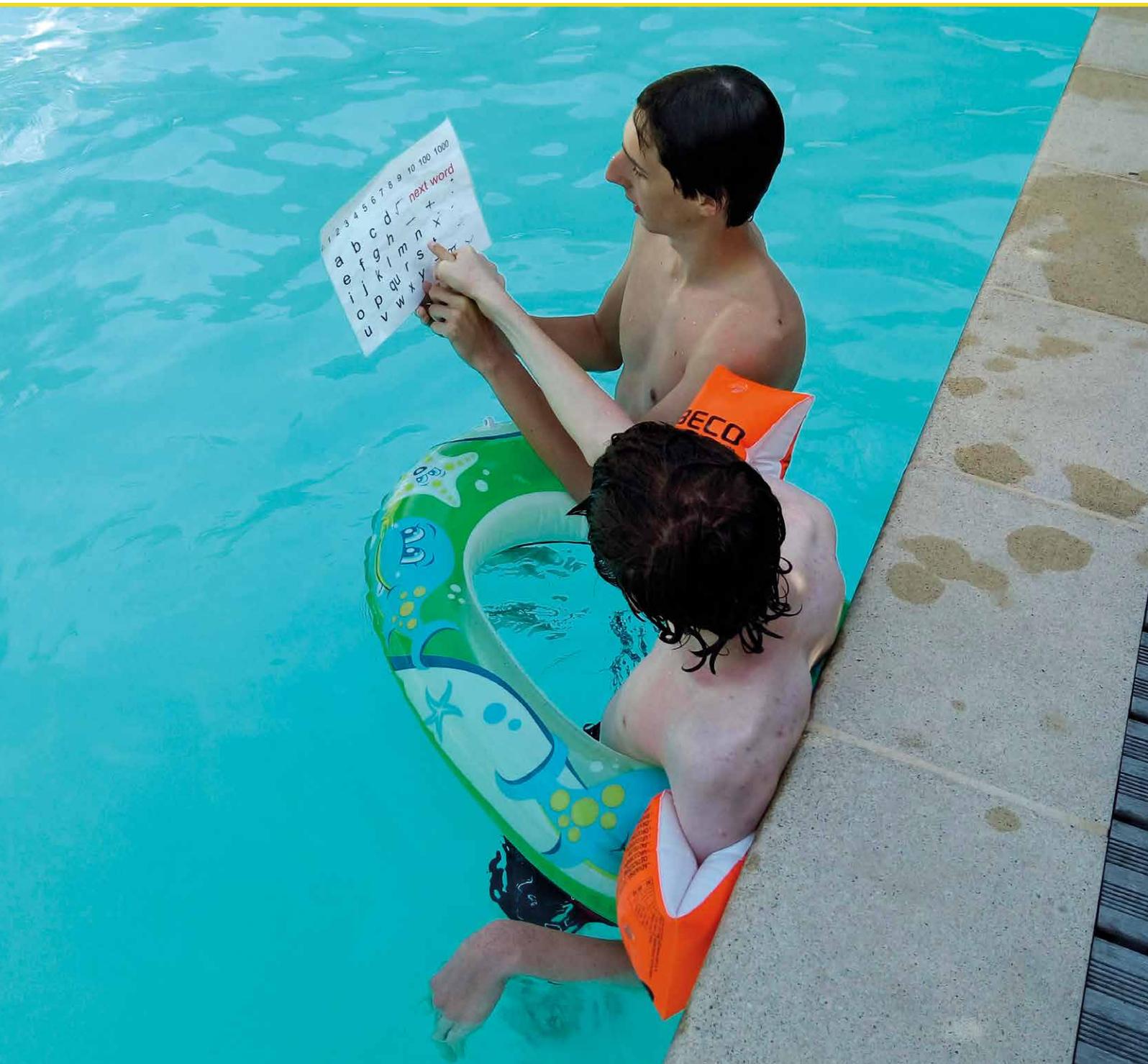


Communication Matters



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Topics include: AAC & Deafness - My Communication Matters - Our Voice Our Stories - SLTs, AAC & ASD - Mental Capacity Act - History of Sequal Trust - Learning for Hubs - Pass IT On - Let's Talk about Talking - NHS England Specialised AAC Services Update





Thank you to CM Trustee Jenny Herd for sharing this photo of her sons (Adam and Dan), a perfect example of the necessity for low-tech AAC!

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Co-chairs' Report

Toby Hewson & Ruth McMorran



The end of the summer and beginning of the autumn is always a busy time for Communication Matters and this year was no exception with our Annual Conference being held at the University of Leeds from 10th to 12th September.

In recent years we have seen attendees from outside the UK and this year was no exception with presenters and delegates from Australia, Belgium, Brazil, Cyprus, Denmark, England, Germany, Israel, Japan, Malta, The Netherlands, Northern Ireland, Norway, the Republic of Ireland, Russia, Scotland, South Africa and Wales making this a truly International Conference.

As the conference opened we joined with 1Voice as part of their 1Voice1Day event, and despite the rain everyone enjoyed games from around the world.

The Keynote presentation was delivered by Bronwyn Hemsley – above centre – (Associate Professor at The University of Newcastle, New South Wales, Australia) who spoke about ‘The Empowerment and Safety of People with Communication Disability in Social Media.

While the Plenary address was given by Lisa Simpson, a Liverpool based choreographer – above right Lisa has quadriplegic cerebral palsy and no verbal communication; therefore, she choreographs using the Simpson Board, an inexpensive but priceless tool that enables disabled people to choreograph her own work.

The social programme at conference is equally as important as the academic programme giving all delegates the opportunity to catch up with old friends and colleagues, make new connections and to generally ‘let their hair

down’. This year the theme was ‘Around the World’. There was excellent food, live music, a chocolate tombola, a world quiz, a stand-up comedy set from our Patron – Lee Ridley (known to many as the Lost Voice Guy and winner of the BBC New Comedy Award 2014) and Brad Watmuff returned as DJ for now traditional CM conference disco. Here’s a snap shot of what you missed!

Date for your diaries
Communication Matters
32nd Annual Conference
will be held at the
University of Leeds from
9th to 11th September
2018, we look forward to
seeing you there.



All photographs by the official Communication Matters Conference Photographer - Sam Knapp (www.samknapp.photography)

CM News

Catherine Harris, Project Coordinator

Communication Access UK (CAUK)

Thank you to those who attended sessions at the CM conference. It was good to have the opportunity to update members at the Annual Meeting and to present 2 workshops and encouraging to see the continued interest and enthusiasm for Communication Access UK (CAUK). Networking and recruiting 'champions' and potential mystery customers is a key element in this whole initiative.

The end of the first year of the pilot project is fast approaching! The second year of funding from the John Ellerman Foundation is dependent on the specified objectives being met so this is an opportunity to reflect on what has been achieved to date.

Objective 1- involvement of AAC users (achieved by May 2017 but ongoing)

- Training of AAC users as mystery customers.
- Training of AAC users as Consultant trainers.

The first training workshop for AAC users as Consultant trainers and mystery customers was delivered in March 2017. In preparation for this, 4 AAC users were trained as workshop presenters and participated in co-presenting the workshops at the University of Leeds in March and May 2017. An application process has been trialled with supporting documentation which can be used for all applicants (including those who do not have a communication difficulty) who wish to apply to be recognised mystery customers and/or workshop presenters. An additional 2 AAC users have recently joined the team. Gill Pearl, Speech and Language Therapist (SLT) and CEO of Speakeasy in Bury, has also been recruited as a workshop presenter through this process.

Objective 2- engagement with Specialist FE colleges (achieved July 2017 but ongoing)

- Visits to selected colleges across the UK to share project aims and to identify 'champions'.

Workshops facilitated during the year at Beaumont, Ingfield, National Star, Percy Hedley and Treloar Colleges have resulted in participation from a number of students

who have used a mystery customer questionnaire to assess local businesses. The questionnaire has been modified in the light of feedback and is available in an 'easy read' English and symbol supported format. Local SLT/teacher 'champions' have been identified in each college. A session for Stroke survivors was delivered in Bury in partnership with Speakeasy stroke support group.

