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Cover: Ian (right) goes sailing using a specially mounted E-tran frame (page 2)

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AAC for Use in a Sailing Boat

A student design project

TOM HOLE

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INTRODUCTION

The purpose of this project is to develop a method of communication between the helm and crew on a small sailing dinghy (Access 303) when one of the sailors is disabled and can only communicate using AAC. The development work was for an 'Extended Project Qualification' at Wells Blue School, Somerset.

This project is important to me because I sail with my friend Ian, aged 14, who has cerebral palsy. We are currently National champions two years running in the Access 303. However, existing AAC techniques are not designed with sailing in mind and so currently it is difficult for me to understand what Ian wants me to do. I would therefore like Ian to be able to communicate with me using a better method so that he can have more involvement in the boat.

APPROACH

To plan my work approach and manage my time, I made a list of things that needed to be done and constructed a Gantt (project planning) chart to give myself deadlines.

For research, I used many sources - including Ian's family, other disabled sailors, the Internet, academic papers on AAC and suppliers of AAC equipment. I also looked at what Ian uses on a day-to-day basis around his home, both electronically and manually. I considered which method was most suitable to be adapted for use in a dinghy and then set about developing a new AAC system for us to use when sailing and racing.

IAN

I started sailing with Ian in August 2011 after we met at my sailing club. Ian has cerebral palsy and is therefore unable to sail by himself. He is unable to control any of his body movements as well as being unable to talk, though he can make some sounds. Ian can control his eyes and has very good mental ability. His parents, Paul and Liza, have developed approaches to communications that utilise this and enable Ian to interact with others.

Ian uses eye movements to communicate utilising both aided and unaided techniques. In the past Ian has tried different methods of communication, from stickers to iPads. He is currently using a computer at home which follows his pupils using an infra-red signal sent by a camera which bounces off his retina. This enables Ian to communicate with other people as the computer talks what Ian is writing with his eyes. It is, however, hard for Ian to use as it requires a lot of effort. He also uses 'yes/no' stickers on his wheelchair which is easy for him to use and he can take anywhere, allowing people to ask him basic questions and for him to give a yes/no response by looking at the appropriate sticker. He also uses a book which has special symbols so that he can make sentences by looking at the appropriate sticker. However, when sailing Ian can only use unaided methods as at present, all aided methods are not suited to sailing. This therefore limits his communications to "yes" and "no" answers, making communication on a

boat difficult. Furthermore, Ian and I sit next to each other, making it hard for me to see his eyes.

THE ACCESS SAILING DINGHY

The Access dinghy is a small two-handed boat designed so that anybody can sail; it is specifically designed for disabled people. The boat is designed around stability and easy use of the controls. The helm and crew are low in the boat giving it a low centre of gravity which, together with a large heavy keel, ensures it does not capsize. Unlike most boats, the helm and crew sit side-by-side in the boat facing forwards. A lever between them controls the rudder and enables either of them to steer. The other controls are the main sheet that controls the main sail and the jib sheets that control the jib (the smaller sail).

The design of the Access dinghy enables people with a range of disabilities to sail. Options are:

- Sail on own with no aids: wheelchair-bound but otherwise able bodied people can sail as there is no need to move about the boat.
- Sail on own using a range of aids.
- Sail with a buddy, with some control, such as being able to steer.
- Sail with a buddy, just giving direction (this is how Ian and I sail but I want Ian to be able to give more instructions).

There are regular races organised for the Access class. I race with Ian; we are currently the National champions for the 2-hander 'buddy' class. The racing



Figure 1 Parts of the boat

is set, depending on venue, with either a triangular, trapezoid or occasionally windward/leeward course, and our Nationals are generally a trapezoid. When going upwind, you can't go straight into the wind so you must tack upwind (sailing at 45 degrees to the wind and turning through it to get to the windward mark). Each race lasts for approximately 45 minutes and there are usually six races in a two day event.

REQUIREMENTS FOR AAC IN A DINGHY

As Ian knows when to tack and get on the laylines (the minimum distance you have to be from the wind whilst still being able to make it to the mark) I'm hoping to develop a method which enables him to communicate with me so he can tell me when to tack, as well as other important things such as where the other boats are, or if he needs to go in. This will therefore give him a more enjoyable experience and greater participation (as well as taking a lot of the pressure off me). In Ian's case it would be very difficult to develop a system for him to control the boat directly so my aim is to develop AAC methods to enable him to communicate with me more effectively.

In order to establish the requirements, I spent time discussing options with Ian and his parents. We came up with the following list of requirements:

- It must be affordable.
- The method must be robust and waterproof (if using electronics).
- It must be able to fit in a boat.
- Easy for Ian to use.
- Easy to see, from the other persons perspective, what Ian is asking for.
- Easy to learn.
- Preferably adaptable to other boats in case Ian wishes to change class.
- Enable the communication of a range of commands including: when to tack; steering the boat (e.g. changing course); when to reef; sail adjustment (tighten/ease sails); stop/finish.

The approach I took was to evaluate available AAC techniques and consider

which could be used by Ian and applied to a sailing dinghy.

AAC OPTIONS AVAILABLE TODAY

There are a variety of methods available for those who use AAC that can make their lives easier and give them "a key to mental freedom" (Brown C.). These methods are categorized by two main titles, aided and unaided communication. Unaided AAC is the use of body and eye movements. Aided AAC is then categorized again into low and high technology. Listed below are the main AAC options available. For each, I have assessed the suitability for use by me and Ian in our Access dinghy. I have done this by evaluating how well they meet the requirements listed above.

UNAIDED AAC

Unaided AAC is communicating with the use of eye pointing and/or body gestures. There is no external help involved.

The advantages of this are:

- Costs nothing to use.
- Will always be available to Ian when he needs it (he doesn't need to keep turning it on or off like the computers).

However:

- It limits what Ian can say to yes/no.
- Whoever is communicating with him needs to guess what Ian wants and ask the correct question.

"Yes/no" gestures

"Yes/no" eye gestures involve Ian looking right for "yes" and left for "no". This is what I predominantly use for communication with Ian but it only enables him to give yes or no answers. This limits what you can ask him. It also means that you have to guess what Ian wants and ask him the right question.

This method could be adapted for the boat by getting Ian to look at where he wants me to go. The problem with this is that it involves a long process as I would have to ask several questions until I reach the right one. It will also require a lot of concentration from Ian and it will be hard for me to tell whether he is just looking out of the boat or whether he wants me to do something. Also there will only be a limited number of instructions. It is, on the other hand, completely free and can easily be set up in a boat.

Advanced gestures

Advanced gestures are methods of communication with body movements, for example sign language. This method, although it could be adapted for sailing use and communication on a boat, is beyond Ian's capability.

"Gestures can get you a cup of coffee in the morning, but they do a poor job of telling your friend about that delicious piece of cake you had the other night"

Michael Williams (1994)

LOW TECHNOLOGY AAC

Low technology is the communication method using equipment that uses no electricity, for example the use of books and picture boards. As with any product, the low technology methods have their advantages and draw backs.

The advantages of low technology methods are:

- Low cost and low repair costs.
- The range of communication is greater than with unaided methods.
- Durable and without electronics so no need to worry about them getting wet.

However:

- There is a limited range of commands.
- It can be difficult to see what Ian is looking at (especially if you are side-by-side).

E-tran frames

E-tran frames are a basic but effective method of communication. They involve a number of symbols positioned around a board with a gap in the centre. Someone holds the board, facing the person using AAC. The other person can then look through the gap and see which symbol they are looking at. However, there is only a limited amount of space for the symbols and it's not very effective when sitting side by side. I am also unable to hold the frame as I need both my hands to sail the boat.

It can, however, be adapted for sailing. It can have stickers to help Ian tell me what he wants. Also, I could use parts of the boat, along with the stickers, as a way for Ian to be more specific in what he is asking. For example, by looking at the main and then the 'sheet in' sticker, I know to sheet in on the main.

Eye-pointing book

Ian uses a book when he is at home that enables him to ask for various things and communicate his thoughts. It is set up similar to the E-tran system. Within each square are a set of words, each with a coloured ring around; Ian will look at another colour square to indicate the word he wants within the first square. His eye-pointing book does have an index so you don't need to guess which page he needs but sometimes you have to do a couple of page turns as Ian navigates to the page, which is time consuming. For example, he might select 'feelings' from the index, you then



Figure 2 Ian's eye-pointing book

turn to that page, he selects 'pain' and then selects 'back to index', and so on. This method is hard to learn but once mastered it is very useful for enabling Ian to communicate. It could be adapted for the boat by having a page for sailing and using these stickers as a method for Ian to instruct me as to what to do. This however, will be hard to use as I would not be able to see his eyes and may take a long time to process a small instruction.

HIGH TECHNOLOGY AAC

High technology is the use of electronics in devices. The advantages of high-tech AAC are:

- Large number of devices to choose from, including iPads and laptops.
- Built to withstand strong forces.
- Can provide structured sentences.

However:

- They are very expensive both to buy and repair.
- They are not built to be waterproof and survive sailing weather.
- They can be difficult to fit into a boat.

Tobii C12 with C-eye

This is a computer designed to follow the eye of the user. It follows Ian's eyes

and speaks what Ian is looking at. It has a grid system with various words and phrases like most other techniques, but it also has the facility for new phrases to be added. This allows us to write in exactly what needs to be said for that day. It is also possible to mount the computer on a stand in front of Ian. However, this computer system is very expensive (£11,000) and not very robust.

I could develop this method for sailing by typing in the instructions Ian would need to use, for example "tack" or "bear away". To prevent water from getting in, I could design a special waterproof case but this would be hard to do as the device needs to detect Ian's eye movement.

Chin switches

It is possible for Ian to use chin switches. There are chin switches that, when pushed, produce speech output. There are also chin switches that can control the movement of chairs and various other pieces of equipment. They can easily be attached to Ian's chair and are robust enough to survive being in a boat. However, although Ian can use them, he finds using them very hard and can sometimes hit a button randomly.

To develop them for sailing, I could program them to speak various instructions so that Ian could hit the instruction he wants. This however, limits what can be instructed to the number of chin switches available and it would be hard for me to tell whether Ian hit the switch on purpose or by accident. Furthermore, as the boat heels over, Ian can't keep a central position within the boat.

Apple iPad

Another possible method is the iPad. There are several apps designed for AAC such as 'ClaroSpeak UK' and

'Image2talk'. It is also possible to get special protective cases and mounting. The iPad could be adapted for sailing by using special cases and mounts to make it waterproof and positioned in a good position for the user. Sailing instructions could be entered into the app allowing it to be used as a communication method on the boat. Although it is beyond Ian's capability it does provide various communication methods designed for people with cerebral palsy and can be a method of communication for others.

DEVELOPING AN AAC METHOD FOR USE ON OUR ACCESS DINGHY

I designed a table (Table 1) allowing me to turn some qualitative data into quantitative data. The methods are assessed against each of the requirements for use in a sailing dinghy and graded 1 (worst) to 5 (best). The method with the highest score is the most recommended.

From the results, I saw that the most effective method of communication is the E-tran fame. This had the highest score because it is relatively easy to use; can be adapted to suit the needs of the user; is cheap; can be adapted to suit sailing; and is robust enough to survive knocks from both Ian and the boat (and if it does break then it can be easily replaced or fixed). However, when using E-tran frames, the people involved need to be facing each other, whereas Ian and I sit side by side and I also need to be able to look out of the boat. On top of this, I need to be able to use my hands rather than holding the E-tran frame.

Idea for 'mirror assisted eye-pointing'

To resolve these problems, I came up with the idea of using a mirror. This will enable me to see Ian's eyes and what he is looking at, whilst sitting next to him. Surrounding the mirror will be the E-tran frame with various sailing instructions.

I emailed Ian and his Mum, Liza, explaining my method and asking whether it was possible. Liza then tested this with Ian, asking his carer to sit next to him, facing a mirror, and then asking him questions the carer did not know the answer to. They reported that the technique worked and so I started thinking about building a prototype we could use in the boat.

Design and build

To build this method I had three components to take into consideration: the mirror, the mount and the E-tran frame. I tried several different types of mirror to see which would be most effective. I

Option	Affordable	Robust	Easy to fit in boat	Easy use	Easy to learn	Adaptable	Total
Eye-pointing	5	5	5	1	1	3	20
Gestures	5	5	5	1	1	3	20
E-Tran	4	3	4	5	4	5	25
Ian's book	4	4	3	2	3	5	21
Tobii C12 with C-eye	1	2	3	5	5	5	21
Chin switches	4	5	3	1	3	5	21
iPad	2	3	3	1	4	3	18

Table 1 Determining most effective communication method



Figure 3 Car mirror and camera mount

then decided on the use of the rear view mirror from a car. This was small enough to fit in the boat, whilst being big enough for me to see Ian's eyes. It was also flexible and could be adjusted to the correct angle. I bought one from a car breaker's yard for £10 and used a camera mount to attach the mirror to the boat. The mount had two adjustable parts, with a clamp at the bottom and a camera mount at the top, which enabled Ian and I to attach the mirror to the boat and then adjust the angle of the mirror to suit us both.

For the E-tran, I created some symbols to use and laminated them to protect them from the water. Once laminated, I cut a hole in the centre to allow the symbols to be positioned around the mirror and make it easier to attach the laminate to the mirror.

I started with four symbols (Fig 4). The end result fitted securely to the boat. I had a quick test with Ian to make sure we could see what was going on. This was successful: I could easily see which symbol Ian was looking at. However, before we launched and tried this method on the water Ian was confident that we could use a frame with eight stickers: *tack*, *head up*, *bear away*, *sheet in*, *sheet out*, *something else*, *stop/finish*, *cold*.

Results

Once on the water, I checked everything was stable and then set Ian a course to sail around some buoys, whilst



Figure 4 Initial set of symbols

I kept my focus on the mirror and the sails rather than on the direction of the buoy. Ian then successfully steered the course by calling each tack using eye-pointing and the E-tran. We predominantly focused on the tack commands, but also developed the use of head up/bear away commands as well. We repeated this several times, each time becoming more efficient than the last. We used a total of four commands effectively: *tack*, *head up*, *bear away*, *stop/finish*.

The mirror was held in place securely and there was little disruption from the wind. It was angled so that it was easy for us both to see what was going and was comfortable for both of us to use. In addition, the E-tran frame and mirror were small enough that they didn't disrupt the sails or get knocked by them despite the tacks and gybes. Furthermore, I was able to continue focusing on what Ian was asking of me, whilst keeping my head out of the boat.

IMPROVEMENTS TO THE DESIGN

Overall, the method worked well. When we got back to shore, I asked Ian how he thought it went and asked him to email me with more details about what he thought worked well and what didn't. Ian and Liza's email was very encouraging: *"Really impressed with E-tran frame mirror combination. Low-tech still has an important place in providing solutions. Ian was pleased with it and felt it worked."*

Ian is now working on new symbols which he understands (Fig 5). This is because it is like learning a new language, but it is easier for him to learn if he designs it. Also, I am working on protecting Ian more as, on occasion, his legs hit the mount which was painful and uncomfortable. Furthermore, I can increase our vocabulary by putting stickers around the boat, not just on the E-tran frame, as the mirror enables me to see which part of the boat Ian is looking at.

We plan to develop the system and use it when we are sailing in 2013. It will definitely enable Ian to be more involved with sailing and get more enjoyment from the racing competitions.

CONCLUSION & RECOMMENDATION

My aim was to develop a system for someone who uses AAC so that they have more involvement in sailing. By adapting two techniques, a mix of eye-pointing and E-tran frames, I have managed to come up with a new communication technique which I have called 'mirror-assisted eye-pointing', that can further increase the enjoyment of sailing. It is a cheap and robust

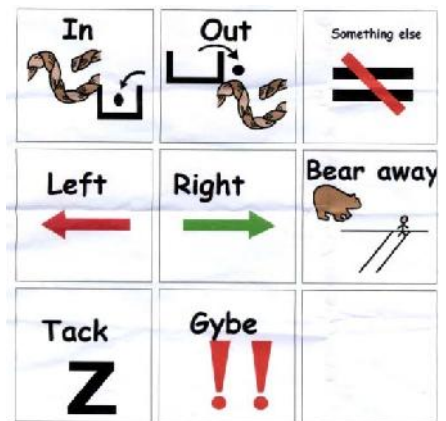


Figure 5 Ian's new symbols

technique, easy to learn, and can be adapted for any situation. As an early prototype, this method has increased Ian's involvement in sailing, so the project has been a success.

In addition, whilst undertaking this project, Ian and I have met many people and this has resulted in increasing sailing opportunities for both of us and inspired us to go further with our sailing. We are currently considering a plan to sail our boat across the English Channel.

I now understand more about how Ian communicates, making it easier for Ian and I to sail together.

I would recommend this method for others with a similar situation as it can be easily adapted for many uses. Furthermore, this method can be adapted to fit a wheelchair, allowing the user to communicate to the person pushing the wheelchair whilst moving, rather than having to stop and see what the problem is. *

Tom Hole

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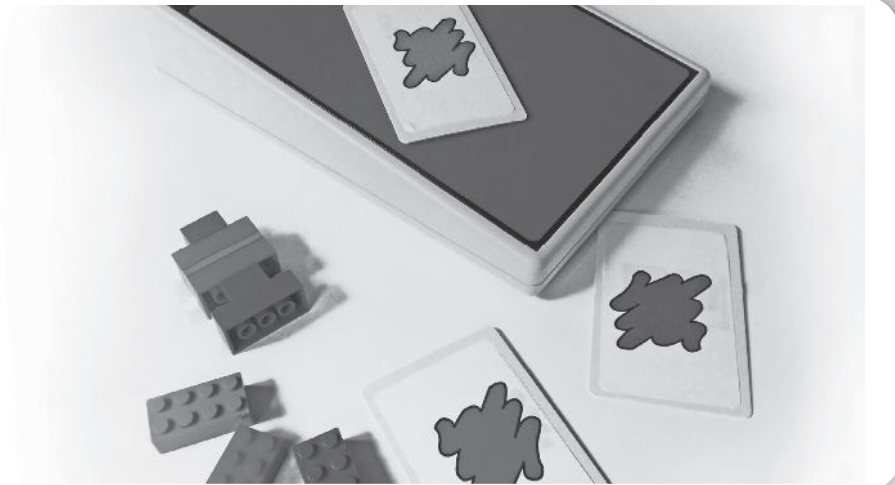
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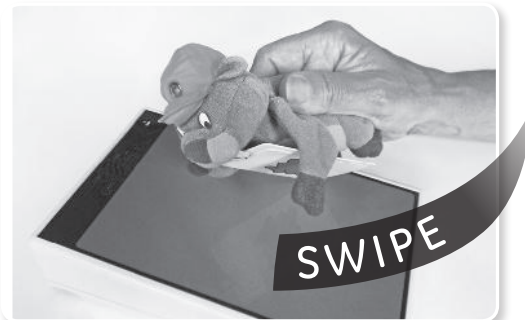
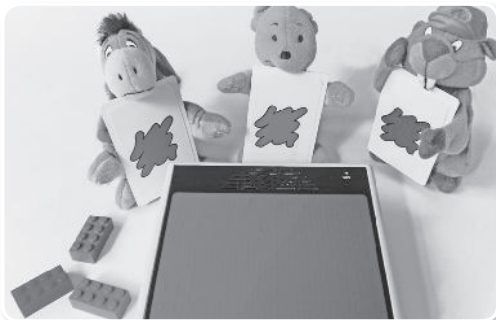


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Eight Years Self-Employed

If I knew then, what I know now...

ALAN MARTIN

Mouse on the Move

Email: mouse_on_the_move@btinternet.com



I've been working as a self-employed creative dance practitioner now for over eight years. I've discovered a lot of things about self-employment that I want to share, so that other people who use AAC can benefit from my experiences and have full knowledge of what they are doing, if they go into self-employment.

BACKGROUND

A little about my background, first. My first communication aid was bought for me by friends when I was 31 years old. Before that, my communication was very limited, with only close family and friends understanding anything of my signing, or facial expressions. I attended a social services day centre and was extremely frustrated with my life. I had no control over anything and lived in the care of a parent and step-family, where I felt lonely and that nobody knew the real me.

