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Communication Matters / ISAAC (UK)
Catchpell House, Carpet Lane
Edinburgh EH6 6SP, 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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Media Representations of AAC Users

How do we want to be seen?

KATE CARYER
Email: midgekate@blueyonder.co.uk

I am Kate Caryer, and I am a dumb spaz!!!

In other words, I have athetoid cerebral palsy and this affects my mouth so I can't speak with it, but I speak through a communication aid. On reflection, my cerebral palsy is athetoid and not spastic and I hope I am not dumb. The fact that I somehow have two degrees to my name, one of which is a Masters from Leeds University should indicate that I am not dumb in the sense of being a bit thick! I said dumb spaz to make a point and I am well aware you might find it offensive.

A WORD ABOUT WORDS AND A WARNING

In this paper there might be words that you do not like. I promise I am not including these to try to offend you but to make a point about the power of language and to work out what words are acceptable to AAC users. Also, in this article I am going to look at some things historical; some of the language they used in the past would seem unacceptable to most of us today. I am going to leave language for now but don't say I didn't warn you!

Another word of warning. In this article I will speak about stories of certain individuals using AAC and show you portrayals of AAC users to make my points. However I am looking at how they are shown and not judging them, the professionals that they are working with, the choices of AAC systems which are made for them and their personal views. What I am trying to say is: I am not judging anyone but ruddy journalists!!

WHAT AM I TALKING ABOUT?

So, what I am going to talk about is media representations of AAC Users. At the conference I started to gather people's views on how AAC and its users should be presented in the media. We did this by looking at examples of news stories and considering if they are a good or bad portrayal. "But what is a good or bad portrayal of AAC?", I hear you ask. Being a very opinionated drama queen, I have my own very strong views. Comments at the conference included:

- AAC users are too often portrayed as poor unfortunate victims whom people should feel sorry for.
- There are too many stories along the lines of: sweet little child gets a VOCA through a charity and her first words are "I love you, mummy". This makes good copy but elicits pity. (Kids are more likely to say something rude like "poo poo head" if they can magically use a communication aid the second it arrives.) Then you have the most famous portrayal of an AAC user, which is Steven Hawking who is the opposite of that little helpless child. AAC users are simplified with simple emotions and motivations.
- Generally, there are not enough examples of AAC users in any media, doing things other than being an AAC user.
- Someone said we should think how AAC is shown because anyone can lose their voice.
- Lee Ridley (Lost Voice Guy) should be on The Last Leg as one of the presenters, which I think is a brilliant idea.

My ideas are that media portrayal of AAC users should:

- Empower AAC users
- Be based on the social model of disability rather than the medical model of disability
- Not be all about this wonder computer which is more important than the person using it
- Not be a tragedy
- The disabled person should be seen as powerful and not weak and helpless.

MEDIA REPRESENTATION: WHAT IS IT AND WHAT ARE THE ISSUES?

Media representation is the way that the media shows a particular group to society. This being Communication Matters, the group in question is people who use AAC. Media is a form of communication.

The website Disability Planet *(www.disabilityplanet.co.uk/critical-analysis.html)* has a very good section on media representations of disabled people.

Representation is an important thing to consider when you are talking about groups of people that are deemed to be some how different from most of society. Stuart Hall, a leading sociology professor who has written a lot about representation, says that:

"Representation is a complex business and, especially when dealing with difference, it engages feelings, attitudes and emotions and it mobilizes fears and anxieties in the viewers, at deeper levels than we can explain in a simple, common-sense way."

I would argue that if we have good representations of difference, then we can change attitudes for the better, but if we are subjected to representations that do not portray certain people well or accurately, negative feelings towards this group might be reinforced.

WHAT I AM DOING AND HOW

The aim of my presentation at the Communication Matters Conference and this article is to start a debate about how AAC users are portrayed in the media and popular culture.

To start with, I sent out a questionnaire to a mix of people concerned with AAC to gather some views about representation, their opinions about five examples of media representation and their thoughts on some choice words. I researched what other disabled people in the Disability Studies field had written about media representation. I considered whether language is really important and asked my questionnaire respondents and the people who came to my presentation their views on certain words.

Finally, I hope to get you thinking about how AAC and its users should be portrayed in the media. One thing everyone did agree on (both questionnaire respondents and at the presentation) was that it is important, and many used words such as 'very', 'massively' and 'extremely'.

WE NEED TO TALK ABOUT KEVIN

My inspiration for my presentation and this article was a news story in the Daily Mail (I don't normally read it, I hasten to add) about a man called Kevin and how the Communication Matters e-mail group went mad because the story did not ring true to those of us in the know. Not only was it inaccurate but, in my view, it was sentimental tosh belittling the disabled person.

Kevin is a man with brain damage developed in adulthood. He was given an iPad with a free communication app, which no one could argue is not a good thing for the man in question. The Daily Mail printed his story with the lines:

"At last, someone can hear me: First words of man left brain damaged after brutal attack who can 'speak' (sic) for first time in 20 years thanks to an iPad."

Communication Matters picked up on this story, pointing out that it might not be the whole story. Catherine Harris, Chair of Communication Matters, wrote:

"We believe the real question is why Kevin, and others like him, are made to wait years and years for support that is already available and makes a monumental difference? We also need to increase awareness of the full range of AAC solutions that are available. The iPad is well known because it is a mainstream product in the public domain, however there is not only one solution available for all people in Kevin's situation."

This echoes the sentiments of something a parent said to me:

"The media still too often seem to present AAC as some kind of wondrous miracle for the occasional individual, which militates against it being seen as something normal to which all who can benefit from it should be entitled."

Also, someone in the communication aid field asked on Twitter:

"How many news stories about non-verbal disabled people do the British media have to cover before the real story is mentioned?"

So this story about Kevin isn't only not to some people's liking, but it might do some damage to the AAC world.

I included Kevin's story in my questionnaire where I asked: "What do you think of this portrayal of AAC? Think about the words and how it makes YOU feel and in your opinion, do you think this is a good or bad portrayal of an AAC user?"

The story aroused strong feelings in most people from the AAC world. Some said it made them angry (two speech and language therapists and two parents) and the two AAC users from England didn't think much of it – one said it was over-sensationalised.

Many people questioned why he didn't get a communication aid before. From reading the story in the Mail there are things that don't sound realistic, such as his all important first words. An AAC user commented: "The press seem to like these 'first word' stories, but they turn people into freak shows". Two disabled people with speech – so with limited experience with AAC – but well versed in disability politics wrote that the story is set in the tragedy model of disability and it makes Kevin seem helpless before the arrival of the super iPad. They also had an issue with how the iPad 'speaks' (in quotation marks) for him. One said that this implies that speech via AAC is not real speech. (Is writing on a computer 'writing'?)

A small number of people thought this story was positive but only two did not question it. Of the people into AAC, most of them felt very strongly that this was an inaccurate portrayal of AAC. It could be a case of us in the know don't like it, but the general public would not know any better, but one lovely Mail reader in the comments section even had a issue about the expense of an iPad:

"And it HAS to be an iPad, does it? No cheaper alternative will work? I mean, if someone wants a carrot, can't they point at a picture of a carrot? Does it have to be a picture of a carrot ON AN iPAD?!?!?! Don't get me wrong... I'm delighted that this guy is finally being heard, but I wonder if the staff couldn't have tried a little harder than waving a £600 gadget under his nose?!?!?"

There is a short TV news report[1] about Kevin's story which could be seen as an example of a piece of media that sets out to inform people about AAC but in my view is ill-informed. Firstly, from the disability rights angle, Kevin, the disabled person doesn't get to say anything about how this makes him feel. People at the conference who watched the clip commented on the fact that Kevin was portrayed as passive, was not shown

[1] *www.aljazeera.com/video/europe/2013/02/201322023194940513 2.html*

respect, and that it was implied that there was a stigma attached to communication aids.

So this story about Kevin isn't only not to some people's liking, it might do some damage to the AAC world. If someone who knows nothing about AAC sees it, the chances are they will take this as gospel. Representation in the media can hold a lot of power and it is important to get it on our terms.

A BRIEF HISTORY OF AAC

So when did the thing we all know as AAC actually start? When did they discover that people without speech or with severely impaired speech could actually communicate? I didn't have time to research fully the history of the field of AAC. However, alternative communication might predate speech or language. When you think about it, cavemen probably used grunts and wall paintings to communicate with each other, so isn't that AAC? Some early people used tablets to write on but I don't think they were quite the same thing as your iPad! People have also used sign languages over the years.

This history is fascinating but is beyond the scope of this article. However, I think it could be interesting to consider very briefly the development of new ways for disabled people without speech to communicate. I think this is relevant to this topic because where we are now and how we got there might tell us why representations of AAC are the way they are or what they should be.

It is believed the earliest communication boards were used in the 1920s with people with cerebral palsy but I feel that the world started to change in the sixties and seventies due to not just technology being developed but also the general change in attitudes towards disabled people that occurred in the last decades of the twentieth century.

THE GROOVY SIXTIES AND SEVENTIES

Many things relevant to this subject occurred in the 1960s and 1970s. Here is my run-down of the seventies.

Coming in at Number 5 is Reg Maling in the 1960s with his invention called Patient Operated Selector Mechanism, or 'Possum', which is thought to be the first communication device. This was a typewriter which was controlled by puffing and sipping and was designed for paralysed people in a hospital in the south of England. Also really interesting is that Reg and his team supposedly addressed the lack of media awareness by commenting that, with technology, disabled people can be seen to reach their full potential. Reg also learned to fly so he could deliver the equipment to people quickly. Without Reg, we wouldn't be where we are today.

At Number 4 is "we need some education". In 1970, the Education Act stated that all disabled children will be educated. Prior to this, some children were deemed 'ineducable' and called 'severely subnormal' (such a nice way to put it). I don't know for sure what kind of children they meant, but I am guessing that in those days, if you have a severe physical impairment and no speech, you might well fall within that category. The good old days, eh? The Education Act 1970 meant that all disabled children had the right to an education, which is surely a good thing, even if kids say they hate school!

A quick little entry at 3 for a certain Mr Churchhill. Toby started making not-so-light Lightwriters in 1973. Then in 1974 a newspaper reported that Toby asked the government for some backing but was given no money! Some things never change.

Number 2 is a high climber for the rights for disabled people everywhere. The Union of the Physical Impaired Against Segregation (UPIAS) was formed in the 1970s. It was one of the first groups of disabled people fighting back against what some thought was too much control from non-disabled people. They brought to the world some of the most revolutionary thinking about disability, which led to the development of the Disability Rights movement.

Number 1 is the naming of AAC which occurred in 1980. ISAAC and then Communication Matters were set up.

So there you have it – my history of AAC. Obviously I am missing a lot of things but my point is: here is where we are now. We are in a brave new world with fantastic technology and stronger rights for disabled people. The representation of AAC and people using it is absolutely fantastic these days! Oh no, it isn't!

In 2012, there was a story in the Daily Mail about a five year old girl with cerebral palsy getting a so-called laptop (a communication aid to you and me). The article is best described by my teenage friend who uses a communication aid: *"It makes me cringe with sweetness overload"*, with sentences such as:

"'I love you mum': First words of girl, 5, after being given high-tech laptop that helps her speak... L C suffers from severe cerebral palsy which leaves her wheelchair bound and means she has to struggle to communicate... But after being given a special eye recognition computer she has finally been able to make herself heard for the first time."

Generally in the questionnaire group, the feelings about this article were more mixed than for the Kevin article, and people at the conference commented on the words. Some of the questionnaire group said it used the medical model of disability, and I agree. I think the models of disability are very important in viewing disability.

SOCIAL MODEL VERSUS MEDICAL MODEL

UPIAS turned the whole idea of disability on its head. They, as disabled people themselves, realized that the main problem that they faced was created by society, in the form of discrimination and segregation, and was not within their impairments. They can say it better than me:

"In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society."

So they set out to differentiate between the idea of disability and impairment thus:

Impairment: Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.

Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participating in the mainstream of social activities.

This way of looking at disability came to be called the social model of disability. Its opposite is the medical model of disability where the problem is deemed to emanate from the individual impairment. For example, my impairment is cerebral palsy and, according to the medical model, the most important thing is trying to lessen or cure the impairment so that I can function in an unchanged society. Whereas in the social model, the problems come from society and the focus is changing society to accommodate disabled people.

Many people argue that UPIAS was the start of the Disability Rights movement. Paul Hunt, the founder of UPIAS, wrote in a book of essays in the 1960s:

"We are tired of being statistics, cases, wonderfully courageous examples to the world, pitiable objects to stimulate funding."

As pointed out by Colin Barnes, professor of Disability Studies at the University

of Leeds, this statement accurately summarizes one of the main obstacles to disabled people's emancipation: the stereotyped portrayal of disabled people in popular culture.

Things had not improved by 1992, when David Hevey, disabled photographer, said:

"The history of the portrayal of disabled people is the history of oppressive and negative representation. This has meant that disabled people have been presented as socially flawed able-bodied people, not as disabled people with their own identities."

Have things got any better? The general consensus amongst the questionnaire respondents and those at the conference was that things are a little better, but there is still a long way to go.

WORDS – A CRIP BY ANY OTHER NAME

Language around disability is a huge subject, so I will briefly list some of the words that I, other disabled people, my questionnaire respondents and those at the conference found inappropriate, negative or offensive: *victim, inspirational, courageous, brave, confined to (a wheelchair), handicapped, sufferer of (the impairment), dumb, tragic*. There are many more.

