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Hanging Out with the Cool Guys!

Making music as motivation for teenagers who use AAC

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The strongest desire to communicate is based on intrinsic motivation.

– Deci & Ryan, 1985

Individuals engage in activities in which they perceive themselves as competent and that promote their self-esteem & self-satisfaction.

– Bandura, 1986

THE BACKGROUND

'Follow the child's lead' is a strategy that is familiar to Speech & Language Therapists and educators alike. When we followed our students' lead it began an exciting project for them and has added a new dimension that has benefited the whole school community.

Ash Field is a maintained day and weekly boarding school for 120 pupils aged 4-19 who have a wide range of abilities with a main presenting disability of a physical nature combined with one or more of a sensory, communication, learning, medical, emotional or behavioural difficulty. A significant

number of pupils have progressive conditions. One third of the students do not use spoken language as their primary means of communication. For many of the students English is not their home language.

At the school, staff from the multi-agency team work in partnership with students and their families to develop the abilities, interests and aptitudes of the students. The aim is to integrate education, therapy and care to meet the students' complex needs.

THE STUDENTS

The five teenage AAC users who led us to the music project were from different classes and worked together with the Speech & Language Therapist (NHS) and the school's Curriculum Assistant Manager whose role is to support the students' access to learning.

The students had been working with their low tech solutions and AAC devices for many years as they progressed through the school. They are now in the secondary department. However as their needs changed we were constantly looking for opportunities for the students to use and practise their skills.

Student A

- No speech.
- Eye points to symbols and objects in the environment.

- Uses facial expression.
- Consistent yes/no.
- Needed a means to participate more effectively and independently in class. Had been using 2 switch scanning but this was very slow and produced many errors which was frustrating for him.
- Project gave opportunity to develop his use of eye gaze with a loaned device. Higher staff ratio enabled this.

Student B

- No speech.
- Eye points to symbols and objects in the environment.
- Uses facial expression.
- Consistent yes (body movement).
- Uses a Dynavox communication aid accessed previously with his left knee. Increased motor difficulties as he has got older. Was changing

his access to a switch which he activates with his left foot.

- During the time of the project he became quicker and more accurate at finding the words he wants. Speed of access also improved.

Student C

- Bilingual.
- Uses speech to produce occasional short phrases and to ask questions.
- Direct access to Dynavox (Gateway 30).
- Combines speech with his Dynavox to help convey his ideas more effectively.

Student D

- Uses some single words (intelligibility poor).
- Direct access to Dynavox (Gateway 40).
- For the performance of the song, chose to use his voice.

Student E

- Uses some single words and short phrases (intelligibility poor) which she is increasingly supporting by using her Dynavox to make her meanings clearer.
- Uses a single head switch and automatic scanning
- Able to use the vocabulary appropriately for formal and informal communication.
- Has a number of one-liners which she delivers with great humour.

At the time of the project all the students were using Dynavox devices. They presented with a range of physical needs and three of the students had severe physical difficulties accessing their devices. These were becoming more marked in their in teenage years, as they grew.

We met each Friday to give the students additional opportunities and support in developing their communication and this included using their communication aids. Generally the students had been enthusiastic members of the group and participated freely. However,

as one term went on we began to notice that our sessions always seemed to be cut short, as the students would look at the clock and indicate that they wanted to be elsewhere.

Then we worked out why: *it was 'Dan and Kev' time!*

Dan Britton and Kev Bayliss are two musicians who regularly visit the school and work with class groups for singing and with students who play instruments. Their lessons are the highlight of many of the students' week and they are undoubtedly the 'coolest' visitors to the school! We decided to join forces and work together.

THE PROJECT

We wanted the AAC users to participate fully in the music making from the start. Working with Dan and Kev, our students decided on a theme for their composition. They wanted a party song to share with their friends. They all collaborated fully with writing the lyrics, suggesting things that they felt should be included in their song.

To achieve this the students had to draw on and integrate their full communicative abilities, moving between no tech, low tech and high tech methods. The structure of the song also allowed them to perform a song of their own choosing, using their communication aids. This ranged from 'Rock around the clock' to 'Promise' by Girls Aloud. There

were additional opportunities for more spontaneous participation in the chorus.

As Dan and Kev were initially unfamiliar with communicating with AAC users, the students had to learn and practise real skills. For example, gaining the attention of the listener and timing their interactions, knowing when to repeat or rephrase things and finding other ways to repair communication breakdown. The time taken at the beginning and end of the sessions, when instruments were made ready, devices plugged into amplifiers, etc. provided very real social communication opportunities. Students chatted to Dan and Kev swapping news, jokes and football scores.

Working on the music project over a full term gave the students time to achieve a piece of work that they could be really proud of. They performed their song live to the whole school assembly. It was also recorded so that the students had their own CD to take home and share with their families and friends.

THE OUTCOMES

Through their music and their approach to the project each student was able to express their views and personalities very clearly. One way in which this was demonstrated was by some cheeky inclusions to the lyrics during the school assembly – only spotted by really attentive listeners! It was daunting to be in front of the whole school but the students rose to the occasion.

Their self esteem grew. They had produced a CD, of which they were rightly proud. They had also gained many positive comments, not just from staff but also from their peers throughout the school. They were able to express their creativity in new ways which they found both highly motivating and rewarding. On a more practical note the students were able to develop and demonstrate fantastic listening and timing skills. Some of the students were able to practice and begin to master new access methods without it seeming a 'chore'.

Since completion of the project all students are now reported to have greatly increased their participation in their whole class music sessions. This has been both using their communication devices and also their voices. Two of the group have taken on roles with speaking parts (using Dynavox) in an end of term school production. The student who was using a borrowed eye gaze device now has his own device to use both at school and at home. For one of the students her improved physical skill made it possible for her to control an electric wheelchair successfully for the first time, which has greatly increased her independence.

The project demonstrates many aspects which we will endeavour to incorporate again when working to support the communication needs of the pupils:

- Benefits of multi-agency working

- Importance of maintaining the profile of AAC within the school

- Need to continually seek new ways to promote the students' voice

- Value of building of students' self esteem through age appropriate activities

- Importance of addressing access issues with and for the users

- Ensuring that activities requiring a great amount of hard work and effort on the part of the students, provide them with equally great rewards

- Knowledge that new challenges can be fun when we collaborate with others.

Following the success of the initial project four more small groups of students have worked with Dan and Kev, school staff and the Speech & Language Therapist. The groups have focused on different aspects to address the communication needs of the children involved. These include timing of switch use, vocalizing with communicative intent, interaction with peers, increasing listening and attention skills and choice making.

We look forward to joining our students in many more motivating music sessions. ✳

<div align="right">

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Curriculum Assistant Manager

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The two opening quotations were adapted from:

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It's Never too Late to Learn: Picture-think

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HOW DID THIS STUDY COME ABOUT?

About three years ago Janice asked Alan to be involved in a research project about the use of high tech communication aids. During that process we got talking about learning aided language systems and Alan, an aided communicator, described himself as someone who thinks in pictures not words. He wanted to understand his language and literacy skills more and also was interested to know if he could acquire greater literacy skills than he felt he had. Janice, a speech and language therapist, who had always had a keen interest in the underpinning language skills of aided communicators, was enthusiastic about exploring the language skills of an adult who had had a life long experience of using a range of aided communication methods.

We agreed that there was a limited amount of information in the literature about adult's language and literacy skills and that we could make a useful contribution to that by formalising this exploration into a single case study design. So, here is how we set it up.

We produced a single case research protocol and submitted it through the Faculty of Health, Psychology and Social Care Ethics Committee at Manchester Metropolitan University.

This was approved and part of this process ensured that both Alan and Janice had equal but different roles to play in the research. An independent advocate was named in the protocol as a layer of protection for Alan, in the event of Janice getting carried away with aspects of the research exploration that Alan was uncomfortable with. We agreed to complete 12 sessions over a one year period. This amounted to a total of approximately 24 hours activity. In addition, Alan agreed to do some further work between the sessions and Janice would begin the evaluations and share those with Alan for discussion at the beginning of each session.

All sessions were video recorded. For single case study design to be most useful to readers who may want to complete a similar study and compare findings, it is helpful for us to provide some further background and biographical information. This will be organised into physical, medical, communication, educational, employment and social information.

Alan is 48 years of age and has a medical diagnosis of cerebral palsy (CP) which affects all four limbs, restricting his movement and mobility. Movement patterns show signs of spasticity and dyskinesia. He uses a powered wheelchair which he operates using his right hand, via a joystick situated on his arm rest. Many individuals with CP are prescribed medications to help things like decreasing muscle tone, digestion etc. Alan is not on any medication.

Alan uses a range of communication modes: unaided systems include: vocalisation, facial expression and body language, and an idiosyncratic gesture system. Aided communication systems currently include a Tellus with Grid software. The majority of symbols used within the Grid system are Picture Communication Symbols (PCS).

Until Alan was 30 years of age he used unaided communication systems only. He received his first high tech system 18 years ago through a local fund raising campaign. Alan has previously used four other high tech communication systems including one Liberator device and three Dynavox devices. Over this period of time he has attempted to use different symbol systems including Minspeak symbol vocabularies and Dynasyms. He described the Minspeak system as very difficult to conceptualise and use. He found the Dynavox 3100 with Dynasyms the most easy, but found later Dynavox systems more challenging to use. He feels most positive about

his current high tech system and software package, which allows him to construct a personalised communication system more easily than any previous system he has used. The device is mounted on his wheel chair but is also used from a table top, when needed. Alan uses his right index finger or a stylus to directly access the screen of his device.

Alan describes himself as having had no formal education and certainly no formal literacy education, in his youth. Since getting his first communication aid, he has attended numerous courses, but none in literacy. He attended a special school and later a day centre. He has only ever received very limited speech and language therapy and with his high tech devices received only the standard induction and familiarisation with the new system that suppliers are able to provide. As he was attending a day centre at that time, he did have more formal support with the Liberator and Minspeak system. He has, himself, initiated all changes of high tech device and explored the potential options with suppliers prior to purchase.

For the last 13 years Alan has lived in his own home. He is supported by Personal Assistants (PA) as and when he needs support. He became self employed in 2004, and in doing so gave up access to all means tested disability allowances. He has one additional Support Worker, employed through the government's 'Access to Work' scheme, to support the delivery of his business activities. His business demands were key in terms of his interest in looking at his own language and literacy skills.

Alan has championed a number of AAC activities. He is a regular supporter of 1Voice and Communication Matters. He has appeared in TV dramas and recently had a short film made of his life which has already won several international film festival awards.

THE STUDY: AN EXPLORATORY INVESTIGATION OF LANGUAGE AND LITERACY SKILLS IN AN ADULT AIDED COMMUNICATOR

The first session involved agreeing the ground rules of what would be explored and why. The what, broadly speaking, was divided into: language comprehension skills, expressive language skills and literacy skills. An initial challenge for both Alan and Janice was to ensure that this was not a negative experience for Alan, especially if Alan was 'unable' to do things asked of him, which initially he was anxious about perhaps resulting in him being perceived as stupid. This was an important process to navigate

and it did take a couple of sessions before Alan said he felt relaxed enough to give things a go and not be anxious about his abilities or difficulties. There was never any question that inability = stupidity.

A formal assessment, the Test of Reception of Grammar (TROG), was completed in the first session. This test requires the respondent to choose from an array of four pictures the picture that best describes the stimulus sentence. It was not scored for age equivalence as it was clear that Alan's level of anxiety about being tested was impacting on the result. Informal observations demonstrated some uncertainty with comprehending meaning where word order was paramount, e.g. the man was pushed by the cow.

Over the remaining sessions we explored a number of areas, some of which are identified in Table 1.

SO WHAT DID WE DO?

The first two elements we explored were focused on language comprehension skills: symbol recognition/sentence comprehension and picture sequencing. It was important to establish whether Alan had a predictable match between symbol meaning and language meaning. Given his own description of 'thinking in pictures, not words', this seemed fundamental to ensure we were both making the same 'meaning assumptions' in relation to symbol (or picture) sequences.

1. Symbol recognition/sentence comprehension

In this task Alan was shown a composite picture, e.g. a helicopter flying over a house, and was then presented with four symbolised sentences. There were 15 pictures in total.

Alan's task was to choose the symbol sentence that in his mind best described the picture, for example, over/helicopter/house/fly; helicop-

ter/fly/over/house; house/helicopter/over/fly; fly/helicopter/over/house). There were two practice items to teach the process of the task. During the practices the symbols were named by Janice, so that Alan had a visual and auditory cue. In the task itself Alan was not provided with the auditory cue.

Alan found this a particularly challenging task – not because he didn't understand the pictures or the symbols but that 'all of the sentences were fine' because they had the right 'words' in them. In other words, there was not a right or a wrong sentence choice. Janice, rather meanly, pushed Alan to choose one that he thought was best. Over the 15 task items this resulted in him choosing between one of two sentence types: e.g. helicopter/fly/over/house or fly/helicopter/over/house. However, there were 6/15 items where he was unable to decide from the visual presentation alone. In these instances Janice then said each symbol sentence in turn and immediately Alan chose the more typical sentence word order.

So, what might this suggest?

It suggests in terms of language priming that Alan is more semantically (meaning driven) than grammatically driven. For some individuals, the key meaning elements are more important and more useful than the grammatically correct sentences.

2. Picture sequencing

In this task Alan was asked to order a set of photographic picture sequences (LDA resources). These included themes like scoring a penalty goal, and a couple going for a walk and one person falling and twisting an ankle. There were a maximum of eight items in the sequences. The pictures were not described prior to the sequence sorting activity.

This article	Other areas explored
Symbol recognition/sentence comprehension	Word recognition
Picture sequencing	Word building
Phrase completion	Working memory strategies
Word access from description	Spelling
Picture - sound and letter associations	Word order strategies
Picture - part of speech match	Word retrieval strategies

Table 1 Areas explored during data collection (12 months)

Alan enjoyed the challenge but found some sequences more challenging than others. For example, the penalty goal - he found it easier to start with the last photograph and work backwards. This still resulted in a couple of 'questionable' sequence choices. This was easily remedied when Alan heard the descriptions of each picture (and therefore the story elements). Whilst, the couple out for a walk was a different challenge…and Alan found it very difficult to see why some elements (pictures) were needed and we eventually agreed to differ on the need for some of them. Alan indicated that some aspects of this particular sequence did not make much sense to him at all.

So, what might this suggest?

It suggests a number of things. Firstly, that world knowledge and experience is critical to making sense of the mundane and should not be judged in terms of deficiency of language, rather as limits to real lived experience – as affects us all. Secondly, that individuals who use aided communication may be supported or hindered by different modes of communication. It seems clear that Alan was much more efficient as a communicator when supported by auditory and gestural modes rather than just visual communication systems.

So, how do we rationalise that in terms of language or communication development or the focus of intervention support? Do we embrace a total communication approach to message generation or do we tend to focus on the aided system only?

The next two elements of exploration considered expressive language skills. Given that Alan felt he thought in pictures not words, it was important to explore the ease with which he could convert thoughts into words as this skill appears to be required if you are to be able to efficiently use a high tech communication system. One confusing issue with voice output technology is recognising whether users are selecting symbols and then listening to the word produced as a message construction strategy, or, using word production as a real time communication process. These tasks offer some commentary on such issues.

3. Phrase completion

In this task Alan was asked to use his high tech aid as his main method of response – a little unfair, as he is a holistic communicator but it was critical to explore his ease of thought to word generation via his VOCA. The tasks included very familiar phrases such as: 'salt and …', 'cup of …'; to less obvious phrases such as 'quiet as a …'.

Alan found some of these easier than others. If he had the word available within the word prediction system he was using, e.g. 'raining cats and …', he found 'dog' very quickly and was happy with that until Janice said it aloud "raining cats and dog", then he located the plural marker and edited correctly. Interestingly, he found that some of the stimulus items flagged up a lack of vocabulary on his aided system, but he was undaunted and immediately used alternative cues, e.g. for 'quiet as a…', he did not have mouse on his aided system (even although he thought he must have and spent some time searching for it – suggesting the 'thought/picture' of the word mouse was a familiar concept to him). Eventually, he concluded he did not have it and immediately became a creative communicator pointing to his computer 'mouse', so we had an agreed understanding of the phrase completion activity.

