COMMUNICATION MATTERS

NOVEMBER 2010 Volume 24 Number 3

THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

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COMMUNICATION MATTERS JOURNAL
VOLUME 24 NUMBER 3
NOVEMBER 2010

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COMMUNICATION MATTERS JOURNAL
ISSN 0969-9554

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Copy Submission
Preferred text format: Microsoft Word
Preferred graphics/photo formats: JPEG, TIFF
Copy deadline: 11 February 2011 (Vol 25 No 1)

The Communication Matters Journal is the official publication of Communication Matters / ISAAC (UK), and is an ISAAC affiliated publication.

Printed by Crowes of Norwich

The Truth, the Whole Truth and Nothing But the Truth – Labelled?

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As a communication aid user I sometimes feel that some people see my equipment before they see me. It's not everyone, but people do say things like, the girl who uses a talker, or a voca, or a communicator. This makes me sometimes feel I have a flashing sign over my head, the girl who uses high tech AAC.

Of course, I do use AAC to communicate. Is it the truth? Of course it is true. I've had seven devices in 11 years, incredible but true. So is it the whole truth? Definitely not, like all communication aid users I think there is more to me than just my device.

I think I communicate just like everyone else, you hopefully pick up clues from my face, my eyes and my body. My communication is not just about my device or the low tech strategies I use. Like everyone I use lots of different strategies to be understood. I love to talk but you have to listen carefully, you have to know me well to understand me.

So if I use a communication aid is it the whole truth? Clearly not. I know my speech is challenging but I know communication is much more than words. In fact I have never heard myself recorded speaking until recently. I was shocked as that is not how I hear myself. It has made me realise the importance of AAC, and why some people really do find it hard to understand me. But, words are only a little bit of the message.

You might know this already, research shows only 7% of communication is the actual words. For most people tone is important, we get about one third of the message from how words are emphasised. But we all know tone is a little bit hard on a communication aid. Body language is the key and we all have plenty of that, nearly 60% of the message and sharing the correct meaning relies on unspoken clues. My electronic voice might be lacking the tone, but I try really hard to make up for it with the words and the body language.

I would like to share with you how my communication has developed and the strategies I use with and without a VOCA to connect with others.

From being little I have known I can communicate. At about 18 months Mum said I was talking for England, the words just came out funny. At two, Mum was told I needed a communication board to make choices of drinks, but she wasn't given a proper explanation, I had a sign of my own for wanting a drink and to eat and I made it known what I wanted. People have always understood when I wanted to play princesses, hairdressers or go to work, and I was always in control. By three and a half my parents knew I needed help for school and an assessment was arranged through our GP. First we went to Charing Cross hospital. All the papers were then sent to education, and Janet Larcher came to my house. When I started school at four, I had a PC in the corner of the classroom, and a Dynavox, and both were bigger than me.

It was when I got to school I knew I was different, I know now I was sad and lonely. I had lots of things to say, but still only Mum, Dad and my child minder understood me. The Dynavox was alright to start with but the assistants in class got to understand my speech and so I didn't use it much.

When I was seven, Mum started insisting it came home every night. I found out later some of my infant school teachers didn't like using computers, and most of them retired soon after, I hope it wasn't me!

At eight, I used a notepad, with the Dynavox software, to try and get everything on one bit of equipment. I liked the touch screen and stylus, but the voice was so quiet it could only be used for one to one work. At this time I found word prediction and stopped using so many symbols, it was much easier as I had to read and write in class anyway. Because of this Janet thought it was a good idea to try a Tellus.

The Tellus Lite came with mind express, so I had to use a new language and to start it didn't have word prediction. Mum paid for a friend who was 13 to come in and play games with me on the Tellus, but it was hard having to learn all the new layouts and linking. Once I had word prediction I was off again. Yet again my assistant in school understood me. We did try to have a rule, if people didn't get what I was trying to say after two go's, I must use my device, but my assistant still often translated for people. By the time I was 10 we were planning for mainstream secondary school. The aim was for the new staff not to be scared of me and my technology.

What Janet recommended was I went back to a laptop, which would be familiar to everyone, and use a Lightwriter as it had the qwerty keyboard, and my spelling was getting better. I loved the Lightwriter from day one, I used it everywhere, even now the only place I can't use it is in the bath. Having a communication aid I like still doesn't stop me wanting to talk with people who know me. Just like when I was two I can still talk for England. But I choose when to use it, who with, and often at home, or in my bungalow at school, its just two or three words for context.

In 2008 I got the Lightwriter SL40, which is great. I just love it, now I can be like my friends because I can text, use environmental controls and programme my speeches. I realise I'm very lucky.

I also have an Alea eye gaze, with its own monitor for recording in English, and a tablet for all my other school work. The tablet has the same voice as my Lightwriter, so now I can be me if I need to read out work in class. I can work anywhere, and at anytime that suits me. To choose the right equipment we had assessments at school, then I had two different week long trials at home, then we decided on what would work best. I am really happy that Janet, and now Ruth McMorran, and Valence, have believed in me, and have been able to help me with changes to my equipment as I have grown up.

Being honest, the whole truth is that for me, in mainstream school being a communication aid user, and with cerebral palsy, was lonely, people didn't really get it. 'It' being what it is like to use AAC. Yes, they were nice, but making and keeping friends is difficult when you always have adults hovering around. There was the teacher who thought it fun to borrow my lightwriter to try it out in his lessons, three times a week. The classes where I never had the work made accessible, and that was over half the time. Then, the teachers in DT and science who said it was too big a health and safety risk to let me have a go. Luckily life is not like that today. I love my school now. I have been at Valence in Kent for three years and just finished my DT GCSE.

What other ways do I have of communicating? I use a lot of gesture, I never learned to sign, but I do use my own signs for drink and food. I only started to really use my eyes to communicate when I went to Valence, it's so easy when I am tired to say yes and no without moving my whole body.

In the past people have said do I have a way of saying yes and no, I thought this meant because I could speak, move my head or use AAC that was what I had to do, by being with other students who use different communication methods, I have learned I can communicate even more easily, if I have to. Mostly when I don't use my communication aid I use text methods of communicating, I air write, use a small electronic dictionary, text on my mobile phone or find pen and paper. I always find a way. I've never had a symbol board or communication book. I started with a small alphabet card in the infants with a few key words. Mum and I designed it together, it was tiny but worked for me. Then I moved to a bigger A4 lettercard which I tried one day at a workshop, with Clare Latham, and this is still my standby, and by my bed at home. But my favourite, and since I designed it I have to say that, is my laminated letter card. It is clear so you can see through it. This means I can sit opposite someone and see their face when we talk, a bit like a low tech version of my lightwriter. I've added some key words and word endings to speed things up, its pretty effective, although at school my English teacher likes the one without extra bits for when she wants to test my spelling, ha ha.

Over the years I have used loads of props to help me communicate, and still do. I am sure you know the stuff. Magnetic letters, teddy doing it for me. For important events, and holidays, we used to make up a small photo album with postcards, tickets, photos and things. Nowadays I always take a journal that I hand write, and when I am tired then Mum or Dad scribe for me, sometimes it gets typed up as a report, with photos, and sometimes I just use it to write thoughts and poetry to share later, or even just keep for me.

When I was preparing this Mum reminded me of when I was six, I came home and told her we had a new boy in class. I was able to tell her his name was Ben, but not his surname because I didn't have my Dynavox at home, and also it wouldn't have been programmed as Mum did that anyway. I made her take me to my bedroom where I pointed to my Beatrix Potter books, I showed her the tale of Jeremy Fisher. His name was Ben Fisher.

I think I am a good communicator. I was lucky to have Janet from an early age to support my high tech communication. I have never had a speech and language therapist who worked with me on my device. My parents have good communication skills, and I have excellent role models. I never had any professional input on good non-verbal communication or how to use low tech communication strategies. Conversations at home always start with open questions, I have used key words from a very young age, such as who, what, where, why, when and how. I practice all the time, before we go anywhere we discuss what I might say, how the conversation might go and if I should programme anything specific. At home if I am speaking and my parents don't understand I am expected to give context, use other words to explain the same thing and as a last resort spell.

Doing GCSEs I asked school to give me extra help with reading and vocabulary for the first time. With my hearing impairment I need to lip read, and have a word explained in context, so I can then read it. I cannot sound out silently, and even aloud is tricky. The vocabulary for GCSE is huge and I have to learn every word as a whole word to read and spell it. No new words are programmed until I put them into the Lightwriter so this is really helpful. The teacher for the hearing impaired provided guidance to school to meet my changing needs and I am choosing to do this instead of art.

I use other high tech than just my Lightwriter, I use different things in every situation. I will point to the keyboard on my laptop or type a word, use my mobile to text but not send. I love to Skype and use the chat feature and now I have the Sero phone which came with my environmental control package at home. I adore Facebook.

It's so true, I use high tech AAC. The whole truth is I use many different communication strategies and that's nothing but the truth. Everyone is different, but I don't know anyone who uses just high tech. Many people mix more than one method, and often we have more than one device for different situations. Just like you I am creative when I communicate. I think you are unlikely to describe me as the girl who communicates, so please, next time you need to explain who I am perhaps you can say that I'm wearing pink, I have short hair or I love to smile. Please see me first and dump the label. ✱

Beth Moulam

‘Talk to me as a teenage girl’

An anthropological study of identity and lifeworlds with teenage AAC users

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INTRODUCTION

Two previous articles (Wickenden 2007 and 2009) have described the theory behind the methods of this study in more detail. Here I will present only brief background before discussing some of the main findings, and their implications.

The study set out to explore the identities and the lifeworlds of disabled teenagers who use AAC, using ethnographic and narrative (story based) approaches.

METHODS

Over an eighteen month period I carried out ethnographic research, spending time with the teenagers in their schools, homes and extracurricular activities, and talking at length to them, as well as to their parents and others who know them well.

The study focuses particularly on aspects of identity. I have used the approaches of Jenkins (2004), who suggests that individual identity continuously evolves throughout life being influenced by experience and context. Broadly the way that a person sees themselves is known as ‘selfhood’ and the way they are seen by others is ‘personhood’. These two aspects are of course closely related and constantly interact with each other.

Using narrative methods gives participants the freedom ‘to tell their story in their own way’ (Frank 1997). An important way in which we become who we are and explore ourselves, is through talking about our experiences, ideas and plans. This helps us to analyse how we feel about events and about ourselves. Telling stories is a way of expressing selfhood, so ‘giving voice’ to one’s identity.

Of course, using language is the usual way to tell stories. So the development of high tech VOCAs which enable users to demonstrate that they have language ‘in their heads’, may be revolutionary in expanding what they can express and more importantly are recognised by others as having. Being able to tell one’s own story is an important part of selfhood and potentially empowering.

RESEARCH QUESTIONS

1. How do young people with severe physical and communication impairments who use AAC see themselves (selfhood)?
2. How are young people who use AAC seen by others (personhood)?
3. What kinds of social relationships do young people who use AAC have?
4. What role does the body play in the development of selfhood, social relationships and personhood, for young people who use AAC?
5. What kinds of methodologies work best when doing research with young people with severe communication impairments?

PARTICIPANTS

There were nine key participants, who attended a variety of schools: special (boarding or day) (6), mainstream (1), or split placements (2). They were aged 10-16 at the start of the study (6 girls, 3 boys). Additionally I talked to a further 15 teenage AAC users aged 14-19, at school or college. I also met young AAC users and their families, through the organization 1Voice. I also drew on the expertise and experiences of 3 adult AAC users who were research advisors. Their perspectives were invaluable as ‘insider’ views. Additionally I interviewed parents and ran focus group discussions with school staff.

All the key participants have cerebral palsy as their main medical diagnosis, and have broadly normal learning abilities. Some have additional difficulties such as hearing impairment, epilepsy and feeding difficulties. They all use a combination of low and high tech AAC systems and some (4) use speech either a little or extensively alongside their AAC.

They use a range of different AAC systems. Access methods vary from direct (6) to joystick (1) and headswitches (2). All (except one advisor) use a wheelchair at least some of the time. All the teenagers lived at home with their families and all except one had siblings.

For more details about the methods used, data obtained and analysis see Wickenden (2008, 2009).

RESULTS

Seven main themes emerged:

- Whose voice is that? (AAC and communication issues)
- Me, Myself I: Different Selves (Selfhood)
- My body and the kit
- My family and other people (Personhood)
- Research reflections
- Structural stuff
- The disability tribe

The last three themes were felt to be overarching and to interweave throughout so are not discussed separately. The core findings from the first two main themes are discussed here, with a summary of the others and overall conclusions.

1. VOICES: WHOSE VOICE IS THAT?

The teenagers generally had positive feelings about their use of AAC, and saw their high tech systems as useful at least in some situations. However they emphasised that often with familiar people they prefer to use their low tech communication such as speech, natural gestures, signs, eyepointing, communication books and spelling charts.

All expressed frustration with the slowness and in some cases unreliability of VOCAs, and with having to adapt to some conversational partners' lack of skill in communicating with them. Some disliked the voice on their VOCA and would prefer to have a regional accent and easier ways to use slang language. Some enjoyed using additional features of their VOCA such as the phone, sending e-mails or playing music.

They varied in whether they saw their AAC as an important part of their identity. There was also variety in the amount of adapting and perseverance they were prepared to do to make a conversation work if a conversational partner was unused to them or insensitive about waiting longer and listening patiently. Some were not keen to use their VOCA in public places because it attracted unwanted attention, whereas others were comfortable and proud to use it when they were out. All were aware that talking in a different way added to them being perceived as 'different', and some saw this as a potential barrier to making friends and doing teenage things. Between them they provided a comprehensive list of tips for those talking to them including: *

> *'GIVE ME TIME TO GET MY MESSAGE READY'*
>
> *'TALK TO ME LIKE A TEENAGE GIRL'*
>
> *'LISTEN CAREFULLY'*
>
> *'DON'T GUESS WHAT I AM GOING TO SAY'*
>
> *'GIVE ME CHOICES'*
>
> *'DON'T LOOK BORED'*
>
> *'BE FLEXIBLE TO MY DIFFERENT WAYS OF TALKING'*
>
> *'DON'T BE SCARED OF ME'*
>
> *'MY BRAIN WORKS FINE'*

2. ME, MYSELF, I: DIFFERENT SELVES (SELFHOOD)

I collected a large quantity of data about how they saw themselves. Some of this directly, e.g. when I asked them to describe themselves, but much was indirect and arose out of informal conversations which demonstrated their attitudes and perceptions. The teenagers see themselves in a number of ways which overlap and interact with each other. These different 'selves' will be discussed separately, although of course in reality they are not so clearly defined, are constantly shifting and being renegotiated, particularly as teenagers are rapidly changing and developing relationships with others.

Family self

The most prominent and important aspect was being a 'family person'. All had a strong sense of belonging and security within their family and at home:

Terry (14): *MY BROTHER MY BEST MATE*

Nathalie (15): *LOVE MEAN FAMILY*

Toby (14): *AT HOME CAN BE MYSELF*

Previous research (Cavet 1998, Smith 2005) shows that often disabled children and young people have a smaller range of friends outside the family than their peers and that their parents often have to make extra efforts to facilitate their social life. My data supports this and this may be one reason why being a family person is perhaps more important than it would otherwise be at a time in the lifespan when often there is a desire to move outwards from the family circle.

