

# COMMUNICATION *MATTERS*

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# 'Hello' Events in Bristol and London

Throughout 2011, Communication Matters is supporting the *Hello* campaign, led by the Communication Trust, to promote 'The National Year of Communication'. The aim of the *Hello* campaign is to increase understanding of how important it is for children and young people to develop good communication skills. For further information about the *Hello* campaign, please visit [www.hello.org.uk](http://www.hello.org.uk).

In May and June, Communication Matters encouraged and supported its Associate members to organise a *Wave* of regional AAC related activities organised and supported by Communication Matters. These events were an opportunity to celebrate where the use of AAC has made a difference to people of all ages, as well as to raise awareness of AAC.

Communication Matters is also offering **grants** of up to £100 to support AAC events during the National Year of Communication. Anyone may apply, at any time between March and September 2011. You will need to provide us with as much information as possible about your proposed event, to help the grants committee decide if it is suitable to receive a grant. Up to four grants will be available each month. For information on how to apply for a grant, please visit [www.communicationmatters.org.uk/hello](http://www.communicationmatters.org.uk/hello).

You can find out what's on in your area by visiting the *Hello* section of the Communication Matters website – there is an up-to-date diary of AAC events and inspiring stories about users of AAC.

This article gives a flavour of some of the many AAC events that have taken place so far this year...

### FRENCHAY COMMUNICATION AID CENTRE OPEN DAY

*Sarah Woodward writes:* On Friday 6th May 2011, to celebrate the South West of England *Wave* of AAC events, the Frenchay Communication Aid Centre (CAC) held an Open Day and communication obstacle course in the grounds of Frenchay Hospital.

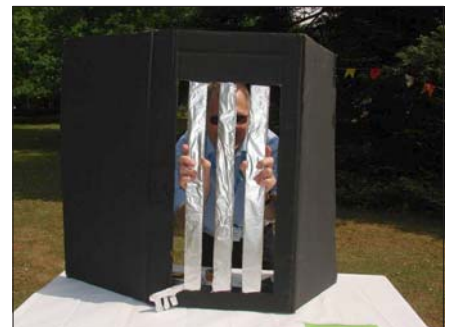


Trying out eye pointing

A wide variety of people attended, ranging from nursery age to retirement age and included AAC users, local residents, children, local organisations, and hospital staff. Thanks to Communication Matters for giving us a grant to help stage the event.



Visiting Frenchay Communication Aids Centre



Using AAC to overcome barriers: Getting out of jail

The open day was a big success. In the morning, visitors were able to visit the CAC, find out what we do, what augmentative communication is, to talk confidentially with specialist SLTs and to try out lots of equipment.

In the afternoon, we enjoyed a very hot and sunny communication obstacle course. This consisted of using different forms of AAC to overcome a variety of barriers (e.g. ordering refreshments, getting out of jail, requesting information leaflets about local services etc.). All those who completed the course left proudly clutching a certificate!

In connection with the *Hello* campaign, we also organised a well attended User Group to allow some people with high-tech AAC devices to meet, chat about issues and concerns as well as exchange top tips and have some fun.

### PICNIC LUNCH IN BRISTOL

*Sally Chan writes:* We held a picnic in May at College Green for children who use AAC. It was a fun day out for about 60 children, with six schools being involved. The Twurzels provided the music for the event, which the children



and the members of the public who chose to join us with their picnic lunch, thoroughly enjoyed. There was face painting, a puppet show, switch-operated games, and a cake in the shape of a Bigmack. We are grateful for a grant from Communication Matters to support the event.

#### PCAS OPEN DAY IN BRISTOL

*Sally Chan also writes:* Also in Bristol, the Paediatric Communication Aids Centre held an Open Day in May which was attended by people from the Children and Young People's Service, the NHS, parents and the general public.

There were demonstrations of communication aids, including 'eyes on' experience with eye gaze systems, and an AAC quiz which was won by our local PCT Commissioner!

That evening, Sally Chan (PCAS Clinical Manager) appeared on the local news talking about PCAS and the benefits of AAC for children.

#### 'COMMUNICATION WORKS' IN LONDON

*Trish Davidson writes:* A *Communication Works* event was held at Charlton School, London, in May 2011. It is a joint venture between Charlton School and



Jean Gross opening 'Communication Works'

CENMAC. This was the third year we have run the event, and it was fantastic to have Jean Gross, Communication Champion, to open it.

We had an exhibition in the school sports hall, and seminars running in four rooms throughout the day. There were twenty-nine companies exhibiting and most presented. We had a special interest section on the inclusion of pupils with Down's Syndrome which was delivered by The Down's Syndrome Association and Symbol UK.

We had been uncertain how many people would attend in these financially constrained times, when it is difficult for school staff to be released. How-

ever, we needn't have worried because there was a full house for the sessions. An improvement for next year will be a timetabled exhibition session to give participants time to visit all the exhibition stands.

Jean made a great speech and launched the South East of England Wave of *Hello* events. The sixth form pupils helped throughout the day with the organization and they were brilliant; one of them almost upstaged Jean!



The great thing about this event was that it was free to the people attending. The organisers only had to pay for the sandwiches for lunch and the posters. Thank you to *Communication Matters* for awarding us a grant of £100 towards printing costs. \*

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# The Callup DVD

## Experiences of a support group

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### INTRODUCTION

*Callup*, a support group for AAC users in Liverpool, has been enabling its members to attend the annual Communication Matters (CM) National Symposium for some years. Following the 2008 event, the group decided it wanted to tell the story of people who had begun to use AAC later in life, either because they had an acquired condition or because AAC had not been available to them at school. To use current terminology, they wanted to describe the experiences of those who are not 'digital natives'.

The group's first thought was to present their experiences personally, the following year, using their communication aids. When they considered the practicalities, they recognised that, due to variable or deteriorating medical conditions, they could not guarantee personal presentations at conference.

They therefore decided to make a DVD, which could be presented by whoever was available. The result is a humorous and touching 18-minute piece, aimed at sharing common issues with other AAC users, their carers and the professionals they encounter. The content, music and poetry were all produced by group members.

### HOW THE DVD WAS MADE

Like most people, *Callup* members had little or no experience of undertaking such a project. So it was decided to seek

professional help. This was made possible through Liverpool Primary Care Trust, which has been consistently generous to *Callup* with expertise and funding for individual projects. The group was able to commission three facilitators, who offered different skills. These were Alan Martin, a Disability Consultant for Mouse on the Move, and Ann Nelson and Mike Wight, from the Comedy Trust.

Before meeting the facilitators, *Callup* agreed on nine topics they wanted to include in the presentation: sourcing of the aids; what it means to be able to communicate with an aid; how others react to a communication aid user; the experience of older communication aid users; sharing of expertise; having conversations; how the group was formed; raising the profile of AAC; and the group's involvement in public consultation.

The only additional instruction was that the DVD should be entertaining and varied! It is a true credit to Mouse on the Move and the Comedy Trust's professional skills that, having never worked



The author shows off the *Callup* DVD at the CM2010 National Symposium

together before, they managed to fulfil the remit in such an apparently effortless way. The experiences, humour and strong views of the *Callup* members, aged between 18 and 80, came through from their conversations, as they talked about their lives. All had experienced some form of discrimination.

Mark talks poignantly about the hurdles placed in front of him as he tried to get a formal education. His parents relate the pressure they were under, from his birth, to abandon any kind of positive expectation of their son's future. The provision of a communication aid opened opportunities that led to Mark obtaining a university degree.

John, who lost his speech gradually, describes his fears about how his new

aided speech would be received by his friends and the relief he felt when all was well. Jackie, his wife, talked of the support gained by attending the group. Interestingly, the general complaints about not being able to speak with a regional accent with a communication aid was thought, at the post presentation discussions at Conference, to be a Northern complaint!

#### THE SPEECH AND LANGUAGE THERAPIST'S PERSPECTIVE

I have been involved with Callup since its inception. Group members attended regular therapy sessions, where communication aid users came together to practise using their aid in a supportive environment. Gradually, proficient users began to instruct others and their carers. The therapy sessions became a natural source of discussion and support, which led to increasing knowledge about legislation and the provision of national and local AAC services.

Eventually John, who is now the Chair of Callup, suggested we start a support group. As a service manager and a therapist, I was enthusiastic about facilitating the genuine inclusion of service users in decision making at personal, service and health care provision levels. The origins of user involvement lie in social and political changes (e.g. women's health and the disability movement), hospital scandals, health care research policy, politicised patients groups (e.g. HIV-Aids, maternity).

Aware that support groups can be either entirely self-run or helped by outsiders (e.g. therapists), I had been involved with a patient group previously, with mixed results. I recognised the need for further training and attended a course entitled "Involving service users and carers with communication difficulties", run by the communication disability charity *Connect*. This allowed me to feel justified in investing the amount of the effort and time that I, Karen (the Communication Aids assistant practitioner) and other colleagues would need to commit, mainly by facilitating the networking of stakeholders, and by fundraising.

Having been involved in the production of the DVD, my next aim as a speech and language therapist was to enable group members to share their experiences with other AAC users nationally, and to be surprised, encouraged and empowered by the experiences presented by AAC users. I hope this for all our participants but particularly for our youngest members, who have recently left school and are approaching "the big wide world", and for their parents.

#### JOAN'S STORY

With us came Joan, her husband and their son Joe, an AAC user. This was their second time at the CM Symposium, and they all agreed that a second visit allowed them to gain more from the experience. The following are Joan's comments:

"My husband, myself and my son Joseph went to the CM Symposium in Leicester. We enjoyed it very much. We enjoyed all the different talks and being able to give our opinion on the different things they talked about. We really enjoy Callup and making the DVD. It was fun and gives a wonderful picture of how a group can give help and support to the people who use communication aids and their helpers.

"I liked the talk about iPhones and iPads. They are things I am sure will be a great asset for the future. Also, to meet other people in the same position was great. As Joe is only 21, it gives me great hope for the future. When you think how things have changed, we can look forward instead of backwards, and we take this chance to thank the Callup group and staff for all their help in organising the wonderful time we had. I am sure my husband and Joseph will be the first to tell you the same."

Since attending CM2010, Joe has kept in touch, via Facebook, with people he met there.

#### JOHN'S STORY

John is a founder member and current Chair of Callup.

"Well, I decided to take my youngest son Gary with me to Leicester to give my wife, Jackie, a break from having to push my wheelchair around, and I think that he enjoyed it, going by the comments that he made before he rushed off to London, where he works. I understand that he was surprised at the level of intelligence shown by both the audience and the presenters. I said that just because we couldn't speak it didn't mean we had nothing to say.

"We launched our DVD this year and it was received very well. Also, there was an opportunity for me to renew some friendships made in previous years such as the aunt of an AAC user who had impressed me with his 'joie de vivre' and because he wasn't bothered by the fact that he couldn't speak. He was aged about 13. His aunt was there because she is also a speech and language therapist. So we spent some time regaling each other with what had happened in the past year and she asked about Jackie and was relieved to hear that she was putting her feet up and

probably thinking of ways to spend some of my money!

"The second person to ask after Jackie was Janice Murray who is the Chair of Communication Matters. She had been to our house to interview me with my communication aid; she was there as a lecturer for Manchester Metropolitan University. All in all, this year's CM was very good and the reception of our DVD was excellent. We sold 15 copies."

#### GARY'S STORY

John's son, Gary, had never attended CM.

"I have to say it really was impressive. As a linguist, I consider myself a good communicator and am used to conversations on an AAC device, but I'd never have believed how much can be effectively communicated by looks and gestures. It was a very encouraging event as it made the situation of my dad and others using AAC seem less isolated. A good range of innovations from the industry which have a huge effect on lives and strongly demonstrate going the extra mile beyond what services require of their staff. You were all fantastic and it really made me realise how important Callup is to my mum and dad - vital support.

"Being a carer at the Symposium is difficult, as it is very fast paced, so there actually aren't enough hours in the day and my dad didn't have time for his 8 hour PEG feed! There is nowhere discreet to do a quick sneaky feed, although people are understanding. I appreciate the reason for the pace and limited space but one request I would make is for consideration to be given to providing softer foods at meals so that no-one is left out.

"The event is valuable in marking the work of all groups and provides a sense of cohesion. There was no rivalry or competition, just an open sharing of ideas. A common approach is vital for the normalisation of issues surrounding AAC as well as giving some hope that the powers-that-be might divert some 'expenses claims' to proper provision. The DVD gave my parents the opportunity to say things openly I would never otherwise have heard, and they wouldn't otherwise have expressed. Thanks!"