So what might this suggest?

This suggests that Alan not only has the picture but also the word in his head in terms of what he needs to or wants to produce. Access to the word associated with the concept or idea seems more challenging for Alan. There is also a suggestion from the data that the specifics of morphology may be more difficult to anticipate and the modes (visual, auditory or written) used may add to the capacity to generate word forms. This needs more detailed exploration than is possible here (Bedrosian 1997; Fallon et al, 2003).

4. Word access from descriptions

This was a truly semantic task, focusing on conceptual descriptions to support Alan generate the relevant word, e.g. round, rubber toy, bounces = ball. Depending on the type of vocabulary item thought of, Alan found this an intriguing activity. Let's explain and see what you think.

With the example given above, Alan did not initially go for the word ball. He clearly indicated he had an idea in his head but it was not clear (to Janice) what that was. He searched his word prediction system and did not immediately find the word 'ball'. So, Janice moved from semantic cues (e.g. round, rubber, etc) to phonological cues, e.g. begins with 'b'. Alan was able to phonologically cue the high tech system to the 'b' page of his predictive system (showing some literacy knowledge). At this point ball did not appear on the page; he was stuck! Janice provided 'a' or 'aw' (how it actually sounds). He input the letter 'a' and from that his predictive system provided a range of options, including 'ball' – which Alan immediately chose.

We discussed what had helped him locate the word and he indicated it was the picture more than the letters in the 'ball' cell that helped him decide. There are many other examples we could give here but this gives us enough for now.

So what might this suggest?

This suggests that some early concept development may be in place and well established but, that in combination with early literacy skill through initial letter recognition, there is still limited whole word construction knowledge (an early literacy skill). Typically, pre-literate individuals pay more attention to the ends of words (the morphology) than the beginnings of words, whilst literate individuals are primed to pay attention to the beginnings of words. Alan shows a differential profile which suggest uncertainty for the 'educator' and is typical of the adult learner, i.e. pockets of skill and depths of uncertainty or inexperience.

Literacy or pre-literacy skills: Even without formal literacy teaching adults, who have had a lifelong experience of making good their skills and abilities, pick up many things. These next two activities were aimed at showing Alan what he had picked up without a formal education, and how they might be the building blocks for continuing personal literacy development.

5. Picture - sound and letter associations

In this task, Alan was shown three or four pictures in a row. From this he was asked to find the picture that began with the sound or letter, e.g. 'p' or 'pee' from shoe, pig, hat, duck. Interestingly, he found the letter name easier than the sound of the letter and was consistently good at these noun recognition activities, even although he believed he did not have the literacy skills to go with such capabilities. He also found the

sounds at the ends of words marginally easier to identify than those at the beginnings of words.

So what might this suggest?

This might suggest that he is more semantically primed for meaning rather than phonologically primed, as he continues to show end of word priming (morphology). Confusingly, he is more primed for the names of letters rather than their phonological representation. This suggests an uneven profile of learning – hardly surprising given Alan's lack of formal learning opportunities...and perhaps testament to his ability to pick up things rather than be formally taught them.

6. Picture - part of speech match

In this task Alan was asked to sort pictures into categories of nouns, verbs and adjectives (LDA card materials). We did this task to explore the building blocks of sentences and it became clear that this had never before been discussed or considered within Alan's experience of a communication system. It proved to be both interesting and illuminating. This led to Alan placing cards in one of three piles of word category. We then had opportunity to discuss and debate the choices made. Alan had never done this before. It resulted in a discussion about good and bad icons and how they represent language and language structure.

So what might this suggest?

For the most part, Alan placed pictures in the categories expected, however, there were a few occasions where he was unhappy to place items in a particular category, e.g. an apple cut in half...should this be apple, cut or half? We discussed this at length...and agreed it best depicted half or apple but that context was paramount. This not only challenged assumptions about the depiction of parts of speech but also how they can usefully be represented on an AAC symbol system.

SO, WE ARE LEFT WITH SOME QUESTIONS AND CONSIDERATIONS

What do we actually know about language development in those who have life long and development language needs? How do we support them beyond those initial school years? And are we truly ever too old to learn new (and motivating) tricks or language access skills? As yet we do not have any answers, just some reflections and thoughts.

Alan's comments on the process

I really, really wanted to do this piece of work. I thought that it could help me a lot, but, also, that lots of other people might have the same difficulties as me, and this might help them also.

I tried very hard to follow Janice's directions, about what exercises to practise between our meetings. I soon found that I simply could not make myself do any exercises that I was not really interested in, however hard I tried. I changed some of her instructions! e.g. "Learn a whole sheet of words, spellings (about 40 words)". After about 10 words, I had to stop. I found learning 10 words easy. I was so pleased with how easy 10 words were, that I wanted to remember them as a list. I tested myself. I found this challenge motivating. Next day, I recalled the first list and then learned another 8 words. I can still remember those lists.

I find it hard to remember words that are not part of my experience, as in the exercise about pictures of a couple walking in a field.

I want readers to understand, that I can understand everything that is said, or read to me. Also, I can read, a little, slowly and with some help. I recognize the shapes of words, not the individual letters. Text readers on my computer are really valuable, as is word prediction.

I was a bit surprised to find that I couldn't easily find the words for very familiar items. Point to a length of computer cable, and I could not name it. I've never needed to! I know what it is, and what it does. I think this must be like when speaking people cannot find people's names, e.g. who is that actor in a film?, even though they know the face and the person very well.

Doing this work has made me more interested in learning more. I'd need less support from PAs if I was totally independent in my writings. I still think I'm quite a good communicator. I think everyone is different in how they learn.

Janice was a good 'investigator', and not really mean at all!

Janice's comments on the process

As a therapist, I have found Stackhouse & Wells' single word speech processing model helpful (Stackhouse & Wells, 1997). It is not usually applied to the field of AAC, primarily because it is derived from a specific language impairment concept...and because it is typically applied to natural speakers; however, it has its uses when applied to people who may have had an atypi-

cal language development opportunity and experience. It is also a paediatric model of language conceptualisation, which I am choosing to use because Alan has had a lifelong experience of atypical communication experiences.

The single word speech processing model helps us look at language in terms of input processing–stored knowledge–output processing, or what sense we make of incoming information (how we process information) and how that relates to our stored knowledge of the world (what we think) and how we act upon it, or, how we articulate our responses to it (what we say).

From the data presented here it seems possible that we could describe Alan's skills as being strong in the areas of Motor Program (stored information on the output side of the model) because he readily recognises the names of letters. His phonological representations (stored information on the input side of the model) seem less well established and certainly more difficult for Alan to access in terms of word generation. This is unsurprising given his limited exposure to literacy learning. However, this range of stored knowledge does help him to organise and categorise words (demonstrating a strength in the area of stored semantic knowledge on the model), which in turn helps him to organise the input of language into meaningful strings of sounds and words, to aid his comprehension of language.

His auditory skills seem in advance of his visual skills. This may be a consequence of the fact that he relied on the auditory route for the first 30 years of his life and has only, relatively recently, used the visual (symbol) route as well. This may be something to challenge all of us in terms of language processing skills, if we rely on a visual language construction system rather than a verbal, or more accurately spoken, system. It also suggests that training or on-going input for adult learners may be beneficial to support the use of all modes of communication.

This model does not help us evaluate the language comprehension skills demonstrated by Alan. However, what does seem possible from the data is that grammatical issues are less relevant to him than semantic issues, in terms of conveying the relevant message to conversational partners. This would fit with the findings of Sutton et al (2004).

What we have not readily addressed in this paper is how it supports Alan's production of language (i.e. the output aspects of the model); this requires more detailed analysis and considera-

tion. However, what does seem clear, from this initial evaluation of the data, is that his output skills seem more intact (for a non-natural speaker), than the single word speech processing model may originally suggest. These findings are the next stage of our data analysis and dissemination.

WHAT HAVE WE FOUND SO FAR?

- Many components of literacy have been learned along the way but they are not always easy to define.

- Word retrieval or access skills remain challenging.

- Initial sound/letter retrieval from a semantic cue is good but doesn't offer an immediate word shape.

- And so, semantic cues don't always help word retrieval (whilst they consistently support concept retrieval).

- Letter name cueing rather than phonological cueing, as a useful strategy of word production, seems in advance of the typical sequence of literacy/word knowledge development.

- Comprehension of a non-spoken symbol sequence is really difficult; whilst the auditory route often offers greater success. This challenges us to explore teaching and learning techniques.

WHAT WAS PRACTISED BY ALAN ALONG THE WAY?

Word spellings (good old fashioned drill and practice) which paid off in the end.

Word generation (words within words). Alan was given a number of polysyllabic words and asked to generate as many words as he could from them. This he found stimulating and challenging, and would go through a trial and error process that included hearing the word attempts – but he generated many, many words from it.

Part-whole (what's missing?) word generation: these were pairs of composite pictures with some elements missing from one. This forced Alan to generate specific words for the missing elements.

Missing items (Kim's game): working memory. What has gone from the tray? Can you rehearse that as it gets increasingly more difficult to recall?

Picture sequencing: word/message order. This was specifically targeted at atypical word or sequence order to support typical sentence generation (and by default, literacy knowledge). We utilised high and low frequency experiences to try to generate a range of world knowledge to draw from that which may not

necessarily be within the person's personal world knowledge or experience.

RESULTS SO FAR

Alan feels he has gained:

- Increased ability to generate words (through spelling).

- Changes in vocabulary organisational strategies.

- More confidence to try.

- More willingness to practise.

IN SUMMARY

It seems it is never too late to learn but somehow this does not, as yet, appear to be on offer to adults with life long communication challenges. It seems that the current system suggests that if you are an adult with no identifiable cognitive needs and no significantly changing physical or cognitive needs that once you have utilised the state educational opportunities of, primarily, special education and specialist college experiences there are no on-going learning opportunities available – other than those on offer to the general community but these are often riddled with barriers to those with perceived complex communication difficulties.

Is this case study the beginnings of evidence to prompt a review of the ways in which language and communication support may enable adults with complex communication needs to take up a place of individual fulfilment in society? Only you can decide. ✳

Alan Martin
Dancer, actor & disability rights trainer
Janice Murray, *Senior Lecturer*

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Smartbox

PowerBox 7

Wheelchair mounted communication aid.

The PowerBox 7 has a protective cover, extra loud speakers, universal wheelchair mounting point, environment control, switch access and 8 hour battery life.

We supply the PowerBox with The Grid 2, providing symbol and text communication and control of other Windows applications.

Features

- Windows 7 PC with Core Duo processsor
- 12" daylight readable touch screen
- 12 switch ports
- Infra-red environment control
- Loud, clear speakers
- Universal wheelchair mounting point
- Integrated stand

Options

- Four colours available
- Radio switches
- USB modem
- Z-Wave environment control
- Keyguard

TRAINS: Visual supports for communication, participation and independence

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This paper introduces the TRAINS network and describes in detail how Visual Supports have been enrolled to develop a workshop about the use of Visual Supports with people with autism spectrum disorder (ASD).

The TRAINS network is an informal network of professionals in Aberdeen and Aberdeenshire with a common interest in ASD and training. The network came out of an awareness of the needs of families and carers, and a vision to provide more training and support within existing resources by pooling the knowledge, skills and time of individuals from various agencies and professions.

The first event was an Open Day, in May 2007. The event was well attended by parents, carers, professionals and other agencies. Members of the network had stalls presenting a taste of the kinds of training and support that they could offer. Those who attended were invited to fill in a feedback form stating what they would like to know more about, what training format, time and location they would prefer, and whether they would like sessions to be specific to their interest group (e.g. parents, carers, professionals, voluntary agencies) or mixed.

The feedback was collated, and the results were used to plan a year's program of talks and workshops. Now in its third year, the network has an established bank of training packages, but continues to develop new resources in response to demand. This year's half day training topics include Transitions, Relationships, Sexuality and Siblings. All sessions are free of charge, although recently a refundable booking fee has been introduced to avoid wasting places when people book but do not attend an event.

At the Open Day, the speech and language stall presented information about a variety of topics and strategies. Feedback highlighted interest in four themes; Visual Timetables and other Visual Ideas, Social Stories™, Communication Passports and Comic Strip Conversations. There was no clear preference for when sessions should be held (there were votes for every day of the week, and for morning, afternoon and after school slots) but there was consensus that the format should be informal, hands on, practical and that sessions should last about 1¾ hours. There was no preference for specific or mixed interest groups, but there was a preference for small groups.

The Speech and Language Therapy additional support needs team therefore scheduled a rolling program of hands on practical workshops on the four topics. Over the course of two years each workshop falls on each day of the week, and at each time of day. Therapists volunteered for the rota of presenters, two per session. The lead therapists then put together a plan for each session, and collected the materials; ready made confirmation letters, pre-course information sheets, and resources; so that

Figure 1   Visual Supports workshop tables

each workshop could be delivered 'out of the box'.

The lead therapist's idea was that all four sessions would follow the same format; welcome and introductions, find out what people are hoping to get out of the session, brief theory and history, practical examples. A break for refreshments and for people to meet each other, then a hands on session to make or plan resources/strategies, so that each person could take away something practical that they could use straight away. This format was easy to apply to Social Stories™, Communication Passports and Comic Strip Conversations. However, when it came to Visual Timetables and Other Visual Ideas, there was such a wealth of materials, and such a diversity of applications, it was difficult to imagine how this could be presented in 1¾ hours without leaving participants completely bemused.
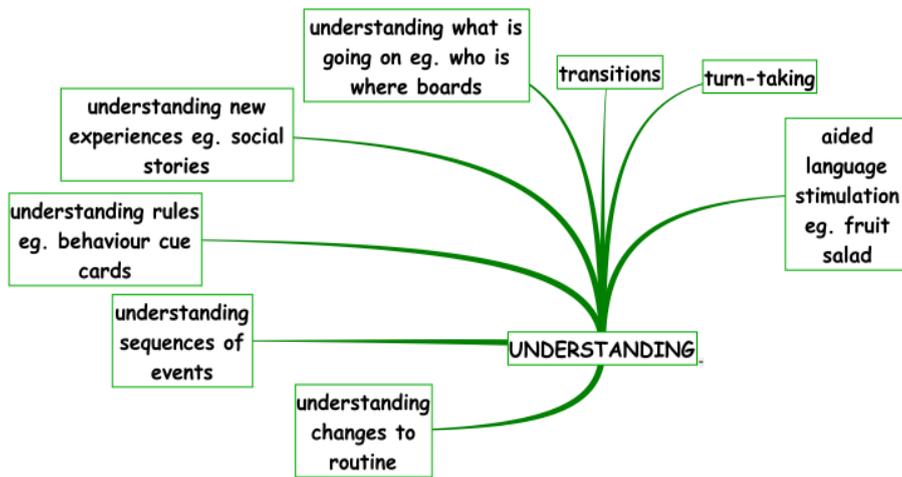
Figure 2 Green branch of the Mind Map

In search of a plan, we laid out all the Visual Resources in our examples cupboard, to get an overview and generate themes. This led to the idea of using Visual Strategies to structure the workshop itself. The resulting session plan involves: the arrangement of the room itself; paper resources; Mind Maps and checklists; and systematic colour coding to link ideas. In the course of the workshop, we discuss over forty practical examples, and also have time for a hands-on element. This may sound like a recipe for rush and confusion, but feedback from this session is consistently extremely positive. It is also a favourite with the therapists who present TRAINS workshops.

Places at all TRAINS practical workshops are limited to twelve, so everyone can fit round a group of four tables pushed together and everyone can see each other. We use pre-prepared, reusable flipcharts and/or handouts rather than PowerPoint. This promotes a collaborative focus and informal atmosphere. For Visual Supports workshop, the room is set up in advance with all the materials organised on three tables around the room. The tables have coloured cloths; red, green and blue (Figure 1).

The first flipchart highlights the three elements in the successful implementation of Visual Support; the Visual Support itself, the person using it and the skilled adult who will facilitate appropriate use.

The second flipchart introduces the three broad reasons for using Supports; Understanding (green), Expression and Participation (blue) and Organisation and Independence (red). These reasons are not explained here; they structure the rest of the workshop, and the meaning becomes clear as more and more examples are presented within the framework.