Teenage self

Secondly, being a teenager was very important. There are many examples, but here are some responses (from different teenagers) to questions about things they love and hate, which indicated clearly a range of typical teenage interests:

Loves: *SHOPPING, FASHION, HANDBAGS, FOOTBALL, CINEMA, IT, MEDIA, CHOCOLATE, GOING OUT WITH FRIENDS, CHATTING, CHILLING OUT, TRIPS, OUTINGS, CLUBBING, SPORT*

Hates: *NOT BEING ABLE TO DO THINGS!, BEING TREATED AS A CHILD, NOT BEING RECOGNISED AS A TEENAGER, ARGUE WITH MUM WATCH TV*

Jemma (13) demonstrates how important it is for her to fit in with her peers, here it is about the way she talks:

Jemma : *I use slang like 'innit'*

MW: *why do you use that?*

Jemma: *because everybody uses it, IT'S THE LANGUAGE OF YOUNG PEOPLE... so I have to use it!*

There are many other subcategories in the teenage theme, including three other types of self: sporty self, private self and rebellious self.

Many of the group are very interested in sport, through supporting a football team and/or being actively involved in boccia, disabled athletics, archery, riding and watersports. For some this is at a competitive level, for others it is purely for fun. To be seen as sporty is an important part of their positive self image. This is particularly true for the boys, although not exclusively.

The 'private self' emerged as important through discussion about negotiating privacy, both in the physical sense, and psychologically, around issues of communication privacy. Using a VOCA is seen to be less private in some ways (unusual voice attracts attention, screen is visible) and also more private, because some ideas may remain unsaid because of the difficulty of expressing them using AAC. Many of the teenagers

---

* Direct quotes are in italics. All names are pseudonyms. Words spoken with a VOCA are represented in UPPER CASE. Those spoken with speech or another method in lower case. The mode is specified in brackets if it is not speech, e.g. book (sign).

have a clear sense of wanting to be private and having their privacy respected.

The rebellious self which is seen as so archetypical of adolescence is demonstrated in many inventive ways. The teenagers are able to be cheeky, refuse to do things or generally resist the power of adults around them. Thus although it is sometimes hard for them to produce fast witty verbal banter, they can ably demonstrate their feelings in subtle or not so subtle nonverbal ways. An outsider might not recognise this but those who know them well confirmed that their teenage rebellion is no different from that of their peers or their siblings. As I got to know them, I saw this in action!

Changing self over time

All the participants have strong images of themselves as younger children in the past and as now becoming adults. There were many well rehearsed stories about themselves as babies and as young children. These are particularly marked as they often included detailed descriptions of themselves as very sick, having lots of physio, getting their first wheelchair or VOCA. This is perhaps in contrast to non-disabled children who may not have heard their parents telling dramatic stories about them to such an extent. These narratives are part of shared family stories of life, and it is thought that they play a part in helping teenagers to put their life in context and develop their identity (Bohanek et al 2008).

Looking forward to their futures as adults, all have strong ideas about what they would like to be and do. These ideas were drawn from mainstream popular culture and from their families. Here Terry (14) is clear about what he expects later:

MW: *so what would be different about being a teenager and being an adult do you think?*

Terry: *(long pause)... BE FREE*

Social-emotional self

The teenagers are keen to emphasise their social-emotional selves and something that annoys them is not being recognised as caring, sensitive and thoughtful people.

George (17): *'I experience a wide range of different emotions, the same as any other man, maybe I even have deeper feelings than other people' (written self description)*

Toby (14): *I WILL HELP ANYWAY I CAN* (offering to help his friend who was campaigning to be elected head boy)

Noticeably many of the group are keen to have a job which involved caring for others, eg with children or for disabled people. Some have strong views about how things could be improved for disabled people and want to contribute to this.

MW: *What do you imagine you'll do after school?*

Ted (12): *NURSE – I WANT TO BE THAT AFTER SCIENCE CLASS. HELP SICK PEOPLE AND I THINK I LIKE IT. DAY NURSE. I WANT TO BE IN A HOSPITAL. I HAVE WARM HEART... CARE ABOUT PEOPLE*

Autonomous and independent self

We had many conversations about the concept of independence and about how they like to be independent in different ways. Most are quite realistic about what is difficult to do alone and pragmatic about needing assistance. However, crucially, 'independence' seems to represent having choice about what happens and feeling consulted and respected, as much as actually doing things alone. This replicates the literature about disabled adults but has not been highlighted for young people much before. All the participants express dislike about being fussed over or helped unnecessarily.

MW: *so what else about 5 years time? What will you be like?*

Jemma (14): *letting me go and be independent, don't moddle coddle me!*

Josie(15): *I ALWAYS GET MY MESSAGE ACROSS SOMEHOW*

MW: *do you ever give up?*

Josie: *No*

Mary: *how do you like people to help you*

Kate (13): *I tell them how to do it*

Mary: *and does that work well?*

Kate: *yeah!*

Many expressed a strong dislike of being denied autonomy:

Nathalie (15): *I hate people not talking to me and ignoring me*

Josie (15): *I hate not being able to go out with friends*

Terry (14): *I hate it when people patronize me*

Toby (14): *I hate not being able to go out places*

Ted (12): *I want to be able to feed myself and dress myself*

George (17): *I hate it when people think I don't understand.*

Disabled self

Although all know and accept that they are seen as 'disabled' by society, they have pragmatic attitudes to what is easy and hard for them to do, and all are clear that their disabled self is not the most important part of them. This mirrors research which shows that disabled people don't see their disability as their primary identity. It is only part of who they are (Watson 2002).

They are interested in being similar to other teenagers rather than seen as very different. Thus they emphasise positive, social-relational aspects such as being normal family people and gendered teenagers, as well as sociable and funny, and also variously sporty, clever, caring, good-looking and sexy. Their reference points draw on the same teenage culture of fashion, sport, IT and media as their non-disabled peers, and their aspirations for the future also reflect this 'mainstream' worldview.

However their physical and communication impairments do impact on their view of themselves. So, although their bodies are 'normal to them', they are aware that they are viewed as different by others perhaps because there are some things which are difficult for them to do, and for which they need special equipment such as wheelchairs and VOCAs. The teenagers' wish to have access to appropriate, reliable technology and respectful assistants who treat them as people. They see these as essential in facilitating them being independent and autonomous. Part of 'growing up' for them is learning how to manage their assistants. They learn these skills both implicitly and explicitly. The tendency for people to patronise and infantalise them means they often feel they have to fight to be recognized as 'proper human beings' despite needing assistance.

3. BODIES AND THE KIT: SEE ME, DON'T JUST SEE THE CHAIR

In relation to their self-image, the teenagers have mostly positive views of how their bodies look and what they can do. Both genders have strong opinions about style and how they want to look (clothing, haircut, jewellery). This is echoed by their ways of individualizing their wheelchairs and VOCAs. These pieces of kit are, to varying extents, regarded as part of their body and included in their expression of identity.

All are aware of their bodies changing during puberty and like others of their age, they are keen to look like adolescents not children (James 2000). Some listed features of their physical bodies which they do or do not like, although it was rare for them to mention their physical impairments or what they could not do specifically. Rather, they talked about aspects which they could change such as being less skinny, more tanned or gelling their hair.

All have matter-of-fact views of their need for physiotherapy, doing exercises and using kit to help them do practical physical tasks more easily. Many are involved in disabled sports and are proud of their achievements in these. Sport was facilitated very actively by their parents, who in this study were a predominantly middle class group who generally had the resources to do so. In summary then, the participants' attitude to their bodies is that they are 'normal' to them (Watson 2002).

The young people experience a variety of reactions to how they look, and are aware that although their bodies are normal for them, they do attract attention from others. All the young people, however, are confident that once someone gets to know them, they will be seen as a person, 'not just as a chair' as Byrony (12) put it.

4. MY FAMILY & OTHERS: PERSONHOOD AND SOCIAL RELATIONSHIPS

There is a clear contrast between the way that the participants are seen by those who know them well, and by less familiar people. Familiar people view them in ways that are similar to the way they see themselves. Thus the teenagers' individual qualities are highlighted rather than aspects of their impairments. Such positive attributes as being fun, feisty, clever, beautiful, patient and caring are appreciated, as well as some negative ones like being scruffy, lazy, cheeky, or stubborn.

Descriptions by people who know them best focus on diverse aspects of them, rather than on 'deficits' or 'missing' functions. For these people then, the teenagers' disabled identity is neither a negative aspect nor a dominant one. Who they *are* as people is emphasised, rather than what they can *do*. Thomas (1999, 2004) suggests that this distinction between *being* vs *doing* is important.

In contrast, newcomers and strangers tend to view the teenagers differently. They are influenced by first impressions, where their attention is drawn immediately to physical differences and unusual communication. Thus the young people often experience being stared at, and people's curiosity. Responses to them often focus on their impairments and what is different, rather than recognizing them as individuals.

The teenagers know it is often assumed initially that they cannot understand (have learning disabilities) and this attribution may be linked to their lack of speech. There is confusion for the uninitiated between being able to talk and being able to think. These assumptions are hurtful. Exceptions are unfamiliar children, who although curious, are perceived as more open-minded and slower to make negative judgments than most adults.

This treatment as the 'other' leaves disabled teenagers 'feeling hurt' and excluded (Reeve 2006:96). Many of the participants and their families reported hating this because it diminishes their worth as people, and potentially denies them ordinary citizenship. They then have to deal with the mismatch between how they see themselves and how they are perceived by unfamiliar others.

As older teenagers, the participants will move from the protective environments of home and school and will have to learn to use some protective strategies. Both they and their parents acknowledged and anticipated this with a mixture of excitement and anxiety. Steps towards independence and negotiation of autonomy are more complex and daunting for these teenagers than for their non-disabled peers.

Within their families and close friendships, teenagers AAC users have rich social relationships which are very important to them and are fully reciprocated. In contrast their social networks outside this home territory are often reduced, as making and maintaining friendships on their own terms is quite difficult, even if they see themselves as friendly and social people.

The teenagers have a very small number of good friends of the same gender, some with disabilities and some without. Often these friendships are longstanding, started at primary school or through family connections. Very few however, have recently formed friendships initiated themselves rather than mediated by their parents. Making new social relationships completely independently is something that many of the teenagers have limited experience of. This is a matter of concern and worry both for many of them and for their parents.

Physical appearance can be a barrier, and this is difficult for young people to counteract, because using a wheelchair and a communication aid is part of them and not negotiable. Additionally because friendships usually depend on fast verbal communication, there is often insufficient time for AAC users to show who they are.

Often conversation is mediated by adults who are assisting them and this can easily form a barrier to friendships. Many of the participants expressed a wish for more friends, especially non-disabled ones and more of a social life outside home. This supports previous work showing the reduced social networks experienced by disabled people, particularly those with communication difficulties (Blackstone et al 2005).

DISCUSSION

Aspects of identity

Using AAC can make it difficult for people to overcome exterior impressions and negotiate a picture of themselves which reflects who they really are. Their predicament is not having easy and quick ways to correct first impressions and represent themselves accurately. For many non-disabled people, selfhood and personhood may be rather closely aligned, but for those with physical and communication difficulties the two aspects of identity may be unreconciled or in conflict with each other. However these teenagers, given time and opportunity are able to express the richness of their various selves.

Is there a disability culture or an AAC culture?

It is unclear to what extent disabled young people feel they are part of a collective 'disabled' or 'AAC user' identity, or want to be in the future. Their involvement in wider disability or AAC group activities is mainly governed by their parents. Some are active members of the 1Voice group, CM or ISAAC. In organizations like these and at special schools, there is some sense of a 'culture' and of being member of a 'tribe'.

Here then teenagers are visibly comfortable, in that they do not have to negotiate about who they are. There is an assumption that everyone there is a member of the tribe or an ally. Within 'the tribe' everyone's communication style is adapted to the AAC users, and like being at home, it can be something of a haven from an outside world that can be quite unforgiving.

An important question might be whether this feeling of acceptance can be accomplished more broadly elsewhere or indeed everywhere? Katie, one of the adult advisors, noted that wheelchair users attract much less attention now than they used to, presumably because as physical access has improved they are more visible.

AAC users will always be a small group, but perhaps as they access mainstream settings more, they will be seen as less unusual and thus will be less quickly categorized as the 'other' (Shakespeare et al 2000). It seems likely though that they will still have to manage the constant struggle between wanting to be seen as the same as others, but being viewed as different.

CONCLUSIONS

The study revealed that teenagers with severe physical disabilities who use AAC view themselves principally as 'normal' teenagers, whose families and few close friends are very important to them, and who aspire to do the same kinds of things as others of their age and gender.

In general they paint positive pictures of themselves as sociable and competent teenagers, and they do not particularly highlight their impairments, although they acknowledge that disability is part of their identity. They have pragmatic attitudes towards the effects of their impairments and their main concerns in relation to these are that they have appropriate and reliable technology, and friendly, respectful assistance, which allows them as much autonomy and choice as possible.

Their perceptions of themselves are matched closely by the views of those who know them best, who also emphasise social relational aspects of them rather than highlighting their physical and communication impairments. These views sometimes contrast strongly with the perceptions of people who know them less well, and strangers, who tend to over-emphasise their differences and fail to recognise their ordinary teenage selves. ✱

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Research Fellow in Disability Studies

ACKNOWLEDGEMENTS

Many thanks to all the young people, their families, friends, school and clubs for welcoming me into their worlds, to the research advisors for their interest, to my supervisors Profs Allison James (Sheffield Univ) and Sheila Wirz (ICH, UCL) and to my funders ESRC/MRC and the Harold Hyam Wingate Foundation.

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Catering: The cost of lunch and refreshments will be met by the suppliers attending.

Advertising: To get a broad cross-section of delegates, you will need to advertise the event to speech and language therapists, teachers, social work staff, people who use AAC and their families, voluntary organisations and other professionals involved with communication aids. Communication Matters does not normally pay for the cost of advertising or mailshots.

Bookings: Communication Matters will provide you with a master copy of a flier/booking form to duplicate and send to your local contacts, the local press, professional magazines, local newsletters, etc. Anyone interested in attending has to complete and send the booking form (by post or online) to Communication Matters.

All bookings will be handled entirely by Communication Matters: delegates will be sent a booking confirmation immediately, and joining instructions (map, directions, timetable) two weeks prior to the event.

On the day: You will be responsible for the smooth running of the day, including: setting up workshop spaces, signage, registering delegates (Communication Matters will provide you with literature, a delegates list, name labels and other information).

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Communication About Emotion Matters

Developing an Emotional Voice

CLAIRE MURRAY
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INTRODUCTION

Current health agendas and educational guidelines across the UK and beyond identify positive relationships and emotionally supportive interactions as key factors in promoting emotional wellbeing in children and young people.

This article will highlight the particular role that communication plays in the development of different emotional skills and understandings. It will then outline an approach that is currently being developed to support pupils who use augmentative and alternative communication (AAC) access learning experiences that contribute to their emotional well-being.

The 'Emotions Talk' approach uses symbol based topic boards to enable pupils learn about and express their feelings within supportive communication exchanges. It is informed by theory and research in the field of emotional development, alongside current good practice in overcoming barriers to learning. It is also fuelled by a campaign to promote mental health and emotional wellbeing for all.

Further information outlining the circumstances and factors that have contributed to the development of this resource to date can be found in Appendix 1.