#### IN CONCLUSION

2010's CM Symposium lived up to its expectations by being the ideal meeting point for AAC users, professionals, academics and manufacturers. Long may it continue! \*

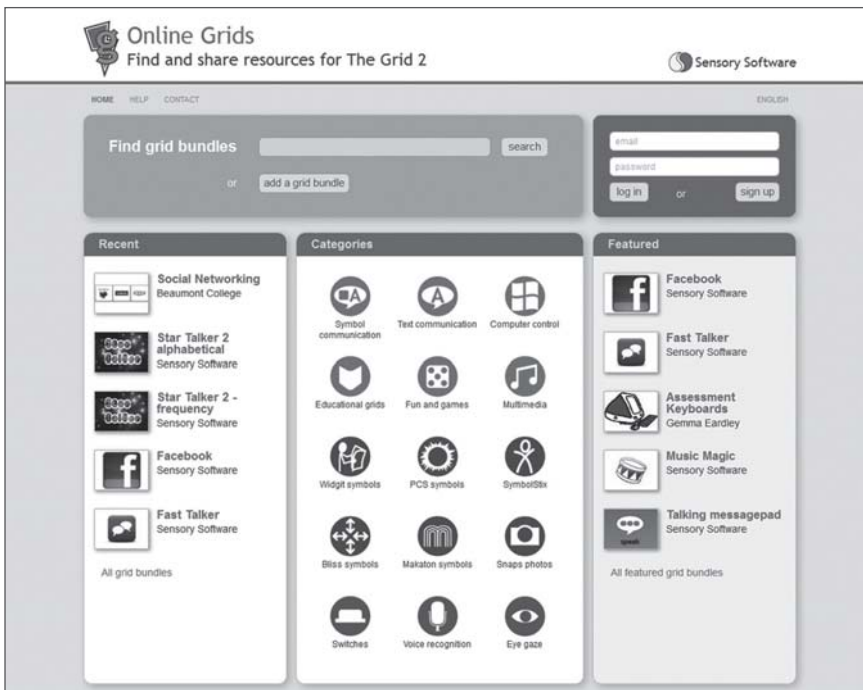
Anita Williams  
Principal Speech and Language Therapist





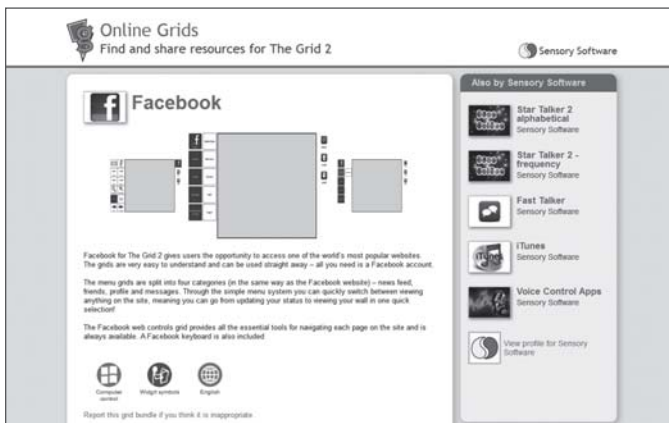
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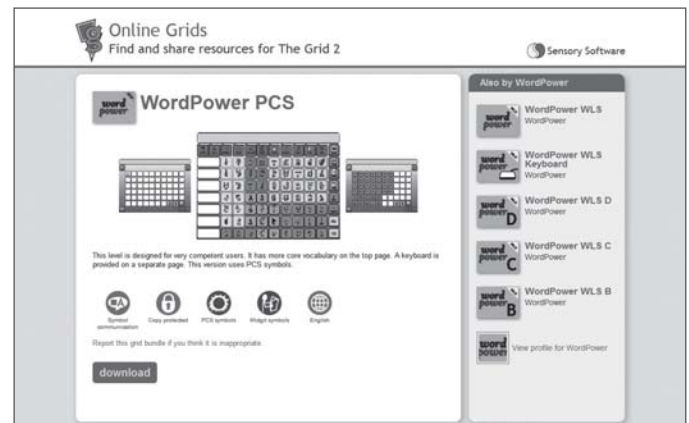


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# Treloar Vocabulary

## A project to meet the AAC needs of teenagers and young adults

**CAROLINE WEIGHTON & SARAH DODD**

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**Treloar College is a National Specialist FE College** for young people between 16 and 25 with physical disabilities. Approximately 30% of learners use Augmentative and Alternative Communication (AAC).

The aim of the project was to develop a symbol-based vocabulary software program suitable for the needs of teenagers and young adults using AAC. With emphasis on functional, social communication, it is designed to be accessible to young people with limited language and memory abilities and limited literacy. Social interaction was seen as a key motivating factor for some students to use AAC.

The development of the vocabulary was initiated in 2007/2008 to meet the clinical need of an individual student. In July 2009 the Speech & Language Therapy Department at Treloars received funding from Becta to develop the vocabulary further with extended research and trial. The project methods comprised: a literature review; questionnaires with young people; and a trial of vocabulary use.

Consent was gained from students or their families and ethics approval confirmed by the Treloar Trust.

### 1. LITERATURE REVIEW

A literature review was undertaken to investigate the following areas:

- Core vocabulary
- How to support AAC users' use of language

- Utterance-based versus online construction
- Vocabulary needs of teenagers and young adults.

### Core Vocabulary

Core vocabulary is small and changes little over time, environments or between individuals. It largely contains structure words and provides a framework for language use (Balandin and Iacono, 1998; Banajee et al, 2003). In contrast, fringe vocabulary is highly individual and mostly built of content words that carry topic based information (Balandin and Iacono, 1998).

In a study of early language development, Banajee et al (2003) found that children appeared to use core vocabulary more than fringe vocabulary. The nine most commonly used words were: *I, no, yes/yeah, want, it, that, my, you, more*. However, a number of studies have recognised the importance of access to frequently used shared topic based vocabulary for successful conversation (Balandin and Iacono, 1998; Stuart et al, 1993; Todman et al, 2008). Combining core and fringe vocabulary may increase AAC use in a range of communicative situations (Banajee et al, 2003).

### Supporting Use of Language

Light (1989, 2003) has long professed that the vocabulary or linguistic element is only one part of achieving communicative competence using AAC, alongside operational, social and strategic skills.

The influence of psychosocial factors – such as motivation, and external demands on communication – has also been acknowledged in this process (Light, 2003).

Todman et al (2008) highlight the negative impressions of AAC users due to slow rates of communication. However, Hoag et al (2004) noted the importance of the right level of information balanced with the speed of message delivery for positive listener impression.

Opportunities to use vocabulary for pragmatic functions (e.g. to initiate and repair conversation) was also found to contribute to successful communication in Muller and Soto's (2002) study. Consequently, successful conversation by AAC users requires sufficient content and some element of speed, combined with the opportunity and vocabulary to initiate, maintain and repair conversation.

### Utterance-based vs Online Construction

Todman et al (2008) argue that linguistic research has shown a large proportion of speech is formulaic. They concluded that whole storage of such generic utterances (e.g. fillers, repairs) may increase speaking rate without compromising information levels.

However, the restrictive nature of purely utterance based devices is also acknowledged. In parallel with Banajee et al's (2003) proposal of combining core and fringe vocabulary, a combination of utterance based features for the formulaic or generic aspects of conversation combined with the ability to construct














Go to contents 							Go back 
Tell me about yourself.	When is your birthday?	How old will you be?	Do you have brothers or sisters?		Really!		
Where do you live?	Who do you fancy at the minute?	What music do you like?	What TV programmes do you like?		Cool		
Is everything ok? 	What's the matter?	Can I help?	Can I talk to you in private?		OK		
I need to speak to you.	Do you want to talk to me?	I'm sorry, I don't want to talk to you.	Leave me alone		Oh no		
Please can you say that again. 	What did you say?	Sorry I didn't hear you.	Hang on a minute!		Chat 3 		

Figure 1 A Chat 2 page

messages online when needed may contribute to effective communication.

### Vocabulary Needs of Teenagers and Young Adults

There have been limited studies related to adolescent vocabulary, both for normative data and for aided communicators. Adamson et al (1992) in their study of 12 symbol based communication aid users aged 7-20, pointed to the predominance of nouns in AAC devices and hypothesized the use of more social regulatory vocabulary in facilitating conversation and positive perceptions of AAC users.

Balandin and Iacono (1998) suggest that quick access to socially relevant vocabulary, gathered from AAC users and natural speakers in context (social validation), can have positive impacts on group participation. However, no single word list is adequate for all people and careful environmental collection of relevant vocabulary, both context and age based, is necessary (Balandin and Iacono, 1998; Fried-Oken and Stuart, 1992).

In conclusion, AAC users need access to a combination of core and fringe vocabulary. This needs to be informed by relevant context and age related topics of conversation from both aided and natural speakers, but specific to the individual using the communication aid. Effective use of the vocabulary also needs to be supported by the inclusion of pragmatic function words or phrases. By using a combination of stored phrases or utterances with the ability to construct messages individually, speed of communication may be increased. This may then benefit positive perceptions of AAC users, group

participation and effective skills of managing conversation.

### 2. QUESTIONNAIRES WITH YOUNG PEOPLE

Following the literature search, topic areas and communicative functions were identified. A questionnaire was devised and used face to face with a cross section of young people as a process of social validation. Twenty nine participants completed questionnaires: fourteen students aged 16-18 years who attended a local sixth form college were interviewed, and fifteen students attending Treloar College. Participants were selected as reflecting a representative/balanced sample in terms of gender, age, and ethnicity. The location of the two colleges in rural Hampshire is reflected in the limited ethnic mix of the participants.

The feedback from the questionnaires demonstrated some clear patterns. Seventy or more of respondents said they would use the following topic areas more than once a day:

- Chat/quick social phrases
- Questions
- Compliments/insults
- Verbs/actions
- Describing words
- Food and drink
- College places
- People and names

#### Treloar Vocabulary

Pages were created using a 9 x 6 grid on Mind Express for the Tellus communication aid. This device was selected because it was the VOCA being used by the potential trial subjects identified for the study. Vocabulary items were

symbolised using PCS symbols. These were selected as they are they are the symbol set of choice used at Treloar College, and the one most familiar to the students.

A predictable page layout was used, with a combination of sentence starters, single vocabulary items on a button, and whole utterance on a button offered depending on the repetitiousness of the message required, the requirement for speed of initiation or response, or the range of creativity and spontaneity potential. The pages were then reproduced in low-tech format as a symbol communication book, using Boardmaker (see example in Figure 1).

The main features of the vocabulary are as follows:

- Combination of individual words, sentence starter phrases and pre-stored sentences.
- Organised by categories accessed from a contents page.
- Clear layout using simple colour coding.
- Consistent placement of function symbols on each page.
- Vocabulary including nouns, verbs, adjectives plus words used to express individual thoughts and opinions. Based around how language is used more than what it contains or how it is constructed.
- Quick links to other relevant pages from each page.
- Interjections and fillers on contents page and chat page. Often not present on AAC (*really*, *cool*, *oh no*) but part of speaking conversation.
- Stored chat phrases and questions – quick access for fast chat situations. Social chat phrases were initially identified by a student AAC user at Treloar College from conversations she heard around her (Figure 1).
- Stored question phrases and the ability to construct individual questions word by word as well.
- Teenage/adult vocabulary for insults, chat up and compliments.
- Pages for specific situations: doctors appointments, hairdressers, shopping, café, cinema, booking a taxi and pub.
- Specific page and vocabulary for expressing opinions and thoughts. Designed to be a starting point and then individualised with vocabulary depending on person's needs. Blank pages and symbol cells incorporated to populate with specific, personal vocabulary, e.g. football, music.

- Chat pages: phrases used in written format. This was based on clinical experience of our AAC users with whole word recognition skills but limited spelling. Phrases are symbolised if needed.

### 3. TRIAL OF VOCABULARY

The trial format of the Treloar Vocabulary was made available to three students at Treloar College (Figure 2).

#### Illustrative case study

Student B was 19 years old when she joined Treloar College in September 2009. She has a diagnosis of cerebral palsy with spastic quadraplegia and epilepsy. She arrived at college using a Tellus communication aid with a bespoke program that had evolved at school. It provided a combination of symbols and words. She also had a personalised communication book, using a combination of words, photographs and Widgit symbols.

She presented with strong receptive language skills, good non-verbal communication skills and a high level of motivation to communicate. Following initial assessment she was given a link to the Treloar Vocabulary on her Tellus in addition to her existing program. She uses dual access methods of Headmouse and single switch scanning. Figure 3 illustrates her developing communication skills using the vocabulary.

### CONCLUSION

The Treloar Vocabulary has contributed positively to the developing high- and low-tech AAC skills of the students in the original study. It has proved motivating and user friendly and continues to evolve with input and feedback from our learners. For further information about the vocabulary or the project, please contact Caroline Weighton at [caroline.weighton@treloar.org.uk](mailto:caroline.weighton@treloar.org.uk) \*

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Subjects	Age	Gender	Ethnicity	Communication Aid	Access Method	Previous Communication programme
A	18	F	White British	Tellus 3	Direct access with key guard	Gateway 40
B	19	F	White British	Tellus 3	Headmouse and switches	Bespoke vocab
C	19	M	White British	Tellus 3	Direct access with key guard	Ingfield level D

Figure 2 Vocabulary trial at Treloar College

Topic area	Date (Sep 09 - May 10)	AAC conversation sample
Asking Questions	Nov	"Hi. How are you?"
	Dec	"Hi. How are you? What are you doing at the weekend? What did you do in the holidays?"
Conversations about the weekend	Nov	(What did you do at the weekend?) "HMV"
	Dec	"I went to shop buy chocolate"
	Jan	"I going to see my boyfriend" (weekend plans)
	May	"I went to hairdressers cinema"
Conversation repair	March	"I don't understand"
	May	"I don't understand. Please can you say that again." "Sorry I didn't hear you."
Initiating and giving information	May	"I have an appointment with doctor 10:45 morning"
Arguing	March	(no break at 11am) "Why? I don't understand. What are you talking about?"
	May	(not celebrating birthdays) "I think it's bad. I don't agree. I don't like it."