"Does the language we use actually really matter?", I hear you ask. Personally I think it is really important because language will influence how people feel about a subject such as impairment. Language can also reinforce negative stereotypes. I would argue that the language which is used in the media could influence attitudes towards disabled people.

WHERE DO WE GO FROM HERE?

I hope you agree with me that representation of AAC and its users is a very important issue. I propose that AAC users and those working with AAC should develop a statement to be added to press releases and sent to publishers of inaccurate or inappropriate articles or images, setting out the true facts about AAC in a realistic, positive way which is not demeaning to disabled people. As someone said at the conference, getting AAC should not be newsworthy, what someone does with it should be important. ✱

Kate Caryer

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Talking about Child Protection

We are researching the experiences and views of children and young adults with deafness or disability about the child protection system.

Do you know of someone who is deaf, or disabled - particularly with communication support needs – who has suffered neglect, maltreatment or abuse, and who may have had contact with Child Protection services?

Led by Professor Julie Taylor, the University of Edinburgh, with partners from Strathclyde and Coventry Universities, is undertaking an NSPCC funded research study exploring the views of maltreated disabled children and young adults about child protection services. The perspective of disabled young people has not been explored before. We hope the study will provide valuable lessons about how child protection services can better protect and support them.

We will be interviewing disabled children and young people aged 11 – 26 years from across the UK who have either (1) experienced the child protection system, or (2) who may have been abused but did not access services. Interviews will be made accessible according to the young person's individual physical and/or communication support needs.

We need help to find children and young people for interviews, and would be very grateful if you would consider publicising the study across relevant networks, and/or passing on information to individuals you think might be interested in taking part.

For further information or if you would like to participate, **please contact Deborah Fry (lead researcher); or Sally Millar (particularly for AAC users); or Audrey Cameron (particularly for deaf and BSL users).**
Tel: 0131 651 6259 Email: childprotection@ed.ac.uk or sally.millar@ed.ac.uk or audrey.cameron@ed.ac.uk

THE UNIVERSITY OF EDINBURGH / NSPCC child protection research centre

NSPCC Cruelty to children must stop. FULL STOP.

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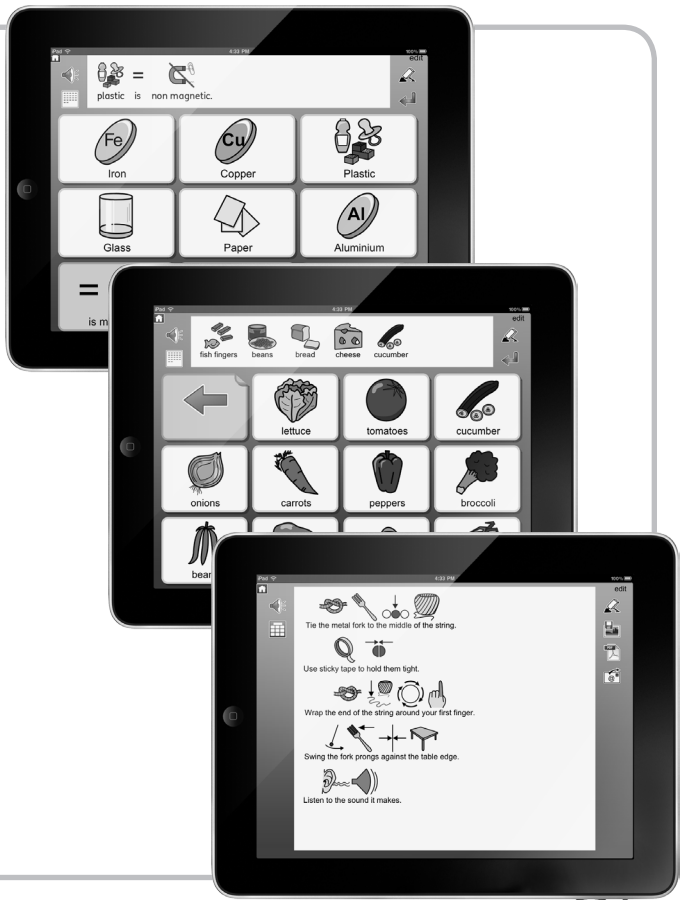
Widgit

Motivating learning on the iPad

Widgit Go



Widgit Go is an app for creating activities and grids to support communication, learning and language development. Use it in the home, in the classroom or on the go.

Widgit Go can be used as a voice output device or to write simple documents with symbols and text from Grids.

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Communication Access

An Australian Journey

HILARY JOHNSON, DENISE WEST, BARBARA SOLARSH, HANK WYLLIE & RON MOREY
Communication Resource Centre, Scope, 830 Whitehorse Rd, Box Hill, VIC 3128, Australia
Email: crc@scopevic.org.au Website: www.scopevic.org.au

BACKGROUND

Participation and social inclusion are basic human rights for everyone in society. These rights can be ensured where universal access is practised. Universal access results in the minimisation of barriers in the physical environment (Stark, Hollingsworth, Morgan & Gray 2007), signage and way finding, transportation, written information, and interpersonal communication.

The first disability symbol, the International Symbol for Access (ISA), was developed in 1968 and adopted by The World Congress of Rehabilitation International in 1969. It was intended that this symbol should represent not only physical access, but access for all types of disability. However, due to its design, the ISA has come to represent access to the physical or built environment.

People with communication difficulties face a range of communication barriers that are largely unrecognised. Yet communication has been identified as a social barrier to be addressed (International Classification of Functioning, Disability and Health, World Health Organisation, 2001) and as a human right (United Nations Convention on the Rights of persons with a Disability, 2006). Social barriers exist in terms of attitudes to people with disability, and interpersonal barriers exist in the way people communicate and interact. It is these barriers that exclude people and create social divide (Collier, Blackstone, & Taylor, 2012). By addressing these barriers, communication access can be created to places, goods, services and people where previously it was absent.

The Communication Access Network in Victoria is uniquely placed to address social communication barriers and communication access. The network is comprised of eleven regional services that provide some direct speech pathology service to adults with little or no speech but also have a directive to build the capacity of the community to include people with communication disabilities. The network is coordinated by the Communication Resource Centre, a service that provides a framework for communication capacity building and provides additional specialised services such as accessible information and the Non-Electronic Communication Aids Scheme (NECAS).

The Communication Access network has been a driving force in developing the concept and practice of communication access. Within Victoria, the current working definition of communication access is: *"Communication Access occurs when people are respectful and responsive to individuals with communication disabilities, and when strategies and resources are used to support successful communication"* (Communication Resource Centre, 2013). Similarly, communication access in Canada has been defined as "having the means, supports and opportunities to communicate effectively, meaningfully accurately and authentically in order to get equal uncompromised access to goods and services" (Collier et al., 2012, p3).

This paper describes how the vision of creating communication access in communities has been translated into action in Victoria, Australia.

AIMS

It is within the context of the Communication Access Network that Scope's Communication Resource Centre began to develop the concept of communication access. This work has led to the identification of a new symbol for communication access and practices to embed communication access into businesses and services.

METHOD

The Communication Access Network has worked alongside people with a communication disability in partnership to:

- identify the symbol for communication access
- develop criteria for communication access
- develop a communication access checklist
- develop a regional initiative to create awareness about communication access
- engage government and private services, disability organisations and retailers to qualify for the symbol (Solarsh, Johnson & West, 2012).

IDENTIFYING A COMMUNICATION ACCESS SYMBOL

From 2008-2010, Scope's Communication Resource Centre led a state-wide consultative process following the Australian Standard AS 2342-1992, to develop the communication access symbol.

Over 1,700 people from 16 different stakeholder groups in Victoria responded to ten possible symbols. People with communication disabilities (including people with intellectual disability) were able to make their selection using a set of custom made Talking Mats, a strategy to support choice making for people who cannot speak (Murphy & Cameron, 2002). The symbol selected became the new symbol for Communication Access.

The second stage of the symbol selection process required that the symbol is shown to a range of people who interpret what they think such a symbol represents. Responses included ideas such as: communication is a two-way process; people talk and people listen; I talk then you talk; people can communicate here.

The new symbol (shown right) was launched in 2011. In 2012, application for endorsement of the Communication Access symbol was made to Rehabilitation International (RI) to give recognition to the symbol as separate from, and additional to, the symbol for physical access introduced by RI 43 years ago, in 1969. RI's International Committee for Technology and Access (ICTA) has recommended that RI endorse the Communication Access Symbol as the international symbol for communication access, and this is being considered by the Rehabilitation International Board.

DEVELOPING COMMUNICATION ACCESS ASSESSMENT CRITERIA

In order to identify the barriers to communication access as perceived by people with communication difficulties and their supporters, thirteen forums took place across Victoria for over 700 relevant stakeholders. Each forum varied in size and included a session on communication access delivered by a person using a voice output aid and concluding with group discussion sessions. A total of fifty small discussion groups were held as part of the forums and data was collected in response to two main questions: Why do you think people with communication disabilities have negative experiences in the community? What do you think could be done to address this?

Fear of people with disabilities and lack of understanding about people with communication disabilities were the most highly ranked themes emerging from those forums.

DEVELOPING A COMMUNICATION ACCESS CHECKLIST

Five categories addressing the barriers to communication access in all settings were identified, and these form the basis for the Communication Access Checklist. The checklist was piloted by people with communication disabilities and is currently being used to assess services, businesses and organisations who wish to be awarded with the communication access symbol.

The five categories include: (a) ten questions about staff that relate to interpersonal communication; (b) three questions about the display of products, and the clarity and accessibility of information provided about products and services; (c) five questions about the place or service and how the environmental supports could improve communication and contact with the place; (d) five questions about signage; and (e) two questions about dealing with money and payment. There are three questions related to staff training, the frequency of people with communication difficulties using the service, and whether the person could successfully get their message across. In addition, where more than 10% of the service or business is conducted over the telephone, there are specific questions about phone access.

From these questions, ten are essential minimum standards for a service to be awarded the symbol. The five categories closely resemble the findings from the research by Collier et al. (2012) in which they asked people with complex communication needs what changes should be made for them to be able to communicate effectively in their communities.

COMMUNICATION ASSESSMENT PROCESS

The process for undertaking communication access assessments has evolved over time and it is not identical for all services, but rather is customised according to the type of business or service, the size, the number of employees, and the number and location of high staff-customer contact points.

An integral part of the communication assessment is that a person with a communication disability, who has undergone training to become a communication access assessor, conducts the assessment. After a period of identifying communication access gaps and addressing these, a trained Communication Access Assessor visits the location and completes the Communication Access Checklist. Services or businesses receive a feedback letter acknowledging the features that have made them communication accessible and making recommendations where this could be further improved.

Becoming communication accessible may be a long term process. The assessment involves the service interacting with people with communication disabilities that in itself sensitises staff to the needs of people with communication difficulties. Over the past few years a growing number of communication assessors have been trained with differences in age, disability and communication skills in order to cater for the varying needs of the industries requesting communication access. The position of communication assessor is one of paid employment and confers rights and responsibilities as with any other employee. All of the assessors (even though most are literate or semi literate) require considerable time and support in preparation for the assessments, discussing the results of the assessment and preparing reports. However, this also results in growing confidence and activism among the people with a disability and a commitment to work in partnership with other professionals and community services to move communication access forward.

The need for staff training is usually identified during the communication access process and this may take different forms, depending on the service involved. The value of staff interacting with the communication assessor has been repeatedly expressed by services as a motivating factor to improve com-

munication access for all community members. The notion of treating people with disabilities with dignity and respect, and of addressing them directly rather the person accompanying them, has historically always been a part of disability awareness training and recognised as good practice (Ward, Nichols & Freedman, 2010).

However, these good practice notions have become essential practices when interacting with people who have difficulties understanding speech or using speech effectively to get their message across.

Thus communication access could be considered part of universal design in that having a range of communication practices not only assists people with a communication disability but others, such as people from cultural and linguistic diverse backgrounds and tourists with limited English, who could be identified as having communication difficulties.

ENGAGING BUSINESSES AND SERVICES

Communication access assessments were initiated in Victoria at the start of 2012. By September 2013, 43 places had been awarded the Communication Access symbol and appear on the Scope Directory of Communication Accessible Places; there are also eight places are in the process of becoming accessible.

SUMMARY AND CHALLENGES AHEAD

People with any kind of communication disability can expect to be treated with dignity and respect wherever they see the Communication Access symbol. The symbol is underpinned with standards that mean a person will be given time to communicate, and the listener will make an effort to communicate in the way that is best for the person, so that s/he can get the message across.

Many of the businesses/services awarded the symbol have been awarded just one or two points of access (e.g. reception area). A different process needs to be developed for organisations with multiple outlets (e.g. multinational corporations).

There is national and international interest in communication access. The challenge that arises is how to implement and monitor this outside Victoria. The Communication Access symbol is the first step to making communication a right, not a privilege. ✱

Dr Hilary Johnson, Denise West, Dr Barbara Solarsh, Hank Wyllie, Ron Morey

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Scope Directory of Communication Accessible Places: *www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre/communicationaccess/businesses*

isaac
International Society for Augmentative and Alternative Communication

Augmentative and Alternative Communication

Thiis 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.

Unterstutzte Kommunikation

This ISAAC affiliated publication is published four times a year in German by ISAAC-GSC.