Objective 3- links to businesses for pilot (achieved by May 2017 ongoing)

- Pilot training to be organised with Leeds University.
- Facilitating links with local businesses and colleges.

Pilot training at the University of Leeds was delivered on 9th and 21st March to 80 staff. This involved running 4 workshops with up to 20 staff in each. AAC users were involved in facilitating and delivering these workshops. A further workshop for security staff was delivered on May 8th for 15 staff. There has been a request to provide more workshops in 2018. The feedback from the evaluations has helped to shape the training packages and resources. In advance of the symbol launch, an interim certificate was awarded to the appropriate teams to acknowledge the training which has been delivered at the University to date. Links are being made with other businesses through a positive marketing model in anticipation of the symbol launch.

Objective 4 - Symbol Selection (by Jan 2018) Parallel workstream through steering group

- To decide on a Communication Access symbol for UK. This is being selected through an extensive consultation with a wide variety of stakeholder groups which started in Feb 2017 and is still in progress.
- The underpinning standards for the symbol are being agreed through the consultation process.



From left to right: Nathan, Helen, Sam, Gregor, Jamie, Toby

CM News

- The responses from the consultation are being evaluated with support from RCSLT who have allocated time and staffing to this initiative from September 2017 until March 2018. Naj Hussain is now working one day a week with a focus on policy issues and links to government.
- The final symbol is due to be launched in 2018.

The consultation on which symbol should be used has been a much slower and more complicated process than anticipated but as Kamini Gadhok (CEO of RCSLT) recently said: 'This is possibly one of the biggest things any of our organisations have ever tried to achieve'. It has become very clear that we need to go through a robust process and engage with government to ensure that this initiative has maximum impact and sustainability.

What next ...

The next stage of the symbol consultation is due to be launched in early November to finalise the concept and confirm the standards. The steering group is aiming to

ensure that people with all types of communication difficulties are able to have the opportunity to respond as several 'gaps' were identified in the earlier consultation stages. We have been working hard to identify key contacts in the many different organisations who support people with communication difficulties resulting from different conditions in preparation for the survey going live. It will be available as an electronic version and as a download. We need your help to ensure that we have enough responses from people with communication difficulties. Once the final concept is decided, a design company will be engaged on a pro bono basis to help with the branding and marketing process. The next meetings of the Steering Group are planned for 26th October and 20th November.

Introductory CAUK workshops are being offered at the Cardiff and Ashford CM Roadshows.

Please make contact if you would like to work with us to facilitate a workshop for your school, college, service or team. accessproject@communicationmatters.org.uk

An Introduction to this year's Board

from Ruth McMorran and Toby Hewson (Co-Chairs)

Every year the makeup of the board changes. This year we were sorry to say good-bye to **Janet Scott** (above) and **Amanda Hynan** (below) and we thank them both for all the work they have undertaken for CM over many years.



We are pleased to welcome back **Zoe Clarke**, **Vicky Healy (deputy chair)** and **Adam Waits** who have been re-elected to serve another term of office. We're also happy to have **Hester Mackay (below)** who has now been elected as a full-trustee, following her year as a co-opt. We are delighted that **Tom Griffiths**, **Nicola Hayton (treasurer)**, **Euan Robertson**, **Kate Caryer** and **Jenny Herd** will continue to serve on the board this year.

Toby and I are delighted to welcome **Rob Gregory** (right centre) who also joins us as a full trustee. Rob's journey in the

field of AAC began over 15 years ago, initially working within Environmental Control systems, he quickly moved into AAC and has never looked back. He has been at Tobii Dynavox for 8 years and his current role is Sales Manager for the UK and Ireland.

Amy Hanschell (below right) will join the board as a co-opted trustee. Co-opted trustees have full voting rights and Amy will serve in this capacity for one year. Amy has been working with the adult acquired service in Tayside as an SLT for the past 6 years. For the majority of that time she has worked in the Centre for Brain Injury Rehab in Dundee. She also helped with local Right to Speak project work and has completed a PGcert in AAC at Manchester Met.

CM is dependent on people volunteering to serve of the board. Toby and I know it is a lot of work and we thank every one of the trustees for all the work they do for Communication Matters.



CM News

AACknowledge Entries

(July - September 2017)

From Judith Chapman, MMU

Our AACknowledge online evidence base presents information in a variety of accessible formats to help anyone who needs access to up to date information on best practice, services, case stories and research.

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Awards

Alan Martin Award

Presented annually for significant contribution to the Arts by someone who uses AAC. This award, first presented in 2013, is in memory of Alan Martin - a remarkable man who was amongst other things a dancer, musician and comedian. He worked for the inclusion of all people within The Arts whatever their disability. Alan was passionate about equality and inclusion for all people with disabilities. He recognised the opportunities offered by access to technological solutions, including AAC, which allowed people with significant impairments, to participate in many creative forms of self-expression.

Winner 2017 of Alan Martin Award

Sarah Ezekiel

nominated by Midge Caryer

Nomination

I should like to nominate the very talented Sarah Ezekiel, eye gaze artist, to receive the Alan Martin Award 2017 for contribution to the arts. Examples of her work can be seen at her online shop, which can be accessed via her website, <http://sarahezekiel.com/#/eyegaze-art/4562566580>.



I had the great pleasure of presenting Sarah Ezekiel with the Alan Martin Award. Sarah is an eyegaze artist and has exhibited all over the UK, including the Royal Academy Schools, and also at the Katara Art Centre in Qatar.

On October 19th I called into

Sarah at her home in London to make the presentation and Sarah said she was honoured and overwhelmed to receive the award and hoped to come to Communication Matters conference in 2018 to see what we do and hand over the award to the new winner.

I had the pleasure of being able to see some of her work displayed on the walls in her house. I was given some insight as to what an amazing artist and what a very worthy winner Sarah is. Sarah has very kindly donated this beautiful signed painting (right), which is going to be auctioned to raise funds for Communication Matters. Watch out for that in 2018!

Toby Hewson



Jamie Munro Inspiration Award

Jamie Munro was the Information Director at Inclusive Technology. He presented at many CM Roadshows and Conferences and was a leading figure in the field of Assistive Technology. His work had an impact on the lives of many. Jamie's career, working with people with special needs, began in 1987 at Stoke Mandeville Spinal Injury Unit. During the 1990s he worked for Don Johnston software in the UK supporting literacy for both young people and adults. When Inclusive Technology became the publisher for Don Johnston software titles in 2009, Jamie became a consultant for the company. Jamie was the face of Inclusive Technology in many mainstream and special schools right across the UK. In the early days of internet access Jamie was often seen disappearing under tables to 'sort out' the connections! It was always reassuring to hear his Liverpool accent at the end of the phone line talking you through the solution to a technology problem.

After his sudden and unexpected death in December 2016, several of the CM Supplier members suggested we should pay tribute to Jamie's commitment to the AAC world. And so... a man who was inspirational to many people will be remembered each year at the Communication Matters Conference through the Jamie Munro Inspiration Award.



Awards

Winner 2017 of Jamie Munro Inspiration Award

Helen Dixon

nominated by Jenny Herd & family

Nomination

I would like to nominate Helen Dixon, specialist AAC SALT in Cumbria, for her tireless and longstanding work, both in her professional, and particularly in her own, time to promote and support AAC use, in all its forms.

Helen's own personal interest in AAC began, I think, as a result of working with an adult who was just starting to use a communication aid at almost the same time as she began work with a much younger AAC user, more than 20 years ago. From then on she has been essentially a one woman AAC-band in Cumbria providing hands on AAC therapeutic support, advice and guidance to other less AAC savvy SALTs, supporting AAC users and their families to get the services and provision they need and also organising (and in many cases subsidising) AAC get togethers in south Cumbria and North Lancashire.

She started AAC user picnics and Xmas parties many years ago to give people the chance to get together and meet other AAC users and their families; which for us as was absolutely invaluable and probably helped make my son the confident, outgoing young man he is today.

When 1 Voice was initiated, Helen was a natural candidate for volunteer, supporter and now trustee, so now, what started as her AAC get togethers, is now a thriving 1 Voice Lakes and Bay branch.

Helen is an extremely modest person who I think does not quite realise the extent of the positive impact she has had on many AAC users and their families. I have attached some photos of Helen getting involved in AAC user activities! (with my son aged 3 or so in nursery, 16 years ago...)

