within LCD that service users with

all levels of communication disability were not always receiving sufficient support - either from LCD itself or from statutory services.

Anticipated outcomes included staff skill and attitude development and an overall reduction in the negative consequences of communication disabilities upon service users' lives. The project centred on the needs of people, living in residential care, with communication disabilities and those using, or who may benefit from using AAC systems.

Researchers from University College London were commissioned to provide an independent and informed evaluation of the project. The remit of this evaluation was to:

1. Investigate staff attitudes and knowledge of communication disabilities and the effects of the LCD staff communication training programme.
2. Establish the experiences and views of service users with reference to staff attitudes and opportunities to participate in everyday activities.
3. Establish the views and experiences of the regional Communication Support Officers (CSOs) employed specifically by LCD to support and

develop communication services for service users and staff.

4. Generate a set of recommendations to LCD in order to contribute to its ongoing commitment to communication disability support for service users and staff.

### EVALUATION METHODS

The project employed three methods to investigate the effects of the LCD initiative on service users and staff: staff questionnaires, service user interviews and interviews with communication support officers. The procedures outlined below received approval from the University College London research ethics committee in 2006.

1. Staff questionnaires: A sample of staff and volunteers participating in the LCD communication training day were asked to complete a questionnaire before their training session and again two weeks and then three months after their training.

The LCD questionnaire was piloted on newly employed communication support officers at the start of the project and discussed with LCD project members before a final form was agreed.

In order to understand any changes over time which might be due to re-



peatedly completing the questionnaire, a control group of staff were asked to complete the form three times, at the same time intervals but before participating in the LCD communication training. The questionnaire was based on one designed previously to evaluate a similar communication training package [6] and which had been piloted successfully.

2. Service user interviews: Based on the heterogeneity of the study population and the potential challenges associated with severe communication impairments it was decided to investigate service user experiences and feedback through a semi-structured interview process.

An interview process was piloted in two LCD homes in 2006 before a final version was generated for data collection across a number of LCD UK regions in 2007-2009. The main study comprised two stages: Interviews with service users prior to staff training within their homes (2007-2008) and repeat interviews with the same service users after staff training within their homes (2009).

On the principle that interviewers should have experience of interacting with people with communication disabilities [7] interviews were carried out by six UCL speech and language therapy students in their final year of study. All interviews were video recorded for subsequent analysis.

3. All 9 CSOs participated in an interview/focus group day. An individual interview schedule was devised to address three central areas of CSO activity: training, service user support, and Leonard Cheshire Disability staff support. With reference to these three areas CSOs were asked, in confidence, to comment on their roles, perceptions, challenges and ideas for future development.

## RESULTS

The evaluation outlined in this report has generated a large set of results. We have selected a sample of relevant findings here (staff training questionnaires and service user interviews). A full report will be available on the project website shortly ([www.ucl.ac.uk/leonard-cheshire-communication](http://www.ucl.ac.uk/leonard-cheshire-communication)).

### Staff views, attitudes and knowledge

The questionnaire gathered information on the following areas:

- Information on perceptions of communication, use of AAC and communication difficulties;

- Self-ratings of knowledge about communication, AAC and communication difficulties;
- Self-ratings of competence in dealing with AAC and communication difficulties;
- Self-ratings of attitudes towards communication, AAC and communication difficulties;
- Information about known strategies to help with different AAC systems and with different communication issues.

All staff members who underwent training between years 1 and 3 of the project were asked to complete the questionnaire prior to their training and then three months later. LCD trained 2746 staff and volunteers during the project period. Of this group, 22% completed pre-training questionnaires and 7% completed post-training questionnaires.

Significant increases were found in participants' mean ratings of their perception of their knowledge, competence and attitudes following training, demonstrating that participants rated their perceived knowledge, competence and attitudes higher following training. The self-rating of attitude was higher pre-training than for knowledge and competence but, nevertheless, participants showed more positive attitudes towards communication and communication difficulties following training. In addition the results suggest that people who did not perceive themselves as having a high level of knowledge and competence benefited most from the training.

Supporting staff to develop a repertoire of appropriate strategies to enable communication with different service users in a range of situations is an es-

ential component of staff training. This was included in the LCD training through examples of service users' communication and descriptions of a range of Total Communication and AAC approaches. Participants' responses were investigated to determine whether training affected the number and appropriateness of strategies that were suggested to help communication with people with the following specific communication difficulties:

- someone who can't understand you;
- someone who uses a communication aid to communicate;
- someone who can't think of the words they want to say;
- someone who has slurred speech;
- someone who is reluctant to communicate.

