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Communication Matters / ISAAC (UK)
Leeds Innovation Centre, 103 Clarendon Road,
Leeds LS2 9DF, UK
Tel & Fax: 0845 456 8211
Email: admin@communicationmatters.org.uk
Website: www.communicationmatters.org.uk
Registered Charity No. 327500
Company Registered in England & Wales No. 01965474

Editors

Sally Millar Email: sally.millar@ed.ac.uk
Patrick Poon Email: admin@communicationmatters.org.uk

Design & Production

Patrick Poon & Peter Head

Advertising and Overseas Subscriptions

Tel & Fax: 0845 456 8211
Email: admin@communicationmatters.org.uk

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Putting the Unspoken Centre Stage

KATE CARYER

The Unspoken Project www.unspokenprojectaac.com

Email: kate.unspoken@gmail.com

“All the world’s a stage, And all the men and women merely players; They have their exits and their entrances.”

Ok Shakespeare, so if ‘All the world’s a stage’, where are the people like me, AAC users, on the stage? As both a life long theatre lover and an AAC user I have thought about this question a lot, the question being, “Are there any theatre shows featuring AAC users?” The answer is, well, kind of - yes and no! If we make our question wider to include film and television plays our answer gets more interesting. The most obvious recent film is the Theory of Everything, the Stephen Hawking movie that is presently smashing both box office and awards.

There are a few plays about people without speech. Two examples are ‘A Day in the Death of Jo Egg’ written by Peter Nichols in 1967 and ‘Brimstone and Treacle’ a television play written by Dennis Potter in 1976 but not transmitted until 1987. (The latter is definitely not for the faint hearted). Both of these are very interesting plays but, because of the time in which they were written, AAC doesn’t feature. Jo Egg is more like a theatrical device for her parents to play their relationship through rather than a character with her own voice in her own right. I have seen this device in more modern plays where the character without speech is stripped down to be a kind of non character sometimes being only represented by an empty wheelchair on stage. As far as I am aware, there are no plays produced, devised or written by an AAC user.

I feel it is time AAC users tell their own stories on the stage. The whole raison d’être of the Unspoken project is to develop positive imagery of disabled people,



especially AAC users. We believe this is important because good, accurate images of AAC will go some way towards increasing greater understanding of AAC and the people who use it. I researched and spoke about representation in 2013 at the Communication Matters conference. In that, it became really clear that good representation in the media is massively important, but is somewhat lacking at the moment for us AAC users. I would argue that good representation could change negative attitudes, while dodgy representation can increase ignorance.

Such ignorance I found was alive and kicking when I went to do my second stretch of continuity announcing for Channel 4. This time I was not filmed and the great British public was only given the sound of my voice. But TV viewers found my

voice too much. I mean, what’s the matter with my voice? Actually, don’t answer that. The delightful members of the telly watching public who, unfortunately, have twitter accounts, generously gave me over fifty pages of tweets about my voice! Most of them very rudely complaining about the ‘robot voice’. So I felt the only thing to do was to laugh at the ridiculous nature of the tweets. We believe they show the level of ignorance that some parts of society have towards AAC.

For many people who have severe speech impairments, their life sadly involves having no access to the communication aids that they need, as reported in the Communication Matters major research findings, *Shining a Light on AAC*, published in 2013. A good dramatic story could be made of a person getting access

to the right communication and finding their voice.

Unspoken's main and initial aim was to put on a play telling the story of a young woman getting her communication aid and in turn finding her voice. I really wanted to work with other communication aid users and actors to tell this story. With a bit of help from my friends I began to think my dream would come to life when we started working together.

I have always found theatre people particularly accepting of disabled people with just the right attitude, which, sad to say, I do not always find in people who should know better, such as those working in education or, dare I say it, health, including speech therapists (but not AAC specialists of course!). Serendipity saw me finding my partner in crime, Paul Mooney, a trained and experienced director/actor. As one of the organisers of 1Voice Southeast, I arranged a pantomime drama workshop for the kids and Paul came along to run it. After being told to 'assume competence' with the children, he totally 'got it' and spoke to and joked with the participants and ran a fabulous workshop where everyone had a part to play. I was so impressed, I told him about my ideas and asked him to get involved.

So the Unspoken Project was born. Soon it became apparent that we would like to do other work besides our main play, such as running workshops in the community using performing arts to explore communication issues. When we became a community interest company on the 14th August we had to set out our activities and aims. I thought it would be good to share these with you, so you know what we are trying to do.

In case you don't know, a community interest company is a form of organisation that is set up to benefit a community. Community can mean certain groups of people such as people with impairments, old people, young unemployed people, or people who live in a certain area.

We decided to become a community interest company because we would be able to apply for grants, and becoming a charity was not for us at all. This quote from another community interest company summed up our feelings very well:

"I am for disabled rights not charity. I don't want people to be giving money because they feel sorry for disabled people."

So we became a community interest company. For this we must define our community, which is people with speech impairments who may use assistive technology to communicate, and our aims which are to create innovative, thought provoking, creative pieces from their ideas

and personal experiences, whilst striving for artistic excellence. The community will benefit by participating in the activities of the company and using its performances and workshops as a starting point for opening up debate and for the sharing of ideas and knowledge around communication issues, and will benefit from having positive images of disabled people promoted through inclusive practices.

So, that is what we were trying to do and this is what we have done.

In addition to applying for grants, we found we needed to raise funds to produce the play. So Unspoken Outspoken Nights were born! The Unspoken Outspoken nights were primarily set up as inclusive variety nights which aimed to make money for the project. However they became a roaring success in their own right. These three events were enjoyed by a growing audience and they saw AAC users joining the cast and our regular audience. An important theme for these nights and our wider project is communication in the widest sense and the importance of our voices. We also used these nights to try and develop our own work linked or not to our main play. This let us create scenes and characters that push the limitations of communication aids and the perceptions of those using them.

Unspoken plans to use all kinds of media to get our message across. The video 'My Voice Is...' shows 12 communication aid users stating what is their voice and why is it important. (www.youtube.com/watch?v=iSiUuPxdXM4)

In March 2014, we ran a week of workshops with a company of professional actors and an AAC user to develop some of our characters and scenes. We are currently organizing a read through at Hackney Empire studio theatre with a cast of professional disabled and non-disabled actors to further develop the script of the play, which has now been renamed 'Speechless'.

Grant applications have had mixed results; some successful, some not but we are still grateful for donations from well-wishers (thank you Liberator Ltd!).

Watch this space! *

Kate Caryer

MORE INFORMATION

For more information please contact Kate Caryer or Paul Mooney at The Unspoken Project:

W: www.unspokenprojectaac.com

E: UnspokenProjectAAC@gmail.com

Facebook: www.facebook.com/UnspokenAAC

Twitter: www.twitter.com/UnspokenAAC

RESOURCES FOR AAC RESEARCH

Research Involvement Network

Communication Matters has set up the Research Involvement Network to encourage more people to take part in research into AAC and to help researchers find the participants they need. The Network is made up of people who use AAC, their families and carers, and professionals who work with people who use AAC.

If you are interested in participating in future AAC research projects visit the Research Involvement Network webpage (link below) for more information. We are particularly keen to recruit more people who use AAC and family members and carers.

Communication Matters welcomes applications from UK post-graduate researchers wishing to recruit participants to AAC research projects. Contact Communication Matters to discuss your project, email: rin@communicationmatters.org.uk
For more information, please visit: www.communicationmatters.org.uk/research

Single Case Study Template

As part of the Communication Matters AAC Evidence Base project, one of the collaborative partners (Manchester Metropolitan University) developed a single case study template. This template was developed to support the collection of consistent and relevant case data. It is intended to support more robust data collection.

If you would like to contribute to Communication Matters' ever growing case study database of submissions from people who use AAC, please download a copy of the participants information sheet about how to contribute by following the link below. Alternatively, you may wish to download a copy of the case study template for your own use.

For more information or to download case study template/resources, visit: www.communicationmatters.org.uk/research



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Empowerment and Living Independently

BETH MOULAM

www.bethmoulam.com

Email: bethmoulam@aol.com

At the CM2014 Conference I spoke about my first year at University and the experiences that led me to question if I was sufficiently prepared for the communication challenge of going it independently. This is a personal reflection of what I found in those 12 months, and what I wish I had known before I started. My aim is to make others (not just those going to university) wanting to live independently to think about these challenges and to anticipate what they might need to plan for.

As background, I went to mainstream playgroup and primary school. I started mainstream secondary school, but at 13 moved to a local authority boarding school in Kent. I need a power chair but use a walking frame in my home, I have a hearing impairment and use a Lightwriter.

To help me reflect on those first steps to independence I looked at the typical development milestones for all young adults: communication, social, learning, emotional and physical skills. I then broke these into the competencies expected of all young adults going off to university, but my focus here is on communication in relation to these. This is where I judged myself to be at the start.

The right to communicate is essential for us all. To be able to convey our needs, wants and desires. I knew I was a good functional communicator. I am very re-

sourceful in getting my message across. But I was also concerned. I would be meeting many new people, most of whom had no experience of people who use AAC, and who might not be patient with me.

Socially, everyone needs to be able to cooperate and collaborate with others. I felt this wouldn't be a problem having been at boarding school, and having my own support staff at weekends and in the holidays. The challenge would be making new people understand that I was no different to them. I was aware I would be completely reliant on a new team of personal assistants 24 hours a day.

Emotionally, all young adults need to be able to cope with change, to control impulses, manage anger and resolve conflict. I had had plenty of change in the past, and done a lot of planning for my move. I felt I could manage my emotions well and had rarely had to deal with conflict.

Going to uni means being able to learn at an appropriate level. I had the qualifications and a place to study Social Policy on the extended degree. However, coming from a special school I was worried I was not the most independent of learners. My concerns included the speed of my com-



munication, needing 1-1 academic support, my slow reading, and just generally that things take longer for me. However, I am ambitious and stubborn so I was determined to achieve.

Physically those leaving home need to be competent to look after themselves. I knew I was in good shape, that I could direct staff, and I was, and still am, an active sports woman. The communication challenge for my physical well being would be to meet and establish relationships with the university doctor, therapists and set up the physical programmes I needed.

In summary, I felt ready for the challenge. So how did it go?

Many students moving away from home experience challenges. Feeling homesick and alone, missing family and friends, needing suddenly to look after themselves, learning new ways of working, and having to make new friends. In addition to these normal student challenges I have had a few other things to contend with. I felt physically and mentally tired, completely frazzled. Not just from the new life style, but also having to direct a brand new team 24 hours a day.

Almost immediately I started university it was clear different people had different ideas about empowerment, independence and being independent. All three concepts have a common theme: of being in control and making your own decisions.

I've had to persevere. A huge challenge has been directing staff without the daily oversight of school or family. I need to show the way, guide and influence. This means trying to set an example in how I behave. I need to take charge, instruct and even when it's difficult, be successful. The starting point was making sure my new team understood I need to succeed, and based on the first year's experience, accept that I am in charge, even if I made mistakes.

Directing others is a skill. This doesn't mean I have to tell people every little thing I need; working with a personal assistant is a form of teamwork. If I need to do the same thing, at the same time every day, we can anticipate together what I want to do next, as it's what I always do, for example, bedtime routines. It's like being with a dance partner. While you learn the steps you are conscious of every movement, and check with each other. Once you are comfortable the dance unconsciously flows in a beautiful rhythm. Working as a team, with good staff who facilitate, and support my needs, means us both anticipating the flow of the routine, without constant decision making, questioning and discussion, especially when I'm tired.

In my humble opinion, I know now that asking for, and receiving help, is not easy. But learning to ask, and accepting support, does not make you a failure, because to me, being empowered and having independence is all about independent thought and control. This means understanding that by directing your support you save energy, not ending up exhausted all the time trying to do it alone. Save yourself for the important things.

I can easily, and often have, got things wrong. I've had literally hundreds of new and sometimes fantastic experiences, as well as some scary experiences that take me outside my comfort zone. These are not things I anticipated or planned for. I know now that I have limited leadership and management experience. Not many people aged 20 have the knowledge and skills to run a team, I was definitely learning on the job, and still am.

Since I was at school, when I need to raise an issue I often find myself writing an email, because it is less confrontational. We all know that tone of voice and AAC don't go together. When using AAC, being diplomatic is key. Using the right words is vital as I don't want to be seen as rude. Even my dysarthric natural speech can

sometimes make me seem abrupt. If I'm emotional, the pitch of my voice changes. This means I worry about upsetting my team as I need them on side.

There is research showing people with complex needs often smile at staff, and say Yes, when they would like to say No. Bob Segalman, who uses AAC, and lives in America has said, "saying 'no' is not something I usually do, possibly because of my exaggerated need to please people". I can identify with this. I need staff to want to be with me, so even if I am not happy I won't show it easily. It is sometimes easier to go with the flow than say No! I've found saying No or Don't means staff can feel threatened. In turn they might act inappropriately. It is funny that they can think I am uncooperative if I don't want to do things their way. Saying Yes does help keep people on side, but, we all have the right to choice. And, I could have planned better for how to handle difficult incidents like having a secret word to convey my anxiety to family, or how to get back up when things went wrong.