BECOMING INDEPENDENT

Getting my first communication aid very rapidly turned my life around. I was able to tell people that I wanted to live independently and to take charge of my own affairs. I was able to ask my social worker to get a solicitor to visit me at the Day Centre and explain my legal rights. This led to years of arguments with my family. Eventually, about three years after getting that first aid, I moved into my own home, with my own support staff, and I have lived there successfully ever since.

Being independent meant that I could choose what to do with my time, and I chose to join many local groups who

were working on getting disabled people equality and fairness in life. Also, I realised that my education had been very poor, to say the least. I had attended school at a time when special schools didn't really have to educate disabled kids. There were no expectations that any of us would have jobs or even move into our own homes, thus little got taught in those early years. I realised that I needed to fill in some big gaps. Being now in control of how I spent my time, I chose to attend courses on the things I felt my education had lacked.

DANCE CAREER

Among all those meetings, and courses, I found time to start my creative dance career. I attended workshops, took part in public performances, and got totally hooked on it. I went to every class that I could, attended residential courses, and finally learned how to lead my own creative contemporary dance workshops by attending the Liverpool Institute of Performing Arts.

BUILDING NETWORKS & EXPERIENCE

Armed with qualifications, I needed to build networks and gain experience. Through contacts, I was invited to lead dance workshops all around the country. One of my first was at this very conference, where I had speech therapists, parents, people using AAC, and some Communication Matters Trustees, leaping around the room and having a riotous time.

I was delighted that this workshop led to lots more invitations, and I did hundreds of dance sessions for friends and

contacts, just asking for my expenses to be covered. Almost every session led to several more, and soon I was working for just my expenses, almost every day, and getting great experience. Some events where I worked wanted to pay me a similar fee to the other creative artists, and I had to refuse payment as it would affect my benefits. At first I didn't mind, because I was having such fun, and getting better at my work each time.

People started telling me that I really should be charging a proper fee for what I was doing, as it was so valuable on so many different levels. Having this said to me, just made me feel so good. What a contrast - from a few years earlier at the day centre, when the only work offered to me was voluntary work, picking up litter in the park with a pointy stick - to now being told to charge a proper fee for doing something that I truly loved, and which so many people valued.

FINDING EMPLOYMENT

By 2002 I had made the decision to try working for my living. I'd met some people with disabilities who worked, and were not on benefits, and I really admired them, and felt that doing this was the real way to educate the public about disability equality, rather than just talking about it.

At this point, I had not thought of self-employment, and began looking for a job where I could use my skills, and hopefully get paid wages for my efforts. I asked my MP for advice, and she told me to speak to a disability employment officer at the local Job Centre. I arranged an appointment, and went along for an

interview. This resulted in being given a list of disability employment brokers, who would try to find work for me.

I got my Personal Assistant to ring around the brokers on this list to arrange interviews. The first barrier to this was just unbelievable. Only one disability job broker had a wheelchair accessible office. That was from a list of about 10. I expected that this accessible one would be well clued up to working with disabled people. Wrong assumption!

He was gobsmacked when I turned up, and didn't know how to react. First he had to move furniture to let me into his room, and then started interviewing my assistant instead of me. He was unbelievably patronising, and asked me if I knew what I was doing. He had never met a person who used AAC, and I had to tell him that I was not a child! I was seeking employment as a dance practitioner or performer. I was told that he would send me any suitable jobs that came in.

Over the next weeks, all I was offered was office work for dance organisations, which would have been totally unsuitable for me. I felt rather let down, and wondered what to try next.

SETTING UP IN BUSINESS

Luckily, at this time, I was actively attending meetings at a local disability arts organisation. They were running a course on setting up your own business for artists with disabilities. It was a four month course and covered all aspects of: setting up a business, market research, pricing your product, writing a CV, presentation skills, advertising, fundraising, book keeping, and most importantly, how to write a business plan. We were given advice and guidance on the business plan, and the whole course was really helpful.

After this experience, I decided to try self-employment, rather than looking for a job.

Armed with my business plan, I went back to the Job Centre where I was given enthusiastic support to start self-employment. The political climate had changed, disability rights were high on every agenda, and I was told about the Access to Work scheme. I was given a specialist assessment for a dance wheelchair and new communication aid. Also I was given funding to pay a business support worker to help me with those things that I could not do for myself, due to my disability. This was all really encouraging, and I embarked on self-employment in March 2004. At that time, I was told that I had a year to try out self-employment, and, if it didn't

work out, I could go back on my benefits. Nothing was mentioned about what would happen if the business failed in the future or if I became unable to do my work, or work just dried up. If I continued self-employment for over the first year, there was no discussion about the wider implications of that!

CREATIVE DANCE WORKSHOPS

My original business plan was to lead creative dance workshops, and give some disability issues presentations. That's how it started, but each year I developed my range of activities, and was also asked to do different things, so that now my business is very diverse and interesting. However, my main work and love is still dance.

My creative dance workshops are for a whole range of clients, from very young to quite old people, people with learning and physical disabilities and non-disabled people. I have worked with University students, and school children. My favourite jobs are with fully inclusive groups, and a whole mix of ages and abilities. Those are the most interesting.

RESEARCH

One very interesting piece of work was a research project, looking into all the ways that non-disabled dancers could dance with dancers using electric wheelchairs. I employed a number of professional dancers, to experiment with me on ways to dance with people like me. I got a lot out of this myself, but I know that I had a lasting effect on the dancers who worked with me. This was so valuable, and I would like to do more of that type of research.

I have also been involved in university research projects around the country, and recently did some work for Communication Matters, and also for the *CreST* network (Creative Speech Technology), which is based in York and Hull universities, and includes many experts in synthetic speech technology. The work is all based around raising awareness, or improving things for people who use synthetic speech, and it's really interesting to meet up with so many different people.

EXPLORATIONS WITH SOUND AND LIGHT

There are many benefits from taking part in creative dance; exercise, team building, developing leadership skills, confidence building, and just relaxation and fun.

Sometimes, I am asked for my group to give a performance at the end of the workshops. Also, I get asked to perform

myself, or with the groups. I have managed large performances on stage, and in front of large audiences, and also performed on the street.

Sometimes, I write my own computer music for my workshops and performances, and have produced two collections on CD.

I use *Soundbeam* in my dance sessions, if it fits in, and also use it in creative music making sessions. *Soundbeam* allows dancers to make sounds and music while dancing in front of infra-red beams. It's great for all dancers, but especially suitable for people with disabilities who could not play a conventional instrument.

I bought two *Skoog* music-making devices and use them in my accessible music-making workshops. The *Skoog* is a remarkable white cube, totally squashable, with a large coloured button on each side. Each button can be changed to any sound or instrument that's wanted, and by pressing or squeezing the buttons, music and sounds, or recorded voice, can be controlled. Very tactile and attractive, they add another dimension to my workshops. Sometimes, a group can form a band with two *skoogs* and two soundbeams, with a conductor, and then play the music for dancers in the group.

Recently, I have added *Light Graffiti* to my creative dance sessions. One of the parents from the *IVoice* organisation, which I support, showed me how to make light paintings. In a blacked out room, my dancers move around, dancing, holding coloured lights. If they use wheelchairs, then several lights can be strapped onto the chair. Using a slow shutter speed camera, I can remotely take pictures of the dancers moving in the dark. These images can be really amazing, and the group can keep the images they have produced to make prints or project, or use in art and craft works. I also sell my images through a website.

DISABILITY AWARENESS & ACTING

I intended to offer disability awareness training, which I have done a few times, but I find that actually going out and doing my work makes more of a difference to attitudes than a dry lecture, and discussion about models of disability.

I have done training sessions on using and employing personal assistants, and independent living, and many other subjects linked to my own experiences in life.

A few modelling jobs have come up, which were good fun. Also, I was asked,

in 2005, to act in TV comedy series on BBC 3.

THE BENEFITS OF SELF-EMPLOYMENT

So my business has developed and grown over the years, according to what my clients have invited me to do. The work is done on the premises of my clients. I do not have my own dance studio, yet, although this is one of my aims for the future. It would be great to have much more local work, so that I didn't spend so much time and effort on travelling.

Starting self-employment meant a total change in my finances. As I live alone in my own home, I am responsible for all my household bills and expenses, and then I have a choice what to do with what's left over when all the bills have been paid. Before self-employment, I was able to claim housing and council tax benefits, and received income support. All that stopped when I started work, which is only right, and I really had to work hard at earning my living. Some years I have a much greater income than others, but not every year. My work is funded from the fees I charge my clients, and sometimes, when I particularly want to do something which I know won't be profitable, I apply for grants from organisations like the Arts Council of England.

There are many great benefits to self-employment. I'm economically active in society, and pay my taxes, and do not claim welfare benefits. I'm very proud of what I am doing; it's good for my self esteem, knowing that I have earned the money that I spend on all the bills, and other costs. It has enabled me to buy my own home and have the security of having a roof over my head. It's good to be my own boss, and to make all the decisions about which jobs I accept and what I charge for my work.

TOP TIPS FOR SELF-EMPLOYMENT

Before going out to do your work, a person who uses AAC needs several things in place for the job to be successful. Some of these apply to all people, and some are just for my particular work. I've made a list in no particular order:

- Your device must be reliable, and well charged, maintained and preferably with a back up method, in case of breakdown.
- Your method of transport must be dependable, whether your own vehicle, taxi, or public transport.
- If you use a wheelchair it needs to be well maintained and fully charged, if electric.

- You must be in good health, so you don't spread diseases to your clients, and also for your own sake.
- If you need support staff - Personal Assistants - they must be dependable, reliable, and enthusiastic about the work that they are supporting you with.
- You must have time, and support, if needed, for preparation for your work, including preparing your AAC device with new vocabulary and any prepared sentences you need quickly.
- Lastly, and most boringly, you must have done all the administrative jobs to enable you to do your work. In my case, often this means accessible hotels to book, invoices to prepare, and making sure public liability insurance and CRB checks are up to date.

SOME HAZARDS OF SELF-EMPLOYMENT

I now need to explain about the downside of self-employment, and the things that were not obvious when I made the choice to give up my welfare benefits.

Wheelchair

The first thing that made me wonder if I had taken the right path, was when I had to ask *Access to Work* for help to replace the equipment they had given me when I started the business. My dance wheelchair was almost eight years old, and was no longer insurable, nor fit for the job. An *Access to Work* assessor interviewed me in my home, and asked if I thought that a wheelchair helped me in my dance work. As I couldn't move around without a wheelchair, I said "Yes." I can't think what else I could have replied. Some days later, I heard that *Access to Work* could not replace my chair, as they considered a wheelchair to be a 'business advantage'.

I had to argue my case, because without a new chair, I would have been unable to carry on with my work, as it would have been a danger to my clients and to myself. If I had enough profit in my business, I would have bought it for myself, but these wheelchairs cost around £9,000. I do make small profits, but not enough for that. *Access to Work* argued and I appealed, and at last, although they were not unanimous in their decision, they did pay for a new wheelchair for me. I was asked to contribute £500, which I did.

Communication aid

At the same time that my chair was wearing out, my AAC device was almost five years old and getting temperamen-

tal. *Access to Work* had paid for an aid at the set up of my business, but that aid had been extremely disappointing. It had to be replaced and totally reprogrammed three times, and in about 2007 I had paid for a new device out of my own money, £7,000, which I couldn't afford to do again.

I tried to find funding for a new aid from various organisations that would only fund one if I could prove that *Access to Work* would not fund it. It was hard to go back to *Access to Work* after the battle over my wheelchair, but I did. They would only consider getting me a new aid if I could prove that the NHS would not fund an aid. I felt like I was going round in circles. With help from some good friends, I finally got written evidence that my health authority did not fund any AAC devices for adults. Then, at last, I got funding for my new aid. All this was exhausting, and very stressful.

Personal Assistants

As I said earlier, *Access to Work* agreed in 2004 to fund a support worker for my business, to assist me with those things that I couldn't do for myself, like driving, paperwork and accounts, carrying equipment, looking after my IT equipment, and helping me with loads of other jobs. I could not do my work without this support. My Personal Assistants are not supposed to help me with jobs to do with my work. My support worker has had to spend a long time, when he should have been helping me, writing reports of exactly how he is helping me. Last year, he had to account for every hour of his day over three months working with me, and explain why he had the necessary skills to do this.

I never know how long his job will be funded, or if future policy changes will reduce or stop this funding. Ideally, if I made enough profit in my business I could employ staff myself to do those jobs, but, at present, my work only brings in enough money for me to live on, and not to employ staff with my own money.

FUNDING & CUTS

Still on the subject of funding, Government cuts in many areas are affecting my customers' ability to pay me. I work for schools, local authorities, charities, universities, arts organisations and individuals who have all had funding cuts. Some of my past clients have gone out of business themselves. My opportunities to get competitive funding are reduced, as there is much greater competition for smaller pots of funding.

I have many former customers, who want me to work for them again and are

attempting to get funding to pay me. In the early days of my business, funding was not nearly so tight. I'm certainly not alone with this issue, and I'm sure that we all hope the economic climate does a turnaround soon.

ADMINISTRATION & PREPARATION TIME

I think that to choose to be self-employed, you really have to love what you are doing, because it is very hard work! I really love dance. Dance is my big motivation to carry on. I had hoped, that being self-employed as a dance practitioner would lead to more opportunities to indulge my passion by doing more dance. That's not how things have worked out. I'm doing a lot less dance than I did before I was doing it to make a living! There are many reasons for this.

Firstly, I have to spend a lot of time preparing for my work. It can take a week of hard slog to prepare for one day's work. Apart from all the administration, correspondence and preparing equipment, I have to make sure that my communication aid has all the necessary vocabulary, or full phrases, pre-programmed into it.

If it's a dance job, I have to have the level of my instruction suitable for my clients. Often, each job is a complete one-off, where I do masses of preparation, and only use it the once.

Also, I work all around the country, and sometimes it can take three days to do one day's work, travelling there and back - two days, working - one day. I have wasted hundreds of days sitting in my van on motorways when I could have been working on dance if the jobs had been local to where I live. Travelling is tiring, boring, and time wasting, but I have to do it to reach my customers.

COPING WITH UNSTEADY WORK

It's even more difficult than I imagined getting your work evenly spread out over the year. I have to accept all jobs that I am offered, but often several clients want me on the same day, and then I get no work for a month.

I know that, in self-employment, this is what most workers have to deal with, but, for a person with a disability, for whom every aspect of life takes much longer than for a non-disabled person, time management is an even bigger issue. I feel that I cannot make plans in advance for things like attending Dance Conferences, supporting the charities that I'm passionate about, like *IVoice*, or even visiting family, because I have to be free to accept work as and when I get it, or to be preparing for future work.

I allow myself one week's holiday a year, which I book in advance, and even then, I often get asked to work that week, after I've booked a holiday.

BALANCING WORK AND LEISURE

Like many self-employed people, my home is also the office. My living room is my workplace. Sometimes I can be working for 12 hours day, because emails are coming in constantly, and take time to reply to, so it's hard to switch off and take time out, to relax. When I've had enough, I have a day out, fishing, and then feel guilty and have to catch up with correspondence when I get home.

I'd love to have a place which was a dance studio and office, locally, where I worked, and could then leave, and go home to unwind. Building time to relax into your life feels like a luxury, but I know it's important. My original business plan did not take this into account. I imagined working five days a week, and having two days off. It's not like that in self-employment.

When I started my business, I was very optimistic about the future. But the anxiety and uncertainty about the future, and worry about what will happen if I have to wind up the business, takes some of the pleasure and satisfaction out of having my own business.

I still want to carry on with my work. I have many testimonials about the value of what I am doing. So far, nobody can tell me what would happen to me, in terms of qualifying for any benefits, if I gave up self-employment. I've proved that I am capable of working. I can't think of any other job that I could do.

MOVING FORWARD

Currently I'm reviewing my business plan, and working on strategies to allow me to find much more local work, while still visiting my clients around the country when I'm asked to.

I'm considering looking for local premises where I can hire out spaces to other local artists, to cover the costs, and also run my own creative dance sessions. This is a big step, and I'm taking advice about it before going ahead with it. I'm passionate about full and equal inclusion of all people with disabilities, and do not want to set up a facility exclusively for disability arts. Usually I avoid any organisations which are just aimed at disabled people. I feel that this is not the way forward and is perpetuating segregation.

Since I set up my business, I've been classed as a sole trader, that is just work-

ing alone, for myself. It seemed the simplest way forward. Now, I'm thinking that perhaps changing my status, maybe to form a Social Enterprise or Community Interest Company may be better for me. I'm taking business advice, and looking at my options. I understand that as a Social Enterprise, I may be able to find sources of funding not available to me at the moment, so that I could hire premises, and start running local inclusive dance sessions, and charge lower fees to my customers than I have to do at the moment.

I'd still travel around to my work in other places, but I really want to spend more time on dance and less on travel. I think in the current funding climate, this may be best for me.

The title of this presentation is "Eight Years self employed: If I had known then, what I know now..." That is "Would I do it again?" Well, my answer is *probably* "Yes!" But I'd like anyone who is considering going down this path to ask themselves certain questions before they start:

- Will I be able to afford to live, if my business is not successful?
- Have I got backup plans if any of my essential equipment or transport fails me on a day when I need to get out and speak with customers?
- Have I got reliable and flexible support staff and personal assistants, and people to call on in an emergency if staff are off sick.
- How will I continue to work, if Access to Work funding is stopped?
- Am I prepared to give up doing things that I enjoy doing, and put paid work first?
- Do I really love what I am doing in my work?
- Am I prepared to work seven days a week if necessary?
- Am I prepared for all the very boring administration jobs that will arise from doing my work? Jobs such as getting public liability insurance, CRB checks, doing risk assessments, paying staff wages, applying for funding, keeping financial records, looking for new clients, keeping records of who has paid and who still owes money, self-assessment, income tax forms - and that's just the start!
- Am I ready to deal with disbelief? "What, do you work? Are you joking?" And suchlike?

Thank you for reading this. *

Alan Martin
Creative Dance Practitioner

“When feelings get too much”

Athetoid cerebral palsy, emotions and AAC

KATIE CARYER & CHRISTINE SHERLOCK¹

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INTRODUCTION

Chris and Katie have known each other for a few years. At ISAAC 2010 Chris greeted Katie enthusiastically, taking Katie by surprise. Katie had a bigger emotional reaction than might be expected for this sort of situation.

When Katie and Chris had recovered they discussed what had happened and wondered if this reaction was part of “emotional overspill” that can be related to having cerebral palsy – particularly athetoid cerebral palsy. This overspill is called many things in medical and scientific literature, including:

- Pseudobulbar Affect (PBA); (www.pbainfo.org)
- Involuntary emotional expression disorder (Cummings et al, 1996)

Katie has always experienced these reactions and they have had a significant impact on her life. When Katie and Chris understood more about what had happened, they wanted to raise awareness through a presentation at Communication Matters.

Katie described living with PBA:

“Occasionally I lose my temper and I yell and I have been known to be violent and I have ruined situations for myself and others.

At nearly thirty, I think I shouldn't have massive temper tantrums and I should try to understand what's happening to me.”

WHAT IS PSEUDOBULBAR AFFECT (PBA)?

“Uncontrollable episodes of emotional expression occur in a variety of neurological conditions. This emotional dis-inhibition syndrome is characterized by episodes of crying or laughing that are unrelated to or out of proportion to the eliciting stimulus ... resulting in episodic and involuntary bouts of uncontrollable emotional expression.” (Cummings et al, 1996)

PBA is a significant part of living with athetoid Cerebral Palsy (CP) and some other neurological conditions such as Motor Neurone Disease (MND) (MNDA 2012) or Multiple Sclerosis (MS). It is perhaps related to the emotional lability sometimes experienced by people after brain injury.

Athetoid Cerebral Palsy is usually characterised by involuntary muscle tone fluctuations and movements caused by conflicting messages from the impaired areas of the brain (Scope 2012). The word ‘athetoid’ means “no fixed point” and this describes the movement picture: the person cannot easily be still, unless asleep. These involuntary movements often affect speech (*dysarthria*) and this may mean that the person needs to use Augmentative and Alternative Communication (AAC).

The areas of the brain that are involved when a person has athetoid or a related type of CP are very close to, and parts of, the same systems related to expressing emotions: the basal ganglia

and limbic systems. If we take the idea of “no fixed point” for the involuntary movements of a person with athetoid CP, we can see how that might apply to how the emotions are also involuntarily expressed.