IDENTIFYING A BARRIER TO LEARNING IN EMOTIONAL HEALTH AND WELLBEING

A review of current educational programmes in this curriculum area and research findings looking at the socialisation of emotion clearly identifies the use of language as a major vehicle for learning about emotion. The talk-based learning activities that are advocated in educational resources are in-line with how adults generally explore emotional experiences with children, and this approach is supported by naturalistic and experimental studies in the research literature (see Denham, 2007, for a summary).

These findings supported a conviction that children and young people with communication needs face a language barrier to learning when trying to access the current educational practices and socialisation processes that generally facilitate emotional development and competence. It was clear that such children would benefit from a resource providing a means of communication on emotional topics.

The resource outlined in this article was originally developed for a group of pu-

1. Physiology		Recognising own emotional states as physical sensations
2. Labels		Labelling and communicating own emotions
3. Triggers		Understanding the causal relationship between situations/events and the emotions they trigger
4. Behaviour		Knowing that emotions can be expressed in behaviour in a variety of ways
5. Regulation		Being aware of, and being able to choose, appropriate responses/self-management techniques to regulate own emotions

Figure 1 Aspects of emotional learning addressed in the 'Emotions Talk' resource
Picture Communication Symbols (PCS) ©2010 Dynavox/Mayer-Johnson

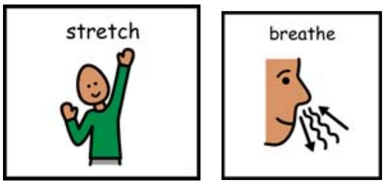
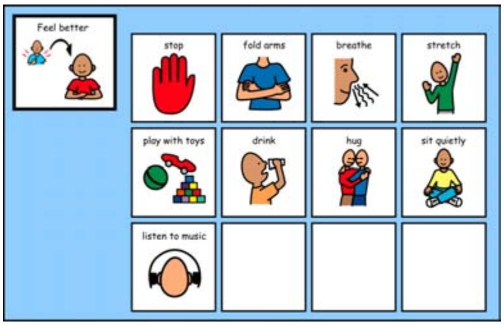
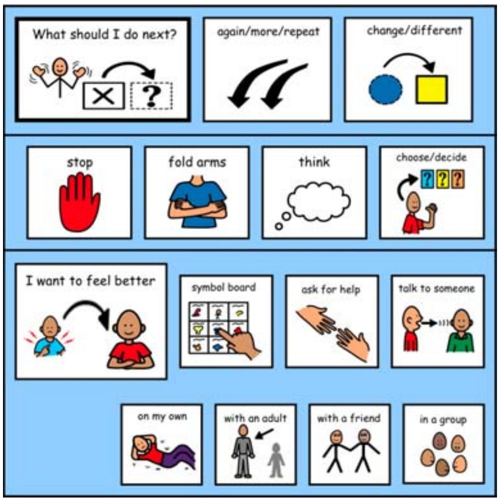
	**Level 1.** Single symbols. Activities to learn simple regulation strategies and their corresponding symbols. 'In-the-moment': adult begins to prompt with symbols to encourage regulation with appropriate strategies. Learner may use symbols to request assistance.
	**Level 2.** A selection of learned strategies are provided on a symbol board. Activities to learn further strategies and symbols. Discussions of preferences, when they might be used, reflection on past experiences etc. 'In-the-moment': adult encourages learner to self-select and attempt appropriate regulation behaviour.
	**Level 3.** A general communication board provides a 'scaffold' for more detailed discussion and understanding of emotion regulation. Also, a personalised board is developed at this stage including strategies identified as useful by the learner. Activities aimed at understanding the relationship between feelings, thoughts, actions and emotion regulation. 'In-the-moment': More independent emotion regulation is encouraged with personalised symbol prompting.

Figure 2 'Emotions Talk' - Examples of differentiated learning experiences and communication support in the area of Emotion Regulation
Picture Communication Symbols (PCS) ©2010 Dynavox/Mayer-Johnson

pils who have communication needs relating to moderate-severe learning disabilities.

RESOURCE DEVELOPMENT AND SUMMARY

In the context of school developments focusing on 'Total Communication' and 'Emotional Literacy', staff at Prospect Bank School in Edinburgh began exploring how AAC could support pupils to access learning about emotions. Low-tech topic boards were already proving to be versatile and popular with pupils and staff as a tool for both learning and communication in many subjects. It was decided to move forward with this approach for emotional literacy.

In order to identify the content for communication boards on the topic of emotions, it was felt that presenting a number of symbols representing the names for different emotions was not enough. Many pupils require a means of learning the names of emotions in the first place, and also need prompts to recognise changes in their body when experiencing different emotional states. In addition, it was felt that there is more to understanding and discussing an emotional experience than just noticing and naming a feeling. Early work in school saw teachers developing symbol boards to support lessons with older children on the causes of different emotions (e.g. "What makes you feel scared/happy/sad/angry?", etc.). Also, it was apparent that the behavioural expression of emotion and its regulation are other important aspects to consider for support and learning with this group of pupils.

Within the literature on Emotional Development, a 'component' approach to identifying different aspects of emotional competence has been outlined (for example, see Denham et al, 2002). It was agreed that such an approach would be helpful for staff in identifying particular skills and understandings to be supported, and also for pupils who would benefit from a 'piece by piece' approach to learning the different aspects of their own emotional competence.

The five components of emotional competence that form the framework for the resource are identified in Figure 1. The ways these different components relate to each other is also made explicit in the resource so that emotional learning is understood as a whole, as well as in its different parts.

The resource advocates two kinds of learning experience:

1. A variety of *planned learning activities* are suggested for each of the five components of the resource. The use of mirrors, games, puppets and emotion-inducing toys and experiences are recommended. Desktop symbol boards offer communication support to all activities.
2. Adults are also encouraged to take advantage of opportunities arising in

everyday situations to promote learning about emotions. These situations are referred to as *'in-the-moment' learning opportunities.* Guidance is provided on how to make use of such opportunities. Portable symbol boards are provided to make communication support possible at all times.

The learning activities and communication boards are differentiated into three different ability levels to enable access to emotional literacy by pupils with a variety of learning and communication needs. An example of the progression across the three levels is provided in Figure 2.

EARLY FINDINGS AND CONCLUSIONS

Feedback from staff using the first level materials has been extremely positive with regard to understanding the approach and the practicality of using the different resource elements. Anecdotal accounts of impact of the resource on pupils have also been promising. There is much enthusiasm for adapting the resource for children with different learning and communication support needs and in applying its use to home situations. The possibilities for further resource development and wider distribution are currently being explored.

As evidence gathers for nurturing emotional competence and fostering resilience in children and young people as a means to promoting their positive mental health and emotional wellbeing, it is particularly apparent that those children who face additional challenges in their lives and learning require particular support in this area. The 'Emotions Talk' approach shows great potential in contributing to this process.

"After using these resources for a year in my classroom, I can honestly say they impacted on the learning of the children in a significant way. They were able to make connections between what they were feeling and how they were expressing that feeling. They were able to give it a name and begin to use this to label others' emotions … In summary, I strongly believe that this is a resource that enables children with learning and communication support needs understand emotions and develop an 'emotional voice'" (Sandra Craig, Teacher). ✱

Claire Murray
Teacher

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APPENDIX 1

The development work dates back to 2007 in Prospect Bank Special School, Edinburgh	• **Pupils** – a source of inspiration for many in-school developments due to their varied learning, communication and behaviour profiles • **Staff** – a creative and determined team who took a collaborative approach to meeting learning and teaching challenges • **Senior management team** – encouraged shared leadership practices
Prospect Bank School Improvement Plan 2007-2008 / 2008-2009	• **'Total Communication' working group** (led by teacher, Sandra Craig) Recognised the central role of language in learning. Identified and developed a variety of communication approaches to support learning in all curriculum areas. Collaboration with speech and language therapists and with CALL Scotland [1] • **'Emotional Literacy' working group** (led by teacher, Claire Murray) Recognised the importance of emotional literacy in emotional wellbeing. Aimed to identify and address barriers to emotional learning in pupils with learning and communication difficulties.Collaboration with City of Edinburgh Council's 'Growing Confidence Project' [2]
2009 - Resource development progressed	• The Growing Confidence Project backed the development of a 'Support for Learning and Communication' resource with Lottery Funding • Claire Murray appointed to take the work forward • Ongoing consultation with Prospect Bank School staff and parents, and other ASL services in Edinburgh • Dynavox/Mayer-Johnson Ltd [3] gave permission to use PCS in the development of the communication boards • Consultation with research staff at The University of Edinburgh on emotional development literature and intervention work • Prospect Bank School piloted first activities and materials
2010 and next steps	• Ongoing funding enables collaboration with other special schools and ASL services across Edinburgh, and making links to the Council's Communication/Literacy Strategy • Presentation of the work at the LTS Health and Wellbeing Conference and The Scottish Learning Festival indicated a demand for the resource across Scotland • Exploring possibilities for further resource development and wider distribution

Appendix 1 Background information outlining the circumstances and factors that have contributed to the development of the 'Emotions Talk' approach to date

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An Evaluation of the Development of a Specialist County-wide Augmentative and Alternative Communication Service

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INTRODUCTION

Following the end of the Communication Aids Project (CAP) in 2006, many areas were left with limited access to any form of AAC service for children or young people.

This paper describes a collaboration between Kent County Council and Eastern and Coastal Kent NHS Community Services which resulted in a specialist service being set up to meet the needs of children aged 0 to 19 years requiring communication and assistive technology assessment and support.

We will discuss and evaluate the process of setting up this specialist service and the developments that have been made since its establishment. The goals of this paper are to examine the style of assessment service delivery and to consider the need for the availability of thorough follow up.

The new service was set up in January 2007 and was commissioned to serve the eastern half of Kent. The aim was to address the vision outlined in *Every Child Matters* (2003) of enabling children and young people to enjoy themselves, to achieve and to reach their full potential through a good quality specialist service provided by the local authority and health service working together. This aspiration underpins the continuing work of the service, which is shortly to expand to cover the whole county.

Additionally, the service meets the requirement of Standard 8 of the *National Service Framework for Children, Young People and Maternity Services* (2004) that children and young people who are disabled or who have complex health needs should ‘receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.’

SERVICE DELIVERY MODEL

Each of our teams consist of an occupational therapist (OT), a speech and language therapist (SLT), a teacher, a therapy assistant practitioner (TAP) and a clinical technologist.

Zangari & Wasson (1997) identify three challenges affecting the delivery of AAC services. One is that AAC involves many disciplines, with no one discipline taking overall responsibility. The second is that there is a wide range of individuals requiring access to these services, and finally that many individuals will require support throughout their life.

There is much investigation into models of service delivery in the AAC literature. It is generally agreed that the transdisciplinary model is the one that should be aspired to in the field of AAC service delivery.

Zangari & Wasson (1997) describe the transdisciplinary model where “team members work together to provide services…by jointly implementing assessment and intervention activities.”

In the light of experience so far, we would endorse the view of Wasson, Arvidson & Lloyd (1997) who state that “the transdisciplinary model should become the model of choice, because it is the most adept at supporting collaboration, not fragmentation” (p174).

As our teams develop and grow together, staff are increasingly using collaborative questioning, problem solving and joint reflective practice, which ultimately leads to a better outcome for the child.

THE REFERRAL PROCESS

A set of strict referral criteria was agreed jointly by the Health and Local Authority Heads of Service. Cook & Hussey (2008) state that referral criteria assist the practitioner in evaluating the match between required needs of the individual and the service offered. Moreover, it could be argued that it is critical to identify appropriate referral criteria in order to establish and maintain an equitable service with fair access for all appropriate individuals.

Referral forms are considered and matched carefully against the referral criteria, by a group of team members; one from each discipline. Clear guidelines are provided to accompany a referral form in order to assist the referrer.

The referral form used by Kent is also perhaps unusual in that it seeks to establish a commitment from the referrer to implement final recommendations at this stage.

ASSESSMENT

When the service was first set up, there was just one pathway for all children referred to the service. However, as the team gained experience, it became clear that different types of children required different levels of assessment and intervention service. Hence in January 2009 additional pathways were written (Fig. 1) giving the team the flexibility to offer different styles of assessment process to different children.

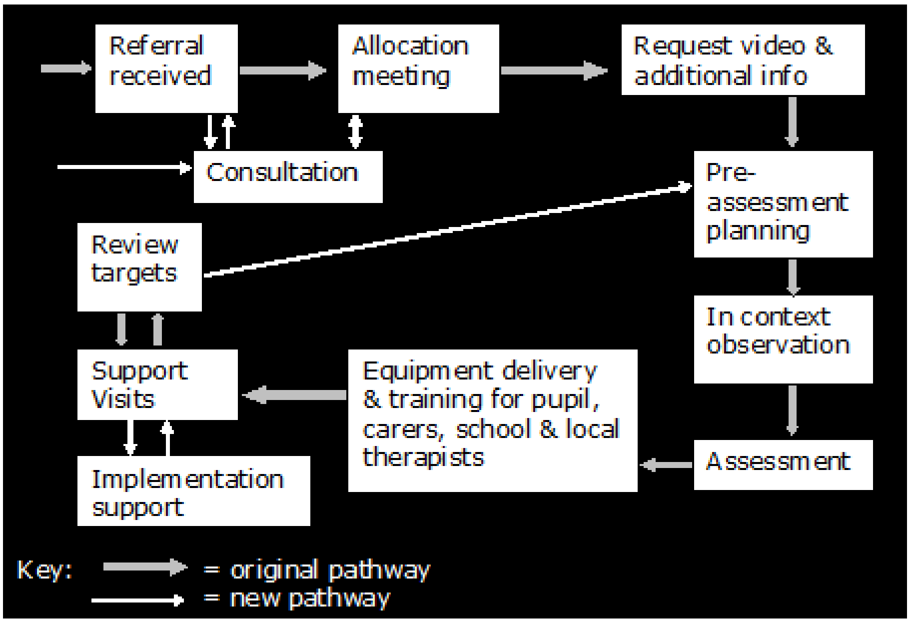

Figure 1 Original and additional pathways

Goossens and Crain (1992) advocated observing and videotaping the child performing familiar tasks in typical environments as part of the assessment process. Inge and Shepherd (1995) suggested a phased approach to examining the position of access devices. With this in mind therefore the style of assessment process was modified to incorporate 'in context observations' where appropriate. This entails all the members of the CAT team visiting the child at school and home before the assessment day held at the centre. Children benefit from getting to know members of the assessment team before the formal assessment day.

Dowden & Marriner (1995) stress that assessment of children with complex needs does not have to wait for them to achieve their expected skills at motor control, language or communicative function and furthermore point out that intervention can begin before formal assessment. The extension of the assessment process to include 'in context observations' has allowed the specialist team to assist the local team in implementing advice to help the child move towards communicative competency and this in turn empowers the local team by giving them an early sense of involvement and achievement.