Because of my course, my team are all graduates, so they are older than me. They work hard, and sometimes saying Thank You is not enough. I heard about Carol Dwek, and her growth mindset, in relation to my sports coaching. I have found it easier to praise the process, rather than the outcome. Saying "I like it when you do that" gets better results than "well done" and makes us all feel good. Managing people means giving them positive and improvement feedback.

Having people around 24 hours a day is testing and exhausting. Sometimes I prefer to be alone, sometimes for my Personal Assistant to be companionable and just sit quietly. Getting the space I need means I had to learn to send staff to do a job, which is easier than telling them to go away.

I've had to learn to know when someone feels threatened or upset, and how they might show it non-verbally. I now know I need to raise an issue to avoid it escalating. I also needed to understand the difference between threatening behaviour, and someone who is enthusiastic, but unaware their actions invade my private space. There are protocols for working with someone disabled; knowing that making us look up, or standing over us, or leaning in too close can be intimidating unintentionally is an important part of staff training.

The first year reinforced the importance of employing great staff who want to be with me. It may be their job, but it is my life! Personality counts, we need to gel together. I need to live, love and laugh. There is the old saying that no one is an

island. Everyone needs a helping hand, I just need an army of them.

I ended the year with a good relationship with the course team and a great rapport with my academic support team. I had sadly left the academic teams to find out about me by assuming they would read my support plan. It is important they understand from day one it takes longer to communicate. I will never undervalue the importance now of good, clear protocols on what is needed.

For this year, I made a short film so staff could understand my communication needs before they met me - see it at: www.youtube.com/watch?v=9EHAKXHUeKY&feature=youtu.be Students moving to university have to change their GP. For most people it is just a case of signing up, then going in if they are under the weather. I've had a great relationship with my home GP surgery since I was born. To get new therapists I had to first register with the GP, then wait for referrals, some of which took months which resulted in me having to find other ways of doing things. The important thing was to have someone trusted (Mum ☺) to advocate for me in all those initial meetings and then sit on the phone chasing things up.

Relationships with other students have been really important. People need to get to know my communication and see me as an equal. I can't demand this, but I need people to understand why I need extra support in halls and around the campus. I learned it's hard for my flat mates having a stream of people in and out of the flat who are working for me. Also, my staff have to remember it's the other students' homes and not their workplace, a tricky balance.

On reflection, pre-uni I did hours and hours of planning with my family. We had lists of lists, and I know I couldn't have predicted everything. But we planned for things to work smoothly and go well. What we didn't plan for were situations going wrong. From the agency appointing staff without me meeting them, to communication breakdowns, to low expectations, delays getting health support and a couple of really stressful situations. Moving forward I know the importance of planning for the good, the bad and the ugly!

In hindsight, knowing how to manage people, being more assertive, dealing with stress, role playing potentially difficult situations and knowing how to deal with emergencies might have made life easier. But, I've survived with the support of some great individuals, including friends, the University Disability Support team and my parents. And, I know I'm stronger for it! *

Beth Moulam

A Right to Communicate: A short film

KIRSTY PATON, LOUISE BLACKLEY, JULIE MCCRACKEN & HELEN FLETCHER

NHS Dumfries and Galloway Speech & Language Therapy Services, Galloway Community Hospital, Dalrymple Street, Stranraer DG9 7EU, UK
Email: dumf-unb.speechlangtherapy@nhs.net

BACKGROUND

Dumfries and Galloway in south west Scotland is the third largest local authority region in Scotland covering an area of 6,426 km² with a population of around 150,000. The vast physical area is predominately rural with the majority of residents centred in the two main towns of Dumfries and Stranraer which lie 75 miles apart. Within the general population people who use high tech forms of Alternative and Augmentative Communication (AAC) are few in number and widely dispersed. As local Speech and Language Therapists (SLTs) it was our strong belief that this could contribute to low awareness and understanding of AAC amongst the wider community as well as potential social isolation for people who use AAC. An AAC users group was established by the Speech and Language Therapy service with support from CALL



Figure 1 Communication Friends Group Logo
designed and produced by group members

(Communication, Access, Literacy and Learning) Scotland in 2010: *The Communication Friends Group*.

This provided a forum allowing people to meet socially and practise their communication skills in a supported environment. The age range within the group is from 8 to 33 years. Within the group there is a wide variety of different AAC equipment and access methods used, reflecting the individual levels of communication ability. The group meets two to three times per year and is supported by local SLTs.

Historically, time had been spent compiling and delivering various training approaches for those supporting people who use AAC. Our challenge was to create a new, powerful tool that would raise awareness of AAC in general and the communication needs of people who use these systems. We also wanted to ensure that the voices heard in this new approach, would be those of the AAC users themselves rather than professionals.

We believed that a film would be a dynamic and immediate way to share basic messages about AAC and an exciting method that harnessed the power of social media in ways that traditional training sessions had not. We knew of another DVD which had been produced (Clarke 2008) showing young people using their



AAC and were keen to develop and possibly repeat this in Dumfries and Galloway. The Communication Friends Group presented us with an ideal body of AAC users able to share their own thoughts and experiences as part of this project.

AIMS

Our two main aims were to raise awareness within the general population regarding AAC and to describe good communication methods with people who use AAC. Many people within Dumfries and Galloway have limited opportunities to meet someone who uses AAC and when they do, they may not be aware of what they can do to better support communication.

We aimed to raise awareness at several levels:

- General population of Dumfries and Galloway
- Family members and support workers
- Peers of the people who use AAC
- SLTs within Dumfries and Galloway
- Education, NHS and Social Services staff

Raising awareness entails sharing key messages about an issue, simple enough to take away and use but profound enough to have an impact on those who receive the message. In promoting the voices of

the AAC users we aimed to make these messages as powerful, relevant and practical as possible.

When planning the structure and content the film, we considered the four parameters of communicative competence as described by Janice Light (Light 1998); in particular, we considered the element of 'social' competence, in terms of the impact communicative partners have on the success on interaction with people who are using AAC. With this in mind, we were keen to enable the young people in the Communication Friends Group to describe the best strategies for communicating with them.

METHODS

Funding from The Right to Speak guidance (Scottish Government, 2012) allowed us to finance our awareness raising film in Dumfries and Galloway. Equal Voices, an arts company who specialize in producing performances with an inclusive ethos were employed to facilitate this process.

All of the Communication Friends Group members were eager to take part and gave their consent to a wider distribution of the film including social media and YouTube. Initial collaboration with Equal Voices ensured that the group's messages could be conveyed accurately and easily within the film's format.



Figure 2 Onboard video recording

Speech and Language Therapists worked with individual AAC users to enable them to take part in question and answer sessions to be filmed on the day. This work included discussion around:

- advice for communicating with someone who uses AAC;
- how the individuals feel about their voice output devices;
- what their devices allow them to do;
- what limits using their devices;
- what helps them to use their devices.

This involved programming each person's device in advance of the day's filming so the appropriate language was available on the day.

The programme for the day's filming was devised by Equal Voices based on the specification provided by the Communi-

cation Friends Group and the SLTs involved.

On the day the group members were not merely "filmed" taking part in their interviews with each other. They took on many active roles within the production including, sound monitoring, contributing to the soundtrack, filming extra footage, directing and editing. Equal Voices then edited the footage, created the soundtrack from the group's contributions on the day, and finalised our 8 minute short film (youtu.be/fx338vnATIA).

Eighty DVD copies were produced which were then shared initially with the group members and their families. NHS Dumfries & Galloway uploaded the film to YouTube and individual SLTs shared it on their own social media accounts.

Press releases were made locally and nationally, including the May 2014 issue of the Royal College of Speech and Language Therapists Bulletin (www.rcslt.org/docs/bulletin/2014/may_2014). The short film was shown at four AAC open days run in conjunction with the two Scottish national centres, CALL Scotland and the Scottish Centre of Technology for the Communication Impaired (SCTCI). This information and awareness raising sessions were held in two locations in Dumfries and Galloway. They were attended by members of the public, professionals and people who use AAC.

The YouTube link for the short film - <http://youtu.be/fx338vnATIA> was publicised on NHS Dumfries and Galloway SLT service public web pages; Facebook and Twitter accounts and through AAC community contacts.

OUTCOMES

Immediate feedback from the young people who took part in the film was very positive. Following the film launch, two group members shared it with their peers to raise awareness and highlight their own communication needs. These sessions took place in a primary school and at an Adult Activity and Resource Centre.

The group member who attends school gained information about his classmates' awareness of AAC prior to showing the film by conducting a short survey. He then re-assessed this knowledge afterwards and was able to show that his peers' understanding and attitudes had changed positively as a result of watching the film. The group member who attends an Adult Activity and Resource Centre took a different approach, allowing his audience to experience using his eye gaze technology first hand following watching the film. This highlighted the concentration and physical effort needed for him to communicate, and helped his peers and support workers develop a deeper understanding of his communication needs.

The film has been used in training with various NHS Dumfries & Galloway staff groups to positive effect. Feedback received included comments such as:

"AAC seems to make more sense now."

Currently the short film has had nearly 3900 YouTube hits; comments received included:

"Wonderful video showcasing the value of AAC technology."

"Genuinely one of the most interesting and moving things I've watched in a long time."



Figure 3 Social media activity and feedback

Megan Hughes, a former AAC Project Coordinator for Dumfries and Galloway explains:

"Making the film gave the group members a platform to express how they feel about communication. But by uploading it to YouTube, we have opened up a whole new way of getting their message across to a much larger audience and we're all thrilled by its success."

Use of social media allowed yet further exposure, with re-tweets and sharing on webpages reaching an international audience. The film prompted enquiries about its use as a training resource with undergraduate SLTs. To this end, has now been supplied to Strathclyde University and the University of Ulster. Work is ongoing to extend this to other Higher Education Institutes which offer undergraduate SLT training.

The short film has been included on the newly launched AAC Scotland website (www.aacscotland.org.uk) hosted by CALL Scotland. Staff from the Scottish Centre of Technology for the Communication Impaired, (SCTCI) have signposted their service users to the short film as an awareness raising resource. As a result of this, the SLT service has now received requests for hard copies of the short film from other health board and local authority areas within Scotland. Due to demand, further copies of the film have now been produced for future distribution.

FUTURE PLANS

The film is freely accessible through YouTube link youtu.be/fx338vnATIA and therefore has the potential to be used by any group or organisation of people wishing to develop awareness and understanding about people who use AAC. The possibilities are abundant.

The short film could be shown within educational facilities. Educational or social care staff in schools or facilities where people currently use AAC, or may do so in the future are able to access the short film. It has the scope to be used in staff training (both professional and the third sector). New recruits to our services would benefit from watching the film as well as colleagues across the NHS. Friends, families and carers can also freely access this resource.

The film has the potential to be replicated in other areas with other AAC users who are keen to participate. Within Dumfries & Galloway there may be the opportunity to revisit the participants in the future and document how people using AAC change over time.

CONCLUSION

The Right to Communicate short film has helped promote awareness of AAC on

many levels. With the funding from the Right to Speak Scottish Government project it made it possible for us to produce a professional universal resource. The short film is a powerful and enduring resource freely accessible to anyone at any time. It has contributed to highlighting the awareness and understanding of AAC amongst the local community, as well as offering positive portrayals of people who use AAC, which is often lacking in traditional media, (Caryer, 2013). Additionally using the global platform of the Internet has expanded the scope of its impact significantly. This opens up extensive possibilities for training and awareness raising that promotes an encouraging message of empowerment of people who use AAC worldwide.



Final words from Communication Friends Group member Rachael Monk (above):

*"It's amazing. I feel so proud to be part of getting the message out there." **

Kirsty Paton

SLT Support Worker

Louise Blackley, Julie McCracken
& Helen Fletcher

Speech & Language Therapists

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 Clarke, K. (2008) 'Listen to Me' 1Voice DVD. *Communication Matters Journal*, 22(1), 19.
 Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, 5(2), 137-144.

Web Links & Social Media

'A Right to Communicate' Short Film youtu.be/fx338vnATIA or search on YouTube 'A right to communicate'.

AAC Scotland www.aacscotland.org.uk

Equal Voices www.equalvoices.co.uk

RCSLT Bulletin article May 2014. www.rcslt.org/docs/bulletin/2014/may-2014

Speech & Language Adult Service - NHS Dumfries & Galloway:

Facebook www.facebook.com/SpeechandLanguageTherapyadultServiceNHSDG

Twitter @SLT_DG

The Scottish Government (2012) A Right to Speak Supporting Individuals who use Augmentative and Alternative Communication. Edinburgh: The Scottish Government. www.scotland.gov.uk/Publications/2012/06/8416

JOINING COMMUNICATION MATTERS & ISAAC

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

What are the benefits of Membership?