WHAT IS KNOWN ABOUT PBA?

We did online searching in Medline, PubMed, NHS library, setting up alerts for papers on “Cerebral+Palsy+emotions” and some related terms. We found little and particularly little UK-based or CP-based. We looked at other conditions where people experience similar things. What we found mainly related to people in the USA and UK with MND (ALS) (www.pbainfo.org; Bellman, 2012).

PBA is not a psychiatric disorder, nor a symptom of learning disability. People *with and without* learning disability can have PBA. People who have PBA may also have mental health needs including depression that *can* be related to their PBA (Cummings et al, 1996).

When people have PBA then the way they show emotions *can* be:

- Extreme and last quite along time
- Not matched to the event or underlying feeling
- Not understood by others
- Damage relationships and opportunities
- Mislabeled and misjudged
- Misdiagnosed

The literature acknowledges the impact for person, those close to them and the need to know about the condition. The literature tells us that PBA is not diagnosed enough and that doctors don't talk about it to people with PBA or those close to them – perhaps because they are worried about further upset, or because the doctor does not have knowledge of PBA.

Katie's experience backs this up:

"A few years ago, I went to the doctor's to see what help is available through the Health Service. Guess what! I got angry because the doctor talked to my mum and not to me."

We had two useful sources shared with us by other speech and language therapists: articles by Sally Millar and Gill Brearley. These described the type of PBA behaviour seen in people with athetoid CP and suggested some ways of managing it, including relaxation practice, understanding what is going on for the person concerned and any carers.

Overall we found little that was easily available or helpful to people with PBA or those around them. Katie said:

"I called Scope's cerebral palsy helpline and the woman talked about generally being angry with the things we disabled people have to put up."

I could find nothing on the Scope website. I have Googled 'athetoid cerebral palsy and emotions' and the first thing that came up is something about this very presentation."

So I guess with this dearth of information there is not much help for people having these issues."

WHAT DID WE DO TO FIND OUT MORE?

We wanted to explore how other people experienced emotional expression associated with their CP and how this related to their lives and use of AAC. Katie asked people about their experiences, using the Communication Matters AAC Forum (email discussion group), her Facebook page and 1-Voice Forum (www.1voice.info). So this was not a fully representative sample of people with PBA and/or CP.

Katie explained:

"We made a simple questionnaire to ask what other people's experiences of this issue were. We asked people to discuss what it is like for both disabled people and those around them. We also asked them not only how does it affect them, but do they have any tips for dealing with it. Another issue was what role AAC plays."

We received 13 questionnaires back:

- 8 were from parents of disabled people.
- 3 from disabled people themselves.
- 1 from a teacher who works with a disabled child.
- 1 from an accessible technology consultant.

We were told about the sort of conditions and views represented:

- 11 responses were about people with athetoid type cerebral palsy.
- 1 response was about a person with traumatic brain injury.
- 1 response was general, from someone who worked with a variety of people who use AAC.

Our respondents told us what it is like to live with PBA:

- *"Can't control it."*
- *"Embarrassing; exhausting."*
- *"I laugh when I should cry."*
- *"It can affect relationships, work and education."*
- *"The consequences are harder to deal with than the actual cerebral palsy."*
- *"People can stare."*
- *"Lost mates and assistants, warnings and employment difficulties."*
- *"Feelings of remorse."*
- *"Damage to belongings and opportunities."*
- *"Makes someone seem younger than they really are and as if they have learning disability."*

The emotional expressions experienced included anger, laughter and crying. While the actual emotions might be at the same level as everyone else, the physical manifestation of it may seem more extreme. Examples of this include mothers who described:

- A son as being homesick on holiday but who cried inconsolably for 1 to 3 hours on most days. To quote:
"I do not think he was in abject misery, just a wee bit homesick, but it manifests in a very out of proportion response."
- A 15 year old girl having *"extreme anger and anxiety and sometimes involving aggression to herself and others. The reactions seem out of synch with the event, for example a huge outburst over a relatively minor incident, like there is difficulty with scaling of emotional response."*

The same person said:

"The big emotional outbursts are very upsetting and often followed by feel-

ings of remorse. Temper tantrums have resulted in damage to belongings or abandonment of planned activities."

- A 17 year old said she can't control her laughing at funerals and other bad behaviour: *"It just happens."*

People close to those who have PBA told us:

- *"It is very hard to watch him being so distressed and feel helpless."*
- *"I have to switch off my own feelings towards the person."*

WHAT IS USEFUL TO KNOW WHEN LIVING WITH PBA?

People told us it was good that this issue was being discussed and it seems quite common amongst Katie's contacts with athetoid cerebral palsy. Our respondents and Katie's experiences told us that:

- It really helps to know you are not the only one.
- Although the reaction looks extreme, the feelings underneath may not be stronger than for other people.
- If someone is laughing, the other person may be hurt, so you need to check.
- May get easier with time for some people but Katie says "as a woman I find hormones don't do us any favours!".

No-one had a magic cure for this phenomenon, although some people told us what can help with dealing with this experience:

- Distraction can help, such as changing the subject if possible.
- Firm pressure on the shoulder can reduce an outburst for some.

However, sometimes the emotion just has to get out – as one mother said, her nine year old must "ride the storm".

CAN AAC HELP?

People said AAC doesn't necessarily help when they are having an emotional outburst. The mother of the 15 year old girl hinted that the difficulties with the limitations of AAC and frustration caused by miss-hits certainly does not help.

However, quite a few people said AAC definitely can help when the person is calm enough to use it. The vocabulary to express feelings is very important on someone's AAC system and should go beyond happy and sad in order to enable the person to talk about what he or she feels and why. But people expressed the risk that bringing up the incident too soon could trigger a fresh outburst. So the "how and when" of talking about feelings needs sensitive support.

People also told us that AAC:

- can help give a pointer to reasons for upset;
- needs to have the right words available.

Even though AAC might not be something a person can use at the time of a PBA upset, people without good access to AAC might get frustrated and therefore have emotional overspill.

Being unable to discuss an issue may make it worse and the person could easily be diagnosed as having emotional and behavioural difficulties when lack of suitable AAC and PBA may be partly the cause.

SOME TOP TIPS FOR DEALING WITH PBA

For people with PBA, the top tips are knowing:

- You are not the only one.
- It is not a mental illness – it is part of the movement condition, e.g. cerebral palsy.
- Other people need your help to understand, so explain before it happens and have an apology ready in your AAC device.
- Take some time to recover yourself.
- It is all right to be happy, cross, sad.

For those encountering people with PBA for the first time, the top tips are:

- Take some time to recover yourself.
- It is not a mental illness – it is part of the movement condition, e.g. cerebral palsy.
- The person may not feeling as strongly as it appears to you.
- How they seem may not match what they feel, e.g. laughing when something is painful.
- Support the person to have suitable explanations and repair of communication comments ready in their system; support the person to learn to use them.
- Find out what helps the person “ride it out” best.

CONCLUSIONS AND NEXT STEPS

Katie says:

“I have started thinking athetoid cerebral palsy delivers a triple whammy:

1. *People with athetoid cerebral palsy tend to be bright and have a lot to say.*
2. *Athetosis often comes with dysarthria.*
3. *On top of all that, we have these difficult emotional reactions to deal with.”*

Chris and Katie have developed a draft leaflet about athetoid cerebral palsy, emotions and AAC. This can be re-

quested by email from Chris and we would like further comments. We would like to have the final leaflet available, perhaps, on the Communication Matters website. Thank you to all the people who contributed their experiences. *

Katie Caryer
Christine Sherlock, SLT

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JANET LARCHER

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INTRODUCTION

I have worked as a Registered Intermediary since the start of that initiative about nine years ago. Registered Intermediaries (RIs) are recruited, trained and accredited by the Ministry of Justice, and assist the police and courts in ensuring effective communication with vulnerable witnesses. RIs come from a variety of backgrounds – SLT, OT, psychology, teaching, social work – but all have extensive experience of communicating with people who have communication difficulties before becoming RIs. The Registered Intermediary scheme operates in England only at the moment.

During my time as an Intermediary I have been faced by many people who wish or need to talk about abuse that they have experienced and yet have had trouble finding a method or the language to ‘say’ what they want. In a legal setting it is imperative that the witness is not led and words are not put into their mouths.

Some witnesses have had some very disturbing experiences. Their lives would have been much easier if they had already been aware of/familiar with the type of vocabulary that they might need in such circumstances, in order to explain their situation. I have therefore worked with Tina and Cate Detheridge at Widgit, members of the legal profession and numerous speech and language therapists to agree a range of symbols that would be helpful to have included in all communication books and devices and/or to have in a separate book to be called upon as and when necessary,

but which is known to all staff and residents/clients/school children.

I have grouped the symbol vocabulary into topic pages which can be copied in any symbol system that is used by the client – assuming the symbols are available in that symbol system. These symbol sets can be bought readymade but they can be freely created by anyone willing to put in the work.

This paper identifies some of the problems and issues that have arisen and seeks your opinions and help in carrying this project forward. I have referred throughout to the person using the symbol set as the witness since this covers all categories of potential user. The grids used in illustrations are made using Widgit Symbols in The Grid2 software. I reiterate, however, that these grid sets can be created using whatever programs are available to the creator in whatever symbol system they require, provided that the symbols for the required concepts are available to them.

PROBLEMS ENCOUNTERED

Sadly many of the problems will not surprise the reader.

1. One size does not fit all

It is impossible to design a communication chart suited to all individuals who may need to talk about abuse. No one chart can suit all individuals but the availability of the symbols and the suggested groupings can provide a starting point to be adapted for each individual.

2. Lack of appropriate symbols in all symbol sets

Not all symbol sets have symbols for some of the concepts that may be needed. I approached Widgit Software and they have been very helpful in designing and producing symbols for concepts that I felt were needed – or where I didn’t think their existing symbol was suitable. Other symbol companies have not been as helpful.

3. Lack of agreement on what symbol is most appropriate

There has not always been agreement between professionals on what is the most appropriate symbol for a concept. The symbols for Guilty and Not Guilty have been the most challenging. Some favour a tick and a cross – which one would be for Guilty? Others favour a happy or sad face – again, which is for Guilty? The immediate answer from most people is the sad face for Guilty. But for the person who has been abused, however, they are happy when the person they claimed has abused them is found guilty of the offence.

4. Maintaining visually simple symbols and pages while covering everything required

The symbols I favour for Guilty and Not Guilty are more visually complex than is ideal but they do appear to generalise well. How many symbols should there be on a page? How should the symbols be grouped – men’s clothing separate from women’s? If only life divided itself so neatly!

5. Coloured or black and white symbols?

Some lawyers would argue that a symbol for trousers that were coloured blue when their client had worn black trousers was inappropriate and therefore the symbol did not identify their client's trousers. Equally some people with learning difficulties would reject a symbol if it was not coloured appropriately for what they are identifying.

6. Acceptance by the legal profession

The original Widgit symbol for a ponytail also included a fringe. Once again this would have been a basis for a legal argument if a witness selected a symbol involving both a pony tail and a fringe when their client had a ponytail but no fringe. Widgit therefore generated a standard face and then placed features upon it, a fringe and a ponytail being separate.

7. Balance of positive and negative symbols and their positioning on a page

When asking a witness how they felt or how the offender was behaving, there needs to be a balance of positive and negative concepts so that the witness is not being led. Should all the positive concepts be together or should they be interspersed?

THE VOCABULARY AS CURRENTLY DEVISED

Topics covered include: numbers, uppercase letters, lowercase letters, colour, quantity, body parts, face parts, female parts, male parts, feelings, demeanour, actions, where, describing people, time of day, hair style, hair colour, skin colour, time of year, days, clothes, footwear, and court (see the example pages following this article).

There are also two pages (Fig. 1) which need to be printed out and placed in an easily accessible position for the user throughout any questioning.

PROBLEMATIC SYMBOLS

For some (most) people, symbols will need to be taught but some concepts are particularly challenging to symbolise. Some symbol sets have better ideas than others for particular concepts and some symbol sets have not attempted to symbolise some concepts.

I suspect that many symbols are just accepted until they are used in real circumstances and then their inadequacies become apparent. When a client experiences problems with a symbol, do we always inform the symbol supplier, advising of the problems encountered and offering suggestions of what might be more relevant? If we do not, then the

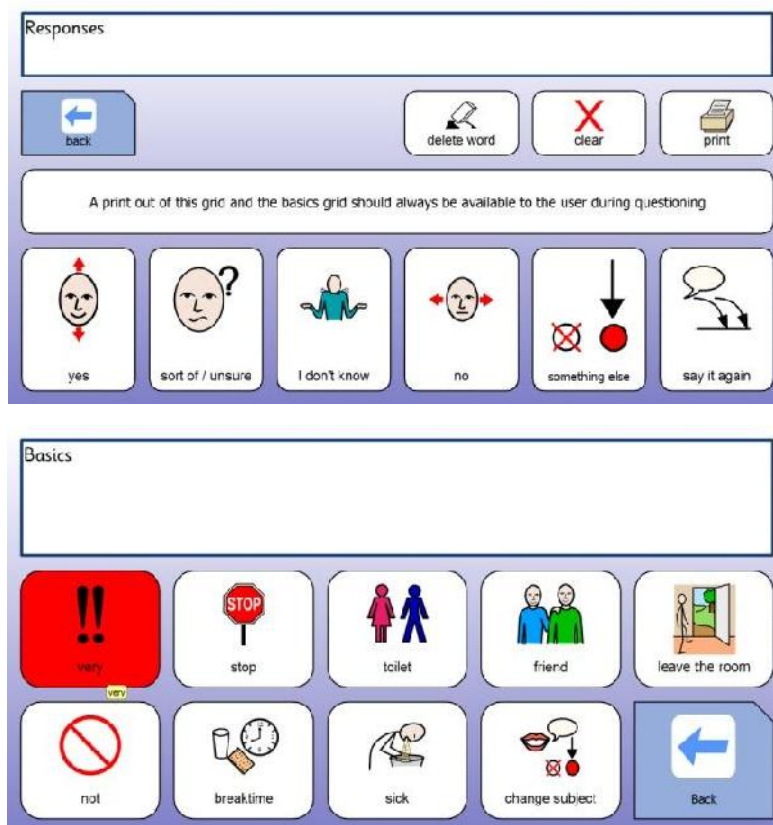


Figure 1 Pages to be available throughout any questioning

symbol set's relevance to real life will not be improved.

Sexual symbols are particularly challenging and I do not think that the symbols for intercourse, vagina and masturbation are very appropriate in any symbol set, although I have failed to come up with anything better. The symbols for rub, inside and outside in this context are also difficult to get right.

You will note that there is a page labelled demeanour which is attempting to offer symbols for the likely behaviour of an individual and again I am not thrilled by the symbols for these behaviours.

Days of the week are complex but hopefully these are frequently used in all relevant environments.

The court symbols have been particularly demanding to satisfy all perspectives and yet remain visually clear and simple. Symbol sets which originate outside the UK will also have different ideas of the concept - American judges use a gavel (like UK auctioneers) but despite TV programmes sometimes suggesting otherwise, UK judges do not use them.

NEXT STEPS

I encourage everyone to discuss with colleagues in their departments, schools, homes, and units, whether clients have the vocabulary to report abuse and then

to agree on how this issue will be addressed in their spheres of influence.

I ask that colleagues also look afresh at the symbols available and make suggestions for those that are missing or need amendment.

I am happy to act as a co-ordinator of comments but encourage people to contact the symbol companies direct so that their thoughts and experiences are shared first hand with the people who can make the changes.

Much inappropriate behaviour occurs because the perpetrator believes that the client cannot or will not report them. If clients do not have the appropriate means to report behaviours that they do not like we are allowing abuse to continue. It is our duty to ensure that everyone has the means to report and to talk about abuse in all its guises.

The symbol vocabulary, grouped into topics, is shown on the next three pages. *

Janet Larcher
Independent Consultant

NOTE

This vocabulary is available from Widgit as a package containing three formats: PDF, for printing directly; in files, for use in *Communicate in Print*; and in files, for use in *The Grid 2* (so that the vocabulary can also be used on the iPad via Gridplayer). Widgit website is: www.widgit.com/talkaboutabuse

Menu Page

responses	basics	colours	numbers abc letters	quantity
descriptors A	descriptors B	descriptors C	describing people	hairstyle
feelings	demeanour	actions A	actions B	hair colour
body parts	face parts	female parts	male parts	skin colour
clothes: top	clothes: bottom	clothes: full body	clothes: footwear	places
clothes: accessories	time: day	time: week	time: year	court

Colours

red	orange	yellow	green	blue	purple
pink	brown	black	gray	beige	white

Back

Descriptors

private	public	naughty	nice	clean	dirty
hard	soft	good	bad	dark	light

Back

Quantity

lots	some	few	none
a lot	a bit		

Back

Describing People

man	woman	fat	thin	young	old
adult	child	short	tall	scruffy	tidy

Back

Descriptors A

big	small	wet	dry	hot	cold
thick	thin	dull	shiny	old	new

Back

Hairstyle

ponytail	short	medium	long	spiky	curly
bald	short	braids	wavy	fringe	

Back

Descriptors B

short	medium	long	straight	wavy	curly
plain	patterned	striped	spots	smooth	rough

Back

Hair Colour

dark	medium	red	fair	grey	white
------	--------	-----	------	------	-------

Back

Feelings

very happy happy ok sad afraid angry

Back

Face Parts

hair ear eyes nose mouth teeth
forehead cheeks chin eyebrow lips tongue

Back

Demeanour

friendly cuddly larking teasing
cross swearing aggressive

Back

Female Parts

breasts front bottom urine bottom
faeces pubic hair vagina menstruation
intercourse masturbation inside outside

Back

Actions A

run walk push hit kick talk

Back

Male Parts

penis erection semen sticky
bottom faeces finger condom
intercourse masturbation inside outside

Back

Actions B

kiss lick touch cuddle
poke rub slap hurt

Back

Skin Colour

A B C D E

Back

Body Parts

head neck shoulder arm hand fingers
back chest tummy bottom
legs foot toes

Back

Clothes Top

bra vest t-shirt blouse shirt
jumper cardigan jacket jacket tie

Back

Clothes: Bottom

trousers	skirt	tights	pants
jeans	shorts	socks	pants

Back

Time: Day

wake up	breakfast	coffee	lunch
tea	dinner	bed	Back

Clothes: Full Body

coat	suit	dress	dressing gown
raincoat	tracksuit	nightdress	pyjamas

Back

Time: Week

Monday	Tuesday	Wednesday	Thursday	Friday
Saturday	Sunday	weekend	last week	this week

long time ago

Back

Clothes: Footwear

shoes	wellies	sandals	bare feet
shoes	boots	trainers	flip flops

Back

Time: Year

New year	Valentines day	Easter	holiday	bonfire night	Christmas
----------	----------------	--------	---------	---------------	-----------

long time ago

last year

this year

Back

Clothes: Accessories

glasses	hat	jewellery	piercings	moustache	beard
---------	-----	-----------	-----------	-----------	-------

Back

Places

living room	hall	kitchen	dining room	office	bedroom
bathroom	toilet	garden	park	street	shopping mall
school	respite	day centre	hospital	Back	

Court

court	waiting room	video room	
judge	jury	guilty	not guilty
usher	oath	RI	
police	barrister	solicitor	Back

ISAAC 2012 Conference: Our World

BETH MOULAM

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Website: www.bethmoulam.com

At the end of July 2012 I travelled to the ISAAC conference in Pittsburgh, USA. Pittsburgh is an amazing city - it's hot and when it rains it's very, very wet. The conference was attended by over 1,200 people. The conference centre was enormous and this meant it was a long distance between the meeting rooms and the exhibition hall. It did mean often we passed people in the corridor, but I still had the opportunity to network with other delegates from around the world and go to a range of sessions. Choosing sessions to attend was seriously challenging, there were so many and often the ones I fancied were all on at the same time. The programme started at 8am each morning and finished at 6pm with no time for breaks or lunch. Whilst this may suit the professionals who attend it made it hard for me and often I had to miss something if I needed food or take the food in with me (which is not very respectful to the presenters!). I made time to go to the exhibition and have a good browse around, taking in the latest developments for people who use AAC.