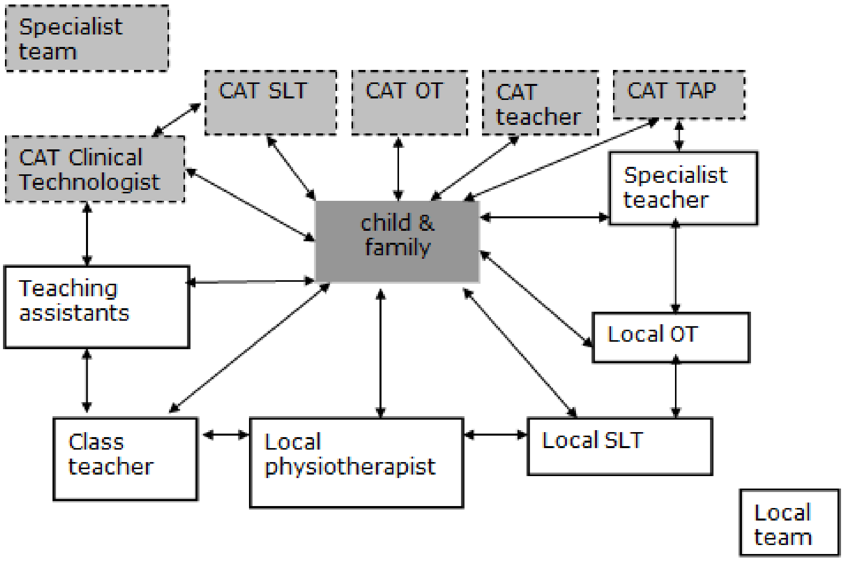

Figure 2 Team members present at the main assessment day

The modification of including 'in context observations' has therefore allowed more time to explore all the essential skills that contribute to communicative competency within context and reduces pressure on the assessment day, allowing more time for informed discussion for decision making.

The 'arena' model after Glennen, S. (1997) has more recently been adopted for the main assessment day, with the majority of team members observing through a video link in the adjacent room. This has had the benefit of not overwhelming children with a large number of adults, but ensures that everyone's contribution is included.

Figure 2 shows the team members present at the main assessment day for a child with complex needs and illustrates the way the team work placing the child and family at the centre.

Originally, once this phase of the assessment was completed, the recommended equipment was purchased. However, again in the light of further experience, where fuller assessment is required the more complex children may now be offered a loan of a recommended device in order to establish that this is indeed the most appropriate model.

TRAINING AND SUPPORT

Consultations

In the first 18 months of the service, if a referral was rejected, this information was fed back to the relevant professional with the option of a re-referral in the future. This system however, did not adequately address the needs of those children and young people who would potentially benefit from specialist intervention, but who did not have the required level of support at a local level to ensure successful intervention.

This has been addressed by providing greater access to advice from the specialist team in the form of a consultation session. It is important that there are mechanisms in place to support the local teams working with children with complex communication needs.

Training

Training needs to be offered at appropriate levels to support the local staff in their development of understanding of the steps towards success with a high tech communication device and to enable local teams to fully meet the needs of the children. The specialist therapists and teachers therefore have designed training day programmes to teach the local staff implementation skills.

In Kent this is known as the *tier one* support, with the specialist service as the *tier two* support. It should be recognised however, that once a child moves from *tier one* to *tier two* the need for support for the local team does not cease. In fact, if anything, it increases. This was lacking in the early days of the service being set up and explains in part why a number of children were failing to achieve the targets set for them in the first six months of receiving their equipment. The *Better Communication Report* (2008) recognises this and acknowledges that “Children who need to use AAC and those who support them often need specialist expertise to help them get the best out of their system” (p36).

There is a balance to be achieved in offering the right amount of specialist support. For example, a school with little experience of supporting a child using AAC would rightly expect to have significant support from the specialist team. However, this team has experienced cases where if too much support is offered, the local team fail to take responsibility for the successful use of the device and becomes passive in dealing with any issues that may arise. On the other hand, too little support could result in the device not being used sufficiently. Experience of the specialist team has led us to the conclusion that schools and therapists need to be empowered to support the child at a local level, but they need to know when to call for help as well as to know when the next visit is scheduled.

The Audit Commission report *Fully Equipped* (2002) found that equipment services tend to waste money by not always providing people who use equipment with training. Experience in Kent has demonstrated that it is imperative that good, relevant training specific to the device is provided, with plenty of opportunities for practice, for all members of the team working with the child on a daily basis.

OUTCOME MEASURES

Once a child is provided with a Voice Output Communication Aid (VOCA), four targets are set in agreement with the local team, the child and family. These are then evaluated six months after the equipment has been in use. In the early days it was found that these targets were not all being achieved even though they had been agreed as relevant at the time by all relevant personnel. Johnson et al (2006) found that lack of training and lack of support were key factors in determining the inappropriate abandonment of a VOCA.

Further investigation needs to be carried out by the service into the reasons for failure to meet targets, to avoid this leading to inappropriate abandonment of VOCAs. One strategy in particular has recently been put into place to address this issue. Therapy Assistant Practitioners (TAPs) are now employed as part of the specialist team. The TAPs work alongside the local team and family in the child’s environment to ensure appropriate implementation of new equipment. Issues such as programming pertinent vocabulary and integrating use of the device into lesson plans are addressed.

The success of the TAPs implementation programme is evaluated in conjunction with another member of the specialist team. This method of working allows the family and local team to become empowered to help the child and should ensure consistent carry-over into the child’s familiar context. Early results indicate that a higher proportion of children are now achieving their targets since this level of support was implemented.

CONCLUSION

Lund & Light (2007) consider that whether or not an individual develops communicative competence depends not only on their development of the four core areas of linguistic, operational, social and strategic skills, but also on policy, practice, attitude, knowledge and skill barriers of the service supporting them which may limit opportunities for communication and determine the challenges that an individual will need to overcome.

The establishment of a specialist service in Kent has certainly ensured that a greater number of children and young people with complex communication needs are receiving appropriate devices, but the service needs to address far more than just appropriate prescription of VOCAs.

Once a child receives a high tech device, the ongoing support from a specialist team, working in close cooperation with the local team is vital to ensure the device is used functionally and in all contexts in which the child spends their daily life. Working towards communicative competence as proposed in the Lund & Light (2007) model is the duty of everyone supporting that child. ✱

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Speech and Language Therapist

Christine Cotterill
Teacher

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Early Intervention

What happened to ‘wait and see’?

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INTRODUCTION

This article began as an essay for ACE North’s AAC unit and was expanded for ISAAC 2008 which I attended thanks to the generosity of Dynavox systems, a grant from The Royal College of Speech and Language Therapists, and funding from Cumbria PCT. It was updated for a SIG and finally presented at the Communication Matters Symposium.

The reason for my interest was that I was surprised to be asked by a colleague “What happened to ‘wait and see’?”. I began to consider the issue further. I carried out a literature search looking at AAC and other speech, language and communication difficulties.

The children I work with may have the opportunity to use high tech AAC. However “the ultimate goal of an AAC intervention is not to find a technological solution to the communication problem but to enable the individual to efficiently and effectively engage in a variety of interactions.” (Beukelman and Mirenda, 1998).

WHAT HAPPENED TO ‘WAIT AND SEE’?

The main reason for ‘wait and see’ may be concern that introducing AAC may adversely affect the development of speech. The literature indicates that this is unfounded. Pennington & McConachie (1999) report children will use “the quickest form of communication”. Weitz et al (1997) describe a study by Silverman in 1995 which found “at least 40% of AAC users increased their output in conjunction with their use of AAC”. Suggested reasons included “reduced pressure to perform verbally, the use of graphic symbols, and the development of alternative input and output channels, taking the pressure off the traditional auditory-vocal channels” (Kangas & Lloyd, 1988).

Parent’s feelings are important. Seaver (1995) reports that “research has shown that communication impairment in the child was a higher stress factor, especially for the mother, than other kinds of physical conditions”.

Much has been written about parents’ feelings of fear, loss and grief (Stanton, 1992; Trachtenberg & Rouse, 1998). However, Stanton (1992) states “Many parents felt that their feelings were influenced by the attitudes of the doctors and other health professionals who talked to them about their child after diagnosis”.

Professionals involved need knowledge and skills to be able to give parents appropriate information. Training establishments for both speech and language therapists and teachers were contacted.

All the speech and language therapy training included AAC but the small number of teacher training colleges who responded did not, one enquiring what AAC was. AAC does appear in sections of National Occupational Standards for supporting teaching and learning in schools for support assistants.

WHAT, IN THE CASE OF AAC, DOES EARLY INTERVENTION MEAN?

“Alternative communication is not simply a non-vocal expression of spoken language but has its own characteristics” Von Tetzchner & Grove (2003). Children develop language and communication by experiencing it used at a higher level, generally children who use AAC rarely see it used in a natural setting and learn through more artificial means. Occasionally professionals are not much more competent in the AAC system than the child. Goossens (1999) advocates Aided Language Stimulation where the teacher uses a symbol board while talking. This enhances children’s comprehension of the activity and demonstrates expressive use. Organisations such as ‘1Voice’ provide opportunities to meet adult role models, allowing children to see AAC used at a higher level of competence.

Previously children received ‘traditional’ speech and language therapy and only when this failed would AAC be considered (Weitz, Dexter, & Moore, 1997). Blockberger and Sutton (2003) state that AAC devices tend to be provided at 3, 4, or 5 years old. At ISAAC in 2008, Mjoen et al recommended identifying AAC needs at diagnosis and described a protocol.

CAN ‘EARLY’ BE TOO EARLY?

As introducing AAC early does not have a detrimental effect on development of natural speech, are there other risks? The only risks seem to be related to in-appropriateness rather than AAC itself. If a system is too simple, a child may 'waste time' proving they can use it before being allowed to progress further. If it is too complex, it may prove frustrating and the child, and their carers, may not want to try another system (Rowland and Schweigert, 2003).

IS THERE A 'TOO LATE'?

Young children practise talking through babble and repetitive speech (Rowland and Schweigert, 2003; Frost & Bondy, 2002; O'Regan & Brown, 2001; Golinkoff & Hirsh-Pasek, 1999). Many children who need AAC are unable to do this and miss opportunities for developing skills other children have so much practice with. Additionally Pennington & McConachie (2001) report that "children with severe difficulties in producing readable (i.e. consistent and predictable) signals may fail to develop a full range of communicative functions".

Adults' speech tends to be adapted for young children, being higher pitched with exaggerated intonation, slower, more pauses and simplified syntax. Where children are not able to respond the danger is adults will 'give up' and not provide necessary input, or input will be appropriate to the child's age and more difficult to respond and learn from.

Babbling is important for the development of early communication and language skills. Deaf babies produce 'manual babbling' including "handshapes, movements, locations and palm orientations". Lust (2006) describes babbling as "a continuous mapping to the phonology of the language being acquired, whether the phonology is expressed orally or visually". Some children may do this producing streams of sounds or nonsense words on high tech devices. Golinkoff and Hirsh-Pasek (1999) talk about deaf babies who vocalise, those who don't, and babies who can hear and vocalise, and conclude "hearing one's own vocalisations is critical for normal language development".

Lack of expressive language on development is a concern especially in relation to thinking skills. However "There is good evidence that language is used for thought, but this use does not need to develop from speaking aloud" (Mogford and Bishop, 1997). Children tend to 'think out loud', until the age of about seven (Piaget, 2002), however they can learn to develop their 'inner voice' or visual thinking earlier. One young child was encouraged by his support assistant to 'see' and 'hear' things in his head, and this seems to have had a beneficial effect as he can now describe how he works things out (in his case often visually).

One danger of later intervention is the possibility of learned helplessness; the child lacks the ability to affect the environment, causing lack of motivation to try, and may eventually become depressed. "The concomitant effects of learned helplessness can be as serious as the disability" (Gray, 1997).

A further risk is the effect on education. Beukelman, and Mirenda (1998) state that "The ultimate goal of communication and other interventions is to facilitate their entry into general education environments" and also it is important "by the time a child reaches first grade, he or she has the tools necessary for academic participation and instruction".

When a child starts school familiarity with their system will mean they do not have to learn a new method of communication in addition to everything else. Staff working with them will need training in using the child's system and the implications of AAC. Literacy is one area where children with continuing speech problems as well as those who use AAC may have difficulties (Sutherland & Gillon, 2007). "Unless a child has established communication through AAC then the introduction of formal reading is likely to result in failure" (Brewis & James, 1998).

In some cases AAC systems are rejected. Seaver (1995) suggest lack of acceptance of AAC may be due to the fact that it is not seen as part of the person's "inner self" but if AAC is provided early it can become "part of the person's developing identity".

IS THERE A CRITICAL OR OPTIMUM PERIOD?

The critical period is "A period of time with a distinct onset and offset during which experience can lead to learning by an organism; assumed to be innately programmed and irreversible. Puberty has sometimes been posed as an "offset" time for language acquisition, potentially linked to development of hemispheric dominance" (Lust, 2006). Mogford & Bishop (1997) state it has been hypothesized based on research related to vision that it is important to use a skill rather than just be exposed to a stimuli and so using speech may be important. This is not supported by research on children who had long term tracheostomies which were reversed, allowing them to speak later in childhood. Some of these children were, however, using signing and so did have a means of expressing language.

There have been suggestions of prerequisites which must be in place before AAC is introduced. One which is inarguable is that "the child has reason to communicate" (Coupe et al, 1998). However as Sigafoos, et al (2000) state "the case for or against prerequisites remains unproven and perhaps unprovable. Some might argue that if the individual learned to use AAC for functional communication, then he or she must have had the required prerequisites to begin with. Others could argue that a well-designed AAC intervention might actually facilitate the emergence of the very skills and abilities that are considered prerequisites". A tempting concept is that of "a sensitive period in which relatively small amounts of finely tuned appropriate intervention has a large effect" (Ward, 1999). Identifying this intervention could be challenging.

WHICH KIND OF AAC SHOULD BE INTRODUCED AND WHEN?

Before working with a child on AAC it is important to "determine the individual's ability to communicate without the use of an external device". (Treviranus & Roberts, 2003). Whichever system the child uses they will also need an unaided system which may be their quickest method with familiar communication partners. Also "A major focus for early intervention is to build a relationship of trust and partnerships with parents" (Blockberger & Sutton, 2003). The parents will not carry out most of the intervention but are the experts on the child and situation. There will be a number of focuses, teaching the child how to use a system, training the family in using it and fitting it into family life.

Evidence shows "There does not seem to be any one best mode or system of AAC for beginning communicators as a whole" (Sigafoos et al, 2000). Whatever system is used "the final goal is that children developing alternative communication forms shall be able to communicate with peers and adults about the same things and in the same situations as speaking children" (Von Tetzchner et al, 2005). The system should be motivating; we have had the sound of Thunderbirds in devices and lots of photographs. It must be constantly reviewed to keep pace with the child's development.

It is vital that early intervention, particularly the system itself, is at the right level, provides potential for development and that there are appropriate levels of support. Without sufficient training and support, introduction of AAC is unlikely to be successful. Families want “ideas about how to introduce and use new communication strategies and systems into family life” (*Together from the Start*, 2002), and also “more information and training in the use of AAC devices, support using the devices, and making contact with other families of children who used AAC” (Goldbart & Marshall, 2004).

Light & Drager (2007) found children aged 1–3 with developmental disabilities increased their acquisition of vocabulary through “access to dynamic display AAC technologies, vocabulary was added on a daily basis, and partners modelled functional use of this vocabulary in meaningful contexts via AAC and speech”. They also found young children (2.5 years) were able to locate vocabulary more accurately using “visual screen displays compared to the grid layouts”.

There has been some discussion about types of symbols. However, it has been found that “graphical readership is an acquired skill” (Petre & Green, 1993; Mineai, Peischl & Pennington, 2008) and children can learn to use most types of symbols.