Now we give out the first handout: Understanding. At the same time, an A3 sized version of this handout is placed on the table tops for the presenter to refer to (Figure 2). This is the green branch of the Mind Map that will eventually be built. Each sub-branch lists a different aspect of using Visual Supports to aid understanding. Later, participants will receive a handout showing the complete Mind Map, but the separate handouts are designed with space to allow people to make notes on examples as they are shown.

The presenter(s) work round the green branch anti-clockwise, presenting a practical example from the green table to illustrate each sub-branch. For example, a 'who is where' board illustrates understanding what is going on; behaviour cue cards for understanding social rules. (Figures 3 & 4). Participants may be interested in applications in various contexts, with adults or children, so the range of examples have been chosen to relate to a range of ages, abilities and needs.

Next, the A3 blue branch (Expression and Participation) is placed in its position on the table tops, and A4 handouts are passed round. Again we work round the branch, showing an example for each aspect. A wipe-clean news book illustrates giving information about the past, whilst a Talking Mat about celebrities illustrates social closeness. Finally, the red branch (Organisation and Independence) is added and examples are presented.

Now the full Mind Map is given out (Figure 5). By this time, all the items on the three coloured tables have been shown, in relation to the reason for using Visual Supports. Having discussed function, we now go on to think about form. This is presented on a second Mind Map, which is given out complete At the centre is 'the person and the skilled adult' to emphasise the importance of the skilled adult(s) to set up and facilitate.

Again, the presenters work round each sub-branch on the map anti-clockwise and again there is an example for each point. However, this time the examples are things we have already spoken about, and now we are looking at them from a different point of view. This helps to emphasise that in every case it is important to be clear about why and how Visual Support is being used. Thus the computer setup checklist is an example of 'practice of using it; manipulated by user; tick boxes' and the wipe-clean news book is an example of 'content; symbols; written words'.

At this point, there is a break for refreshments. Participants value this as an opportunity to meet others who may
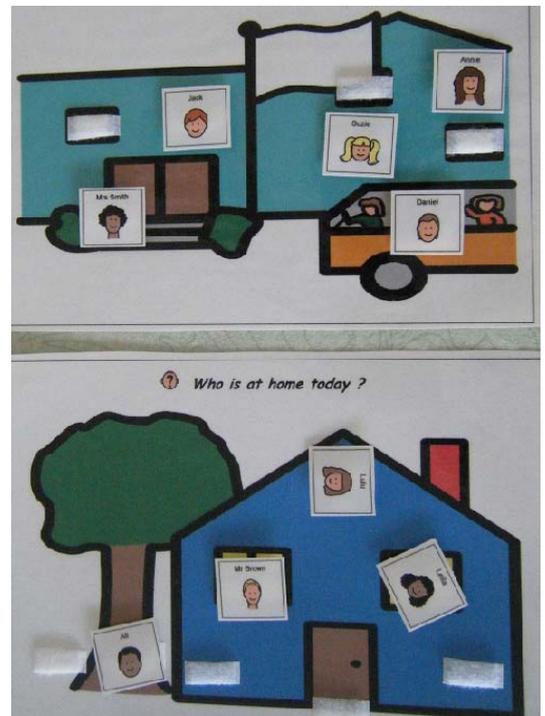

Figure 3 'Who is where' board


Figure 4 Behaviour cue cards
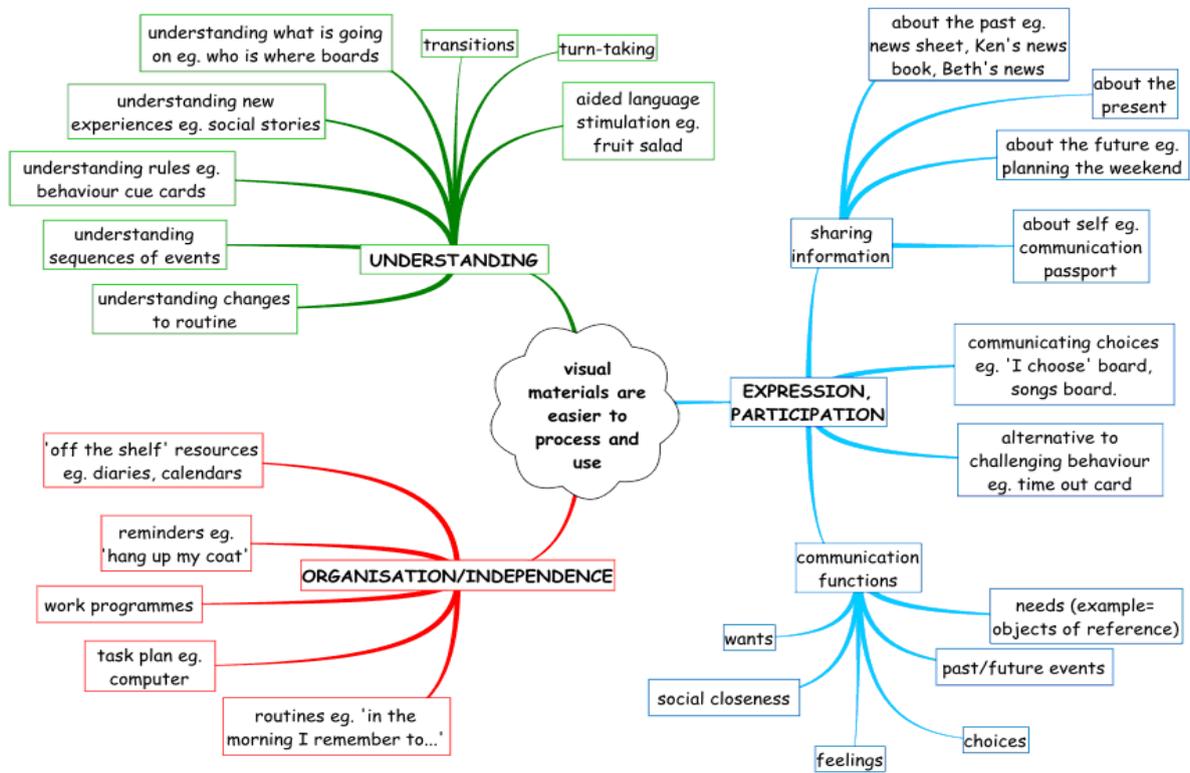
Figure 5 The full Mind Map

share their own concerns and experiences. Prior to the workshop, participants receive a confirmation letter which encourages them to think about situations which challenge the person with ASD, where Visual Supports might be beneficial. During the break, presenters find out what situations participants have in mind, and identify who might be able to work together in the practical session which follows.

The last handout is a checklist of questions designed to structure decision making when implementing a visual support (Figure 6).

In practice, these questions are not overtly addressed every time a visual support is developed. However, the decisions will all have been made implicitly, and for the purposes of the workshop pairs/groups work through them in relation to a specific situation in order to make a plan that can be put into use straight away. All the materials are still available on the tables, and people are encouraged to browse through them to stimulate ideas.

The workshop ends with everyone round the tables again to share what ideas they have developed for something they can use. We encourage them to think about how this will be introduced in context. We also briefly discuss the resources that can be used to produce visual materials. Most participants report that they can access the internet; some have access to symbol software. Those who do not are invited to make

an arrangement to come in and use the department's own resources.

TRAINS workshops are free, and are open to anyone, from anywhere. We have welcomed participants from other parts of Scotland and from England, as well as some overseas visitors. Although the common theme is ASD,

there is much which will be of interest to people who are concerned with other diagnoses.

To see the latest program showing all forthcoming TRAINS sessions, and to find out how to book please visit *www.nas.org* ✳

Dithe Fisher, *Speech and Language Therapist*

1. What is the visual support for?	
2. Layout a) Do I need to think about the numberof items on display? b) What would be the best size? c) Does the visual support show something happening in sequence? d) Does it have a clear start and finish?	
3. Would you be interested in a users social group in the area? a) Does it need something to grab the interest of the person using it (e.g. a favourite colour or picture)? b) What colour scheme is best (colour, black and white, high contrasts)? c) What kind of symbol will be best for theperson using the visual support? • Objects of reference • Photos • Pictures/illustrations • Mayer Johnson PCS • Written words	
4. Storage and Access a) What will make it easy to store and use the visual support? (e.g. craft drawers/folder with velcro strips on pages/boxes/ concertina file/plastic wallet/other) b) Does everyone know where it is kept?	
5. Putting it into practice a) What does the person using it have to do? b) What does the person helping have to c) Are we making it consistently available for use	

Figure 6 Checklist to structure decision making

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Click & Read

Mark

Settings

Show homophones

• support for those with dyslexia

• includes Microsoft Word toolbar

• listen to your documents, internet pages, email etc.

• hear words as you type them

Mind Express 4 features...
• Agenda/Alarm functionality
• Free draw cell function
• Symbol & sentence prediction
• Dynamic lists
• Integrated multimedia player

all these & more are also available from techcess...

Zingui

Headmouse

Tellus 4

Allora

Smart II

Measuring Outcomes

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When reviewing data from a set of interviews with adults who use AAC, we found ourselves considering a metaphor to describe the tensions between the comments received about their aspirations, goals and achievements and the encumbrances of their current and past AAC systems as a means of facilitating achievement of personal goals.

The metaphor that emerged in our discussions was that of a parachute without a rip-cord. The following paper takes this analogy as a platform for considering how we might define clinical or educational outcomes and their relevance to people who use AAC when viewed through their life-long lenses.

OUTCOME MEASUREMENT

We first turn to outcome measurement. Outcome measurement is not a new concept and is one that pervades many aspects of business, commerce and public sector life. However, in the field of AAC it has become a critical aspect of an evidence based practice approach to facilitating effective and independent communication skills. What remains uncertain and possibly unspecified is what should be the focus of that measurement. Granlund and Blackstone (1999) suggest the challenge of setting and attaining a desired outcome requires flexibility and a long term view that is responsive to the needs of the consumer.

Outcome measurement approaches enable practitioners, educators, service users and families to break down aims and attainments into particular components, making them easier to describe and identify. These could be called domains. So let's consider what may be the domains of outcome measurement. One of the most commonly used tools in the UK is Therapy Outcome Measures for Rehabilitation Professionals (Enderby, John and Petheram, 2006). These scales cover four domains: impairment, activity, participation and well-being/distress. They provide the user with a way of calibrating and describing change, positively or negatively. They will be reflected in the following discussion.

One of our dilemmas is knowing when we have had a good outcome with something. What are the components and processes that contribute to us achieving a good outcome? And, is an outcome a unitary thing or does it change according to the perspective of the persons involved?

So, what do you think of the above scene … is this a good or a bad outcome?

We imagine most of you agree it is a good outcome…unless of course, you are this wee chap's older sibling, to whom the chocolate pudding actually belonged!

Perspectives seem to be a critical component in determining whether an outcome has been a good one or a bad one. Let's now return to our parachute metaphor as a way of exploring the component parts of outcome measurement as they may apply to people who use AAC.

PARACHUTES AND PARACHUTING

Firstly, we need to have an agreed understanding of parachutes and parachuting.

Clearly, the component parts of the parachute are critical to defining it. This would naturally include the silk canopy for aesthetics and success, the harness for security and control, the ripcord for decisive action, the ropes for navigation, and the skydiver at the controls.

Parachuting includes consideration of other variables such as the wind and weather, the height and weight distribution of the skydiver, the jump, intended destination and the terrain of the landing site.

Extending the metaphor to aided communication, what does this mean?

What is the silk canopy? We will use it here to mean the aided communication component. In effect, it is the most obvious element; it is the additional piece that allows the skydive to happen. Just as with an aided communication system, choosing the right parachute can be quite overwhelming. It has to be the right colour or colours. Its texture, size, and durability are all important components in terms of value for money. It also has to be suitable for the weight and experience of the skydiver and the likely number of sky dives.

The harness allows the connection between the skydiver and **the ripcord**, enabling a skydive to actually happen. This could be likened to the motivation and resilience of the aided communicator to keep going with communication attempts and system operation.

The ropes are the connection between the skydiver and the silk canopy. They are the crucial elements that make the silk more than a piece of material. If you examine a rope closely, you will find that it consists of ropes within ropes.

For the aided communicator, these could be likened to Light's (Light, 1989; Light, Beukelman, & Reichle, 2003) operational, strategic and social competences, shown through a unique set of user resources, skills, experiences and motivators, built up over time.

All communicators rely on both aided and unaided forms of communication – and so a range of different ropes is essential. Knowing what ropes to pull and when to pull them (i.e., strategic and social competence) is central to success. Many individuals who use aided communication face difficulties with other modes of communication also. While our eyes are quickly pulled to the parachute's silk canopy, without good ropes that 'fit' the individual, skydives may be very risky indeed!

The jump is a two-stage process composed of the free fall and the opening of the canopy. Timing is crucial, whilst enjoyment is optional, at least the first time! In aided communication terms this analogy continues with Light's competencies but also includes the linguistic components in terms of deciding what to say and when to say it.

Learning some of those skills in an 'offline' context, when conversation or communication is not the key aim, is a critical component of learning and becoming a confident communicator in other settings. This latter point is akin to landing at a destination, when suddenly everything changes in terms of operational skills, timings and the components of the parachuting apparatus that remain relevant.

This seems to be analogous to the desire for social participation and community integration. It is that moment to show flexibility of skill in aided communication strategies, linguistic knowledge and achieve some sense of self-fulfilment. When it all works together, the parachute and parachutist seem as one, able to react to the prevailing winds, to obstacles encountered along the way – and maybe even to create something new and magical with other skydivers along the way. Similarly, a total communication system is tailored to the user, unique to that individual and adaptive to the prevailing winds of the communication context.

In sum, applying the metaphor of skydiving to aided communication interaction, clearly, you have to enjoy the ride! It doesn't always go to plan and it can be risky. At the early stages, a backup is needed. It is in essence an apprenticeship.

UNPICKING THE METAPHOR

What are the ways in which we might scaffold the apprenticeship? If we consider that the desired outcome, or destination, is a sense of social participation, community integration and self fulfilment, we see that where you land can sometimes be unexpected! So, if we want to land somewhere particular, what helps?

Here are some reflections from the literature. Lefebvre, Cloutier & Levert, (2008) explored levels of satisfaction experienced by the individual in their life situation, their sense of community affiliation and their self-image. They concluded that this was enabled by four main elements:

- Maintaining a range of interpersonal relationships that extend beyond the family.
- Being able to contribute to society.
- Having access to recreational activities that allow self expression and the fulfilment of potential.
- Having access to a normalized and adequate living environment.

Applying this to the opportunities currently afforded many who use AAC, it may be helpful to consider the ICF domains of Activity and Participation (WHO, 2001). Whilst not necessarily easy to tease apart, activity could be considered as communication skill; participation as meaningful authentic interaction with reciprocal engagement, leading to inclusion over a sustained period of time.

Commonly cited facilitators for people with disabilities include: skills (a range across domains, not just communication), support systems, and resources (personal and environmental factors within the ICF framework). The relative salience of these components may differ across people with disabilities and practitioners. This suggests that in returning to our premise of outcomes, and how we feel about them, is relative to individual perspectives. Another important commentary from the literature includes consideration of lack of inclusion, which may mean feelings of isolation and loneliness.

ISOLATION

Inclusion and participation are more than geographical: landing in the field doesn't mean you can stay there or even want to. What matters is not where, but how people participate (Milner & Kelly, 2009). "Participants felt others were around them but not with them some of the time" (Balandin, Berg, & Waller, 2006; 476).

One helpful way of considering the success of outcomes may be to consider the five metrics identified by Milner & Kelly (op cit):

1. Self determination: the power to choose activities undertaken with a degree of autonomy … *Choosing which field to land in.*

2. Social identity: built up through sustained interpersonal contact over long periods of time, e.g. families, places of worship, some recreational settings … *Frequent jumps.*

3. Reciprocity and valued contribution (echoing Lefebvre et al); the desire to add value to others' lives. This implies equality, and challenges implied dependence. It can be

achieved through work or through other activities. It is "the glue that bound friendships and key to humanising important relationships" (Milner & Kelly, 2009; 57) ... *Enjoying and sharing the ride.*

4. Participatory expectations: challenging the limited expectations which are amongst the most disabling barriers to real participation ...*Operational & social competencies.*

5. Psychological safety: sharing space with trusted others, being incorporated into the social history of particular community spaces, the sense of a collective courage of a trusted group.