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

What is ISAAC?

Formed in 1983, ISAAC is a multidisciplinary organization devoted to advancing the field of augmentative and alternative communication. ISAAC has over 3,600 members around the world, including national chapters in Australia, Brazil, Canada, Denmark, Finland, French speaking countries and regions, India, Israel, Italy, Netherlands and Flanders, Norway, Sweden, Taiwan United Kingdom and USA.

The Mission of ISAAC is to promote the best possible communication for people with complex communication needs. The vision of ISAAC is that AAC will be recognized, valued and used throughout the world.

How do I become a Member?

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

If you are outside the UK, you can become a member of ISAAC or subscribe to this Journal by contacting: ISAAC, 312 Dolomite Drive, Suite 216 Toronto, ON M3J 2N2, Canada Tel: +1 905 850 6848 Email: info@isaac-online.org www.isaac-online.org



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A Systematic Literature Review

Communication Training for Healthcare Assistants Supporting Young People with Complex Communication Needs

CHERYL HANSON

Faculty of Health, Psychology & Social Care, Manchester Metropolitan University, Brooks Building, 53 Bonsall Street, Manchester M15 6GX, UK
Email: cheryl.u.hanson@stu.mmu.ac.uk

INTRODUCTION

In this paper I aim to identify and evaluate existing communication partner training packages or approaches available for healthcare assistants working with young people with complex communication needs.

This paper forms part of a PhD project. The aims of this project are to develop a communication training package in collaboration with the communication partners of young people with complex communication needs. For the purpose of this project, communication partners are identified as the families of young people with complex communication needs and the healthcare assistants that work with them in the education establishment they attend.

This project recognises that staff working in a range of education settings with young people with complex communication needs already receive training in relation to communication skills. However, this project also recognises that this is not always the case for healthcare assistants who work with young people as part of Continuing Care (National Framework for Children and Young People's Continuing Care, 2010) funded support.

Both the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013) and The Cavendish Review (2013) iden-

tify access to a standardised approach to training for healthcare assistants as a key issue in the delivery of high quality care. The Cavendish Review also highlights it is difficult to show how healthcare assistants use skills and knowledge gained from training in their work.

It was felt that carrying out a review of published research literature was the best way to identify what evidence based communication training packages or approaches are available for use with healthcare assistants working with young people with complex communication needs.

METHODOLOGY

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Liberati, Altman, Tetzlaff, Mulrow, Gøtzsche, et al. 2009) checklist has been used to write this paper. This checklist consists of twenty-seven evidence-based items: its purpose is to provide a structure to report clearly why a systematic literature review was needed, how it was carried out, what literature was included in the review and what the included literature indicates. Research literature included in the review had to meet set criteria.

The population being researched had to include both:

1. Young people aged <25yrs with a diagnosis of Profound and Multiple Learning Disability (PMLD) or Profound Intellectual and Multiple Disabilities (PIMD). Young people were also included if they had PMLD/PIMD and another diagnosis e.g. Autistic Spectrum Disorder, Downs Syndrome, Cerebral Palsy.
2. Healthcare assistants, support staff, caregivers or residential support staff.

The intervention being researched had to include:

- Any training programme that aimed to change the behaviour of the communication partner towards the person with PMLD/PIMD.

The outcomes from the research had to report any of the following:

- Change in the communication partners' behaviour, interactive style, approach to the person with PMLD/PIMD.
- Change in the quality of observations made of the person with PMLD/PIMD by their communication partner.
- Increased use of strategies to support communication by the communication partner of the person with PMLD/PIMD.
- Increased knowledge and or understanding of communication in the communication partner of the person with PMLD/PIMD.

- Increased levels of attentional response to the person with PMLD/PIMD by their communication partner.
- Increased quality of response to the person with PMLD/PIMD by their communication partner.
- Increase in responsiveness in the person with PMLD/PIMD during communication exchanges with their communication partners.
- No change in the behaviour of the communication partner with the person with PMLD/PIMD they communicate with.

The design of research studies had to report:

- Some element of control e.g. multiple baseline across subjects design, experimental and control group.

Systematic literature reviews were also included.

Research literature was excluded from the review if the research population included:

- Adults aged >25yrs with PMLD/PIMD, any person with a named disability other than PMLD/PIMD e.g. Autistic Spectrum Disorder, Severe Learning

Disability, Moderate Learning Disability, Social Emotional and Behavioural Difficulties, Attention Deficit Hyperactivity Disorder, Cerebral Palsy, Downs Syndrome.

- Healthcare assistants, support staff, caregivers, residential support staff working with non-communication disabled client groups.

Research literature was also excluded from this review if:

- the intervention researched included changing the communication behaviour of the individual with PMLD/PIMD e.g. functional communication skills training;
- change in the communication partner's behaviour, either positive or negative, was not reported;
- no element of experimental control was reported.

DATA COLLECTION PROCESS

A range of information sources were selected based on their relevance: a limited subset were then selected to pilot the search strategy developed for this paper.

The following information sources were searched from 1994 to September 2014:

- Academic One File: Arts, humanities, social sciences, science and technology.
- CINAHL: Nursing, physical therapy, health education, occupational therapy, and consumer health.

- Web of Knowledge: Web of Science and Medline.

The electronic search strategy detailed in Table 1 was used for all three information sources.

Searches were solely completed by the author of this paper. The titles of all studies were screened against the set inclusion criteria using the data collection form example in Table 2.

Abstracts of studies that partially or fully met the set inclusion criteria were retrieved and searched to check whether or not they met the inclusion criteria: this data was recorded in a form similar to that in Table 2.

Full texts of these studies were then retrieved and searched to confirm their inclusion in the review. The reference lists used in each of the selected studies were also searched to identify any additional studies that may meet the set inclusion criteria for the review.

SUMMARY OF DATA COLLECTED

Figure 1 summarises the outcome of searches completed across all three information sources.

Some of the studies excluded from the search at Stage 1 focused on:

- Assessment of interactions between the young person with PMLD/PMID and the people who support them.
- Interventions that promoted change in the behaviour of young people with PMLD/PIMD by directly teaching them a potential communication skill e.g. teaching them how to use micro-switches, symbols or Voice Output Communication Aids to control their communication environments.

Electronic Search Strategy	
	child* OR infant OR adolescent OR student OR (young person) OR (young people) OR (young adult) OR teen*
AND	(profound and multiple learning disab*) OR (profound and multiple intellectual disab*) OR (profound intellectual and multiple dis*) OR (profound* learning disab*)
AND	(health care*) OR healthcare* OR support* OR (residential support*) OR (informal caregiver) OR (paid carer) OR care* OR auxiliary* OR (school nurse assistant) OR (respite support*) OR personal* OR (direct support worker) OR paraprofessional
AND	(communication partner training) OR (communication skills training) OR (partner assisted communication) OR (facilitated communication) OR (aided communication) OR (communication competenc*) OR (communication skills) OR (communication strategies) OR (alternative and augmentative communication) OR (intensive interaction) OR interaction OR sign* OR Makaton OR (objects of reference) OR (multi-sensory environment*) OR (multi-media profil*) OR (responsiveness) OR (attentional responsiveness) OR (eye gaze) OR (communication passports)
AND	change OR improv* OR develop* OR (skills transfer*) OR (knowledge transfer*) OR modif* OR adapt* OR facilitat* OR outcome

Table 1 Electronic Search Strategy

Database: CINAHL Date data retrieved: 12 September 014									
Abstract no.	1	2	3	4	5	6	7	8	9
Population 1: young person 0-25yrs with PIMD	Y	Y	U	Y	N	Y	Y	Y	Y
Population 2: HCA	N	N	Y	N	N	N	N	N	N
Intervention: training	N	N	Y	N	N	N	N	N	N
Outcome: change in communication partner	N	N	Y	N	N	N	N	N	N
Type of study: some element of control	N	N	U	N	N	N	Y	N	N
ACTION	N	N	U	N	N	N	N	N	N
ACTION RATIONALE	Y = YES: Fits Criteria N = NO: Does Not Fit Criteria U = UNSURE: Read Paper								

Table 2 Data collection form example

Of the four studies excluded from the search at Stage 2:

- All four met the inclusion criteria for both populations.
- Three were excluded as they did not meet the inclusion criteria for intervention: one reported the effectiveness of using wait-time procedures during interaction; another reported coding the interactive style of staff; another reported the characteristics of staff that influence interaction.
- One was excluded as it did not meet the inclusion criteria for type of study i.e. no experimental control reported.

As so few studies met the inclusion criteria for the review, it was decided not to undertake a quality appraisal of the selected papers. However, a brief summary of each study and their findings are discussed.

RESULTS

All four studies selected indicate that training can have a positive impact on how staff interact with young people with PMLD/PIMD.

Samuel, Nind, Volnes & Scriven (2008) describe how support staff in residential settings learned to use mirroring and contingent responding following their engagement in an Intensive Interaction training workshop. Whilst Croghan (2009)

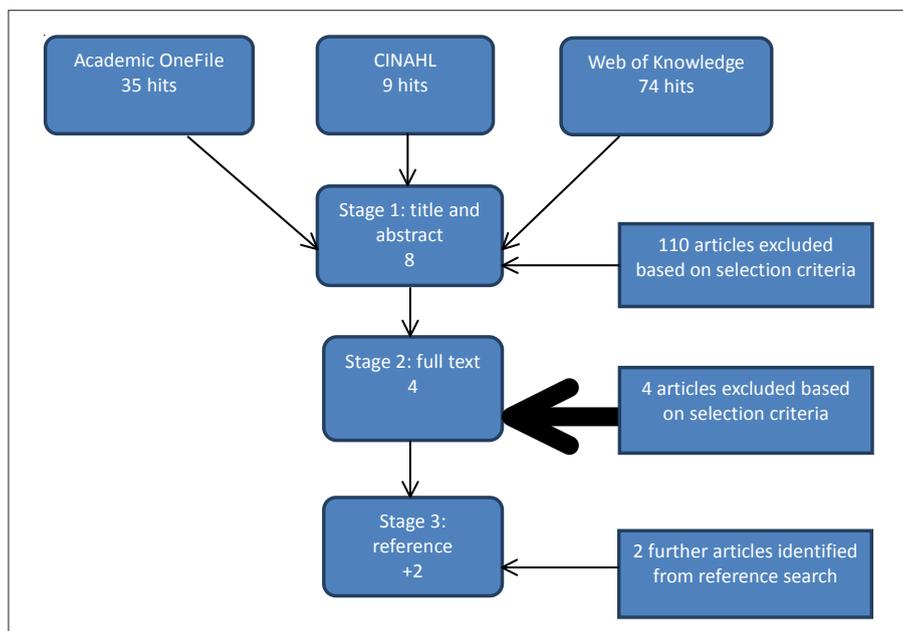


Figure 1 Summary of data collected

reports how staff gained an improved understanding of how to interact with a young person with PMLD/PIMD using hand massage after taking part in a focused training programme.

Munde, Vlaskamp, Ruijsenaars & Nakken (2009) discuss several studies as part of their systematic literature review that describe improved recording of behaviour of young people with PMLD/PIMD by staff following training. This finding is also supported by Croghan (2009) who

ports improvement in staff observation and recording of communication behaviour following training in use of the Affective Communication Assessment.

Damen, Janssen, Kef, Schuengel & Worm (2011) report improved quality of interaction following staff using video-feedback to modify their attentional responses to young people with PMLD/PIMD during interaction. Improvement in quality of interaction following training is reported by all selected papers.

Reference	Population 1	Population 2	Intervention	Outcome	Study Design
Damen, Kef, Worm, Janssen & Schuengel (2011)	1 participant aged 13yrs of 5 participants in total with PIMD age range 13-54yrs (M = 35yrs) from total sample of 12	1 male; 6 female Mean age = 32 Mean no. years working in group home = 3 Mean no. working hrs = 14	Contact programme: identify target, interaction analysis, coaching (group session to discuss analysis and four video feedback sessions), evaluation	General pattern of improved interaction with person with PIMD across support team on average in comparison to baseline	AB-design across subjects with two baseline and three intervention observations
Croghan (2009)	1 participant aged 13yrs	Hospice staff	How to use the Affective Communication Assessment to measure responses to hand massage	Improved understanding of young person's communication behaviours	AB-design within subjects with two baseline and one intervention observation
Munde, Vlaskamp, Ruijsenaars & Nakken (2009)	People with PIMD	Direct support staff	10 studies identified as making reference to staff training	Improvements in staff interactions with people with PIMD and thus their alertness	Systematic literature review
Samuel, Nind & Vollans (2008)	Four women with profound intellectual disabilities living in supported housing service	Staff supporting the women in this service	Training re intensive interaction principles	Staff learned to use mirroring and contingent responding with people with PIMD	An interrupted time-series multiple-baseline-across-four -participants design

Table 3 Summary of studies selected

As previously stated the current evidence base is limited, which makes it difficult to comment on the quality of the data.