Jenny Herd & family, Aug 2017



Thank you to the Communication Matters Trustees and to the suppliers particularly Inclusive Technology. I am truly honoured and humbled to have received the first Jamie Munro Inspiration Award. Sally Millar always inspires me and having spent some time with Jamie Preece last night after dinner and also today I am even more surprised that I was the person voted to win. Everyone has been really nice with such kind and generous comments and the award itself is lovely and meaningful as it reflects Jamie's pictures from his hotel windows. My son has volunteered to dust the top shelf on our dresser so it can go there on display safe from cats, and my parents have insisted that I take it with me when I next go to visit them!

Thanks again, Helen Dixon

Augmentative and Alternative Communication (AAC) and Deafness

CLAIRE HAYWARD

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Considering the AAC needs of an individual requires a holistic assessment which takes into account the wide range of factors which impact on communication. In recent years there has been an increasing interest in the role of vision for communication, however little has been written about the impact of deafness on AAC, despite the fact that there are twice as many children living with deafness (44,000; National Deaf Children's Society) than are blind or visually impaired in the UK (22,000; Royal Society for Blind Children).

Deafness in context

For the purposes of this paper we will use the term deafness to describe any level of difference from full hearing (i.e. from mild through profound). We will focus on children who were born deaf, or acquired their deafness before they were able to speak. This is termed pre-lingual deafness. The needs and skills of this group are very different to people who had hearing and speech, but lost this through disease or injury, who can be described as deafened. There are a range of other relevant terms: for example, deaf people who use British Sign Language and identify with the cultural aspects of the Deaf community may use a capital D to denote this, whereas people whose primary language is English often describe themselves as

deaf with a lower-case d. Although the term "hearing loss" is often used, this may be inaccurate for many prelingually D/deaf people as they may have been born deaf and therefore have no hearing actually to "lose".

The impact of deafness on a child is significant and the effects of even mild/moderate deafness are wide ranging and often underestimated. Children may experience fatigue, behavioural difficulties and communication and interaction issues; which in turn can affect educational achievement and social skills. So, for the children we work with who do have additional needs those factors are likely to be further amplified.

Many children with more common types of permanent deafness are identified through the newborn hearing screening program. More comprehensive auditory brainstem testing is indicated for babies who have spent time in neonatal care. Deafness can fluctuate, for example where the child has glue ear which may overlay an existing hearing impairment. It is important to remember that hearing aids and cochlear implants do not provide full access to sound as if the child was hearing, rather they give some auditory information across limited frequencies which a child must learn to interpret over time.

Significantly, around 52% of deaf individuals also have additional disability

- 19% also have a Learning Disability
- 3.5% are deaf-blind
- 3% have cerebral palsy (National Deaf Children's Society - NDCS)

The report *Complex Needs, Complex Challenges* by NDCS (McCracken & Pettitt, 2011) asked parents of deaf children with additional disabilities about their experiences. Parents emphasised that children who are deaf and have one or more additional diagnoses have needs that are different to those with either diagnosis occurring in isolation. This opinion is echoed by the professional literature (Luckner & Carter, 2001).

The report also found that many parents were concerned that having a deaf child with additional complex needs, frequently meant the deafness was seen as a minor aspect of the child's needs.

AAC and deafness: language input, language output

Typically developing children are immersed in spoken language which helps them to learn to communicate using speech, while also developing their cognitive skills and internal language. However, for deaf children, immersion in spoken languages does not necessarily ensure

that they are able to hear enough of that language to make similar gains. For deaf children with additional needs this is even more acute as we are less likely to know with any certainty (in a functional setting) how much language they are hearing. Not least because testing of audition is often significantly harder for children with additional disabilities

"I mean they ask him to try and knock blocks off a tray when he hears something... he is just not capable of doing that..."

(Complex Needs, Complex Challenges, NDCS 2015)

For teams around a child with AAC needs, the concern is often that the child with complex communication needs does not have a communication output method. However, a fundamental issue remains that many children who would benefit from AAC methods, and certainly those who are deaf, have little or no visual language input. Signed language advocates have used the term "language deprivation" to describe the outcome of restricted access to early language models, a term which holds power and meaning to all children with AAC needs. It is a challenging and perhaps controversial thought, but if a typically developing child was found to be receiving extremely restricted language input it could be viewed as a form of neglect. The least dangerous assumption is that we shouldn't rely on what we think the child can hear, especially if it has been difficult to get clear and reliable results about the presence, and degree, of deafness.

AAC is often described as "another language", but by true linguistic definition this is not the case. It is a partial visual representation of a spoken language, and not a full language in its own right, much like Makaton. For deaf children this is a critical distinction. When we model AAC we rarely model the full grammatical structure of English (or any other spoken language), instead using key words and the general scaffold of the base language. On visual terms alone, AAC is not a language which is fully visually represented for early learners as, even when modelled well, it relies heavily on the speech which accompanies it. Asking children to then output in spoken language based AAC where the visual (AAC) model is incomplete (and we are unsure how much they can hear) is a profound demand; requiring much time, effort, consistency and understanding of the activity and goals as possible.

An 18-year-old man with learning disability, mild cerebral palsy, autism and a moderate hearing impairment was leaving a specialist college in 3 months and was referred for a specialist assessment. The local Speech and Language Therapist reported that he had good low-tech and would benefit from voice output. At the assessment his low-tech Picture Exchange Communication Symbol book consisted of 84 symbols (all nouns except 'I want'). He had been exposed to Makaton in college, he did not use any speech. This young man has not had a full language modelled to him visually at any stage in his life. He would have had speech modelled to him, but speech has not worked as a way that he can communicate. He will not have heard everything said to him. Without a consistent language input using a full language it is in many ways unsurprising that he will have had problems with learning and struggled with change, communicating through behaviour and showing preference for routines.

Advocates for signed language exposure for all deaf children contend that without early, comprehensive first language acquisition through fluent modelling (L1), a second language (L2) cannot be learnt, and that the language we can be most certain a deaf child can learn fluently is a signed language. An option therefore, could be to expose all deaf potential AAC users to a signed language. However, there are no AAC packages which fully replicate expressive sign language for obvious reasons; although some packages such as Seashell have catered specifically for Deaf children. There are a number of Deaf AAC users who use signed languages receptively, but output in spoken language based AAC. Bilingual children who use two spoken languages are uni-modal bilinguals, in that they are using one communication mode (speech); whereas deaf AAC users whose receptive language is signed are using sign and English based AAC and therefore can be described as bi-modal bilinguals. Seen in this way the level and complexity skills needed to communicate is clear (Knoors & Marschark, 2012).

What information is currently available?

There is a recognised need for more AAC research in general, and it will be no surprise that there is extremely limited research to address the AAC needs of deaf clients. Most research in this area includes very rare and low incidence conditions, using older participants (e.g. not often young children) and small sample sizes. The purpose of AAC seems to be lost in some studies; for example, Lee et al. (2013) focus on the use of communication aids for the purpose of increasing speech clarity but not augmentative or

alternative communication. None of the studies we found discussed the degree of deafness of the participants, and none considered digitised vs synthetic speech and how this might influence the usefulness of the auditory feedback for the AAC user themselves.

A review of websites that parents and professionals are likely to look to for support provided a limited amount of information. The National Deaf Children's Society (NDCS) only provides information about text based voice output apps. Information from the Royal College of Speech and Language Therapists website is limited, speech focused, and presents a somewhat negative view of deafness not shared by the Deaf community. Interestingly it lists AAC as a role for SLT's for deaf adults, but not deaf children. Specific concerns are that there is no clear advice on how to support when there are concurrent disabilities, and there is no emphasis on the need for an early language system. ISAAC includes signed languages within the definition of AAC, however it is not clear that this view has been informed by discussion with the Deaf community, who may take the view that signed languages are not instead of or in addition to speech, and exist independently and in their own right.