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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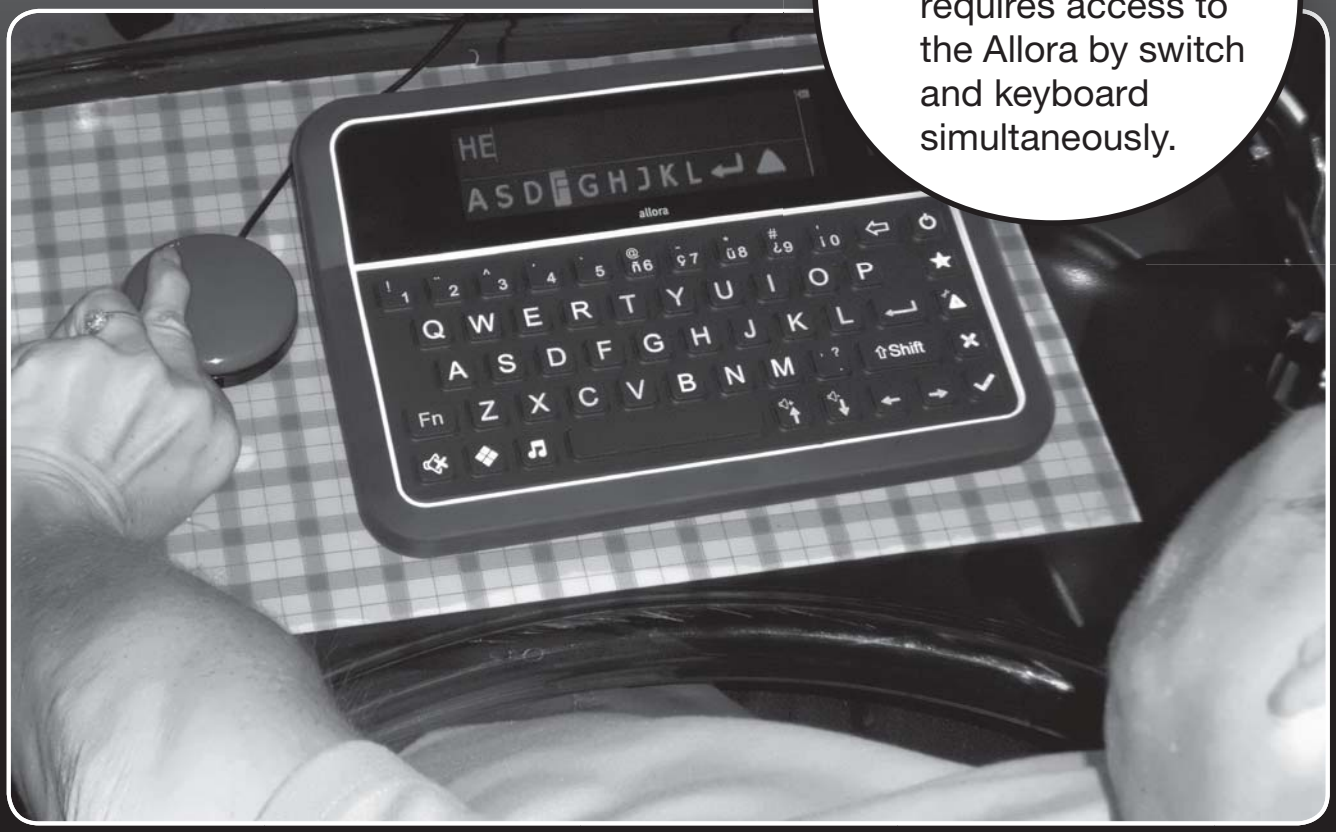

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Planning and Going to the Communication Matters Conference in Leeds

... and what I got out of it, good things and bad

BARRY SMITH
Email: bsbsmith40@googlemail.com

Hi, I am Barry Smith. I am 34 years old. I have cerebral palsy and use a power chair and communication aid too (Lightwriter Connect).

For the last five years, I have been a member of a network called Communication Matters for people who use any form of communication aid, and anyone who works with them, and also family and friends. Each September Communication Matters has a two and a half day conference.

HOW DID I PLAN MY TRIP TO CM2013?

I asked for funding from Toby Churchill for the train fare for myself and my support worker to go, and for our registration fee. They were happy to do this for us.

So I got the train timetable. Then I had to arrange with the railways, a few days before going, for ramps to let my power hair on and off the trains.

On the morning of 14th of September the support worker came to get me and we got a taxi to the station. When we got off the train in Leeds, we took another taxi to Leeds Uni where the conference was on. It looked so big and rather like a small town in itself.

After we got booked in, I wanted to go to the first meeting, so I asked my support worker to take our bags to the bedrooms and he was happy to do this for me.

CAN I GET INTO THE MEETING?

Before I went into the hall a man stopped me and said, "The meeting has already started, we can't let people in after it has started, but we have set up a room up with a screen so people can hear and watch."

After 10 minutes of trying to hear what was going on, the speaker in the hall asked if there were any questions. I put my hand up and typed this into my Lightwriter: "Do you mind if the people in this room come into the big hall because we can't hear right, and feel a bit out of it." Then I was let in.

WHAT WAS THE BEDROOM LIKE?

After the first session I went to see the place where I was staying, before opening of the exhibition. When I went into the bedroom I couldn't believe my eyes because each room had a double bed, which I felt was great!

WHAT WAS UP WITH THE PLACE WHERE THE EXHIBITION WAS?

After I got sorted out, me and my support worker went to the exhibition. There was a ramp but not proper disabled access – we had to go round the back and in a side door, which put 10 minutes on.

When I got in, I looked around and start to talk to a few people like people who work for Toby Churchill, it's always nice to meet them. And people from CALL Scotland too.

Over the next few days I had lots of people I wanted to talk to and network with, so I just started speaking, and some people I spoke to thought the same way.

Cathy Harris, Chair of CM, presents Barry with The Alan Martin Trophy for Creativity

SUNDAY DINNER

Then it was time for dinner. So we make our way to the dinner hall, that was set out like a food court, it was all nice.

People started to network and have good food. I was chatting about past conferences and why this year is so different.

After dinner we had a quiz night and more chat and social time, which is good: people can say how they really feel about things, and sometimes people can get new ideas about things.

EXHIBITION AND TALKS

Because there were no talks I wanted to hear on the Monday morning, I went for a better look at the exhibition and to chat to some people working on different stands, about communication.

When I went to Toby Churchill I spoke to the lady about the User Handbook that I had written and emailed her about, in July. She asked me, could she put this on Toby Churchill's website in a few

weeks time? I was over the moon about this because I put a lot of work into this project and was hoping that one day people will see this work.

I saw they had a power chair, and me being the person I am, I asked if I could I try it out, and my support worker helped me into it. The lady told me a bit about the chair. It works by eye movements. I felt it was great for a person who can't use their hands but your head needs to stay in the same place all the time. When I got back into my own chair, I felt bliss because I could use my hands.

After I had something for lunch, we went to hear an AAC user's story called *'Making My Kind of Music'*. In the workshop, Mark Rowland told his story from when he was a young boy and he wanted to be in the school band, to this day.

At the next workshop I had a little bit of input. A few weeks before the conference, CALL Scotland had organised an AAC Day. Sandra Hartley, who is the Marketing Consultant for Communication Matters (CM), had asked me if I could I do something about CM at that meeting. So I did – I told people how to become a member, and what they would get out of being a member. Then we did a questionnaire what about what people knew (or didn't know) about CM and what they wanted from CM. I fed back on this at the workshop in Leeds. (I had it all programmed into my Lightwriter but I forgot where it was saved – so it was a good job Sandra had a copy of what I was going to say!).

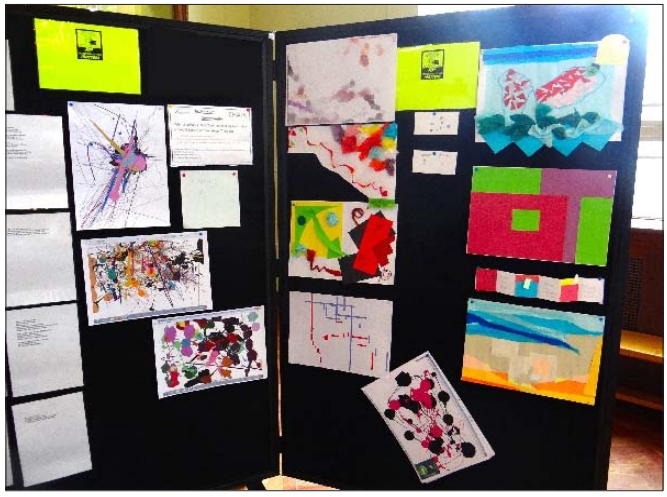
At the same workshop we were told ISAAC was having an 'AAC month' in October, and all round the world. I had a idea that when I went back to college I would ask to do a talk on what it's like to use a communication aid and what people should do when talking to someone who uses AAC. After this workshop I went back to my room to get changed for dinner.

CONFERENCE DINNER AND DRESSING UP

But I didn't dress for the party starting just after dinner - you might wonder why. Each year at the Conference there is dressing-up at the party. This year the dress code was 'white'. One thing about this that was not so good is that if you are a messy eater like I am, you couldn't get dressed before dinner!

The food at dinner was out of this world, it was so nice. I started to chat to people sitting at my table, asking them: What do you think of the conference so far? Everybody gave good feedback, saying this year is better in every way.

After a nice meal, I went back to my room to get changed. Someone thought I was going to my bed and said goodnight to me. I said, "Do you think a Scots man will go to bed when there is a party on? I am just going to get ready for the party!"



Artwork created and displayed at the CM2013 Conference (Barry's poems on left)

When I went back to the party wearing white, I had a few dances. I felt the group was good (though I've heard better at past conferences). I got speaking to two ladies who were dressed up as Pandas - we had good long chat and a few more people as well.

PEOPLE WITH COMMUNICATION NEEDS, AND DISABILITIES: THINGS I WOULD LIKE TO SEE INVESTIGATED

The next morning I got talking to 1Voice which is a network for people age between 5 and 18, who speak with communication aids. They told me the group liked older AAC users to join, to support the young people. One of lady asked me to join, and said they have members in Scotland, so I say I would join then. Sitting next to her was a toy dog, but if you put your finger in, it would bite down on it.

I got talking to the woman and played her these questions I had stored in my Lightwriter:

Over the years of living with cerebral palsy and knowing many people with the same disability as myself, I have seen some things...

1. *When people with cerebral palsy get upset, sometimes the person bites their self - why?*
2. *Most people who have cerebral palsy find it hard to write and they have poor grammar and spelling. Why? A few months ago I asked for a dyslexia test. But I was told that to do this test I have to go onto a computer and I have to be a fast typist to do it.*
3. *When people who have a disability leave school, what is out there for us - like college or work?*

I think these are things Communication Matters should look into.

Then I ask the lady what does she think? She took me to her friend, who told me she had looked into how people with cerebral palsy get upset, and she had written a book about what she had found out about it. She did because she has a son with cerebral palsy.

The last workshop, in the main hall, updated everyone about what is going on in AAC in England, Scotland, Wales and Northern Ireland. Scotland had three speakers to talk about what is going on. I personally thought this was a good thing, because we are a part of the UK.

ALAN MARTIN TROPHY FOR CREATIVITY

Just before the Conference ended, they announced the winner of the *Alan Martin Trophy for Creativity.*

Alan Martin had cerebral palsy and was a communication aid user, and he taught people how to dance. He was always at conference but soon after last year's conference, sadly, he died. In his memory Communication Matters donated a trophy for the most inspiring and creative work.

Then I heard that the winner of the award was me, for writing poems. I was very happy to win the award but also sad because I personally knew Alan and spoke to him every time we met. I remember at one conference in particular going to hear him speaking about how he came off his benefits and set up a dance school, which was brave.

Then I got my three trains back home.

Apart from winning the award, the thing that I liked best about this conference in Leeds was the room being more accessible. The one thing that was a let-down was that there were not many talks by AAC users. ✱

Barry Smith

NHS Education for Scotland Update

A Right to Speak

MORAG FERGUSON & SUSAN SHANDLEY
NHS Education for Scotland, 102 Westport, Edinburgh EH3 9DN, UK
Email: aac@nes.scot.nhs.uk Tel: 0131 656 3200

INTRODUCTION

The Scottish Government published *'A Right to Speak: Supporting Individuals who use Augmentative and Alternative Communication'* in 2012 and within it articulated the following vision for Scotland:

"Individuals who use augmentative and alternative communication are included, free from discrimination, and live in an environment that recognises and their needs and adapts accordingly" (Scottish Government, 2012: 10)

Four strategic aims, underpinned by eight recommendations are central to the delivery of this vision and the Scottish Government has committed to £4 million across 2012 and 2015 to making these happen. The four strategic aims (Scottish Government, 2012: 10 – 11) are:

1. The communication needs of people who require to use AAC are universally recognised.
2. Individuals who require to use AAC have equal access to quality AAC services at a level commensurate with their needs at any point in their lives.
3. Individuals who require to use AAC are supplied with appropriate equipment in a timely manner.
4. Services supporting people who use AAC contribute to developing a robust evidence base for the effectiveness and cost effectiveness of AAC.

NHS Scotland is made up of 14 regional NHS Boards and seven Special NHS Boards. Regional NHS Boards are responsible for the delivery of frontline healthcare services as well as the protection and improvement of their population's health and Special NHS Boards support them by providing a range of specialist and national services. NHS Education for Scotland (NES)

is one of the Special NHS Boards and is NHS Scotland's education and training body, ensuring that patients and their families get the best healthcare possible from well trained and educated staff.