However, of the three experimental design studies selected for this review, two describe the use of multiple baselines across subjects and one describes multiple baselines within subjects. Both types of design enable the measurement of change in subjects during and after they have taken part in a training approach. These measurements are then compared to the subjects' behaviour before they took part in the training approach. This type of experimental control allows the impact of the training approach to be measured.

Further analysis of the data collected for this review is needed: detailed exploration of reference lists and expanding the search to other databases may identify additional data.

LIMITATIONS

This paper acknowledges that there is a need to investigate the potential for both study and publisher bias from the studies selected for inclusion in this review. The author is also aware that there is the po-

tential for selection bias, particularly as the review was conducted solely by the author.

CONCLUSIONS

Given the data sample in this review is so limited, one can conclude that the impact of communication training on the behaviour of the communication partners of young people with complex communication needs is significantly under researched. This suggests that the PhD project this paper is associated with continues to be justified, particularly in light of the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry and The Cavendish Review. *

Cheryl Hanson

Postgraduate Research Student

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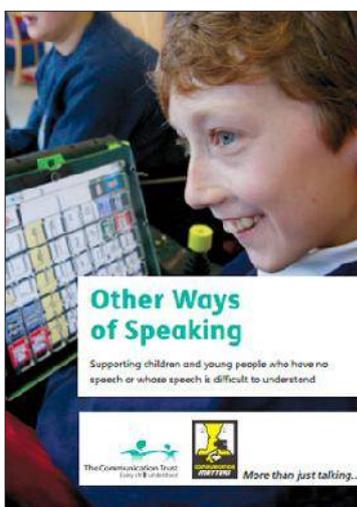
Munde, V. S., Vlaskamp, C., Ruijsseenaars, A.J.J.M. & Nakken H. (2009) Alertness in individuals with profound intellectual and multiple disabilities: A literature review, *Research in Developmental Disabilities*, 30 (3) p462-480.

Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013) Chaired by Robert Francis QC

Samuel, J., Nind, M., Volans, A. & Scriven, I. (2008) An evaluation of Intensive Interaction in community living settings for adults with profound intellectual disabilities, *Journal of Intellectual Disabilities*, 12 (2) p111-126.

The Cavendish Review (2013): An independent review into healthcare assistants and support workers in the NHS and social care settings, Crown Copyright: London

OTHER WAYS OF SPEAKING FROM COMMUNICATION MATTERS



This short booklet provides information about children and young people who use a variety of different ways to communicate, how you can help support them and where to go for further information. You should read this booklet if you live or work with children and young people whose speech is difficult to understand or who have no speech.

Other Ways of Speaking has been produced in partnership by Communication Matters, The Communication Trust, 1Voice, ACE Centre, The Makaton Charity, Scope and Signalong.

The booklet is **free** - you can download an electronic copy or order a printed copy from Communication Matters (you only pay postage & packing).

Free Download and further information:

www.communicationmatters.org.uk/other-ways-of-speaking

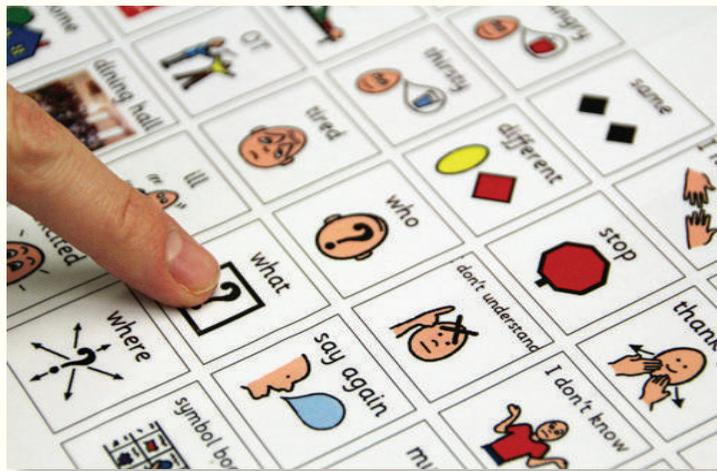
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COMMUNICATION MATTERS

AAC Study Day

Symbolisation *towards* Literacy



Janice Murray, PhD

Manchester Metropolitan University

Martine Smith, PhD

Trinity College Dublin

Monday 15 June 2015

Manchester Metropolitan University



www.communicationmatters.org.uk/studydays



FROM CATHERINE HARRIS, CHAIR OF BOARD OF TRUSTEES

I am not sure where the time has gone since the beginning of 2015. So much seems to have happened in a short time! As I am sure you are now aware, alongside our other activity, there has been significant input to succession planning in preparation for Patrick Poon and Peter Head's retirement from Communication Matters at the end of March 2015.



DAWN OF A NEW ERA

We appointed a General Manager / Communications Officer, Hilary Gardner, who has been working three days a week since the beginning of January 2015. We have also appointed a full-time Administrator, Emily Campbell, who started her contract in February. Both are based at the new CM office in the Leeds Innovation Centre, which is part of University of Leeds. The Leeds office was officially opened on 6 March. Patrick and Peter have been closely involved in the induction of our new staff. Hilary and Emily spent time in the old Edinburgh office before it closed at the end of February, and Peter Head has kindly supported them in the Leeds office to oversee the installation of the computers and related training on the databases. We recognise that it is a steep learning curve for Hilary and Emily, and are grateful to Peter and Patrick for their patience and efficiency in ensuring that things are handed over and continue to run as smoothly as possible. Patrick did make the comment that it was a bit like handing over a baby for adoption – I have assured him that he will never be denied access!

This is an exciting new stage but is also daunting for all concerned. There have been additional costs incurred with the office relocation and overlap in staffing during the induction period. These were anticipated and planned for in the budget but we recognise that getting sponsorship and additional funding to support our ongoing and future activity will be a key focus over future months.

CELEBRATION LUNCH

The Trustees held a farewell event for Patrick and Peter was on Saturday 7 March. We combined it with a presentation to **Janet Larcher**, who received her ISAAC Distinguished Service award from former Trustee Beth Moulam, and Janice Murray (former CM Chair) gave the presentation speech. Toby Hewson presented a gift to **Sally Millar** in appreciation of her long contribution as CM Journal editor. Sandra Hartley (former Trustee) presented a speech for Peter Head, and I had the daunting task of doing the tribute for Patrick. After the speeches and presentations, Peter and Patrick shared some of their experiences over the years. Although sad to say goodbye, it was a really special and happy occasion with a real sense of cel-

bration of all that CM has been and is, due to the input of so many committed individuals.



Peter Head, Patrick Poon, Sally Millar & Janet Larcher

The University's *Meet In Leeds* events team really pulled out the stops to make it a very memorable event. You can read more about the celebration lunch on page 19 of this issue, and do go to our new look Facebook page www.facebook.com/communicationmattersuk for more photos. Thanks must go especially to Ruth McMorrnan for all her work in helping to organise and co-ordinate this event.

NATIONAL AAC CONFERENCE HOTTING UP!

We are well in to our planning for the 2015 Conference which is obviously a key event in the CM calendar. The keynote speakers are confirmed as **Denise West** and **Brett Reynolds** from Australia who will be sharing their work on the *Communication Access project*; they will be presenting workshops after their keynote presentation. We are really keen to learn more about this project and whether it is something we can promote within the UK. Find out more about the keynote speakers from www.communicationmatters.org.uk/page/CM2015-keynote-speakers. We are receiving a good response from the Call for Abstracts – we encourage all of you to consider submitting an abstract, especially if you have not done so in the past. The Conference is a great place to share and learn from each other.

Between now and September, there will obviously be a considerable amount of work required to ensure that this year's Conference is a success. We are pleased that both Hilary and Emily will be at the Conference so that they can get to know more of the delegates and experience things first hand. Book your place now!

MARKETING AND SPONSORSHIP

After a number of delays, we have finally launched our new look website which we hope is much clearer and easier to navigate. We are really pleased with the fresher and cleaner look. Check out www.communicationmatters.org.uk for yourself and send us your comments if there are things you would like added. We have also increased our social networking activity (Twitter & Facebook), and would value involvement and feedback from the membership so that we can continue to build on this. Marketing and

TRUSTEES'
NEWS

sponsorship will be key to our ability to deliver our strategy over the next year. It will be a focus as we look towards Conference. The *Communication Access project* is a great opportunity to raise awareness and promote partnerships with some key players.

STUDY DAYS AND ROADSHOWS

Our Roadshows continue to attract people who are not yet members of CM, and serve to raise awareness and provide updates about developments in AAC. We are grateful to our supplier members who enable us to run these events. We are running at least five Roadshows this year around the UK. Over the coming year, we will be reviewing both the focus and structure of future study days and Roadshows to ensure we are achieving our aims and maximising our reach. We need to plan further ahead to ensure that we secure dates well in advance. Our next planned study day in Manchester will be a repeat of the popular Symbolisation to Literacy Day held last year in London and Stirling. We are also hoping to run a study day in the autumn on 'Autism and AAC'.

SPECIALISED HEALTHCARE ALLIANCE (SHA)

As Chair of Communication Matters, I have continued to represent CM on the SHA. I regularly forward information to Sally Chan who is Chair of the AAC subgroup (which is the subgroup for NHS England's Clinical Reference Group for complex disability equipment); this has contributed to showing where AAC fits into the bigger picture. CM is also represented on the AAC Subgroup and this has been a useful link with the Leads for specialised services as Specialised Commissioning begins to take effect in England. If there are issues of concern related to your specific geographical area please do contact us so that we can endeavour to support you.

LOBBYING

As the election approaches, it is important that individual CM members try to contact their election candidates to ensure the candidates understand or even know about AAC. The toolkit on the CM website is being updated so do use the templates provided to help with this. AAC now included in Specialised Commissioning but we have to ensure that everyone who would benefit from using AAC has access to services and funding.

So it has been all change, but because of a lot of hard work from a lot of people in the last year we feel well placed to meet the challenges ahead. Thanks to all the Trustees who have helped throughout this transition period. Thanks again and goodbye to Patrick Poon and Peter Head! Welcome to Hilary and Emily! Onwards and Upwards! *

Catherine Harris, CM Chair

BHTA AAC
NEWS

In August 2013 I spoke about changes – the fact that the body that monitors the Code of Practice of the BHTA which is binding on its members, changed from the Office of Fair Trading (OFT) to the Trading Standards Institute (TSI); the changes within the industry with mergers and acquisitions and indeed the change of the BHTA sector name from eCAT to AAC.

Well there are more changes happening. On 1 March, Ray Hodgkinson MBE retired as Director General of BHTA after many years service. His leadership has undoubtedly resulted in the BHTA becoming such a strong organisation, with access to government departments. Tracey Lloyd has been appointed as his successor. Tracey has worked for the BHTA as Commercial Director for the past three years, and will work closely with the Board and Secretariat to ensure that the BHTA continues to grow and support its members.

Another change that was announced in November last year was that the *Shoptmobility* network is now under the management of the BHTA. The *Shoptmobility* scheme will continue as normal but it strengthens both organisations and shows yet again the value of a Code of Practice that can be relied upon to act independently and to protect the buyer – which is something I have been stressing for many years in the AAC arena.

A year prior to that – in the November 2013 issue of this column – I gave details of the Assistive Technology Practitioner Society (ATP Society) registration scheme for individuals in healthcare. Since then, it has been decided to widen the scope of this organisation into establishing a full national professional register for those working within Healthcare and Assistive Technology and to change the name to the Healthcare and Assistive Technology Society (HATS). I have no doubt you will hear more about HATS in the future.