For this section, a coding system was devised, and the qualitative data (i.e. the strategies) were rated by a panel of ten Speech and Language Therapy professionals and ten Speech and Language Therapy students. A Wilcoxon signed ranks test was used to compare the number of strategies suggested before and after training, shown in Table 1.

### Summary of staff questionnaire results

- LCD staff and volunteers were able to benefit from the LCD communication training and were able to sustain that benefit over time.
- LCD staff and volunteers showed significant increases in their self ratings of knowledge, competence and attitudes towards communication and communicating with people with communication difficulties post-training.
- LCD staff and volunteers with lower self ratings of knowledge, competence and attitudes pre-training

Number of Strategies	% change post training	P Value (Wilcoxon)
Difficulty 1: someone who can't understand you	23.5%	.05*
Difficulty 2: someone who uses a communication aid to communicate	49.4%	.05*
Difficulty 3: someone who can't think of the words they want to say	33%	.01**
Difficulty 4: someone who has slurred speech	38.2%	.01**
Difficulty 5: someone who is reluctant to communicate	78%	.001***
Total number of strategies suggested	41.7%	.001***

Table 1 Number of strategies suggested by staff for each communication difficulty

benefited most from the training and were able to maintain this benefit over time.

- LCD staff and volunteers were able to provide an increased number of strategies to help communication with people with communication difficulties and those using AAC post-training.

#### Service user views and experiences

A sample of 70 LCD residential service users (equal numbers of male and female) was interviewed prior to staff training. Following staff training a subgroup of 40 service users were re-interviewed. This difference in numbers is attributable to several reasons including: unavailability at time of interview, home closure, moving out of residential care, and death. The service users covered a wide age range and length of time spent living within LCD residential care.

At least 22 different diagnostic categories were represented in the sample. 32 respondents were reported as having congenital disabilities and 38 acquired (Table 2).

Each interviewee's communication disability rating was based on an overall impression of intelligibility. This rating used an adapted form of an existing scale [8]. The range of ratings is presented in Figure 1.

A series of questions relating to communication between service users and staff were asked (pre-staff training and post-training). A summary of the pre-training results is presented in Table 3. No statistically significant differences were found between responses pre- and post-staff training.

- Overall, the results reflect a positive view of communication by service users. The majority express confidence in staff interest and their approachability regarding personal

Acquired Brain Injury	4
Brain Haemorrhage	2
Brain Tumour	2
Broken Spine	1
Burns (Blind and Deaf)	1
Cerebral Infection	1
Cerebral palsy	24
CP and CVA	1
CVA (stroke)	7
Epilepsy	2
Huntington's Disease	1
Hydrocephalus	2
Learning disability (LD)	1
Marfan's Syndrome	1
Michondrial Myopathy	1
LD and Hydrocephalus	1
Multiple sclerosis	12
Neurological Shock	1
Neurological Disorder	1
Spina Bifida	2
Spinal Cord Injury	1

Table 2 Range and proportions of service user interviewee diagnostic categories

problems. Many of the service users reported communication opportunities with people other than staff. There was a high rating for the ways in which staff communicate with service users and general verbal information sharing between staff and service users.

- Opportunities to communicate with staff were rated highly (78% pre- and 74% post-staff training; no significance identified).
- When asked "do staff listen?", the majority (65%) said 'yes', 35 responded 'no' (10%) or 'sometimes' (25%). This figure rose slightly in the post-training responses with 70% saying 'yes' and 30% 'no' or 'sometimes'.

- Regarding staff time: pre-training, 45% of respondents said that staff did have enough time for communication with service users, 43% said 'sometimes', and 12% said 'no'. Post-training the responses were: 'yes' (48%), 'sometimes', 29% 'sometimes' and 23% 'no'.

- When asked "do you understand any of the printed notices or messages here at home?" Approximately one third said 'no' (31% pre-staff training).

Service users were asked a number of questions regarding any changes they had noticed since the beginning of the communication project and/or the staff training in their home.

- 70% of respondents were unaware that someone visited their home to help service users with communication
- 78% said that they had noticed no change in the way staff communicated with them since they were first interviewed
- 72% of respondents had not heard of the 'Communication Support Office'.