NES was identified as a key partner in supporting the delivery of the strategic aims and a project team was appointed to lead a national, multiagency project focussed on realising the vision which Scotland is aspiring to. The £4 million was divided between direct allocations to designated AAC Leads in each regional NHS Board for multiagency use and NES. The funds allocated to NES, reflecting the multiagency nature of AAC, are being used to support national, strategic developments across the health, education, social care and voluntary sectors.

As we enter the second half of the project, it is possible to reflect on a number of achievements that have been made to date across three broad streams of work, namely: Multiagency Partnerships, Learning and Education and Research.

MULTIAGENCY PARTNERSHIPS

Reflecting the multiagency nature of AAC, partnership working is fundamental to achieving the vision of "A Right to Speak". At the start of the project AAC services varied greatly across the country therefore NES prioritised partnership development in 2012-13 and 2013-14. In view of the diversity of current partnership working practices and arrangements NES invested in both the initiation and establishment of partnerships alongside the enhancement and evolution of existing partnerships.

Examples of the activities / projects NES has supported include:

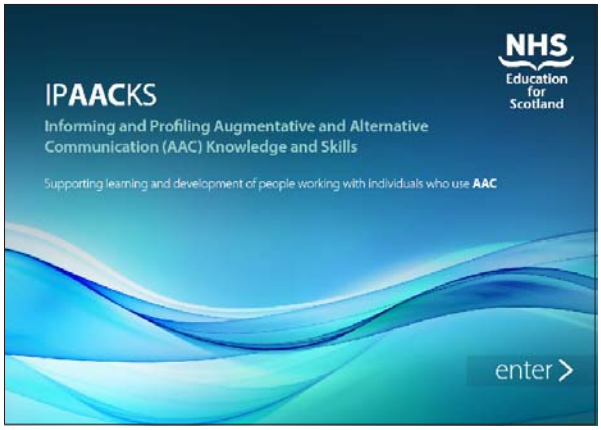
- Multiagency consultation events exploring the most effective means of supporting individuals who use AAC both currently and post 2015
- Provided funding to enable individuals to increase their capacity to focus directly on partnership development
- Supported pilot projects exploring the establishment of new roles e.g. an AAC principle teacher post

LEARNING AND EDUCATION

In *'A Right to Speak'* it is made clear that everybody in society has a role to play in helping to ensure that people who use AAC are fully included. In recognition of this, NES has commissioned and supported the development of a number of projects targeting all sectors of society – including people who have minimal and potentially only occasional contact with individuals who use AAC through to highly specialist professionals for whom AAC is at the core of their practice.

CALL Scotland was commissioned to produce a suite of 'Universal Support' materials targeted at the general public and/or those who may meet people who use AAC in their work e.g. public facing workers in shops, restaurants etc. The main aim of these materials (which

includes posters, online learning materials and resources) is to raise awareness and support people to understand and respond to the needs of people who use AAC thereby promoting their inclusion in society



In collaboration with the Scottish Centre of Technology for the Communication Impaired (SCTCI), NES has commissioned and supported the development of an Education and Development Framework for AAC that will help everybody to understand their AAC learning needs and how to meet them. This framework will be known as Informing and Profiling AAC Knowledge and Skills (IP***AAC***KS) and will support anybody, from any agency to evaluate their learning and development needs in order to support their professional development in relation to AAC. Use of IP***AAC***KS will be supported by a self assessment form and accompanying sign posting to appropriate learning opportunities. It will be available electronically in December 2013 with published copies forthcoming in March 2014.

Complementary to each of these projects NES has also commissioned a scoping exercise to identify what learning opportunities already exist so that gaps can be identified and solutions explored in the next year of the project. Furthermore, through a dedicated learning and development fund NES has supported 35 applications from staff across the health, education, social care and voluntary sectors to access AAC related training opportunities.

RESEARCH

In the context of a climate of competition for resources it is essential that those working with individuals who use AAC have access to evidence that demonstrates the value of AAC. In line with the fourth strategic aim of *'A Right to Speak'*, during 2012/13 NES commissioned four research projects.

These projects were about: Outcome Measures, Quality Indicators for AAC Services, Cost Effectiveness and Data Collection Systems. Both individually and collectively these projects contribute to the evidence base for and have influence on the delivery of AAC services.

Each project is being progressed in a slightly different way with a follow up Outcome Measures project being explored (to provide a reliable and common method of AAC services measuring their impact), the Quality Indicators project report being used to inform the service specific aspects of the IPAACKs resource and the Data Collection report being used by NES to inform further discussions.

The Cost Effectiveness project produced both a report and two cost calculators that can support AAC services to demonstrate the value (in monetary terms) of the impact of their work for two paediatric client groups.

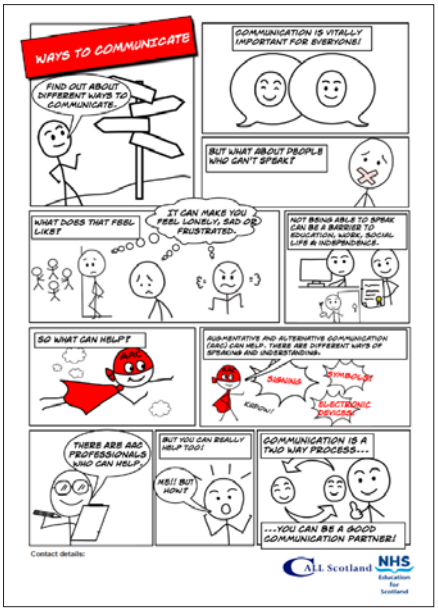
With a view to the future NES will explore how best to support the development of an AAC research infrastructure for Scotland. In terms of sustainability everybody needs to recognise their responsibility for contributing to the evidence base and NES will look to define how this can happen. This may include looking at the knowledge and skills of the workforce in relation to research and how we can build capacity for research at a service level.

THE FUTURE

The NES project will run until March 2015, therefore sustainability has been – and continues to be – a key underpinning value. In order to support the developing infrastructure of AAC partnerships, an online hub is being explored which could support collaboration across partnerships and provide a central reference and access point for service information and learning and development materials.

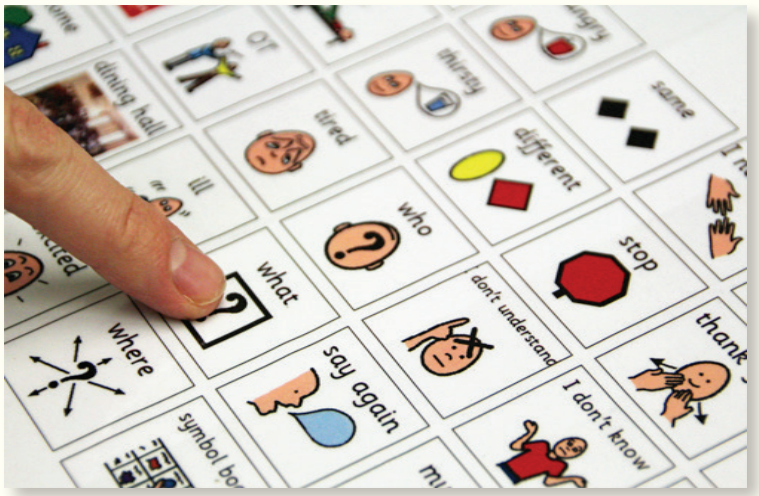
In addition, marketing will be a key task through the remaining part of the project to ensure the products and services that have been developed are accessible to and used by those who need them. As we move towards the final phase, the picture created by the vision of *'A Right to Speak'* is being built piece by piece and NES would welcome all contributions that will ensure the project's legacy. ✱

Morag Ferguson
NES Educational Projects Manager (AAC)
Susan Shandley
NES Educational Projects Manager (AAC)



COMMUNICATION MATTERS STUDY DAY

Symbolisation *towards* Literacy



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TRUSTEES'

NEWS

FROM CATHERINE HARRIS, CHAIR OF BOARD OF TRUSTEES

LOBBYING PAYS OFF!

As I am writing this, the AAC Sub-Group for the Clinical Reference Group for Complex Disability Equipment has just received news of the provisional release of a substantial amount of funding for AAC services and equipment in England.

Communication Matters (CM) has a high profile among stakeholders and it continues to be a privilege to be able to influence for positive change. It is still a transition time for service delivery and funding but it really does look as though all the work and lobbying over recent years is beginning to produce results.

I continue to represent CM on the Communication Trust Consortium, the Specialised Healthcare Alliance, and the AAC Sub-Group for the Clinical Reference Group for Complex Disability Equipment. These groups have all contributed to shaping government legislation.

It has been encouraging to hear from the CM membership that they appreciate the investment that Communication Matters has put into lobbying. It is also acknowledged more widely that, without the investment from CM (so ably supported by Whitehouse Consulting), AAC services would not have the profile they have today.

It is always a real challenge to balance Communication Matters' finances but we hope that, with careful management, we will be able to continue this investment in lobbying activities, at least until April 2014 when the new AAC funding model in England will be launched.

CM2013 NATIONAL AAC CONFERENCE

After a year of planning and much hard work by many people, the 2013 Conference at Leeds University has been declared overall a resounding success. Thank you for all your positive and constructive feedback.

The programme was full and varied, with over 70 presentations and 400 delegates. For the first time, we organised a **'twilight' seminar** to introduce over 80 speech and language therapy students to Communication Matters and AAC. Toby Hewson shared in presenting this session which was very well received. We hope this event will shape and influence the practice of the students who are at the start of their careers.

There were a number of other new initiatives, including the CM **'On the Sofa' Chat Show** chaired by our own chat show host Tom Griffiths, who displayed hidden talents. Our special guest **Paul Maynard MP** was grounded and inspiring, both when interviewed on the sofa and when delivering the keynote speech. There was a **Creative Art Workshop** for people who use AAC facilitated by Claire Evans from the University of Leeds, with support from some of the Smartbox team. The tour of the University's Stanley Burton Art Gallery was informative and inspiring. The artwork produced in the workshop, including pieces created by eye gaze, was displayed in the Exhibition Hall.

Keynote speaker Paul Maynard MP (L) was also 'On the Sofa'

There were also opportunities for the membership to contribute to discussion about the future plans for Communication Matters. The food and accommodation at Leeds was really good and the Conference dinner (meal and décor) exceptional, even if the Beatles Tribute Band was rather loud!

While many people were having holidays, the summer was a really busy time for our administrators Patrick Poon and Peter Head in the office, so I want to express my particular thanks to them again for all they did in Conference planning and logistics.

The Conference is a great place for networking, sharing ideas, and being (re)inspired. Following a conference debriefing and evaluation with Trustees and university staff, there are already lots of ideas for building on the success of this year and for making next year even better. One of our main aims will be to try to secure sponsorship for the Conference. This will enable us to free up funding to allow us to support other new and existing initiatives.

TRUSTEES' NEWS

THE NEW BOARD OF TRUSTEES

It is good to welcome **Marion Stanton** to the Board as a full Trustee. Marion brings a wide range of experience and we look forward to working with her. **John Hicks** and **Beth Moulam** have been invited onto the Board as co-opts for one year. John brings marketing experience and also suppliers' insights. Beth has just started her university course and so will bring us a student perspective.

As the new Board starts this term of office it is important again to remember that Trustees serve on a voluntary basis. I want to express my appreciation for all those who have served in previous years and have made CM what it is today. I am also grateful to those who are willing to stand as Trustees at the present time and look forward to working together.

Trustee Name	*Job title*	*Roles and Main Responsibilities*
Sally Chan	*SLT*	*Southern link; Small Grants; Events for PWUAAC*
Dithe Fisher	*SLT*	*Deputy Chair; Scottish link; Online training*
Tom Griffiths	*Assistive Technologist*	*London link; Research*
Neil Hansen	*Supplier*	*Treasurer*
Cathy Harris	*Independent SLT*	*Chair*
Nicola Hayton	*SLT*	*Northern Link; Finance*
Gillian Hazell	*Independent SLT*	*Deputy Chair; Small Grants; Abstracts*
Toby Hewson	*CEO*	*Representing PWUAAC*
John Hicks	*Consultant; Supplier*	*Marketing*
Beth Moulam	*Student*	*Representing PWUAAC*
Ruth McMorran	*Teacher*	*Abstracts; Conference Programme & Events for PWUAAC*
Marion Stanton	*Teacher*	*Communications*

CHAIR'S DIARY HIGHLIGHTS: SEPT-DEC 2013

13 Sep Conference planning meeting in Leeds
21 Oct Conference debrief & evaluation meeting
22 Oct Children and Families SLCN Working Group
24 Oct AAC Subgroup presentation to Commissioners
30 Oct CM Strategy group meeting
4 Nov Conference call re. ACE/CM/1Voice project
5 Nov Communication Trust Consortium meeting
12 Nov Meeting with CM administrators at HQ
9 Dec Specialised Healthcare Alliance event

If you wish to raise an issue with a Trustee, please email via *admin@communicationmatters.org.uk* ✱

Catherine Harris, *CM Chair*

BHTA AAC NEWS

One area of the BHTA that has largely gone un-noticed, especially in the AAC industry, is the Assistive Technology Practitioner Society – or the ATP Society.