LONELINESS

Loneliness is a subjective experience and one not neatly tied to objective characteristics such as social network size or frequency of contact with friends (Ballin & Balandin, 2007). It would seem that *perceived* social isolation is a more important predictor of adverse health outcomes than objective social isolation (Cacioppo, Fowler & Christakis, 2009), suggesting a collective responsibility for attitudes that may influence such outcomes.

WHAT ARE THE IMPLICATIONS OF THESE CONSIDERATIONS?

One might suggest that to maximise the chances of landing somewhere you want to actually be (i.e. a good outcome), you need to have:

1. Autonomy and choice along the journey.

2. Long term planning for the journey, including immersion and stability (of key components).

3. Acknowledgement of the importance of reciprocity during the journey.

4. Access to peer group mentoring to challenge limited expectations.

5. An opportunity to create trusted networks.

This suggests that we are collectively aiming to support the skills to enable the aided communicator to become a flexible, robust and adaptable communicator. The skydiver needs to have skills that are transferrable: transferrable to a new parachute, new gear, or new destinations.

How do we measure this flexibility in terms of outcomes? Do we take a short term or a long-term view, or a combination of these? How do we support this in terms of service delivery and continuity?

Let's consider the skydiver (or the aided communicator). Of course, one important question that highlights some of the limits of the metaphor relates to whether or not they are truly skydivers until they can jump independently? There may be days when jumping is not attractive, and indeed, there may be destinations that are not attractive to jump to – skydivers don't lose their identity once the dive is over or on the days they choose not to jump.

However, the evidence cited here suggests that to become a skydiver there is need for careful scaffolding of learning that may take years rather than weeks to achieve, in terms of agreeable outcomes.

One last reflection on the skydiver – they are often less visible than the parachute. From a distance you might even say "they all look the same". What's more, the ropes you may never see at all, as the silk canopy becomes the foreground visual image.

A parallel with aided communication was described by Bailey and colleagues (Bailey, Parette, Stoner, Angell, & Carroll, 2006) who reported that in their study, high tech aided systems changed community perception and expectation of the person in a positive way. However, it is commonly cited that unaided modes of communication are often preferred communication methods (Bailey et al., 2006; Clarke, McConachie, Price, & Wood, 2001; Smith & Connolly, 2008; Smith, Murray, von Tetzchner, & Langan, 2010) suggesting that views about when a parachute is needed, helpful or should be deployed probably depends on the perspective of the viewer.

As noted at the start, the metaphor of the parachute without a ripcord emerged from discussions about the views of adults who have used aided communication over many years, and the challenges and achievements they recounted in interviews. As clinicians focus often on planning and evaluating specific episodes of intervention with clients, it is easy to lose some perspective of the longer picture.

After several decades of high technology supports for communication, it is helpful sometimes to pause and to reflect on the bigger picture and question whether the steps taken along the way cumulatively have led us to where we thought we were going.

COMMENTS

We have grouped the comments below under the various elements of the metaphor of skydiving discussed above. These comments were collected in interviews with 38 adults in the UK and Ireland. All were aged between 18 and 45 years and had used aided communication for more than 10 years.

At the time of the interview, the metaphor was far from our minds, and so this is a post hoc linking of comments to the metaphor of the parachute, the harness and ropes, the parachutist's personal attributes, the need for scaffolding, repeated opportunities to practice and consideration of final destinations.

1. Evaluating the parachute

- *really it was the texting*
- *Email*
- *This can go on the internet*
- *I wanted to use the mobile phone*
- [keeping] *the same programme* [when changing device]
- *can't be used in sun*
- *in wet weather, hard to use*
- *I'd like to be able to speak outdoors in daylight*
- *I cannot use my device outside*
- *Rain kills it*
- *it does go dead*
- *shopping – battery can be low (so I don't use the device)*

2. Harness and ropes

- *(I want) a robust desk and also wheelchair mounting system where when using the aid in my wheelchair I can still see over the top to drive*
- *I would like to see the key guard thing I talked about changed* [Talking about the difficulty of accessing a dynamic screen rather than a static keyboard]
- *In powered chair – cannot be used simultaneously*

3. Scaffolding & apprenticeship

- *Do not know how to trouble shoot problems*
- *You are able to transfer text from a PC onto a Lightwriter, but I don't know how to*
- *Would like to be better at reading*
- *I want to go to a PC based where I can use a joystick*
- *When I understand it more, I'll use it more*
- *Get more confidence, because if nervous I forget how to spell words*

4. Repeated jumps

- *Although I can't speak, I fully comprehend everything and can answer with my speech device*

- *It is faster to use and as I am not a fantastic speller*

- *I find talking just a piece of cake now and building up better sentences* [Speaking about a new device and language system]

5. Parachutist's resilience & motivation

- *Learn it* [Advice about what to do when given an aided system]

- *It's going to be hard work*

- *If they get it wrong I will put them right*

- *Never let anybody tell you that you'll never be able to do something*

6. Destinations

- *People chat to me.* [Commenting on what having a communication aid enables]

- *This is my second year here* [college]

- *I live independently and I have people to support me to do everyday things and they do my care needs*

- *People don't give me the time to talk and it* [runs - deleted] *isn't working*

- *I like keeping myself busy and I am the secretary of a disabled sports club*

- *I am interested in a lot of things but my major interests are dancing and drinking, I also like visiting friends. I like to go to the theatre but I do not like the way that I can not sit with my friends at ***. This is because I have to sit in the section for people who use a wheelchair. I think this is unfair.*

7. Evaluating the jump

Evaluating the insider experience of the skydive of aided communication, participants shared both highs and lows:

- *I found exciting* [learning the symbol language system]

- *I got this* [device] *July this year and I wanted to change my access method as I was getting back and shoulder problems*

- *It's going to be hard work*

- *I would say at first you will find it very very hard but keep going*

- *People will understand you* [if you keep practising]

- *I would say that to keep going as it opens a world of communicate*

BACK TO THE BEGINNING: OUTCOMES!

This metaphor arose because of an overwhelming sense in reviewing interview transcripts that many of the adults we talked to had been provided with many elements that were necessary but not sufficient to enable successful skydiving into communication interaction and participation in society – hence the parachute without the ripcord. How might these comments influence our conceptualization of outcome measurement?

We expect that readers will take their own meanings from the metaphor, to apply to their own learning situation. For us, the metaphor is a reminder of the care needed when choosing the parachute; the potential of the parachute to obscure the parachutist; the importance of the harness, ropes and practice to ensure that the potential of the parachute is realized; and the concept that not all days are good days for skydiving – it really is important to pay attention to the prevailing weather conditions in deciding whether or not to jump. Poor decisions here can have very negative consequences.

Most of all, the metaphor reminded us that, as we pay attention to the various elements to varying degrees at different stages in our interventions, it's also important to be vigilant to the whole sky dive, remembering that the whole is greater than the sum of its parts! ✳

Janice Murray, *Senior Lecturer*
Martine Smith, *Senior Lecturer*

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ISAAC Israel Newsletter

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

Members of Communication Matters (ISAAC UK) must send their orders to CM (address below)

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

Communication Matters, Catchpell House, Carpet Lane, Edinburgh EH6 6SP
CM Tel & Fax: 0845 456 8211 Email: admin@communicationmatters.org.uk www.communicationmatters.org.uk

JOINING COMMUNICATION MATTERS & ISAAC

What is Communication Matters?

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

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

Our Mission: Communication Matters values people who use any form of communication and promotes the individual's right to participate in all aspects of life by using their most appropriate means of communication to express their thoughts, feelings, needs and desires.

What are the benefits of Membership?

Members of Communication Matters receive:
- The Communication Matters Journal three times a year.
- Reduced rate at Communication Matters Study Days.
- Reduced delegate rate at the CM National Symposium.
- Regular electronic newsletters with the latest news in AAC developments, Road Shows, study days and more.
- Access the members' area of the CM website.
- All the benefits of ISAAC membership.

How do I become a Member?

If you live in the UK, you can become a member of Communication Matters (and therefore of ISAAC) by contacting: Tel: 0845 456 8211 www.communicationmatters.org.uk

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

What is ISAAC?

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

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

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

What does ISAAC do?

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

What do ISAAC members receive?

- Full access to *ISAAC Information Exchange,* 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.

COLLATED BY JANICE MURRAY, CHAIR

It has been a busy time for the Board of Trustees with many new and innovative opportunities coming the way of Communication Matters' Associate Members and Friends.

'AWARDS FOR ALL' GRANT FOR ON-LINE TRAINING

We heard last month that our employment of a bid writer had already given us a two-fold return, on receipt of a grant of £10,000 from Awards for All. This grant will fund the set up of on-line training and educational materials which will be freely accessible from the website. We will keep you posted on its progress.

SAFE SOCIAL NETWORKING DAYS

Our newest member of the Board, Scott Stack, is throwing himself into initiatives that will increase our membership of young adults who use AAC. He is particularly keen to target students at college. This fits in very nicely with our three scheduled 'Safe Social Networking' events in collaboration with Treloar, Beaumont and National Star Colleges. Visit the Communication Matters website for more information about these days which are being well supported by a number of Friends and Associate Members of Communication Matters.

NATIONAL AAC REVIEW IN SCOTLAND

In Scotland, Alison Gray has been seconded to develop the national review of AAC services and models of provision. We look forward to hearing the outcomes of this review in due course. Also in Scotland, there was a re-scheduled meeting on disability and employment held in Edinburgh in January; it is anticipated that a position paper may be produced from the meeting.

THE 'HELLO' CAMPAIGN & AAC EVENTS

Communication Matters' events for the Hello Campaign have started with a bang. A huge thank-you to all of you involved in planning a range of interesting and fun events up and down the length of the UK. Particular thanks to Trustees Sally Chan and Dithe Fisher for their co-ordination work with an 'AAC Wave' of events from Devon to the Scottish Highlands. There is loads of information on our website about what is happening, and showing you how there is still time to get involved - visit *www.communicationmatters.org.uk/hello*

ISAAC NEWS

ISAAC is now gearing up for the annual International AAC Awareness Month in October, and initial discussions include something of a relay of activities between ISAAC Chapters…it sounds rather similar to our Wave concept. Again, we will provide updates as we get them, through the E-News and website. Anyone interested in being more directly involved in the ISAAC activities should contact Janice Murray at *jancommatters@mmu.ac.uk*.

Other ISAAC news: Liz Moulam, our Associate Member representative on the ISAAC Council, has been involved in a working group revising ISAAC Governance documentation. Janice Murray has contributed to the revisions on ISAAC publications policy documents. Most recent news from Erna Alant, ISAAC President, indicates a focus on business strategy developments. Sadly, Mona Zaccak, who has been the main-stay of administrative activity for many years, took early retirement at the end of February. We wish her well.

Whilst on a recent work trip to India, Janice Murray had opportunity to meet with the ISAAC India's Chapter President, Dr Rajul Padmanabhan. ISAAC India is a relatively new Chapter - just celebrating its third birthday. It seemed like a good opportunity to explore the possibility of some collaboration between Communication Matters and ISAAC India. They are currently heavily involved in the BUILD project. Anyone interested in knowing more about possible collaborations should contact Janice.

NEW AAC INFORMATION BOOKLET

The Communication Trust and a number of AAC organisations, including Communication Matters, have been working on a new AAC information booklet. Thanks to Sandra Hartley, Trustee, for steering on this for us. The booklet will complement our *Focus on* series, and Communication Matters will lead on its dissemination to the AAC community and further afield. We will highlight the publication in a future edition of the E-News.

AAC ASSESSMENT STANDARDS

The AAC Assessment Standards documentation is in the final phase of editing. This is the culmination of intensive collaboration between AAC stakeholder groups, including service Commissioners. The launch of the documents is immanent and will be publicised on the website. The Board members who were key players in this were Anna Reeves, Sally Chan, Dithe Fisher, Gillian Hazell and Simon Judge.

This work has also led on to plans for development of documentation on competencies and outcome measures. An initial planning meeting on 8 February mapped out plans that will take these two new initiatives forward.

AAC EVIDENCE BASE RESEARCH PROJECT

The Communication Matters led AAC Evidence Base research project is progressing well – turn to page 23 for a project update from Katie Holmes and David Morgan.

FINALLY

There are many other things that we have been attending, exploring and planning for. Our next big push is planning this year's National Conference - we have received many abstract submissions and look forward to seeing many of you in Leicester. New Trustees are sought on an annual basis as some 'oldies' complete their term(s) of office. It is very rewarding being a Trustee, so if you have some spare time, lots of energy and enthusiasm we would like to receive your application; look out for the Call for Trustees in June. ❋

BBC *OUCH!* FOCUSES ON AAC

The BBC's disability site, *Ouch!* interviews two inspiring people who use AAC: Toby Churchill - the inventor of the Lightwriter - and Beth Moulam, who is working towards her GCSEs and aims to study occupational therapy at university... *tinyurl.com/ouch-morethanwords*

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HOT OFF THE PRESS
LEAFLETS AVAILABLE FOR THE
AAC EVIDENCE BASE RESEARCH PROJECT

A leaflet describing the 'Communication Matters - Research Matters: An AAC Evidence Base' research project is now available on our website at *www.communicationmatters.org.uk/evidencebase*

If you would like printed copies to distribute, please contact Katie Holmes, Research Manager, at *katieholmes@communicationmatters.org.uk*

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GOVERNMENT FUNDS FOR ACE CENTRE

The ACE Centre has been awarded £70,000 from the Government's Transition Fund. The money will enable the centre to take advantage of new funding opportunities expected to result from the Government's Big Society agenda.

Minister for the Cabinet Office, Francis Maude, said, "I'm pleased we are able to help support the ACE Centre which has shown it provides vital services for people with communication difficulties and has impressed us with strong plans for developing its services in the future."

More information at *tinyurl.com/ace-awarded-funds*

*

THE AUTISM SHOW FEATURES
'THE COMMUNICATION MATTERS ZONE'

This year's The Autism Show will feature a dedicated *Communication Matters Zone* with exhibitors from leading AAC suppliers in the UK, including Inclusive Technology, Liberator, QED, Possum, Toby Churchill and Widgit Software - Communication Matters will also be exhibiting of course! The event will be held at ExCel, London on 24-25 June 2011.

For more information, visit *www.autismshow.co.uk*

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BOLTON MAN WITH MND 'BANKS' HIS VOICE

BBC News Manchester: A man from Bolton who has motor neurone disease (MND) is recording his words so his baby son will be able to hear his voice... *tinyurl.com/bolton-voicebanking*

The main news from the BHTA eCAT section (electronic Communication and Assistive Technology), which met in early February, is a complete change of 'officers'. David Weatherburn, who has been Chairman for the last two years has had to step down due to his growing work commitment with Ability World, and Paul Hawes, who was Vice Chairman also indicated that not only did he not want to be considered for the chair's role, but he also needed to resign his position.

As you can imagine this has left a huge hole and there were no willing volunteers to take over the chair's role at, what we believe, is a vital time for suppliers and the market generally. With it being the National Year of Communication, the push from Jean Gross for structured funding, and the Communication Matters research project, it would be a great shame if BHTA eCAT did not have a willing chairman and had to amalgamate with another BHTA sector, which would lose its identity.

Consequently I have raised my hand again to do a second stint as chairman (I sincerely hope that was not a chorus of "boo's" I heard from the back row!) To do this means I have to resign my position as Director of BHTA (according to their own rules I am not allowed to be a Board Director and Section chairman) – but I considered there would be plenty of others willing to become part of the board but if no-one wanted to be chair of eCAT I needed to 'step up to the plate'.

Ian Thompson (Liberator) and John Hicks (Toby Churchill) have agreed to become Vice Chairman and Alternate respectively, although in practice they may end up almost being joint Vice chairs.

I hope all members of Communication Matters will join me in expressing our sincere thanks to David for all the splendid work he has done over the last 24 months, and to Paul Hawes and Ian Bullock (the previous Alternates) for their support of David.