#### RECOMMENDATIONS FOR THE FUTURE

Drawing on this evaluation evidence, and from other sources, a number of recommendations have been made to LCD for developing communication support throughout its organisation. These recommendations cover four key areas:

1. Staff training and learning development e.g. The training package would be enhanced through service user participation wherever possible - ideally to contribute to the training in person (e.g. to give a personal perspective) or through tailor made audio-visual resources (e.g. a DVD) featuring current service users and staff.
2. Service user communication support and development e.g. A number of service users have profound physical, cognitive and linguistic difficulties. The evaluation research attempted to establish their views but this was not always possible for a number of reasons. Communication and consultation with this group is challenging, takes time and confidence but is possible and is certainly desirable. In almost all cases such as this communicative needs cannot be met by the recommendation of an AAC system alone. Further work by LCD is recommended to establish the highly individualistic needs of these service users and the participatory opportunities available to them.

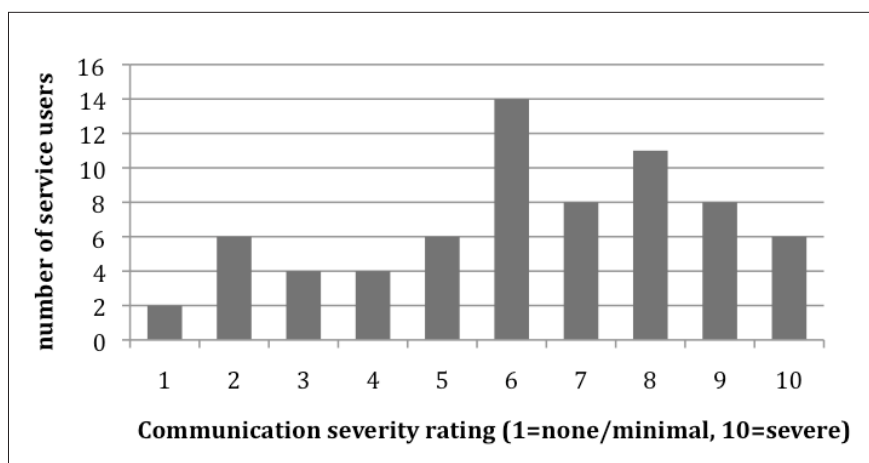


Figure 1 Communication severity range

Question	Yes	No	Sometimes
If you have personal problems, can you talk to staff about them?	92% (47/51)	6% (3/51)	2% (1/51)
Do you think the staff are interested in your problems and take the time to listen?	87% (39/45)	13% (6/45)	0% (0/45)
Do you have the opportunity to talk to the staff here? (36/46)	78% (3/46)	7% (7/46)	15%
Do the staff tell you about things happening in the home?	70% (38/54)	15% (8/54)	15% (8/54)
Are you able to take part in the activities here?	75% (45/60)	7% (4/60)	18% (11/60)
Do staff listen?	65% (34/52)	10% (5/52)	25% (13/52)
Do you like the way staff communicate with you?	80% (44/55)	7% (4/55)	13% (7/55)
Do you understand any of the printed notices or written messages here at home?	61% (30/49)	31% (15/49)	8% (4/49)
Do you have a say in how the home is run?	66% (38/58)	21% (12/58)	13% (8/58)
Do staff have the time?	41% (24/58)	19% (11/58)	40% (23/58)

Table 3 Responses to questions requiring a yes/no/sometimes response

3. CSO/U Communicate advisor and home link development e.g. Communication support officer time at each home has been limited and the new U Communicate advisors will have even less contact time. As a result it is recommended that a communication link programme is established whereby each home has a named member of staff AND service user who offer support and advice for the home overall. This will facilitate ownership of the programme and ensure that information of interest is communicated to all levels of staff/service users.

4. Outcomes, sustainability and wider engagement e.g. Collaboration with statutory speech and language therapy services: whilst NHS speech and language therapy services cannot provide dedicated services for LCD residential care homes within existing contracts they do have a duty of care for individuals in need of intervention. It is recommended that regions and homes investigate opportunities for collaborating with individual SLTs and SLT services. This may take the form of consultative representation on clinical guideline groups or more ad hoc

strategy advice. The key principle is that SLT expertise should be utilised to complement existing and future LCD communication work.