The ATP Society is a registration scheme for individuals in the healthcare industry that runs alongside the company membership scheme run by the BHTA. It was set up about 10 years ago by the BHTA after recognition that people in the healthcare industry, like wheelchair repair engineers, stairlift installers, and especially salespeople, often needed no qualification to carry out their roles and no requirement for any Continuing Professional Development (CPD). Over the years this had led to a number of incidents either where vulnerable people where targeted by unscrupulous individuals or staff were employed who did not have the skills or training to carry out their role.

It has always been fairly easy for a member of the public, or another professional to check up on therapists, social workers, nurses, etc - they will be registered and certificated by the HPC, the RCN or an equivalent body. But how do you check the competency of a salesman or woman, or a technical specialist?

Until the ATP Society was formed there was no organisation to register individual's credentials and to ensure their knowledge is kept up to date, but the need for a 'qualification' in the healthcare industry for those not part of an existing professional body is both obvious and long overdue.

Other industry sectors have recognised and trusted schemes to assess and register the competence of hands-on individuals and to signpost them to appropriate skill-enhancement courses. Their Societies monitor their members' commitment to CPD so you then know who you can trust.

So the BHTA encourages individuals from member companies to show they are serious about the industry by taking the required entry qualification tests and then keep up their level of expertise and knowledge through CPD.

Although this qualification, which allows the use of the letters 'ATP Soc' after the name of the practitioner, is not specific to any part of the industry, it does have its value within AAC and several members of staff from Commercial Member companies of Communication Matters are now also members of the ATP Society.

So if you see 'ATP Soc' after someone's name, you can be sure they have passed an entry level test to show their commitment, help raise standards, and ensure their own personal development.

The ATP Society is another way that the BHTA is trying to raise the profile of individuals and companies involved in the healthcare industry, and to ensure no 'rogue traders', unscrupulous individuals or plain untrained or incompetent people are in the industry.

More information can be obtained from *www.atpsociety.org* ✱

David Morgan, *BHTA AAC Chair*

DIARY DATES

16 January 2014 — *Edinburgh*
Speech Recognition
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

21 January 2014 — *Manchester*
Using iPads to Improve Learning Outcomes
Contact MMU: enterprise.hpsc@mmu.ac.uk

24 January 2014 — *Edinburgh*
iPads and Use for Pupils with Additional Support Needs
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

26 February 2014 — *Hull*
Social Networking: Study Day
Contact: 0845 456 8211 www.communicationmatters.org.uk

27 February 2014 — *Edinburgh*
iPads and Communication – AAC Apps from Symbols to Text
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

4 March 2014 — *Oxford*
AAC SIG Meeting (Oxford)
More information: www.aacsig.org.uk

13 March 2014 — *London*
Symbolisation Towards Literacy study day
Contact: 0845 456 8211 www.communicationmatters.org.uk

18 March 2014 — *Manchester*
Using iPads to Improve Learning Outcomes
Contact MMU: enterprise.hpsc@mmu.ac.uk

20 March 2014 — *South Yorkshire & Humber*
AAC SIG Meeting (South Yorkshire & Humber)
More information: nicolahayton@nhs.net

3 June 2014 — *Oxford*
AAC SIG Meeting (Oxford)
More information: www.aacsig.org.uk

DIARY DATES

6 June 2014 — *Edinburgh*
iPads to Support Pupils with a Visual Impairment
Contact CALL Scotland: 0131 651 6235 www.callscotland.org.uk

17 & 19 June 2014 — *London & Manchester (TBC)*
"There is something I want to say" (to be confirmed)
AAC to support temporary and permanent loss of speech at critical times in life: Study Day presented by John Costello, Boston Children's Hospital
Email: admin@communicationmatters.org.uk to register interest

19-24 July 2014 — *Lisbon, Portugal*
ISAAC 2014 Conference
www.isaac-online.org/english/conference-2014

25-26 July 2014 — *Lisbon, Portugal*
ISAAC Research Symposium
www.isaac-online.org/english/conference-2014

14-16 September 2014 — *Leeds*
CM2014 National AAC Conference
Email: admin@communicationmatters.org.uk to register interest

16 October 2014 — *South Yorkshire & Humber*
AAC SIG Meeting (South Yorkshire & Humber)
More information: nicolahayton@nhs.net

4 November 2014 — *Oxford*
AAC SIG Meeting (Oxford)
More information: www.aacsig.org.uk

6 November 2014 — *London (TBC)*
Access Technology: Introduction (to be confirmed)
Email: admin@communicationmatters.org.uk to register interest

7 November 2014 — *London (TBC)*
Access Technology: Advanced (to be confirmed)
Email: admin@communicationmatters.org.uk to register interest

WANT TO HOST A COMMUNICATION MATTERS ROADSHOW?

The Communication Matters Roadshows are great opportunities to learn all about the latest communication aids and software from some of the UK's leading AAC suppliers.

CM Road Shows are held every year at various locations in the UK - and they are free!

We are always looking for new venues to hold CM Roadshows, so if you would like to host one in your area, please do let us know.

Communication Matters will handle much of the adminstration and organisation, including taking delegate bookings.

For more information, please contact Patrick Poon on Tel: 0845 456 8211 *admin@communicationmatters.org.uk*

Raising Awareness of AAC by Training South Devon Police about Hate and Mate Crime

SCOTT STACK
Email: scottstack@hotmail.com

This article explains how I am raising awareness of AAC through the training I am currently delivering to South Devon police.

I am 34 years old, and have cerebral palsy. I use a communication device to talk. This allows me to take control of my life and every day I can tell my staff my needs and what I want to do. I also live with learning disabilities. I need help understanding complicated sentences, so I need information broken down to a much more simple way.

I want to give a brief insight into my life, with an overview of the experience I already have of working across the UK, to deliver presentations about AAC. I want to discuss my most recent qualification, The City and Guilds 'Train the Trainer', and how that has led me onto working with South Devon police. I will explain the things I enjoy about my job and my hopes for the future.

But first, a little bit of background about me. I am currently living in Cornerways Residential Home in Tavistock, Devon. I share my home with another two friends. At home, we have to make the decisions about how we live, like what food to buy, what outings to go on and where we go to work. We have carers 24 hours a day. They support us with all the things we want to do, and also with all our needs. It is important I tell them what I want and also how I want to do things. I have a busy life, just like anybody.

I go to work, do physiotherapy, go swimming and enjoy visiting my family in Hertfordshire. I like going on holiday and love to socialise with my friends regularly. So the key thing that enables me to do all of these things is my communication aid.

The device I use to talk is called an ECO 2. I was 17 years old when I got my first device and I have been working with communication devices ever since then.

I cannot read but I have some word recognition. I am a single switch user, and I operate it with my head. The communication aid will scan through the icons, and I press the switch that is in my headrest when the light is over the icon I want to select.

This is time consuming, and also takes a lot of concentration and energy from me. However, it is very important that I communicate as much as possible with the ECO 2. This is because it enables staff and family to understand me best. It is also much easier for people who do not know me, to get to know me.

I cannot imagine not having my communication aid. I often think of my ECO 2 as a part of my body! And when it goes wrong or breaks, I feel ill. If it stops working, I stop talking so I cannot say my needs to my carers, or tell people how I'm feeling or give my opinion on things.

PAST EXPERIENCES

I have been a trustee for Communication Matters, for three years. But this year I decided to stop. I no longer have the

time to fully commit to all the work required from a trustee because I need to do my work for the police. I really liked working for Communication Matters, but I am ready to let another person enjoy the experiences I have had.

I am also vice chairperson for a speaking-up group in Tavistock. We discuss issues about the town, and I attend a Parliament Day every year. I was involved with helping to make recent changes to the kerbs in Tavistock, so they are now more wheelchair accessible. I like making a difference, especially in my home town.

Furthermore, over the years, I have attended many events and discussions, including: 1Voice, the Access Group Committee, and the Better Health Conference.

Last Christmas, I went on a ten week course to learn how to make presentations, and be a qualified trainer. We did group tasks and had to do homework every week. I wanted to do it, because I knew it would help make the way I deliver presentations better. I also thought that it would improve my opportunities to earn money in the future. At the end of the course, I was assessed on a presentation I had been working on, and I had to do a multiple choice test. I found the test hard, but I passed it all. I was very happy.

EAT THAT FROG

Meanwhile, a non-profit organisation called *'Eat That Frog'* was consistently raising awareness of the treatment of those living with a learning disability. Two of their volunteers met the commander for South Devon Police. They expressed their issues and proposed a training programme, based on how the police can improve their ability to help people with a learning disability when they are victims of abuse, also known as Hate Crimes. He supported the idea, and agreed to push for six months of preliminary training, in Totnes and Paignton.

This is where I come in. Six of us were asked to go to Totnes in Devon. We were asked if we would help design and run the training for the police. I said yes!

There was a mixture of funding from various organisations to pay for the training, including banks and charities. It took a lot of constant pushing from various important people in the police to get the project started in Devon. And now we are hoping to extend it to Cornwall.

The first ten weeks of the training programme was for 300 front line police officers. We taught 30 of them at a time.

The police read the PowerPoint slides at the same time as they listen to what I said

It was based on hate and mate crime and how to help people with learning disabilities.

At this point I want to define what a Hate Crime and a Mate Crime is, as these are relatively new terms, which are likely to be unfamiliar to most people.

Hate Crime: "Any criminal offence which is perceived, by the victim or any other person, to be motivated by a hostility or prejudice based on a person's disability or perceived disability" (CPS & ACPO Agreed Definition).

Mate Crime: "A mate crime is where someone befriends a vulnerable person in order to take advantage of them" (ARC Safety Net Project).

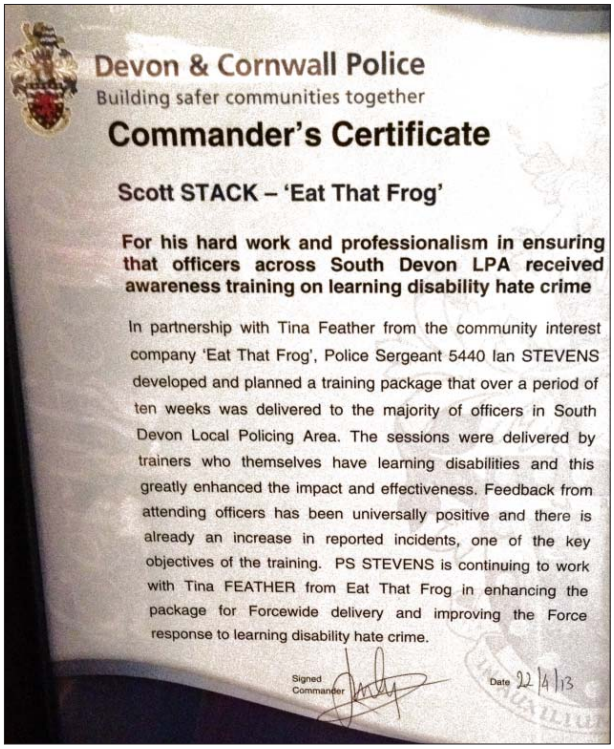
I think the police being taught by five adults with learning disabilities really helped their learning of the topic. Because they were able to ask us questions, and see for themselves about how we are all individuals and live very different lifestyles to one another.

The police learned a lot from me. Mainly about my communication, and that they need to talk to me, not to my carers. Those that I have trained now know that I tell my carers what I want to do with my day. I believe they don't know any other people with a communication device, because they enjoyed meeting me. I also think it was good that the police saw for themselves my commitment to the project. This is because I often travelled to various locations, including the police headquarters in Exeter, to help produce and deliver the training.

The roles for the presentation were shared out evenly. When we designed the training, we all chose the slides from PowerPoint, and what we wanted to say. Then, once we started delivering the training to the police, we got better each week as a team and my confidence got better. I really enjoyed it.

Our overall aim for each training session was to teach the police:

- What a learning disability is.
- How to better recognise and understand people with learning disabilities.
- What a hate crime and a mate crime is.
- How to increase reporting of disability hate crime.
- Increase their confidence to communicate with people with a learning disability, and to provide better support for disabled victims.



Devon & Cornwall Police

Building safer communities together

Commander's Certificate

Scott STACK – 'Eat That Frog'

For his hard work and professionalism in ensuring that officers across South Devon LPA received awareness training on learning disability hate crime

In partnership with Tina Feather from the community interest company 'Eat That Frog', Police Sergeant 5440 Ian STEVENS developed and planned a training package that over a period of ten weeks was delivered to the majority of officers in South Devon Local Policing Area. The sessions were delivered by trainers who themselves have learning disabilities and this greatly enhanced the impact and effectiveness. Feedback from attending officers has been universally positive and there is already an increase in reported incidents, one of the key objectives of the training. PS STEVENS is continuing to work with Tina FEATHER from Eat That Frog in enhancing the package for Forcewide delivery and improving the Force response to learning disability hate crime.

Signed Commander

Date 22/4/13

Certificate from the police that I received for my work

I really liked my experience of doing the training for South Devon police. I especially liked that despite having learning disabilities, we deliver the training for the police.

We teach them how to work with us, and help them to do an important job. Because helping people with learning disabilities is very important for the police to do. Because we need help as well. So, if they can understand our disability a bit more, they can help us better.

I liked that the police had to stop their work, to come and listen to us. I liked that the police think that what I say is important enough to come and listen, and learn from me. I feel valuable because they stop their job to listen to me. I also feel good in my heart because I know I help the police and other people who have learning disabilities.