Choosing an AAC system for a deaf child

Some children with physical disabilities may initially not present as physically capable of using sign expressively, however their motor skills might change over time. Just as some adults use speech which is understandable but not 100% clear, many sign language users with physical disabilities can be understood to others fluent in sign. Time spent in

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HANNAH JAMES

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Mobi 3



Allora 2

the Deaf community will quickly reveal capable sign language users with significant motor impairment due to cerebral palsy, or limited fine motor skills and facial expression due to CHARGE syndrome. Professionals involved in making recommendations about communication options should also consider the powerful and positive identity of belonging to a cultural community can bring. It is also important to recognise that a signed language can be used receptively, even if a child never signs expressively.

The quality and therefore accessibility of the voice may be critical for deaf children with some hearing, in particular, attention should be given to the difference between digitised and synthesised speech. Providing a direct link between the audio output and the hearing aid/cochlear implant may be possible. A message bar can give visual feedback where auditory feedback is insufficient, the response from the listener needs to be immediate and clear.

Any level of deafness should be taken into account within an AAC assessment.

Advice should be sought from a Teacher of the Deaf, for children with complex needs and especially those in special school. There may be limited access to this specialist advice but AAC professionals should advocate for this crucial input. Deaf children may be able to access a communication support worker to provide additional support and resources to enable both receptive and expressive communication, however this role is often overlooked for children with multiple disabilities.

What should we as the AAC community be doing?

- Educating ourselves about types of deafness, the Deaf community and audiological testing Evaluating the suitability of AAC systems for deaf children
- Considering that a child may not have full access to the spoken scaffold which we use alongside AAC skills
- Developing links with and working collaboratively on training with NDCS, Sense and BATOD

- Including D/deaf people when making leaflets, websites and information for parents and professionals

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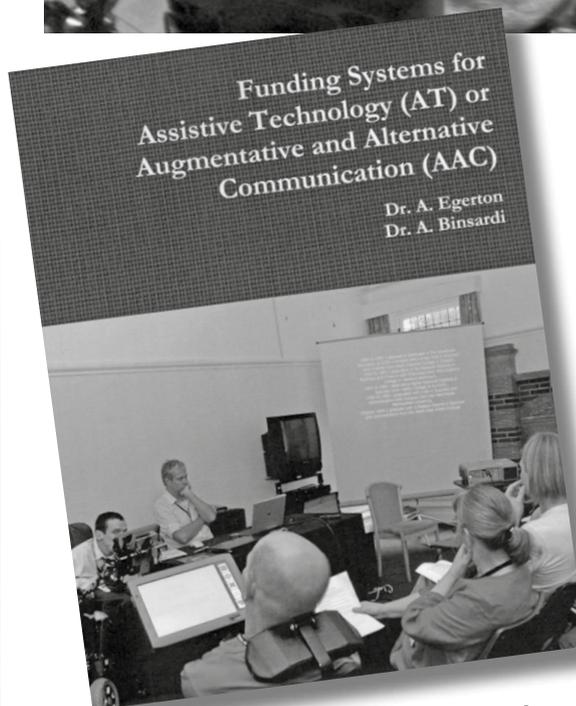
My Communication Matters

ALEXIS EGERTON

I have used my communication aid in the past to progress from leaving my special school with no qualifications to gradually making my way through three colleges and two universities. Eventually making my way up to postgraduate level and attaining a PhD in Philosophy entitled *The Effectiveness of the Present Funding System for Electronic Communication Aids*, in November 2012 at the Glyndwr University in North Wales.

Subsequently, a monograph of my work was published entitled *Funding System for Assistive Technology (AT) or Alternative Augmentative Communication (AAC)*. A copy of which is kept in the House of Commons' Library.

The attainment of my PhD meant that I was awarded both the Alpha Kappa Alpha Prize and the Alumni Prize for my achievements.



In the interim periods of my educational career, I have done voluntary work for a national disability charity, delivering disability awareness workshops to a variety of organisations such as; schools, colleges and hospitals (Alder Hey and the Oldham Royal). I also assisted this same voluntary organisation to secure a national lottery bid to finance its future activities. My equipment has enabled me also to hold down a paid job working for my local authority's Sure Start Division.

The equipment has also assisted me to feature in two informative videos in the mid-1990s. One was to promote the equipment that I was using at the time (which was sponsored by Rank Xerox)





and the other was by the University of Wolverhampton showcasing inclusive education in further and higher education using several case studies.

After graduating with my PhD from the Glyndwr University, I was asked to sit on the NHS Advisory Commissioning Group for Specialist Equipment (which now includes the NHS provision for AAC). Furthermore, myself and another more experienced academic from Manchester Metropolitan University, was tasked with the job of approving the sixteen pilot communication aid services' proposals, to receive their share of the British Government's £15 million contingency fund to finance their NHS communication aid services around the national scale.

Presently, I'm assisting my mother in her business with the building and maintaining a website and updating two social media platforms etc. In the social context, I use my equipment to tell my personal assistant what I would like to do each day whether it is going for a walk, going to the cinema or museum, along with articulating my personal and general needs.

Our Voice: Our Stories

KATE CARYER AND ALISON BATTYE

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Have you a story inside you? Do you fancy yourself as the next Shakespeare, Jane Austen or J.K Rowling? Do you want to improve your writing?

If so, you should join Our Voice Our Stories, a new creative writing group run by and for AAC users over 18 (with the help of token speech therapist Alison Battye!)

There are a lot of creative people using augmentative and alternative communication and we thought it would be brilliant to get together to share ideas. It is a new project in-the-making, so if you have any ideas we would love to hear from you. You don't have to have any experience of writing, just an interest in having a go. You can use text or symbols. We will come up with an idea to get you

started and where you go from there is up to you. You can choose to write a poem, rap, rant, story, script, free flow... We will share our writing as a group and might even write pieces together.

Join our Facebook group: Our Voice, Our Stories. We also have an email: our.voices.our.stories@gmail.com We look forward to welcoming you!

This group is supported by the Unspoken Project CIC.



How SLTs use AAC to encourage functional communication with minimally verbal children with ASD: a survey

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(research was carried out as part of the MSc 'Language & Communication Impairment in Children' University of Sheffield, 2016)

Introduction

Approximately 50% of children with Autism Spectrum Disorder (ASD) do not develop speech or develop limited speech insufficient for communication (Centers for Disease Control and Prevention, 2007). These children typically require Augmentative and Alternative Communication (AAC) to communicate functionally and to have their basic needs met. To date, there has been limited information available about how UK based Speech and Language Therapists (SLTs) working with children with Autism Spectrum Disorder (ASD) are sourcing, trialling, implementing & monitoring functional communication systems.

Professionals have been challenged to reassess how minimally verbal children with ASD are supported to communicate functionally and to look at success stories retrospectively to determine why some children or systems have had significantly more success than others (Miranda, 2008). Traditionally research has focused on what is possible with AAC & less on what is achieved in current practice. Therefore this study aimed to investigate how SLTs evaluate the need for and then implement AAC in the UK. It also aimed to collate different AAC systems being used with the ASD population and with what level of perceived success. A questionnaire was developed and distributed to SLTs to answer the following research questions:

1. How do SLTs use AAC to encourage functional communication with school-aged minimally verbal children with a diagnosis of ASD?

2. What is the professional UK view regarding how 'successful' current practice is?

Method

Thirty-nine SLTs completed a 10-minute online questionnaire, designed to investigate current AAC service provision. All participants had worked with/were working with at least one child with ASD, who had required an AAC system to be implemented. Surveys were emailed to prospective participants via nine SLT Clinical Excellence Networks (CENs) across the UK, with either an ASD or AAC focus. Participants mostly worked for the National Health Service (NHS) (62%), but also worked for state and private schools (18%), private practices (5%), local authorities, charities and other organisations. The questionnaire was completed online, through Survey Monkey. Results were analysed quantitatively and qualitatively. The SLTs' views and feelings on the supports and barriers to AAC service delivery for the ASD population were also explored. The results are presented below.

Results

AAC systems in use

Participants used a range of AAC systems, including aided and unaided, low-tech and high-tech systems, with the ASD population. The most prevalent AAC system being used was:

- (1) Picture Exchange Communication System (PECS), which was used by all SLTs who completed the survey. PECS

is a behavioural approach, which involves six training phases, teaching functional communication to children with autism who have little or no speech, through the exchange of a graphic symbol for a motivating item (Bondy & Frost, 2001).