Figure 3 Student B conversation sample using Treloar Vocabulary

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# Communication Effectiveness using AAC

## What is it? And how do we know if we have achieved it?

### DEBORAH JANS

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**What is a successful AAC communicator?** And how do we know the young person or child is an effective communicator? These are the two questions that we set out to answer.

Firstly, we need to define 'communicative competence'. There are many definitions from many different areas of education and learning. The earliest definition and use of the phrase 'communication competence' came from the field of Teaching English as a Second Language. Spitzberg (1989) describes communication competence as "the ability to interact well with others" and Weirmann and Backlund (1980) suggest communication competence is "the ability of an interactant to choose among available communicative behaviours in order that he may successfully accomplish his own interpersonal goals during an encounter."

In 1989, Janice Light put this in an AAC context with her definition: "ability to functionally communicate within the natural environment and to adequately meet daily communication needs. It does not imply total mastery of the art of communication."

Looking at all these definitions, there are six identifiable common threads:

- interpersonal behaviour
- interaction

- involvement
- goals
- environment/context
- flexibility/adaptability

We have based our communication competency framework on Janice Light's theory of Communicative Competence (1989) with additional features outlined in an online presentation

(2007). Referring to Figure 1, we are not only looking at the original four competencies but also need to consider three other factors:

- internal psychosocial factors
- communication demands
- external barriers

We also felt it was important to add an environmental/activity component to

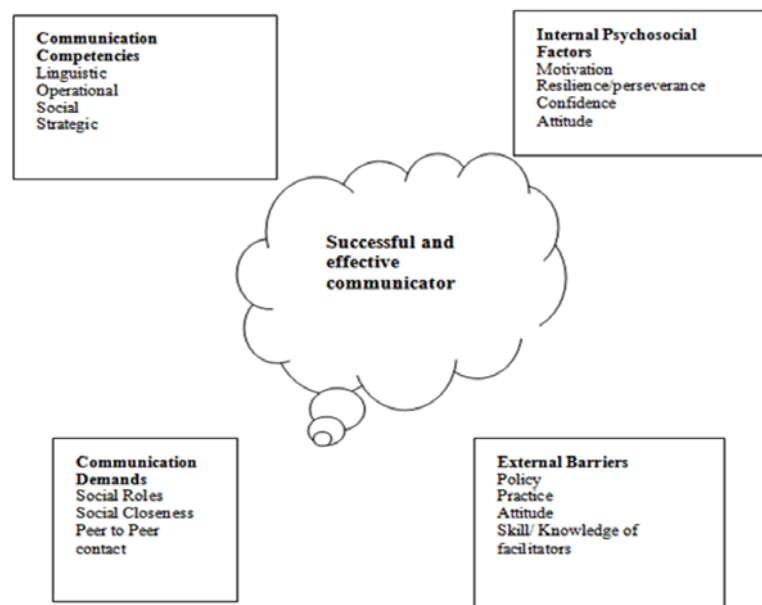


Figure 1 Keycomm's Communication Competency Framework based on Janice Light's theory of Communicative Competence (1989-2007)



our framework. The Model of Human Occupation identifies some key elements which when added to Janice Light's theory rounds off the framework. The Model of Human Occupation is an environmental and participation model with a focus on the individual becoming as independent as possible in the environment and taking on new roles. There are three occupational domains: self care (ADL), work/school, and play/leisure (Hagedorn, 1996).

Using this model within our framework allows us to consider the types of communication required for individuals whilst participating in activities of daily living/occupational life. This is relevant to both children and adults, though a person's occupations change frequently throughout different parts of the lifespan (Early, 2009).

The key elements of this model can be summarised as:

- situations and conditions in the environment will influence the individual's motivation;

- role of environment and people impact on occupational performance;
- intervention aimed at modifying one's environment to promote opportunities for change;
- maximising independence and potential through skill acquisition;
- intervention effective in natural environment;
- need to overcome barriers.

#### SUCCESSFUL AND EFFECTIVE COMMUNICATION

For an individual to be a successful and effective communicator all of the above elements need to be taken into account.

Our framework uses collaborative and joint working as fundamental principles. Therapists, teachers, parents, learning assistants all must be involved in the decision making process, the learning and training phase and the implementation (use) phase within the natural environment. Each professional's role needs to be valued and

identified by the team as part of the decision making and planning process.

Our *C.O.D.E.S. Framework* stands for Competency, Opportunities, Driving Communication Forward, Engagement and Skill Acquisition. These are all the elements we want to focus on when supporting a person who uses AAC. We have focused our use of the framework mainly in special and mainstream schools. We also want the framework to be multipurpose. It is not going to be used if it is seen as just another bit of paperwork to fill out.

The framework is not an assessment. It is a multipurpose tool which can be used as a focus for joint planning, to record an individual's progress over time and to identify appropriate communication targets. It can also be viewed as a record of the individual's communication achievements over time.

#### THE C.O.D.E.S. FRAMEWORK

The C.O.D.E.S. Framework consists of various tables, questionnaires, and plan-

Linguistic	+/-	Comments	Operational	+/-	Comments
Nouns			Access		
Verbs			Shut down		
Adjectives			Navigation		
Prepositions			Page Back		
Time words			Clear button		
Question words			Message window		
Sentence Building			Turning on		
Joining words			Page layout		
Pronouns			Programming independently		
<b>Social roles</b>			<b>Social interaction/ communicative functions</b>		
Initiator			To relay information		
Responder			To make requests		
Messenger			Use social greetings		
Narrator			Answer questions		
Director			Asking questions		
Presenter/Trainer			Give opinions/comments		
Questioner			Make predictions		
<b>Strategic</b>			To tell jokes/riddles		
Use of gesture, signing			To gain attention		
Use of spelling			To protest/reject		
Make up new words			Engaging in short conversation		
Silences			Elaborating on a topic		
Use explanation/circumlocution			Ending a conversation		
Request clarification					
Repair a conversation					

Figure 2 Keycomm Communication Competence Table: to provide an overview of existing skills using AAC systems

Educational Environment (number, literacy, out of class projects, phonics, timetable, keyboard):
Leisure and Community Environment (music, attendance at clubs, photo album):
Self Care/Health and Wellbeing (pain indicators, medication needs, comfort and positioning, health, emotional intelligence):
Worker Role (paid employment, volunteer, enterprise):
Environmental Control (telephone, intercom system, door entry, infrared control):
Other:

Figure 3 Keycomm Communication Competence Table: to identify environment/activities that AAC system is presently being used in

ning sheets which can be used over time to record targets and outcomes for an individual who uses AAC. The quick look view table can give you a bird's eye view of the child's communication skills at any one time. It includes five competency areas: linguistic, operational, social interaction/communicative functions, social roles, and strategic competency.

In addition, there is ample opportunity to identify the environments and activities the individual has the opportunity to communicate in. These environments have been broken down into five areas including: educational, leisure and community, self care and health and well being, worker role, and environmental control. The tables shown in Figures 2 and 3, when used over time, can give the facilitators a good view of progress over time.

The framework also consists of joint planning sheets to be used as a focus during multi-professional planning meetings. These joint planning sheets provide a starting point for introducing a new system and for identifying communication targets to be included in the individual's IEP. They also can serve as a record of communication achievement over time.

We also have put together a questionnaire for schools to be able to look at their policy and practice with regard to implementing an AAC system. The questionnaire has four distinct areas for schools to consider: policy, practice, attitude, and skill/knowledge of facilitators.

We are also very keen to include the person who uses AAC as much as possible in their own planning and communication achievements. We have now added a symbolised goal sheet

which identifies the goals they want to work on.

#### CASE EXAMPLE: JAY

Jay is a 9 year old boy who has a physical disability and is non verbal. He has been using a Techtalk 8 voice output communication aid for 12 months. He attends a special school for children with complex needs and has regular speech and language therapy. When reviewed after using a Techtalk 8 for 12 months, the following communication competency skills were identified:

- Linguistic competency - using nouns, names of things;
- Operational competency - fist approach, beginning to use isolated finger movement for direct access, inconsistently;
- Social roles - responding in class and giving directions to others;
- Social interaction - relays information through news time, answering questions;
- Environment/participation - in class, news time.

Targets were identified with the Speech & Language Therapist and the teacher to include: operational access to work with Occupational Therapist on isolated finger pointing; linguistic goal was to use verbs, adjectives and starter phrases for sentence building; social roles were to improve initiation of communication.

In addition, the school agreed that Jay could begin to have opportunities to use his communication system both in class activities and out of class activities such as the Tuck Shop.

Jay's communication skills were then reviewed 11 months later. Progress had

been seen in all the targeted areas. Jay was now using his communication system to communicate nouns, verbs, adjectives and beginning to sentence-build using starter phrases. He was now able to use isolated finger movement consistently. In addition, Jay was now initiating communication consistently within a communication group. Furthermore, considerable progress was seen in his use of his communication system during a variety of social interactive functions, including: relaying information between home and school; giving opinions; answering questions; and making requests spontaneously. Due to the significant amount of progress made over the last eleven months, the following targets were set for Jay for the following year:

- Upgrade to a dynamic display device with 20 location keyguard;
- Operational goal - become independent with device, i.e. turning on, turning off and improving navigation between pages;
- Social roles - taking on a messenger role, delivering messages between classes; and taking on a director role, directing others outside of class;
- Social interactions - to tell jokes/riddles, using social greetings, asking questions and gaining someone's attention;
- Environment opportunities - begin to use device at home by choosing activities and telling people whether he liked the activity.

#### OUTCOMES SO FAR

Since implementing this framework within some schools, we have found many positive changes in both the facilitators and the people who use AAC.

Children are now being given more opportunities and more diverse opportunities to use their communication skills. There is now a shared language between teachers and therapists and reports are now recording more specific competencies rather than fuzzy language such as "He is doing great with his machine".

We have also found that using this framework is now providing evidence for teachers to communicate progress to parents during reviews and parents evenings. It also provides a focus for teachers to integrate communication into the classroom. The framework also helps us to get away from a focus on the equipment to looking at communication skill development.

We have begun to use this framework with young adults who have left school

and who are now spending time within the community and supported through Adult Services.

#### WHAT NEXT?

We are now planning to launch the use of the C.O.D.E.S. framework in all Lothian schools where appropriate. This will give us an opportunity to monitor its effectiveness and usefulness over the next year. We are also introducing a self perception rating scale for young people to give their opinion on their own communicative competence.

Further information and updates on communication competence and the C.O.D.E.S. framework is available at [www.keycommac.ic.org](http://www.keycommac.ic.org) \*

Deborah Jans  
Keycomm Coordinator  
Specialist Speech & Language Therapist

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# Not a Bandage

## Advocating AAC assessment in aphasia

**EUAN ROBERTSON & HOLLY SCHNEIDER**

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***"To achieve real independence, a stroke survivor not only needs to approach the outside world, but communicate in it as well."***

(Senelick & Dougherty, 2001)

Aphasia is an acquired communication disorder resulting in an array of complex language, motor and/or cognitive deficits. The goals of aphasia treatment include assisting individuals in recovering as much communication as their deficit allows, learning how to compensate for residual deficits, and learning how to live in harmony with the way they are now and the way they used to be (Ansel & Weinrich, 2002).

Many individuals improve speech, reading and writing skills with traditional stimulation therapy or impairment-oriented therapy. However, some individuals may continue with chronic communication deficits and their communication needs cannot be met without support. Thus, many aphasiologists now stress functional communication as an important treatment goal advocating a shift towards a communication focus for intervention.

The World Health Organisation (2001) advocated a shift of attention from the level of impairment to the level of ac-

tivities and participation of the individual. This brings such concepts as 'functional communication' and 'communicative roles' into the spotlight for aphasia rehabilitation (Van de Sandt-Koenderman, 2004).

Similarly, "AAC treatment philosophy stresses the functional value of communication and the use of any strategies and technologies to achieve successful communication" (Ansel & Weinrich, 2002). In its most general definition, augmentative and alternative communication (AAC) assists individuals with such complex communication limitations that they are unable to meet their daily communication needs through natural speech (Beukelman & Mirenda, 2005). AAC offers communication strategies that "provide external support for people who cannot understand or generate messages on their own" (Lasker & Garrett, 2008). For some individuals, AAC may be a temporary or occasional means for communication while others may require AAC for a larger proportion of their daily communication needs.

ASHA (2002) defines AAC as a "set of procedures and processes by which an individual's communication skills can be maximized for functional and effective

communication". Moreover, research suggests that AAC techniques in aphasia treatment can offer a compensatory means of communication in lieu of spoken language, a facilitation technique for re-acquisition of spoken language skills and an associative link to enable spoken language to take place (Kraat, 1990). So, AAC directly links to our professional goals as Speech and Language Pathologists - whether therapy is remediation or compensation, the goal is the same: communication intervention.