I had had some involvement with the social committee organizing the Welcome Reception and was asked to give the welcome speech on the roof top of the conference centre. Even at 6pm this was hot and windy, but fun, although the wind whipped away my words and not everyone was able to hear so easily. This is what I said:

"Good evening. My name is Beth Moulam and it is my very great honour to be with all of you at the ISAAC 2012 Welcome Reception.

I was thrilled when I received the email from the social committee, asking me to welcome you to tonight's reception. ISAAC is an amazing organisation which means a great deal to me, both in my home country of England, where I am a member of the thriving chapter, and internationally where I have made many friends over the last six years.

This trip to Pittsburgh is my fourth ISAAC conference. I was welcomed into the ISAAC family in 2006 in Düsseldorf. I made some fantastic friends who I

have since hooked up with in Montreal and Barcelona, and I now look forward to spending quality time with you, once more,

this week. These friends are not just people who use AAC but are also professionals from around the world.

"The theme for Pittsburgh 2012 is Highest Performance. Best Life Experience. WOW. And it promises to be fantastic. For me ISAAC is a celebration of everything that is great about people. Whilst members of the ISAAC family have in common augmentative and alternative communication, whether we use it, make it, sell it, train people to use it or research around it. I see clearly that we demonstrate respect and value every member of the ISAAC community. I asked some of my friends from around the world what ISAAC means to them and the same theme came back from all of them. ISAAC is a place to share, learn and grow, and a time to love, laugh and live. ISAAC is about inclusion and celebration.

"When I made my first presentation back in 2006 to a packed room in Düsseldorf, I was just 12 years old. This experience was amazing and I believe changed my life. For the first time ever people listened carefully to what I had to say. I know they listened as they asked me relevant questions both at the end and during the rest of the conference. Some people even wrote to me later and it was the start of my journey to advocating for other young people who use AAC. This has led to me presenting at 16 conferences around the world. But more than that the friendship and support of members of ISAAC made me choose to leave a mainstream school at 13 when I didn't feel valued and find a special school who have supported me through my education, helping me achieve academic success.



"I'd like to share a poem called, 'My World', which I wrote in January 2007.

My World

It is now next year.
That doesn't seem so long,
Six months down,
And only eighteen more to go.
I can't wait to see you all again.
In my world,
A place where you will give me time,
To express my feelings, fears and hopes.
We know the dates, August 2008.
The time, for 5 whole days.
The place, Montreal, Canada.
A world away. MY WORLD.
I'll see you there, I know I will.
And we can make it. OUR WORLD.

Those words are for me just as powerful today as they were five years ago. On behalf of ISAAC and the Social Events Committee please make new friends and let us make ISAAC 2012 'Our World'."

I applied for a Communication Matters grant as I had had a paper accepted - I got to present the paper early on the last morning. It was about taking GCSEs in the UK, a paper that was published last year in this journal and adapted for an international audience.

ISAAC 2012 was a different experience to Düsseldorf, Montreal and Barcelona. There were less UK delegates, more people and more cultural differences. It was however a great experience and I will be first at the door for ISAAC 2014 which is to be in Lisbon.

Thank you Communication Matters. *

Beth Moulam

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Communication Difficulties and Talking Mats

Advantages and disadvantages of an online training course

JOAN MURPHY¹, LOIS CAMERON¹ & ANNE REID

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Email: info@talkingmats.com

This paper will explain the background and the design of an online AAC training course. It will provide feedback from course participants and will discuss the advantages and disadvantages of the online training model.

BACKGROUND

At the ISAAC Conference in Barcelona 2010 we were inspired by a presentation by Finnish colleagues which described their development of online training on communication. We wished to investigate the possibility of developing an online training course for our work with Talking Mats and discussed with the Finnish team how to host an online training website. Subsequently, we took advice from IT professionals and investigated several software platforms. We decided to use Moodle (www.moodle.org) and obtained funding from NHS Education for Scotland to design and run an online course on communication and Talking Mats.

Talking Mats is a research evidence based low-tech communication framework that supports people who have difficulty communicating for whatever reason, to understand, organise their thoughts and then express their views [1-4]. It can be used by staff and family members in a variety of settings with both children and adults. Talking Mats can help people arrive at a decision by providing a structure where information is presented in small chunks supported by symbols. It gives people time and space to think about information, work out what it means and say what they

feel in a visual way that can be easily recorded. Talking Mats is actively being used across many diverse specialist areas and encompasses people

with and without communication difficulties. Individuals using Talking Mats find it enjoyable and easy to use, as it provides them with a simple but effective, non-threatening way of expressing themselves.

Since its original conception at the University of Stirling, additional research has taken place and Talking Mats is now an established communication tool which is used worldwide.

In order for people to appreciate the complexities of AAC, and Talking Mats in particular, they need time to learn, reflect and practice skills. For this reason the Talking Mats team have developed a range of high quality training courses.

However, we are aware that for some people it is difficult to travel to attend training and we therefore wished to develop an online course to allow people to complete the training in their own environment and in their own time.

DESIGN

The course runs over twelve weeks and comprises four modules which aim to provide participants with:

- Increased understanding of communication and communication difficulties.



- Knowledge of how to include people with communication difficulties in interactions.
- Understanding of the principles of the Talking Mats framework.
- Ability to use Talking Mats within their work setting using a symbol set developed from the World Health Organisation ICF [5,6].

The first three modules are designed in three sections and each section aims to be completed in approximately an hour each week. Each section includes an introduction, teaching materials and activities such as watching DVDs, a quiz or an open forum where participants contribute to an online discussion with each other. Each weekly section concludes with a reflective task which participants complete and send to the trainers for evaluation.

The final module requires the participants to make a DVD recording of themselves using Talking Mats with someone with a communication difficulty. They are provided with set of symbols developed from the WHO-ICF by the Talking Mats team, a Talking Mats template and a reflection template. This final assignment allows the trainers to evaluate the participants' ability to use

the Talking Mats framework with clients and to reflect on their own communication skills.

FEEDBACK FROM PARTICIPANTS

The following is the perspective of one of the course participants, Anne Reid who is a Speech and Language Therapy Assistant in Grampian:

"I had undertaken online training before but found it quite an isolated and restricted way to learn. Talking Mats online was different - providing varied teaching and assessment methods.

There was also the opportunity to extend your learning using the recommended article and/or book references and signposting to websites.

If time available was limited these sources could always be revisited at a later date.

Modular in its structure, the progression through the course was logical with learning materials and instructions easily understood. The content was relevant and could be readily related to workplace experience. Any issues arising could be resolved via the regular tutor support.

The final module, undertaking a Talking Mats session with a client, was not only a means of assessment for the tutors; it also was an opportunity for the student to put training into practice, producing a reflective evaluation of that experience to support further learning.

The result of training is that Talking Mats has now become part of my 'kit', a tool I may use at any time to support clients as/when the need arises."

We invited Anne to present with Joan at the Communication Matters Conference as we felt that the presentation would benefit from a student perspective in illustrating the advantages/disadvantages of an online training course. Anne added many valuable insights.

The following comments from other participants are taken from the post-course evaluation:

"Brilliant, can access anywhere, can do a section, leave it, and then go back when time allows" (Physio Technical Instructor).

"I have learnt so much about communication in general. I feel this has to help me be a better communicator with everyone I deal with - not only those with communication difficulties" (Occupational Therapy Support Worker).

"I will definitely use Talking Mats with my clients as my caseload is 90% complex needs and the clients would benefit enormously by using this as a thinking tool. I will also share my new found knowledge and skills with my colleagues and encourage them to use it with suitable clients on their caseloads" (Speech and Language Therapy Assistant).

DISCUSSION

Access to quality training can be problematic for many people. This format allows people in any location and from any cultural background to access training and enables them to fit their learning into their own personal circumstances, e.g. people working in rural locations or people who have carer responsibilities.

The design of a web based course can take account of different learning styles, e.g. through watching, listening, discussing and doing. It allows the trainers to conduct the training from their office and thus avoids travel time and costs.

Although direct face-to-face interaction and discussion is missing, the use of online forums allows participants to share their views and telephone or Skype discussions help overcome this.

ADVANTAGES OF ONLINE TRAINING

We were able to reach participants from a range of backgrounds and from a variety of geographical locations. Their feedback included many positive insights including the following:

- They felt that the content and quality of the course was interesting, varied and thought provoking.
- It offered them an opportunity within their work situation to put the learning from the course straight into practice
- It helped them to communicate better with their patients.
- The course broke the training down into small, manageable chunks which they could relate immediately to their work situations.
- Using this course online enabled them to work on the modules as and when was convenient for them.
- They appreciated that the trainers were able to provide quick and personalised feedback.

DIFFICULTIES ENCOUNTERED

- There were a number of initial technical difficulties with some participants who were not familiar with computers and how to upload

documents. However we had good technical support and provided phone assistance to help explain any problems.

- Some health organisations were reluctant to allow the participants to film a patient using Talking Mats. Following discussion and provision of consent information this was largely overcome.
- Some participants had difficulty completing assignments on time because of holidays or illness. This resulted in the trainers spending more time assessing assignments than they intended.

CONCLUSION

Overall this model of training has been very successful. It provides the opportunity for people to understand the purposes of communication and the impact of communication difficulties. It allows them to develop their own communication skills and build confidence in using the Talking Mats Framework.

We have now run four courses with participants from Australia, USA, Germany and Brazil as well as the UK. There has also been a wide range of participants including Allied Health Professionals, care staff, researchers and family members. We plan a rolling programme of three courses per year from now on. *

Dr Joan Murphy
SLT & Director of Talking Mats Ltd
Lois Cameron
SLT & Director of Talking Mats Ltd
Anne Reid
Speech & language therapist

ACKNOWLEDGEMENT

We are very grateful to NHS Education for Scotland for their continued support. Funding for the course is currently available for any AHP working in Scotland.

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AAC OUTCOME MEASUREMENT PROJECT



The **Outcome Measurement Project** was initiated from within the membership of Communication Matters.

Currently there are few resources that support practitioners, people who use augmentative and alternative communication and their families to demonstrate change or development of communication skills. Current service provision across the UK is required to demonstrate effectiveness and efficiency of provision. Outcome Measurement tools are recognised as a means of demonstrating efficacy. There are no outcome measurement tools in use in the UK that were designed from a perspective of aided communication needs.

The project team was tasked with reviewing a range of tools and measures commonly used in the UK and appraising them in terms of their usefulness to aided communication measurement.

The document, published in September 2012, is offered as a guide to the reader; it is not exhaustive but has a multi-disciplinary focus. This focus reflects the composition of the working party who must be congratulated for their enthusiasm and commitment to the production of this 'first edition'.

Download document: tinyurl.com/outcome-measure

AAC SERVICES STANDARDS DOCUMENT



In August 2012, Communication Matters published an **AAC Services Standards document** which aims to provide accepted and recognised quality statements against which an AAC Service can be measured. This will help:

- individuals who use AAC, their families and support workers, to understand what they should be able to expect from current services and the standard that services should aim to achieve after they undertake a reasonable period of development;
- AAC service providers to know what standards they are expected to deliver currently and which to aim to deliver in future;
- those commissioning AAC Services by providing a set of minimum standards against which to measure the services being purchased.

The document currently covers both child and adult services in England. It has been created and reviewed by a number of professionals, family members and carers.

The document will be further reviewed in 18 months' time by a panel led by a CM Trustee and will include at least one person who uses AAC.

Download document: tinyurl.com/services-standards

A BIG THANK YOU TO OUR FUNDRAISERS!



Duncan Harris (pictured left) cycled from London to Brighton in September and raised over £400 to support the work of Communication Matters. Well done, Duncan; his mother (who is none other than the Chair of CM) is very proud of him!

Katie Holmes, CM's Research Manager, ran her first ever half marathon, the Ikano Robin Hood Half Marathon, in September. Katie (pictured right) raised over £300 for Communication Matters. Congratulations, Katie - the weekly Park Runs must have been good preparation for the marathon!



FROM CATHERINE HARRIS, CHAIR OF BOARD OF TRUSTEES

Hello and welcome to my first contribution to the Trustees' News.

THE CM2012 NATIONAL CONFERENCE

My experience of this year's Communication Matters National Conference was very different from previously.

I had been approached earlier in the year about the possibility of standing as a potential Chair and had been co-opted as a Trustee in May to help me try to get up to speed on the current issues. Now that idea had become a reality! I must say thank you to Janice Murray for her ongoing support and for leaving me with such a good team of Trustees.

My first official duty at the Conference was to chair a plenary session on the future of AAC services in England ('Hub and Spoke' model) and in Scotland ('A Right to Speak' report). This session proved to be well presented and very interesting - a video of the session is available on the CM website.

I discovered that, as Chair, getting to other sessions proved more difficult, but I did manage to go to an entertaining presentation on how to stage a 'Cinderella' AAC panto. You can see a video of the panto session on the CM website, as well as an insightful and hilarious opening presentation by Lee Ridley, who is (probably) the first stand-up comedian to use a communication aid.



Lee Ridley, 'Lost Voice Guy'

I spent time in the exhibition getting to know the different suppliers and was generally available to field queries - usually, I have to say, directing them to Patrick Poon who seems to be the fount of all knowledge when it comes to conference logistics!

After the delegates had all left, Patrick, Neil Hansen (Treasurer) and I met with the Leicester Conference organiser for a debrief. Issues around quality of food and accommodation were top of the agenda this year.

A full evaluation of feedback from delegates and exhibitors will be discussed at the next Board of Trustees meeting.

I would like to give a Big Thank You to all the delegates, speakers, exhibitors and volunteers who contributed to make this year's Conference so stimulating and enjoyable.

WESTMINSTER BRIEFING SESSION

Having got back to Bournemouth at around 11pm, I was on the early train into London the next day for a *Westminster Briefing*. Nothing like hitting the ground running!

The content was actually rather disappointing but I did manage to sit next to an MP at lunch and he is now thoroughly briefed about CM and AAC!

I have done a significant amount of reading and reflecting in recent weeks. After so much activity in the last few years my feeling is that for this next term we need a period of consolidation and focus.

AAC EVIDENCE BASE RESEARCH

The CM-RM AAC Evidence Base research project is due to be handed over to the Board of Trustees in June 2013. This will need ongoing review and I am pleased to say the Independent Research Panel (IRP) will be chaired by Janice Murray.

NEW MARKETING CONSULTANT

Sandra Hartley has been appointed to a part-time Marketing post. The Marketing Strategy will aim to raise awareness, increase membership and encourage fund-raising.

PARLIAMENTARY LOBBYING

The Lobbying has resulted in some significant progress with AAC now being included within Specialist Commissioning for England. The next stage will be to ensure that the Health and Wellbeing Boards take on responsibility for the 90% of people who will need to be managed locally. We continue to work with the Whitehouse Consultancy and this is making a real difference to our lobbying activities. Although time-consuming, with the reports from the four regional areas on the Hub and Spoke model due in by the end of March 2013, this is a great opportunity and very timely.

CORE ACTIVITIES

In addition to the above, there is also a need to keep delivering our 'core business' activities to a high standard. Road shows, study days and events for people who use AAC are arranged throughout the year.

ISAAC

ISAAC is introducing some new initiatives which may help the less developed Chapters but which may have

TRUSTEES' NEWS

a less positive impact for CM. We are trying to maintain an open debate.

As Janice stated in her last update, ISAAC remains an important organisation for many people. We (the Chair and Trustees) have to ensure that the UK gets the most from its membership of ISAAC.

INTRODUCING THE BOARD OF TRUSTEES

I thought it might be helpful for the membership to be reminded of the composition of the Board. We are fortunate to have representation from across the country, including Scotland.

Name	Job title	Roles and Main Responsibilities
Sally Chan	SLT	Southern link; Small grants
Dithe Fisher	SLT	Scottish link; Online training
Tom Griffiths	Assistive Technologist	London link; Research
Neil Hansen	Supplier	Treasurer
Cathy Harris	Independent SLT	Chair
Gillian Hazell	Independent SLT	Deputy Chair; Small grants; Abstracts
Toby Hewson	CEO, Just Different	Representing PWUAAC
Simon Judge	Clinical Scientist	Northern link; Research; Online training
Vicky Lundie	SLT	Midlands link; Competencies
Ruth McMoran	Teacher	Abstracts; Conference programme & Events for PWUAAC
Kath Paintin	Retired teacher; business	Conference
Scott Stack	Comerways resident	Representing PWUAAC

If you wish to raise an issue with a specific Trustee, please do contact them via this email: admin@communicationmatters.org.uk

FINALLY...

As the new Board meet for the Business, Strategy and Finance meeting it is important to remember that Trustees serve on a voluntary basis.

I want to express my appreciation for all those who have served in previous years and have made Communication Matters what it is today.

I am also grateful to those who are willing to stand as Trustees at the present time and look forward to working together. *

Catherine Harris
Chair of Communication Matters

BHTA eCAT NEWS

What does BHTA eCAT mean to you, and I don't mean literally (see the end of this item for that answer) but practically?

It *should* mean that obtaining or using a product or service from a BHTA eCAT member company can be done in the knowledge that if anything goes horribly wrong and you cannot get your complaint resolved amicably by the supplier, you can refer it to BHTA who will take it up on your behalf (assuming that the complaint has substance, or course!). But did you know that?

Whether you are the actual purchaser, the person who recommends or proposes that specific product or even the user, dealing with a BHTA eCAT member should give you that little bit more confidence than dealing with a supplier that is not a member of it or some other equivalent organisation that has such a stringent Code of Practice, monitored Complaints Procedure (in BHTA's case by the Office of Fair Trading) and a Board that has both the experience and authority to deal with non compliant suppliers.

Members of eCAT have been discussing and reviewing how membership is viewed in the AAC community and whether professionals, carers and users really understand the advantages associated with buying from a company who is a member of a recognised and monitored Trade Association as opposed to one who isn't. Have we really got the message across that there are advantages or not?

In addition to this important question, the eCAT members have been discussing the future of the group and what we can effectively do for the AAC community. There is still much discussion to take place about how the Trade Association can really benefit professionals, carers and users of communication aids, so "Watch this space...".

However, there is one change we want to make as soon as possible – and that comes back to the literal meaning of "eCAT". Originally thought up to indicate that member companies work with and supply products that are both **Communication Technology** and **Assistive Technology**, the majority of which are **electronic**, we are aware that even this can be confusing as products such as powered wheelchairs, stairlifts and powered bathlifts, are also considered 'electronic assistive technology'. We also think that most of the AAC community who know of eCAT probably couldn't tell you what it stands for! So we have decided to request a name change (it has to be agreed by the BHTA Board) – and after much deliberation we have come up with the **BHTA AAC** section. We hope that, assuming this change is accepted, it will help those who see the name and the BHTA logo understand more of what member companies are about. Again, please watch this space...

David Morgan
BHTA eCAT Chair



DIARY DATES

7 February 2013 *Merseyside*
Voice for Life (Merseyside)
 Contact Afasic: 0845 355 5577 www.afasicengland.org.uk

5 March 2013 *London*
Voice for Life (London)
 Contact Afasic: 0845 355 5577 www.afasicengland.org.uk

21 March 2013 *Coventry*
Kidz in the Middle
 Contact: 0161 607 8200 www.disabledliving.co.uk/Kidz/Middle 

26 March 2013 *venue TBC*
AAC SIG Meeting
 More information: www.aacsig.org.uk

April 2013 (Date TBC) *Belfast*
Communication Matters Road Show: Belfast
 FREE Tel: 0845 456 8211 www.communicationmatters.org.uk 

26 April 2013 *Edinburgh*
Clicker 6
 Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

9 May 2013 (Date TBC) *Glasgow*
Communication Matters Road Show: Glasgow
 FREE Tel: 0845 456 8211 www.communicationmatters.org.uk 

DIARY DATES

June 2013 (Date TBC) *Birmingham*
Communication Matters Road Show: Birmingham
 FREE Tel: 0845 456 8211 www.communicationmatters.org.uk 

13 June 2013 *Reading*
Kidz South
 Contact: 0161 607 8200 www.disabledliving.co.uk/Kidz/South 

20 June 2013 (Date TBC) *London*
Vision for Communication Study Day
 Contact: 0845 456 8211 www.communicationmatters.org.uk 

26 June 2013 *venue TBC*
AAC SIG Meeting
 More information: www.aacsig.org.uk

15-17 September 2013
CM2013 National Conference
 Contact: 0845 456 8211 www.communicationmatters.org.uk 

19 November 2013 *venue TBC*
AAC SIG Meeting
 More information: www.aacsig.org.uk

21 November 2013 *Manchester*
Kidz up North
 Contact: 0161 607 8200 www.disabledliving.co.uk/Kidz/North 

CALL FOR

ACTION

LOBBY FOR COMPREHENSIVE LOCAL AAC SERVICES IN YOUR REGION

Communication Matters strongly encourages anyone concerned with AAC to develop good relationships in their region to support our campaign to improve services for anyone who finds communication difficult because they have little or no clear speech.