- (2) Signing and symbols, were being used by 85% of SLTs;
- (3) Communication boards by 64%;
- (4) Communication books by 62%;
- (5) Speech Generating Devices (including traditional SGDs and iPads with communication apps) by 46%; SGDs are portable electronic devices which produce auditory output (Schlosser, Sigafoos & Koul, 2009).
- (6) Pragmatic Organisational Dynamic Display (PODD) communication books were used by 26% of SLTs, and
- (7) Word boards by only one SLT.

On average SLTs were using four to five different AAC systems with their ASD population.

ASSESSMENT PROCESS

Only 28% of SLTs who completed the survey, assess as standard practice prior to choosing and implementing AAC with a child who has a diagnosis of ASD. Observations, information gathering, and general qualitative assessments were the most commonly used assessments. SLTs looked at motivators, understanding of symbols, photos, objects, grid size access, supports in the environment and communication samples. Some services had developed their own AAC pre-assessment, which were guided by the child's

current communication, skills and needs. Pre-developed assessments being used were: (1) the assessment section of the Elklan Communication Builder for AAC (Kirton, McLachlan & Elks, 2013), and (2) the Frenchay Screening Tool for AAC (North Bristol NHS Trust, 2010).

OUTCOME MEASURES

Just over half (53%) of SLTs were using outcome measures ('TOMs') to monitor AAC success with the ASD population; TOM AAC (Enderby, John & Petheram, 2006) was the most commonly used outcome measure. Some services and trusts had developed their own outcome measures or competency frameworks. Many other therapists monitored outcomes according to individualised SMART targets. EKOS (Johnson & Elias, 2010) and variations of this system, PECS outcome forms and Communication Competencies (Light, 2003, cited in Light & McNaughton, 2014) were also being used to measure outcomes.

LONG TERM AAC PLAN

51% of the SLTs surveyed had a long-term AAC plan for children with ASD on their caseload. Many took a person-centred approach and the plan was based on the individual child's success with trialled systems, considering their specific abilities. The most common AAC plan described was: starting with PECS and then transitioning to SGDs. Some SLTs started with PECS and transitioned children on to PODDs or core vocabulary boards when they needed their AAC system to be more vocabulary-rich. Other SLTs started children on low-tech AAC systems and then transitioned them to high-tech devices.

AAC SYSTEM SUCCESS

74% of SLTs said children on their caseload with ASD frequently used their AAC system successfully to communicate. Only 44% of respondents said children on their caseload's AAC systems were frequently sufficient to develop their language. The development of literacy skills through the use of AAC systems was identified as even more challenging, with only 18% saying they were frequently sufficient to develop literacy skills.

Out of all the AAC systems, 79% of responders identified having the most success with PECS (in some instances along with other systems). The second largest success was associated with SGDs (36% of responders). Only 46% of

responders were using SGDs, this means 78% of SLTs using SGDs indicated they had particular success with them with the ASD population. SGDs mentioned were GoTalk (Liberator Ltd, 2016a), the Accent devices (Liberator Ltd, 2016b) and Lightwriter (Toby Churchill Ltd, 2011). The most popular iPad app was Proloquo2go (Assistiveware, 2016), followed by Grid Player (Smartbox, 2016). TapSpeak Choice AAC (Conley, 2014), and LAMP Words for Life app (Liberator Ltd, 2016c) were other communication mentioned.

The third most frequent success was identified as being associated with other picture-based systems: PODDs (18%), communication books (8%), communication boards (8%), and single activity displays (3%). Next were signing (15%) and visuals (15%), which included symbols, visual timetables, now-and-then boards, visual checklists, task boards, Emotion Fans, and choice boards. Although just 18% of SLTs surveyed identified as having success with PODDs, that was 70% of SLTs using PODDs, whereas only 18% of SLTs using signing and symbols noted any particular success with their use with the ASD population.

KEY FACTORS FOR SUCCESSFUL AAC USE

There were clear themes that recurred in the data with regards to what the SLTs felt were the key factors associated with successful AAC use, with the ASD population. The five core themes were: (1) motivation, (2) support, (3) the child's skills, (4) the AAC system/s and (5) the communication environment. Motivation included both the child's motivation to communicate and that of the significant adults to support the child with ASD and to utilise the AAC system. There was further emphasis on how important teachers' and parents' competence, attitude, expectations, consistency of approach, ownership, and reinforcement were. Most SLTs identifying the importance of their role in training and empowering other key adults. It was clear from the data that SLTs are training parents and teachers as standard practice and most are training them frequently or always.

Another recurring theme identified as having an impact on success of AAC use with the ASD population was that of the child's skills. The most common skills SLTs identified as affecting successful AAC use in the ASD population were cognitive skills, pragmatic skills, language levels,

attention and listening, understanding and communicative intent. The AAC system itself was also identified as being a factor in the success of AAC use. Most noted was how functional and meaningful the AAC system was. Ease of use for both the child and the adults, whose responsibility it was to customise and update the system, were also highlighted. It was also noted that the AAC system needed to be up to date and relevant for the child, including a comprehensive and appropriate vocabulary to meet their changing and developing needs. Some SLTs highlighted the importance of not restricting a child to one AAC system or following a blanket approach of 'one-size-fits-all', implementing the same AAC system for all children.

The importance of the environment in successful AAC use with the ASD population was also a recurring theme. The importance of an environment with clear models and partner-augmented input was highlighted. This was reflected in 62% of SLTs saying they frequently or always use the child's AAC system to augment the language they use. Despite recent popularity around aided language stimulation, 5.13% of SLTs never use the child's AAC system to augment their verbal language input.

SUPPORTS

There was a trend in the data, that SLTs were not utilising/had limited access to (and indeed limited awareness of) specialist services, advisory bodies & charities. This was despite 72% of the SLTs saying they needed more AAC training and support, when dealing with the ASD population. The most common form of support identified was within service support from colleagues, supervisors, AAC tutors, experienced school staff, and ASD and AAC specialist SLTs. Guys and St Thomas' Assistive Technology Communication Service, Communication Aid Services, Portage Service, Advisory Teaching Service, Autism Outreach Service, support services from local authorities, Tier Four services, ACE Centre, ACT involvement and RCSLT were all mentioned as specialist services utilised. Many identified training as being the support they relied on, including formal AAC training in specific systems, in-service training, study days, and self-directed learning (reading journal articles and accessing online guidance). CENs and support groups were identified as being relied on for assisting AAC implementation with the ASD population.

BARRIERS

The most frequently identified barrier to achieving evidence based practice in AAC use with the ASD population was “time constraints”, with 92% of respondents identifying this as a barrier. This was followed by “budget constraints”, with 60% of respondents identifying this as a barrier. Limited training opportunities (49%) and insufficient support (46%) were the next most commonly cited barriers. “Inadequate available AAC systems” and “insufficient knowledge” were also identified as barriers by 30% and 27% of responders respectively. Other barriers identified were inflexibility in services and the closure of specialist ASD services, with these children now being directed to mainstream SLT services for non-specialist input; schools being reluctant to spend money on more than one type of software, fostering a “one-size-fits-all” approach; and a lack of rigorous evidence in the field of AAC use with ASD population.

ARE AAC SYSTEMS FOR ASD POPULATIONS ‘GOOD ENOUGH’?

Most SLTs (77%) identified the AAC systems available for the ASD population to be ‘good enough’ to meet their clients’ needs. Some SLTs noted that they were ‘good enough’ with certain provisos: (1) if used properly and consistently, (2) if specialist support is utilised, and/or (3) through the use of specific AAC systems. However some respondents (23%) disagreed, noting that AAC systems for the ASD school-age population in their opinion were not ‘good enough’. The heterogeneity of ASD was commented on and SLTs identified that a “one-size-fits-all” approach does not work. Some noted that due to challenges or constraints of implementation, including lack of resources, training, time pressures, service constraints affecting frequency of implementation, cost affecting choice of AAC system implemented, and difficulties identifying the iPad as a communication device, AAC use within the ASD school-age population was not always successful.