Although the goals of both aphasia treatment and AAC treatment are parallel, AAC is traditionally introduced to an individual with aphasia during the end stages of rehabilitation "when treatment gains can no longer be measured with classic aphasia treatment" (Ansel & Weinrich, 2002).

There are many additional factors to consider when introducing AAC treatment at this time including: the degree of speech return an individual experiences; the client's and family's willingness to use AAC as a temporary or ongoing means of communication; and the SLT's familiarity with AAC. Offering communication alternatives at this stage challenges individuals to ei-



ther accept a proposed AAC system or not. Those not ready to make that decision are often considered to be resistant or in denial when, in fact, these individuals are having to decide about an alternative means of communication while at the same time adjusting to such life changes as artificial nutrition, artificial mobility, loss of employment, change in social roles, loss of autonomy and even perhaps a change in living arrangements (Beukelman, Yorkston & Garret, 2007). In addition, this scenario suggests that AAC is a bandage at best and a last resort at worst and/or that AAC is not a part of speech therapy.

Garrett and Lasker (2007) invite SLTs at all levels of service to "broaden their scope of therapeutic intervention to include (partner-supported, transitional and independent) AAC techniques". Therapy focusing on AAC is language therapy using an alternative or supplemental means of production. Because of the broad spectrum of communicative ability among individuals with aphasia, whose needs and abilities are dynamic, AAC should be incorporated throughout the rehabilitation process (Shertz, 2005).

Due to the changing nature of recovery, it is also imperative that AAC systems and strategies are carefully matched to the individual's "cognitive-linguistic strengths, challenges and preferences" (Garret & Lasker, 2007). As SLTs, we are service providers for identifying communication needs and are part of the key decision making team for intervention. If we identify that an individual does not have functional speech, we should feel compelled to explore alternative means of communication to ensure participation in important life activities.

Thus, by including AAC as part of our initial assessment battery, we can provide more optimal support to the adult who experiences a communication impairment as they learn to "acknowledge a loss of skills and goals and then establish a new normal way of participating in his/her social community" (Shertz, 2005). Treatment goals for both AAC and aphasia are parallel. A Speech and Language Therapist may use AAC as part of the assessment process in the hope that it will be more readily accepted by the person with aphasia. Traditional assessment batteries can give useful information for AAC assessment, however AAC needs assessments provide a better insight into the communicative desires of our clients and their communication partners.

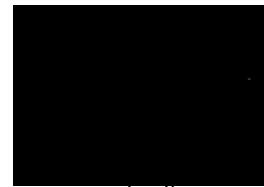
The AAC-Aphasia assessment protocol (Garret, Lasker & Fox, 2007) may help expand our initial assessments to perhaps increase acceptance of AAC strategies and a multi-modality approach to communication earlier in the rehabilitation process. Since it is clear there are parallels in the aims of both AAC therapy and aphasia therapy, AAC should form part of an SLT assessment as well as forming part of a person with aphasia's communication system. This may be made up of a number of different techniques from pad and paper to alphabet chart or voice output communication aid.

These techniques may need to change to reflect changes in the communication ability of the individual. For many, AAC may form part of their communication for the rest of their lives and must give them the ability to "maintain their social network and recapture some social roles" (Beukelman, 2005). \*

Euan Robertson & Holly Schneider  
Clinical Application Specialists

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[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). 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 & perspectives on AAC.
- An International Directory with a list of all ISAAC members.
- ISAAC members can buy the AAC Journal at 54% discounted rate.
- ISAAC members can attend ISAAC conferences and meetings at 15% or more discounted rate.



## TRUSTEES' NEWS

COLLATED BY JANICE MURRAY, CHAIR

### CM2011 NATIONAL CONFERENCE

Preparations are well under way for the Communication Matters CM2011 National Conference at the University of Leicester on 25-27 September.

We are in the process of finalising the academic programme, which this year seems fuller than ever with a diverse range of topics.

Leicester campus is undergoing a few changes so we have reviewed some logistical arrangements. This will include an extended marquee space with more social areas available.

So far, the number of registrations are exceeding those of last year's, so we look forward to another stimulating conference with the usual opportunities for networking and learning from each other.

I am delighted to be able to say, "Book now, to avoid disappointment!"

### SUPPORTING YOUNG PEOPLE WHO USE AAC

The second of our Safe Social Networking days went off very well at Beaumont College, Lancaster. The day was aimed at students at the college, as well as to other young adults (aged 16-25) using AAC from nearby colleges or who are living at home. There was an opportunity for attendees to Skype some of the people who attended the first of these days at Lord Mayor Treloar College, Hampshire.

Look out for the session at the CM2011 Conference which will provide more information on how these days were organised and how we hope to extend this and other activities to support young people who use AAC.

### REVIEW OF AAC SERVICES

Reviews of AAC services continue across England (Anna Reeves) and Scotland (Alison Gray), and discussions have begun in Wales that currently look as though they will consider the work already mapped in England as a template to kick start their review process.

Janice Murray and Anna Reeves recently visited Alison Gray and then met with representatives of the 'Augmentative Communication in Practice: Scotland' group. There are clear challenges for all areas of the UK to overcome in terms of identifying a model or models of AAC provision that are fair, equitable and do not jeopardise existing services. Anna Reeves is hoping to report on many aspects of this (not just England) in her Keynote speech at the CM2011 Conference.

### COMPETENCIES & OUTCOME MEASURES

The work on Competencies and Outcome Measures continues to develop. There will be reports

from these working parties during the Annual Meeting of Associate Members on 25 September, and Victoria Lundie will provide an update on the competencies work during the Conference. Those members unable to be present for either of these will receive a written report following Conference.

### 'OTHER WAYS OF SPEAKING'

The new booklet *Other Ways of Speaking*, launched in collaboration with the Communication Trust, has been received very favourably by its target audience, i.e. those coming new to AAC and needing some clear and uncomplicated information. It has been so popular that we anticipate another print run very soon.

### ELECTION OF TRUSTEES

Contingency planning has been a significant consideration for the Board in the last few months. This includes consideration of the inevitable changes to the Board at September's election of Trustees.

This is my opportunity to thank all Trustees, especially Neil Hansen, Anna Reeves, Gillian Hazell and Sally Chan, all of whom are coming to the end of a term of office. Their energy and enthusiasm have made a significant difference to Communication Matters. Some of these individuals will stand for re-election along with a number of other willing volunteers who have already contacted me for discussion about the role. Look out for the ballot paper which will be with you soon.

In addition, we have been aware that Communication Matters' work capacity is creaking a little under the strain of lots to do, and lots we want to be involved with – but with – only so many hours in the day that volunteers (Trustees) can do. As a consequence we have been exploring routes to funded posts to support the work of the Board of Trustees and to further Communication Matters' reach and activities. I intend to report on how this is progressing at the Annual Meeting of Associate members.

### RESEARCH PROJECT

The AAC Evidence Base project continues to gather pace, with data collection in full swing – please turn to page 21 for the latest report on developments.

### FINALLY

I wish you all an opportunity this summer to re-charge the batteries, get a sun tan (or a rust tan, depending on your destination!) and look forward to seeing many of you at the CM2011 Conference in Leicester. \*

**PRESS**  
**RELEASES**

**'THE GHOST BOY'**

'The Ghost Boy', an inspiring memoir by Martin Pistorius, has been published to much acclaim. Kerri Sharp, commissioning editor for Simon & Schuster Publishers, said, "It's a publishing challenge to draw large numbers of readers to any memoir of illness, but Ghost Boy transcends the genre by its intensity of emotion and the quality of the writing.

"Ghost Boy takes you inside the consciousness of a young man trapped inside an unmoveable body, unable to communicate, yet feeling and understanding everything. We have an extraordinary opportunity to experience, through Martin's story, what it is like to be here and yet not here.

"It's wake-up call to cherish our lives. Now Martin has emerged from his darkness we can celebrate this amazing, deeply moving story of recovery and the power of the imagination."

[Editor's note: Communication Matters is delighted that Martin Pistorius will be speaking at the CM2011 National Conference in September.]

\*

**SCOTTISH VOICE HEARD ON BBC RADIO 4**

Cereproc, producers of the Scottish Voice, and CALL Scotland were featured on BBC Radio 4's 'Giving the Critic Back his Voice' on 9 August. Cereproc produced a new voice for American film critic Roger Ebert using his past recordings, and have recently worked on an electronic voice for an Aberdeen-based man with Motor Neurone Disease. Listen to the broadcast at [www.bbc.co.uk/programmes/b01321hj](http://www.bbc.co.uk/programmes/b01321hj)

The programme also describes the use of the 'Heather' voice in Scotland and the impact it has had on people who rely on a computer to read text, or require a communication aid to give them a voice. With a grant from Scottish Government, CALL Scotland promotes and distributes Heather, and is working with Cereproc to develop a male Scottish voice 'Stuart'. Heather and Stuart voices are available for use in Scottish schools, colleges and the public sector, and can be licenced by developers. Further information from [www.thescottishvoice.org.uk](http://www.thescottishvoice.org.uk)

\*

**A 'QUIET RIOT'**

A group of people who use AAC has formed with the name 'Quiet Riot'. The group currently consists of nine adults meeting in Manchester and, though diverse in every way, they all need assistance to communicate.

If you want to learn more about the group and would like to direct them to funding opportunities so they can meet and work together more frequently, please contact Joe Whittaker at [whittakerjoe@gmail.com](mailto:whittakerjoe@gmail.com) or ring 07747 448 236.

**BHTA eCAT**  
**NEWS**

**Over the last few months, in my role as Chair of BHTA eCAT, I have been heavily involved in two issues that could be of interest to members of Communication Matters and the wider AAC community.**

The first is that of making introductions (no I haven't become the male Cilla Black and started an AAC Blind Date program). These have been using connections within the BHTA. I felt it was important to introduce Ray Hodgkinson MBE, the Director General of the BHTA, to Jean Gross, the Communication Champion; and through this, the introduction of Jean Gross to the new BHTA Director of Communications, Lord Rennard.

Lord Rennard is credited with the growing success of the Lib Dems over the last 15 years and was the Lib Dem's chief executive from 2003 to 2009. In Ray's words, "...Chris (Lord Rennard) knows exactly who in government to tap on the shoulder when he wants something done...!" Jean met Lord Rennard in July and the hope is that he will help her in her drive for better funding in the field of SLT support and AAC provision.

The second introduction was Ray to the Chair of Communication Matters, Janice Murray. The objective here was to get the BHTA and CM talking to each other to understand if and how the BHTA could help CM. There has been one meeting so far, with another planned soon. It is too early to say what the outcome might be, but there are a number of ideas 'on the table' that have been taken to the Trustees meeting and could prove to be beneficial to members in the future. As is so often said, "watch this space!"

The second issue that I have been involved in is that of representing the eCAT sector at the BHTA strategy meeting in Lincolnshire. Although I had to resign as a Board Director of the BHTA when I took on the role of eCAT Chair (BHTA rules don't allow individuals to be a Sector Chair and a Board member), I am still a member of the BHTA Strategy Council which guides the Board on the way the Trade Association should move forward. I am conscious that although membership of the BHTA by all AAC suppliers could lead to more benefits for the AAC community generally, many smaller companies may be put off by the membership fees (and as a 'one man band' myself now, I fully understand that). So I have raised the idea of having a lower entry band for very small businesses. Again we need to wait and see if it leads to a positive outcome.

Meanwhile the eCAT group met and the main talking point was what we could do for the "Year of Communication" – possibly in October, the month dedicated to AAC. We have some ideas that could involve the Houses of Parliament (no – we are not thinking of doing a 'Guy Fawkes') but again more details will be shared when we have something more concrete. \*

**David Morgan**  
Chair of eCAT section, BHTA





## DIARY DATES

28 August 2011 Edinburgh  
**'A Most Curious Detour' – Dramatised Book Reading**  
 Tel: 0131 221 2277 [www.festivalofspirituality.org.uk/Performances.html](http://www.festivalofspirituality.org.uk/Performances.html)

14-15 September 2011 Glasgow  
**Naidex Scotland @ SECC Glasgow**  
 FREE ticket: [www.naidex.co.uk/communicationmatters](http://www.naidex.co.uk/communicationmatters)

20 September 2011 Eastbourne  
**Fun Event for People with Autism Spectrum Conditions**  
 Contact Helen Page: [helen.page@sussexpartnership.nhs.uk](mailto:helen.page@sussexpartnership.nhs.uk)

21 September 2011 Bristol  
**Introducing Clicker 5**  
 Contact PCAS: 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

25-27 September 2011 Leicester  
**CM2011 National Conference**  
 Contact: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

15 October 2011 Bristol  
**SW 1Voice Showtime Fun Day**  
 Contact 1Voice: [heskethanne@hotmail.com](mailto:heskethanne@hotmail.com)

19 October 2011 Bristol  
**Introduction to AAC**  
 Contact PCAS: 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

1 November 2011 Edinburgh  
**Clicker 5 to Support Language, Literacy & Communication**  
 Contact CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)



## DIARY DATES

4 November 2011 Bristol  
**Boardmaker Training**  
 Contact PCAS: 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

8 November 2011 London  
**Communication Matters Road Show in London**  
 FREE Tel: 0845 456 8211 [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

9 November 2011 Bristol  
**Communicate: in Print 2**  
 Contact PCAS: 0117 3533613 [www.pcas.claremont.bristol.sch.uk](http://www.pcas.claremont.bristol.sch.uk)

12 November 2011 Edinburgh  
**Technology and ASN: Information Day for Parents**  
 Contact CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

23 November 2011 Oldham  
**Using Boardmaker to create Communication Books**  
 Contact ACE Centre North: 0161 358 0151 [www.ace-north.org.uk](http://www.ace-north.org.uk)

27 November 2011 Aberdeen  
**AAC Pantomime: 'Oh Go On, Cinderella'**  
 By invitation only; contact [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)

29 November 2011 Oldham  
**AAC and Autistic Spectrum Disorder**  
 Contact ACE Centre North: 0161 358 0151 [www.ace-north.org.uk](http://www.ace-north.org.uk)

2 December 2011 Edinburgh  
**Using iPads, iPods & Other Mobile Devices for AAC/ASD**  
 Contact CALL Scotland: 0131 651 6235 [www.callscotland.org.uk](http://www.callscotland.org.uk)

CM  
ROAD SHOW



## PRESTIGIOUS AWARD FOR PAUL NISBET



Paul Nisbet, Joint Co-ordinator of CALL Scotland, has been honoured by the University of Edinburgh with the prestigious Principal's Medal. The award is in recognition of his outstanding contribution to the Scottish education community, and beyond.