To support this process Communication Matters have worked with the Whitehouse Consultancy to produce the attached toolkit to help you engage with your local community and your Member of Parliament (MP).

Over recent months Communication Matters have been successful in lobbying for specialised AAC to be commissioned via the NHS Commissioning Board and discussions are taking place which we hope will make this a reality from next year.

However, we would particularly like your support to ensure that local commissioners in your area establish a comprehensive coverage of local AAC services across their region.

We would, therefore, like you to contact your local Health and Wellbeing Board, Healthwatch representative and build (or in some cases maintain) a constructive relationship with your local MP.



This updated Toolkit gives all the information you need to make difference in your local area.

Download the Toolkit from: tinyurl.com/local-toolkit

If you have any problems, then Gary Jones at The Whitehouse Consultancy will be happy to answer any questions; contact him on 020 7463 0697 or by email at gary.jones@whitehouseconsulting.co.uk



Communication Matters – Research Matters: An AAC Evidence Base

DAVID MORGAN & KATIE HOLMES

Communication Matters, Catchpell House, Carpet Lane, Edinburgh EH6 6SP, UK

Email: davidmorgan@communicationmatters.org.uk

Email: katieholmes@communicationmatters.org.uk



The third year of the project started with a presentation at ISAAC 2012 in July. This was a great way to share our research with an international audience. This was followed by two presentations at the Communication Matters Conference in September. These were well attended and many visitors to the project's exhibition stand were keen to support the research.

As we approach the halfway point of this final year we are increasingly thinking about endings. Before the end of the project in June 2013 we aim to find the best ways to share the research findings with the right audiences; complete all the work on the project and report on it to the Big Lottery Fund; and put in place the structures needed to continue the project's legacy after it ends. Over the next six months we will work with the trustees, the research partners and other organisations to ensure we meet these aims.

The final research report will bring together all the elements of the project:

- Mapping AAC service provision in the UK
- Determining prevalence of need for AAC in the UK
- The AAC Evidence Base website
- The case study database
- The Research Involvement Network
- Stakeholder involvement in the research

It will explain the methodologies used and report the findings. The report is due to be published in April 2013. It will be available to download on the Communication Matters website and a limited number of printed copies will be distributed to key contacts.

The research team at the University of Sheffield (in collaboration with Barnsley Hospital) are meeting at the end of November to review and analyse the

research data they have collected and to start to write their contribution to the research report.

Manchester Metropolitan University have continued to develop the AAC Evidence Base website. The website will present knowledge and evidence about AAC in a variety of formats, with the aim of helping visitors to the site to find the information they need, whether they are an AAC expert or someone new to AAC. Information available on the website will include case stories and factsheets; along with a bibliography of AAC-related research.

The website is currently undergoing testing prior to it going live. Twenty-eight people participated in testing in October. They included people who use AAC, support staff and family members; speech & language therapists, teachers, clinical scientists, occupational therapists and researchers. The research team at Manchester Metropolitan University is currently busy creating further content for the site.

The website launch will be publicised in the Communication Matters E-News. We would welcome your feedback on the website once it is live.

COLLABORATION

We are pleased to report that even before the findings are published the research project is already contributing to changes to service provision. Communication Matters has been able to share some of the data gathered by the University of Sheffield with the consortia that received the Department for Education AAC grants. This work is designed to help organisations in England transition to new commissioning arrangements and to prepare for the implementation of the specialist hubs model. Additionally an audit tool developed by the University of Sheffield as part of the AAC Evidence Base project

has been shared with the consortia in order to enable them to develop it further and carry out a more detailed audit.

THE LAST SIX MONTHS OF THE PROJECT

The project is on target to meet its milestones and is running within budget. We will report to the Big Lottery Fund at the mid-year point in December and agree our dissemination plans with them, along with our plans for the budget expenditure.

We have established links with key organisations in England, Scotland, Wales and Northern Ireland that are keen to support the project and we will work with them to disseminate the final report.

We are working with the Handover Group set up by the trustees to ensure a smooth closedown to the project and the continuation of the work started by the project. We will also be looking back to the beginning of the project in 2010 to evaluate how successful it has been in delivering its objectives. *

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 will produce fundamental evidence of the need for, and the provision of, AAC which can be used to improve services across the UK. The project will also create an online AAC Evidence Base that will make current knowledge about AAC available to all.

For more information, contact Katie Holmes, CM Research Manager, at katieholmes@communicationmatters.org.uk

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Using PODD Books

How effective are they in a busy classroom?

ALLI GASKIN

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Email: a.gaskin@lancasterian.manchester.sch.uk



This paper aims to explore the principles of *Pragmatic Organisation Dynamic Display* communication books (PODD books) and their introduction to Lancasterian School, a school for children with physical disabilities and/or medical conditions aged 2-16 years. It will share experiences relating to the implementation of PODD books with 4 pupils and outline some potential pros and cons when using PODD books in a busy classroom and the staff support required.

HISTORICAL PERSPECTIVE

Many Lancasterian pupils require alternative and augmentative communication (AAC) strategies to support the development of their communication skills and improve learning.

The school promotes a Total Communication approach providing low, light and high tech communication systems:

- **Low Tech:** *Visual timetables, objects of reference, signing, choiceboards, playboards, communication books etc.*
- **Light Tech:** *BigMack, Step-by-Step, GoTalk*
- **High Tech:** *Pathfinder, ECO2, Vantage Lite, Palmtop, DynaVox.*

Traditionally, our communication books have been *taxonomic*, i.e. vocabulary has been organised in categories, with some *schematic* messages, i.e. related to pupil events/activities. They have included core vocabulary (commonly

used words) and fringe vocabulary (words specifically related to the individual pupil, i.e. family names, personal interests, places unique to the pupil) as recommended by Clare Latham (2004).

However, the communication books have not always been used appropriately and their content has not always been the most interactive. The Communication Team were often required to update/add to the vocabulary within the books. The content could become quite muddled for pupils to find target messages as the content within the books increased.

Symbol boards such as *topic boards, playboards, songboards*, etc., provide appropriate vocabulary for a specific activity at a specific moment in time. This vocabulary is not always available at a different time making the generalisation of the language skills used, more difficult.

Our challenge has been to provide a communication system with an appropriate amount of language which can be used across a range of situations and allowing pupils to develop a range of communication functions. The communication system needs to facilitate a suitable progression of linguistic skills as well as opportunities for social communication.

INTRODUCTION OF PODD

Lancasterian was fortunate to benefit from the knowledge and expertise of

speech and language therapist Suzanne Martin – she had worked in Australia for several years and received PODD training from Gayle Porter, the Australian speech pathologist responsible for the design and development of PODD books. Suzanne shared her experiences of using PODD books, enabling us to develop and implement PODD books, initially with four pupils across both primary and secondary departments in school.

WHAT IS A PODD BOOK?

A PODD book replicates the principles of a dynamic display communication aid in a low tech form. There are a range of different PODD book layouts available, as the image above shows. Some key components of PODD books are:

- **Consistently placed vocabulary** – this allows users to develop automaticity. They can practise finding vocabulary by repeatedly going to the same place in their communication book.
- **Clear tab system** – this enables the user and their communication partner to navigate through their communication book more easily. It provides a numbered and colour coded system to find topic pages. The tabs can be seen on some of the sample pages included in this article.
- **Automatic level changes** are facilitated through the communication partner. It is actively encouraged that

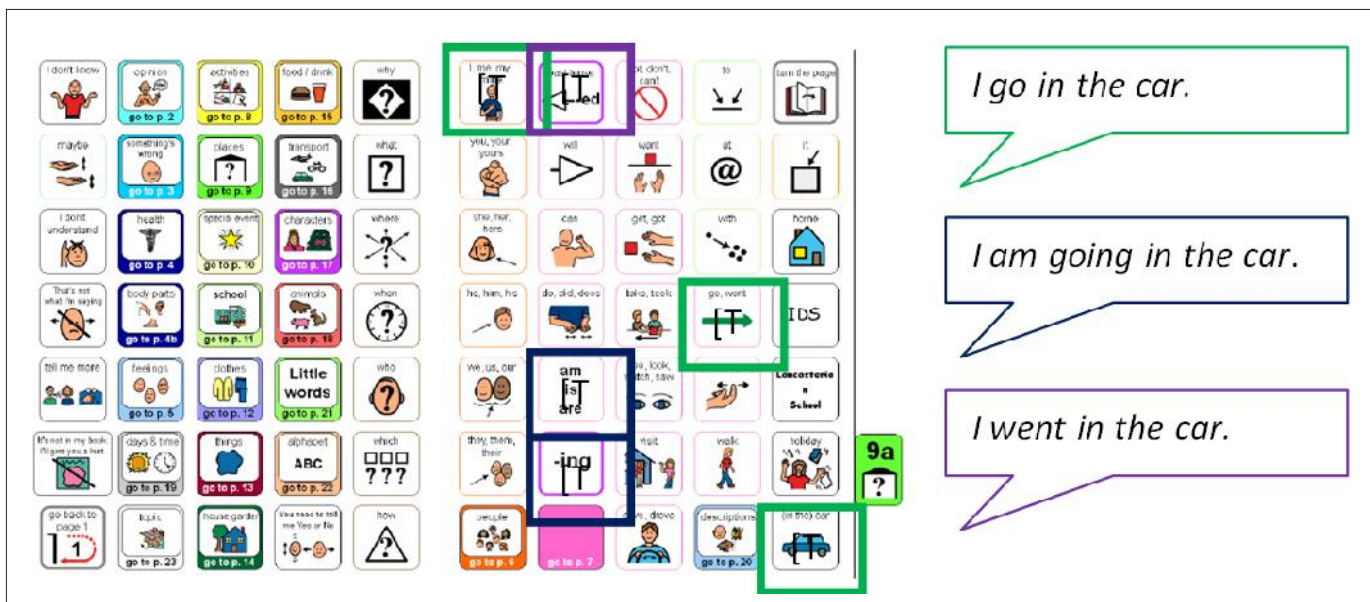


Figure 1 Relevantly placed vocabulary

the communication partner takes responsibility for turning the pages within the book, so that the child can focus on what they want to say.

- **Relevantly placed vocabulary** - this means that vocabulary which most frequently goes together is available on the same page (Fig 1).
- **Colour coded vocabulary** - word groups are colour coded based on a version of the Fitzgerald key to improve word retrieval.
- **Pragmatic Branch Starters** - allow predictive links to pages of vocabulary required to express a communicative function (Fig 2). They provide the listener with an immediate clue to the type of message the user may want to say. They vary according to developmental language levels.

The Pragmatic Branch Starters (PBS) help clarify the intended meaning of a message in the absence of paralinguistic cues such as intonation, facial expression, etc. For example:

- Use of PBS "I'm telling you something" + "go" + "shop" would mean that the child is going shopping or has been shopping.
- Use of PBS "I have a question" + "go" + "shop" would mean that the child is asking "Can we go shopping?" or "When are we going shopping?"
- **List Pages** - allow customisation of the PODD book quickly and efficiently. The pages in Fig 3 show an example of an ACTIVITIES page and an associated LIST page for additional personal vocabulary.

PODD BOOKS AT LANCASTERIAN

Child A

He uses a one page opening 20 location PODD book through direct access (pointing). He previously used a DynaVox 3100, but his vocabulary package was limiting and staff were not always confident supporting A to use his device. His PODD book was introduced in March 2011. It is suitable for children who can communicate a range of communication intents - can ask questions, give information etc. It focuses on meanings in everyday environments, stories and play.

Child A has been taught to use specific navigational pathways for social messages, giving information, expressing feelings and describing things. He has learnt these pathways quickly.

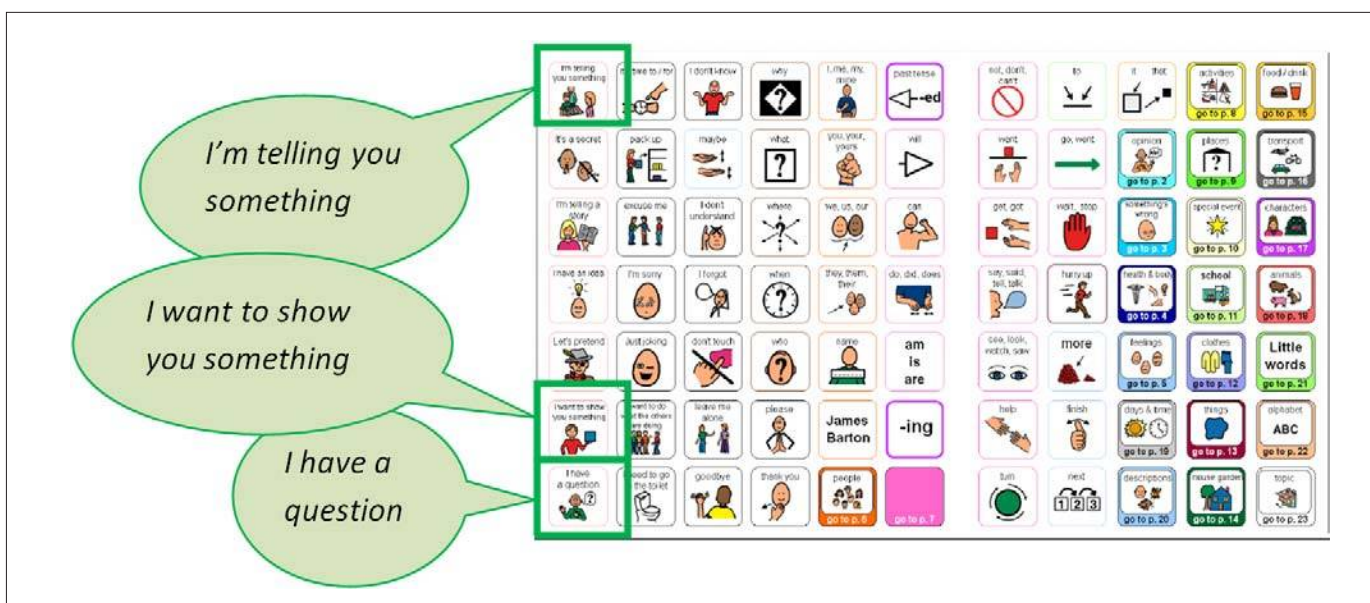


Figure 2 Pragmatic Branch Starters



Figure 3 ACTIVITIES page and associated LIST page

Child B

He uses a one page opening 20 location PODD book through partner-assisted scanning. His PODD book has the same content as *Child A*, but the information has been divided into clearly defined columns for column/row partner assisted scanning (Fig 6).



Child B uses eye movements to indicate Yes/No. His communication partner (CP) works through the vocabulary using column-row scanning. *B* will indicate when the CP has reached the right column for his message through Yes/No. The CP will then read/point to the choice of vocabulary within the column and wait for *B* to give his Yes/No response again to indicate his target message.

Child B previously tried a simple scanning voice output communication aid (TechScan) but his physical access to messages was difficult.

He did not have the timing skills to activate the switch for messages at the right time. He continues to be assessed for the most effective and efficient switch position.

The PODD book has provided an opportunity to work on developing his scanning skills in a low tech form and given him increased opportunities to communicate. He has been learning the same navigational pathways as *Child A*.

Child C

She uses a two page opening 40 key word book. She previously used a communication book with loose symbols. She was able to form simple sentences containing two key words, but symbols were frequently missing and therefore the language required for interaction was not always available. The 40 key word PODD book provides a more consistent vocabulary for *Child C*.

Staff have been encouraged to continue to model appropriate sentence structures using the PODD book. *Child*

C has been encouraged to use target messages out in the community, i.e. to request a drink/snack in the café or to ask for a specific item when shopping.

Child D

He uses a two page opening 70 expanded key word book. A sample of his PODD book was used when describing the key components of PODD books.

His book was introduced as a backup for when his Pathfinder voice output communication aid is not working. It has been designed for pupils combining 2-4 key word utterances and expressing a range of communication functions.

Child D is using simple sentences with his Pathfinder, but had no other communication system available before the introduction of the PODD book. He has also been encouraged to use more complex syntax to be used within sentences, i.e. tense markers.

OUTCOME

We evaluated the effect of PODD books on our pupils by exploring the four areas of communication competence identified by Janice Light (1989) and eliciting staff feedback.

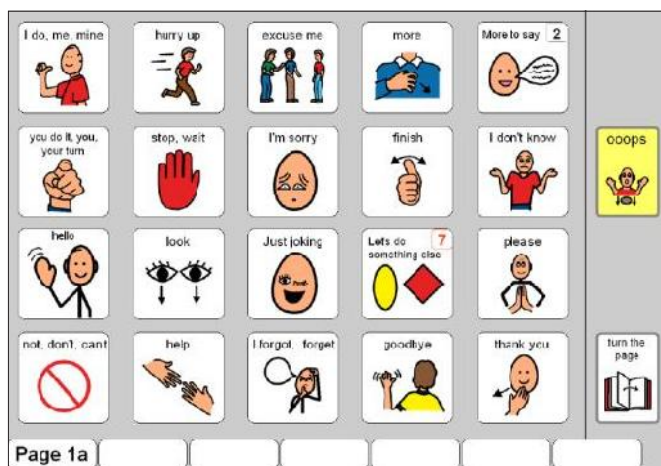


Figure 4 Child A's MAIN page

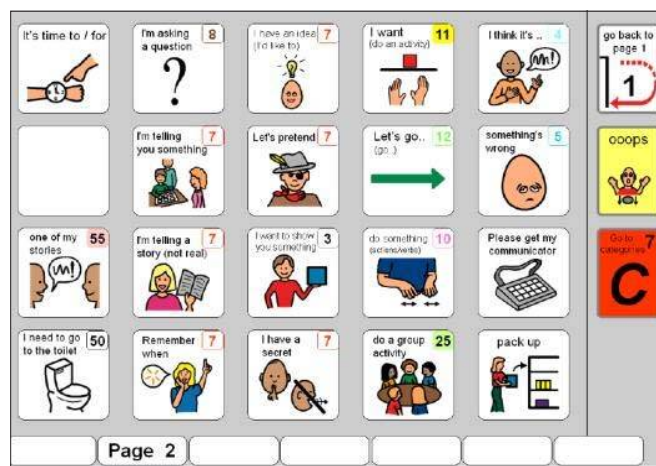


Figure 5 Child A's STARTERS page

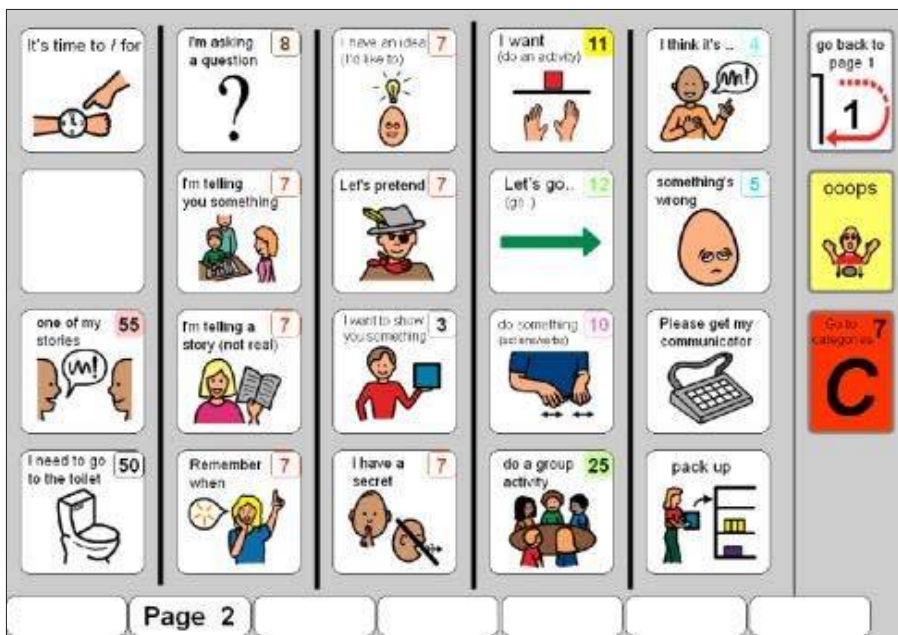


Figure 6 Page from Child B's PODD book with clearly defined columns

Operational Competency

Pros

- The tab system provides a clear focus for staff to support PODD users. This has been positively received.
- Staff have been able to promote successful communication interaction; their page turns are more accurate, making the process less time consuming and thereby more immediate for the PODD user.