Conclusion

The current study indicated that there are a range of AAC systems being used in current practice in the UK to encourage functional communication. SLTs, on the whole, have embraced AAC for the ASD population and are using multi-modal AAC implementation to encourage

functional communication. The worldwide popularity of PECS is also reflected in the UK. Despite a lack of evidence for the use of signing and symbols with the ASD population (Ganz, 2015), they are still being used with children with ASD by most SLTs in the UK, however these SLTs identified limited success with their use with this population. Even with a growing research base indicating the value of using SGDs with the ASD population, only a third of SLTs are using SGDs with the ASD population. While there is some pressure to move away from SGD use within certain contexts, three-quarters of the prescribing SLTs noted a high level of success in SGD use by their ASD clients, which supports current research that has identified SGDs as a ‘good fit’ for the ASD population (Ganz, 2015). Contrary to the lack of evidence for PODD use in the literature, a significant number of the SLTs using PODD in the UK have indicated they have had particular success with it, with children with ASD.

The professional view on the success of AAC implementation with the ASD population is mixed. The majority of SLTs in the study found children on their caseload with ASD frequently use their AAC system successfully to communicate and identified the AAC systems available for the ASD population to be ‘good enough’ to meet their clients’ needs. However, roughly one-quarter of SLTs did not feel the available AAC systems allowed for the development of consistent functional communication, and labelled the available AAC systems for this population as not being ‘good enough’. However, many services appear to be actively trying to create assessments, outcome measures and pathways in order to overcome barriers and achieve best practice in managing the AAC needs of the ASD population in the UK.

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Mental Capacity Act (2005)

Enabling student learning through teaching provided by service users who use augmentative and alternative communication

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Introduction

Service users have been actively involved as visiting lecturers at City, University of London since 2005 (Harding, 2009; Harding, et al, 2012). Principally, speech and language therapy students (SLT) have been taught by service users with learning disabilities about their experiences interviewing support staff, work experiences, daily living activities, and accessing health care. All lectures have been presented by service users using multi-modal approaches to communication. Types of augmentative and alternative communication (AAC) used have involved use of Makaton (Walker, 1977), natural gesture, symbols and other pictorial methods of support, use of an iPad, voice output communication devices, use of Multi-Media Profiles and Objects of Reference (Park, 1987), as well as spoken language accompanied by natural gestures. Reflecting on the Mental Capacity Act (2005) is an important part of the service user led teaching.

Service user led teaching for speech and language therapy students

It is important that students are taught about the problems AAC users,

specifically those with learning disabilities, experience on a daily basis, especially when accessing healthcare. Students will be the healthcare practitioners of the future and these teaching and learning opportunities are essential in the development of clinical problem solving as well as understanding the communication styles and needs of service users

with learning disabilities, particularly in a healthcare context. Before meeting the service users, students receive lectures about AAC, including practical training, and the difficulties and challenges that may be experienced by both the students themselves, and when meeting the service users.

Table 1: The Advocacy Project

The Advocacy Project: www.advocacyproject.org.uk

This is a London based charity that supports marginalised communities to speak up, understand their rights and make choices, challenging stigma, isolation and inequality. The Advocacy Project works with people, including older adults, children and young people, who have learning disabilities, mental health problems, eating disorders and dementia.

Success of the teaching described encouraged university staff to discuss with the service users the development of other teaching topics, in particular, difficulties accessing healthcare and the relevance of the Mental Capacity Act (2005) for people with learning disabilities. Although SLT students have regular placement opportunities, they often experience difficulties linking theory to practice. One problem in particular is being able to be effective communicators when working with service users using AAC to support both their understanding as well as their expressive skills. Another problem is being able to use accessible information effectively when on placement to check that service users have understood what has been discussed during a consultation.

Table 2: Student preparatory reading

- A short overview of the Mental Capacity Act 2005. (Mental Capacity Act, (2005). Mental; pub, TSO).
- A short summary of the Care Act 2014. (Care Act 2014; pub, TSO).
- The Mencap report about deaths of people with learning disabilities whilst in acute care (Mencap, (2012). Death by Indifference: 74 Deaths and Counting: A Progress Report 5 Years on. Pub. Mencap.
- An eight-page summary of the CIPOLD report. (Heslop, P., Blaire, P., & Flemming, P. (2013). Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD). University of Bristol: Norah Fry Research Centre. 10(1), 14.
- A fourteen-page summary report of the Winterbourne View scandal. (Flynn, M. (2012). Winterbourne View Hospital: a serious case review. South Gloucestershire Safeguarding Adults Board).
- A reappraisal of previous teaching notes and PowerPoint presentations about augmentative and alternative communication, and the relevance of this teaching to their interaction and learning with service users.

At City, University of London, the involvement of service users in teaching has become an important part of the curriculum. Traditionally, this teaching has involved service users communicating about work experience; living a healthy lifestyle; specific training opportunities for service users; being involved in interviewing support staff and everyday life experiences. All presentations have been given by service users who use a range of AAC. This project has been developed in collaboration with The Advocacy Project (Table 1).

What do students learn in the Mental Capacity Act (2005) teaching session?

Resources to develop an understanding of The Mental Capacity Act (2005) in relation to people with learning disabilities were developed. Education involved both direct teaching as well as self-directed learning in small groups before meeting the service users (see Table 2).

The aims of the direct teaching session for the SLT students by the service users about the Mental Capacity Act (2005) are as follows:

- To learn about and demonstrate an awareness of the Mental Capacity Act (2005) and its relevance to the SLT students themselves as developing healthcare practitioners and its importance when working with people who have learning disabilities
- To learn about and demonstrate an awareness of the difficulties that people with learning disabilities have in accessing healthcare, specifically in relation to examples such as Winterbourne View, and those highlighted in the Death by Indifference report (2012), and the CIPOLD Inquiry (2013)
- To reflect on how to check a service user has understood information shared during a consultation, and reflect on how healthcare practitioners should use AAC to enable service users to ask questions, check information and participate in the decision-making process relevant to their own healthcare
- Students to reflect on their own communication style when working with people with learning disabilities, and demonstrate an awareness of how to “jargon bust”
- To be aware of the Accessible

Table 3: Topics selected by service users on accessing health care for video materials

<p>John (with Dave, his support worker)</p> <p><i>Topics:</i></p> <ul style="list-style-type: none"> i) Accessing the dentist; ii) accessing speech and language therapy support <p><i>Methods used to support John:</i> Preparation, including role play; checking the sequence of what happens at the dentist; letting others know how to tell when John is in pain; how to gain a referral and therefore access to speech and language therapy, so John can sign and gain confidence with his spoken vocabulary as well as using pictorial materials.</p>	<p>Saiful (with Azad, his brother)</p> <p><i>Topics:</i></p> <ul style="list-style-type: none"> i) Health checks with the nurse and doctor; ii) Being healthy by exercising and eating the right foods <p><i>Methods used to support Saiful:</i> Using visual information to help Saiful remember appointments, and what will happen; using objects to help Saiful understand; using simplified language and repetition with the nurse and doctor.</p>
<p>Maryam (with Jane, her carer and Aisha her advocate)</p> <p><i>Topic:</i> Accessing good, safe health care</p> <p><i>Methods used to support Maryam:</i> It is important that Maryam sees a familiar doctor who knows her medical history, and knows how to communicate with her (she uses multi – modal methods of communication); she explains about a difficult experience where she saw a different doctor, and became unwell with medication prescribed which she would not usually have.</p>	<p>David (with Aisha, his advocate)</p> <p><i>Topic:</i> Communication barriers when accessing the GP.</p> <p><i>Methods used to support David:</i> David talks about non-accessible information; jargon and too much information; having to take his mother to appointments with him; difficulties processing information; unfamiliar vocabulary; David discusses his Health Action Plan and his Health Passport; his preferred vocabulary so he has understood; someone asking him to repeat back so he has understood; and use of traffic light cards.</p>

Information Standard, (NHS England) and how it applies to people with learning disabilities

- To be aware of Health Action Plans, Communication Passports, Easy Read Crisis Card information and how this is relevant to people with learning disabilities

Service user visiting lecturers involved in the project

Four service users, Maryam, Saiful, David and John, were involved with creating videos of their experiences accessing healthcare (Table 3). All four service users are regular visiting lecturers at City, University of London. Maryam, Saiful, David and John have helped develop the curriculum in relation to understanding the importance of effective communication with people who use augmentative and alternative communication and they are diverse in the way they communicate. John uses some single Makaton (Walker, 1977) signs, single words, facial expression, pictures, symbols and Objects of Reference (Park, 1997). He has significant difficulties with his understanding of language, and is supported by use of simplified language, visual cues and prompts, e.g. signs, gestures, Objects of Reference (Park, 1997) and repetition. David is able to use spoken language, but his difficulties with language processing, as well as problems with comprehending less familiar vocabulary impact on his confidence, independence and ability to participate. Saiful uses some Makaton signs (Walker, 1977), some spoken words, Objects of Reference (Park, 1997), and visual / pictorial information. As with John, David has difficulties understanding language and therefore needs information presented in a way which allows him to participate. This includes use of repetition, familiar vocabulary, no jargon words and simplified language, i.e. use of shorter sentences, with pauses by the speaker to allow for processing time. The fourth service user is Maryam, who uses some natural gestures, facial expressions, pictures, symbols, Objects of Reference (Park, 1997), a voice output communication device and an iPad interchangeably.