### CONCLUSIONS

LCD are now in the process of launching their new UCommunicate programme; this has arisen from their 2006-2009 project and will attempt to provide enhance communication participation and opportunities for all its service users. With such a heterogenous service user population, and variety of staff groups, many challenges remain.

However, it is clear that LCD has demonstrated a very strong commitment to recognising communication disabilities and looking at sustainable ways of improving the communication culture throughout all of its services. \*

Steven Bloch

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### Acknowledgements

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## The Newcastle Symbol Project

# One Symbol Language for All Children

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### OVERVIEW

Graphic symbols are widely used to support language and communication with a wide range of children (Moulam, L., 2008). In Newcastle upon Tyne three special schools were using three different commercial symbol sets and within each school a different symbol may have been in use to represent the same language item. Symbols were also increasingly being used in the special pre-school service.

Transition from pre-school services into school and between primary and secondary school was hampered by each place using different symbol sets. The children were exposed to unfamiliar symbols in a new environment. Given that symbols first “*come to stand for an individual’s internal representation of the environment and second, they serve as an external medium, or vehicle, for portraying that world to others*” (Sevcik et al, 1991, p162) this presented an avoidable barrier to their comprehension and expression.

The need for consistency of symbol use was identified, initially to ease transitions. In May 2007 the Speech and Language Therapy (SLT) manager of the Community Team for Learning Disability (CTLD from Northumberland Tyne and Wear NHS (National Health Service)

Trust) and Newcastle Local Authority (LA) School Improvements Advisor for SEN (Special Educational Needs) and Inclusion agreed to identify NHS and LA personnel to discuss this issue. This article outlines the journey to agree: a symbol set; a ‘library’ of core symbols; the symbol software; the roles of those involved; the issues identified; and the decisions made to date.

### PROJECT GOAL AND PARTIES INVOLVED

The goal of the project was to agree collaboratively a ‘dictionary’ of consistent symbols to represent specific language items/words. These are to be used in Early Years Settings & Special School services – including Additionally Resourced Centres (ARCs) and SLT supporting children with Special Needs in mainstream schools and two NHS Trusts in Newcastle upon Tyne.

The purpose is to give the students a consistent ‘symbol language’ that will be available throughout their childhood and adolescence in both home and education settings. This would also have the benefit of enabling staff between establishments to share resources.

It was decided to start by addressing the symbol use within Special Education and later look to include mainstream settings and wider use within Learning Disability services.

Newcastle’s LA School Improvements Advisor for SEN and Inclusion and the SLT manager of the CTLD agreed to jointly facilitate collaborative work around symbol use in health and education. They invited a manager and teacher from the three special schools, the pre-school service and a NHS SLT working into each establishment to discuss the proposal. These people met once a term to work towards a shared understanding of issues to underpin the project.

True multi-agency collaboration between establishments in the LA and NHS SLT service has been, and remains, key to the project. Latterly this collaboration has included the symbol software company DynaVox Mayer-Johnson. Central to the initial facilitation and continued co-ordination was the 0.5wte (NHS) SLT employed by Newcastle to support the use of aided Augmentative and Alternative Communication (AAC).

Also, the LA’s School Improvements Advisor for SEN and Inclusion has been committed to drive the project in schools. Once the project was initiated, funding was found to assign a Special Needs Assistant to a Communication Facilitator role. She has a unique remit bridging educational settings and the LA and NHS, resulting in benefits beyond the Symbol Project. The LA has also funded the purchase of the agreed sym-



bol software, enabling all the establishments to progress and embed the work. And within all the establishments involved, management has provided support both strategically and practically to progress the project.

Without this support, the project could not have progressed in the manner it has.

### WHY USE SYMBOLS?

The first discussion centred around why we use symbols, sharing Education and SLT perspectives, drawing on experience and the work of Chinner S., Hazell G., Skinner P., Thomas P. & Williams G. (2001) – see Tables 1 and 2.

### SYMBOLS AND PICTURES

We also explored what the difference is between a picture and a symbol, agreeing that a symbol is "something that represents something else by association, resemblance or convention." ([www.answers.com/topic/symbol](http://www.answers.com/topic/symbol)). We discussed that visual aids and pictures are routinely used in class room settings and that a picture becomes a symbol when it is consistently used to represent a specific language item.