I sincerely hope that I will be able to do the role justice and with my Research Lead hat on; there will be crossovers that will benefit both positions. Indeed I have already started this by trying to get BHTA and Communication Matters to work closer together especially with regard to statistical data. One of the areas that we are short of is detailed and accurate (and provable) statistics – indeed that is one of the objectives of the research project. BHTA does have some stats going back over four years of AAC sales – but not every supplier of AAC is a BHTA member – but wouldn't it be great if we could get more accurate figures from BHTA members and other commercial members of CM providing data to one source. That, I'm sure, would help Jean Gross in her push and Communication Matters in their research.

David Morgan
Chair of eCAT section, BHTA
dmorgan@possum.co.uk

DIARY
DATES

5 May 2011   Bristol
PCAS Open Day
Contact PCAS: 0117 3533613 www.pcas.claremont.bristol.sch.uk

6 May 2011   London
Communication Works
Contact Cenmac: 020 8854 1019 www.cenmac.com

7 May 2011   Newton Abbott
SW 1Voice Musical and Arts Fun Day
Contact 1Voice: heskethanne@hotmail.com

11 May 2011   Shrewsbury
Communication Matters Road Show in Shrewsbury   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

16 May 2011   Lancaster
Safe Social Networking Day (Beaumont College)   `COMMUNICATION MATTERS`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

17 May 2011   Newton Abbott
Communication Matters Road Show in Devon   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

26 May 2011   Birmingham
Film Night 'The Diving Bell and the Butterfly'
Tel: 0121 6278235

27 May 2011   Horsham
Communication Matters Road Show in Horsham   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

7 June 2011   Carlisle
Communication Matters Road Show in Carlisle   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

14 June 2011   London
Talking About Experiences: Personal Narratives   `COMMUNICATION MATTERS`
Tel: 0845 456 8211 www.communicationmatters.org.uk

16 June 2011   Oxford
On a Shoestring
Contact ACE Centre: 01865 759800 www.ace-centre.org.uk

18 & 19 June 2011   Alfreton, Derbyshire
1Voice National Summer Event
Tel: 0845 330 7862 www.1voice.info

21 June 2011   Belfast
Communication Matters Road Show in Belfast   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

21 June 2011 (rescheduled from 10 May)   Oxford
Making Sense of Eye Gaze Technology
Contact ACE Centre: 01865 759800 www.ace-centre.org.uk

24 & 24 June 2011   London
The Autism Show   `COMMUNICATION MATTERS`
Tel: 020 8882 0629 www.autismshow.co.uk

28 June 2011   Oxford
Giving People a Voice
Contact ACE Centre: 01865 759800 www.ace-centre.org.uk

30 June 2011 (rescheduled from 5 May)   Oxford
Getting it down on paper
Contact ACE Centre: 01865 759800 www.ace-centre.org.uk

5 July 2011   Harrogate
Communication Matters Road Show in Harrogate   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

25-27 September 2011   Leicester
CM2011 National Conference   `COMMUNICATION MATTERS`
Contact: 0845 456 8211 www.communicationmatters.org.uk

8 November 2011   London
Communication Matters Road Show in London   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

16 November 2011   Latimer, Bucks
Communication Matters Road Show in Bucks   `CM ROAD SHOW`
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

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

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SAFE SOCIAL NETWORKING DAY
16 MAY 2011, Beaumont College

This day at Beaumont College is the second of three Safe Social Networking Days being organised by Communication Matters in conjunction with Beaumont, Treloar and National Star Colleges.

These days are open to students at the three colleges, as well as to other young adults (aged 16-25) using AAC from nearby colleges or who are living at home.

The programme includes: Introduction to Twitter, Facebook & Skype; Ensuring safety - privacy settings and issues; Accessibility; On-line resources and support; Demonstrations from AAC suppliers; Exhibition

www.communicationmatters.org.uk/studydays

WAVE 'HELLO' TO
THE NATIONAL YEAR OF COMMUNICATION !

A Wave of AAC events will travel throughout the UK, starting in Cornwall and finishing in Aberdeen.

This will be an opportunity to focus local and national events collectively, to raise the profile of AAC, and capture media attention, both regionally and nationally.

If you are organising an AAC event, why not apply for a **grant** from Communication Matters (see page 36)?

Diary of AAC Events

Visit the Communication Matters website for a list of AAC events taking place in the UK this year:

www.communicationmatters.org.uk/hello

Communication Matters – Research Matters: An AAC Evidence Base

Katie Holmes & David Morgan
Communication Matters, Catchpell House, Carpet Lane, Edinburgh EH6 6SP
Email: katieholmes@communicationmatters.org.uk   Email: davidmorgan@communicationmatters.org.uk

Good research is not achieved overnight and therefore there is not always much change from one month to the next (or indeed from one Communication Matters Journal to the next!). But we do feel it is important to report on the progress of the research and to highlight that things are actually happening, even though results from the research have not yet been published.

SYSTEMATIC REVIEW

The systematic review by the University of Sheffield is now finished and the final report has been written. The Principal Investigator, Professor Pam Enderby, plans to submit articles for publication to three journals. Communication Matters will also disseminate information about the review's findings. The review looked at peer-reviewed papers on evidence of need for AAC and service provision. Its findings will inform the next stage of the research that will look at these topics in more depth.

LITERATURE REVIEW

Manchester Metropolitan University has completed its initial literature review. This will be used to structure and inform the focus group work that is a key part of the development of the AAC Evidence Database.

RESEARCHERS APPOINTED

Another move forward is that the three researchers are now in post in the partner organisations, and the project can really start to progress in all areas. The project is still on target to complete by its scheduled end date of April 2013, but planned dates for individual tasks will be extended, as the start-up activities, including the recruitment of the researchers, took considerably longer than planned for both Communication Matters and the partners.

FINANCIAL AND REPORTING

On the financial side, we remain 'on plan' although some issues have been identified that need careful monitoring and we have made the Trustees aware of these.

The Research Manager, Katie Holmes, has issued the mid-year report to the Big Lottery Fund and this has been reviewed with the BLF Grant Manager who praised it for being very clear and concise.

INDEPENDENT RESEARCH PANEL

A family member has been recruited to join the Independent Research Panel. The Panel met for the second time in January and the members contributed advice and ideas that will be helpful for the next stage of the research.

DISSEMINATION

One of the most important aspects of any large research project is dissemination. It is better to communicate information regularly throughout the life of the project rather than leave dissemination until the end and run the risk of not having enough time. Katie Holmes and Dave Morgan, Research Lead, have been working on a plan and have met with Sandra Hartley as a representative of the Trustees to discuss ways that the research project and Communication Matters can share dissemination lists and ideas, rather than both invent systems that will almost certainly overlap.

LINKING WITH OTHER ORGANISATIONS

In addition we are trying to link in with the work being done by other organisations, for instance the Communication Trust, which is running the Hello year (the National Year of Speech, Language and Communication), and the British Healthcare Trades Association (BHTA) which has strong links to government and experience of lobbying ministers.

At times it may appear that things are quiet on the research project, but in practice things are moving ahead well and there will be further reports in the E-News, on the website and in this journal as we progress. ✳

Katie Holmes, *Research Manager*
Dave Morgan, *Research Lead*

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.

NEW FOR 2011

2011 started with a bang at Logan Technologies as we continually strive to bring you some easy to use resources and ideas.

LOGAN
TECHNOLOGIES

OPENING DOORS
TO COMMUNICATION

Speak All Tag – a new function

The **Speak All** tag is round, green and button like in appearance. When it is placed on any button on the ProxTalker all sound tags in place will play automatically from left to right. This gives a more flexible option for those users who are competent at sentence building. This function is available as an upgrade to existing ProxTalkers.

"I want orange juice please"

Visual Suite from Silver Lining
- a new resource

Glen at ProxTalker.com has worked with Silver Lining to create an easy to use resource with readymade ProxTalker sticker sheet templates. The Visual Suite DVD interface is intuitive for anybody familiar with word and allows you to easily import your own images from your PC as well as using the 15,000 distraction-free images. The photos on this DVD are excellent for behavioral charts, communication cards, community outings, picture schedules, life skills and school routines.

Texas Tactile Symbols
- a new idea

Some families and therapists have been using Tactile symbols to enable their visually impaired children to access the ProxTalker visit **www.tsbvi.edu/tactile-symbols** to learn more. This is an exciting and creative way to extend to reach of the ProxTalker.

Logan® BrailleCoach™
– a new product for 2011

Developed from the same technology as the ProxTalker and just as easy to use the BrailleCoach™ teaching device is a unique way to support the learning of Braille.

Just **Pick** a Braille Tag, **Place** it on the button and **Press** - the BrailleCoach™ teaching device will say what is on the tag enabling the student to work independently between lessons enhancing the progress.

Contact **sandra@logan-technologies.com** or visit **www.logan-technologies.co.uk**
to learn more about all of the above or to arrange a demonstration or a free trial of the Logan ProxTalker®.

The Intermediary Witness Scheme

SALLY CHAN

Member of the Quality Assurance Board, Intermediary Witness Scheme, Ministry of Justice
Email: sally.chan@nbt.nhs.uk

Registered Intermediaries (RIs) help victims and witnesses with communication impairments to give their best evidence in criminal investigations and at trial by ensuring that they can understand questions put to them and can communicate their answers effectively.

Vulnerable witnesses can be anyone under 18 years of age, or anyone whose quality of evidence may be affected by mental disorder, learning disability, impairment of social functioning, or a physical impairment. RIs are available for both prosecution and defence witnesses. There are likely to be witnesses who use AAC (Augmentative and Alternative Communication) that would qualify for such support; some RIs would therefore need to be familiar with AAC in order to achieve best evidence.

Achieving Best Evidence is crucial in any criminal investigation, and therefore Special Measures to achieve this were created through legislation in the Youth Justice and Criminal Evidence Act 1999. The Intermediary Special Measure was launched in six Pathfinder Areas in 2004, before the completed National roll-out in September 2008.

The Scheme is currently available in all 43 police forces and Crown Prosecution Service (CPS) areas in England and Wales. There are 118 active RIs registered on the Intermediary Register (a national database). There have been over 4,000 requests for RIs since 2004, with monthly referrals averaging 100.

A recruitment campaign was carried out in Autumn 2010. A presentation at the CM2010 National Symposium in Leicester aimed to raise awareness of the work undertaken by RIs, as well as attract interest from those involved in the field of AAC as possible candidates. The presentation was jointly given by myself (as a member of the Quality Assurance Board for the Witness Intermediary Scheme), with Gillian Hazell and Janet Larcher who are both RIs.

RIs are Officers of the Court, and are self-employed. They are appointed as a result of a Special Measure application to the Court, which then must decide that help with communication and/or understanding will improve the witness' quality of evidence. They come from a wide range of backgrounds – speech and language therapy, occupational therapy, psychology, social work, teaching and nursing (Figure 1) – and each bring the skills and experience gained in these roles to their work as RIs.

The application process to become a RI involves opportunities for the candidate to demonstrate and report on their

Speech and Language Therapist	81
Psychologist	10
Teacher	5
Retired	4
Other Therapist	3
Advocate	2
Educational Consultant	2
Nurse	2
Social Worker	2
Children's Guardian	1
Health Visitor	1
Other	5

Figure 1 Primary Employment of Registered Intermediaries

competencies and skills. Core competencies required to work as a RI have been identified and it is these competencies that are assessed, rather than formal qualifications.

Having completed a successful interview, the candidate is required to complete an accredited course for a week in London. This training is provided by The City Law School, and provides the knowledge and skills to understand and work within the legal process. The successful candidate is then registered on the national database of RIs. This database matches a request for an RI with the appropriate RI with experience of working with that particular client group.

There is a Conference every year for RIs, as well as a RI refresher course for inactive RIs, or those who are active but wish to be as up-to-date as possible on developments. Registered Intermediaries Online provides a forum for questions and answers, and support from other RIs and the City Law School.

Applications to become an RI should include evidence that the applicant can assess communication needs; legal knowledge will be provided by the training.

RIs are required to carry out an initial assessment of the witness' communication needs in order to:

- evaluate the abilities and needs of the witness;
- evaluate whether they, as an RI, have the particular skills to help that witness;
- establish rapport so they can help the witness give best evidence.

**RIs are also required to give advice** to help the police and CPS achieve evi-
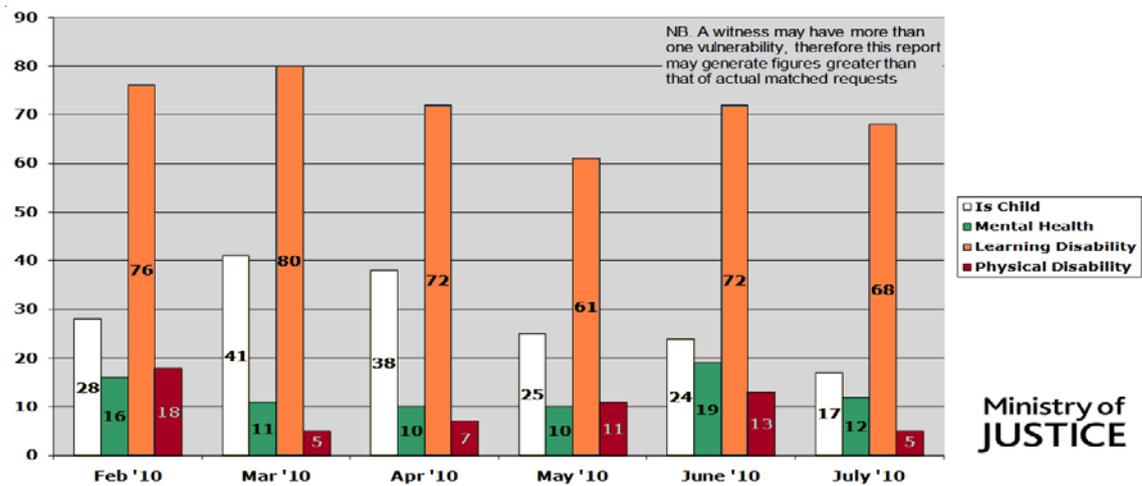
Figure 2 NPIA Witness Intermediary Service – Monthly composition of requests matched by witness vulnerability

dence during the investigation and trial stages of a case:

- How a witness communicates.
- The levels of understanding of the witness.
- How to phrase questions to the witness in order to achieve best evidence.
- Help with pre-trial preparation, e.g. court familiarisation visit.

To date, there have been very few requests for an RI with experience of AAC. However, knowledge of signing and symbols and how these systems can support communication, both in understanding and expression, is often needed to promote best evidence. The

use of visual timetables to help a witness understand the process could reduce anxiety or the use of signing can help a witness understand the question. These are AAC strategies that can enhance communication and are familiar to those of us working within the AAC field, but perhaps not to others.

Since the CM2010 National Symposium, the recent recruitment of RIs has been completed and newly registered Intermediaries added to the national database. Recruitment usually occurs every one to two years, to ensure that the database includes those RIs with the knowledge and skills to be matched with all client groups, as well as ensuring that all geographical areas are

covered. Continuing Professional Development (CPD) is monitored on an annual basis to ensure that the core competencies are maintained and developed, and that RIs remain active on the database.

The Witness Intermediary Scheme has successfully supported vulnerable witnesses since 2004. In many cases this has led to convictions, when previously these cases would have failed due to the difficulty of achieving best evidence.

If you are interested in this scheme, please contact me for further information, email: *sally.chan@nbt.nhs.uk* ✳

Sally Chan
Specialist Speech and Language Therapist

Preparation and Practise

The key to success?

NICOLA HAYTON & TRACEY HADFIELD
Speech and Language Therapy, Centenary House, Heritage Park, 55 Albert Terrace Road, Sheffield S6 3BR
Email: nicolahayton@nhs.net

This case study looks at the cost effectiveness of supporting a lady to make informed choices about her care and use of technology, and to be ready to use the equipment as soon as it was installed.

BACKGROUND

The subject is a 'young' 79 year old lady with a long standing degenerative condition (Pseudo Bulbar Palsy). This condition affected her speech first and subsequently reduced her movements. She has some residual speech but this is at a single word level, frequently unclear and not consistent. She has very limited movements of her limbs. The condition does not affect her cognition or understanding of language.