WHAT HAPPENED TO ‘WAIT AND SEE’?

It would appear that ‘wait and see’ is unsupportable with family agreement and appropriate support. Later intervention is effective but there is potential increased risk of rejection. There is nothing to be gained from ‘wait and see’ and much to be lost by delaying the child’s development of communication. ✱

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Augmentative and Alternative Communication

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

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JOINING COMMUNICATION MATTERS & ISAAC

What is Communication Matters?

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

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

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

What are the benefits of Membership?

Members of Communication Matters receive:

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

How do I become a Member?

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www.isaac-online.org

What is ISAAC?

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

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

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

What does ISAAC do?

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

What do ISAAC members receive?

- Full access to *ISAAC Information Exchange,* an international resource for sharing knowledge, experiences & perspectives on AAC.
- An International Directory with a list of all ISAAC members.
- ISAAC members can buy the AAC Journal at 54% discounted rate.
- ISAAC members can attend ISAAC conferences and meetings at 15% or more discounted rate.

TRUSTEES' NEWS

COLLATED BY JANICE MURRAY, CHAIR

COMMUNICATION MATTERS EVENTS

Feedback from the CM2010 National Symposium in September has been very encouraging. The range and quality of presentations were very well received. Some of the highlights include: Carol Allen who got the whole symposium off on the right foot with her idiosyncratic style of approaching education of children with complex communication needs. Jean Gross, The Communication Champion (England), not only presented a thought provoking and challenging update on initiatives involving AAC but she also took the time to talk with many delegates. This was mentioned in her most recent contribution to the RCSLT Bulletin (October 2010). Joan Murphy posed the intriguing question: Can AAC ever really work? Her keynote received rave reviews, in terms of a collective responsibility to move AAC forward.

The follow-up Communication Matters study day on the theme of Eye Gaze technology (4 November) has clearly been a winner too. We have received great feedback on all aspects of the day. I am sure we will find an opportunity to share this more widely in the future.

SAY 'HELLO' TO THE NATIONAL YEAR OF SPEECH, LANGUAGE AND COMMUNICATION

Trustees are about to begin planning for 2011. Immediate focus will include detailing the initiatives and events for *'Hello', The National Year of Speech, Language and Communication.* Thank you for the enthusiastic support received thus far but we continue to need involvement of the UK membership to ensure we capitalise on the publicity and education opportunities that *The Year* will enable. If you have some ideas and would like some support to get them off the ground, or, if you would like to be involved in some of the events already organised, get in touch with Patrick Poon *(admin@communicationmatters.org.uk)* or Sally Chan *(sallychan@blueyonder.so.uk).*

STRATEGIC PLANNING

We also continue with our planning through 2011 to 2018 and this includes strategies to support effective fund raising and longer term sustainability; membership development and involvement and exploring how we can put Communication Matters on the international AAC map through a range of events and activities, including publications, research and conferences and workshops.

NEW BOARD OF TRUSTEES

Since election of the new Board of Trustees in September, I can confirm that Liz Hewson has been co-opted as a Trustee. Liz already has some experience of CM Trustee work through her son, ex-Chair Toby Hewson and she also has considerable experience of third sector activity. We look forward to welcoming her to our first meeting. We will be able to update you on the appointment of a person who uses AAC to the Board very soon, watch out for an update on the website.

Currently, our Board includes: Janice Murray (Chair), Neil Hansen (Treasurer), Sandra Hartley and Gillian Hazell (Deputy Chairs), Sally Chan, Mike Clarke, Dithe Fisher, Liz Hewson, Simon Judge, Vicky Lundie, Ruth McMorran, Kathleen Paintin, and Anna Reeves. You can find out more about the role of Trustees from our website.

OTHER ACTIVITIES

We continue with our other familiar activities, this journal being one example, with another bumper edition full of the usual high quality papers. Liaison with the Communication Trust is on-going. Our current work here, led by Sandra Hartley, is focussed on the development of generic educational leaflets on AAC. This is being funded through the Awards for Innovations in AAC and is a collaboration with 1Voice, SCOPE, ACE-Advisory Trust, ACE-Centre North, Makaton and Signalong. Janice Murray represented Communication Matters at a round table debate in Edinburgh on employment and disability in November. Road Shows are already being planned for next year. Our continued thanks to our commercial members and to the hosts of these important and informative days.

Look to the website for regular updates on activities and opportunities that your membership offers *www.communicationmatters.org.uk*

AAC EVIDENCE BASE RESEARCH PROJECT

Katie Holmes, Research Manager, writes:

There was a project launch at the CM2010 National Symposium, during which the Big Lottery Fund grant cheque was presented to Communication Matters.

There was also a talk and a discussion session about the project during the Symposium. In the discussion session the audience was particularly interested in the proposed map of UK service provision for people who need AAC. If you want more information about the talk, please contact me (email details below).

The University of Sheffield has appointed two Research Assistants who are due to start work on the project later this year. Manchester Metropolitan University is appointing a Research Assistant to join the project.

Thank you to everyone who has expressed an interest in participating in the research. If you are a person who uses AAC, a family member, carer or practitioner, and you are interested in taking part in the project, contact me at *katieholmes@communicationmatters.org.uk*

The AAC Evidence Base research project is a three-year project led by Communication Matters and funded by the National Lottery through the Big Lottery Fund. The project's research partners are: University of Sheffield, Barnsley Hospital NHS Foundation Trust and Manchester Metropolitan University.

The project aims to improve the quality of life of people with severe communication impairments who need AAC by raising awareness of their needs and by improving service provision. For more information visit: *www.communicationmatters.org.uk/research*

HOT NEWS

COMMUNICATION MATTERS TWEETS!

You can now follow Communication Matters on Twitter **@Comm_Matters** Please Retweet! Web: twitter.com/Comm_Matters

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PARENT, FAMILY MEMBER OR CARER NEEDED FOR INDEPENDENT RESEARCH PANEL

Are you a parent, carer or family member of someone who uses communication aids? Are you interested in supporting research?

Communication Matters is looking for a parent, family member or carer of someone who uses communication aids (such as PECS, charts or electronic aids) to join its Independent Research Panel.

The Independent Research Panel provides guidance and advice to Communication Matters for its research projects. Meetings are held twice a year (January and July) in London. Expenses will be paid and a small honorarium is available.

You do not need to have knowledge of research to join the panel; what we value is your personal perspective on our work.

Contact Katie Holmes, Research Manager, for more details: *katieholmes@communicationmatters.org.uk*

*

ACE CENTRE LAUNCHES *SPEECHBUBBLE*

The ACE Centre has launched a brilliant new resource, the *Speechbubble* website, where you can search and compare information on nearly every communication aid available in the UK, as well as get details on communication software, vocabularies and suppliers! Visit *www.speechbubble.org.uk*

*

HOUSE OF COMMONS DEBATE ON 'SPEECH THERAPY SERVICES FOR CHILDREN'

Watch the House of Commons adjournment debate on ‘Speech Therapy Services for Children’, tabled by Paul Maynard MP (3 November 2010). Visit: *tinyurl.com/debatenov2010*

*

SEE THE *SING UP* PROGRAMME IN ACTION

Sing Up is a programme in primary schools in England which aims to ensure that singing is at the heart of every child's life.

You can now see a 15 min video about the programme at *www.youtube.com/watch?v=50IPQpnOjvI*

The *Sing Up* website has lots of information as well as downloadable songs and resources *www.singup.org*

eCAT NEWS

Since my last report, I have submitted the BHTA eCAT response to the Government’s Equity and Excellence White Paper. The proposals raised serious concerns for suppliers, as well as healthcare professionals, but also presented us with an opportunity. We are concerned that there is still no ‘right’ to a communication aid and related assistive technology and support, and that there is severe underfunding. It is estimated that the need is 3-5 times the amount spent on communication aids each year. This funding shortfall is serious for all ages, but especially acute for adults.

There is no defined and consistent system for obtaining funding for assessment, equipment or support - depending on age or location, equipment might be funded by NHS, local authorities, charities or private fundraising. Obtaining funding is often difficult and frustrating for individuals and their families, and time consuming for education and health professionals.

We argued that funding and commissioning of communication aids and related services needs review and clarification. For us to provide a service that matches the real level of need, as well as best practice in other Northern European countries and the USA, we need policies that deliver:

1. A basic right to a communication aid and support for those who need one.
2. Adequate funding to meet the real need.
3. A clearer, simpler structure for assessment, trials, application for funds, maintenance of equipment and professional support (before assessment and after provision).
4. A reasonable timeframe for providing communication aids and support services, recognising the condition of the patient and (for children) their educational needs.
5. Clarification of the role of the main agencies (education, social services and health) in provision of equipment and services for different groups of people.
6. A fairer assessment of need that is not dependent on the individual living in a well funded area, or having a well funded disability.
7. One possible model could be similar to the existing environmental control systems model. If adopted for AAC, this will have implications for the current NHS EAT Framework Agreement in which AAC does not feature strongly.

We look forward to seeing the detail! On a different note, we welcomed the official launch of the National Year of Speech, Language and Communication: ‘Hello’ (visit *www.hello.org.uk*).

I will report on the new Assistive Technology Practitioners Society in a future issue of this Journal.

David Weatherburn
Chair of eCAT section, BHTA
david@ability-world.com

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Welcome

Communication Matters is committed to supporting people who find communication difficult because they have little or no clear speech.

You will find here information on methods of communication which can be used to supplement the more usual methods of speech and writing. These methods are called **Augmentative and Alternative Communication,** or **AAC** for short.

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Engineering the Environment with Story, Drama, and Music

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Abbey Hill School & Technology College caters for children and young people with special needs in Stockton Borough.

Students who have significant communication difficulties work in our developing Access class, which promotes communication through signing, picture exchange communication systems, communication symbol books and the use of high and low tech communication aids. The principle of 'engineering the environment' is embedded in the philosophy of the class.

Students can 'access' this group on a full time or part time basis. The speech and language team works with this class providing assessment and support, and, with the team, developing the principles on which the class is based and planning for individual student's needs.

This paper will give a background into the formation of the Access class, its current practice and future plans.

During 2007 it was recognised that some of our students were not fully engaging in (accessing) their lessons in the main body of the School because of their restricted expressive communication and lack of effective augmentative strategies.

It was decided to create a new 'Access Class' with a high staff-student ratio that focused on students acquiring and developing communication strategies.

The core of this group was formed from students in our Sensory Education Base operating at P4 and above. We then looked at all of the students in the main body of the School and selected those with restricted communication skills; operating typically between level P4 and L1. These students' severe learning difficulties result in delayed language skills. In addition to this, most have severe dysarthria, dyspraxia or a hearing loss. The age of the students currently ranges between 11 and 16.

From the class's conception, the Speech and Language Therapy Team were involved and it is this multidisciplinary approach in meetings and planning that has facilitated the learning environment and student success.

All lessons use 'aided language stimulation' and a combination of signing, pictures, symbols, communication books and VOCAs. Careful planning means that appropriate vocabulary is available for students. There is sufficient time allowed to model communication methods, to prompt and facilitate use.

Lessons build in models, opportunities and prompts for students to communicate for a variety of reasons. Staff involved in the lessons use the communication systems themselves and watch for communication of all kinds from which to build.

Whenever possible attempts are made to 'engineer the environment'; using missing or incorrect items, omitted steps, incomplete or mischievous actions, interruptions, pausing and waiting for a response from the students; all opportunities for communication between peers as well as between students and adults.

At our presentation at Communication Matters CM2009 National Symposium, we gave an insight into how we use story, drama and music in lessons to develop student confidence to engage in communication using a range of strategies appropriate to the individual.

We have chosen to centre each half term or term on one story; this is dependant on the length of the term and the complexity of the story. An essential feature of the story is that it must have a predictable sequence of events; core phrases that are repeated through the text are also desirable. The story must be of interest and accessible to the target students.

The story is then broken down into key components, which are represented

Figure 1 Communication Book

using symbols (we use PCS on Boardmaker). The symbols are then presented either as single symbols, on stand-alone charts or as grids to be used in our VOCAs (currently GO Talk, Tech Talk, BAP, Big Mac). Vocabulary learned in this way is then incorporated into students' individual communication books as appropriate. A progressive core vocabulary, both within the students' books and presented as stand alone charts has been inspired by Clare Latham's work on 'Making and Using a Communication Book'.

Once the story has become familiar the students join in with the telling of the story, predicting next steps, or commenting on omissions or mistakes. A version of the story is also developed as a Powerpoint presentation with which the students are encouraged to interact; this uses pictures, video clips, signs and symbols to help students engage thoroughly with the story. At the conference we used 'We're Going On a Bear Hunt' as our example. We have also used Gruffalo stories, Walters Windy Washing, Ridiculous and others.

Where possible multiple copies of the book have been purchased, but this is of lesser importance in terms of communication targets, but does teach students how to follow a story in a book.

Our next stage is to turn the story into an interactive drama. We have the luxury of a 'Virtual Environment Theatre'. The students help to create props to go with the stories; these are then used in conjunction with scene backdrops and sound effects; these are either taken directly from the books or actual photographs or film clips that relate directly to the story. Stories are then acted out with the students taking roles of the characters in the story. They then take a journey through the story using their communication aids to help them.

This 'drama' evolves over the period of a term with the students becoming more familiar and confident in the events as time goes by. Following the underlying ethos of the Access Class any possible communication opportunity is seized on.

An important health warning here, is that this classroom model does require a lot of resourcing, for planning, production of materials and to provide the high staff: student ratio necessary to implement our principles. We are in the very fortunate position that the School and Speech and Language Therapy Department have supported the increased resources needed for development of this class, and that the staff involved in working with the students have a very positive approach and are highly skilled. We have also found that as we get used to the approach it is quicker and easier to produce the communication charts.

Figure 2 Working with a student in the Access Class

We also use music as a prompt for communication and development of vocabulary; this is done in a stand alone lesson, which is linked to the work that is being done on the story.

Pieces of music are chosen for their properties that are relevant to the vocabulary being used in the story, for example slow, fast, loud or quiet, exciting and so forth. Students then listen to and experience the music – they are encouraged to use single symbols, stand-alone charts, grids or VOCAs to, in the first instance develop simple vocabulary associated with the music. This is then extended by asking the students their opinions about the music, modelling like/don't like for them; they are then encouraged to ask for more of the same type of music if they so wish.

In the early stages of this work we used easily identifiable contrasts (fast/slow; loud/quiet). As the work has progressed we have tried to encourage the students to respond with emotions attached to the music (happy, sad, exciting, confusing, angry) always backed up with, "do you want more?" or indeed, "which would you like to hear?" They almost always choose 'loud' and 'fast'!

Students are encouraged to move around to the music and express themselves; instruments are available for them to use to join in with the music. Communication aids are always at hand so that the students can express themselves. As with the story we use symbols and signs on powerpoint to help focus the students attention to vocabulary.

As the sessions progress and develop we regularly reflect back on our students' functional communication and on the vocabulary developed so far.

At the time of writing we are working on music to help describe different animals; the classics, Carnival of the Animals by Saint-Saens and Peter and the Wolf by Prokofiev; both proving stimulating for the students.

Big slow animals will be associated with big (loud) slow music, whereas a small fast animal may be linked to fast light music. The limitation here is the experience of the students of the animals that we use; picture and video cues are used, as are taking the students out on environmental visits.