Educationalists and SLTs were using three different symbol sets in a range of settings. These were Picture Communication Symbols (PCS), Widgit Literacy Symbols (WLS) and Pics for PECS. There was some initial feeling that symbols were guessable and so students could cope with changing to different symbol sets. To promote discussion, participants were asked to bring and share their establishment's symbols for



Figure 1: Some common symbols

nine language items representing different word classes: bus, milk, scared, happy, more, want, holiday, playtime/break, Wednesday. This highlighted that we were using two or three different symbols for the same language item.

This was followed by an activity to highlight that the meaning of a symbol is not always 'guessable', how symbols are perceived is influenced by culture, time and experience (Huer, 2000). We showed the group symbols from all three different symbol sets and asked them to share what they thought they meant. See the examples in Figure 2.



Figure 2 (clockwise from top left) car (PCS); dry (Pics for PECS); Dad (WLS); want (WLS); sorry (WLS); Dad (PCS)

The group came up with different meanings for many of them. This led to the agreement that for frequently used language items, it is important to be consistent with what we present to the students.

### SYMBOL TYPES

There are three types of symbols: **Transparent**, **Translucent** and **Opaque**.

**Transparent:** highly guessable, e.g.: apple, television



**Translucent:** guessable once explained/shown; relationship may be semantic, conceptual or linguistic, for example:



**Opaque:** No specific resemblance to referent, e.g.: but



Having agreed the need to be consistent with the use of symbols, we revisited which students these are intended for. The children in question present with one or a combination of learning difficulties, cerebral palsy or are on the autistic spectrum. We agreed that our dictionary of symbols will be for those students who are at the appropriate developmental level to be able to use these visual symbols. Consistent symbols will generally be used, but there is scope for variation to meet individual student's needs. We considered the 'Ladder of iconicity' (see Table 3, adapted from Jans & Sheritt, 2003, p10) and are looking for a core set of symbols to suit level 'e' onwards.

### LANGUAGE ITEMS TO INCLUDE

Having agreed that the symbols need to be consistent for frequently used language items, the next step was to identify these and the symbols to represent them. After discussion, it was agreed that the Symbol Dictionary will include language for communication & some curriculum language will be included. Therefore both core and fringe vocabulary will be represented.

Core language is agreed to include: generic high frequency in spoken language e.g. more, want, on, off and personal language e.g. Mum, Dad, name of brother/sister(s), name of pet(s); be

Group	Reason
<b>Expressive language</b>	Characterised by large gap between understanding of language and expression of spoken language. Their alternative forms of communication may become the preferred means of expression.
<b>Supportive language</b>	The augmentative system is intended to function as a 'scaffold' to the development of normal mastery of speech and reduce the effects of language disorders.
<b>Alternative Language</b>	Characterised by both using and understanding little or no speech - these children will need to be taught language through alternative means of communication and to be taught to use this means expressively.

Table 1 Characteristics of language groups

Develop communication skills (tools for interaction)	Develop language skills (tools for learning)
needs & wants ideas feelings & opinions social closeness self expression	recall predict explain hypothesise enquire imagine

Table 2 Communication & language skills

Ladder of Iconicity (most to least transparent)	
<b>Simplest</b>	a. Real object
	b. Object of Reference - Representational object [a toy/part of toy/associated object]
	c. Colour photo of real object [same colours]
	d. Coloured line drawing [same colours]
↓	e. Coloured line drawing / B&W line drawing
<b>Most Complex</b>	f. Rule/language based symbol set g. The word [written or spoken]

Table 3 Ladder of Iconicity

developmentally appropriate; all word classes; fulfill basic functions/needs (request actions, information, things, give information, etc.); enable social exchanges (turn taking, initiation, repair, maintenance, etc.); be highly reinforcing and highly responsive (others respond to them).

Fringe vocabulary is always available (but maybe not quite so easily). It enhances participation; is content rich; topic related; specific to individuals and specific to environments (Glennan & DeCoste, 1997). This led to 900 plus language items being identified from several sources, including requests from SLTs and teachers, Tatenhove (2005) and Latham (2004). We also proposed consistency of resources in terms of font style, position of text, and have yet to decide on colour coding or not.