She has lived with this condition for over 10 years. During this time she has used a range of technologies to support her to communicate and access her environment. These include a Lightwriter SL35, that at one point she accessed using a chop stick, and a Steeper Environmental Control system.

IN HOSPITAL

In late 2008, she was admitted to hospital following degeneration in her physical condition. At this point she was unable to use any of the systems she had been using and her health was poor. The speech and language therapist in the hospital needed to look at the client's capacity to make choices and to support her to make decisions about her long term care. She did this through a series of laminated sheets with options on that the client would read and then use eye gaze and her strong yes/no responses to indicate her preference. This enabled the hospital staff to establish capacity, and enabled the client to be involved in the decision-making process about her treatment.

MEETING COMMUNICATION NEEDS

In February 2009, she was discharged from hospital to a nursing home and this is when the Neuro Enablement Service (NES) and in particular the AAC service became involved.

The client's communication system of laminated alphabet charts were passed on to the nursing home, but unfortunately these were not well used. The client also found this system difficult as it did not give her any feedback on where she was up to on her spelling and she would easily lose track.

The initial intervention was to add phrase sheets with relevant needs. However again this was not well used in the home. The client was becoming in-creasingly distressed and staff reported protracted periods of crying as she was unable to communicate what she needed or what was wrong. The staff felt that they were unable to get to know this lady due to the barriers in communication.

INTRODUCING THE MEGABEE

It was at this point that we introduced the MegaBee. This is a light-tech aid that uses eye gaze to spell words and has an LCD display so that both parties involved can see what is being written. The aid uses a colour-coded system. So, for example, to select the letter 'A' the person needs to look at the yellow square

Figure 1 The MegaBee

and the facilitator then presses the yellow button with their right hand. A light is illuminated in that square. The person then looks at the blue square to indicate the blue letter in the yellow square. The facilitator then presses the blue button with their right hand and 'A' appears on the display.

Our client does not follow this exactly as she prefers to use her residual speech to indicate the letter colour. With limited choices and familiarity this currently works well for her and for her communication partners. At times she is ahead of us all by looking at the square and saying the letter colour simultaneously.

As her condition continues she may need in the future to use the aid as it has been designed, but for the present she is able to use this system with friends, family and staff. It has re-opened the world to her and dramatically reduced her frustration. The staff in the home feel that they now know her and she has clearly been able to demonstrate her character and determination. The client is a very sociable and popular character and the use of this communication aid has enabled this personality to be re-established in her new home. Unfortunately, her husband has been unable to use the MegaBee, but they are able to interact still, and do not feel this is a big issue.

EXPLORING OTHER SYSTEMS

Following this reduction in frustration, we began to look at enhancing and exploring other systems. The client's daughter, after seeing an eye gaze computer system used in the television series *CSI*[1] was keen to try one with her mum. With the help of Inclusive Technology a demonstration was arranged. The client had an opportunity to try the aid, but having never used a computer she felt this was too high-tech for her and she preferred the MegaBee. She was now very comfortable in using this aid and, while she does not think it is worth the £640 price tag; she would happily pay £300. Fortunately in Sheffield, due to the nature of her condition, we are able to offer her this aid on a long term loan.

Once the client's communication issues were resolved to her satisfaction, we began to look more at her environment. We looked first at the activities the client had previously enjoyed. Initially we considered a page turner as the client did enjoy reading magazines. However, she was discouraged from

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[1] *CSI,* Series 9, Episode 19, 'The Descent of Man'

this by the cost and also indicated that now she would rather watch television.

We were also concerned about how she gained attention from the staff in the nursing home. The client reported that she would shout and could become very distressed by the effort involved in gaining the required attention. So we looked at an environmental control (EC).

ACCESS METHODS

The first issue to resolve was how to access the system. Following discussions with the client and her friend it was established that she had consistent control of her left foot. Following Von Tetzchner and Martinsen (2000) recommendations around using the movements that are consistent, but considering that the use of a switch positioned out of the person's sight is more difficult to control, we had a look at using this movement to activate a switch.

The first option we considered was a kick-forward and then a backward movement however both of these were inconsistent as she was unable to aim accurately. So we moved onto stamping on a Specs switch.

This took a little time to position correctly but after a few squashed fingers we found an appropriate place. This enabled the client to easily access the switch and activate it as required.

We then moved on to looking at scanning options. We used a laptop with The Grid 2 installed to explore the options:

- Simple scan with press to activate.
- Simple scan with tap to advance.
- Simple scan with hold to advance and activated on release – Bingo.

The system of hold to advance and release to activate removed the issues of anticipating the movement and enabled consistent and accurate access. So the client practised using the hold to advance with activation for release with the laptop for a number of weeks prior to the installation of her EC system. During this time we slowly increased the number of cells to meet her needs, again enhancing the installation process.

MONITORING AND REFINING

The result of the time and effort spent by the client and our service was a

Figure 2 Specs switch

smooth installation and a confident user from the start. The client is now enjoying her independent control of her television and can flick channels to avoid being stuck on CBeebies for an afternoon. She did initially enjoy testing the system by repeatedly calling for the staff with the EC control. However, this did not last long and now the staff report that she rarely uses it, and so they know when she does she really needs their help.

We have worked with the staff to ensure that the aids are set up appropriately and charged. We are monitoring the use of the EC and are currently exploring the use of the short cuts on the MegaBee which enables the client to produce long words and phrases by typing a number and a letter. This increases the speed of the interaction, but does rely on memory. At this stage the client is using a prompt sheet to support her in using this system.

CONCLUSION

The conclusion of this case study and what we have learnt from working with this charming and determined lady is that the initial cost of staff time to practise and prepare is off-set by a successful and easy installation and use of the systems.

At a time when expenditure is under the spotlight, it is vital that we advocate time for the staff to ensure that these expensive systems are used to the fullest, and that our clients are able to have the most independent and confident lives possible. ✳

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SCAMP:
Specialist Communication Access Mobility Potential

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INTRODUCTION

The choice of your GCSE subjects is a tense time in any teenager's life, so imagine the problems when English is not your first language, you have no intelligible speech and no form of augmentative communication. These were the problems facing a teenager in a mainstream school, who was referred to the Communication SCAMP clinic at Chailey Heritage Clinical Services (CHCS).

This article will give examples of the assessment and outreach/training offered from a Communication SCAMP, including the benefits and difficulties encountered. It will highlight the need for more awareness and understanding of AAC (alternative and augmentative communication) and SLCN (speech language and communication needs) within the general community.

SCAMP CLINIC

This clinic is a multi-professional service based at CHCS in East Sussex which caters for children and young people who have complex needs, including physical, sensory and/or learning disabilities. Our aim is to provide a comprehensive assessment of an individual's potential to access a range of activities including powered mobility, communication, computers and environmental controls through the use of Assistive Technology.

A full SCAMP clinic may last 2-3 days with follow up within the home/community if required, and includes a full postural assessment.

COMMUNICATION SCAMP CLINIC

The Communication SCAMP clinic was developed from the full SCAMP clinic in October 2008, and is aimed at any young person with complex needs in a mainstream, special school or residential setting, who requires a specific AAC assessment, which could include issues with access, but does not require an assessment of posture or mobility.

The multi-professional team for a Communication SCAMP consists of a Specialist Speech and Language Therapist, a Speech and Language Therapy Technical Assistant and a Clinical Engineer. It is important to have the young person's family/carer and community Speech and Language Therapist and/or teacher present.

The trial and provision of an AAC system is supported by the availability of an outreach and training package, which can be delivered by a Specialist Speech and Language Therapist and a Speech and Language Therapy Technical Assistant. This can be delivered in the home, school or social setting and training can cover low- or high-tech systems of communication.

If a VOCA was recommended for the young person, the package would include training on areas such as the use, functions and maintenance of a VOCA for family and school staff, issues of acceptability of the VOCA, monitoring daily use of the VOCA and ideas on how to integrate the VOCA into the young person's total communication system.

ASSESSMENT METHODS

Assessment includes reference to Latham and Miles' *Communication and Cognition Framework*, relating the communication level of the 'bands' of young person to the appropriate system of augmentative communication, including the level of VOCA if applicable (Figure 1).

A VOCA Users Checklist has been devised in which a young person's communication skills can be recorded within the bands, the main areas being attention, verbal comprehension, ex-

Band 1: Pre-Intentional
Band 1: Intentional: single-message device
Band 2: Static screen VOCA
Band 3: Introducing a dynamic display VOCA
Band 4: Using a dynamic display VOCA

Figure 1 VOCA Bands (Miles & Latham)

Smooth Talker

Simply the most versatile single switch communicator

Versatility and simplicity in one single switch communicator! Up to two minutes high quality recording time with the option of single message, sequential and random message playback. Add another switch (using a standard jack plug) for two message functionality and a co-operative mode. Includes built-in wireless technology ready to use with Simply Works toy controllers and it-Click-On Plus. Available in red, yellow, blue and green.

Random messages

Single message

Sequential messages

Use Smooth Talker with an additional external switch to give:

- Two switch message choice
- Auditory scanning
- Co-operative mode
- Remote switch control
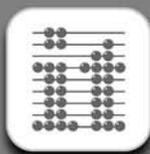
Wired or wireless toy control using Simply Works Technology

A Busy Bee

Pop-up symbol holder

LED mode indicators

Digital amplifier with 2 minutes recording time

Two loud speakers for great sound

pressive language and understanding of switch use.

CASE STUDIES

Transitions are very important stages and can present challenges as well as opportunities. We all face many transitions in life and the challenges faced are especially daunting if you also have speech, language and communication needs. We will consider these issues by looking at the problems faced by some young people who have attended a communication SCAMP.

Case Study 1 (Band 4 VOCA user)

Andrew, aged 11½ years old, has a diagnosis of athetoid cerebral palsy and his main method of communication is speech, which is intelligible only to his family and familiar carers at his junior school. Andrew was about to start mainstream secondary school and he and his parents felt that it was the right time to explore different options to support his current communication skills.

Andrew had good verbal comprehension, no problems with vision and hearing and adequate literacy skills. He did have some problems with fine motor control for access.

Andrew had the opportunity to trial a mounted tablet PC and a palm top VOCA at Chailey and at home. He was also referred to the ENT/Oral Motor Difficulties clinic at Chailey and was recommended for palatal training therapy.

The outcome was that both speech and saliva control improved after palatal training therapy. Andrew and his family

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VOCA User Checklist - Band 4

Attention:

• Two channelled attention (Reynell levels 4-5).

Verbal Comprehension:

• Appropriate understanding of verbal language.

Expressive language:

• User capable of using VOCA everyday for functional or sophisticated communication with familiar/unfamiliar people in variety of situations.

• Using grammar and alphabet if appropriate.

• Creating own novel utterances.

Understanding of switch use:

• User would be competent with their method of access.

Figure 2 Checklist for Andrew - Band 4 (Independent use of high-tech VOCA)

also decided to purchase a Toughbook which has multiple uses including the facility of being a VOCA. Unfortunately eighteen months after the clinic Andrew's LEA had still not agreed funding and Andrew did not have access to his own personalised VOCA.

This case study highlights the effect that lack of awareness and understanding of speech, language and communication needs have on the individual client and their whole family. Andrew was without essential aids for communication and the family were obliged to constantly battle on his behalf.

Case Study 2 (Band 3 VOCA user)

Lenny is 15 years old and facing his GCSEs in a large mainstream secondary school. Lenny has cerebral palsy, English is his second language and he has significant receptive language delays in both English and Tagalog (Filipino) which is his first language. When he was referred to the SCAMP clinic, he had no formal communication system and even now, despite his significant difficulties, does not have a statement of special educational needs.

Although Lenny had developed some speech, he mostly used single words and occasionally short utterances. However, his speech was difficult to understand, particularly out of context.

Lenny was referred to speech and language therapy when he came to England (at 13 years old) and he had had no previous therapy input. Lenny was very smiley and keen to please, but he had also become very passive.

During the assessment, Lenny and his parents were given time to consider and try different options for AAC. Lenny was not motivated to use a low tech system such as a communication book; however, he was very keen to try using a hand-held VOCA. He was able to access the touch screen and use the stylus pen.

Following the assessment, Lenny had trials of different VOCAs and decided that the Dynavox Palmtop would be the best device to meet his needs.

Lenny's school funded his VOCA and some outreach package sessions. During the outreach sessions, the aim was to integrate the use of the VOCA into his everyday life and to train the mainstream staff in the use and maintenance of a VOCA. Staff were also given strategies to help Lenny to use his VOCA. Following these sessions, Lenny still required some prompting in order to use his VOCA.

VOCA User Checklist - Band 3 (with some evidence of skills within Band 4)

Attention:

• Able to alternate between speaker and task, minimal direction (Reynell levels 3-4).

Verbal Comprehension:

• Basic understanding of concepts.

• Requires an adult to clarify misunderstandings.

Expressive language:

• Uses words in short sentences/phrases.

Understanding cause and effect/switch use:

• Understands the concept and operational aspects of using a dynamic screen.

Figure 3 Checklist for Lenny - Band 3 (use of high-tech VOCA with support)

However, he was able and keen to play a role in programming useful phrases for himself.

This case study highlights the need to raise awareness of speech, language and communication needs – in particular the use of AAC systems to mainstream schools. It also raises the issue that there are children and young people who have complex communication needs in mainstream schools at crucial stages of their education (such as exams or transition) with little or no support.

Case Study 3 (Band 4 VOCA user)

David is a 27 year old competent and experienced AAC user. He attended the SCAMP clinic because his current VOCA was only working intermittently and he wanted an assessment to discover what

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VOCA User Checklist - Band 4

Attention:

• Two-channelled attention (Reynell levels 4-5).

Verbal Comprehension:

• Appropriate understanding of verbal and written language.

Expressive language:

• Uses VOCA daily.

• Good knowledge of vocabulary/layout – creates own pathways.

• Expresses a range of functions.

• Uses complex sentences.

Understanding cause and effect/switch use:

• Competent user of switches.

Figure 4 Checklist for David - Band 4 (independent use of high-tech VOCA)

would be the most appropriate device. Although face to face communication was a key need for David, he also had priorities around social networking and staying in touch with friends via text messaging and email.

During the assessment, David was very clear about his choices. He wanted to keep the same language system as he had been used to – LLL, on a Pathfinder. So he trialled the newer version, the Eco2, and chose to have his existing symbols. David also wanted to access this using the same switches as he had previously used. A trial was set up of this system and David received charity funding for this device and switches.

At the time of the assessment, David was relying on his communication book as his VOCA was not reliable. Since moving to his new home after college, his book had not been updated. During the clinic, discussions took place about the importance of keeping this book up to date. This was then updated by David's care staff and David reported that he was using it more frequently.

David was very able to express his needs and his wishes regarding his communication systems and he had a team of care workers who were able to support him. It does however highlight that there is still a frustrating period of time for VOCA users when their system breaks down and they are waiting for a new system to be funded and then arrive.

OPPORTUNITIES AND DIFFICULTIES

There have been clear opportunities and difficulties encountered in the provision of AAC, since this clinic started, particularly with young people in a mainstream setting.

There is the opportunity to reach young people who have previously been struggling to cope in their social or educational setting, maybe with no formal method of communication, which has resulted in passivity or behaviour problems.

The challenges include encompassing both the social and educational needs presented by the young person, the expectations of their family and school, which may differ from those of the young person, liaising with and co-ordinating a wide number of people and agencies, finding a key person to take responsibility for the AAC trial, integrating the system or VOCA into the young person's life, and obtaining necessary funding.

Although the difficulties appear to outweigh the opportunities on paper, in practice it has been highly motivating to help meet the needs of young people with SLCN, and to raise awareness of methods to overcome communication difficulties. It is hoped that campaigns such as the *National Year of Communication* will continue to raise understanding, lead to further practical solutions, and ensure every young person is able to access the resources required to meet their communication needs. ✻

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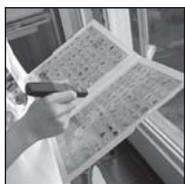
A Survey and Evaluation of the AAC Strategies used by School-aged Children with Learning Disabilities and their Parents' Perceptions of their Needs

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INTRODUCTION

This small study explores the Augmentative and Alternative Communication (AAC) used by a school population of children with profound and multiple disabilities (PMLD) in an inner city UK area and considers some questions that may be of relevance for future research.