- *Child A* was easily distracted by turning pages in his previous book. The involvement of the communication partner navigating through the PODD book encourages him to wait & watch. It facilitates more accurate message selections.
- The navigational skills developed can be applied to a more sophisticated device. This has become apparent for *Child B* whose scanning skills are improving.

- *Child C* has been observed independently exploring her PODD book. She has taken ownership of her PODD book better than her previous system, carrying her book around school with less prompting. Her symbols are now constant and available for her at all times.

Cons

- Some staff have difficulty prompting children when they are not sure where a specific vocabulary item may be.
- *Child A* still wants to turn the pages himself.

Linguistic Competency

Pros

- The ready-made vocabulary within the PODD books is a familiar concept for some staff as pupils are using vocabulary packages such as CALLtalk on high tech voice output devices. The PODD book uses a similar.
- The communication partner allows modelling and expansion strategies to be used to develop language skills further.
- The range of vocabulary within the PODD book allows for spontaneous messages to be created. *Child A* had been taught the navigational pathway for DESCRIPTIONS. He spontaneously directed his CP to "loud" to indicate that the staff and pupils in the class

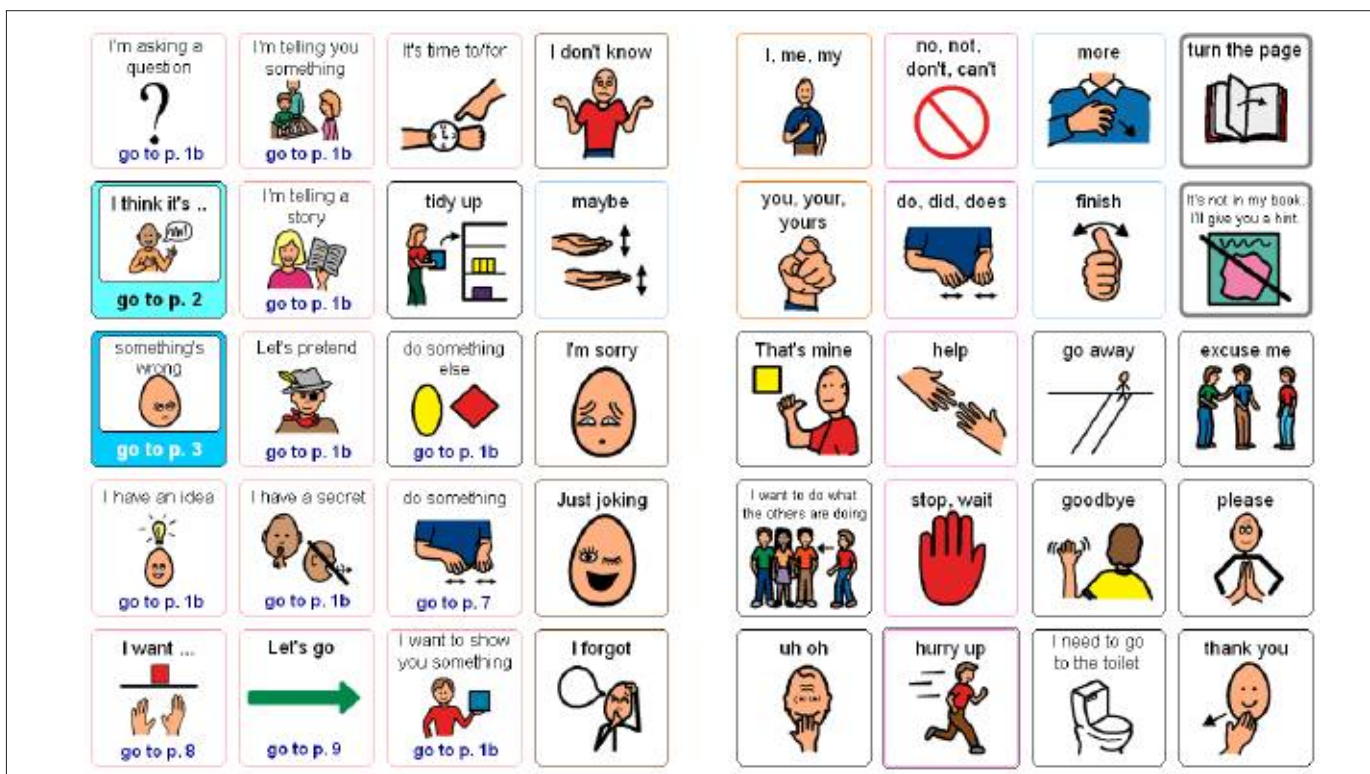


Figure 7 Page from Child C's PODD book

next door, were being noisy. A very exciting moment! A new, novel message produced without prompting using a navigational pathway taught in a previous session for a different context.

- The vocabulary requires minimal editing and is easy to update/customize through the use of LIST PAGES. The process of maintaining and updating communication books has been much easier than previously.

Cons

- It can be difficult to promote linking of vocabulary to form simple sentences when target vocabulary is across pages.
- Staff supporting *Child C* have requested separate communication boards for specific situations to reduce the need to navigate through pages to find target vocabulary. They have reported too much vocabulary for specific situations, i.e. when C is waitress in the school Coffee Shop.

Social Competency

Pros

- One member of staff commented that the PODD book "has a broad vocabulary useful to model functional language". This is a key benefit of PODD books.
- The Pragmatic Branch Starters (PBS) make it easier for the listener to anticipate what the user is going to say. They help structure the interaction for both the user and the CP.
- The PBS focuses on communication function and conversational discourse needs, which is acknowledged by some writers as being a more effective means of developing communication initially - before semantics and syntax (Burkhart & Porter, 2006).
- The PBS facilitate more successful interactions as they help clarify meaning.
- Child B has enjoyed using the "Only joking" message. This was a purposeful incorrect response.

Cons

The interaction between the CP and pupil during the navigation process, can interfere with the communication interaction between teacher/session facilitator and pupil. Staff supporting the PODD user, have required specific training to ensure that their levels of prompting are appropriate and that they do not have a conversation with the pupil as they navigate.

Strategic Competency

Pros

- The PODD books provide opportunities to develop conversational repair strategies. There are specific messages to indicate to the listener that a mistake has been made - "Oops!"
- The tab system helps the user navigate and there are [Turn the page] and [Back page] to help locate messages.

Cons

- There may be navigational constraints for getting to messages for communication repair.

FINAL THOUGHTS

The overall impact of PODD books has been positive. One member of staff said: "I think it is fantastic! It gives A a chance to get his voice across."

The involvement of the communication partner has been fundamental to the successful implementation of PODD books. The CP role within interaction process has given staff confidence to use communication books more consistently and more effectively. Staff who have expressed difficulties navigating, have learnt relevant navigational pathways over time alongside the pupils.

However, concerns have been raised that too much input is required from staff to support pupils and that as more PODD books are introduced, the demands on staff increase. It could be argued that PODD books require no more time than the high tech devices already in school and they are considerably cheaper to acquire.

PODD books are time consuming to produce but Gayle Porter's Resource CD provides ready-made PODD book layouts and instructions for making books according to different language levels. Once the most appropriate PODD layout has been determined through assessment, professionals can customise the ready-made layout making the process faster than starting from scratch.

Lancasterian School now has nine PODD books in place. They continue to be positively received on the whole. *

Alli Gaskin

Specialist Speech & Language Therapist

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RESOURCE CD-ROM

This is available to support practitioners with the selection and development of an appropriate PODD book for pupils. It provides a range of Boardmaker grids containing the vocabulary needs for specific PODD books and gives instructions for making the books themselves.

JOINING COMMUNICATION MATTERS & ISAAC

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

What are the benefits of Membership?

Members of *Communication Matters* receive this *Journal* three times a year, reduced delegate rate at the Annual CM National Symposium, and all the benefits of ISAAC membership, including ISAAC publications at substantially reduced rates, and special delegate rates for the Biennial ISAAC Conference. You can also access the member's area of the ISAAC website and, if you join early in the year, you will receive a Membership Directory.

What is ISAAC?

Formed in 1983, ISAAC is a multidisciplinary organization devoted to advancing the field of AAC. ISAAC has over 3,000 members in more than 50 countries. The Mission of ISAAC is to promote the best possible communication for people with complex communication needs. The vision of ISAAC is that AAC will be recognized, valued and used throughout the world.

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: admin@communicationmatters.org.uk

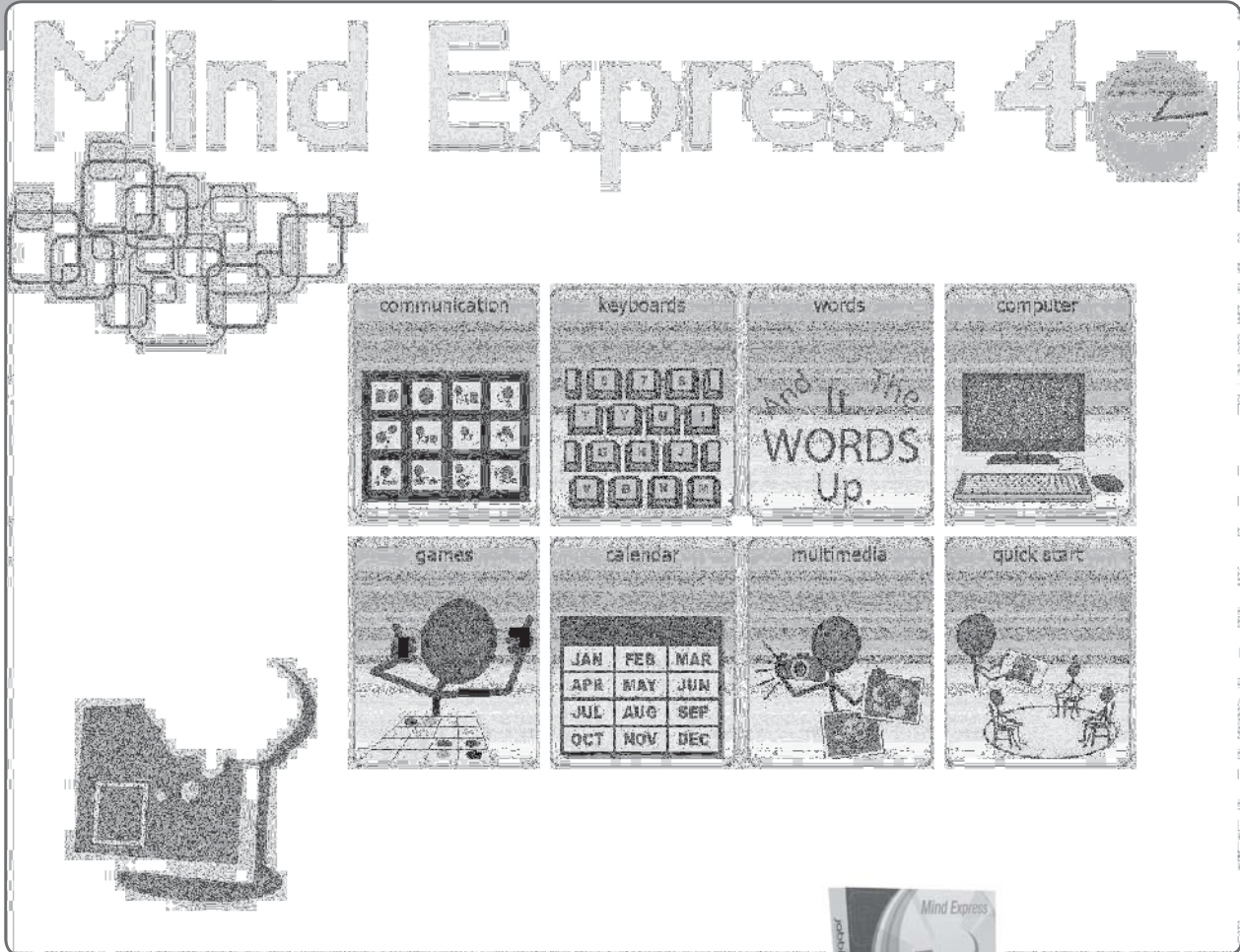
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MND Review of Communication Aids Provision and Introduction to MND AAC Care Pathway

CATHERINE HARRIS

Email: catherineharris@blueyonder.co.uk

In November 2011 the Motor Neurone Disease (MND) Association commissioned a review of their Communication Aid management and provision. The project objectives were as follows:

1. To characterize the needs of people with MND with regards to AAC.
 2. To identify technologies and aided communication techniques which are not the responsibility of statutory services.
 3. To identify gaps in training and to propose solutions.
 4. To develop criteria for funding as guidance for the financial support team.
 5. To develop online information in association with the Digital Media team.
- This paper aims to share the outcomes of this project.

BACKGROUND

With the ongoing developments in technology, the MND Association were finding that there was a growing demand for a wider range of voice output and access solutions (hardware and software) with significant cost implications and in some cases very limited recycling potential.

There was also a concern that the provision of equipment through the MND loan bank had masked the need, as of-

ten there had been no application submitted for statutory funding. With more 'mainstream' solutions available on the market there was evidence that people were sometimes being supplied with equipment, funded by the Association, which was not always appropriate. There was also evidence that people were not being reviewed for their ongoing and changing needs.

METHOD

Information was gathered over the three months of the project duration through consultation with staff from the Specialist AAC Assessment Centres and MND Care Centres; local SLTs and other professionals; people with MND who use AAC; the main companies who supply the equipment; and the equipment loans team at the MND Association.

This was a fascinating insight into needs, expectations and realities. It became apparent through the consultation that the main issue was not the equipment itself, but the need for a more robust and timely assessment process before the equipment was supplied, and the provision of ongoing support and training as appropriate.

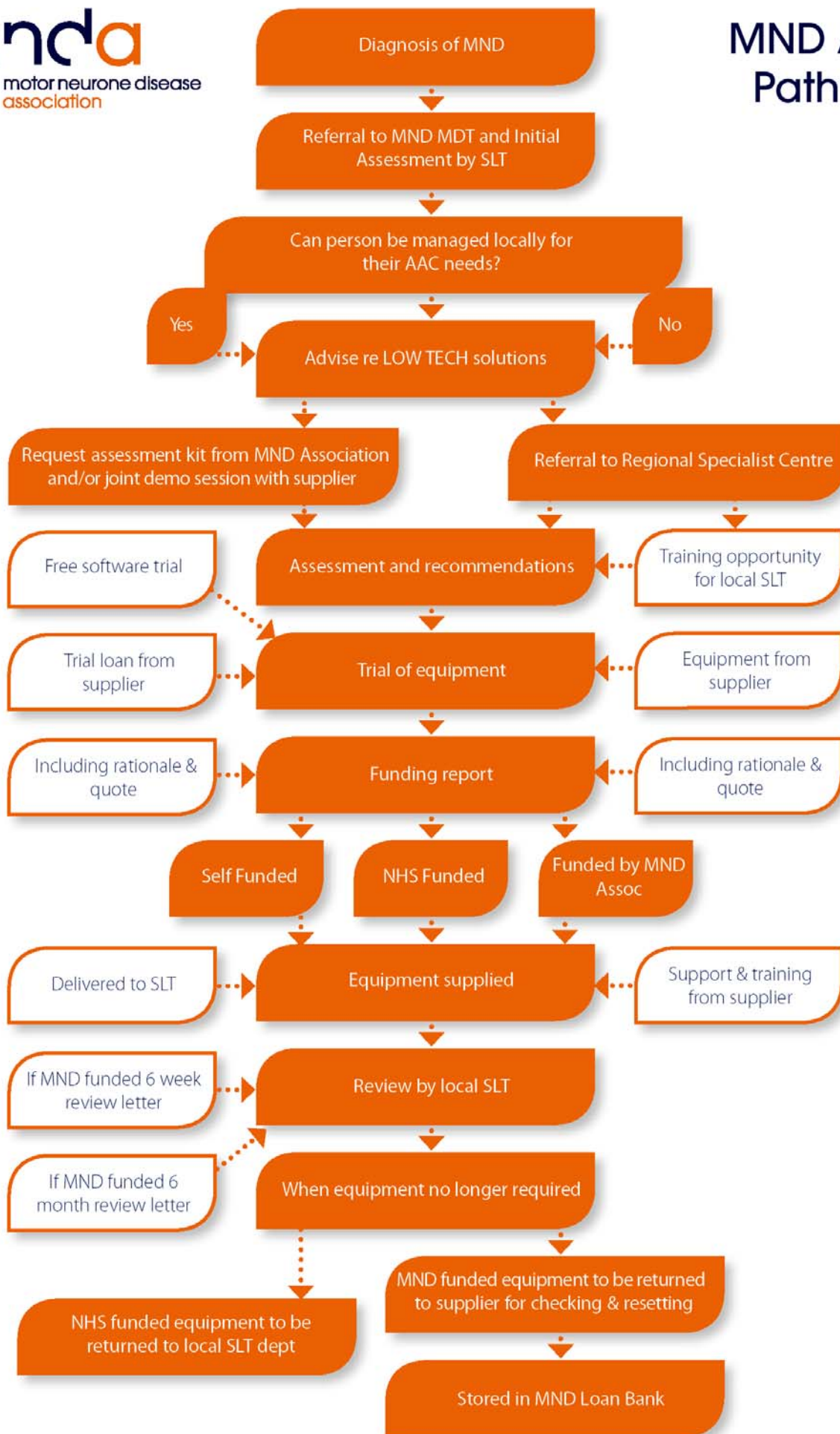


MND AAC CARE PATHWAY

As a result of the project, an MND AAC Care Pathway has been developed with short and full guidelines to give a framework for people with MND and professionals around AAC provision, particularly in relation to assessment, training and funding applications and to guide the decision making process of the equipment loans team as they manage expectations around financial assistance. The pathway is specifically to outline the process which must be followed when there is a request for funding support from the MND Association. However the principles of someone needing a comprehensive assessment, opportunity to trial equipment with adequate training and



MND AAC Pathway



support and the discussion about funding are ones which relate to good practice and quality of service delivery. Here is a summary of steps in the MND Care Pathway:

- Following diagnosis, a person should receive a referral for and initial assessment with a speech and language therapist. At this appointment the decision should be made as to whether the person with MND can be managed locally for their communication needs.
- It is recommended that low-tech AAC solutions are discussed as appropriate. If specific high-tech solutions (both for speech output and computer access) are introduced it is recommended that there is partnership working with the relevant supplier to ensure that there is adequate training and support. It will also be important to consider the needs of the person in relation to environmental controls.
- A trial of equipment should be arranged before a final decision is made.
- If self-funding is not possible, a request for statutory funding needs to be submitted even if this is not usually agreed to raise the awareness of need. If there is a referral to a Regional Assessment Centre, the same process will then need to be followed if funding support from the MND Association is required.

OTHER RECOMMENDATIONS

In addition to the Care Pathway it was recommended that the MND Association should develop a 'bottom-up' training programme around 'core' equipment to raise levels of competencies around MND and AAC for speech and language therapy teams.

The opportunity of closer partnership working with Regional Centres of Excellence for AAC (CAC and AT) in line with the Hub and Spoke project was recommended to provide a more timely and responsive service. Development of partnership with AAC companies and suppliers was recommended to provide a more effective support network for people with MND, their families and carers and the professionals who are supporting them. Online low-tech resources were developed to be available on the MND Association website.

OUTCOMES

The MND Association are already using the Pathway to establish a more robust process around assessment for AAC

and equipment provision for people with MND. There have already been encouraging results with statutory funding being secured when the Pathway has been followed.

The Association is looking into the possibility of developing partnership working with the Regional Assessment Centres to support ongoing training of SLTs in managing the communication and access needs of people with MND.

A pilot training programme has been introduced at Frenchay Communication Aid Centre and ACE Centre (Oldham) so that, following a training workshop, a local SLT can borrow the equipment to use for initial screening or cascade training of their teams.