Even though I love my job, there were some aspects of it that I did not particularly like at the beginning. The first ten weeks of the training I delivered was completely voluntary. I did not get paid for any of it. But my hard work paid off in the end. We have now moved on to training the control room staff (those that take 101 and 999 calls) in Exeter and Plymouth, and I am now earning money from it.

Also, at the start of the training, the information that they asked me to say was scripted. I was told what I had to say in their words, and not mine. I did not like this. I wanted to say the information in my own words. I prefer to use my own words because I want to properly understand what I say. I wanted to spend time at home, reading and understanding the new terminology, and saying my parts in my own words.

I was asked to say more after three weeks. People still did not realise how long it takes me to put information onto my device. I agreed, but regretted it. This is because I had other commitments as well as this work. I did it, but I was tired and had to stay up late on some nights to do it. I over estimated how much I had to do. I learnt from this, and only do what I think I can now, in the time frame given. I want that I do my own words and spend time doing it properly.

FUTURE PLANS

In terms of my future, I hope to work for the police for however long they need me. I want to do work for them on a regular basis. I want to help make changes in the police, to help vulnerable people get better treatment from the police. I will give up my time to help achieve what they need.

I want to also help train other professions, like doctors. I think they need help, like the police, to improve their services to vulnerable adults and people who have learning disabilities. What I do for the police is good. I know because I have very positive feedback from them, so I know it would help other jobs as well.

I would love to have my own office to work in. I concentrate better when there are no distractions around me. In my home, there are lots of people about, but if I was to have my own office, I could work privately. I did a presentation for third year speech and language students at the University of St Mark & St John, Plymouth, and the Head of Department has spoken to me about the idea of having an office there to use. I am still waiting to hear about it though.

Overall, I love to earn my own money and really enjoy what I am doing. I want to carry on doing this for the foreseeable future.

Please feel free to email me. ✱

Scott Stack

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*

Three's Company – An Experimental Proposal for AAC

NORMAN ALM
School of Computing, University of Dundee, Dundee DD1 4HN, UK
Email: nalm@computing.dundee.ac.uk

INTRODUCTION

From the first appearance of technical AAC devices, there has been a problem with their effectiveness that always tends to detract from the assistance offered. This is a feature that is usually too obvious to merit comment. Technical AAC requires the imposition of technology between the AAC and the person or people they are communicating with.

There are occasions when communication, for all of us, would not be possible without technical mediation: for example, communicating over a long distance. In face-to-face communication, however, a technical AAC device may be a tool but it is also a distraction in two ways. The user must turn their attention (and gaze) away from the person they are interacting with in order to compose their message – and this process may take some time. Also, the device tends to draw attention to itself, particularly with unfamiliar communication partners.

Thus a technical AAC system often is seen as a necessary evil. Much design effort has gone into minimising the degree to which the system is an encumbrance to communication, for instance by systems that encourage automaticity of use [1], and devising interfaces that are as effortless as possible to use [2]. With all this development, however, an AAC system can still seem to be as much of a hindrance as a help to good communication, and users will regularly make use of any alternatives, such as vocalisation and gesture, when it is possible.

While efforts must continue to make technical AAC systems as unobtrusive as possible in an interaction, it may be worthwhile to also experiment with a completely different approach. What if we considered an AAC system, not as a tool to be used by one person in an interaction, but as a third element in the interaction, to be used by *both* parties, as shown in Figure 1?

How could a computer-based AAC system become a third element of an interaction between two people, in a way that enhanced their communication experience? There are at least three challenges here. The AAC user will be constrained in how quickly they can provide input to the system. In addition, the naturally speaking partner will have a preference for just using their voice to communicate. Finally, how can the third element avoid seeming too contrived, artificial and irrelevant to conversational goals?

It might be instructive to note that there are two recently developed systems which were designed to work round the communication difficulty of one participant in a dialogue by engaging both participants in a structured activity which results in a satisfying communicational encounter. There may be clues here to suggest how we might proceed.

CONVERSATION SUPPORT FOR PEOPLE WITH DEMENTIA

A computer-based communication support system has been developed which can assist older people with dementia to converse and interact more successfully with relatives and carers. The system, called *CIRCA* (Figure 2), consists of two parts. A conversation support system prompts the user's long term memories by means of

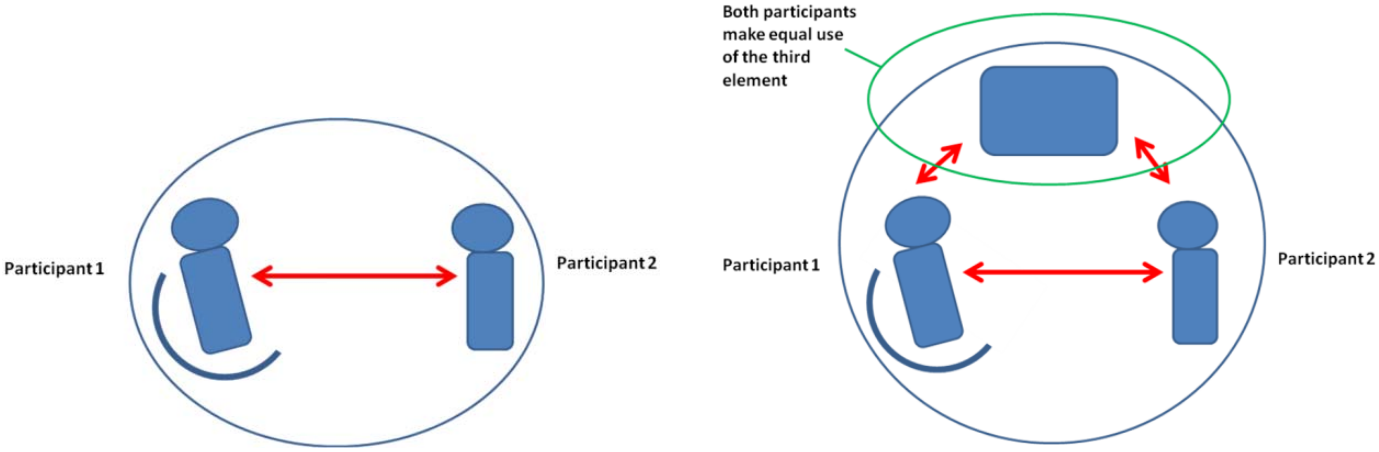


Figure 1 Introducing a third element to a communicational encounter

Figure 2 CIRCA in use, courtesy of CIRCA Connect Ltd

touchscreen access to reminiscence material drawn from public archives [3]. The system also includes a set of interactive games, playable via the touchscreen, which have been developed specifically to be useable and enjoyable for people with dementia [4].

Here, a third element has been introduced into the face-to-face encounter that draws the attention of interactants to itself and alters the interaction from a direct one into an encounter which it mediates. This has proved helpful in assisting an interaction to take place.

The expedient of providing a focus of attention for the participants external to themselves can be of great assistance in making the encounter more relaxing. In this new situation the task becomes, for the participants, not the difficult one of managing the face-to-face interaction, but the relatively easier one of jointly attending to and reacting to something of interest. If what is being attended to is itself an active participant, such as a computer generated interactive display, so much the better: achieving engagement and a sense of conversational flow is significantly enhanced. Interacting with a person who has dementia is aided by making use of a scrapbook of photos, but it is considerably easier if the artefact you are using is itself interactive and inventively engaging.

A COMMUNICATION STRUCTURE TO SUPPORT EXPRESSING OPINIONS AND PREFERENCES

Another communication support method that has made use of this third element principle, to make communication possible where it was difficult or impossible before, is the *Talking Mats* system. *Talking Mats* is a communication framework to help people with communication difficulties express their views and opinions more effectively [5, 6] (see Figure 3).

The system uses a mat, such as a doormat or carpet tile, to which symbols and pictures can be attached by hook and loop tape (a touch screen tablet-based version is also available). Symbols representing emotions are placed along the top to form a visual rating scale. The emotions can be as simple as 'positive', 'neutral' and 'negative' or more detailed, depending on the user. A relevant topic is discussed and a symbol representing it is placed at the bottom of the mat. As the session progresses, the user expresses their views by placing pictures representing various aspects of the topic on the mat, grouping them underneath the appropriate rating symbols.

Talking Mats have been successful with a number of different sorts of people: those with dementia, with a learning disability, with autism and with communication difficulties due to physical impairment. Even if the person has the physical and cognitive ability to communicate, the system can often still be helpful as a support for discussions to clarify, confirm, and increase the person's confidence to put forward their point of view. It has been proved, for example, in working with children who are in care, to help them get their point of view across.

POSSIBLE FUTURE RESEARCH DIRECTIONS

This principle of introducing a third element to a problematic communicational encounter, to which both participants can direct their attention, which both can control, but which can also provide prompts for communication, may provide the basis for a new type of AAC.

What would such a system look like? To a certain extent, interaction through language is a game with rules. What if we were to devise alternative language games that could be played equally by the AAC user and the person with whom they interact, which did not severely disadvantage the AAC user, and which had the effect of providing a satisfying encounter for all parties?

The widespread adoption of social media such as *Facebook* has shown that communicating through technology, by means of an alternative set of interactional tools, is feasible, engaging, and satisfying as an alternative form of social interaction. Studying successful social media platforms might provide a useful starting point in beginning to develop a new kind of AAC which would be controlled jointly by the AAC user and their interactants. In addition to interacting by exchanging of text messages, users also interact by sharing photos, video clips and favourite websites. There are also games that users can play with each other. The 'Like' button provides a quick way to give an opinion.

Figure 3 Talking Mats in use, courtesy of Talking Mats

An AAC system operated by both parties in an interaction would no doubt offer touch screen control, options for a variety of input devices, and scanning. The screen would need to be large enough to be seen well by both parties.

A starting point for developing such a system would be to clarify the communicational goals which the system would support and enable. *CIRCA* supports the goal of recalling stories from your past, and enjoying experiencing generic reminiscence material. *Talking Mats* supports the goal of expressing opinions in detail about a particular subject. A good goal for a new system might be to support the expression of personality. We can convey our personality through clothing, style of music we prefer, or sports team we follow. We can also express our personality through the way we play a complex interactive game.

There is potential here for AAC users and games designers to come together to devise a new way of interacting through a computer based system. Such a system, if successfully developed, may well have applications beyond AAC. ✱

Norman Alm
Honorary Research Fellow

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Quality of Communication Support for People with Severe or Profound Intellectual Disability and Complex Needs

JILL BRADSHAW[1], JULIE BEADLE-BROWN[1], JENNIFER BEECHAM[2], JIM MANSELL[1], THERESIA BAUMKER[2], JENNIFER LEIGH[1], REBECCA WHELTON[1] AND LISA RICHARDSON[1]

[1] Tizard Centre, University of Kent, Woodlands, Giles Lane, Canterbury CT2 7LR, UK

[2] Personal Social Services Research Unit, University of Kent, Cornwallis Building, Canterbury CT2 7NF, UK

Email: j.bradshaw@kent.ac.uk

This paper describes the differences in communication strategies between good and poor services for people with severe or profound intellectual disability (ID) and complex needs. As part of a wider research project into skilled support (Beadle-Brown et al, in submission), information about communication was collected using a range of measures. Additional data on communication was collected via qualitative interviews with service managers and this will be reported elsewhere.

Most staff did not use appropriate and effective ways of communicating with people they supported. A third of people were being supported in a team where communication was rated as good and appropriate most/all of the time. Services providing good support in terms of providing choice, assistance and higher levels of activity were also better at communicating with people

Communication partnerships (between staff and people they supported) were significantly better in services which were providing skilled support in other areas. Person-Centred Active Support is one way in which staff can acquire these skills. This type of intervention, which aims to give staff the core skills necessary to engage people in meaningful activities and relationships, may be necessary to ensure the success of communication interventions.

INTRODUCTION

Mansell & Beadle-Brown (2012) have argued that the "enabling relationship" between staff and the people they support is vital. They suggest that allocating resources so that staff are simply spending more time with people with ID is not sufficient to improve outcomes: it is the quality of that support that matters most. Adults with ID have typically been supported in environments where levels of interaction were low and of poor quality (Bradshaw, 2001). In a more recent review of the literature, Martin, O'Connor-Fenelon and Lyons (2010) highlight the communication mismatches which occur between adults with ID and the staff who are supporting them. Mismatches include staff using too complex communication so that the people they support would not be able to make sense of what was communicated. They also reported a lack of use and recognition of non-verbal communication. Finlay, Walton and Antaki (2008) remark that this reliance on verbal communication is of concern. It can contribute to people with ID having little choice and control. They suggest that, while means of addressing this issue have been developed (e.g. through staff training in communication), "the translation of these understandings into standard practice seems a long way off" (p358).

Person-centred active support aims to provide enough support to enable people with ID to participate successfully in meaningful activities and relationships. Through this participation, people with ID are able to experience greater choice and control and to gain more independence (Mansell et al, 2005). The focus is on providing just enough support or assistance to bridge the gap between what people are able to do and what the task requires (Mansell and Beadle-Brown, 2012).

We now have a large body of evidence which shows that active support can be very effective in increasing engagement in activity and relationships. This research aimed to explore the relationship between active support and communication.