Finally, a timely reminder to all suppliers, whether members of the BHTA or not, that changes were introduced last year to how companies do business with members of the public (even if they only do so occasionally). The Consumer Contracts (Information, Cancellation and Additional Charges) Regulations 2014 are new rules that cover transactions conducted on business premises, as well as rules about selling to someone in their own home or via distance means. Some of the main changes include what you must tell your customers prior to or during a sales transaction; what, if any, are allowed as extra charges; and if you sell in the customer's home or via the internet, phone or catalogue, the cancellation period has changed from 7 to 14 calendar days from the day after delivery of the goods. So it is best to check straightaway how these changes might affect how you do business or your rights as a consumer. *

David Morgan, BHTA AAC Chair



DIARY
DATES

28-30 April 2015 Birmingham
Naidex National 2015
 Visit www.naidex.co.uk

30 April 2015 Edinburgh
Using Symbols in Schools
 Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

6-8 May 2015 MMU, Manchester
Evidence Based Assessment in Complex Communication Needs
 Visit www2.mmu.ac.uk/hpsc/courses/cpd/detail/?id=68

8 May 2015 Edinburgh
ICT for Autism Spectrum Disorder
 Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

8-10 May 2015 Derbyshire
1Voice National Residential Weekend 2015
 Contact: 1voice-admin@1voice.info www.1voice.info

19 May 2015 Glasgow
Communication Matters Roadshow: Glasgow
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

4 June 2015 Reading
Kidz South 2015
 Visit www.disabledliving.co.uk/Kidz/South

15 June 2015 Manchester
Symbolisation Towards Literacy
 Visit www.communicationmatters.org.uk/studydays

16 June 2015 MMU, Manchester
Symbols, Language & Literacy: Follow Up Workshop
 Visit www.bit.ly/1mTwD0 to book this MMU workshop

DIARY
DATES

18 June 2015 Sheffield
Communication Matters Roadshow: Sheffield
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

26 June 2015 Norwich
Communication Matters Roadshow: Norwich
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

30 June 2015 Bristol
Communication Matters Roadshow: Bristol
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

13 September 2015 Leeds
1Voice-1Day 2015
 Contact: 1voice-admin@1voice.info www.1voice.info

13-15 September 2015 Leeds
CM2015 National AAC Conference
 Visit www.communicationmatters.org.uk/conference

17 September 2015 Edinburgh
Kidz Scotland 2015
 Visit www.disabledliving.co.uk/Kidz/Scotland

5 November 2015 Edinburgh
Using Eye Gaze to Support Learning and Communication
 Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

19 November 2015 Manchester
Kidz up North 2015
 Visit www.disabledliving.co.uk/Kidz/North

8 December 2015 London
Communication Matters Roadshow: London
FREE Tel: 0845 456 8211 www.communicationmatters.org.uk

AAC WORKSHOP

'SYMBOLS, LANGUAGE AND LITERACY'

Tuesday 16 June 2015

Manchester Metropolitan University

This one day workshop, organised by Manchester Metropolitan University, provides a follow-up to the original Communication Matters 'Symbolisation Towards Literacy' study days in London, Stirling and Manchester. The course is only for individuals who have attended the original study day.

The workshop offers attendees an opportunity to develop practical, evidenced activities to support language and literacy development through aided communication technologies.

The course will be delivered by:

Janice Murray, PhD and Reader in Community Rehabilitation, Manchester Metropolitan University

Martine M Smith, PhD Head, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, Dublin

For more information or to make an online booking directly with Manchester Metropolitan University, visit www.bit.ly/1mTwD0

Celebrations at Communication Matters

RUTH MCMORRAN & HILARY GARDNER

Email: manager@communicationmatters.org.uk

A CELEBRATION LUNCH

On Saturday 7 March 2015 the Chair and Trustees of Communication Matters were joined by 'old' friends and colleagues to celebrate the work of Janet Larcher, Peter Head, Sally Millar and Patrick Poon.



The lunchtime event took place at the University of Leeds where CM currently holds its annual conference and now has the new office on campus.

ISAAC DISTINGUISHED SERVICE AWARD

Last summer at the ISAAC Conference in Lisbon, it was announced that **Janet Larcher** had been awarded the *ISAAC*



Distinguished Service Award. Janet Murray, speaking as Chair of the ISAAC Council and Executive Board representative, reminded us of the amazing work Janet has carried out over many years. Beth Moulam, whom Janet worked with directly from before she started school, presented the award.



RETIRING CM JOURNAL EDITOR

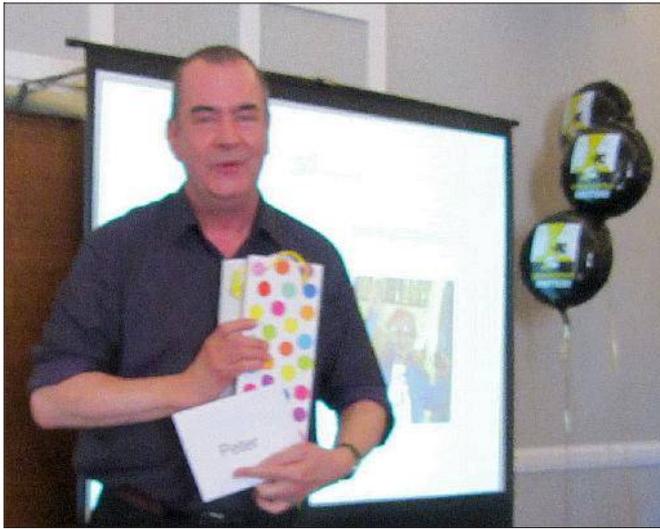
Sally Millar has been a committed member of Communication Matters since its inception, and editor of the *CM Journal* for 25 years. The Journal was first created by Liz Panton, and Sally and Liz worked together (in the days of typewriters and postal services!) until Sally later took it on. Sally and Patrick Poon produced their first edition together in 1992.

Over the years the production process was completely revamped and the *CM Journal* was transformed into the world respected publication it is today, while retaining the friendly elements of a newsletter.



RETIRING ADMINISTRATION STAFF

How many of you have spoken to **Peter Head** but never met him? In her presentation Sandra Hartley, former CM Trustee, described Peter, Assistant Administrator, as being to CM what 'The Stig' is to Top Gear - vital to the running of the organisation but never seen by the public!



Peter was gratefully thanked for the many years he and Patrick had worked together for the good of Communication Matters. In return Peter regaled the gathered guests with some mischievous tales of the early days, collaborative inventiveness and unusual answerphone messages!

The afternoon culminated with Cathy Harris, current Chair of CM, presenting a tribute to **Patrick Poon** - something she described as a seriously daunting task. A quick geography lesson



showed us the route Patrick made from Hong Kong to Edinburgh and to his role as Administrator and Company Secretary of Communication Matters. Everyone who has anything to do with Communication Matters has emailed, phoned, written to or spoken to Patrick Poon. Cathy described how over many years he was "always available, showed endless patience, up for a laugh, respected by all his colleagues and who will, of course, be remembered for his famous collection of wigs!".

The wonderful lunch was hosted by the University conference team 'Meet in Leeds' who are a great support to CM for all meetings & events at the present time. The Trustees were once again impressed by the attention to detail and great food, enjoyed by all!

Celebrating the Launch of the New Communication Matters Office

As the Trustees said goodbye to Patrick Poon and Peter Head who have managed Communication Matters for over a decade, they also held an event to publicise the new CM address and the new office team.

The official opening of the new Communication Matters headquarters was held on 6 March 2015. Friends of the charity and representatives from various bodies within the University of Leeds and the city were invited to drop in for Bucks Fizz and pastries, generously supplied by the University conference team.

Representatives from the faculties of medicine and engineering, the careers team and chaplaincy attended alongside NHS services and independent suppliers.



The new office, based at **Leeds Innovation Centre** in the heart of the University of Leeds Campus, is very well appointed and with a great view!

Emily Campbell is the full-time Administrator (left) and **Hilary Gardner** (right) is the Manager and Information Officer, seen below with Patrick Poon. Emily has a background in Biological Sciences and Hilary is a Speech Language Therapist/lecturer in Human Communication Sciences. Realising they can never replace the retiring duo, Patrick and Peter, they are hoping to bring a different skillset and style to the charity. They look forward to working with the Trustees and the wider friends and members, including international links as the UK Chapter of ISAAC. *



Update on the work of the AAC Sub-Group

The Development of Specialised AAC Services in England

SALLY CHAN

Email: sallychan@nbt.nhs.uk

INTRODUCTION

In April 2013, specialised Augmentative & Alternative Communication (AAC) services were confirmed as 'prescribed specialised services' by NHS England. In April 2014, £15 million per year was identified to be made available from NHS England as convergence funding for developing specialised AAC services. This allocation was to 'top up' existing identified baseline allocations, ensuring that identified services would work towards meeting the service specifications and address disparities in quality and coverage of service and equipment provision identified in prior work.^{1&2}

NHS ENGLAND

Specialised AAC services, Environmental Control services and Prosthetic services, form the *Complex Disability Equipment Group* within NHS England. There are 145 specialised services within the NHS³, each one grouped into one of the six National Programmes of Care; the Complex Disability Equipment Group sits within the Trauma National Programme of Care.

There are 70 Clinical Reference Groups (CRGs) which provide expert advice to NHS England for the development of specialised services. The CRGs review and develop the service specifications and clinical access policies, as well as define quality measures and build quality standards. *The Complex Disability Equipment CRG* oversees such development for specialised AAC services.

THE AAC SUBGROUP

The AAC Subgroup feeds into the CRG, providing advice and recommendations. The subgroup consists of specialist clinicians and managers, as well as representatives of people who use AAC. The Subgroup, with the specialised AAC services, are currently working on developing documents to facilitate the understanding of the process involved in

referring an individual to a specialised service - clarification of criteria and a decision making flow chart. Additionally, as the specialised AAC services are required to promote and develop the local AAC services, there is a working party currently producing a guidance document for local commissioners and local AAC services. All these documents will be on the Communication Matters website (www.communicationmatters.org.uk).

SERVICE SPECIFICATIONS FOR SPECIALISED AAC SERVICES

The existing service specifications remain in draft form until they are ratified by NHS England; however, it will be these service specifications against which the specialised AAC services will be measured in October 2015. The current draft form of the service specifications is available on the Communication Matters website. These specifications also include the criteria for referral to the specialised AAC services.

THE SPECIALISED AAC SERVICES

15 services have been identified, and have submitted business plans to NHS England. These services are at different stages of negotiation with their respective NHS England Area Teams (responsible for the commissioning of specialised services within an NHS area). Due to significant prior variation in service and commissioning models, all services are also starting from a different baseline. Some services have developed a phased roll out of their service to ensure they can effectively meet the needs of all those in their area requiring AAC, once they have a full complement of trained staff.

It is recognised that there has been a delay in agreeing contracts across all services, which has extended the process of transition.

The specialised services are responsible for assessing those who meet the criteria

for a complex assessment, and the provision of the recommended specialist communication aids. Their remit also includes the maintenance and repair of such communication aids.

THE LOCAL AAC SERVICE

The specialised AAC services rely on effective local AAC services to identify potential beneficiaries, to implement recommendations and programmes and to develop supportive local AAC environments. It is the specialised services' responsibility to provide support, development and training for local services, and to work collaboratively to develop a seamless AAC pathway. Therefore, liaison between the specialised AAC services and local commissioners (Clinical Commissioning Groups and Local Authorities) is crucial in establishing that seamless pathway for those requiring AAC. However, NHS England and specialised services have no power to oblige CCGs or local commissioners to commission specific services or specifications.

This has been a very positive period for AAC - an opportunity to build on the enduring work of many who have been able to influence decisions at a political and national level. By raising the profile of AAC through hard work over many years, and reaching out to decision makers, the value of AAC has been recognised and supported by this additional funding, no mean task in the current financial climate. *

Sally Chan
Speech and Language Therapist
Chair of the AAC Subgroup &
RCSLT representative on the CRG

¹ www.communicationmatters.org.uk/beyond-the-anecdote

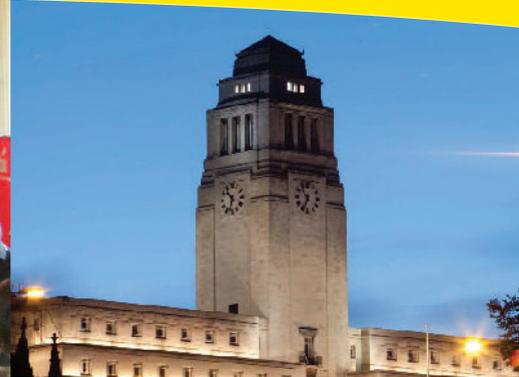
² www.communicationmatters.org.uk/development-of-aac-project/objective-2

³ www.england.nhs.uk/wp-content/uploads/2014/01/pss-manual.pdf

COMMUNICATION MATTERS

National AAC Conference

13th -15th
September 2015
at
University of Leeds



Communication Matters is the UK wide charity which works for and brings together everybody who has an interest in AAC (Augmentative and Alternative Communication). Membership includes people who use AAC, family members, professionals who support them and suppliers who design and manufacture AAC solutions.

Following last year's very successful conference at the University of Leeds, be sure to book early for the UK's leading AAC event.

- Plenary, seminar rooms and exhibition hall are close together in pedestrianised campus
- All areas are fully wheelchair accessible
- High standard of residential accommodation
- Large dining room and good food

Conference Programme

A busy two and a half days covering a wide range of topics: practical solutions, personal experiences, latest research, plus clinical and technological developments in the field of AAC.

- plenary sessions
- full seminar timetable
- research stream
- case studies & workshops
- poster session
- social events

The conference is supported by our organisational members – meet them at the exhibition and get hands-on experience with the latest technology.