#### CHOICE OF SYMBOL SET

Next the requirements of the symbol set were addressed. It was agreed the symbol set should be:

1. Commercially available;
2. Meet all the children's language needs - represent all language classes;

3. Visually clear - 'not busy', items overlap as little as possible;

4. As transparent as possible;

5. Can easily be reproduced by staff - i.e. on computer software;

6. Available to the students on computer;

7. Compatible with dynamic screen voice output communication aids (VOCA).

8. Have a reasonably high likelihood of being used out of the LA if child moves.

It is suggested that it is preferable to use symbols from within one set:

1. So that the symbols are of the same visual family, otherwise symbols from one set can visually dominate a layout e.g. line thickness & complexity varies.
2. There may also be 'rules' within a set which children may learn to recognise but would be lost if symbol sets are mixed.
3. Mixed symbols might be difficult to manage and program on a VOCA.
4. May be difficult or confusing to have access to more than one symbol set available within the symbol software on a computer.

Pics for PECS were excluded as they did not meet these criteria, leading to us comparing Picture Communication Symbols (PCS) & Widgit Literacy Symbols (WLS). We looked at symbols for 51 language items from both sets, which included a range of word classes

e.g. nouns, verbs, adjectives; the conventions within the symbol sets and asked what was being used around the region and why. Both sets met the requirements and there was not much to recommend one set over the other.

The decision then was influenced by the features of the software available to support the use of the symbols. We drew up a list with

58 symbol and software requirements based on:

1. Software features staff liked in the commercially available symbol software they were familiar with

2. New features we wanted:

- a way to facilitate sharing our agreed dictionary of symbols...
- ...which could easily be updated
- ability to easily share resources across establishment using 'our' symbols

3. Some new symbols we wanted to be drawn.

#### THE SYMBOL SOFTWARE SOLUTION

This document was submitted to two symbol software companies in line with the LA's procurement procedure. In July 2009 we accepted the tender from the company DynaVox Mayer-Johnson (DVMJ) to use PCS and a family of symbol software to meet our needs. The hub of the solution is a website ([www.AdaptedLearning.com](http://www.AdaptedLearning.com)) providing access to customised symbol software (Print Editor) in our Newcastle Group area. This software allows us to easily select and use the agreed 900 consistent symbols (from a symbol library of about 11,000) to create and modify resources. These resources can be saved on the Web site and so accessed by all group members, enabling us to easily share them across establishments.

Interactive resources can be made with a computer based piece of software (Boardmaker Plus). These interactive resources can in turn be saved in the Group area on the Web site. They can then be downloaded and accessed via a student interface (Boardmaker Plus Player) on a computer or Smart board e.g. in a classroom (see Figure 3).

We purchased licences for *customised* Print Editor accessed through AdaptedLearning.com; Boardmaker Plus & Boardmaker Plus Player. The agreement also includes DVMJ providing adjusted & newly drawn symbols, along with training and consultation to support the implementation of the PCS symbol set and software.

#### SELECTING SYMBOLS FOR THE LANGUAGE ITEMS

Having selected PCS and the language items needed for the Newcastle Symbol Dictionary, we identified a symbol to represent each vocabulary item. When choosing symbols we used:

1. Selected PCS conventions. These are not widely publicised as there is often a choice of symbols for each

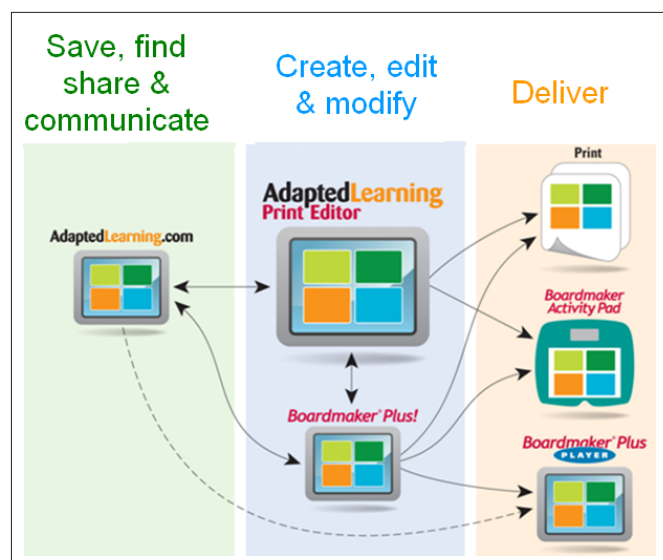


Figure 3 Making interactive resources (from Rowe D., 2009)

language item e.g. prepositions, verbs. The conventions we chose to use are being collated in to a document to accompany the Newcastle Symbols Dictionary.