PARTICIPANTS

There were 110 participants from 35 residential or supported living services

	Whole sample N=106	ABS <151 N=64
No communication	8	10
Any verbal	38	27
Any vocalisation	54	56
Any gestures on their own	31	31
Gestures + vocalisation	20	18
Gestures + verbal	15	9
Object of reference	2	3
Object of ref. + vocalisation	1	1
Object of ref + verbal	0	0
Symbols	1	0
Signs	4	1
Signs + vocalisation	3	3
Signs + verbal	1	0
Communication effective most of the time	65	59
Communication effective all of the time	28	19

Table 1 Percentage of participants observed to use different forms of communication and effectiveness of that communication

	Whole sample N=106	ABS <151 N=71
Any non-verbal communication (including gestures)	62%	69%
Any non-verbal communication (without gestures)	31%	34%
No communication used by staff	2	3
Gestures alone	15	13
Gestures with verbal	53	59
Object of reference	13	17
Object of reference plus verbal	20	25
Photos	3	3
Symbols/photos and verbal Communication	2	3
Sign	3	1
Sign and verbal	4	3
Verbal only	80	78
Communication rated as mostly appropriate	79	65

Table 2 Communication support from staff

for people with severe or profound ID, autism, multiple physical disabilities and challenging behaviour. Services were either nominated by their organisations as providing good support for these groups of people or randomly selected from Care Quality Commission lists for the same geographic areas as nominated services.

METHODS

As part of a wider research project into skilled support (Beadle-Brown et al, in submission), information about communication was collected using a range of measures. This included observations of social interaction and contact from staff, the use of alternative and augmentative communication (AAC), reviews of written information, questionnaires about the needs and characteristics of the people supported and interviews with managers. Communication data from manager interviews will be reported elsewhere.

An observational measure combined the Engagement in Meaningful activities and relationships (EMACR Mansell and Beadle-Brown, 2005), The Active Support Measure (ASM) (Mansell, Elliott & Beadle-Brown, 2005) and a specific measure about the nature and variety of communication methods used by staff and the people they support. In addition, a staff-reported measure of adaptive functioning and communication needs was completed by each person's key worker.

SUMMARY OF RESULTS

Reported and observed communication

Over two thirds (69%) of participants were reported not to use verbal communication and nearly one fifth (18%) were reported as not understanding verbal communication (Tables 1 & 2).

Those people who were rated by staff as non-verbal were:

- more likely to have objects of reference used with them
- less likely to have appropriate forms of communication used with them
- less likely to have communication that was effective at getting staff attention and a response.

During observations, communication was rated as consistently matching client level for just over one third of people. Just under half of people (49%) were rated as consistently having their communication responded to.

Engagement of people with ID in activity

On average:

- people were engaged in activity for just under half of the time (44%)
- had any contact from staff for around 25% of the time
- received direct assistance to take part in activities for only 6% of the time.

Just over one third of the people were rated as receiving good active support. To be coded as receiving good active support, opportunities for involvement had to be consistently provided by staff, who then gave just enough support to the individual to enable that person to take advantage of those opportunities (see Beadle-Brown, Hutchinson and Whelton, 2012 for more details).

Under a quarter (22%) of people received good support for choice.

Did skilled support make a difference?

We know that people with more severe disabilities need more support from staff in order to achieve good quality of life outcomes.

We therefore looked just at the group of people who had more severe disabili-

	Mixed/weak support N=45	Good support N=18	Significance
Any non-verbal communication (including gestures)	71%	78%	Not sig.
Any non-verbal communication (without gestures)	24%	61%	$X^2 = 7.61^{**}$
No communication used by staff	2	0	Not sig.
Gestures alone	15	6	Not sig.
Gestures with verbal	53	56	Not sig.
Object of reference	13	33	$X^2 = 5.75^{*}$
Object of reference plus verbal	19	50	$X^2 = 5.67^{*}$
Photos	3	11	$X^2 = 5.16^{*}$
Photos and verbal	2	0	Not sig.
Sign	3	0	Not sig.
Sign and verbal	4	0	Not sig.
Verbal only	80	89	Not sig.
Communication rated as appropriate most of the time	69	100	$X^2 = 22.7^{***}$
All communication appropriate	2	39	

Table 3 Communication support for more severely disabled sample
$^{*}p<0.05$ $^{**}p<0.01$ $^{***}p<0.001$

ties (defined as those with an ABS score of less than 151). When people were receiving better active support, they experienced better outcomes in a number of areas. They also received better support in other areas, in particular support for communication.

Where active support was implemented consistently, staff were more likely to use more formal non-verbal forms of communication, such as objects of reference and photos, and less gestures. (Table 3)

People living in services where active support was good were more likely to be:

- receiving appropriate communication from staff most or all of the time (100% for this sample, compared with just 50% for those people receiving less skilled support)
- living in services where support for communication was consistently good and appropriate most of the time (34% compared with just 0.9% for those people receiving less skilled support).

DISCUSSION

There was variability in quality of support and outcomes but where people with more severe disabilities received consistently good active support they had better outcomes and received better support in other areas, in particular around communication.

It is very difficult to introduce communication interventions when people have little to do and receive little contact from staff. For staff, it is easier to interact with people in a meaningful way over a real activity that can be done together.

An intervention which focuses on providing people with opportunities to participate in meaningful activities and relationships, and which teaches staff to recognise and support participation, seems also to be one which provides support for communication.

When active support is implemented it appears that staff are also likely to have developed the skills to 'bridge the communication gap' and to provide the right amount of communication support to enable participation in communicative acts.

More research is needed to understand what makes staff good communicators, and whether improved communication is an inevitable outcome of person-centred active support or a finding specific to the few services that were assessed as providing good support in this study. It would also be interesting to explore the data collected in greater depth. Questions include:

- Whether the type of setting (single person vs group) influences outcomes?
- What support do staff need to develop their skills in communication?
- What are the views of service managers around the communication taking place?
- How might this have influenced the quantity and quality of communication? ✱

Jill Bradshaw, Julie Beadle-Brown, Jennifer Beecham, Jim Mansell, Theresia Baumker, Jennifer Leigh, Rebecca Whelton & Lisa Richardson

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What Are We Learning From Our Clients With Aphasia Who Use High-Tech AAC?

KAREN REED & FIONA PANTHI
Kent Adult Communication and Assistive Technology Service, Kent and Canterbury Hospital, Canterbury, Kent CT1 3NG, UK
Email: fiona.panthi@nhs.net

INTRODUCTION

Stroke and aphasia

Every year an estimated 150,000 people in the UK have a stroke (Stroke Association, 2013). About a third of those people will have aphasia, a language impairment (Connect, 2013) whereby one, multiple, or all language modalities are impaired: speaking, comprehension of speech, reading and writing.

This paper discusses seven clients with aphasia (six male and one female) aged 45-67 years. Five clients were referred by their speech and language therapists to the Adult Communication and Assistive Technology (ACAT) service for AAC assessment. Two clients were provided with devices via the ACAT provision service. Although all of the clients were using iPads with communication apps, the focus of this paper is not on the AAC device itself. This paper describes how the clients and their families responded to AAC and what we can learn through the successes, obstacles and failings in the implementation of high-tech AAC.

The clients & their family circumstances

Two of the seven clients were a few months post-stroke; the other clients were between two and ten years post-stroke. Three of the clients were in employment at the time of their stroke and were no longer working, four were retired. All the clients had severe expressive difficulties due to aphasia and aphasia/dyspraxia. The clients were restricted to a few spoken words and the occasional written word. Three clients had some problems understanding speech but they were able manage with strategies put in place by their conversation partners.

All the clients had difficulties with spelling and reading comprehension. Three clients were still receiving speech and language therapy rehabilitation. One of the younger clients lived alone with no support from family or friends. Two clients lived with their family but they spent many hours alone. The clients who were retired lived with their spouses and led more active lives.

AAC ASSESSMENT AND INTERVENTION

At the time of referral, two clients had their own iPads and wanted to explore using the device as a communication aid. Low- and light-tech AAC were considered for the other clients but they wanted to try high-tech AAC. All clients had varying levels of computer skills prior to their stroke, ranging from very basic to competent computer users. Some of the clients had already tried using a communication book following their stroke but these had been abandoned. There appeared to be limited use of AAC during earlier speech therapy sessions. Robertson & Schneider (2011) have emphasised the need for earlier AAC intervention rather than when speech and language rehabilitation is drawing to a close, where AAC acts as a 'bandage'.

The communication systems chosen were in keeping with each client's cognitive and linguistic capabilities. All clients were provided with symbol-based apps, either *Proloquo2Go* (AssistiveWare) or *Symbol Talker A* (Sensory Software). One client had a symbol-based app and later he was also provided with a text-based app. All apps were customised. The AAC system included access to commonly used words and personalised vocabulary: for example, one client wanted to be able to join in with nursery rhymes and games with his daughter.

Another client used the keyboard on his communication app during speech therapy activities to help with reading and spelling, facilitated by the word prediction feature. When prompted, he could use the text-based system to augment his communication to help with word finding difficulties. The effectiveness of getting his message across was variable. This client demonstrated a lack of acceptance to use his symbol-based AAC as the text-based AAC appeared more natural for him, despite his limited spelling skills.

AAC training and support was provided for the clients, their family, the speech therapists and Stroke Association staff. The clients were encouraged to use AAC during speech therapy (where applicable), at home and in the community to generalise their skills. All the clients required plenty of time and support to learn their AAC system.

The clients, their families, carers and speech therapists, were invited to a one day AAC user group. During the day, the clients had opportunities to meet other people and to use their AAC system. Specific activities enabled clients to give their opinions on different topics and to enhance their AAC skills. One client was seen initiating topics by pressing photographs on the other client's AAC system! During conversation, clients were encouraged to use other features on their iPads, the Internet and photographs. One client used a map to show others where he had travelled on holiday. The clients' families and carers also had opportunities to communicate using the AAC system.

ACCEPTANCE OF AAC AND EXPECTATIONS

Some clients appeared discouraged by a symbol-based communication system. This was partly due to difficulties with selecting some symbols, especially abstract ones, but it is also possible that

symbol-based systems were perceived as childish in appearance.

Some of the clients said they wanted more messages on their AAC. Although new activities and events resulted in the development of their vocabulary, overall their messages were fairly limited as their AAC system was set to match their language and cognitive capabilities. One family member hoped that the AAC would enable her husband to compose complete grammatical sentences but unfortunately this was beyond his language skills. However, the client was able to use his AAC creatively to compose some three-symbol messages and use photographs to talk about a topic, his news and family events.

Three of the clients were in low spirits, possibly depressed by their circumstances after their stroke. One client was not ready to accept AAC for many months and another client has had several episodes of AAC abandonment during periods of depression.

ATTITUDES AND BELIEFS ABOUT AAC

Some close family members expressed that there was no real need to use AAC at home as they were able to "get by" with their usual methods, or commented "I know what he wants". Furthermore, AAC was rarely considered even when communication by the usual methods broke down.

Generally speaking, although clients with aphasia can make good attempts at communicating with gesture, air writing, and so forth, these are not always understood, especially by unfamiliar/less familiar conversation partners. So AAC systems can be a useful tool to help deliver a clear message.

The family members who did not support the use of AAC at home were also less involved with the editing of the AAC system. In some cases, families were busy working and dealing with day to day life, and were possibly unable to cope with all the life changes as a consequence of the stroke. However, AAC was effective for the clients whose families regularly updated the vocabulary to include personalised, meaningful vocabulary for current activities and future events.

REDUCED PARTICIPATION AND SOCIAL ISOLATION

The clients' lives had changed considerably since their stroke due to their communication and physical difficulties. These changes included: loss of work, inability to drive, and less social interaction. Some of these clients were not participating in many activities outside of their home and in their community.

Some clients had little or no contact with their friends following their stroke. In a research project (Pound, 2013), twenty eight adults with aphasia of working age were interviewed about friends and friendship. The study showed that some people with aphasia expressed that difficulty talking and understanding were major barriers to interacting with friends. Those in the study felt their friends avoided them because their friends felt embarrassed, and some people had lost friends after their stroke. However, for others their relationships with friends had grown closer.

Unfortunately, one client did not have any support from family and friends, so ACAT and the Stroke Association representatives worked together to support him with his AAC. Beck (2011) stresses the importance of supportive communication partners in the overall goal of increased interaction and participation in activities of daily life; this client lacked this crucial support.

Overall, clients did not always take their AAC system out in the community, and opportunities to use AAC with people outside of their family were limited. However, the majority of the clients had experience of using AAC with new conversation partners who visited their home.

CONCLUSIONS

Incorporating high-tech AAC into everyday life can be a convoluted process for aphasic clients. The time and commitment required to acquire the skills to use AAC, and to support the user, might be underestimated by those involved. Clients who are still undergoing speech and language rehabilitation appear to have this as their focus and an AAC system is not necessarily viewed as a 'companion' during this process.

Clients can have difficulties accepting a symbol-based communication system and sometimes experience difficulties using symbols to communicate. Clients and their families may expect that the AAC will provide comprehensive communication. The challenge is matching an AAC system with the client's residual language skills whilst providing enough functional and meaningful vocabulary to motivate and empower the client. Regarding family, for some the intensity of trying to understand someone's message supersedes the thought of prompting use of AAC to help convey and understand the message. However, without sufficient opportunities to build AAC skills and gain confidence, the client is at risk of being a bystander in social situations rather than a participant.

Due to the psychological effects that can occur following a stroke, it is important to consider the client's readiness to use AAC, and also whether the family is able to provide enough support. As opportunities to use AAC can be hampered by social isolation, the need for conversation partners is paramount. Volunteers and befriending schemes need to be explored to help people with aphasia, interact and to promote wellbeing.