The Association are also beginning to develop partnership agreements with AAC companies to help in maximising the recycling potential of higher cost hardware and software applications. In addition to the MND Care Pathway, a parallel piece of work outlining Best Practice Guidelines, which was co-ordinated by Steven Bloch, is also available on the MND Association website, on the 'Professionals' page. This includes information on managing different presentations of MND, signposting and a selection of low-tech resources which can be downloaded.

CONCLUSION

This project was funded by a donor who has a particular interest in AAC and getting the best solution for people with MND. It was a timely piece of work in the light of a potential Hub and Spoke model for AAC provision.

It is hoped that the MND AAC Care Pathway will give a framework for professionals, people with MND and their families and carers. The training programme should help to raise competencies and standards.

A more comprehensive assessment, trial of equipment and adequate ongoing support and training, combined with adequate documentation, should result in statutory funding being achieved more often and, when that does not happen, the MND Association will be able to provide more targeted support and resources. *

Catherine Harris
Independent speech & language therapist

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MND Care Pathway

This can be downloaded as a PDF:
www.mndassociation.org/Resources/MNDA/Professionals/Documents/AAC%20pathway%202012.pdf

A version with shorter guidelines:
www.mndassociation.org/Resources/MNDA/Professionals/Documents/AAC%20pathway%202011-Short.pdf

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A Collaborative Approach to Communication Support in a Hospital Environment

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The aim of this paper is to share the experience of supporting a functionally nonspeaking young man with severe learning difficulties through a major surgical procedure. The paper shares ideas and resources used, discusses the value of a collaborative approach with the various services involved and the potential for developing additional resources with these service providers.

BACKGROUND

In this case study, a young man with severe learning difficulties, attending Selworthy School in Taunton, Somerset, was supported through a planned spinal operation at Musgrove Hospital, Taunton. The family and the young man involved in this case study have given their full consent for the presentation and publication of this paper.

The young man concerned, Ed, is 16 years old with severe global developmental delay and an undiagnosed medical condition. Ed presents with a sensory integration disorder, a verbal and developmental co-ordination disorder (*dyspraxia*) and considerable difficulties with his independence and social skills. Ed has significantly delayed speech and language skills but despite this he is keen to communicate, is sociable and generally happy. He has a short concentration and attention span, is eas-

ily distracted and needs support using visual cues to encourage him to remain on task. Ed has particular difficulties with concepts of time and change, and needs clear warnings when changes in activities and events are likely to happen.

Ed uses a small, hand-held communication device (Tellus Smart) to help him with his communication and learning. He generally uses single symbols to communicate his needs but can put two or three symbols together when prompted. In terms of communication in the home environment, Ed signs everyday words and sometimes uses his communication device to communicate more complex thoughts and ideas.

UNDERSTANDING THE ISSUES

In 2011 Ed's consultant recommended spinal surgery. The surgery, for a scoliosis correction, involved screwing two titanium rods either side of his spinal column to provide the necessary correction to his curvature, allowing Ed to walk and to continue managing daily activities independently. Ed's family were concerned about his understanding of what was going to happen to him and approached the school regarding this. They were particularly concerned about his understanding of the time scale of his operation and his communication needs in the hospital environment.

A COLLABORATIVE APPROACH

Following discussions with the family and the school nurse, it was decided that there were several strands to the support required and it was therefore agreed that the strategies in Table 1 would be put in place:

1. Understanding the concept of time

One of the first difficulties to overcome was that of 'time'. Ed struggles with the concept of time and past experience has shown that this could become a cause of great concern and frustration in the family environment. We had some success in the past with the use of a calendar to show how many days there were before an event and this was replicated for the hospital visits (Fig 1). Ed's family had communicated that they did not want any of this work to start until after Christmas. We therefore started work with Ed in January, a full three weeks before his operation.

2. Expressing needs and visual support

Selworthy School's community nurse was involved in preparatory discussions with Ed's family and together we were able to come up with words and concepts that Ed would need to understand. Photographs and images of some medical procedures were included in a small communication book. Parts of the body,

	What	Who
1	A resource to help with the concept of time - leading up to the operation and his stay in hospital	- School communication specialist - Family
2	A resource to help express his needs in the hospital environment and to help with the understanding of what was going to happen to him	- Ed - Family - School communication specialist - School nurse and hospital nurses
3	A resource for expressing pain	- Ed - School communication specialist - Family - School nurse & play therapist
4	Familiarisation visit for Ed and his family	- Ed - Family - School nurse & play therapist
5	Familiarisation visit for Ed and school friends	- Ed & classmates - Teaching staff - School communication specialist - School nurse & play therapist

Table 1 Schedule of resources

feelings and people made up the majority of the pages with some additional 'hospital specific' vocabulary. These included 'cannula' and 'catheter' as well as 'surgical tights'.

The value of working collaboratively here is obvious, as these were not words which would typically be generated by a speech and language therapist or a parent. The play specialist provided additional photographic material showing a young lady who had undergone the same surgery and some of the equipment and physical changes (scars) he would experience. The play specialist also provided a gas mask for 'practising' with at home, as Ed was going to be anaesthetised in this way.

3. Expressing pain

A very important consideration for both the family and Ed was how he was going to express his pain. Ed's level of understanding did not allow him to use the traditional 'Wong-Baker' (2012) pain chart (Fig 2). Ed does not have sufficient understanding of emotions to enable him to express his pain using these faces, neither is his understanding of numbers sufficiently embedded to relate to pain in this way.

Enabling non-verbal children and young people to express pain has been an ongoing concern of mine and over the years I have developed a couple of resources which have helped meet the need in my practice. The symbols used change as my thoughts around the topic change, but the basic concept has remained the same for a number of years now (Fig 3). At the time, it was a laminated paper resource, with Velcro tags. It not only allowed Ed to express his level of pain ('hurt' was the terminology used

by the family) but also to independently express other concerns.

Ed had used this tool before his operation and he was therefore able to show the staff at the hospital how to use it. He had considerable anxiety over the use of needles and medication, so this pain chart was specifically developed to enable Ed to talk about this with the nursing staff.

4. Familiarisation visit for Ed and his family

Ed and his family went for a pre-op visit on the Monday before his operation. At this visit Ed was able to handle some of the equipment. He was shown the bed and the ward he would be in and was able to meet the staff who would be looking after him.

5. Familiarisation visit for Ed and his school friends

What worked surprisingly well was a repeat visit the next day, where Ed took

his class friends into the hospital and showed them round. As Ed had been the day before, he was able to show everyone the equipment, the ward and introduce the nursing team to his friends. Ed took great pride in showing everyone around and it was a very empowering process for him. Support from Musgrove Hospital play therapists made these visits possible and Ed was definitely more relaxed about his surgery as a result of these visits.

RESULTS

The operation went ahead as planned and Ed's recovery was remarkably quick. The family were very grateful for the support they were given and felt the resources had played an important role in contributing to his speedy recovery.

Comments from family

"The lead-up to surgery was far less stressful than we had imagined. The calendar proved to be an invaluable resource. It allowed us to discuss with him when it was happening, and allayed some of the anxieties previously demonstrated prior to any major events in Ed's life. Ed's use of the pain chart not only eased our concerns, as his parents, but also put the control of his pain management in his hands. We had no doubts that he was able to clearly and definitively communicate the level of pain he was experiencing. Ed was extremely relaxed on the day of the surgery and when the time came to be anaesthetised, even the anaesthetist was surprised by how calm he was and easy to deal with."

Comments from school nurse

"In my experience the benefits of preparing children for hospitalisation have long been recognised, however communication still does not get the

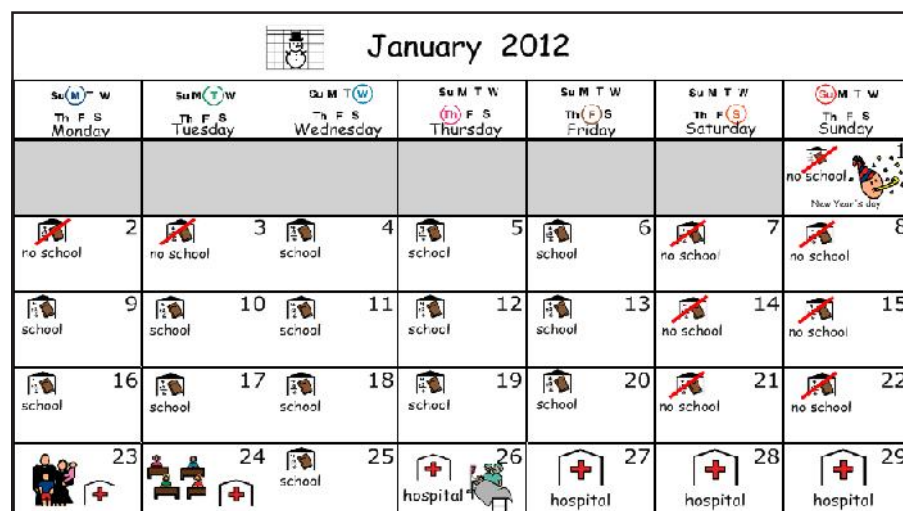


Figure 1 Calendar to show how many days there were before an event

recognition it deserves. I have cared for children undergoing spinal surgery for fourteen years and it is my opinion that this multi-disciplinary project played a large part in enabling Ed to make an uncomplicated recovery and, as a result, have the shortest hospital stay of any spinal patient.

“As well as enabling Ed to communicate his pain, the pain chart enabled the nurses to assess the effectiveness of the analgesics given. In turn, if a child is not in pain and is less anxious, they are more likely to mobilise thus preventing post-operative complications such as chest infections and thromboses. I am looking forward to continuing this valuable working relationship and developing further resources for children in the hospital environment.”

Musgrove Hospital

The lead play therapist involved communicated that the resources had been of significant benefit and that the whole nursing team had used them extensively. As a result of this, she expressed an interest in looking at developing additional resources for people with communication difficulties for use at Musgrove Hospital and I was invited to speak at the Play Therapists’ annual conference in May 2012.

The conference was a great opportunity for an insight into the nursing perspective. After a short introduction into basic speech, language and communication needs, we discussed the use of symbols and alternative methods of communicating and came up with some possible low-tech solutions for the hospital environment.

The issue of expressing levels of pain was of course a major concern. The nurses were all very positive in their comments regarding the pain scale used and were keen to incorporate this tool into their everyday practice. This prompted an open discussion and reflection on their current practice regarding pain assessment.

It was clear that the nurses firmly believed that managing a child’s pain should involve the child. However, it was also agreed that common practice is to use ‘observer-rated behavioural pain assessment tools’ which do not involve the child. The nurses suggested that the reason for this was the lack of nurses’ knowledge and understanding with regard to disability and communication. It was certainly a privilege to be part of such an honest, professional discussion but it left me with more questions than answers.

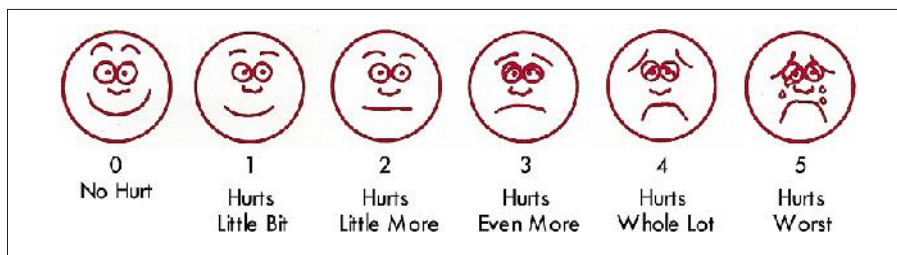


Figure 2 Wong-Baker pain chart

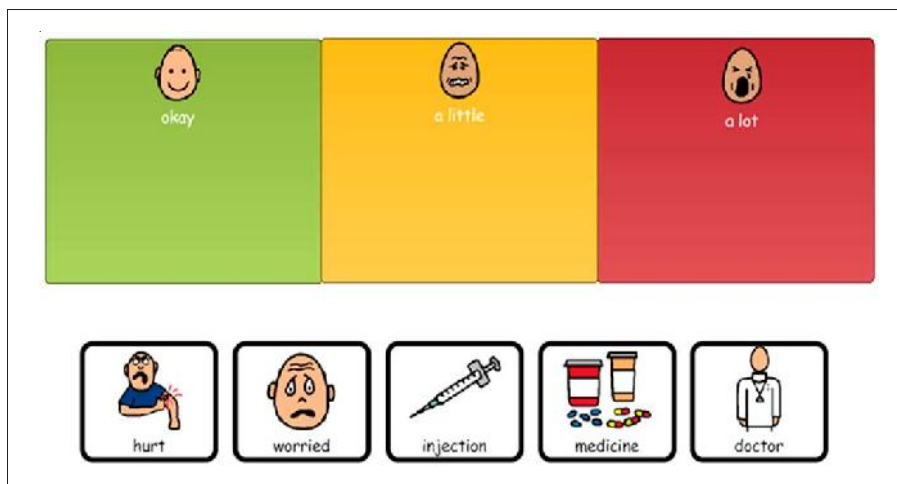


Figure 3 Symbol chart for expressing pain

CONCLUSION

Subsequent research in the area of pain assessment led me to an article which fully supported the nurses’ practice. McKay and Clarke (2012) state that not only is observer-rated behavioural pain assessment common practice but it is recommended as ‘good practice’. The suggestion is that children with severe learning difficulties are not able to communicate their pain; therefore observer-rated assessment tools are more appropriate. The article goes on to critically review three pain assessment tools, none of which include the child.

There is obviously much work to be done in bringing professions together to consider these issues and to find alternative ways for assessing pain that include the young person.

I would suggest that not all children with severe learning difficulties are unable to express their pain and that a combination of observer-rated and self-reported assessment methods could be jointly used.

Unrelieved pain is due to ineffective pain assessment and management; children with severe learning disabilities have the same rights as any other child with regard to this.

As practitioners, we need to find ways of making expressing pain accessible for this group of people.

FOLLOW UP

The pain scale was of particular interest to the nurses at Musgrove Hospital and has always received such a positive response that it prompted further developments for a device suitable for the hospital environment.

It has now been made into a low-tech device with magnetic symbol tags and anti-microbial surfaces suitable for a range of clinical environments (Fig 4). *

Laila Emms
Communication Specialist



Figure 4 Pain scale device

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Elklan AAC Training Package

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Elklan has developed a training package for people supporting those using AAC (Augmentative and Alternative Communication), written and collated by an AAC specialist Speech and Language Therapist who is also an Elklan tutor. Elklan works by training local speech and language therapists and specialist advisory teachers to work together to equip the local team supporting those with speech, language and communication needs. Over a period of 11 years Elklan has trained over 1,200 speech and language therapists to be Elklan tutors and over 550 specialist advisory teachers to work in a co-tutor role. The Elklan *Train the Trainer* programme has enabled training to be cascaded to over 20,000 staff working in pre-school, primary and secondary education in both mainstream and specialist settings as well as parents.¹

Currently, there are core Elklan courses for staff working with Children with Speech and Language Needs, and with Children with Severe and Complex Needs. There are also specialist courses for those working with: Children with Unclear Speech; with Hearing Difficulties; and with Autistic Spectrum Disorder. The Elklan 'Supporting Children and Adults using AAC' course will be an additional specialist course.

The Elklan 'Supporting Adults and Children using AAC' course is suitable for school, college, work or residential support staff, speech therapy assistants, generalist or newly qualified speech and language therapists and all those supporting children and/or adults using AAC. Training days will be offered for Elklan trainers who would like to deliver this course but feel they need additional training themselves in the specialist course content.

All Elklan courses are externally accredited through Open College Network South West (OCNSWR) which makes them valuable to employers and employees. Course participants on all courses can achieve 6 credits at Open College Network (OCN) Level 2 or 3. The

choice of level is made by the individual with guidance from the course tutors.¹ This course has an additional level of accreditation, at OCN Level 4, which would be appropriate for generalist or newly qualified speech and language therapists needing to develop their AAC skills as part of their continued professional development.

The author's role at the time of writing the Elklan AAC module was as a specialist AAC speech and language therapist and a clinical lead for a special needs service. An integral part of this role was to support people using AAC, and to deliver AAC training at various levels to a range of generalist speech and language therapists, teachers, teaching assistants and parents, and to deliver Elklan Complex Needs courses to staff working in a special needs school.

The author had noted how the confidence and motivation of staff increased as Elklan courses developed their understanding and their ability to discuss the children's difficulties, and strategies to support them. The incentive of the accreditation was clearly a motivator and gained commitment to the training. The students who had attended Elklan courses appeared confident when putting strategies in place, carrying out programmes and providing information for the referral, assessment or review process.

Training for staff supporting AAC users commonly consists of teaching the support group how to use a particular high tech device or low tech system. That approach may work in the short term, however when the AAC user changes environment, or their AAC needs change, further training will be needed. That type of training is a very compartmentalized way of supporting the child's AAC as it focuses on the technique or system that is being introduced or developed at that time rather than looking holistically at all the AAC needs. That sort of training only touches the tip of the iceberg and does

not integrate the areas of no tech, low tech, high tech and environmental AAC, or target development of a wider staff group's overall understanding of AAC principles.

There is a general move within speech and language therapy departments towards prioritising the need to train a wider workforce and this has been clearly supported by the Bercow review and the RCSLT (Royal College of Speech and Language Therapists) position paper 2006.

The RCSLT position paper, '*Supporting children with speech, language and communication needs within integrated children's services*' (M Gascoigne, 2006) is widely accepted by the Department of Health and the Department of Education as the optimal way of delivering services to children with speech, language and communication need (SLCN). The report states that the training of others, including parents, should be viewed as a central activity for SLTs. The Bercow review of services for children and young people and the subsequent Government action plan 'Better communication' also states that training of others is fundamental to the SLT role. Every SLT service needs to be commissioned to meet the needs of a wide range of children; in some instances the best way to work with a child is to train those who are supporting them.²

AAC, in particular, is an area of speech and language therapy where the idea of improving and expanding training is fundamental. AAC support needs to be a whole team approach. Training in AAC is not just about programming a high tech communication aid, making resources or introducing a specific low tech system. On the contrary, it is about looking holistically at the person's AAC needs and understanding how to integrate and support everything they use. It cannot therefore be supported by one trained person in isolation but requires the whole team to understand the ideas and the general principles.

A need was identified for a structured training package to provide a general background understanding of all aspects of AAC.

It was important that this new course be as accessible as possible to a wide range of staff supporting AAC users. The Elklan AAC training package is designed to be taught over five weekly sessions of two hours each. This should allow the participants to also complete the associated portfolio activities during each week. The materials include a course book called 'Communication Builders for AAC' which all participants receive, Powerpoints for the five teaching sessions with video clips, and a course manual with teaching notes and practical activities. The participants must complete a portfolio of activities in order to gain accreditation.

The course content covers a wide range of unaided, low and high tech AAC. It does not aim to teach any specific AAC system but aims to provide staff with skills they can adapt to use with a range of AAC users or to create an environment which promotes AAC use. The course is written with both children and adults in mind and all the ideas and materials are intended to be applicable to AAC with both adults and children.

The initial sessions focus on describing the roles of people in the AAC team and ensuring participants are comfortable with some of the terminology used when discussing AAC. The prerequisite skills needed for AAC use and the gen-

eral areas of assessment are then presented and discussed. Some theoretical models are introduced at this point to provide a structure for thinking about different aspects of AAC. The later sessions are split into unaided communication, low tech and high tech AAC, although it is emphasised throughout the course that the skills for these overlap, and that the use of these must be integrated.

A range of unaided communication methods are presented and the diversity and value of these methods is stressed. Practical activities and video enable the participants to observe and evaluate unaided AAC methods used and to think about modifying their environments to support these methods. It is emphasised throughout the course that low tech and high tech AAC are of equal importance and often require some of the same skills and the same support. The course discusses the social skills needed, the range of access methods, the vocabulary choices to be considered and the design issues of low and high tech communication aids available.

The overall course aims to help participants understand their role in assessing and supporting individuals and also to encourage them to look more widely at all aspects of AAC in their environment. Participants are not expected to become AAC specialists but to have the confidence to participate in discussions, to know where to go for further

resources or advice and to understand how they can best support the people they work with.