Each service user spent time preparing a script to enable them to be video recorded discussing their own experiences of accessing health care (Table 3). It was important that Maryam, Saiful, David and John used a variety of AAC methods to communicate and to highlight the problems that would prevent them from accessing healthcare information and support. David wanted to share his view of confidentiality in that his mother has to attend appointments with him. Understanding language used by healthcare staff was something that all four service users raised. John needs visual AAC support such as signs, Objects of Reference (Park, 1987) and repetition to help him understand what is being said. He also benefits from role play related to the potential scenarios that he may experience and, in his video, he talks about going to the dentist. Saiful also needs the same AAC cues as John when he goes for his regular health check-up. The nurse asks him to repeat back what they have discussed so that she can check he has understood. Maryam reported that engaging with a familiar healthcare worker made a difference, as familiar people tended to show awareness about how much she understood, how she communicated and what her specific needs were. David commented that he is anxious about receiving too much information verbally, as well as not being literate. He finds simplification of language important. John, Maryam and Saiful all have unique communication styles supported by AAC. Their specific methods of communication are described in personal documents such as Communication Passports and Health Action plans.

Students view video materials created by Maryam, Saiful, David and John as part of their preparatory work. They consider what they would need to do if they were working with each service user both directly, and with the wider team (e.g. training about AAC approaches, for example). Part of the preparatory work encourages them to think about how to present information, and discuss it in an accessible way. Students identify what is challenging about using AAC, and what

they will need to develop to be effective when interacting with others who need support through use of augmentative and alternative methods. They are also asked to identify how they could be proactive in preventing any significant adverse health events. Finally, students meet Maryam, Saiful, David and John, to hear about their experiences live, and to have time to ask them questions linked to their previous teaching and self-directed study.

Conclusion

Although students have placement opportunities to develop the necessary skills to prepare them for being speech and language therapists, they still need education experiences that allow them to reflect on potential challenges. Service users with learning disabilities often find accessing healthcare difficult, and their personal experiences can be important in helping to shape students' understanding on capacity in relation to working with people who have different ways of communicating. Understanding how to engage with those who need and use AAC remains an important part of the curriculum for SLT students.

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Read all about the experiences of two parents who attended our CM2017 conference for the first time this year (their subsidised places were sponsored by AssistiveWare)
<http://www.assistiveware.com/communication-matters-our-experience>



A potted history of the Sequal Trust!

LIZ DOWNES

The Sequal Trust

info@thesequaltrust.org.uk

Prior to the 1960's there was little acceptance of the potential of people with disabilities and problems in communicating, having anything to contribute. Two pioneers of developing technology to communicate were Reg Maling and Derryck Clarkson, a research chemist and electronics engineer. Their experiments triggered a movement to use technology to provide greater independence for people with restricted speech and physical ability, and were forerunners of the 'Possum' – the first environmental control unit which enabled a person with disabilities to control a wide range of domestic electrical items.

Hence, The Possum Users Association (PUA) (forerunner to Sequal) was launched in 1969. Possum is Latin for "I can" and "I am able" and seemed an appropriate name for the organisation. The initial management committee was made up of people who were suffering from major disabilities, but who had very active minds and the determination not to let the disability stand in their way. It was dedicated to the financial and social improvement of conditions of its members and other disabled people by fundraising to provide communication equipment which would transform peoples' lives.

Back then, a young woman named Hilary Pole, who had only been training as a PE Instructor for 6 months, was struck down by Myasthenia Gravis, which attacks the nervous system and gradually the body's abilities shut down. Hilary became unable to speak, see, eat or move and she required a respirator to breathe. Her only means of communication was by ringing a bell attached to her right toe, in which she had the only movement left, of 1/16 inch,

and with which she tapped out letters of the alphabet.

Roger Jefcoate, CBE, DL, one of our present-day Patrons, who was heavily involved with PUA at that time, visited Hilary, and he and his team eventually successfully designed sensitive micro-switches that modified Possum to meet Hilary's unique requirements. Hilary now could control several machines with her toe such as an electric typewriter, a bell to summon help, a radio and a television.

As time went on and technology advanced, a range of products designed to alleviate communication problems of all kinds was developed and a whole new world was opening.

In the early 1980's PUA changed its name to 'SEQUAL', an acronym for 'Special Equipment and Aids for Living'. The main reason for this was that as new products were coming on to the market an increasing number of members (i.e. applicants) were not possum users.

In 1989 Sequal reached its 21st Birthday with an awareness that something needed to be done to guarantee the long-term future of the charity. Department of Health grants which had been previously

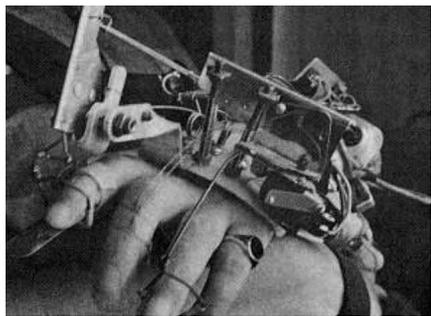
received, were stopped due to a change in policy; waiting lists of members needing equipment were at an all-time high and action was needed to ensure that the overheads of the charity would be met. With the twin aim of reducing the waiting list and providing an Endowment Fund, an Appeals Committee was formed and a national appeal launched. Thanks to the hard work of everyone involved, these targets were raised and the income we receive from the Endowment Fund (named after Robert Bowell, a founder member) helps to meet the costs of the charity and means that we can use every penny we receive by way of donation for the provision of equipment for our members.

Sequal has seen many changes in its 48 years of operation – the most noticeable one being the advances in assistive technology which have come along in leaps and bounds.

In 1969 'portable' computers were fairly recent developments and were pretty cumbersome affairs!

In fact, some of the access devices such as the fingertip control, pictured above, looked quite gruesome and reminiscent of The Addams Family!





Today we find that disabled people still need our help to obtain communication equipment. In so doing, we have helped people to rebuild their lives and get back in touch with the world; we have enabled children and young adults to study and further their careers; we have given each individual the means to communicate their most basic thoughts and needs, something most of us take for granted. We do this by constant fund raising - our support is life long and we maintain all issued systems at our own cost.

Technology is ever changing, and the variety of equipment we provide ranges from simple hand-held iPads with communicational apps to sophisticated eye-gaze systems. It is vital that each person receives the best solution to their particular needs, and we do our best to ensure that this happens by liaising with each person's SLT who can recommend the equipment best suited to that individual's needs.



Our main aim is – and has always been – to 'Set Lively Minds Free', so if you need our help or can support us with donations or by holding fund raising campaigns, we would be extremely grateful.

Two recent beneficiaries of our equipment provision are Jake and Meg who were both supplied with eye gaze equipment and now have a whole new world opened up for them, enabling them to move on to bigger and better things – their smiles say it all!



Roadshows 2018

The CM Office staff and trustees are beginning to plan our 2018 Roadshows. From January 2018, we will be introducing a payment of £10 for a place at a Roadshow, this is due to increased costs and an increasingly high dropout rate on places booked and confirmed on the system.