Find out more at:

www.communicationmatters.org.uk/conference

Conference Registration

- conference opens on Sunday 13th September at 4pm
- registered delegates have full access to all conference events plus plenty of networking opportunities
- registration also includes refreshments, lunch and evening meals plus breakfast for residential places
- **SUBSIDISED** places are available for people who use AAC and their PAs. These are limited and available on first come basis, so book early to avoid disappointment

Don't miss out on the only National AAC conference which brings together people who use AAC, families, professionals and suppliers of AAC solutions



Book and pay before 31st July to claim your **EARLY BIRD DISCOUNT**

You can download the registration form at:

www.communicationmatters.org.uk/conference



Teaching with Core Words: Building Blocks for Communication and Curriculum

JENNIFER MARDEN

AssistiveWare, Laurierstraat 193, 1016 PL Amsterdam, The Netherlands

Email: j.marden@assistiveware.com

Hi Michael!

*Gladiator
Oven glove
Microwave*

Huh?

These words are useless!

*The Language Stealers (Michael Brian Reed, 2010)
www.youtube.com/watch?v=Vib2__BDCXc*

INTRODUCTION

Since the first published AAC boards were created in the 1920s, AAC systems have used core words to allow non-speaking people to communicate. Core words are those 50 to 400 words that make up most of what we say in typical conversation and writing. Many studies across different languages and age groups have found that about 50 words account for 40 to 50% of what we say, 100 words account for about 60%, and 200 to 400 words account for 80% of the words we use every day.

If we give AAC learners quick access to these core words, we're providing them with a powerful tool to communicate whatever they want to say. Rather than relying on preprogrammed sentences or phrases such as "I want" and "I see", they can choose from a relatively small set of words to create their own sentences, express a wider variety of ideas, and work on more advanced grammar.

One necessary part will be missing from these sentences, though - nouns. While languages usually vary in what percent of their core words are pronouns, verbs, adjectives, and prepositions, one finding is very consistent - nouns are rarely core words. According to one study of English (Dynamic Learning Maps™ Core Vocabu-

lary, Center for Literacy and Disability Studies):

Core Word List Position	% of nouns
1 – 50	0%
51 – 100	1%
101 – 200	9%
201 – 300	12%
301 – 400	20%

Nouns are usually considered *fringe* words. These are the highly specific words like "giraffe", "leaping", "bored", and "Julia" that are needed to communicate very specific messages. Having access to fringe words is essential for clear and specific communication, but each individual fringe word is not used that often. While it may be very useful to be able to say "velociraptor", it doesn't usually come up in daily conversation. Even more common fringe words like "apple" are highly personal. Some people may need quick access to "apple" while others prefer different fruits.

There are several core-word based vocabularies available in apps or dedicated AAC devices. In theory, these vocabularies should give an AAC learner 80% of the words he needs to communicate without any additional programming. Yet much of the limited time that SLTs, spe-

cial educators, and parents have to support AAC use is typically spent programming and teaching pages of fringe words for specific lessons and activities. The AAC learner would likely benefit more from learning how to find and combine core words to express personal thoughts and preferences.

Why are core words often not provided or taught to AAC learners? One of the major barriers to using core words is that they can be hard to teach. Unlike nouns, most core words are not "picturable". We can use symbols or photos of most nouns to teach the meaning of the words and represent that meaning on an AAC system. But how do we teach and represent "is", one of the most frequently used words in English?

Techniques for teaching core words have increasingly been the focus of research and clinical presentations over the last few years. The purpose of this article is to share some of these techniques and resources with a wider audience.

MODELLING

Typically developing children learn language by hearing it spoken around them all day in real-life conversations for years before they develop the ability to put to-

gether sentences. Yet often we hand a non-speaking child a communication device and expect him to use it effectively after a short demonstration.

All AAC learners need to see what it looks like to communicate using their AAC systems in real conversations. This simple idea goes by many names – Aided Language Stimulation, Aided Language Input, Natural Aided Language to cite a few. The idea is to use the AAC learner’s system, or another similar AAC system, when you talk with the AAC learner.

You don’t need to model every single word you say, especially to start with. This would likely be overwhelming to all concerned. Instead, model one step above the AAC learner’s current skill level. So if the AAC learner is not yet using the system to communicate in single words, model at the single word level. For example, if you’re leaving the classroom to go to the cafeteria, you can verbally say “It’s time to go to the cafeteria” and press the “go” button on the AAC system when you say the word “go”. Once the AAC learner is at the one word level, you can step up your game – add a word when you model. So if you’re leaving the house to go to see grandmother, you can verbally say “Let’s go see Granny” and press “go” and “Granny” while you’re speaking these words. For more tips on modelling in specific situations, see Van Tatenhove (2013).

WORDS OF THE WEEK

One way of structuring the process of teaching and modelling core words is to schedule a set of words to focus on each week or month. This makes the modelling more manageable, and as long as you keep modelling words from previous weeks, you will end up teaching a robust vocabulary with many core words.

A wonderful program for teaching core words using this method has been developed by Carole Zangari, Gloria Soto, and Lori Wise. The program is called TELL-ME (Teaching Early Language and Literacy through Multimodal Expression). This 30-week preschool program teaches three to six core words every two weeks. A different picture book is used for each two-week period, and the words of the week are used throughout the day in various activities:

- Daily reading of the book of the week for different purposes, with emphasis on the words of the week (saying the words of the week using AAC when they occur in the story reading, creating a poster about a character in the story, acting out the story, picking a favourite character or event).
- Predictable chart writing (each student uses their system to complete a sentence that starts with core words such

as “I can”, “I like to”, “We saw”. The sentences can be combined with photos to create a book the students can re-read at school and at home).

- Using words of the week during other school activities (snack, cooking, art, music, creative play centres).
- Modelling words of the week whenever possible using large core word displays located throughout the classroom as well as on students’ AAC systems.
- Sending home information to families about the words currently being learned and how to model them using the students’ systems.

These strategies teach core words in natural contexts. Through repeated modelling of the words to communicate during real, fun activities, students learn the meaning of non-picturable words and how to use them to communicate. For more details, see the handouts from Carole Zangari’s ISAAC 2012 pre-conference presentation in the references. Similar approaches are described in Hatch, Geist, & Erickson (2015) and Erwin, Maglinte, & Lovell (2014).

DESCRIPTIVE TEACHING METHOD

So you’ve been modelling core words during real conversations and using words of the week strategies! Your AAC learners are starting to use core words on their own! But you’re still getting requests to spend your instructional, therapy, or home time programming nouns for academic lessons – nouns you know your AAC learners will not use once the lesson is over. What can you do to make sure your efforts are focused on developing useful communication skills?

The Descriptive Teaching Model, developed by Gail Van Tatenhove, may be the answer. In this model, instead of asking the student to memorize specific nouns to answer academic questions, the student uses core words to describe the concepts in the lesson. For example, in a lesson about the life cycle of the butterfly, the teacher may ask the student about the chrysalis stage. The teacher could ask a closed question with one right answer, such as “What is the name of the third stage of a butterfly’s life?” To answer this question, the student has to have chrysalis programmed into his system, or at least have a low-tech choice board with the stages represented.

Using the descriptive teaching model, the teacher could instead ask “What happens during the chrysalis stage?” The student could answer using core words: “It sleeps inside.” “It changes to a new thing.” “It turns pretty.” Each of these sentences shows the student understands this stage of the life cycle.

There are several bonuses to the descriptive teaching method:

- It gives the student more practice retrieving core words and combining them into meaningful sentences.
- It requires the student to think more deeply and creatively about a concept in order to describe it his own words.
- It saves time spent programming and learning how to retrieve infrequently used words.

TEACHING COMMUNICATION FOR LIFE

In the end, most parents, teachers, and therapists have the same goal for the AAC learners they help – to give them the ability to communicate their thoughts clearly to anyone they need to talk to.

We know that core words will give AAC learners access to about 80% of the words they will need. The remaining 20% are picturable and easy to learn. Why not spend most of our time teaching the 80% of words that are needed most frequently but are harder to learn? Why not teach how to combine these words to form sentences we never anticipated they would want to say? When we do this, we are not just enabling AAC learners to demonstrate knowledge of academics – we are teaching them how to communicate effectively for the rest of their lives. *

Jennifer Marden, MA CCC-SLP
Speech-Language Pathologist

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Supporting Pupils with Communication Difficulties

A Right to Speak: Development of an AAC resource pack for Forth Valley schools

DAVID FLETCHER

ASN Outreach Service, Raploch Community Campus, Drip Road, Stirling FK8 1SD, UK
Email: aac@stirling.gov.uk

The Scottish Government published the document *A Right to Speak - Supporting Individuals who use Augmentative and Alternative Communication (AAC)* in 2012, which made a number of recommendations to improve services to users of AAC. In common with other areas in Scotland, a Right to Speak Partnership was formed in Forth Valley including professionals from NHS Forth Valley and Education and Social Work colleagues from Clackmannanshire, Falkirk and Stirling Councils, to address the recommendations made by the Scottish Government.

The partnership has a remit to leave a legacy of improved services for AAC users when A Right to Speak initiative ends in March 2015. Unlike some areas of Scotland, Forth Valley does not have a central AAC service.

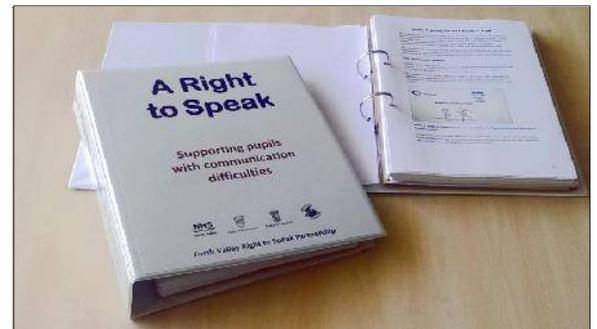
The partnership employed (on secondment) a principal teacher and a support for learning assistant to work on the education legacy for the 2013/14 session. As part of their work, a Schools Pack was produced to share good practice about supporting pupils with communication difficulties, including users, or potential users, of AAC.

As the numbers of AAC users in local schools is limited, there may be a tendency for schools to consider that AAC is not relevant to them. We reinforced that

the approach applies to all schools as a pupil with communication difficulties could enrol at any time (or existing pupils could acquire a communication impairment through accident or illness) and it is already the responsibility of schools to support pupils with communication difficulties under legislation and government guidance, which in Scotland includes:

- Education (Additional Support for Learning) (Scotland) Acts 2004 and 2009
- Getting it Right for Every Child
- A Curriculum for Excellence (Scottish national curriculum)
- How Good Is Our School? Quality indicators (used by Education Scotland inspectorate and for self-evaluation by schools)
- General Teaching Council for Scotland: Professional Standards for Teachers

However, we identified a number of barriers to schools independently addressing the needs of pupils with impaired communication. These included a lack of staff training and perceived lack of knowledge of where to start; schools relying on outreach support from Additional Support Needs services or speech and language therapists and school staff having a lack of time to produce resources.



We sought to bring together good practice from colleagues in the following organisations, as well as local guidance prepared by the Forth Valley Right to Speak Partnership:

- NHS Education for Scotland (NES)
- CALL (Communication, Access, Literacy and Learning) Scotland, University of Edinburgh
- Fife AAC Team (FAACT)
- KEYCOMM (Lothians AAC Service)
- Communication Matters

THE SCHOOLS PACK

The Schools Pack contains the following sections:

- Ways to communicate and CPD opportunities for staff
- First steps for schools when a pupil with communication difficulties is enrolled
- Information about local AAC assessment process
- Links to curriculum and standards for schools and teachers
- Supporting high-tech AAC users - roles for school staff
- Communication resources
- CD-ROM

Ways to Communicate & CPD

The CPD section includes links to the content on CALL Scotland / NES website www.aacscotland.org.uk and also has links to the Communication Matters *Focus on...* series of information leaflets (www.communicationmatters.org.uk/focuson):

- First Steps
- What is AAC?
- What can I say?
- Let your hands do the Talking
- Using Symbols for Communication
- Speaking with Someone who uses AAC
- Accessing Communication Aids and Computers
- Communicating with Patients who have Speech/Language Difficulties

The CPD section also highlights how colleagues could access the books about AAC provided by NES:

- *Keep Talking* (CALL Scotland) – a very practical guide with exemplar activities to get a user familiar with a new AAC device. Ideal for communication assistants and teachers. This book is also available as a free download from www.callscotland.org.uk/Resources/Books/Keep-Talking
- *Making Communication Even Better* DVD and workbook (NES) – a guide to improving access to health and social care services for people with communication difficulties.
- *Personal Communication Passports* (CALL Scotland) – a practical guide to making PCPs.
- *Talking Mats* – a resource to enhance communication – introduction to the Talking Mats concept.
- *The Diving Bell and the Butterfly* by J D Baudy – a book dictated by eyelid movement by a stroke patient; this could be used as a context for discussion about AAC with older learners.
- *Transition strategies for adolescents and young adults who use AAC* – a reference manual for all professionals in the team around the child/young person.
- *Ghost Boy* by Martin Pistorius – a biography of young person who suffered abuse when unable to communicate following acquired disability.
- *Developing and Using a Communication Book* (ACE Centre) – a very practical resource with exemplar materials.
- *Communicating with Pictures and Symbols* (Augmentative Communication in Practice: Scotland) – a good introduction to symbol communication for

those new to ASN or with new AAC users in their establishment.