2. Our knowledge of symbols currently used in the schools and home environments - so they would be as familiar to as many children as possible.
3. Research where available e.g. Visser, Alant & Hartley [2008] re how graphic symbols are perceived by 4yr olds for 4 basic emotions.
4. Also identified language items to have new symbol drawn for or adjusted - bearing in mind not to make too many changes, as our new symbols may not be available in all VOCAs.

## 2009 PLAN

In September 2009 we drew up our action plan which included:

1. Monthly meetings of named key people from each establishment (with a consistent alternative representative.) They are to coordinate and oversee all activities, communicating decisions to and from the group.
2. A cascade of training about the ethos of the Symbols Project and how the software works.
3. The need to address many practicalities such as:

### Software:

- What guidelines will be in place for users?
- How will boards/resources be named and shared?
- Will there be specific templates? Who will be creating them?
- How will the product be distributed?

### Symbols:

- Finalising initial symbol changes
- How will additional symbol for language items be agreed?
- What new symbols need to be drawn?

### Training:

- Arranging training implementation plan with the various organisations
- Organising all the training and details

### Other:

- Coordination with DVMJ to schedule consultation and training
- Transition from existing symbols to new solution.

Our intention is to establish the consistent use of Newcastle Symbols in Special Needs School and preschool services and home environments, in the NHS and LA, using one symbol software solution. Our vision for the future is to explore extending this consistent use of symbols into all Newcastle schools & Early Years settings in private & voluntary sector, social care, adult services and then exploring the opportunity to provide direct access for families and into the community.

## REFLECTION

Reflection on the project has highlighted the following areas as essential in this type of collaborative venture:

1. The need for strategic managerial support, with an understanding of what is involved and authority to release staff for the work involved. Such work goes from early collaborative planning through to training of colleagues about the whole project, and the software.
2. Funding to enable people to carry out the work for the project and buy resources, such as software, colour printers and laminates. The capital outlay for the symbol software has been vital.
3. Collaboration and momentum has been greatly aided by having:
  - A lead in the form of the Newcastle SLT, who maintained an overview and kept the momentum going.
  - The Communication Facilitator within the LA to facilitate the project linking schools in many ways and the LA and NHS.
4. Collaboration takes time but pays dividends:
  - It brought everyone together and resulted in better communication.
  - We learned from each other.
  - SLT and Education shared their perspectives through developing a common goal.
  - Acceptance of need to change.
  - Then willingness to change.

## SUMMARY & FUTURE

The Newcastle Symbol Project is an exciting multi-agency collaborative venture involving the Special Needs LA, two NHS organisations and a commercial company, DVMJ.

We are on target to achieve our aim of agreeing a shared symbol set with specific symbols to represent 900 language items and in a manner which makes it

easy to share resources between establishments.

These achievements have been underpinned by strategic and managerial support by all involved. It has involved a lot of work and still does, but hopefully will pay dividends for the children and staff alike. \*

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# The Pittsburgh Employment Conference for Augmented Communicators

**PETER ZEIN**

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I was happy to be invited to the USA and I gave a talk last year at the Pittsburgh Employment Conference for Augmented Communicators, organised by SHOUT, a non-profit organisation.

The major theme of the PEC 2009 conference was overcoming depression and loneliness. At times during the three days it became quite hard going to listen to people talking about how they felt depressed and by the end of the day I came away feeling very low myself even though I had nothing to feel depressed about. Although it was not useful for me I did feel it was helpful to a lot of people who were there to get their feelings out. I think it was useful for some of the professionals who were there to get an understanding of how people really feel when they can't communicate.

## TOWN MEETING

The conference consisted of several different workshops and presentations. There was also a Town Meeting which people were invited to discuss different topics as a large group. The Town Meeting was a really good way for everyone to talk about all the issues that were important to them.

Everyone was able to take their time to say anything they wanted without feeling they were being rushed. I found this refreshing because as a communication aid user I often feel I am being rushed when I am trying to talk.



I would have loved to have met other communication aid users that used Bliss - which is the language that I use - but there was nobody. I met people from all over the world who had heard of Bliss, but I feel sad because they were unable to get the support to use the Bliss system - other systems had been given priority.