Paul, a Chartered Engineer, has been with CALL since 1983 and has taken a leading role in a number of innovative developments in Scotland, including:

- designing the original CALLbox and many other interfaces which allowed children with severe disabilities to interact with a computer;
- developing the Smart Wheelchair, now manufactured in the UK;
- working in partnership with the Scottish Qualifications Authority on the introduction of Adapted Digital Exams for pupils unable to use the traditional written format;
- leading the 'Books for All' project to make books and print materials more accessible for people with a print disability.

## ONLINE AAC AWARENESS COURSE



Communication Matters has been awarded a grant from 'Awards for All' to produce an online training course to explain what AAC is; the working title is **'Solutions for people who can't speak'**.

We are designing a package to fill a gap in existing training, within the available budget. The course will use a highly delivery interactive style, including video, case studies, quizzes and animations, to engage and influence a target audience who have no prior knowledge about AAC. The course will use multiple choice assessments to ensure that the learner takes away the desired messages.

However, time is short as the project must be completed by February 2012. We are keen to hear comments and suggestions about the outline plan above. Members of the AAC community from all backgrounds are warmly invited to a **discussion session** (Tuesday 27 Sept) at the CM2011 Conference. The project team will present the outline, invite discussion and listen to the feedback.

If you are unable to attend the conference, but would like to contribute your thoughts, please email [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk) and put 'Online Course' in the subject line.



## Research Project News

# Communication Matters – Research Matters: An AAC Evidence Base

Katie Holmes & David Morgan

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**They say that “Time flies when you’re having fun!”** and we all know how true that is. It’s amazing that we’re already at the end of the first year of the research project which started on 14 June 2010, so rather than just an update on what we have done since the last report, this seems an ideal time to produce an “annual report”.

### PEOPLE

I joined the project in April 2010 during the start-up phase. The next appointment was the Research Lead, David Morgan, who was previously the International Director for DynaVox and now runs his own consultancy company. The addition of David has been helpful to me as, although he is only contracted for one day a month, his experience in business and the AAC industry has meant I can use him as a “sounding board” to discuss ideas and issues and we are working together on all aspects of the dissemination plans for the project.

Our research partners have recruited their Research Assistants so all the staff required for the project are now in place. Two Research Assistants started work at the University of Sheffield in December and one started at Manchester Metropolitan University (MMU) in February.

We experienced some delays during our start-up phase which meant revising the milestone dates agreed with the Big Lottery Fund. However they have all been agreed and the project is on target to meet them and its scheduled end date of April 2013.

The first milestone was met in January when the University of Sheffield (working with Barnsley Hospital) completed its systematic literature review. This looked at peer-reviewed papers on evidence of need for ‘high-tech’ AAC and service provision. Two articles have been submitted for publication to peer-reviewed journals. The first highlights the factors that may affect whether high-tech AAC is provided and used. The second reviews the findings from research literature relating to the effectiveness of interventions using high-tech AAC. Once the publication dates of the articles are known we will publish lay reports on the research project page of the Communication Matters website.

The appropriate **ethics approvals** have been secured by both universities for their work.

### FINANCES & REPORTING

I manage the financial aspects of the project in conjunction with the Re-

search Lead and the Communication Matters Treasurer.

We have worked within budget during year one and are expecting to continue to work within the agreed financial plan in years two and three.

There are regular reports to the Research Sub-group and to the Trustees and usually either I or the Research Lead attends Trustees meetings.

The end of year report has been submitted to the Big Lottery Fund.

### ABOUT THE PROJECT

The AAC Evidence Base research project is a three-year project funded by the National Lottery through Big Lottery Fund.

Communication Matters is leading the project and working with three research partners: the University of Sheffield, Barnsley Hospital NHS Foundation Trust and Manchester Metropolitan University.

The project aims to improve the quality of life of people with severe communication impairments who need AAC by raising awareness of their needs and by improving service provision.

### MILESTONES

## FOCUS GROUPS

Focus Groups have been held by the research partners with practitioners, commercial suppliers and family members of people who use AAC. These have provided valuable input into the process of designing the questionnaires to be used in the University of Sheffield's research work and into the design of the online AAC Evidence Base by MMU. Further focus groups will be held in the course of 2011.

## INDEPENDENT RESEARCH PANEL

The Independent Research Panel has met three times and is providing advice and guidance to Communication Matters. It is made up of eight people who represent different interests, including a person who uses AAC, a family member, a commissioner and professionals working in the field.

## RESEARCH INVOLVEMENT NETWORK

Communication Matters is establishing the Research Involvement Network

which will be made up of people who are interested in participating in AAC research. Examples of participation could be as research subjects; as advisers to researchers or as members of steering panels for research projects. It is hoped that the Network will make it easier for AAC researchers to find participants and widen the pool of people they can draw on. The Network will be launched this Autumn.

## COMMUNICATION & DISSEMINATION

We have carried out the first stage of our dissemination plan, putting in place regular communication via Communication Matters' own channels: the e-news, the research page on the website and this journal, as well as via Twitter. A leaflet has been printed and over 3,000 copies distributed. Leaflets are available at road shows and study days, as well as at other events where Communication Matters has a presence.

I have given presentations about the project at Naidex Birmingham (the dis-

ability living show) and at a network day organised by ACE Centre North. In addition, the MMU research team gave a poster presentation at a conference organised by the university's Research Institute.

We have started the second stage of our dissemination plan: communicating information via other organisations. A short article has been written which is suitable for e-bulletins or website news. This has been published by some organisations and we plan to contact more. We have also made links with a number of disability organisations and hope to use these effectively to reach new audiences.

We will give two presentations at this year's CM National Conference and we are submitting a presentation to International ISAAC 2012.

So, in summary, all is going well and we look forward to a successful year two. \*

Katie Holmes, *Research Manager*

Dave Morgan, *Research Lead*

# COMMUNICATION MATTERS



## NATIONAL CONFERENCE

25-27 SEPTEMBER 2011 UNIVERSITY OF LEICESTER

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

### SYMPOSIUM PROGRAMME

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

### REGISTRATION

All registrations allow full access to all the presentations and trade exhibition. The registration fee also includes refreshments, lunch and evening meals. Residential registration additionally covers accommodation in student halls (with breakfast). Full residential, one-night and non-residential rates are available.

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)



# Teaching Pointing for Communication

## Means, opportunities, reasons and the missing ingredient

ANNE EMERSON<sup>1</sup> & JACKIE DEARDEN<sup>2</sup>

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<sup>2</sup> Nottingham City Children and Families Services

### INTRODUCTION

The role of pointing in children with autism is well-reported (Baron-Cohen, 1989). The differences between proto-imperative and proto-declarative pointing is considered to be one of the indicative findings for autism in young children. Assessment of non-verbal children mostly relies on their ability to point and those who do not respond in test situations are therefore considered to be lacking in cognitive capacity.

This paper reports a case study of one of the pupils who participated in a two year action research project in a school for pupils with autism.

The researchers have backgrounds in speech and language therapy and educational psychology and set out to attempt to teach children with no current formal communication methods to point for communication purposes. The motivation to work on pointing is both in terms of demonstrating understanding and ability and in providing a means for expression.

### BASELINE MEASURES

Before starting direct work with James, we videotaped him engaging in activities in class with particular interest in how he interacted with adults, ex-

pressed his needs and what he did. Key members of staff were interviewed using a tool previously adapted from Money & Thurman (1994) which focuses on the means, reasons and opportunities (MRO) for communication. The form prompts the recording of all aspects of 'means' of communication ranging from vocalisations, through body movement, gesture and facial expression to eye-gaze and pointing.

In the 'reasons' section, the focus is on whether the student appears to be motivated to communicate to comment, to ask or respond to questions, or for social reasons such as greetings.

Within 'opportunities', the person completing the form is asked to consider how the student might communicate, for example through the use of low or high tech communication aids or within the context of a 'communication relationship' that is with someone who understands the young person's communication needs and has an expectation that the pupil will respond given the appropriate supports.

### INTERVENTION

One or both of the researchers attended James's regular one-to-one work sessions. The main working

method was to present the pupil and keyworker with a range of activities designed to promote eye-hand coordination, hand control and finger pointing. Although they were used to working in a one-to-one situation, our sessions presented a very different way of working. Prior to the intervention they were adult led, focusing on aspects of the curriculum and based on assessment of the pupil's current attainment. In the research sessions, emphasis was placed on following the young person's interests mainly starting with visual materials such as magazines, comics and books.

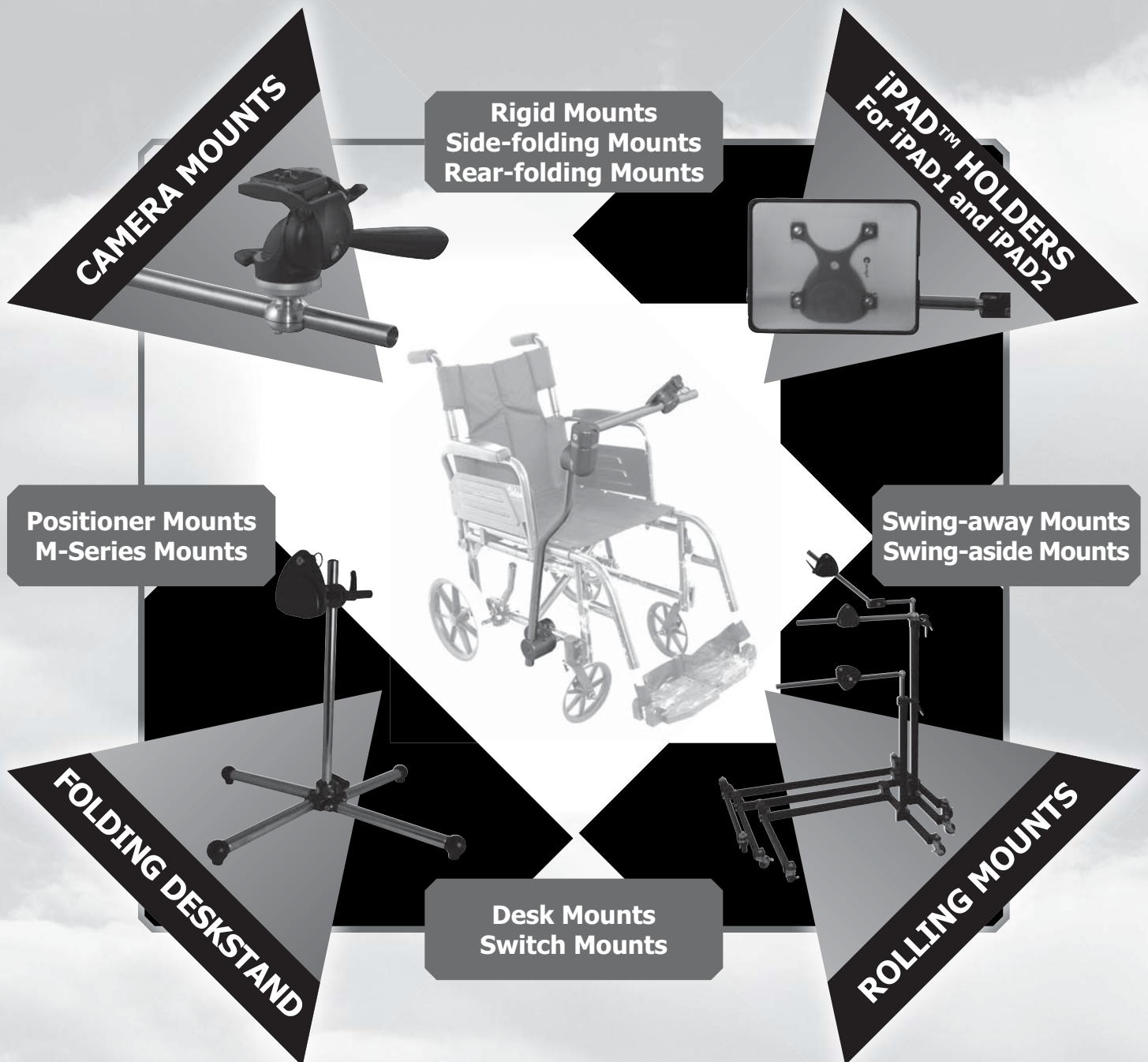
Sessions were typically video-taped and notes were kept. It was intended that the keyworkers would repeat or continue the activities with the pupil in the time between research sessions. This happened with various degrees of regularity.