First Steps for Schools

The next section provides a checklist of practical strategies for schools to follow when a pupil with communication difficulties is enrolled, while awaiting outreach support and assessment (nothing in this guidance replaces personalised children's plans):

- Gather information.
- Begin additional support needs (SEN) protocols (known in Forth Valley as staged intervention).
- Seek assistance from relevant partner agencies and education outreach teams.
- Symbolise the school environment – a catalogued starter pack of printed PCS resources was included in the pack, including area labelling, classroom labelling and visual timetable resources. We are grateful to FAACT, Fife Council, for sharing their symbolised school resources which formed the basis of this starter pack and to Dynavox Mayer-Johnson for granting permission to share the PCS symbols in the pack. An electronic version of the files in Boardmaker format was included on the CD-ROM accompanying the pack.
- Use specimen communication resources (printed and electronic copies of CALL Scotland / NES communication boards from www.aacscotland.org.uk were included in the pack).
- Make your own communication resources.
- Signposting of CPD opportunities for staff.
- Voice output devices – advice on free and inexpensive voice output devices including switches, talking postcards and iPad apps.
- Use pupil voice (involving the pupil in the decision making process).
- Information on how to access AAC assessment services locally.

Roles for School Staff

The pack identified the different roles staff supporting AAC users may be asked to perform:

- Support for Learning Co-ordinator (SENCO, typically a deputy headteacher in Forth Valley schools).
- Communication Champion (a member of school staff who leads AAC awareness among colleagues and co-ordinates communication initiatives, e.g. symbolisation of the school).

- Teachers (general responsibilities for all teachers and a separate sheet indicating responsibilities for teachers who have an AAC user in their class).
- Communication Assistant (typically a role for a support for learning assistant).
- Communication Partners (this role may also apply to pupils).
- Technical Support Assistant (someone who takes responsibility for troubleshooting technical difficulties, e.g. contacting AAC suppliers, sending devices for repair – this role is intended for school staff to endeavour to resolve technical problems without awaiting outreach support from therapists or ICT teachers).
- Roles for outreach teachers.

The IPAACKS (Informing and Profiling AAC Knowledge and Skills¹) framework, published by NES in January 2014, was used to benchmark each role to the relevant AAC specific strands:

- Identifying need
- AAC assessment
- Implementation
- Review
- Technology – preparation, adaptation and integration
- Technology – management of resources
- AAC Leadership
- Facilitating AAC learning

In each strand, there are four skill levels which relate to the level of knowledge and skills required for each role – note that these are not related to seniority within a profession or job title.

The pack contains a knowledge and skills factsheet for each staff role, outlining suggested best practice for schools and outreach staff, to help identify appropriate staff to support AAC users, identify professional development priorities and to give clarity to each person's role.

SUMMARY

The pack was designed as local guidance for Forth Valley and intended to raise capacity within schools to support pupils with communication support needs, as a legacy of A Right to Speak. We would be happy to share the resources for you to adapt for your local circumstances – please contact aac@stirling.gov.uk for further information. *

David Fletcher
Principal Teacher – AAC
Forth Valley Right to Speak Partnership

¹ IPAACKS is available online at tinyurl.com/ipaacks

A Model for Local AAC Services

The AAC Service for Adults in Gloucestershire

KATHERINE BROOMFIELD & LOUISE WALTERS

Speech & Language Therapy Department, Gloucester Royal Hospital, Great Western Road, Gloucester GL1 3NN, UK
Email: katherine.broomfield@glos-care.nhs.uk

BACKGROUND

It is now a year since the Hub and Spoke Model was officially launched as a framework to support commissioning and funding of specialist AAC Equipment and services in England. Under this new framework, regional specialist assessment centres, or 'Hubs', will access the National Commissioning Board funding for the 10% of the population who require specialist AAC equipment and services. The remaining 90% of the AAC-using population can expect to be supported by their local 'Spoke' AAC service [1]. Service specifications for specialist and local services can be found on the Communication Matters website [2].

The remit of local Spoke service focuses on provision and activities:

- **Provision:** to provide an expertise in non-complex, low-tech AAC strategies and techniques with a limited multi-disciplinary team.
- **Activities:** to include raising awareness locally to collaboratively as well as co-ordinating the care of their local AAC population.

There needs to be a close interdependence between local teams and specialised teams. Specialised AAC services are not viable without local AAC services who will be a main source of referrals to the specialised AAC assessment centres and

who will support implementation programmes.

In Gloucestershire we have a local AAC service which meets most of the criteria laid out in the recent service specification for Spokes. Our main motivation for sharing how the service in Gloucestershire functions is to encourage discussion about how existing 'local' services can support emerging services by sharing our experience and examples of good practice.

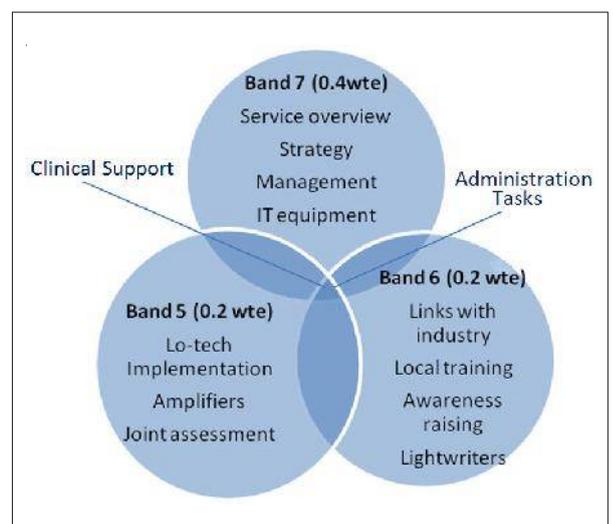
HISTORICAL PERSPECTIVE

The service in Gloucestershire has evolved over the past thirty years. Historically (1990s) the three health trusts in Gloucestershire put £10,000 each towards AAC provision, which was managed via the adult speech and language therapy (SLT) service. Catherine Harris moved to the area in 1993 and, in conjunction with the then SLT service manager, developed the specialist AAC post to lead a local service. The aim of the service was to provide care closer to home and to reduce lengthy waits and long journeys to the regional specialist centre.

Changes in Trust configurations and boundaries, coupled with a tenacious service manager, resulted in the monies staying with the post. The subsequent service manager continued to recognise the importance of AAC and consequently honoured the availability of the monies for procurement of AAC devices.

WHO WE ARE

The AAC team is an integrated part of the Adult SLT service in Gloucestershire. There are other local AAC services meeting the needs of other client groups. The



Roles of AAC Team



Care Pathway

team is based at the Gloucestershire Royal Hospital but provides a county-wide service including assessments and reviews at local hospital sites, patient's homes and any other relevant environment.

SERVICE SPECIFICATION

We provide our service in line with the departmental referral guidelines. We operate an open referral system for people who have a Gloucestershire GP, are over 18 years old and have a communication difficulty. Out-of-county referrals are accepted provided funding arrangements are in place, and we don't accept referrals for people already open to an SLT from another service.

WHAT DO WE PROVIDE?

We provide a range of low-tech equipment available for long term loan including talking photo albums, E-Tran frames and communication books/charts.

Due to the longevity of the service we have also established a library of mid- and high-tech devices: Lightwriters (SL35, SL40 and Swift), V-Pens, amplifiers, iPads & iPod Touches (AAC apps available), Tobii PCEye Go, and laptops with The Grid 2, Smart Nav, Joy cables, and a range of switches.

CARE PATHWAY

- Referrals are received from external referrers, and internally from therapists working in the department.
- Assessment is carried out by local SLTs, if they have skill and experience; as joint assessments; or as specialist assessments by the AAC team.
- Equipment loans are arranged following assessment. Some equipment (e.g. eye-gaze camera) is for demonstration only. Computers and iPads can be loaned for periods up to three months in order for the patient and therapist to establish whether private/charitable purchase is appropriate.
- Following assessment, equipment can be loaned on a long term basis if required, and individual items can be purchased for patients if within budget.

- Short term and long term loans need to be followed up by therapists until equipment is being effectively used by individuals.
- Onward referrals made to Bristol Communication Aid Service or involvement of industry reps are arranged by members of the AAC team.

EQUIPMENT MANAGEMENT

We use Microsoft Access to keep a database of the equipment. All new equipment is logged as soon as it arrives in the department. All loans are logged out (any items that leave the department). All repairs are logged before being sent away to medical engineering or AAC companies.

Reports can be drawn from Access each year to identify which items have been loaned, length of loan periods, etc. The system is used to audit the equipment library annually.

LOAN PROCESS

1. Device issued by treating therapist. Equipment Loan Information Pack given to patient and/or family/carers has Conditions of Loan Form, Equipment Care Form, AAC leaflet, and two copies of Equipment Loan Form.
2. Demonstration and training provided by treating therapist. Goal setting.
3. Three month review: Is device appropriate? Is patient using it effectively? Is any further support required? Have goals been achieved? New goals? An Annual Review.

Support Systems and Equipment Maintenance

We receive support for our IT equipment from the Trust's IT department. They have supported us to purchase tablets, restore and maintain our laptops and they enabled access to WiFi within the hospital.

We also have an arrangement with Medical Engineering, via a Trust contract, who repair our mechanical devices when possible. We have good relationships with industry and access regular demonstrations, training and joint assessments when required.

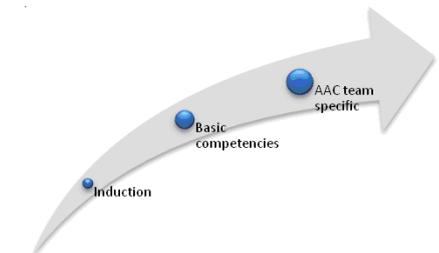
Annual Review

An important part of our service governance is our annual review process. This comprises of a stock take of equipment within the department, including cleaning, servicing and PAT testing as required. We also review the AAC devices on loan within the county by drawing on the information held on the database.

We contact patients who have equipment on loan by letter in the first instance, then by telephone if required, and request that they contact us to let us know whether they are still using the device, and whether it is still fully functioning.

The Microsoft Access database allows us to pull reports on the equipment including number of loans made, most commonly loaned pieces of equipment and the total number of items within the department. We often use this opportunity to clear out any old, obsolete or broken stock and condemn them via Medical Engineering. The AAC lead writes a report for the service manager accounting for any losses and produces a service strategy for the coming year.

TRAINING AND DEVELOPMENT



All members of the Adult Speech and Language Therapy team have a thorough induction to AAC at the point they join the service. This is carried out in two phases: (a) an introduction to the equipment; (b) an introduction to the policies and processes.

We expect all team members to complete basic AAC competencies which relate specifically to the equipment we have within the service. This meets one of the requirements of the Care Quality Commission with regards to issuing equipment to patients.



Annual Review

Within the AAC team, at least one team member attends the Communication Matters Roadshows annually. We also make use of supplier training, AAC SIGs, our regional Link Therapist meeting, and attend the Communication Matters annual conference in order to keep up to date with new developments in equipment and clinical practice.

SERVICE DEVELOPMENTS

As a result of having a well-established service, we have been able to take advantage of interesting development opportunities. The AAC team have been able to offer a support group for people using SL40s within the county, with the help of representatives from Toby Churchill. The group meet three times a year to share their experiences of using a communication aid, practise specific techniques or skills, and troubleshoot any problems they are having.

Recently the AAC team lead therapist has secured funding from Health Education South West to enable her to analyse attendance data from the SL40 group, collect qualitative data from AAC users, and write up this initiative with support from the Bristol Speech and Language Therapy Research Unit and University of the West of England.

CASE STUDY

Background: 56 year old female (US) with diagnosis of Motor Neurone Disease. Working as a nurse, lives alone. Bilingual: English and German. Monitored by local Speech and Language therapist from the point of diagnosis with MND (including support with dysphagia).

Dec 2013: Referral to AAC specialist. AAC SLT demo: SL40, Lightwriter Swift, iPad, Smartnav Headmouse, switch accessible Grid2 on a laptop.

Jan 2014: Issued with SL40 from department stock. US expressed an interest in

eye gaze. Referral to Bristol Communication Aid Service (BCAS).

Feb 2014: Low-tech aids provided for use with carers to support with night time positioning.

April 2014: Purchase of SL40 Scanning Connect (bilingual). US increasingly concerned about computer access: no longer able to directly access keyboard. The Grid2 demo installed; onscreen keyboard accessed via a standard mouse.