PROFOUND AND MULTIPLE LEARNING DISABILITIES

A learning disability is classified by an IQ of less than 70 and a severe learning disability considered as an IQ of 20-34, (WHO, 2001; APA, 2002). Individuals with profound learning disabilities are classified as having an IQ of 20 or below, (WHO, 2001; APA, 2002). People with PMLD are also more at risk of having physical and / or multi- sensory impairments affecting their physical independence, vision and auditory skills (Emerson, 2009). People who have multi-sensory impairments benefit from AAC to facilitate their learning and understanding of their environment (Hoge and Newsome, 2002).

LIMITATIONS OF AAC FOR PEOPLE WITH COMPLEX NEEDS

Shepherd et al (2009) explored the reliability of speech generating devices and found that 40% of the devices needed repairs within the first year. McNaughton et al, (2008) found that regular and consistent use and access to their communication device is vital for communicative competence to be established.

Systems such as such as Objects of Reference (Park 1997) may limit the complexity of the message that can be delivered. A final AAC limitation is the unnaturalness of the communicative act as extra time is needed, in order for successful interactions to take place, (Beukelman et al, 1992). For the most effective implementation of an AAC system to take place, the client needs to be involved as much as possible, (Parette et al, 1996; 2000).

DEMOGRAPHIC STUDIES

Three studies have surveyed different numbers of AAC users (Weiss et al, 2005; Sutherland et al, 2005; Binger et al, 2006). These papers found that communication boards/books are the most commonly used AAC system, (Binger et al, 2006; Sutherland et al, 2005; Weiss et al 2005). Binger et al, (2006) found that more than half of their surveyed AAC users were 'making use of gestures and communication boards/books'. This common use of gestures was also supported by the findings of Sutherland et al (2005) who noted that this was the most frequent form of AAC used by people with 'intellectual disabilities'. None of the studies indicated whether the AAC devices were used for expressive and/or receptive purposes.

AIMS

The aims of this small research project were to explore the range of AAC used as well as demographic characteristics of a primary school in an inner city school for children with severe to profound and multiple learning disabilities.

METHOD

The Participants

Thirty five children aged between 3.2 years and 11.8 years of age were used in this survey. All children had a severe or profound learning disability either as their primary disability classification or a characteristic of their difficulties. Consent was gained from parents and carers prior to the data collection.

RESULTS

Sex

Forty three percent (15/35) of the AAC users surveyed were girls and 57% (20/35) were boys.

Ethnicity

Table 1 provides percentages regarding the range of ethnicities surveyed.

Languages Spoken

Figure 1 shows the home languages spoken by the children in the survey.

Disability Classification

Thirty percent (12/35) of the students surveyed had a primary disability classification of severe global developmental delay. Another category with a substantial number of students being diagnosed with the same diagnosis was cerebral palsy (17%) (Table 2).

Pre-AAC Strategies

Approximately 17% (6/35) of the children were engaged in Intensive Interaction (Nind and Hewitt 1994) and four out of the 35 children surveyed attended ICT sessions to develop their skills of scanning and switch use.

AAC Use

The children used between 2 and 5 AAC systems to support their communication. Approximately 49% of the pupils were using Objects of Reference (Park, 1997) and 49% of the children were also using gesture and Makaton (Walker, 1977) to support their understanding and to communicate. A further 34% of the students were using PECS (Bondy and Frost, 1994) at varying levels to enhance their communication skills. A wide range of other low-tech AAC systems were used by the pupils e.g. eye pointing and body signing (Table 3 and Figure 2). Results showed little use of high-tech AAC systems. Around 28% of the children showed some use of BIGmack switches during familiar routines within the school day e.g. circle time.

Disability Classification and AAC Use

A comparison between primary disability classification and type of AAC use was carried out. The most common AAC systems used by children with severe global developmental delay were Objects of Reference (Park, 1997) (9/12 children) and Makaton signing (Walker, 1977) (7/12 children) (see figure 3). When comparing the AAC use of 6 children with cerebral palsy, it was found that only 33% (2/6) of these children used Objects of Reference (Park, 1997) in comparison to 58% of children with severe global developmental delay.

The most common form of AAC used by children with cerebral palsy was BIGmack switches (67%). Fifty percent of the children surveyed with cerebral palsy used eye pointing as their main form of AAC compared with none of the children surveyed with severe global developmental delay. Figure 4 illustrates the children with cerebral palsy's AAC use.

Two out of the 35 children surveyed had primary diagnosis of autism. Both of these children used Makaton signing (Walker, 1977) and 'first and then' boards (Mesibov et al, 2005) AAC systems. One of these children also used a communication book.

The surveyed gathered information on two children with Angelman's Syndrome. Both these children were accessing PECS (Frost and Bondy, 1994) at level IIIb and Objects of Reference (Park, 1997). One of the children was also using a 'First and Then' board (Mesibov et al, 2005) to support his communication. These children were within 18 months of the same age.

Age and AAC use

The children surveyed were aged between 3.2 years and 11.8 years. Table 3 shows the amount of children in each age band. This is important when drawing comparisons about the use of AAC at different ages. The age and percentage of children were compared to identify any relationships between age and AAC use. The three systems compared were Makaton (Walker, 1977), Objects of Reference (Park, 1997) and PECS (Bondy and Frost, 1994).

Ethnicity	Number of people/35	Percentage
Black African	7	20%
Black British	5	14.27%
White British	4	11.43%
Arabian	4	11.43%
Mixed Race	3	8.5%
American	1	2.86%
Moroccan	1	2.86%
Egyptian	1	2.86%
Sudanese	1	2.86%
Filipino	1	2.86%
Bengali	1	2.86%
South African	1	2.86%
Thai	1	2.86%
Spanish	1	2.86%
Chinese	1	2.86%
Pakistani	1	2.86%
Unknown	1	2.86%

Table 1 Range of ethnicities of those surveyed

Disability Classification	No. of Children	Percentage
Severe Global Developmental Delay	12	34.28%
Cerebral Palsy	6	17.14%
Autism	2	5.71%
Down's Syndrome	2	5.71%
Angelman's Syndrome	2	5.71%
Not yet statemented	2	5.71%
CHARGE Syndrome	1	2.86%
Dandy Walker Syndrome	1	2.86%
Profound Developmental Delay	1	2.86%
Severe Learning Disability	1	2.86%
Bilary Atresia	1	2.86%
Hypoxic-ischemic Encephalopathy	1	2.86%
Tyrosinaemia	1	2.86%
Williams Syndrome	1	2.86%
General Learning Difficulties	1	2.86%

Table 2 Range of disability classifications surveyed
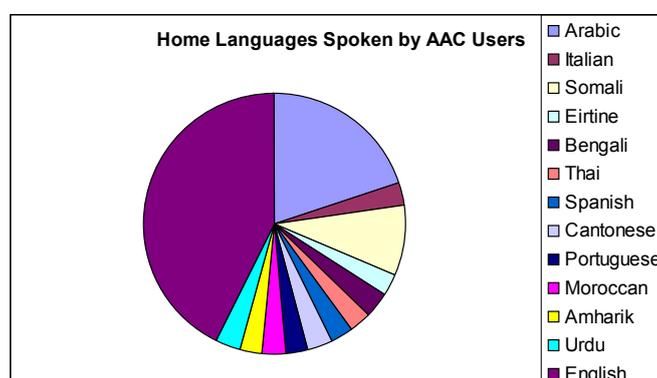
Figure 1 Home Languages spoken by those surveyed

The data seems to provide no relationship between Makaton (Walker, 1977) use and age. A reduction in the use of Objects of Reference (Park, 1997) as children get older with the exception of the 7 year old age children can be seen. It might be useful to note here however that the 3 seven year old children represented in the data all have severe visual impairments which may have impacted on their use of Makaton (Walker, 1977) and PECS (Bondy and Frost, 1994), and increased their need for Objects of Reference (Park, 1997). This is important for this population as Objects of Reference (Park, 1997) provide a tactile way to develop a consistent

understanding of their routines without the need for visual information.

A slight trend was noted in the increase of the use of PECS (Bondy and Frost, 1994) with age, again with the exception of the 7 year old children. A stronger trend would have been seen if some of the 5 year old children were using PECS (Bondy and Frost, 1994). The cognitive abilities of the 5 year old children could have impacted upon their ability to use of PECS (Bondy and Frost, 1994) functionally. Three out of five of these children also had visual impairments affecting their abilities to use the small symbols involved in PECS (Bondy and Frost, 1994).

Involvement of Other Professionals

All of the children surveyed were receiving specialist input from an allied health professional to assist with setting up appropriate supports for AAC use, e.g. equipment for seating or for switches. It was found that 94% of these children were on the caseload of the occupational therapist and 83% were receiving support from a physiotherapist.

DISCUSSION AND CONCLUSION

The percentages of males and females surveyed were approximately equal (57% male and 43% female) as expected within this population, (Emerson, 2009). The children had access to a wide range of languages and this reflects the multi-cultural and ethnically diverse nature of central London as described by the 2001 Census (Office of National Statistics, 2010).

The most common primary disabilities were severe global developmental delay (34%) and cerebral palsy (17%). A large proportion of the children surveyed (83%) had additional difficulties e.g. visual impairment, hearing impairment and epilepsy.

All the children surveyed were using more than one AAC system to support their communication. The use of between two and five modes of communication by, and with these children, portrays the total communication approach to interaction promoted by speech and language therapists for this population (RCSLT, 2006). None of the children were using VOCAs. Children with such complex difficulties are possibly unlikely to be able to use high-tech AAC systems such as VOCAs due to their reduced cognitive abilities and physical restrictions. It was found that 11/35 (31%) of the children surveyed were using BIGmack switches as a form of AAC; however it is not clear how often, and under which circumstances these switches were being used.

Ambiguity of the function of AAC devices in terms of how they were supporting communication e.g. receptively/expressively, was another interesting finding which was similar to the studies described, (Binger et al, 2006, Weiss et al 2005 and Sutherland et al 2005). With lack of clarity in describing how AAC users are actually using their devices it is difficult to understand the best and most appropriate ways to develop their communication further.

There was a high prevalence of the use of Objects of Reference (Park, 1997) 43%. This concrete form of AAC is commonly used by individuals with complex communication needs and low cognitive levels. Increased prevalence of the use of this system within this school is therefore likely to be due to the level of functioning of these individuals.

With regard to disability classification, it was found that 75% of the children with severe global developmental delay made use of Objects of Reference (Park, 1997). This strong relationship may be due to the level of cognition and receptive
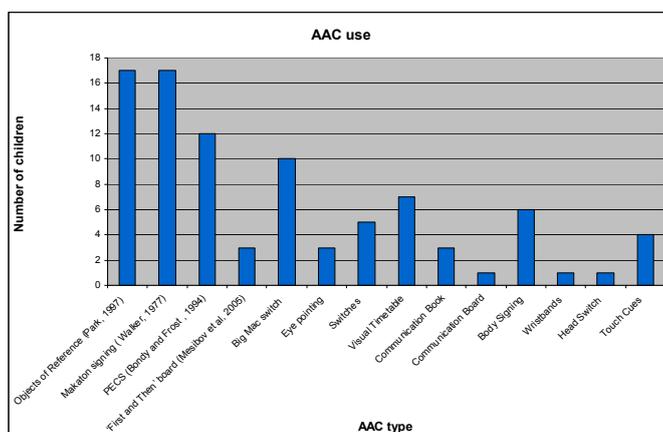
Figure 2   Range of AAC systems used by those surveyed

AAC system	No. of Children	Percentage
Objects of Reference (Park, 1997)	17	49%
Makaton signing (Walker, 1977)	17	49%
PECS (Bondy and Frost , 1994)	12	34%
'First and Then' board (Mesibov et al, 2005)	3	9%
Big Mac switch	10	29%
Eye pointing	3	9%
Switches	5	14%
Visual Timetable	7	20%
Communication Book	3	9%
Communication Board	1	3%
Body Signing	6	17%
Wristbands	1	3%
Head Switch	1	3%
Touch Cues	4	11%

Table 3   Range of AAC systems used by those surveyed
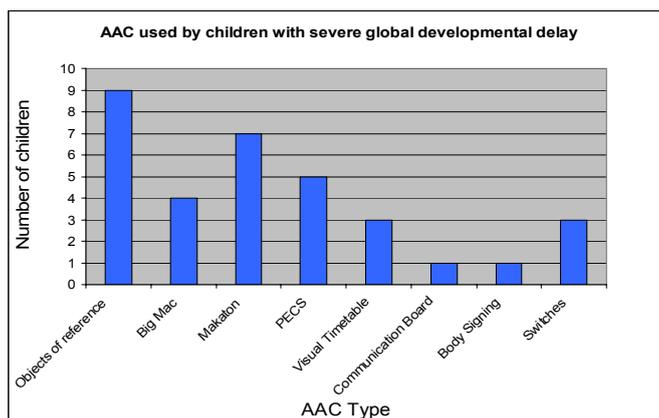
Figure 3   AAC systems used by children with severe global developmental delay
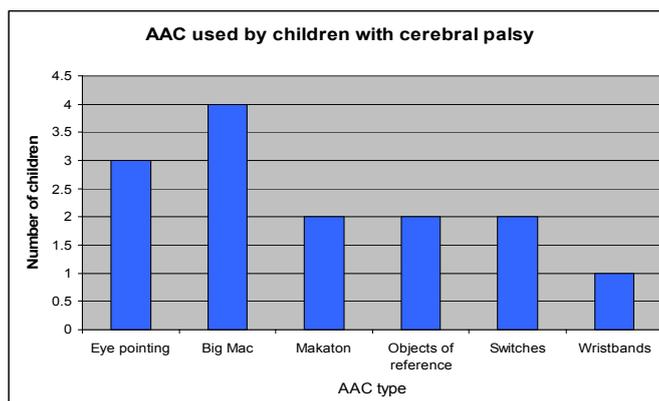
Figure 4   AAC systems used by children with cerebral palsy

skills presented by these children. The use of Objects of Reference (Park, 1997) was less common in children with a diagnosis of cerebral palsy (2/6). Two children with a diagnosis of Angelman's syndrome were both found to be using PECS (Bondy and Frost, 1994) at level IIIb and Objects of Reference (Park, 1997). Two children with a primary diagnosis of autism were both using Makaton (Walker, 1977) and 'First and Then' board AAC systems (Mesibov et al, 2005). Another child in the school had a diagnosis of Down's syndrome and social communication difficulties and was also using PECS (Bondy and Frost, 1994) as his main form of AAC. Capone et al, (2005) found that children with Down syndrome and children with Down syndrome *and* autism have features that clearly distinguish themselves from one another and that these can be identified using the 'Aberrant Behaviour Checklist', (Aman et al, 1985; Capone et al, 2005). This could suggest that the characteristics of these diagnoses require different AAC systems to enhance communication, and that there is a relationship between diagnosis and AAC system use.

CONCLUSION

This study showed some similarities with the findings of the work in the USA, Israel and New Zealand. The severity of the children surveyed in the United Kingdom however was more significant than the other studies that encompassed data from children attending mainstream schools. By developing demographic knowledge of AAC users who have severe and profound learning disabilities, we can begin to understand this heterogeneous population and develop more effective, appropriate and meaningful AAC support to enhance access and choice. ✳

<div align="right">
Alice Moody, *Speech & Language Therapist*

Celia Harding, *Senior Lecturer*
</div>

A full list of references is available from the authors.

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Voice Output Technology

Does it enhance communication in children with autism who use exchange based communication?

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INTRODUCTION

Many young people with autism struggle to achieve effective communication skills and have significant impairment in both verbal and non-verbal communication. The use of augmentative and alternative communication (AAC) can be used to supplement or replace natural speech but its use remains relatively unquantified.

The Picture Exchange Communication System (PECS) is a graphic symbol based intervention package developed specifically for individuals with autistic spectrum disorders. Developed in 1985, PECS focuses on the initiation component of communication. The body of research from around the world supporting its effectivesness "continues to expand" *(www.pecs.org.uk)*. However, whilst some young people become good PECS users, there is also evidence to suggest that some individuals could be supported to move on with or from PECS to voice output communication aids (Checkley & Gaskin, 2006).