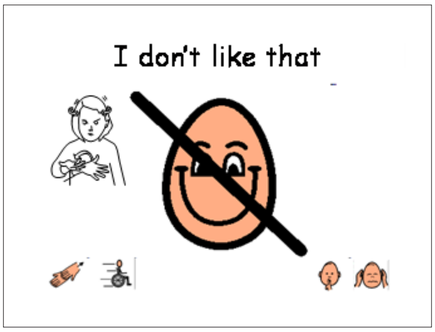
Most of the stories we retell have animals, so it is useful to use these pieces

Figure 3 Classroom display of Gruffalo work

of music. We link the musical properties of the animals to our drama presentations. In 'Rediculous' for example we may play students slow music and then ask 'who is this?' – it is a story about a tortoise!

Since our presentation we have changed the structure of the Access Class. One criticism that we listened to seriously was that of age appropriateness of the stories that we were retelling. We considered this viewpoint carefully but believe the stories are appropriate because the students enjoy them and are accessing them at a level appropriate to their development. However we have now split the class into Upper and Lower – effectively KS3 and KS4. The KS3 group run in exactly the way described above and have since our presentation worked on two new stories.

The ethos for the KS4 group remains the same as does the resourcing, the subject matter has changed. We are focusing on communication for life skills with this group. These students are timetabled for two, two hour sessions; one is classroom based and the other takes the students out into the community.



I don't like that

Figure 4 Slide from PowerPoint used in music class

As you would expect all of the visits have learning objectives associated with them. For example we may visit a supermarket; the students will have to make decisions about what they want to buy, and then use their communication strategies in the supermarket to make their purchases, asking for directions and then paying for items.

A recent and successful session was planning for and then having a party. The students had to make choices about what they wanted to eat and drink at the party and then go and buy those provisions from a supermarket using the skills that they had previously learnt. The next stage was to decide who they would like to invite as their guests; invitations were made and delivered.

On the afternoon of the party the food had to be prepared along with organising the music and seating. Guests then arrived and were looked after by the students throughout the afternoon. This was clearly a good excuse for communication strategies to be used in abundance.

Photographs and video clips taken are always used as follow ups to prompt discussion.

At present our KS4 group only comprises 5 students; two of the students are learning how to use their Jive communication aids; of the other 3, two are using communication books coupled with vocalisation and some signing, and one uses single symbol communication.

The Access Class started life somewhat in isolation; using staff training sessions we are now informing all staff of the strategies that we use and are encouraging the use of these in all appropriate lessons. We now have Go Talks, with vocabulary charts, in many of our classrooms; this will further encourage students from the main body of the school who come along to Access lessons to engage more fully in other lessons. As those who use Boardmaker will know there are many symbols for the same thing; by adopting a whole school approach we hope to standardise all the core vocabulary symbols, and where appropriate all common use symbols. Clearly there will be occasions when using unique or different symbols may be necessary.

Target setting, assessment and pupil progress are all seen as vital in school life these days. The Access class is no different. All of our students are given individual targets relating to Expressive Communication and Communication Modes used (a copy of our pro forma can be requested from the authors). We review targets at least termly and are making assessments continually.

In the main this target setting and assessment is qualitative in that it does

Figure 5 Bear Hunt Go Talk 9+ grid

Figure 6 Bear Hunt Go Talk 4+ grid

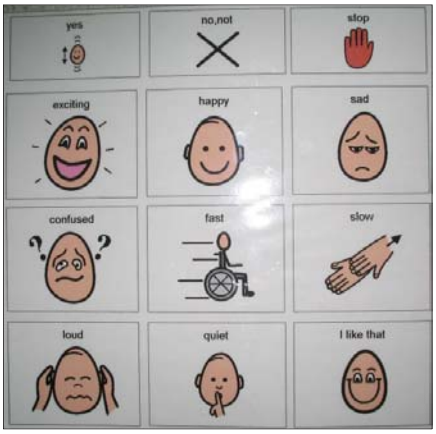


Figure 7 Music Go Talk 9+ grid

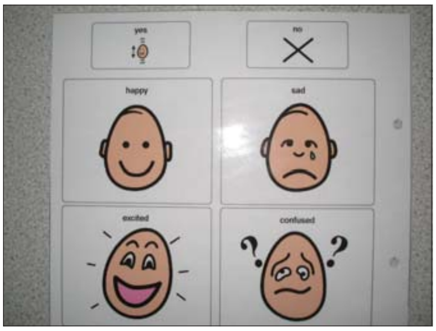


Figure 8 Music Go Talk 4+ grid

not have any numerical value attached to it, although it does follow a progressive structure. It should be noted that some time is spent working with individual or very small groups of students focusing on their specific needs, this also gives the opportunity to carry out individual assessments and review student's targets.

At Abbey Hill we have a whole school assessment programme linked directly to National Curriculum levels that is quantitative and progress is measured numerically. Clearly it is important that our Access Class can contribute to this and that it can be shown that our students are making measured progress within this system. We are able to show progress particularly in English Speaking and Listening and to an extent in Reading and Writing.

We believe our greatest success is in giving our students the confidence to engage more fully in their other lessons, which in turn is reflected in the quantitatively measured progress that they are making in other subjects.

It would be difficult to make exact measurements of the influence of the Access Class, however the anecdotal evidence is clear. ✱

Chris Roberts
Teacher

Sue Rowney
Specialist Speech and Language Therapist

ACKNOWLEDGEMENTS

Friedrike Schulz from Freiburg University was working at Abbey Hill School on a student placement from September 2008 to February 2009. Her input and work with the students with the music made an invaluable contribution to this work. Without the skilled work and enthusiasm of our teaching assistants – Lynsey Thornton, Michelle Harbottle, Vicky Calder, Kath Tillitson and Brenda Morley – the Access Class would not be able to function.

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Figure 9 Teaching a typical lesson

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‘Telling Stories’

A Pilot Study investigating the key features of AAC speakers' fictional narrative interaction

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BACKGROUND

This paper reports the findings of a pilot study carried out as part of a PhD research project comprising a single case series and aiming to test the feasibility of the methodology chosen. The focus is on augmentative and alternative communication (AAC) in education, specifically in relation to the use of narrative.

Within education, the most important conversation partners for a child who uses AAC are the teaching staff (Popich & Alant, 1999) who support the construction of meanings. This support takes many forms, for example through the provision of modelling, physical support and frequently through inference in interpreting and then scaffolding messages produced by the AAC user. Therefore, staff-pupil interactions are highly significant for the child’s language development (Millar, 2001).

Narrative plays a critical role in a child's language development and emerges from as early as 3 years old (Owens, 2008). Later on, language and the use of narrative assume great significance in the educational process, where there is the sharing of experience. For example, it is viewed as central to the English curriculum (Grove, 2005). Similarly, narrative is key to development amongst AAC speakers (Liboiron & Soto, 2006). Despite this, the narrative interaction between AAC speakers and their teaching staff remains under-researched.

METHODOLOGY

The study follows a single case design employing naturalistic research using applied linguistics to investigate interaction under two conditions: personal narrative and fictional narrative. Motivated by a need to refine the protocol and methodology for the main PhD study, a small pilot study was conducted.

The aim was to examine the key features and communicative roles employed in fictional narrative interaction between pupil (aided speaker, AS) and teaching staff (natural speaker, NS). Ethical approval for the pilot and main study was granted by the University of East Anglia School of Education and Lifelong Learning Ethics Committee. Informed Consent was gained from the NS participant, the parents of the AS participant and informed agreement was solicited from the AS participant at the beginning of the pilot data collection session.

Due to the small population of high-tech AAC users, recruitment employed a snowballing technique (Pring, 2005) whereby existing specialist contacts were extended. For example, participants were identified through special interest groups, local specialist speech and language therapists and other relevant organisations.

Each potential participant was then checked against inclusion/exclusion criteria prior to full recruitment. For the pilot study the participant recruited was an 11 year old girl, who used a laptop with MindExpress Software and was able to use 3 to 4 word phrases. The NS participant was a familiar teaching assistant who had been working with the AS participant for several terms.

The pilot data collection session was completed in a quiet familiar room within the participant’s school to minimise distraction and reactivity to the environment. Once both participants were comfortable in the research environment the NS held an informal conversation with the AS and explained the narrative task to be completed. This

Communication	AS1	AS % Total	NS1	NS % Total	Total
Speech	0	0	65	29.5	65
Vocal Gesture	0	0	0	0	0
AAC-Encoding	4	3.8	3	1.4	7
AAC-Output	2	1.9	0	0	2
Eye Contact	18	17.3	46	20.9	64
Gesture	2	1.9	8	3.6	10
Sign	0	0	3	1.4	3
Facial Expression	2	1.9	1	0.5	3
Env. Reference	1	1.0	19	8.6	20
Shared Attention	75	72.1	75	34.1	150
Neutral	12	N/A	12	N/A	24
Not Possible to Code	5	N/A	0	N/A	5
Total	121		232		353
Total Comm. Acts	104	32.10%	220	67.90%	324

Figure 1 Table indicating frequency and proportional use of each communication modality used, total number and proportion of communicative acts for each participant

ensured that both participants became more relaxed in the research environment prior to starting the tasks and also limited reactivity to the video cameras being used to capture data.

Two video cameras were used for the data collection: one camera to capture both the AS and the NS from the front, and a second camera to capture the AS's device screen and a more accurate picture of the NS face. A digital voice recorder was also used to ensure a high quality of audio recording.

The narrative task was used to elicit a fictional narrative construction from the AS. For this task the NS presented the AS with a picture book positioning it to ensure both participants could see it. For this pilot study the book to be used was 'The Squirrel Story', from the Black Sheep Press Narrative Assessment, as this is a well known stimulus in speech and language therapy Practice. The NS then asked the AS to tell the story shown by the pictures.

Once the AS appeared to have finished her narrative the NS asked "is that everything?" before assuming the AS had finished to ensure she was happy with the narrative she had produced. Once the task had been completed the recording equipment was switched off and both participants were thanked for their participation.

ANALYSIS

The informal conversation and brief introduction of the task were deleted from final analysis to limit the effect of camera reactivity on the findings. All verbal and non verbal acts recorded were transcribed into standard orthography in accordance with the conventions from Johnson (1995) and Walsh (2006). Transcripts were used alongside video capture to improve accuracy of coding each interaction

Two levels of coding were carried out on the transcribed data. Firstly, modality of communication was coded by using momentary time sampling (MTS): see Figure 1. MTS is a systematic observation method in which it is recorded whether a target behaviour is happening at the end of a specified interval. This was done by superimposing bleeps onto each recording at 10 second intervals. The researcher then coded the communication modality in use at each bleep (Brulle & Repp, 1984). Once coded, this data was used to yield the proportions for modalities used and to provide comparisons between usage by NS and AS.

The second coding structure used was the Human Communication Research Centre Move Category Codes (Based on Carletta et al, 1997). This structure codes the purpose of each communicative move taken by the participants. This provides a breakdown of the role of the NS and AS within the interaction. This structure was developed for the analysis of an instructional task interaction, and therefore required some alteration for the narrative interactions being investigated.

Throughout the initial data coding it was apparent that several linguistic moves were being neglected by the HCRC structure in use. This led to adjustments to the coding structure to which codes for narration, choice, praise, comments and response to an instruction were added.

A reliability study was completed on both of the above coding structures in which 30% of the data was coded by the primary supervisor. A Cohen's Kappa Coefficient was completed to test inter-rater reliability. Communication modality coding structure produced a good reliability rating (K= 0.73) according to Fleiss (1981) interpretation. The linguistic move types produced a K value of K= 0.55 showing a fair level of reliability (Fleiss, 1981).

FINDINGS

Through the range of outcome measures in use, the findings from the pilot present an overview of the fictional narrative interaction between an AS and NS.

Communication Modality

It was evident from the data coded that there were some distinct differences in the frequencies of communication modalities used and the number of communicative acts completed between the NS and AS (Fig. 1). For example, eye contact is shown to be important in the interaction, however the NS appears to use this considerably more than the AS (NS=46 AS=18).

This raw data was analysed to provide the proportion of total communication acts for the AS and NS expressed as a percentage (Fig. 1). This demonstrates the well documented tendency for the AS to take a passive role as the NS holds 67.9% of the total communicative acts. These proportions highlight shared attention as a very important aspect of communication between AS and NS with this holding the highest proportion of communicative acts for both participants.

Linguistic Moves

As above, some distinct differences were shown by the coding of linguistic moves produced by the NS and AS (see Figure 2).

For example, the majority of the NS moves come from acknowledgements (79) and yes/no questions (59) whereas the AS predominantly produces positive

Move	AS1	NS1
Ready	0	1
Instruct	0	28
Explain	0	39
Check	0	36
Align	0	5
Query-Y/N	0	59
Query-W	0	29
Choice	0	23
Acknowledge	1	79
Object	0	5
Reply-Y	30	0
Reply-N	15	0
Reply-W	0	0
Reply-I	14	0
Clarify	0	0
Comment	0	5
Narrate	22	0
Praise	0	24
Total Prep	0	0
Total Initiation	0	219
Total Response	82	108
Total	82	327
Total % of moves	20.0	80.0

Figure 2 Table showing the frequency of linguistic move types used and total moves for each participant

response moves. Again this measure also demonstrated the dominance of the NS as they took 80% of the linguistic moves made. The AS made no initiations during the narrative task, and responded principally to yes/no questions or choices given by the NS.

The findings from this pilot study lend support for the methodology to be used in the main study. Findings have shown that despite this being a narrative interaction, in which some initiation from the AS may be expected, the interaction demonstrates the NS dominance shown in past studies of conversational interaction. The findings also demonstrate the multi-modal nature of AS/NS interaction with both participants demonstrating use of a wide range of communication modalities. Overall the findings indicate an interesting detailed observation of narrative interaction that has not been explored previously.

CONCLUSION

As a result of the pilot study, two new linguistic move codes; narrative summary and response to a choice question, were added to the coding framework. Sequential analysis will also be completed on linguistic moves from full study data. This will provide more detailed exploration of how the interaction takes place and how moves may be modified or simplified in relation to the response received. Finally, better definitions of the codes will be produced to improve inter-rater reliability when this is re-tested on the full study data. ✱

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Speech & Language Therapist & PhD Student

Dr Karen Bunning
Speech & Language Therapist & Reader

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JASON TUTIN
Leeds Library and Information Service, Leeds City Council
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In 2008, the mother of a young boy with autism went into her local library in Leeds to ask if the library service could buy Boardmaker symbol software to support her son's communication needs. In response, Leeds Library and Information Service revolutionised the services and support we offer to families who have children with Autistic Spectrum Disorders (ASD).

Leeds libraries have:

- Provided autism awareness training to library staff
- Installed Boardmaker software in 25 libraries across Leeds
- Trained Librarians to use the software so that they can train families
- Introduced an ongoing programme of monthly advice sessions for parents of children with ASD, delivered in partnership with a team of specialist autism teachers.

Parents of children with ASD are now coming into Leeds libraries to:

- Learn how to use Boardmaker software to print their own symbols
- Meet autism professionals for advice about their child's behaviour and communication needs
- Share their problems and solutions with other parents in a mutually supportive group.