### CASE STUDY

James was 12 at the time of initial observations. The baseline interviews described his means of communication as consisting of some vocalisations to express happiness or discontent, facial expressions, body movements, gestures, pointing to pictures and symbols (inconsistent pointing to words and letters).



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Reasons for communication were reported to be all inconsistent intentional communication of basic needs, frequently related to obsessional interests, and to expressing himself. He had been provided with opportunities to use Makaton signs and symbols, and knew a few of each, and PECS. The barriers to communicating were identified by staff as fine motor impairments and word finding difficulties.

James was recommended for the research project as staff had expectations of untapped potential, and believed that he wanted to communicate more but was unable to demonstrate his full ability.

### Observations in Class

When observed in class, James was occupied with one of his typical pastimes, sprinkling rice and sand into a tray. We saw him sign 'yes' and 'no' to respond to staff, but also hit staff to refuse. He pointed and vocalised towards the laptop in an apparent request. In response to a prompt from the teacher he used the sign for 'brush teeth'.

During a one-to-one work session with a teaching assistant, with whom he appeared to have a warm relationship, he showed enjoyment of looking at pictures and books and was able to signal when he wanted her to talk about something he had seen.

One of the activities was to order the eight letters in his name. The teaching assistant asked him for each in turn, saying the letter and signing, and he found most of them straight away but made some errors. When they shared reading of a book the teaching assistant often took his hand to follow the words as she read or to help him to point to something in a picture.

#### Reading P6

- Find a specific book on request / identify beginning and end of book
- Match colour words brown, black, orange, pink
- Use magnetic letters to learn sounds.

#### English comprehension P4

- Demonstrate understanding of own name and class names
- Follow verb instructions jump, turn, supported by signing and symbols
- Show understanding of big/small and different colours
- Imitate oral movements.

Table 1

Some of his P-level targets at this time can be seen in Table 1. All of the information we had collected demonstrated that staff were confident in their knowledge of James, that this was based on at least one year of working with him, that they felt they were making some progress and that he was being challenged at his cognitive level. Targets had been thought about carefully and work was intended to stretch him.

### Areas for Exploration

Having completed our baseline observations we had a number of areas we wanted to explore:

- James seemed to be interested in books and pictures but was not being asked to do much independently in relation to them. The work was staff directed as if the expectation was that James would not engage on his own terms. In fact his own choice of activity was always to sprinkle rice, water or any other small objects he could find, or to play with the tap flicking water.
- James seemed to be able to point, and yet was often helped to do this, and was described as having difficulties with fine motor control, possibly based on the sorts of activities he engaged in when not being directed and supported by staff.
- James looked clearly at things he was interested in but was not using this in any consistent way to communicate.
- Staff always spoke to James in telegraphic phrases placing emphasis on key words in accordance with good practice when working with children with autism.

### The First Year

We decided to use books to investigate what he would do spontaneously when not directed by staff to follow text as they read. Our approach from the beginning was to use more complex language than he was used to and books that required him to respond in some way with his hands, for example to lift a flap or pull a tab. For most of the first two terms of working with James he was responsive to what we were showing with only occasional requests for other activities or protests.

Progress was rapid, with James showing within the first few weeks that he recognised some written words. He used his hands and pointed independently from the first session, and when

left to point to things of his own choice he would find pictures that particularly interested him but also point to words and letters. He demonstrated understanding at a much higher level than anyone had expected and was soon responding to complex questions.

His responses were always so fast that at first they appeared to be random. Some of the early work involved using books with many choices of picture and asking him to make a selection of something that he liked, wanted to wear, wanted to eat, etc. He could be seen to scan the page but would point to something so quickly that it appeared that he was not considering a choice. However, when another member of staff used the same book in the same way he was found to make exactly the same choices.

When James started to point to words, staff were very reluctant to believe that he was reading. At first we gave him a choice of two words, so staff thought he was correct by chance. We gradually increased the number he was pointing to and when he was selecting reliably from six words it was agreed that he did have a sight vocabulary but that it was probably limited to a small number of common words.

Further investigation has shown that he has an extensive reading vocabulary and that he learns new words remarkably fast. When his mother was interviewed she reported that she had always known he could read because he always took the television programme paper and then knew when he wanted to watch.

### Progress in the Second Year

During the second year of the project it has at times been more difficult to engage James. The skills we discovered he had, his ability to understand and to read, had led to changes in his school day but his behaviour was changing only slowly so he was still demanding to engage in repetitive activities and becoming upset if he was refused. When he became obsessed with asking to use a computer, staff removed the symbol to prevent his repetitive demands. James then scoured pages of text in school documents and would point to the word computer. When he was obsessed with an upcoming trip to a zoo, staff again removed the symbol. This time James would find anything with the date 2009 and go to staff covering the 9 with his finger so it looked like 'zoo'.

Our work had helped James to extend the means of communication he had access to, including the school instituting a spelling programme to help him to

have his own choice of vocabulary. They were also able to give him more opportunities to communicate since they now knew that he could understand most of what was said to him and that he could reliably respond.

However, his reasons for communicating remained much the same: to ask for things that he was obsessed by. During sessions it was possible to extend these reasons, and we worked on the expression of emotions by asking him to attribute statements to characters in a story; but it has been much harder to get him to generalise these abilities to the rest of the day. Although he shows understanding of emotions when responding to books, he consistently does not respond to questions about his own feelings.

### CONCLUSIONS AND FURTHER QUESTIONS

Within the first few sessions with James, he demonstrated skills and abilities that he had not previously been thought to have. He did not change his 'means' of communication as he had always been able to point and sign 'yes' and 'no'.

During sessions we increased his 'reasons' by helping him to engage in topics he did not usually have access to, although 'reasons' outside the sessions remained the same.

We also increased his opportunities by following his line of interest and offering him the option of pointing at words and pictures to answer questions, and in fact by asking him questions he had never been asked at school due to the expectation that he would not understand.

However, our work mainly led us to consider another element of our approach, and subsequently to add another section to the MRO. We feel that just as important as providing means, reasons and opportunities to communicate the role of 'expectations' (E) was key in enhancing overall communicative ability for James and subsequently we have extended our approach to MORE. \*

Dr Anne Emerson

Lecturer & Speech and Language Therapist

Dr Jackie Dearden

Educational Psychologist & Consultant

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## A Case Study

# Evolving AAC and Assistive Technology Provision during Neuro-rehabilitation for Locked-in Syndrome

JANE BACHE

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**Marini is a 57 year old lady whose first language is Spanish, although she is also fluent in English and German. In December 2008, following a short period of headaches and dizziness, Marini suffered a brain-stem stroke. She was transferred from acute hospital to the Royal Hospital for Neuro-disability (RHN) for ongoing rehabilitation in March 2009.**

On admission, Marini had no active movement in her arms and legs, was unable to speak and was extremely low in mood. Initial assessments and observations indicated that she had no cognitive or linguistic deficits and she was using a system of eyes up for 'yes' and eyes down for 'no'. When lying in bed, with her head elevated to 30°, Marini was able to rotate her head very slightly, but this movement was weak and effortful.

### EARLY INTERVENTION

For Marini to benefit from access to assistive technology, positioning in both her bed and a wheelchair were extremely important. Her therapy team focused on bed positioning and on assessing her for an appropriate wheelchair and seating system soon after admission. At this stage, the assistive technology team were involved with identifying possible switch control sites, so that Marini could have access to the nurse call system. As Marini's movements were limited to head rotation, switch trials focused on assessing different switches positioned

next to Marini's cheeks and forehead. It was soon evident that a mechanical switch would be too effortful for her to operate, as she did not have sufficient power in her movement to do so. Therefore a touch sensitive switch was used, placed next to Marini's left cheek, to enable her to activate the nurse call system.

Once Marini could be seated in a loan wheelchair, it was possible to attach the touch switch to her headrest to allow her to use the switch functionally within therapy sessions. Her switch was connected to a PC so that she could play simple games, with the aim of helping her to increase range and strength in her neck and build switch timing skills.

Additionally, these games sessions helped Marini to feel that she was working towards the use of technology for wider and more fulfilling activities. The assistive technology team also set up a Steeper Activ 500 environmental control system (ECS) so that Marini could control her TV when in her room. She was able to learn the scanning process very easily and so progressed to games involving scanning as well. In this case, scanning was introduced to Marini quite early, despite her head/neck movements being weak. She had demonstrated clear learning ability and conversations revealed no cognitive or linguistic impairment. Therefore both she and the team felt that moving on to more complex scanning activities was appropriate.

Whilst long term goals were in place aiming at the provision of a high-tech communication device, the speech & language therapists also provided sessions focused on low tech communication, in this case, an E-Tran frame. Marini quickly became a very proficient user of this eye pointing system and used it for daily communication with her husband and trained ward staff.

This method of communication was very effective for Marini but it had the disadvantage of being reliant on a skilled communication partner. Additionally, Marini was also very keen to be in touch with her family and friends, both in Britain and abroad. She had been a keen user of a computer prior to her stroke and expressed a desire to use email and web facilities.

It was felt that email and web access would be the most appropriate place to start in terms of more complex scanning activities. A series of scanning grids were set up, based on the Startalker grid set in the Grid 2 software, to enable Marini to send and receive emails. Marini employed skills learned using her ECS and switch games and mastered cell selection in no time. Practice sessions continued with ongoing grid development to include both Spanish and English grid sets, as well as predictive cells and various shortcuts to give Marini complete independence.

Communication grids were gradually added in both languages so that Marini





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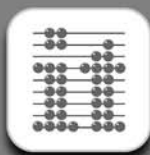


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could communicate independently on a daily basis with people who were not familiar with her E-Tran frame. She soon mastered the use of phrase-based communication to speed interactions around her basic needs and was able to practice this using the loan tablet PC which the Compass team mounted to her wheelchair.

As time moved on, Marini began to get some return of movement in her hands, first in the right and then the left. This movement was weak at first and required practice sessions both with and without technology to make it useable functionally (see *Rehabilitation Technology* box).

Marini was unable to flex and extend her fingers but was able to raise them from the PIP joint. With her hands placed flat on her wheelchair tray, she was able to lift her fingers far enough to activate a touch sensitive switch positioned just above her fingers. Her movements were initially very small and without sufficient power to operate a mechanical switch but this soon changed as Marini practised, first single and then two switch scanning with her fingers.

Marini became a skilled user of the tablet based communication aid, using the Grid 2 software. She was able to independently send and receive emails, browse the Internet and play games, in addition to communicating when she needed to.

### THE LURE OF EYE GAZE

Marini and her husband had always been interested in the possibility of using eye gaze technology for communication and computer access. Whilst the team were keen to ensure that Marini had a switch scanning system with which she was proficient, it was also recognised that Marini had good reliable eye movements and had demonstrated her skills in this area using the E-Tran frame. There were certain considerations which had to be discussed, not least the cost of the eye gaze system and how it would be funded, should it be found suitable for Marini's needs. However, it was decided to set up a trial of some eye gaze equipment and a Tobii P10 was rented for this purpose.

At first, Marini required large target sizes in order to achieve accuracy using the eye gaze system. However, she soon became more accurate with daily practice sessions and was able to start using the grid sets with which she was familiar, once they had been adapted to make them more user-friendly from an eye gaze point of view.

Based on the loan period with the Tobii P10, Marini decided to purchase her own eye gaze system and in the end purchased a Tobii C12, which had just been released. Tobii kindly provided a C12 for an assessment session before purchase, to make sure that the reduction in screen size did not impact on her accuracy. Marini was pleased with the increased speed of access that she achieved with the eye gaze system over switch scanning, proclaiming that she would not return to scanning unless she absolutely had to! The Compass team felt that having the backup of a switch scanning system was important and ensured that grid profiles for switch scanning were included on the Tobii C12.

### POWERED WHEELCHAIR

Marini's head movement had continued to improve over the months that she had been at RHN. The fact that she had no cognitive or visual impairments, indicated that she would be a good candidate for a powered wheelchair. This would give her further independence, especially when she returned



Figure 1 Custom powered wheelchair headrest

home, and optimise her opportunities for communication and interaction.

Initially, a small chin joystick was trialled because it seemed the obvious choice considering Marini's significant head movement. However, it soon became clear that this was not a suitable solution. Although Marini's head rotation was good, she lacked the extension and forward chin thrust to use the joystick in all directions. Single switch and multiple switch access using her chin were both considered and rejected because of the considerable movement available and the restrictions of these driving methods.