Throughout the course, participants are asked to focus their thoughts and apply their learning to particular situations relevant to their role or people they support. The weekly portfolio tasks reinforce this thinking.

The coursebook, teaching materials and portfolio are written in an accessible style designed to encourage discussion. Clear visual images and video clips are used to illustrate points described in the course or for practical activities such as observational assessment or comparison of different methods.

This course is intended for publication in January 2013. Two courses are currently planned for Spring 2013. The first will be on March 21st 2013 for Elklan tutors who would like to develop their confidence in the course content before delivering the course themselves. The second will be a two day course, date to be confirmed, for generalist or newly qualified therapists wishing to develop their AAC skills and to complete the course at level 4 as part of their continued professional development. *

Andrea Kirton
Specialist speech & language therapist

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- [2] www.elklan.co.uk/information/commissioners-slts/why-commission-training



Augmentative and Alternative Communication

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

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AGOSCI in Focus

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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.

Arthur's AAC Journey

A case study showing how non-VOCA technology and mounting influences VOCA use

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INTRODUCTION

The aim of this paper is to review Arthur's journey from Lightwriter to iPad, to gain insight into key factors leading to new voice output communication aid (VOCA) preference.

Arthur is 68 years old and lives at Royal Hospital for Neuro-disability (RHN), which is a national medical charity, independent from the NHS, which rebuilds the lives of adults affected by severe neurological disability. Arthur moved to RHN following a cerebellar infarct which resulted in damage to the nerves that supply the oro-facial and laryngeal musculature such that he is unable to vocalise or articulate the sounds and shapes required for speech. His cognitive language function, however,



Figure 1 AlphaSmart and Lightwriter

remained intact. The infarct also led to frozen left shoulder and reduced range in right elbow and right shoulder (all planes) and pain in the right shoulder at ends of range. The injury also led to memory and learning deficits. At the starting point for this alternative and augmentative communication (AAC) journey, Arthur has been a competent Lightwriter (Toby Churchill, £3,500) user for several years.

ALPHASMART

Arthur was a prolific letter writer prior to his injury. The Lightwriter can print to a 57mm wide roll, which is not ideal for printing letters. Arthur explored using a computer-based word processor but found navigating the computer environment too challenging. He was successful at managing an AlphaSmart (Neo Direct, £154) which is a portable word processor, because of the simplicity of saving and accessing documents. Like the Lightwriter, the vast majority of its physical profile is a keyboard and it stores only eight documents, which are accessed by a single key press.

The introduction of the AlphaSmart had a profound effect on Arthur's life. Soon, he was spending the majority of his waking hours writing. But when the AlphaSmart was in front of him, he did not have access to his voice. However, installing a key guard (Maxcess, £40) on the AlphaSmart allowed the Lightwriter

to be stacked on top of it, which allowed Arthur to change devices quickly with one arm. The guard prevented accidental adding or deleting from the document he was working on. This simple solution worked for several years (Fig 1).

FATIGUE & PAIN

Eventually Arthur's presentation changed, resulting in fatigue and reduced range in his elbow. The reduced range led to more pain so a new mounting solution was introduced to take the load from Arthur having to lift the Lightwriter. Using a slide from a kitchen drawer, a telescoping arm was made for the Lightwriter. The mounting arm still took advantage of the AlphaSmart key guard. But now, Arthur could just flick his wrist to move the Lightwriter (Fig 2).

STABILITY

An unintended consequence of the telescoping arm was that, even in the extended position, it was taking up some of the weight of the Lightwriter. Conse-



Figure 2 Telescoping Arm

quentially, as Arthur typed, it bounced. To address this instability, a custom rigid mount was built. The lower portion housed the AlphaSmart on a wedge. The upper portion moved left or right on a rigid slider and housed the Lightwriter and a clock just behind it. Previously, the clock had been on the corner of his tray. The mount featured stops at the extreme left and at the point it is directly over the AlphaSmart. A hole was cut into the base so that it did not block the Lightwriter's speaker (Fig 3).

IPAD

Then Arthur decided to buy an iPad (Apple, £399) with the intention of replacing his AlphaSmart. He eventually learned to use the Notes app (part of iOS) in the same way that he used his AlphaSmart. The intuitive nature of the app environment was beneficial in helping Arthur become a competent user. For example, the keyboard simply pops into view when the app is expecting the user to type. Also, navigating the cursor was much easier as the direct access of the touch screen meant Arthur did not have to learn to use a mouse pointer.

When it was obvious that Arthur had become competent in Notes, he was shown several VOCA apps with the thought that it would be easier to switch apps than to switch devices and the Lightwriter could be withdrawn. He looked at Predictable (Therapy Box, £110), TalkAssist (Mubaloo, free), and GridPlayer (Sensory Software, free). He indicated his preference for GridPlayer, and it was installed on his iPad. However, he still wanted to have the option to use his Lightwriter.

The angle Arthur needed for using the iPad was slightly steeper than for the AlphaSmart, which interfered slightly with the Lightwriter. Although he wanted to keep the Lightwriter, it was expected that he would quickly abandon it, so no modifications were made. Weeks passed, and he never chose to use the iPad as a VOCA. So we had to adjust the mount to accommodate the iPad (see Fig 4).

TALKING MAT

Arthur explored potential hindrances to his using the iPad as a VOCA via Talking Mats, a communication tool that helps people express their views. The Talking Mat (Fig 5) revealed that he was most worried that:

- The iPad would run out of power.
- Staff would not charge the Lightwriter (for back-up use) if he did not take it with him.



Figure 3 Custom Rigid Mount

- He could not effectively call for help with the iPad.
- It was not loud enough in noisy environments.

Changes were made addressing these issues including getting a more powerful speaker, changing the ward charging protocol, and adding The Ultimate Buzzer app (TigerShark, free) to call for help. But he still persisted in using the Lightwriter as his preferred VOCA.

OPPORTUNITY

An unfortunate accident on the ward resulted in Arthur's Lightwriter being smashed, but it led to an extended opportunity for him to practise using his VOCA app. The Lightwriter was away for two weeks and on its return Arthur



Figure 4 Lightwriter and iPad

had numerous suggestions of how he would like the iPad positioned now that he was going to be using it as his VOCA. This led to changing the mounting system to a wedge with a built in speaker (Fig 6).

DISCUSSION

When Arthur's primary daily activity became using his AlphaSmart, it had the potential to interfere with access to his communication device. If Arthur could only choose one device to be mounted, he would have to choose between writing letters and speaking. The ability to switch between these devices had an immediate and profound effect on the quality of his life. The addition of a new technology might, therefore, be an indicator of a need for reassessment, a view further supported by the need for mounting modifications when Arthur later switched VOCA preference.

When Arthur could no longer switch between devices by lifting the Lightwriter, this change in his ability had the potential to restrict access to his speaking or letter writing, suggesting that a change in a client's presentation might require reassessing access.

Arthur switched VOCAs only after an extended trial period, during which he developed specific opinions and recommendations. This extra time gave Arthur insight into specific logistics of regular use that he did not have otherwise. This experience suggests that clients might benefit from extended loans of equipment to find out if the performance seen in assessment conditions translates into real world use.

After an extended loan, the client is more knowledgeable about the realities of using a device and can provide feedback that is more likely to lead to adaptations resulting in acceptance of the device, a position further reinforced by Arthur's agreeing to trial the iPad as a VOCA in assessment but initially choosing the Lightwriter in real life situations. After rejecting the iPad across a spectrum of scenarios, Arthur was able to give specific reasons for his choice of VOCA via Talking Mats. Having this specific information led to the types of changes that resulted in eventual acceptance of the new technology.

Looking at mounting solutions employed throughout Arthur's journey provides a view of the role that mounting plays in VOCA use. When only one device is in use, a simple solution such as a device placed on a wheelchair tray easily sufficed. The need to switch between two devices called for more complex solutions. The initial solution



Figure 5 Talking Mat



Figure 6 Wedge with Built-in Speaker

of using an off-the-shelf key guard as a mounting surface proved quite useful for several years. The simplicity and low profile of this solution probably contributed to its success.

The next solution involved the use of materials to hand and was initially successful as it provided easier access to both devices. The rigid mount that followed showed that in complex situations bespoke mounting might be needed. The journey eventually comes full circle when it returns to a single device mounted on a wedge on a wheelchair tray with the innovation of embedding the speakers into the wedge. This aspect of the journey suggests that mounting is integral to VOCA solutions.

An interesting aspect of Arthur's journey is his initial use of his iPad for letter writing but not speaking. At RHN, clients with newly acquired brain injury often accept technology for non-communication activities first, such as environmental control or computer access. The additional cognitive load associated with accessing language while learning new access methods has been considered a likely factor in these situations. However, what is interesting about Arthur's chosen leisure activity is that letter writing includes a language component. This leads us to examine the differences between communicating via letter and communicating face to face in search of a new hypothesis.

Letter writing is a solo activity and includes an expected delay, while on-the-spot communication happens under the watchful eyes of your communication partners with an expectation of an immediate response. The presence of the communication partner(s) and the implied time pressure may contribute to making face-to-face communication a less than optimum

choice for learning new access methods. Practising new access methods in a leisure context might provide a more comfortable, less stressful environment that is more amenable to learning, giving the user a chance to build up skill and confidence before having to use it in face-to-face communication.

CONCLUSION

This case study follows Arthur's AAC journey over a period that included a change in voice output communication aid (VOCA) preference. Reviewing this journey with an eye toward which factors featured prominently in the change revealed that an interest in additional new technologies can lead to eventual changes in VOCA preference. Furthermore, the addition of new technology is a good time to review access as the new technology may interfere with VOCA use and vice versa. Another important time to review VOCA access is if the client's presentation changes because something that may have worked in the past has become inadequate.

Arthur's ability to provide useful feedback after an extended trial was invaluable in allowing the team to make modifications making his VOCA a more attractive option. Such a trial makes the client an expert in practical application of the device in real life situations. A more informed client can better self-advocate.


Mounting was key to Arthur's success at nearly every stage, which demonstrates how crucial proper mounting is for success. Arthur's experience suggests that mounting is integral to the VOCA assessment process.

Finally, an unexpected finding was Arthur's reluctance to switch VOCAs despite having the skill to use the same device for non-VOCA tasks. One possible explanation for this particular

scenario, in which both the VOCA and non-VOCA tasks included a language component, is that leisure based solo tasks might give users a chance to build up skill and confidence without the pressures of others watching, and of immediacy, that come with face-to-face communication. *

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Creative Speech Technology

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INTRODUCTION

The position of many people with regard to the idea of a machine talking is akin to Samuel Johnson's attitude to dogs walking on their hind legs: "It is not done well; but you are surprised to find it done at all." They may be amused by its foibles. They may make allowance for its lack of human characteristics – as long as it is doing a useful job.

However, those who use synthetic speech for communication because they cannot use their own voices have different attitudes to the technology: while on the one hand they are generally grateful that the machine enables them to talk at all, at the same time, they will find much to criticise about the technology.

Often the criticisms are at a very practical level, and the quality of the voice is only one of many areas of concern. For instance, the comprehensive review by Baxter, Enderby et al. (2012) identified *Voice/language of the device* as just one theme in the literature, along with those listed in Table 1. Judge & Townsend (2012) carried out a survey of AAC users intended to "explore the issues around the design and use of voice output communication aids". Having identified the important issues, they went on to collect data from a larger number of users and associate professionals. One of the issues identified was *Voice output*, and the others are listed in Table 1.

The point is that voice is only one of many matters of concern to users. This may partly account for the current situation in which the majority of VOCA devices are based on 1980s speech synthesizer technology.

The technology has moved on a long way since then. Many of the developments have potential benefits for AAC users, for others, though, the improvements are debatable. The Creative Speech Technology Network (or *CreST*) is a research network set up with the aim of exploring and extending the current state of the art in speech technology¹.

CreST was established with funding from the Engineering and Physical Sciences Research Council² (EPSRC). It succeeded in its explicit objective of involving participants from a wide range of backgrounds and disciplines, including artists and writers who are interested in voice, technologists who build and research speech synthesizers, speech and language therapists and people who use speech synthesizers – including for AAC.

The diversity of interests was reflected in the fact that later additional funding was obtained from the Arts Council for



Figure 1 'My voice is me' exhibit featuring Lee Ridley

England (ACE). We believe that it may be unique for one research project to get funding from these two bodies.

CreST has had a number of meetings at which members have met and swapped ideas. It culminated in a public roadshow entitled *Articulate: The Art and Science of Synthetic Speech*. The idea of the roadshow is to share ideas and developments that have arisen from the Network with the public. It took place at three venues in December 2012:

- City Screen Cinema, York (UN International Day of Persons with Disabilities)
- Sheffield Winter Gardens
- Hull Truck Theatre, Hull

There were interactive exhibits in each of the venues. The York event, though, had a particular emphasis on the use of synthetic speech in AAC, and also had

¹ <http://crestnetwork.org.uk>

² EPSRC refs EP/I013512/1, EP/I010416/1

an evening programme. That included the showing of three films about users of AAC devices, and a comedy show, featuring Lee Ridley (the *Lost Voice Guy*, stand-up comedian and AAC user) and Cal Halbert, impressionist.

EXHIBITS

The roadshow incorporates the following exhibits:

My Voice is Me

This exhibit (Fig 1) draws people’s attention to completing the statement “My voice is...”. It features a video about Lee Ridley in which he says something about his voice. Then visitors are invited to complete the statement from their own point of view.

Can’t sing, won’t sing

There is no reason why synthetic voices should be limited to speaking: they can sing. In this exhibit, people can use a games controller to vary the sound of one of the voices in a four-part harmony.

Controllable Expressive Speech Synthesis

One of the obvious limitations of many existing speech synthesizers is their flat, inexpressive tone of voice. Whatever the user says tends to be delivered with the same neutral emotional inflection. It has been said³ that “No man is truly English if he cannot say ‘Really’ in seventeen different ways” but the average speech synthesizer will say it one way only.

While many AAC users would probably prefer to have the appropriate emotional inflection, they realize that it takes long enough to compose what they want to say without having to take extra time to specify the emotional content. Certainly such nuances were not mentioned as a desire in either of the surveys mentioned above.



Yet it is possible to shape the way a synthesizer speaks and these two exhibits experiment with ways of doing this using novel forms of interaction with the synthesizer.

The first (*Controllable, Expressive Speech Synthesis*) presents some comic strips

to the user. The user can select a voice for each character and change the emotion used in each speech bubble.

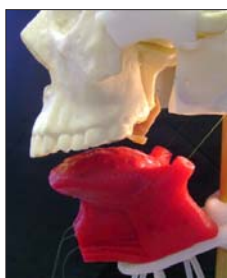
Interaction is via a touch screen and two custom hand-made large trackballs: one controlling the speaker characteristics (e.g. man, woman, child) and the other controlling emotion. The comic strip can then be played back in full using the chosen speaking styles.



In *It ain’t what you say, it’s the way that you say it*, the person controls the way the synthesizer speaks using arm gestures. One arm varies the rate of speaking and the other its pitch.

AnTon, the Animatronic Tongue

People who can talk with their own voices rarely think about what a complex task it is, involving coordination of multiple muscles, organs and



Baxter, Enderby et al. (2012)	Judge & Townsend (2012)
Ease-of-use	Ease of use
Reliability	Device reliability
Technical support	Help and Support
Time generating a message	Effect of slowed speed of communication
Making decisions	Effect of good and bad device design
Family	How a device is made
Other people’s responses	Device performance
Other factors	Physical characteristics
Service provision	Physical environment and transport
Staff training	Design and layout
	Device configuration
	Impact of training and learning
	Influence of AAC service delivery
	Restricted use of communication aid
	Support of aided communication within immediate environments

Table 1 Aspects of AAC design considered important, in addition to the voice.

articulators. This exhibit (Fig 2) illustrates this by allowing people to control some of these components on a plastic model.

Conversational kiosk

Speech synthesis is not the only area of development: speech recognition has improved greatly in recent years. This makes it feasible to have a conversation with a computer. That is, the user speaks and the computer speaks back with some ‘sensible’ reply. The *Conversational kiosk* is somewhat whimsical, being programmable to respond in different ways to conversations on any topic.

Bespoke

There are many reasons why a person may not be able to express themselves in speech. In this exhibit, an actor passively stands while a speech synthesizer



Figure 2 ‘Animatronic tongue’ exhibit

³ Attributed to Paul Johnson

recites poetry 'for' them, poetry which has been especially written to be presented by a synthetic voice.

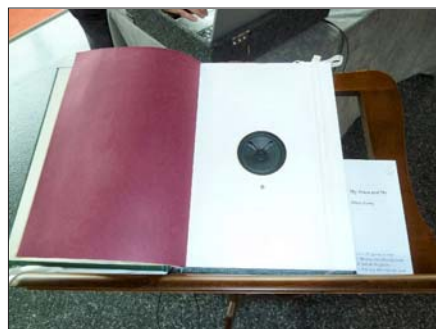
Professor Moore's Digital Voice Factory

This is a chance to play with speech. Visitors can record their own voice, but then play back their utterance backwards, with the sounds reversed.

Of course, then the fun thing to do is to try to imitate the reverse speech and see if you can hear the original when you play that backwards. It is then possible to play with one's voice in many different ways, producing either subtle variations or gross distortions.

My Voice and Me

This is a melodrama played by a book with an embedded speaker. It tells the story of an opera singer who has lost his voice and now must speak through a speech synthesizer.



Frank

Experiments in sympathetic engagement elicited through silence in synthetic speech.

This telephone-based piece seeks to enhance the effect of an artificial voice by incorporating pauses of a random duration, within credible limits, at punctuation points in the text.



Beyond speech

Many of the above exhibits enable people to manipulate synthetic speech sounds. Sometimes these are 'credible' in the sense that they mimic the kinds of variations that natural speakers can achieve but sometimes they go to an extreme.



The *Beyond speech* exhibit explores those extremes, going to sounds which are based on speech, but no longer sound like speech – and yet can be made pleasing to the ear. These can be controlled and 'played' by gestures from the user.

CONCLUSIONS

Most people have little experience of speech technology and often what they have is quite negative – the frustrations of dealing with an automatic telephone booking system, for instance. While the prominence of Stephen Hawking has done much to raise public consciousness of the existence of speech and communication aids, he is far from being a typical user. This roadshow should help to educate some of these people into the more general use of the technology. At the same time, the people who do know the existing technology, its users, should have a chance to learn and to think about how it could be improved.

Funding for CreST ends in February 2013, but it is anticipated that many of its activities will continue, including new research projects. One which is already in the process of being assembled will have the aim of using technology to give much more comprehensive support to AAC users. *

Dr Alistair Edwards, *Senior Lecturer*
Dr Chris Newell, *Lecturer*

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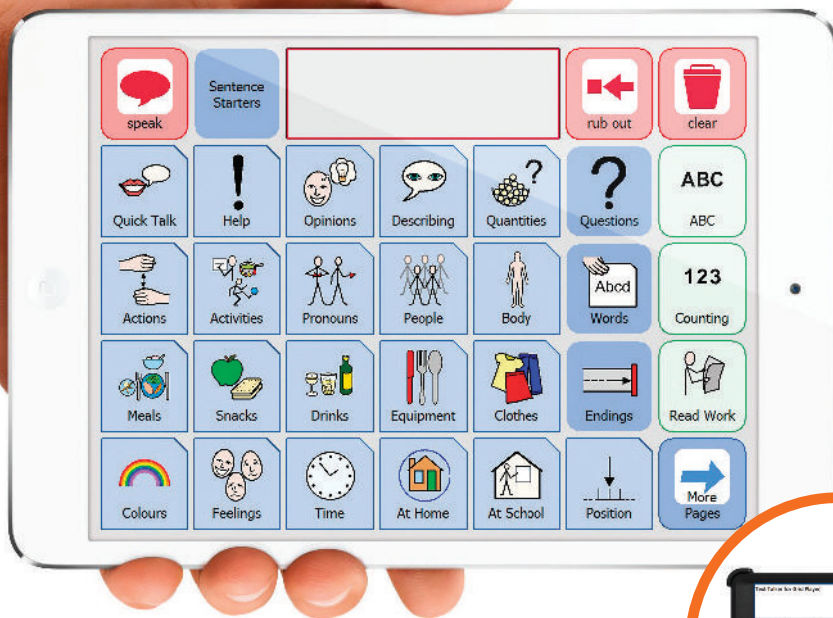


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