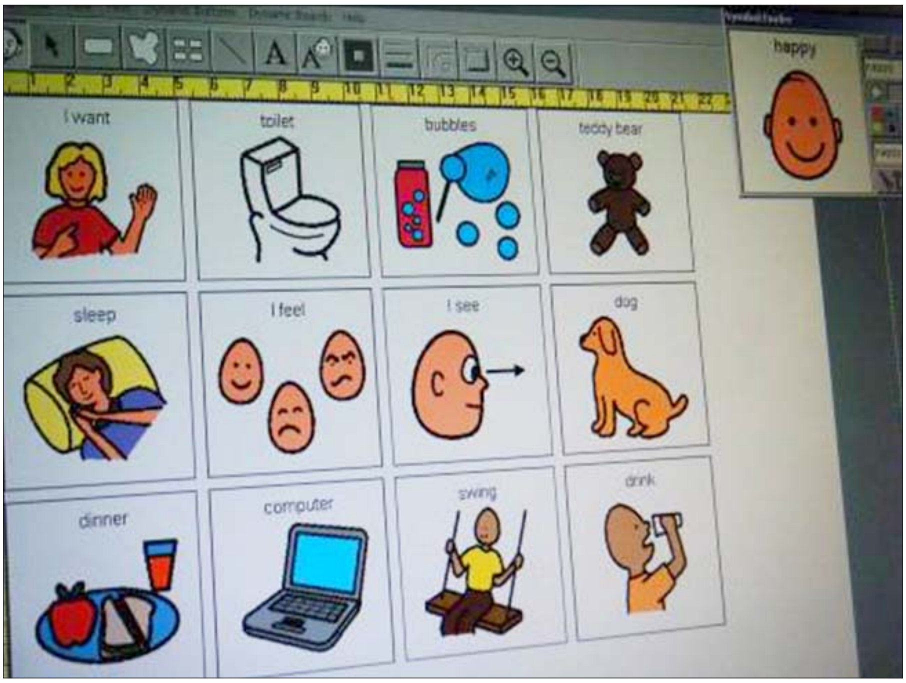
BACKGROUND

The parent who made the original request has a son who has autism and is non-verbal. He uses symbols at school and brings home the symbols on his communication board. Because his mum didn't have access to Boardmaker software to create more symbols, she was finding it hard to support her child's development.

If you are relying on symbols to communicate you need access to new symbols all the time, as children have new experiences or learn new things or just to replace symbols that wear out or go missing.

Most of the families we work with use printed symbols that have been laminated, cut out and stuck up around the house or stuck onto personal communication boards that children can carry around with them.

In Leeds, Boardmaker is used by teachers, speech and language therapists and



other professionals to create symbols that they use with children and families.

All of the special schools in Leeds are known as SILCs (Specialist Inclusive Learning Centres). STARS is the Specialist Teachers Autism Response Service, a city-wide outreach service provided by Education Leeds for students with a diagnosis of Autism. The Leeds NHS Speech and Language Therapy Service provides a named Speech and Language Therapist (SLT) to all educational settings from pre-school to mainstream and SILC settings.

Throughout this project we have worked closely with the STARS team and the Specialist SLT and Clinical Lead for the SILCs SLT Service in Leeds. These partnerships have added value to the project and enabled Leeds library service to do much more than offer Boardmaker software.

IMPLEMENTATION

Before deciding how to respond to the parent's request, Leeds Library and Information Service had to answer two questions: Could we afford to do it, and how many other families might benefit?

We knew we could afford it because we had some external funding from UK Online centres to deliver a project that would demonstrate the social impact of computers and ICT. The second question was more difficult to answer because we didn't know how many other families might benefit from the project.

To find out, Leeds Libraries' Learning Coordinator had meetings with the STARS specialist autism teachers team and the speech and language therapy service. They told us all about Boardmaker, how they use it to support children with communication difficulties, how it's used in SILCs and therapy settings across Leeds and how the idea to make it available in libraries had the potential to benefit hundreds of families. We all saw the likely benefits at that very first meeting and we agreed to work together to make it happen. Once the library service had partners from the Education service and the NHS on board, the project really started to take off.

We knew that Leeds Library staff would be able to support people using Boardmaker software in libraries if they had the relevant training. Librarians deliver thousands of ICT learning sessions in Leeds Libraries every year and showing people how to use Boardmaker would fit right into that programme of sessions.

Training was delivered by representatives from Dynavox Mayer-Johnson (the company that makes Boardmaker).

However, as well as attaining the necessary technical skills, we also wanted staff in Leeds Libraries to learn more about autism, about the needs of the families who would be using Boardmaker, and about visual communication.

To address those needs our partners delivered a training session for our Librarians. The training looked at the impact of autism, showed our staff some of the main features of visual support, discussed who would use symbols and examined some of the benefits.

A shorter version of this training was delivered to other staff in the libraries that would be getting Boardmaker. Those staff wouldn't be sitting with parents to show them how to use it, but we still wanted them to have an awareness of the issues.

As we worked with the teachers and SLTs, our partnerships developed. And as we worked with parents and listened to what they wanted, the project developed. We quickly realised that we could be doing much more than simply offering Boardmaker software.

DEVELOPMENT

Our most important development was to introduce monthly autism advice sessions. Parents told us they wanted somewhere to get together, meet other parents, share experiences, get professional help and advice – but they wanted it to be informal. They didn't want to commit to joining a 'support group' and feel under pressure to attend if they didn't want to. They just wanted to know there was somewhere like that available if they needed it.

Now, sessions are held at Leeds Central Library every month during term time. Sessions last for two hours on a Friday morning, usually the first Friday in the month.

Sessions run on a drop-in basis and they're very informal. Parents can just have a drink and a biscuit and look at the books, leaflets and information that's provided by Leeds ABC parent support group; they can talk to the STARS team to get professional help and advice about their personal situation; they can meet and chat to other parents who also have children with autism; or

talk to library staff to learn how to use Boardmaker and get help creating symbols.

As the project has developed Leeds Libraries have bought over 70 copies of Boardmaker and installed it in 25 libraries.

We have also bought laminating equipment to go into each library that has the software. We have bought a collection of books about Autistic Spectrum Disorders and Makaton resources that our partners recommended. We have designed and printed a Boardmaker booklet to advertise the service.

But if we hadn't had the original external funding available to us, we could have bought just one copy of Boardmaker and made it available on one PC in our central library. It may not have had as much impact, but I think it would still have been worth doing.

EVALUATION

- Librarians have delivered Boardmaker learning sessions to over 200 people including parents and carers, teachers and school support staff, Children's Centre staff, social workers, clinical psychologists and speech and language therapists .
- In the 12 months to the end of March 2010, Boardmaker in Leeds Libraries was used 641 times for 177 hours. In the three months from April – June 2010 it had already been used 243 times for 112 hours.
- On the library PCs where it is installed, Boardmaker is often the third most popular application after Internet Explorer and Microsoft Word.
- As a result of using Boardmaker in libraries, more schools in Leeds have purchased Boardmaker software so that even more children with specific needs will benefit.
- Parents, STARS team and library staff have found the monthly advice sessions extremely rewarding. As well as families already known to the STARS team, parents of children who have not yet received their diagnoses are coming to the sessions for guidance and support.

IMPACT

The impact of the project is illustrated by these comments from parents:

“Without the symbols, he just doesn't even make the effort to speak… For me and him, in our little world, pictures are fantastic.”

How the project has changed lives for families of children with ASD	How the project has improved the service offered to this user group
Families know that ASD and associated communication and behavioural issues are more widely understood and accepted by library staff. Families find friendly and understanding library staff who can give them practical help.	Autism awareness training for library staff, designed and delivered by experts in autism and communication.
Families do not have to travel across the city to access Boardmaker. The software is freely available in the communities that will most benefit from it.	Successful roll-out of Boardmaker software to 25 libraries in Leeds, with partners identifying areas of the city with the highest levels of need.
Families are no longer faced with a long wait for new symbols. The wide availability of Boardmaker across the city makes it much easier for professionals to access the software in between visits to families. This cuts down on travelling time and gives a more responsive service to families. Parents are also signposted to the library learning sessions where they can learn how to use Boardmaker for themselves.	Speech and Language Therapists and the STARS team use Boardmaker software to produce resources for picture communication and symbol support materials. Much of their work involves travelling around Leeds to visit families at home or at different community venues. As a result of this project, those teams of staff now have access to Boardmaker software in libraries when they are away from their offices.
Families come to advice sessions at an informal, accessible venue in the centre of Leeds. Sessions are run on a drop-in basis so parents are under no pressure to attend. Families can use the sessions to get professional advice from STARS, print and laminate their own symbols with the help of library staff, build up a network of contacts and share ideas with other parents, get information from the Leeds ABC group, or just relax and have a coffee and a chat in a supportive atmosphere.	Leeds Central Library hosts monthly advice sessions for parents of children with ASD. These sessions are run jointly by library staff and the STARS team. Library staff help parents use Boardmaker to design and print visual resources. STARS team advise parents on issues relating to individual children and young people and their specific needs. Library staff across the city can refer parents to these sessions if a parent comes into a library with specific questions or concerns about their child's behaviour or their family's situation.
Families do not have to be current or regular library users to hear about the services available to them in Leeds Libraries.	The whole range of services that Leeds Libraries now offer to families with children with ASD is being publicised by the SLT service, the STARS team and Leeds ABC group to other professionals and to parents.

“The symbols give Christopher some control and they give him a voice. He can say what he wants to happen. In terms of his confidence, he's much happier now. I'm building up the number of symbols that I've got at home by coming to the library.”

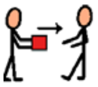
“I honestly don't know what I would have done without this service, I really don't. It just felt like, in this world where you have to fight for everything, somebody cared.”

CONCLUSION

Our experience with the Across the Board project has taught us some really valuable lessons about engaging with a new community. Those lessons could be summarised as:

Listen to what the community is telling you.

Respond positively to requests.



Give people what they want.

It's not always easy to achieve that but Leeds Library and Information Service has tried to do it at every step of the way with this project.

For more information about the project, visit *www.leeds.gov.uk/boardmaker* ✱

Jason Tutin
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AAC and Autism

How are people really using voice output communication aids?

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INTRODUCTION

The benefits and application of Augmentative and Alternative (AAC) for children and young adults with autistic spectrum disorders (ASD) has been, and continues to be, widely discussed and debated. Many of these children and young adults will not develop or use functional speech, leading professionals and care givers to consider AAC approaches to support communication. Although low-tech graphic AAC approaches such as the Picture Exchange Communication System (PECS) are widely used for this population, the benefits of high-tech approaches have received mixed reviews.

One common argument in relation to individuals with ASD using high-tech AAC is that the social interaction and communication difficulties inherent with this population severely inhibits their abilities to use such devices functionally. Goldman (2002) supports this view, believing that learning about communication and interaction would not be greatly aided by the use of high-technology AAC systems. Mirenda (2008) challenges this, arguing that children on the autistic spectrum are rarely provided with flexible, generative, AAC systems that can support long-term language development because of the restrictive assumptions made by professionals about the communication and learning abilities of people with autism.

This presentation made at the Communication Matters National Symposium in September 2010 used case studies to illustrate and attempt to pinpoint how four individuals with ASD are functionally using voice output communication aids (VOCAs) above and beyond making requests. Requesting a desired action or object is a communicative function known to be often used by individuals with ASD and found to be as frequent and successful whether using a low-tech AAC system (PECS) or voice output device (Sigafoos et al 2009). What Sigafoos (2009) also concluded was that while both were equally used for requests, neither promoted social interaction and it was this that was explored through these case studies.

Light's (2003) framework of AAC competencies (operational, linguistic, social and strategic) was used as a structure to evaluate how the individuals chosen for the case studies used their VOCAs with specific focus on social and strategic competencies, as it was assumed that it would be in these areas that the individuals would experience most difficulty. A comparison of use of low-tech systems was also made, to demonstrate any benefit of the use of high-tech systems.

CASE STUDIES

The subjects of the case studies all have a diagnosis of ASD and attend specialist educational provisions for students with ASD. They are all between 16 and 19 years of age and all had experience of using low-tech AAC systems prior to using VOCAs.

Questionnaires and interviews with supporting speech and language therapists, teachers and families were used to gain the required information, including information about the individuals and their past use of AAC systems. They were also used to elicit descriptions of the individuals' use of low- and high-tech AAC systems in relation to the range of communication functions as follows: shows a social interest in others, expresses emotion (positive and negative), communicates messages to control others (stop, go, more, don't...), shares information (past events, personal info...), expresses preferences, comments, greets others, initiates interaction, takes turns in conversation, closes conversation, asks questions, makes requests and rejects / refuses. Problem solving (strategic skills) abilities were also discussed along with issues such as changing communication mode dependent on communication partner, employing strategies such as description, initial letter identification or explanation if required vocabulary was not present, and correcting mistakes and communication breakdowns. Again these issues were discussed in relation to both low- and high-tech systems.

- **David** had used low-tech AAC systems from age 4 to 15 years and was extremely reliant on prompting when using these. He has a reliable yes/no response, however use of this as a communication strategy relies entirely on his communication partner asking him the right question. David could become extremely frustrated at times and consequently alternative AAC systems were investigated. David used a Go Talk 20 from Sept 2007. He used this well, with a greatly reduced need for prompting and quickly outgrew the vocabulary available. He then used the Grid 2 software on a laptop in the school and home environments. David has had a personal VOCA using the Grid 2 since Sept 2008.
- **Christopher** had used low-tech symbol exchange for a number of years. He was reported to be unclear on occasions with symbol exchange and unable to self correct if he selects an incorrect symbol. Christopher used some signs, especially within the home environment. Expansion of his sign vocabulary was difficult and Christopher often imitated rather than using them in spontaneous initiation. Christopher found using low-tech symbol exchange difficult with new communication partners and in new environments. Christopher began to use a Proxtalker in May 2010 at home and school.
- **Darren** has used low-tech symbol exchange for a number of years. He has used this successfully with familiar communication partners, however remains reliant on an outstretched hand from his communication partner as a prompt to exchange. This often results in a breakdown of communication and

increased anxiety. Darren also uses gesture and facial expression to support his communication, but these are extremely subtle and can be easily missed, especially by unfamiliar communication partners. Darren therefore did not have a successful, reliable communication system and his behaviour could be challenging as a result. Darren was provided with a Proxtalker in March 2010.

Luke used natural gestures, facial expression, signing and symbol exchange as his communication strategies for a number of years. Luke used a TechSpeak 32, but quickly outgrew this and moved on to using a laptop with communication software successfully in school. Luke has had a personal VOCA using the Grid 2 software since February 2009.

RESULTS

Christopher – Although reports of Christopher's use of the Proxtalker were good, the range of communicative functions Christopher used the VOCA for were not increased. Christopher continued to use the VOCA to make requests, as he did with his low tech symbol exchange. However the clarity of his requests and the range of people Christopher interacted with did increase.

Christopher has increasingly used the system to interact with peers who can easily understand the voice output of the system. Christopher does not cope well in new situations and his support team are hopeful the VOCA will help with this. It is also reported that the number of successful requests made by Christopher at school and home has increased.

See the tables for David, Darren & Luke.

STRATEGIC COMPETENCY

This remained a difficult area for all four participants. Acquiring problem solving skills involves an awareness of the existence of the initial difficulty. Due to the inherent triad of impairments relating to the students' ASD diagnoses i.e. social relationships, social communication and social imagination, it can be hypothesised that knowledge of the communication partners needs and communication breakdown will be significantly impaired.