The assistive technology team searched for a reasonably priced head switch array which could be attached to standard wheelchair controllers to allow Marini to steer using head rotation. Unfortunately, nothing could be found that employed mechanical switches. Those head controls which did exist were based on proximity switches, costing a considerable amount of money. Therefore, the rehabilitation engineer on the team designed and built a custom solution (Fig. 1) incorporating three mechanical switches built into a standard wheelchair headrest. This was attached to a P&G Omni wheelchair controller which was mounted to the tray of a Spectra Plus wheelchair. Marini was given a fourth switch positioned over her right fingers to give her access to reverse, speed control and an emergency stop.

Marini was soon able to master the wheelchair and received regular practice sessions within therapy and then with her husband on a regular daily basis. Within a few weeks Marini was independently driving around RHN, popping into the computer room for therapy sessions and going out into the grounds.

### SUMMARY

Marini's final assistive technology solution incorporated a Tobii C12 communication aid, accessible both via switches and eye gaze and offering environmental control and SMS messaging, as well as the email and web access described above. She was also provided with a head-switch controlled Spectra

#### Rehabilitation Technology

Alongside building switch skills for access to assistive technology, Marini also utilised the facilities within the Computer Therapy Room to work on more physical goals such as increasing strength and range of movement in her head and neck and building on the small movements that had started to appear in her right fingers. This movement, a slight raising of Marini's middle and index finger from the PIP joint, was very small at first and Marini became tired quite quickly when performing this movement.

For both her neck movement and the emerging finger movement, Marini was set up with the AngleX tool, which is part of the Biometrics<sup>1</sup> exercise system. The AngleX uses unique sensors that respond to active movement against gravity for computerised interactive exercise. With the AngleX sensor attached to either her forehead or the top of her finger, she was able to play games whilst building strength and endurance and increasing range. Computerised printouts of her performance demonstrated progress and improvement, which were highly motivating.

<sup>1</sup> Biometrics Ltd, Units 25-26, Nine Mile Point Ind. Estate, Gwent, NP11 7HZ, 01495 200800, [www.biometricsltd.com](http://www.biometricsltd.com)

Plus powered wheelchair with an Omni controller. On discharge from RHN, Marini had the option of having her Tobii C12 wheelchair mounted or floor mounted for different communication situations. She continued to use the Tobii heavily for emailing and surfing the web, although she often preferred to use her E-Tran frame with familiar communication partners.

This has been a common outcome for clients using high tech equipment at RHN. Our experience is that with familiar communication partners, low tech communication methods are always faster than high tech solutions, even with very proficient switch and eye gaze users employing rate enhancement techniques.

Marini ended up having to fund her own eye gaze system as her PCT refused a funding request made by the Compass team. Marini felt that the benefits of the system, such as the increased speed of access and the reduction in effort, were so significant that it was worth the financial cost. There is a difficult ethical dilemma faced by assistive technology assessment services in offering eye gaze as an option for individuals like Marini. If an assessment

is carried out and an eye gaze system found to be the most suitable access method for an individual but there is no funding available, would it have been better not to have raised hopes and to have recommended a more affordable option? However, if the option of eye gaze were to be dismissed simply on the basis that funding might be difficult, then the assistive technology team would be denying the individual access to what may prove the best solution for them.

The Compass team feel that, as a specialist rehabilitation service, it is both appropriate and necessary to offer eye gaze assessments which may give an individual increased independence and quality of life, despite the cost. Dr Mick Donegan recently discussed this issue at a Communication Matters Eye Gaze Study Day and pointed out that when gaze control can have such a positive impact on posture, pain reduction, speed, quality of life, academic achievement and employability, the cost compared to other access methods might seem cheap at any price.

One of the standout features of this case study is the length of time that the Compass team spent in working

with Marini. It was identified that 186 hours worth of input had been provided across the whole team over a period of 18 months. Although, it is unusual for services to have access to clients for this length of time, it is strongly felt by the Compass team that this intensive input, resulted in a very flexible and robust customised solution that will stand the test of time and provide Marini with all that she needs in terms of electronic assistive technology for some time.

However, the Compass team acknowledge that this length of rehabilitation admission is rare and in the current climate is increasingly unlikely to occur. In fact, shorter admissions are already the order of the day and the Compass team will have to adapt its procedures and think creatively about how it can best meet the needs of individuals with profound disabilities in future, which may involve changes in our service delivery model. \*

Jane Bache, Occupational Therapist

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# AAC and ASD – Making it Visual

## When the developmental approach just doesn't work

**SARAH TUCKER**

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### BACKGROUND

I am a Speech and Language Therapist (SLT) working with children and young people with little or no speech, complex needs and significant communication difficulties. Many have a diagnosis of Autism.

Because of the nature of these children's significant communication difficulties it is imperative that everyone around the person understand what the person's communication needs are and how to facilitate them effectively. Getting everyone to use the appropriate communication strategy can appear to be an almost impossible task, as parents are often extremely tired, and nursery and school staff have many other demands on their time.

Eight years ago, when I joined the schools where I currently work, the Picture Exchange Communication System (PECS, Frost and Bondy, 2002) was used inconsistently across the schools. The children rarely moved on from one PECS stage to another and, in the first two years, none of the children managed to reach the extremely important phase of PECS where they are able to express their feelings. In addition, following their Autism Spectrum Disorders (ASD) training, staff would also implement Treatment and Education of Autistic and related

Communication Handicapped Children (TEACCH, Schopler, Mesibov and Hearsay, 1995) strategies. This too was inconsistent as not all staff were trained effectively in its use. This resulted in outbursts of difficult behaviour and stubbornness. Some staff did not understand the importance of the use of visual strategies.

In addition, social stories were used intermittently. Generally staff and children were confused. Parents were not trained in their child's PECS and TEACCH use and consequently children with pro-active staff tended to 'lose' over the long summer holiday any progress that they had made in school previously.

The children accessed respite places and the staff there found it difficult to understand that communication is not schoolwork. PECS books were unused and VOCAs left in reception. To help people to understand about the very different communication needs of these children, I needed to develop an easily understandable, visual method to explain quickly how best to help each individual person achieve functional communication in whatever form it may take.

Fortunately, both schools had significant changes in their Senior

Management Teams (SMT) and were keen to develop their students' communication skills.

### IS AUTISM FUNDAMENTALLY AN APHASIC CONDITION?

Education staff often have a rather generalised training in ASD that is based on the developmental model of language processing. As a result they may believe that children with ASD who can speak can understand what is said to them and that the children with no speech are cognitively incapable and unable to understand what is said to them.

I have learned through close association with them that people with ASD are able to do a lot more than they may seem capable of at first sight. For example, I know one young man who can choose which video to watch just from the bar code on the video – the pictures have all disappeared.

Following this line of thinking, I began to think of their skills and difficulties against an alternative model of communication – the cognitive neuropsychology model (Ellis and Young). This model is normally used to assess and describe the communication skills of adults who have aphasia: "the partial or total inability to produce and/or understand



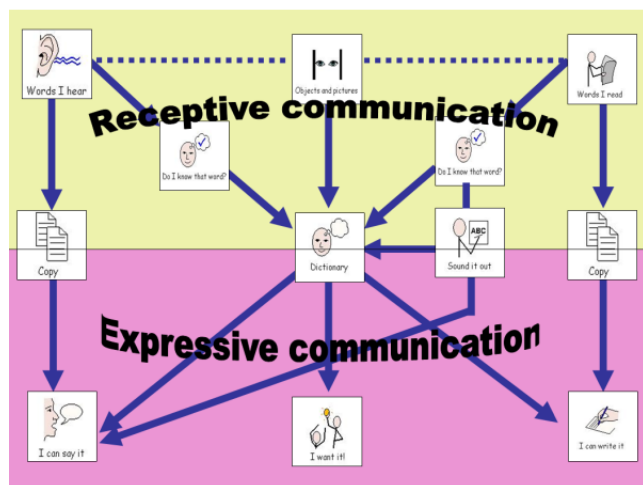


Figure 1 Communication Model

speech as a result of brain damage caused by injury or disease." The model is also very useful to see what strategies may be used to bypass any difficulties.

**The Communication Model** (Figure 1) shows all the pathways that communication can use. The top half shows how information is understood ('receptive communication'). The bottom half shows how we use communication to say what we want ('expressive communication').

Over several years, and with a great deal of help from several supportive staff at the schools where I work, I was able to demonstrate that some of the children that I was seeing had aphasic communication patterns:

- Unable to speak but demonstrated good comprehension.
- Able to speak, but unable to demonstrate understanding of speech.
- Unable to demonstrate understanding of speech or use speech themselves but able to do quite complex tasks with visual support (e.g. know which video they wanted only by the bar code).
- Able to read without being able to demonstrate understanding of what they were reading.

I applied the principles used to assess aphasic adults but the assessment tasks needed to be adjusted to work around the differences between the different groups of people. The available assessment materials were not useful.

Adult assessments are designed for testing people who have previously understood the concept of testing, are generally able to read, write and speak prior to their brain injury. The people that I was assessing have never learned to read, write or, in some cases, speak,

and several had significant behavioural difficulties that made assessment in the ordinary manner impossible. To test the different skills, school staff made sure that they used normal situations within the school and tested only one thing at a time.

#### CASE STUDY: SAM

At the time of my studies Sam was a tall, slender teenager who could not speak but spent a great deal of time moaning with his fingers in his ears. He was quiet within the classroom but did have some episodes of severely scratching adults who sat too close if he was upset.

However, home visits found that Sam is a very different person. He is extremely clean and tidy and enjoys watching videos and DVDs in Norwegian which he accesses himself using the remote control. This did not reflect the Sam that we saw at school and was not expected behaviour for a teenager with a learning disability.

When Sam was small he was very active and took a couple of years to learn how to behave at school. The school was very keen to use Makaton Signing throughout the school but did not use any symbols. The previous SLT and a teacher had heard about PECS and went on a course which proved very good for Sam and he learned how to request motivating items. However, this was not developed and Sam returned to his sitting, moaning and scratching. He has never used any signing and did not have access to PECS until he was once again in a class with staff who supported its use. The SMT changed and I was able to work closely with Sam's teacher.

In addition to PECS, TEACCH strategies were also used across the school and the staff were trained to develop some

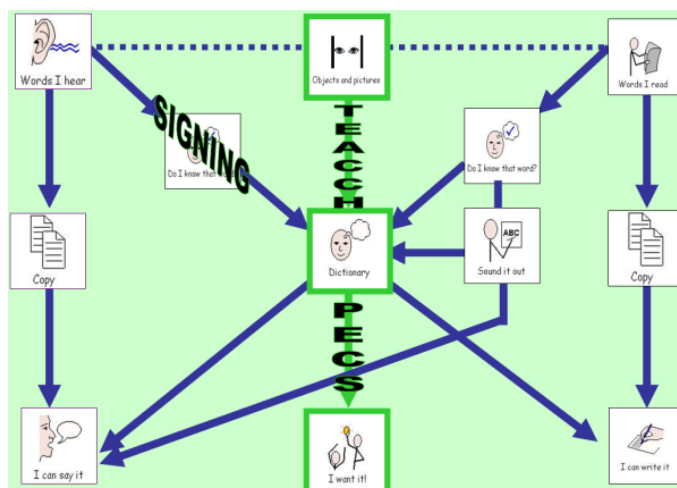


Figure 2 Sam's profile

simple activities that Sam could manage easily. He became calmer in class and appeared to enjoy being occupied.

Previous attempts to formally assess Sam's communication skills failed as he did not look at what I was looking at and would point at everything on the assessment materials as if he knew that I wanted him to point. I altered the Pre-school Language Scales 3 UK by copying the pictures (with permission) and mounting them on black card using Velcro. This allows a person used to exchange the cards, in a way that is familiar for PECS users, to respond. Sam was not able to do this either. His class teacher tested his understanding of spoken language across the day by purposely not giving any gestures or physical support to Sam. We concluded that he does not have any functional comprehension of spoken language – even at single word level.

#### Sam's profile using the model

Sam's communication skills were plotted on the model (Figure 2). The vertical lines directly down the centre of the model show the only lines of communication available for Sam and those who live and work with him – he is not able to understand what is said to him or to speak. He can however, understand symbols and express himself using symbols.

Teaching him to read and write would be the ultimate bypass of his communication difficulties. We do this by consistently using symbols with written words to help him understand what is happening (TEACCH) and also to enable him to communicate with others (using PECS). He is able to read some of these familiar words and match them to their symbols. Three years on Sam is also able to use money (taught using TEACCH training), go shopping (TEACCH and PECS), pay for his purchases (TEACCH)

and cook his lunch (TEACCH) – independently of adult intervention. Although he still enjoys jigsaws and watching DVDs in Norwegian, he now also helps his Dad with his catering business.

In spite of his good progress Sam has had periods where the staff working with him did not understand that the consistent use of TEACCH and PECS has to be in place for him to manage. At these times his behaviour deteriorated. I needed to create a user friendly way to describe for staff what strategies to use and when.