The Logan ProxTalker, developed by ProxTalker.com, LLC, is a voice output communication aid (VOCA) designed for children with autism. Like many parents, the father who developed this communication device wanted his son to have verbal communication and the ProxTalker was designed to build on the skills his son already had as a PECS user.

Since its introduction into the UK market, the ProxTalker has received much anecdotal praise. However, seeking more empirical evidence, Logan Technologies, the UK subsidiary of ProxTalker.com, LLC, set out to record clinical evidence to support the use of the ProxTalker by children with autism.

THE STUDY

This pilot study set out to measure the number of exchanges made using a low tech symbol exchange system (PECS) and the number of exchanges made using a mid-tech voice output communiction aid (the ProxTalker). It involved nine participants from three different special schools.

Three participants from each school took part in the study (N=9). Age range CA 15:0-19:0. All nine participants were experienced PECS users. Following parental consent, two participants (randomly allocated) from each school were given ProxTalkers for the duration of the study; the third participant was used as a control measure (evidence measured using PECS). Personal vocabulary available to each participant in PECS form was replicated and made available for use with the ProxTalker. It should be noted that no training was given to students on how to use the ProxTalker.

For the duration of the four week study, three classroom based activities and

three snack based activities were observed per week and exchanges recorded: first and last week with PECS books middle 2 weeks with ProxTalker.

Following completion of the four-week classroom observations, the participants were allowed to take the ProxTalker home and qualitative data was recorded by the parent/carer. Participant 3 (the control) was allowed full use of the ProxTalker for two weeks, at school and at home after the study period was complete and qualitative data recorded by both parents and teachers.

The table below sets out the schedule of observations recorded.

QUANTITATVE RESULTS

For the purposes of this article, the results are presented as an averaged figure across the three schools; if you would like the individual results please contact me for a copy of my 2010 Communication Matters conference presentation. Figure 1 represents the participants using the ProxTalker for the study (show in red) and Figure 2 represents the 'control' group.

CONCLUSION

There was no statistically significant difference between the number of exchanges made using the ProxTalker and the number of exchanges made using PECS: see Figures 1 and 2. There-

	Participant 1	Participant 2	Participant 3 (control)
Week 1	Own PECS book	Own PECS book	Own PECS book
Week 2 & 3	ProxTalker with matched personal vocabulary	ProxTalker with matched personal vocabulary	Own PECS book
Week 4	Own PECS book	Own PECS book	Own PECS book
Week 5	Use of ProxTalker at home - qualitative observations recorded	Use of ProxTalker at home - qualitative observations recorded	Own PECS book
Week 6			Use of ProxTalker for two weeks at school & at home - qualitative observations recorded

Table 1 Schedule of observations recorded

fore, to answer our initial question "Does voice output technology enhance communication in children with autism, who use exchange based communication?" we can conclude communication using the ProxTalker, an example of voice output technology, was equal to that of exchange based communication with no voice output.

QUALITATIVE DATA

The benefits of collecting both quantitative and qualitative data are clearly evident in this study. The participating schools gave a profile for each participant and, for presentation at the CM2010 National Symposium, I summa-

rised these alongside individual participant results. Some of this descriptive profile information clearly matched the participants and some did not.

Figure 3 is an example of data that clearly does appear to accurately reflect the participant ("a confident PECS user", as evidenced by the number of spontaneous exchanges made). Figure 4 is an example of data that does not appear to well represent the participant (who was reported to be a very reluctant PECS user and very passive, although this was clearly not reflected in the data).

These examples are a reminder that when collecting qualitative data the in-

formation given is subjective and may be unknowingly prejudiced by a wide range of variables. Or in fact participants may respond differently however hard we try to keep parameters constant. This is not in any way critical, it simply supports the importance of gathering both quantitative and qualitative date where possible.

ASSISTANT/THERAPY FEEDBACK

- *Very motivated but over excited and needed to be told to calm down!*

- *Usually reluctant to change of any kind, the students quickly adapted to using the ProxTalker in preference to their books.*

- *Student was motivated to use the ProxTalker when the other students were using it.*

- *He will only press one symbol unless prompted.*

- *Very motivated and exchanges were a lot faster.*

- *Spontaneously organised symbols into categories.*

- *Highly motivated by food activity, tried to verbalise too.*

- *Even though his folder was in sight, he found the ProxTalker and asked for a snack.*

- *He sequenced the buttons, had his snack and then changed the symbol to pretzel. All done independently, I was surprised!*
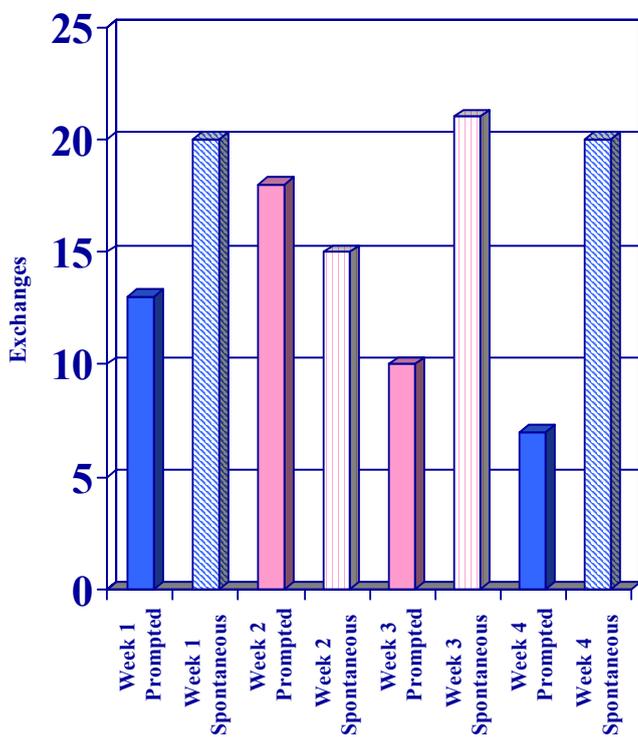
Figure 1 Average ProxTalker Results
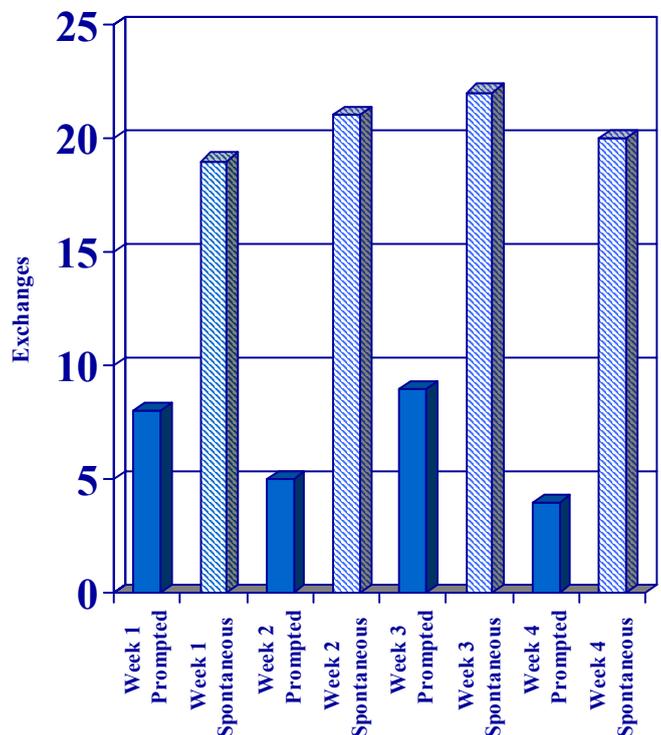
Figure 2 Average Control Results
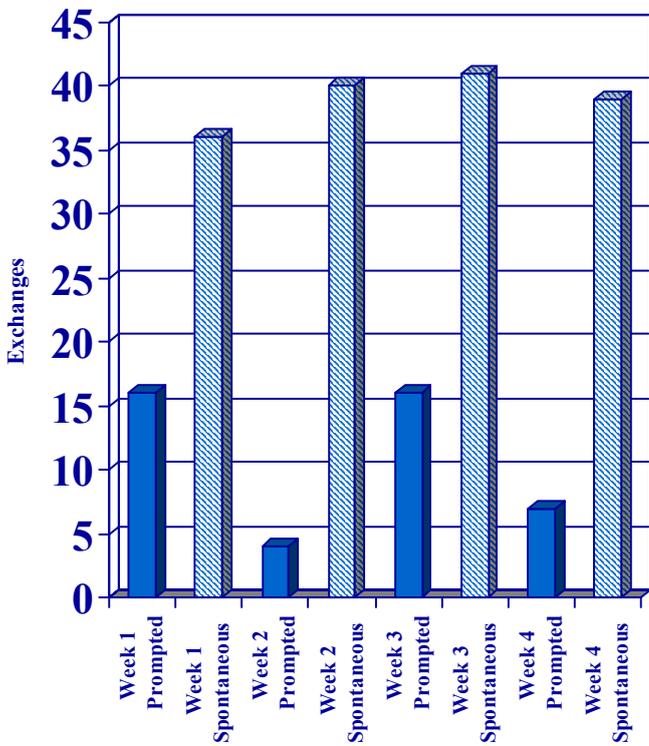
Figure 3 Confident PECS user
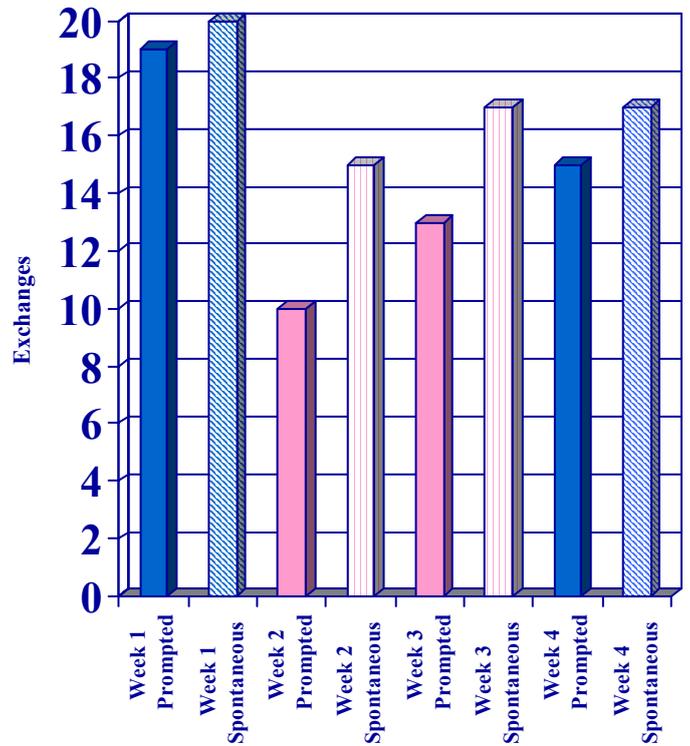
Figure 4 Reluctant PECS user

SLT FEEDBACK

- *In group activities we have seen a positive increase in turn taking and waiting skills.*
- *Anticipation has improved.*
- *Sentence structure has improved and sentences are frequently of a 5 word length with competent users.*
- *Student was confused by change of device. Seemed quite relieved to have his PECS book back.*

This final statement is very clearly supported by the statistical data as shown in Figure 5. Much prompting is given initially but with very few spontaneous responses using the ProxTalker.
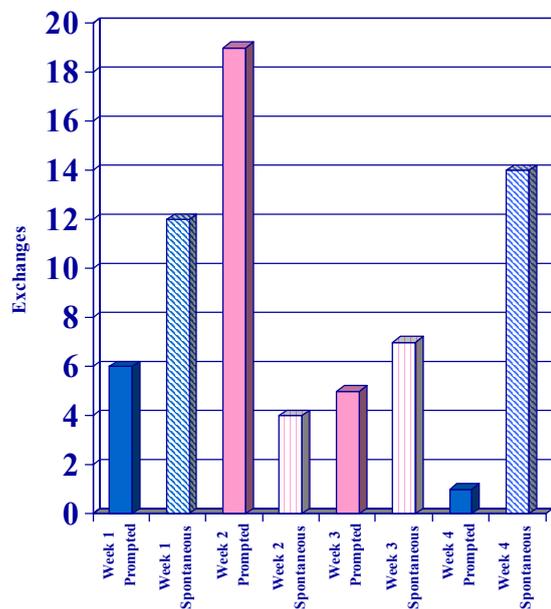
Figure 5 Prompted use of ProxTalker

The data shows spontaneous responses picking up again when returning to use of the PECS book. But in fact, in the context of this study, it was not a typical response. For a group of people who find change difficult, it was a surprise not to have had more results like this.

DISCUSSION

These are the salient points that need to be considered when interpreting these results:

No formal instruction was given on the use of the ProxTalker

To ensure consistency and for the purposes of the study only, it was felt that to give no instruction would yield fairer results. Ultimately, this strategy reinforces the simplicity of the device and raised questions concerning where input would be most valuable.

Some of the qualitative comments suggest that therapy input may well be better spent with support staff, rather than the user.

As a practitioner I have not previously experienced providing communication equipment without formal instruction – and lots of it! Finding out how the device works and communicating this to the user can be very time intensive; this is not the case with the ProxTalker.

The ProxTalker statistics were gathered over a period of two weeks only

I consider this to be the most significant factor in this study. Over a period of two weeks the participants were making the same number of exchanges as they previously made using their PECS books. This, with no formal instruction and no additional therapy input. Obviously, a longer term, larger scale study is required to draw any firm conclusions, but this was a very impressive result.

Personal vocabulary was matched to PECS books but was limited

Vocabulary was matched to PECS books for snacks and for topic specific lessons. Entire personal vocabulary sets were not reproduced so participants did not have full access to their vocabulary. This may well have had an influence on the number of exchanges made.

Data was collected by learning support assistants familiar to the participants

This was necessary to minimise the number of changes for the participants. In our initial consultations, the participating schools all felt it absolutely necessary not to change the staff working with the participants. However, statistically this is considered a confounding variable.

CONFERENCE PRESENTATION

The benefit of the Communication Matters National Symposium is that you are offered the opportunity to share professionally with like-minded busy practitioners who understand that noth-

ing is perfect but who value your contribution and offer constructive comments.

Following the presentation of this study, I engaged in a number of lengthy conversations about the results and was truly encouraged by the observations made. In my own mind I had concluded that if you only trial a device for two weeks, you will probably spend the first week getting to know it (and the person working with you will probably prompt more, thus producing a lot of prompted responses in this period). Therefore, I concluded, the second week of trial would be statistically more valuable.

This premise was rightly challenged and it was suggested that during the first week there were more responses because the participants were genuinely excited about the device. Absolutely, why not? Of course we cannot know the answer, but it was great to have input from people not involved in the study, simply looking at the results.

And finally, the best omission of all – had I asked the participants whether they preferred their PECS book or the ProxTalker?

Sometimes even the most obvious elements are omitted and this is one of them. Thank you to the practitioner who so casually asked me this innocent question! It's on the new recording form already!

So those were our mistakes. Now for the bit which was really valuable and one which I urge you to consider even in very small studies such as this – the use of 'randomised control participants'. This was invaluable in our study and certainly considered good practice, adding weight to the efficacy of the study.

Quite often it feels as though you are reducing participant numbers by using some of your participants as a control, but it has only been possible to compare our results because data was also collected for the PECS group.

FUTURE AREAS FOR STUDY

- A longer term or follow-up study would generate valuable statistics.

- This study looked at young adults, age range CA 15:0 - 19:0. A study involving younger children would be very informative.

- Criteria for this study included participants being PECS users. A comparative study involving children who have not been PECS users would be very interesting.

- Time and speed of communication.

- Measuring the impact on verbal output – a concern for many parents.

- The Social impact of using the ProxTalker – use within the family and the wider community.

I hope the essence of this study will inspire and encourage those of you who are thinking about research for it is in this way that evidence-based practice will truly become a reality. Maybe then we will have available more user-inspired devices like the Logan ProxTalker. ✳

Laila Emms
Speech & Language Therapist

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WEBSITE

Pyramid Education Consultants website: www.pecs.org.uk

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