I think it was great to hear about other people's stories of how they overcame their feelings of depression. In particular I remember a guy who said he was feeling like he wanted to die but then he got a job within the fire brigade and turned his life around. It was nice to see someone who had followed a completely different path and fulfilled a dream.

I think the Town Meeting was a useful tool and should be adopted at conferences and groups in this country.

## A UNIQUE CONFERENCE

I think the Pittsburgh Employment Conference is unique in the way that it brings professionals and communication aid users together from all over the world as one team to discuss and tackle issues from both sides.

I found it interesting to see that although the issues are tackled in different ways, primarily the problems were the same no matter which corner of the earth you came from.

You can view the 2009 programme, photos and much more by visiting [www.shoutaac.org](http://www.shoutaac.org) \*

Peter Zein

## ACKNOWLEDGEMENTS

Photograph (bottom right) from PEC@2005 courtesy of SHOUT [www.shoutaac.org](http://www.shoutaac.org)







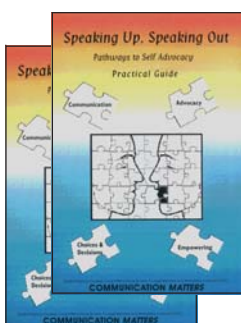
## ESSENTIAL PUBLICATIONS FROM COMMUNICATION MATTERS



### 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

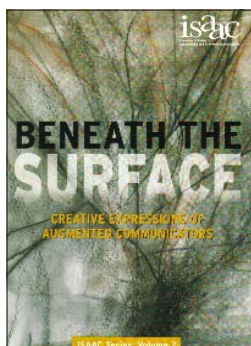
This pack is intended for carers, facilitators and others concerned with the advocacy needs of people with severe communication difficulties who need or use AAC. It is useful for staff development, especially for those working with adults. The pack comprises two books: a comprehensive Handbook and a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



### Beneath the Surface

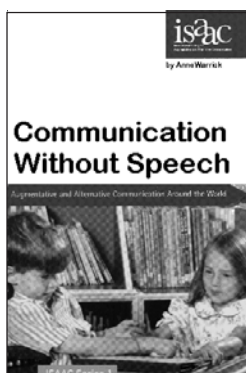
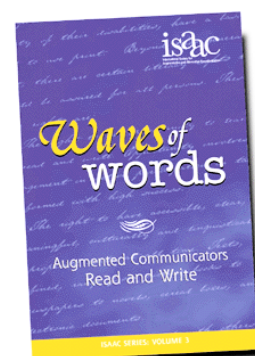
In August 2000, the creative works of 51 authors and artists from around the world were published in this ISAAC book, Beneath the Surface. What these writers and artists have in common is that they are unable to speak and thus rely on assistive technology to communicate.

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.

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

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# THE LOGAN PROXTALKER...

JUST BECAUSE  
MY SON LOGAN  
CANNOT TALK...  
DOESN'T MEAN  
HE HAS NOTHING  
TO SAY



The **Logan ProxTalker**, developed by a dad for his autistic son, is an easy to use mid-tech device which adds a new dimension to picture communication. Now Logan uses his ProxTalker to 'talk' to new people and to phone to home.



## Pick Place Press

- 5 location buttons allow language to develop from single word to simple phrases
- unique Programming Tags and inbuilt microphone enable easy management of sound tags
- 2 – 8 seconds of sounds per tag sound tags can be labeled with wide range of symbols, photos, text or objects of reference
- stores up to 10,000 words easily adjustable volume
- robust, water resistant design survives even the heaviest use
- portable in a backpack or binder
- 6 month battery life

## MegaBee

The MegaBee is an assisted communication tablet. Easy to use, low tech, eye pointing device for people who have no speech and are unable to have direct or switch access to other AAC devices.



- Portable and easy to use for both speaker and listener
- Dual screens accommodate 20 characters in 2 lines
- 260 easy to access abbreviation possibilities
- Bluetooth pc connectivity for large, remote display and text storage/printing options
- Ideal secondary aid for any eye gaze user

## FAB

A range of key guarded alphabet boards, developed with Frenchay Hospital, which can be used anywhere, even in the bath! Used to support clients across the hospital or as a secondary aid to high tech devices.

- qwerty or matrix layout
- Pocket or tabletop sizes
- Built in E.Coli and MRSA resistance
- Non-slip anti-bacterial rubber base
- Washable