#### HOW TO BRIDGE THE GAP IN UNDERSTANDING AND PRACTICE

My basic idea for training was to help parents and teachers to understand how *they* may affect the individual's ability to learn to communicate, and also how this will affect their behaviour.

Early attempts to use this model of communication showed that it needed to be simplified. Training took place in a range of settings using the model and questionnaires from the trainees were used to form the basis of the feedback.

However, the practice of the trainees did not change.

Eventually, friends of mine pointed out that I was not practising what I was preaching. The model was not visual enough for people to understand the complex theory. I duly simplified further and tried to use it again for training.

The model now includes a gradual and more visual format and is now useable to help train people with a wide range of language skills, cultural differences and educational levels.

At both schools where I work the practices of all staff changed for the better. The Senior Management Teams instigated a rolling programme of training for staff required to use PECS and TEACCH consistently and both have since achieved outstanding Ofsted inspection results with one of them being congratulated on "the best PECS use in Surrey" by the examiner. Both schools now invite parents into school and have instigated support programmes to help parents and other carers use TEACCH and PECS consistently at home. I hope that this change in practice may be at

least in part due to the development of the model.

I would like to see whether the model may be used effectively by other therapists and teachers to help parents and carers understand the communication needs of the people that they look after. If you would be interested in helping with this please would you contact me and I would be happy to send you the full model training presentation. I will forward a short questionnaire and a review of the trainees' practice in a few months. I would also value feedback on how to improve it and make it more user friendly. I'm now thinking that I should make an 'app' for it! \*

Sarah Tucker  
Speech and Language Therapist

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# Development of an Accessible Receptive Language Assessment

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**The aim of this project is to develop a** receptive language assessment which will be accessible to children using alternative access methods. It was inspired by working with a child with severe physical disability whom everyone perceived to have age appropriate cognitive and receptive language levels. Whilst assessing this child, it became clear that there were no standardised assessments she could access due to her physical disability. This meant that any assessment needed to be carried out through informal observation, which always has a subjective element, or through using published assessments with extensive modifications made to enable her to eye point to pictures to give her response.

Speech and language therapists use a variety of published assessments in order to determine a child's receptive language level. These assessments traditionally use drawings which the child points to in order to make a selection. Therapists usually adapt these for children with physical disability by copying and separating out the pictures, using alternative pictures or objects, or trying to match what they see the child do in their natural environment to levels on the assessment. The adaptations made generally invalidate the standardisation of the assessment.

Our research team, comprising a speech and language therapist and two clinical scientists all specialising in alternative and augmentative communication (AAC), felt that receptive language testing for children with a physical disability was an area of unmet need. This project set out to develop a receptive language assessment that would be accessible to children with physical disability via switches, headmouse or eye gaze. This

would mean the child's choice would not be open to interpretation by the assessor and therefore would provide an objective record of their responses. This project aimed to design and evaluate the feasibility of such an assessment.

It is not intended that this assessment would undermine the current assessment methods but that it would provide an additional tool for speech and language therapists or teachers to use when further measures are needed.

This research project was organised into the following stages:

1. Audit of current receptive language assessments
2. Literature search of related projects
3. Development of assessment tool
4. Pilot study to carry out trials of assessment and gain feedback from participants
5. Feedback from a professional group
6. Adaptations following feedback.

This is an ongoing project and we are currently part way through the pilot study.

## RESULTS OF THE AUDIT

Full details of the results of the audit will be published in further work. This was a national audit carried out online and targeted at speech and language therapists. Key results were as follows:

- A range of 13 language assessments are currently used by the respondents, none of which are accessible to children with physical disability.
- Respondents often assess children who are unable to access formal comprehension assessments or for whom they feel the results are not an accurate representation due to the child's physical difficulties, at-

tention difficulties, visual difficulties or demand avoidance.

- Speech and language therapists would be keen to use a computer based assessment and would value an automated recording system.
- Photographs were identified as the preferred stimuli.
- Respondents felt the assessment should last approximately 30 minutes.
- Concerns were highlighted about a computer-based assessment in terms of laptop availability, technical support, data security and reliance on a computerised score rather than a holistic assessment of the child.
- Respondents highly scored the need for the following areas of receptive language to be included:
  - Single word vocabulary
  - Two & three word level sentences
  - Prepositions
  - Pronouns
  - Negatives
  - Plurals
  - Past and future tenses
  - Cognitive concepts

We feel that the computer related issues can be overcome by ensuring the assessment can be used in line with the assessor's policies regarding safe use of information technology and data protection. Unfortunately, the concern regarding misinterpretation of pure data applies to all methods of formal assessment. We would therefore encourage professionals to use the assessment as only one part of their overall process and to provide a holistic and descriptive picture of the child when interpreting results.

Several points identified in the audit shaped the final assessment design:

- Photographs were used as opposed to symbols or line drawings.
- A data recording system was developed.
- As the time needed to complete the assessment will vary greatly according to individual access methods, we felt the 30 minute preference could be met through designing the test in four short sub-tests each taking approximately ten minutes. The results for each sub-test are saved so the assessment does not need to be completed in one session.
- The areas of language included were those identified in the audit.

Further comments which were expressed, but which we were unable to incorporate at this time, were that: people wanted an assessment with more adult pictures; and one designed for adults with learning disabilities. We would consider these future developments.

#### DESCRIPTION OF THE ASSESSMENT

The Grid 2 software was used to create the assessment. This software was chosen as it met the requirements needed for the prototype assessment, the researchers were already familiar with it, and the supplier had offered support as required. The assessment can be run on any computer with the Grid 2 installed and the results are then displayed in an attached spreadsheet.

We had considered making an existing assessment accessible however we felt that we could utilise modern technology to improve on existing assessments, for example, by using photographs instead of line drawings, by personalising the assessment and by enabling us to make it more motivating and user friendly. Consequently the new assessment uses photographic stimuli, contains motivating graphics, and relies on minimal computer skills from the operator.

The assessment includes a pre-assessment access method check. This requires the participant to select a coloured cell (see Figure 1) which then plays music. The coloured cell then moves to a different position on the screen to enable the assessor to check that the participant is able to access all areas. We felt the participant needed to achieve 6/6 correct to ensure errors made later were not due to access method.

The assessment has four introductory grids which can be personalised with photographs of familiar items to the child. These may be people, pets, fa-

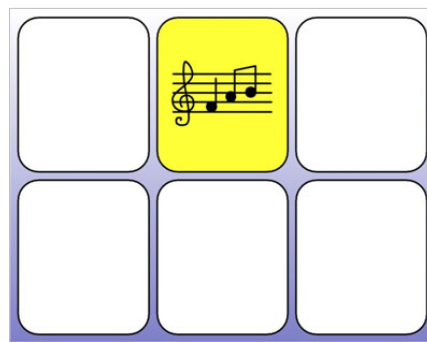


Figure 1 Pre-test access assessment

vourite toys, etc. The purpose of this is to assess those children who may be at a cognitive level of recognising and understanding highly familiar vocabulary or objects but may not yet be ready to use generalised vocabulary to show this understanding.

The assessment is divided into four sub-tests which allows for natural breaks. The assessment ranges from very early vocabulary to complex three word level sentences and syntax such as tenses used in language. The sub-tests and areas covered are as follows:

#### 1. Cognitive Concepts

- Colours
- Shapes (Figure 2)

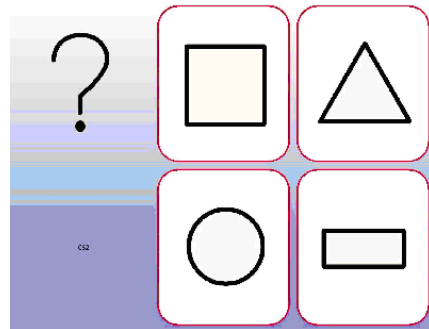


Figure 2 Screen demonstrating question: "Show me the triangle"

#### 2. Vocabulary

- Nouns
- Adjectives
- Verbs (Figure 3)



Figure 3 Screen demonstrating question: "Who is sleeping?"

#### 3. Linguistic Concepts

- Prepositions (Figure 4)
- Pronouns
- Plural
- Negatives

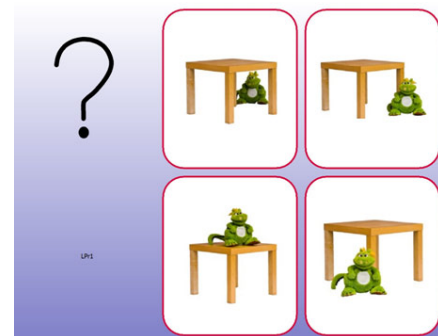


Figure 4 Screen demonstrating question: "Which monster is on the table?"

#### 4. Sentence Comprehension

- Tenses (Figure 5)
- Sentence length



Figure 5 Screen demonstrating question: "Who has built a tower?"

#### DATA LOGGING FOR RECEPTIVE LANGUAGE ASSESSMENT

It was identified that the receptive language assessment must have a data logging facility in order to reliably record the selections made by the child. The data logger within the Grid 2 was utilised, however further processing of this was required to reveal the data required for our assessment tool.

Work was carried out to enable an Excel spreadsheet to be generated, illustrating the results of the assessment. Within our pilot study we are collecting information from professionals about the format of the report and how they would like this to appear. Figure 7 shows a sample of the current reporting structure.

#### TRIALS

Following development of the assessment, the pilot study was set up in order to get feedback from children and their teachers about the assessment. Schools



were contacted via their headteachers who were asked if they were interested in being involved and whether they had appropriate children for the project. Children were identified who met the inclusion criteria, and consent from parents obtained. The following case example illustrates the process undertaken.

This participant was a child aged 7 years 4 months who has severe athetoid cerebral palsy. She has no speech and after several years of trialling switches and headmouse, she is now a competent eye gaze user. She has had her own eye gaze computer system for two years which she uses regularly within school and at home. Her effectiveness with the eye gaze system is very dependent on her positioning but on a good day she can manage cells measuring 2cm<sup>2</sup>. The child selects via Dwell set at approximately 1.5 seconds, however this is varied according to her level of access on a given day.

The assessment was completed in one session, which was the child's choice. It took approximately 45 minutes and included drink and chat breaks after each sub-test, approximately every 10 minutes.

A pre-assessment questionnaire was carried out with the child's teacher. The teacher felt that the child understood colours, shapes, vocabulary (transport, animals, food, clothes), negatives, 1 word level, 2 word level and 3 word level sentences, pronouns, prepositions, verbs, tenses, plurals and adjectives. She made additional comments that:

- The child had demonstrated understanding of pronouns through work done in class and had shown, through humour, when mistakes were made.
- Prepositions had been learnt in earlier classes within school so the teacher presumed that she could understand them.
- She thought the child understood tenses but that this is not always clear in her work. The teacher stated she felt that the child knew but had no evidence to support this.

The assessment was carried out in the staff room at school. The pre-assessment access test was carried out

	A	B	C	D	E	F	G	H
1	grid_name	item_required	item_chosen	right_or_wrong		% Right		
2	VN5	Shoe	Shoe	Right		100	from 10 selections	
3	VN6	Ball	Ball	Right				
4	VN7	Book	Book	Right				
5	VN8	Cup	Cup	Right				
6	VN9	Sock	Sock	Right				
7	VN10	Bed	Bed	Right				
8	VN11	Banana	Banana	Right				
9	VN12	Car	Car	Right				
10	VN13	Trousers	Trousers	Right				
11	VN14	Coat	Coat	Right				
12								

Figure 7 Sample section of current report produced from assessment

initially and the child scored 6/6 correct answers. Photographs of the child's classmates had been used in the personalised cells as the child's teacher had felt she would easily recognise these. The child also answered these correctly.

Notes were taken throughout the assessment alongside video recordings. One difficulty noted was that the child started to work through the assessment at a very fast pace, which appeared to be very effortful for her and also a cause of errors.

The researcher then paced the assessment by pausing after each question to allow thinking/visual scanning time. This made the assessment feel more relaxed and fewer errors were made. The child was encouraged to indicate if she had made an unintended selection.

Occasionally the child looked at the researcher for clarification or reassurance. The question was repeated and the child was reassured that if she didn't know she just needed to choose the one she thought it could be.

The post assessment interview was then carried out with the teacher. She responded that she felt the child did the assessment to the best of her ability and that it was an accurate representation of her skills and access method.

She reported the assessment day was a good day in terms of health, tiredness, other factors and she described the child during the assessment as happy, anxious, excited, highly motivated, competitive and determined. She felt the activity was "totally beneficial" and had made the child happy as the "child likes to get things right".

## CONCLUSION

To date, we have completed an audit to establish current practice in receptive language assessment and have developed a new assessment comprising of four sub-tests and utilising photographs.

We are currently trialling this in schools and attending special interest groups for feedback. We have completed two trials and attended one professional's group and have had positive feedback regarding both the concept and the actual assessment and also had some useful recommendations. Teachers expressed particular interest in how a similar tool could be used with mainstream children to quickly and reliably assess a wide range of skills.

The team now intend to investigate ways of standardising the assessment and to take on board the feedback from the pilot study and the professional groups to further develop the tool. \*

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Zoë Clarke, Clinical Scientist

Marcus Friday, Clinical Scientist

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