May 2014: SLT contacted BCAS. No assessment date available. Joint assessment carried out with Smartbox. Good calibration achieved with Tobii camera. Referral made to MNDA for loan of a Tobii PCEye Go.

Unable to achieve a suitable camera position without a floor mount due to the increase in tilt US required when sat in wheelchair. Discussion with and updated assessment report sent to BCAS.

June 2014: Assessment with members of BCAS. PCEye Go camera available on loan from MNDA. US no longer had use of her hands, so was unable to access her on-screen keyboard or the keyboard on the SL40.

After two visits, specific feedback and close discussion US is now set up with a Daessy floor mount, monitor (provided by BCAS), Tobii PCEye Go camera (on loan from MNDA), and a laptop stand (modelled by Remap). She accesses desktop PC functions via Gaze Interaction Windows Control and has a bilingual Grid 2 with modified Fast Talker 2 as her communication aid.

This system has enabled her to carry on communicating with friends and family, participating in astrology workshops, managing her care needs and writing her book!

CONCLUSION

We were motivated to share the model for local AAC service delivery that we have established in Gloucestershire in or-

der to open up the conversation about the future for local services.

We look forward to having closer links to our regional specialist assessment centre and to other local services to support the development of high quality Spoke services and to promote service development initiatives.

It is our hope that local services will lead the way in:

- Innovative implementation of AAC, e.g. groups, conversation partner schemes
- Developing assessment skills and quality assured reports in order to access National Commissioning Funding
- Continue to provide sensitive, timely and dynamic services to meet the changing needs of our clients
- Training and awareness raising within local teams and local geographic areas.

Recent clarification on the role of local services provides a useful framework from which we can identify our strengths and knowledge but also be clear about the limitations of local services.

Classifying local services using the service specification now available provides us with an identity and recognises local skill and experience. This clarity can support local services to work more closely together in order to share good practice, innovation and service development. *

Katherine Broomfield
Speech and Language Therapist
Louise Walters
Speech and Language Therapist

REFERENCES

- 1 The future of AAC services in England: Commissioning: a framework for equitable and effective commissioning, Department for Education Grants Project, 2013.
- 2 Service specifications:
www.communicationmatters.org.uk/news-item/2014-update-on-local-aac-services



Developing an Effective AAC Service Within the NHS and Education Settings

HELEN ROBINSON¹ & SHELAGH CROSSLEY²

¹ Bradford District Care Trust

Doncaster & Bassetlaw Hospitals NHS FT, Children's Speech and Language Therapy, Chequer Road Clinic, Chequer Road, Doncaster DN1 2AD, UK
Email: helen.robinson@dbh.nhs.uk

² Chellow Heights School, Thorn Lane, Bingley Road, Bradford BD9 6AL, UK

INTRODUCTION

We are a Speech and Language Therapist and a Teacher who have worked together over the past five years alongside other colleagues to develop an effective AAC service jointly between the NHS and Local Education Authority, finding solutions to a range of challenges presented within both these settings, where time and resources are often limited. Many reported AAC experiences come from independent education settings and we can often struggle to apply these to our day to day work. We aim to share some of the challenges faced in implementing AAC within a Local Authority setting and some of our solutions.

CHALLENGES

Completing an assessment for appropriate AAC and achieving funding is the first step, but often where we, as professionals, fail is in the implementation and continued use of AAC. So many times we put all our efforts into providing the right piece of equipment, only to find it left locked away in a cupboard. Here are some of the key issues we find ourselves facing regarding the implementation of AAC:

TIME

One of the greatest challenges to the successful implementation of AAC is lack of time. Speech and Language Therapists working in the NHS frequently experience high caseload numbers and feel the impact of this on the quality of service they can provide. Teachers too also feel this strain with large class sizes and other education agendas.

Those working with AAC users will be aware of the large amount of time required to support the implementation of an AAC system. Time is needed to train education staff regarding all aspects of that AAC system, from the operation and maintenance of the device to the teaching of the vocabulary package as well as how to embed it into everyday classroom practice.

Schools frequently struggle to release staff from class during the day to be trained, and staff are often reluctant to stay behind after school for training if they are not paid. This often results in one member of staff being released for training rather than all those who are working with the child.

ATTITUDES TO CHANGE

People often fear what they do not know or understand. Even though they are accepting of the need for AAC and welcome an initial assessment, we find that once a system is introduced education staff and parents resist the change, often stating that they understand the person's existing communication methods adequately. Where technology is introduced, there is often a fear of 'getting it wrong' or 'breaking it.'

DEVELOPING STAFF COMPETENCIES

Frequently there is one SLT and one Teacher/Teaching Assistant who has responsibility for supporting AAC users. All too often we are faced with this key person being absent through maternity leave, sick leave, or moving on to another role. As mentioned above, we often find that

one staff member from class is allocated the responsibility of supporting the AAC user. Other staff members tend to then see AAC as not being their role and actively avoid supporting the user whilst in the classroom.

WHAT HAVE WE TRIED TO ACHIEVE?

We did not set out with a specific plan as such, but over the years we have tried to tackle some of the key issues preventing the implementation of AAC, listed below.

- Developing expertise
- Parent involvement - AAC at home
- Collaborative working

SOLUTIONS

We have developed a variety of forums to meet the challenges faced in implementing AAC effectively across Health and Education, where time and financial resources are often stretched, alongside the challenge of poor parent/carer engagement. These are: An SLT Peer support group, An AAC multi-professional committee, A regular advice and information day for families, professionals and AAC users, a newsletter, a Communication Conformity Group and training packages. Here we explore each of these solutions further.

PEER SUPPORT GROUP

The SLT Peer support group meets three times a year and is attended by all SLTs working with AAC in our local service (Bradford District Care Trust) We discuss service development and policies, current AAC technology and case

discussions. We often invite Product Specialists from the communication aid manufacturers to demonstrate new AAC systems. This group has proved to be a valuable forum in which to share our ideas and develop the competencies of SLT's within our team.

COMMUNICATION AID LINK MEETINGS

We have developed the Communication Aid Link Meetings (CALM) between a variety of professionals in Health and Education. These are held termly and aim to plan the most effective use of SLT time within Special Schools in Bradford.

Emphasis is placed on all agencies agreeing how best to use SLT time, rather than it being the decision of the SLT alone. It also serves as a forum for developing professional competencies amongst all agencies with the aim that support for AAC can be shared.

We also hold two client specific case discussions within these meetings aimed at establishing a clear action plan for our most complex AAC cases. Parents/carers are invited to these case discussions and encouraged to contribute and be part of the team approach.

AAC ADVICE AND INFORMATION DAYS

The Communication Aid Link Meetings feed into our termly AAC advice and information days, where we offer an open forum for professionals, families and users to access advice, information and training relating to any AAC needs. Hosted by ourselves in alternating Special Schools, we invite local Product Specialists from manufacturers such as Liberator, Tobii DynaVox and Smartbox to come along and be available to help with device issues and also to allow children to trial products. As professionals, we benefit from having the opportunity to look at new products and network with colleagues in the field of AAC.

These days provide a much needed solution to those AAC issues which often 'pop up,' such as a communication aid not working, a child's skills suddenly changing or staff changes. Rather than have to wait months for an appointment with an SLT, we can invite the family and/or teaching staff along to the advice day and hopefully resolve the issues on the day, or at least provide an interim solution until an appointment can be made with an SLT.

We find these sessions helpful for parents when first thinking about exploring AAC for their child. They can come along and have an informal chat with teachers, therapists and product specialists and see the equipment available. Parents of existing users also appreciate the opportunity to

come into school and meet with the professionals supporting their child.

AAC NEWSLETTER

The Speech and Language Therapy Service publish a termly AAC team newsletter, aimed at highlighting key events within Bradford and the local region (e.g. 1Voice events). The newsletter also features interviews with those working with AAC to relay personal experiences and also highlight our profile amongst service users. The newsletter is distributed to all families on the SLT AAC caseload and all Special Schools in the local area.

TRAINING COURSES

We offer a range of training courses for families and teaching staff. These include the 'You Matter' course (Clare Latham & Amanda Bousaki, NHS Milton Keynes Community Health Services) and a training course "Identifying and supporting AAC users within the classroom," developed by Helen for the Special Schools in Bradford. Shelagh also works as an independent trainer and provides training on a range of AAC topics to schools within the region.

The Speech and Language Therapy Service is currently looking at offering a one hour workshop giving an overview of AAC for all staff in Special Schools to attend with the aim of making all staff aware of how to support someone using AAC.

COMMUNICATION CONFORMITY GROUPS

This group was established to try and develop and maintain a consistent use of communication approaches within the special schools across the Bradford and Airedale regions. It is attended by nine Special School representatives, Speech and Language Therapists and specialist services such as Visual Impairment and Hearing Impairment. The group aims to agree policies and an equitable local offer in each special school. We meet twice a year and have established various sub-groups, including:

- AAC (high-tech)
- Intensive Interaction
- Signs & Symbols
- Tactile Communication

Further information can be found at www.btcg.org.uk

SCHOOL RESOURCE 'DROP INS'

Chellow Heights Special School run half termly workshops for school staff to create and renew resources (objects of reference, symbols etc). Mini training sessions are offered (e.g. Using Boardmaker), switch toys are available to borrow and

staff become more aware of what resources are available and how they might use them within their classroom.

Ongoing challenges

Whilst our service has developed and improved over the years, the challenges identified earlier still exist and we are by no means close to solving them. The format of some of our forums has needed adjusting and our service has been shaped over the years by the needs of both professionals and parents/carers.

Whilst the Communication Aid Link Meetings helped to bring professionals together from across the local area and develop competencies amongst education staff, the parents who attended felt overwhelmed at the size of the group. Although the initial aim of the group was to bring together staff from all five of the Special Schools in Bradford, with each meeting attendance numbers have reduced because staff could not be released from the school timetable.

We continue to struggle to engage parents in the implementation of AAC. Even if free training is offered, very few attend. We notice that the children who are the most successful with AAC systems are those who have the support of their parents as well as education staff.

HOPES AND AIMS FOR THE FUTURE

Our AAC service is continuing to evolve and we are continually evaluating and adapting our forums. We are currently looking to use the iPAACKS competency framework (www.nes.scot.nhs.uk/media/2507407/nesd0214aacframework-re.pdf) and hope to use this both within the Speech and Language Therapy team and across schools.

We believe strongly that effective AAC implementation is the joint responsibility of health professionals, education staff and parents/carers and our interventions are therefore routed in multi-agency working. We feel we have made significant progress and are proud of our achievements given the time and financial limitations associated with working in the NHS and Local Authority Education.

We are hopeful that the new specialised commissioning of AAC services will have a significant impact on the effective and equitable provision of AAC for the children in our region and look forward to further developing our local service alongside the new specialist hubs. *

Helen Robinson
Paediatric Speech & Language Therapist
specialising in complex needs and AAC

Shelagh Crossley
Assistant Head Teacher & Independent
Specialist Communication Consultant & Trainer

Are you looking for AAC knowledge?

www.AACknowledge.org.uk brings together information and research evidence about AAC in one place. In order to meet the needs of a wide audience it provides different ways of finding out more about AAC.

Do have a look at **www.AACknowledge.org.uk** and let us know what you think using the site feedback form.

The website features:

- A bibliography of published research into AAC
- Plain English summaries of research articles
- Case stories
- Factsheets
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- Glossary
- Links to many other sources of information



Augmentative and Alternative Communication

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

AGOSCI in Focus

AGOSCI in Focus (formerly AGOSCI News) is the newsletter of the Australian Group on Severe Communication Impairment. It is an ISAAC affiliated publication and is published twice a year.

ISAAC Israel Newsletter

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

Members of Communication Matters (ISAAC UK) can order these publications by contacting:

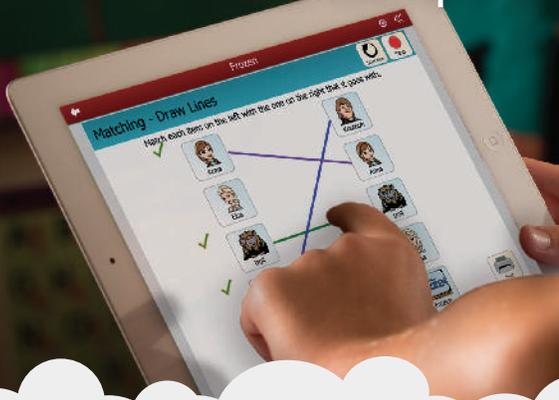
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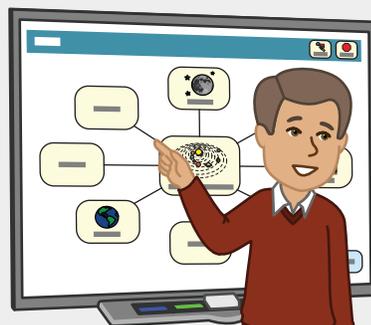
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