Students did demonstrate problem solving skills when a desired vocabulary item was not present. This is a very obvious problem to the person using the AAC system. Strategies that were employed in this case included self programming and spelling.

SUMMARY

It is important to note that these case studies are not entirely objective, but are based on informal observations and as such influenced by the opinions of those involved. However, some initial conclusions have been drawn.

The range of communicative functions used by the students increased in some cases. In particular David demonstrated a large increase in unprompted use of the system and an increase in the range of communicative functions used. Darren and Luke also demonstrated an increased use of communicative functions.

The main benefits to Christopher can be demonstrated on the Social Networks Profile (Blackstone, 2003) as his range of communication partners increased significantly. Additional benefits of voice output were also noted, namely an increase in self teaching of new vocabulary with unprompted exploration of the system evident in some cases. Also, a decreased dependency on prompts was noted.

The findings of these case studies are also comparable to those of Checkley (2006) who found high-tech VOCAs to be a promising communication support for children in curricular sessions.

FURTHER AREAS OF INVESTIGATION

Carrying out this case study work could be said to have raised more questions than answers, such as:

- Why does implementation of a voice output system have such a significant impact with some individuals with ASD and not others?
- Could a secondary impairment (e.g. dyspraxia) be a significant contributory factor to the communication impairment of some individuals with a primary diagnosis of ASD?

DAVID

Communicative Function	Prior to VOCA	With VOCA	Examples
Shows social interest in others	Occasionally smiles in response	Social conversations	Wide range of topics
Express emotion	Did exchange occasionally to show 'happy' 'sad' 'angry'	Large emotional vocab: 'frightened' 'excited' 'tired'	Home report this has greatly improved quality of life and has reduced anxiety
Directs others, e.g. 'go', 'more'	Inconsistent 'yes' and 'no', needs as forced alternatives	David uses page of 'messages'	Used to direct others e.g. 'go'
Shares information	Momentos from trips, no rich language	Lots of pages about events, David often programmed	Past events e.g. wedding, trips etc
Expresses preferences	In structured sessions	Spontaneous use of 'I like' pages	Start of self programming
Comments	No	Wide range of topics	
Greets others	Prompted sign	Spontaneous	Access to names
Initiates	No	Yes	Wide range of situations
Takes turns in conversations	1 - 2 turns, led by him	Wider vocab available	Increased conversational turns
Makes requests	Very dependent on prompts	Spontaneous	Began to cope better with refusal of requests as well!
Closes conversations	No	No	
Asks questions	No	Yes, questions page	Asks social questions
Rejects / refuses	Yes / no very confused	'yes' and 'no' on every page	This has vastly improved David's ability to answer these questions

DARREN

Communicative Function	Prior to VOCA	With VOCA	Examples
Shows social interest in others	Occasional subtle initiations	In response	Responds to simple questions
Express emotion	Physically	No	Difficult for Darren to understand
Directs others, e.g. 'go', 'more'	Physically	With Proxtalker	Tell others to 'go', directs others, indicates 'more'
Shares information	No	No	Aim at school
Expresses preferences	No	Will express likes and dislikes	In structured setting
Comments	No	No	
Greets others	Subtle wave	With Proxtalker	With natural prompt
Initiates	Very subtle	Will initiate requests	Responds to others greetings e.g. 'bye'
Takes turns in conversations	Responds to questions	Responds to questions	
Makes requests	Would make symbol strip but not exchange without physical prompt	Extremely successful	e.g. asked Dad for help to shave
Closes conversations	No	No	
Asks questions	No	No	
Rejects / refuses	physically	With Proxtalker	'no' symbol

LUKE

Communicative Function	Prior to VOCA	With VOCA	Examples
Shows social interest in others	Limited	Yes	Increased contact sought, not always with VOCA
Express emotion	Physical actions	Within constraints of ASD, increased signing of emotions	Says he is happy, doesn't like to say he is sad
Directs others, e.g. 'go', 'more'	Yes	Yes	Still through signing not VOCA
Shares information	No	Yes	In structured sessions
Expresses preferences	Through signing	Not with VOCA	Continues to use signing
Comments	No	No	
Greets others	Physical actions	In structured situations	Can be inappropriate outside of structured settings
Initiates	Yes	In structured situations	
Takes turns in conversations	No	Yes	Increased vocabulary available
Makes requests	Yes	In structured situations e.g. snack	Through signing and vocalisation spontaneously
Closes conversations	No	No	
Asks questions	No	In structured situations	Seeks reassurance
Rejects / refuses	Yes	Not with VOCA	Continued use of sign and vocalisation

Further, more formal, study would be beneficial in this area to give clinicians an indicator as to the potential impact of voice output AAC systems with students who have a diagnosis of ASD. ✱

Andrea McGuinness & Lisa Farrand

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The Pixon Project

Implementing an AAC Language Development Curriculum

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A blueprint, a plan, a defined long-range course of action! Do you have one when it comes to supporting language development with a student with complex communication needs?

In a survey (Van Tatenhove, 2006) of speech-language pathologists serving students within the public school setting, the following question was asked: How many of you have, in your school district, a documented plan for *systematically introducing core vocabulary* to students using any kind of augmentative and alternative communication system? Of the 157 speech-language pathologists who responded, not a single one was able to answer “yes” to that question, which leads to additional questions:

- Can elementary school speech-language therapists and educators be assured that, during the preschool years, specific vocabulary and language functions were introduced during the critical, formative language learning years?
- Can middle school speech-language therapists and educators be assured that the students they inherit, who have been using AAC strategies or devices for the past 2 to 5 years, have access to a core vocabulary they can use in their educational program?
- Is anyone making plans or keeping records of the language they introduce and teach to students using AAC strategies?

PURPOSE OF THE PIXON PROJECT

The Pixon Project was initiated by an international team of speech therapists and teachers to create a natural language development curriculum for students needing AAC. This mission was driven by 3 key beliefs:

1. Natural language acquisition is only possible when the student has access to 50 to 400 permanently available, high frequency, re-usable words and word variations.
2. To promote maximum independent language practice, the student needs a language-friendly AAC system.
3. Intervention teams are obliged to use AAC pictures with no-tech and lite-tech systems that maintain an “open door” to the full range of effective AAC speech generating devices available.

These beliefs drove the Pixon Project team to (1) create a curriculum based on core vocabulary, (2) design simple manual communication boards, and (3) develop single meaning pictures which coordinated with symbols on speech generating devices, specifically Minspeak® symbols.

THE PIXON PROJECT VOCABULARY & CURRICULUM

The curriculum developed is called the Pixon Language and Learning Activity Notebook (PLLAN) and includes 12 modules that systematically introduce core vocabulary. Each module focuses on a small set of words selected for a specific pragmatic function (e.g., requesting information). The 12 modules teach 150 core words.

Vocabulary was selected based on frequency of use data (Banajee, 2003; Marvin, 1994; Balandin, 1999; Hill, 2004; Fried-Oken, 1992; King, 1995; Light, 1999; Yorkston, 1990). The words targeted in the PLLAN promote growth from a single word utterance level to the production of 2, 3, and 4 word utterances and simple morphology.

The PLLAN is supported with materials developed for use in the classroom. These educational and environmental materials include a wall chart with removeable symbols, symbol props for initial symbol learning, posters for specific word groups, and descriptive labels (e.g., “go out” or “where go” posted on a door).

THE PIXON PROJECT MANUAL COMMUNICATION BOARDS

The Project provided students with manual communication boards to develop language skills prior to and/or in conjunction with the use of speech generating devices. By using manual boards, more students had access to communication without regard to financial issues.

Ten manual communication boards were developed: 7 boards for individuals using direct selection and seated in wheelchairs with laptrays; 2 boards for individuals using eye pointing or partner

Figure 1 Multiple Simultaneous design

assisted scanning; and 1 board for individuals who are ambulatory. Boards were designed based on the importance of motor automaticity in language production and the power of a single sheet design to facilitate independent generative language.

To promote motor automaticity, the 7 laptray-style boards were based on a long-range blueprint. The simplest board has 20 locations and the most robust board has 216 locations. The words stay in relatively the same location as the board "grows" from 20, to 30, 50, 77, 112, 198, and finally 216 locations. When the student "moves up," the student relies on motor automaticity to assist in retrieving vocabulary on the more robust board. A similar plan was used for the 2 boards (e.g., 75, 147) accessed via eye pointing or partner assisted scanning.

To facilitate "ease" in language production, boards for core vocabulary were designed, whenever possible, with a single sheet design. Single sheet designs provide the core vocabulary "at-a-glance." Historically, this design is the most "language-friendly" and effective design for independent language generation (Vicker, 1974). As an alternative strategy, a multiple simultaneous design was used for the portable Pixon board with a cloth carrying case that opens up with different two-sided pages of words (Figure 1).

To provide extended vocabulary, multiple sequential displays (e.g., flip charts) were created. This vocabulary is presented in single, tabbed rows and placed at the top of the core vocabulary board (Figure 2).

THE PIXON PICTURE SET

All vocabulary is represented with a new picture system, called Pixons. Each Pixon picture is based on common metaphors used in current AAC single meaning pictures and the icon sequence used in the Unity® vocabulary program from the Prentke Romich Company (2009). Examples are shown in Figure 3.

To date, over 500 Pixons have been drawn for core vocabulary words and approximately 2000 for extended vocabulary. Pixons are available on a CD importing into authoring software to support custom–ization of Pixon boards and to create additional boards and materials.

IMPLEMENTATION IN THE CLASSROOM

Currently, teachers and therapists in the USA, Australia, Singapore, China, South Africa, Canada, and the UK are using Pixons and Pixon-based boards and educational materials. The teachers involved in the Project organized "core vocabulary classrooms." Based on typical classroom routines (e.g. morning circle time, reading, music), specific core words and pragmatic functions were targeted for use during these activities, creating opportunities throughout the school day to use as many core words as possible.

The Pixon Language and Learning Activity Notebook contains instructions and guidelines to help teachers teach core vocabulary and language development. For example, in order to focus on specific target words, selective visual masking of a Pixon board was recommended. Use of the wall chart with re-moveable Pixon pictures was another recommended strategy to limit choices to students or to help students build simple sentences by moving around the Pixon pictures during language activities.

TALKING PIXON BOARDS

Teachers implementing the Pixon Project within their classrooms wanted "to make the Pixons talk," therefore, they provided speech output using available classroom technology and inexpensive digital voice output devices. They wanted speech output (1) while providing aided language stimulation (ALgS) during classroom lessons; (2) for improved interaction with nonreading peers and untrained communication partners; and (3) for distance communication.

Initially, teachers suggested strategies historically used in their classrooms, such as single and/or sequential mes-

Figure 2 Single Sheet Design with Multiple Sequence Design at the top

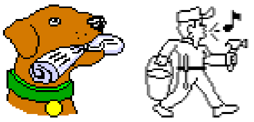
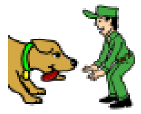
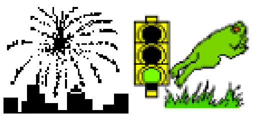
Word	Unity Icon Sequence	Pixon Picture
come		
all gone		
busy		

Figure 3 Examples of Pixon Pictures

sage devices. This strategy was adequate for pre-developed sentences and routines; however, it was not a viable speech output solution for long-term language development. Instead, teachers used interactive whiteboards during group lessons for ALgS and for peers to interact with students using the Pixon boards. Using this technology with the Pixon boards supported language development outcomes for all students.

A second strategy used was the Talk To Me100™ (Birr, 2009). This device provides digital voice output using 100 locations with pre-recorded single word, core vocabulary. The vocabulary and layout of the pre-recorded words did not match the students' Pixon boards, therefore, Pixon-based overlays were made for the device. Several teachers, in order to maintain motor automaticity, re-arranged the vocabulary on the students' Pixon communication boards to match the layout on the TalkToMe100™.

PIXON PROJECT OUTCOMES

The Pixon Project lasted approximately 2 years, with field-testing in multiple classrooms. At the start, 18 students were randomly selected to track specific language outcomes. Language samples were taken with each student to determine words used spontaneously and appropriately, based on the context of the situation. As seen in the table below (Figure 4), all students made significant gains in vocabulary acquisition over an 18-month period of intervention.

After 3 months, 14 of 18 students were using 1-word utterances only. The remaining 4 students were producing some initial 2-word utterances spontaneously. After 18 months of intervention, 11 of 18 students were producing 3+ word utterances, 4 of 18 were consistently producing 2-word utterances, and the remaining 3 students continued to produce primarily 1-word utterances.

Teachers reported that the student were becoming more active and independent communicators, including those students using eye pointing and/or partner assisted scanning. The factors which the teachers felt contributed the most to their students' successes were: (1) the consistent focus on core vocabulary; (2) the use of ALgS by all communication partners; and (3) the involvement of the entire school team in the targeted use of core vocabulary.

Subject	Type of Board on 1 Aug 2007	Average no. words used in spontaneous & appropriate way after 3 months instruction	Type of Board on 31 Jan 2009	Average no. words used in spontaneous & appropriate way after 18 months instruction
1	10 location	3	30 location	19
2	10 location	6	30 location	21
3	10 location	9	50 location	34
4	30 location	11	50 location	41
5	50 location	19	112 location	76
6	50 location	24	198 location	128
7	50 location	31	198 location	119
8	50 location	21	198 location	139
9	50 location	29	198 location	149
10	77 location	31	198 location	148
11	112 location	42	198 location	151
12	16 location	9	32 location	25
13	32 location	11	77 location	51
14	77 location	18	77 location	66
15	50 location	20	100 location	82
16	100 location	19	150 location	110
17	150 location	22	150 location	128
18	150 location	31	150 location	132

Figure 4 Table showing gains in vocabulary acquisition over an 18-month period

TRANSITION TO TECHNOLOGY

Of the 18 students tracked in the Project, 6 made transitions to a speech generating device. Each student made a transition to a Minspeak® device (e.g., ECO, Vantage Lite, Vanguard) using the Unity®60 or Unity®84 location program. In 4 to 8 hours of training, the students were communicating the same words and language structures using their AAC devices that they could communicate with their Pixon boards. While they are now using personal speech generating devices as primary communication systems, they are all multi-modal communicators and continue to use their Pixon boards as back-up systems. Consensus of the intervention teams was that use of the simple Pixon manual boards helped build linguistic competence, while use of the Pixon pictures promoted future use of Minspeak® and a smooth and easy transition to the Unity program.

AVAILABILITY & FUTURE DIRECTIONS

Phase One of the Pixon Project was completed in 2009 and the materials developed into a commercial product, called the Pixon™ Project Kit. This Kit is available through Liberator, Ltd. in the United Kingdom and Australia and through Prentke Romich Company in the United States. Work is ongoing in the Project to develop additional Pixon pictures, manual communication boards and educational support materials. Collaborative work is being done to use Pixons with other commercially available manual communication board developers and manufacturers of speech generating devices. ✱

Gail M. Van Tatenhove

ACKNOWLEDGEMENT

The Pixon Project team thanks Semantic Compaction Systems, Pittsburgh, USA for its generous and on-going support of this Project.

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- ‘Just On’ mode for instant startup
- The Grid 2 Included
- Protective Carry Case
- Built-in Wi-Fi and SIM Card slot

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