Looking forward, further gains in AAC can be achieved by developing appropriate AAC systems (high/light/low-tech) early on in speech therapy rehabilitation and AAC should be an integral part of the process. Regarding high-tech AAC, the growing availability of computer-based speech therapy programs and apps could provide an opportunity for speech therapists to naturally integrate AAC in to therapy sessions. Clients could use their communication app/software to augment their communication during the session and start building on AAC skills which could then be generalised in other settings.

The published accounts of successful use of high-tech AAC with aphasic clients is limited, although there is hope for the future of AAC in aphasia rehabilitation (Phillips, 2009). Somehow, we need to find further ways of demonstrating the gain of using AAC in a condition where there can be so many losses. ✱

Karen Reed
Therapy assistant practitioner
Fiona Panthi
Specialist speech and language therapist

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Assessment of Functional Gaze Control Skills in Young Children with Cerebral Palsy

SAMANTHA WALLIS [1], KATE EDWARDS [1], KATHERINE SHORT [1], TOM GRIFFITHS [2], KATIE PRICE [2], JENEFER SARGENT [2], SIMON JUDGE [3], JOHN SWETTENHAM [1], MICHAEL CLARKE [1]

[1] University College London
[2] Great Ormond Street Hospital NHS Trust
[3] Barnsley Hospital NHS Trust
Email: samantha.wallis@ucl.ac.uk

INTRODUCTION

Young children with cerebral palsy affecting the whole body rely heavily on their looking skills to communicate and learn, particularly when they have little or no speech.

For parents and professionals, careful observation of these children's looking behaviours is a key way of gaining access to communicative skills and learning preferences. Equally, 'eye-pointing' can be a powerful route for children to communicate and access alternative or augmentative communication (AAC) systems (Sargent et al., 2013).

However, in some instances, difficulties using eye gaze for communicative purposes may be attributed to difficulties with basic 'functional gaze control skills'. For example, with an understanding of gaze control abilities, professionals can determine whether poor performance on receptive language assessments is a consequence of language ability or insufficient gaze control skills to selectively attend to the stimuli presented.

Our clinical experience indicates that systematic assessment of functional gaze control (FGC) in young children is not routinely practiced, despite the obvious potential for gaze use as a response mode in assessment and communicative modality in everyday life. There is a risk that, without effective practical tools, clinicians are liable to misinterpret children's abilities and give inappropriate recommendations. This, in turn, has the potential to cause significant difficulties with effective planning and delivering of individualised intervention, with consequences on the support given to children and families in everyday life.

THE FUNCTIONAL GAZE CONTROL RESEARCH STUDY

University College London, in collaboration with Great Ormond Street Hospital and Barnsley Hospital, has been working to establish procedures for the direct assessment of functional gaze control through the development of two criterion-referenced procedures: Behavioural observation of functional gaze control; and Objective measurement of functional gaze control.

These procedures consist of a number of simple tasks exploring basic looking skills. The behavioural observation procedure uses foam-board shapes appearing, moving and disappearing on a black background (Fig 1). This routine is replicated on an eye tracker for the objective measurement procedure. This article will describe the behavioural observation procedure only.

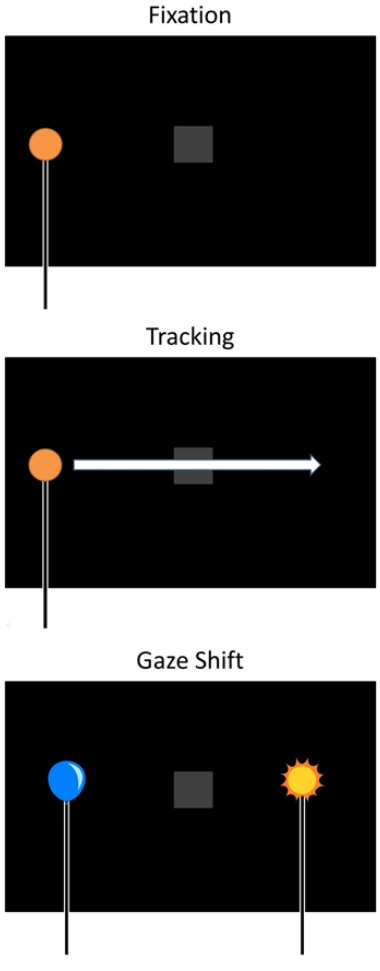

Figure 1

To date, the study has recruited 38 children developmentally aged 1:6-5:8 years (chronologically aged between 2:0-11:0 years) with cerebral palsy affecting the whole body. Background measures of cognitive development, language development and speech intelligibility have also been collected.

Additionally, the behavioural observation procedure has been administered to a cohort of typically developing children aged 1:0-4:0 years.

BEHAVIOURAL OBSERVATION FUNCTIONAL GAZE CONTROL PROCEDURE

The functional gaze control procedure was designed with three primary objectives in mind:

1. To be easily and affordably reproduced in a clinical setting
2. To limit distractions and the social, cognitive and language demands of the tasks, making the procedure accessible to a wide range of children
3. To be quick and simple to administer and score.

The child is positioned approximately one metre from a blackboard. Their gaze response to the presentation and movement of coloured shapes is observed through a small aperture in the centre of the board, which is covered in semi-transparent material, to minimise the distraction presented by faces. This ensures that the scorer has the best possible view of the child in order to observe their looking behaviours.

The skills assessed include the ability to fix gaze, disengage and shift gaze, track moving items, and visually search and selectively attend to objects.

Fixation

The ability to look steadily at a stationary target is assessed using coloured shapes (5cm in diameter) which appear in a number of positions (left/right/centre/top/bottom). The time taken to fix gaze on the stimuli and the length of gaze fixation are recorded. The shape appears in each position twice.

Tracking

Children demonstrate the ability to track when they watch a moving object. In this task, the coloured shape moves either from left-to-right, right-to-left, top-to-bottom or bottom-to-top, at a set speed. Ability to track a stimulus for all or part of the journey is observed as the stimulus moves in each direction four times.

Gaze Disengagement and Shift

In this task, children are required to shift their gaze directly from one object to another. Ability to shift gaze and the time taken to shift gaze are recorded during two conditions:

- 1st condition: the first shape appears and then disappears as a second different one appears to the side.
- 2nd condition: the first shape appears followed by the second shape, and both stimuli remain visible.

This task is designed to highlight those children who find it harder to shift their gaze and attention if another item is visible (2nd condition). Eight trials of each condition are completed.

PRELIMINARY FINDINGS

The data collection for this research project will conclude in January 2014. Early examination of the data has been conducted and indicates that the procedure has good inter-rater reliability and clinical utility (e.g. time of administration).

We have observed considerable variation in functional gaze control skills between participants, with differing profiles of fixation, tracking and gaze shift ability, suggesting that the procedure distinguishes between children with good and moderate skills, as well as those with difficulties in this area.

DISCUSSION

Reliable evidence of functional gaze control is needed by professionals working with young children with cerebral palsy, in order to support the provision of effective, individualised support for children and families in the short and long term.

Parents and professionals can utilise this functional gaze control information to enhance their input and adapt their early interactions with these children. In addition, gaze control information will aid clinicians in interpreting children's responses to different assessments, tasks and situations.

In early 2014, a video tutorial will be made available on the project website *(www.ucl.ac.uk/gaze)* which will give instructions on how to complete the behavioural observation FGC procedure and produce the materials needed. ✱

Samantha Wallis, Kate Edwards, Katherine Short, Tom Griffiths, Katie Price, Jenefer Sargent, Simon Judge, John Swettenham, Michael Clarke

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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, German speaking countries, India, Israel, Italy, Netherlands-Flanders, Norway, Sweden, United Kingdom and the 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.

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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

Establishing and Maintaining a Local AAC Service that Transcends Boundaries

TINA PECK
Community Learning Disability Team, Queen St Health & Wellbeing Centre, Queen St, Grimsby DN31 1QG, UK
Email: tinapeck@nhs.net

INTRODUCTION

In 2006 there was no system for assessing and providing communication aids for adults in North and North East Lincolnshire. The national Communication Aids Project (CAP) was also due to end, meaning there was no longer going to be free access to the ACE Centre in Oldham for the assessment, loan and purchase of systems for children and young people.

We faced the problem of reverting to an unacceptable situation where there was no agreed system regarding communication aids for children, young people and adults. Also, there was no ring-fenced funding and no capital to set up a service with accommodation, a supply of assessment loan aids and personnel.

Across Northern Lincolnshire there was no agreement between agencies regarding the responsibility to fund this aspect of the service. There was no clarity regarding who or where to go for information and help. The local community equipment budgets were always hard pressed with demand exceeding funding and there was evidence of an unmet need.

There was increasing frustration among patients and clinicians. Individuals had approached the local Primary Care Trust (PCT) directly and *ad hoc* solutions were sometimes arrived at, although these were not always satisfactory.

This reactive system resulted in high costs – such as those incurred when sending individuals to a variety of out-of-area centres for assessment with little or no joined-up working with local services. There was inadequate long-term support and evidence of the provision of inappropriate aids.

DEVELOPING THE EXPERTISE

We had an excellent relationship with the ACE Centre in Oldham during the CAP years and were reluctant to lose this when the project funding ceased.

We developed a service level agreement (SLA) solution whereby the ACE Centre would offer us a tailor-made package of training for local staff to help us build the vital infrastructure of knowledge and skills, access to their loan bank of aids, and support and advice regarding the provision of equipment.

Our next step was to invite stakeholders from health, local authority, voluntary and patient organisations to an initial meeting to arrive at a consensus regarding a vision and strategy for Northern Lincolnshire. This built on the already constructive relationships that existed between agencies and professions. We agreed our objectives as:

- Provision of a cradle-to-grave service.
- Sustainability – not linked to one agency or person.
- Value for money.
- Transparency and logicality for patients and staff.
- Building of local skills and knowledge to benefit the maximum number of people.
- Provision to support communication in all environments – not just for the provision of high-tech, expensive kit but also the training of local staff about low-tech systems.

There was agreement to sign up to an SLA with ACE Centre and to gradually reduce this over a period of years as local skills and knowledge became embedded – recognising that we would maintain a

level of SLA permanently around the loan of aids for assessment.

We established a two level structure with a Communication Aids Referral Team (CART) and a steering group comprising representatives from all stakeholder groups. Agencies drew up and signed an inter-agency agreement to fund developments.

OUTCOMES

We now have a structured, transparent and sustainable process for the assessment and provision of AAC solutions for the people of Northern Lincolnshire. The building of local knowledge and skills across agencies and professions has ensured that each person gets the right aid at the right time and for the right price. There is ongoing support for the people using communication aids to ensure that they get the most from the aid and that they are enabled to use it, with training for those they interact with.

Agencies are assured of value for money because we do not support and purchase aids until the assessment process has been fully completed and all are in agreement that the recommendation is the best way forward. There has also been no need to invest in an expensive 'bank' of aids that need maintenance, deteriorate and become obsolete. Expertise is shared and not invested in one or two people who may leave the area. Time has shown that as staff have moved on, the system has survived.

EVALUATING THE SERVICE

CART was quoted in the Bercow report (2008) as "a leading service of its kind". In 2011, the Communication Champion's report said of CART that it was "a positive example of joined up working". Also in 2011, CART received a Highly Commended Finalist Award for 'Team of the Year – Multi Agency' in the Shine a Light awards.

CART used the Communication Matters AAC Service Standards to evaluate the service in May 2013. Out of the 42 standards evaluated, CART met and could provide evidence for 38 (90%). An action plan was put in place to ensure that the four standards not met would be addressed in the near future, including the development of a local user group with the support of 1Voice.

A time audit was carried out in June 2013 to measure AAC related activity during the month for CART members. It was found that the mean average of the working month that was spent on CART related activity was fourteen hours, or ten percent. This piece of work enabled us to clearly demonstrate the time commitment needed for current and future members of CART.

SUCCESS SECRETS

The coming together of all stakeholders to clearly define and share responsibility for the problem has led to a joined-up solution. Moreover, a strategy, signed up to by all stakeholders, has provided a transparency for users. The determination of all involved to make the project succeed has also been an essential driving force.

A key factor in the success of the project was the solid professionalism, expertise and support provided by the ACE Centre in Oldham and we anticipate we will be linked with them for many years to come. A small investment with them has made all our work possible.

Finally, we would like to pay tribute to the patience and commitment of all our users and their families, as well as the hard work and dedication of all the staff involved.

FUTURE GOALS

We are beginning to contribute to national developments via collaboration with ACE Centre, the National Services Forum for AAC and Communication Matters, which is helping us to establish and maintain regional and national links.

One of our key roles has been, and will continue to be, developing local knowledge about AAC across all age groups, professionals, services and individuals. We recognise, in this changing world of budgets and NHS provision, the need to liaise with health boards and Clinical Commissioning Groups in the local area to provide knowledge and to develop future robust funding streams.

We recognise that AAC needs research evidence to support the work we do and hope to develop local research projects to support both local and wider services.

Finally, our main aim for the future is to continue to provide a leading, award winning service for AAC. ✱

Tina Peck
Principal Speech and Language Therapist & Cross Site Clinical Specialist for Adults with Learning Disabilities

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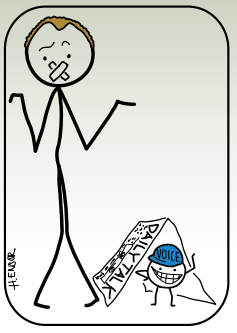

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