There will be a reduced charge of £5 for those who are members of Communication Matters, PwuAAC and their family members will also be charged £5, one accompanying personal support assistant will be eligible for a free place.

This fee will be non-refundable but will be transferrable. Attendees will be able to register and pay for Roadshow places on the Communication Matters website. It will be possible to make these payments online.

Look out for 2018 roadshow dates on the CM Website

The Board of Trustees thank everyone for continuing to support Communication Matters by attending Roadshows across the UK.

What do patients think? – learning for hubs

HANNAH JEFFERY

Highly Specialist Occupational Therapist, Access to Communication and Technology, 0121 466 3050
www.bhamcommunity.nhs.uk/ACT

The Service

Access to Communication and Technology (ACT) in Birmingham is one of the specialised Augmentative and Alternative Communication (AAC) assessment hubs funded by NHS England. It is an integrated service and assesses people with AAC, environmental control (EC) and computer access needs.

The Project

Each year the ACT team initiates projects to move the service forwards alongside the day to day delivery of services. One project initiated for 2017/18 entitled 'Patient Journey' aimed to undertake a structured survey of a sample of patients and their families/carers to identify their experiences of the service provided by ACT, thus improving the patient experience and develop more efficient ACT processes.

The Patients

- 164 patients assessed by ACT in 2015/2016 and provided with equipment were sampled.
- 45 agreed to participate, 21 declined and 98 were unable to be contacted.
- Of the 45 surveyed, 21 were AAC users, 22 were EC users and 2 were users of both AAC and EC.
- 14 parents responded on behalf of their child or young person and 31 patients responded themselves.

The Questions

Patients were contacted on the telephone

and offered the opportunity to complete the survey either on the telephone or face to face in the patient's home or care setting if the patient was unable to communicate on the phone.

Five structured (closed-ended) questions were asked and participants were asked to answer on a 1-5 scale. They could do this verbally, using their communication aid, by pointing, or by partner assisted scanning (author scanned along the visual scale and waited for a confirmation response from the patient).

Follow up prompt questions were asked to gather more in-depth qualitative data for those participants who were willing and able to communicate in more detail, or when a carer or family member was present to add their experience. Each question ended with the probe "Is there anything else you would like to add?" to encourage the respondent to elaborate on an initial response.

Results

- 79% of clients surveyed were satisfied with the information received prior to assessment
- 96% were satisfied with how well they were listened to during the assessment
- 95% were satisfied with how involved they were in the assessment process
- 83% were satisfied with the equipment provided
- 72% were satisfied with the information provided after the assessment

There was no statistically significant difference in the satisfaction of respondents on the AAC pathway vs EC pathway or between parents vs patients on any of the five questions.

Themes

Theme 1: Profile of ACT

ACT has a low profile prior to patients receiving assessment information (which is perhaps of no surprise being a specialist tertiary service) and there is a perceived lack of publicity about the service with key charities.

"...knew nothing about ACT before the information (service leaflet) was received" (respondent 6)

"The MNDA (Motor Neurone Disease Association) were good...but they didn't tell us about ACT" (respondent 102)

Lessons learned: Consideration is needed of the profile of ACT with key charities.

Theme 2: Format of service information

The ACT service leaflet was not memorable to patients and they suggested other formats such as a DVD.

"A DVD would have been good, it's a bit of a new world if you don't know what's available, you don't know what would suit your child" (respondent 65)

"A more visual explanation especially for children with limited communication being able to show them where they're going, the assessment room, what things might happen, would allay the parents fears as well as the child's"

(respondent 154)

Lessons learned: A change is needed to the format of the information about ACT pre- assessment.

Theme 3: Expectation of assessment

Patients had a reasonable expectation of the assessment, with information coming from either being a previous client of ACT or from the local team.

"We knew the service but not what was on offer from the service" (respondent 65)

"...someone had said some sort of thing to help his communication" (respondent 131)

Knowledge about ACT came from being; a previous client (n=6), informed by their local team (n=13) which included therapists (n=5), staff (n=3), school (n=3), family (n=2) and an AAC company (n=1). 7 respondents couldn't remember any information being provided before the assessment.

Lessons learned: The local team are a key source of information about ACT and are made up of a diverse group of people, not just the referrer.

Theme 4: Staff qualities

Respondents described many positive attributes of the staff at ACT, pictured in figure 1.



Figure 1

Clients felt listened to when staff: answered questions, explained everything, asked the patient first, made contact prior to the assessment, were organized, had detailed discussions, worked together, made alterations to meet client needs, allowed time, asked questions, and used an interpreter when needed.

Theme 5: Involving the patient first

Respondents detailed the ways in which ACT had put the patient first during assessments which had contributed to them feeling involved.

"Showing how things worked at my pace. They never rushed me" (respondent 104)

Theme 6: The local team

Respondents acknowledged the numerous people involved in an assessment and that good communication is needed in order for this to be successful. They also talked about some of the challenges they had experienced with the assessment process.

"There were areas for improvement around liaising with the local team and other agencies:

"They should have spoken to (local SLT) first" (respondent 31) "I was expecting them to talk to other agencies" (respondent 49)

Lessons learned: Liaison and communication with the local team prior to the assessment is important to patients including arranging appointments with parents. Involving other agencies is expected when particular expertise is needed e.g. visual impairment. Attention is needed to work more closely with the companies installing equipment to ensure transparency and clarity for the patient.

Theme 7: The equipment

Some respondents talked about the technical application of the equipment and also what the equipment enabled them to do in their everyday life (figure 2).



Figure 2: Functional application of equipment

"All of his communication before was what he wanted and needed, but now he uses the device to share his opinion on things" – parent of AAC user

Some respondents reported problems with the equipment that require time for ACT to follow up.

"He told us it's broken at the moment as a member of staff dropped it" (respondent 6)

"Since then situation has deteriorated... (the equipment) is obsolete" (respondent 24)

"The battery is lasting 12 hours, it's meant to last 3-4 days" (respondent 61)

Lessons learned: Greater/more frequent contact with the patient is needed to check on the success of the equipment and to identify problems.

Respondents also talked about the support needed from the people around them in order to use the equipment.

"College are making adjustments to the communication aid" (respondent 8)

"..(local speech and language therapist) has learnt how to change things...if (she) hadn't made it easier she (patient) wouldn't be using it" (respondent 31)

Lessons learned: The team around the patient is critical to the successful use of the equipment.

Others talked about their expectations around the equipment:

"It was all about modeling really, they explained a lot about how not to put expectations on him but to show him how we would use it without any

pressure and that was very clearly explained and demonstrated. It was as I expected workload wise” (respondent 58)

“I expected it to be work because we’ve had a paper based system before” (respondent 65)

“(It was) more work than I expected just because it’s quite comprehensive and there’s a lot on there and navigating through things is quite difficult” (respondent 131)

“Some parents think they’re going to get something that the child is going to be able to use straight away...there’s a lot of hard work to get to the point where a child can use it on their own” (respondent 154)

Theme 8: Home vs School

Parents frequently reported their child uses their equipment at school but not at home.

“School keep it (the device) there for maximum use. We use the low-tech book at home” (respondent 6)

“We don’t use the communication aid at home at the moment due to the amount

of stress on me...I’m not good on the computer...” (respondent 8)

“He doesn’t always use it at home...the kids are better with the technology than us...” (respondent 29)

“...mainly uses it at school at the moment...he points and signs more at home because it’s quicker and easier than finding everything on his device... It’s more work than I expected just because it’s quite comprehensive and there’s a lot on there and navigating through things is quite difficult” (respondent 131)

“He doesn’t use it much at home, but he uses it really well at school.” (respondent 154)

Lessons learned: More support is needed for parents to embed communication aids in the home environment for children and young people.

Theme 9: The trouble with post

Although respondents reported paper-work given to them on the day had been useful, many could not recall receiving anything in the post, or were not likely to see their post due to the level of their physical disability.

Lessons learned: Posting written information to clients may not reach them.

Theme 10: Making a plan

As a result of not recalling receiving any information post-assessment or not having access to their post, many respondents were unsure of the next steps in their care from ACT.

Lessons learned: Reflection on how to better communicate the plan/next steps to clients is required.

Figure 3 shows the responses of satisfaction across the five questions.

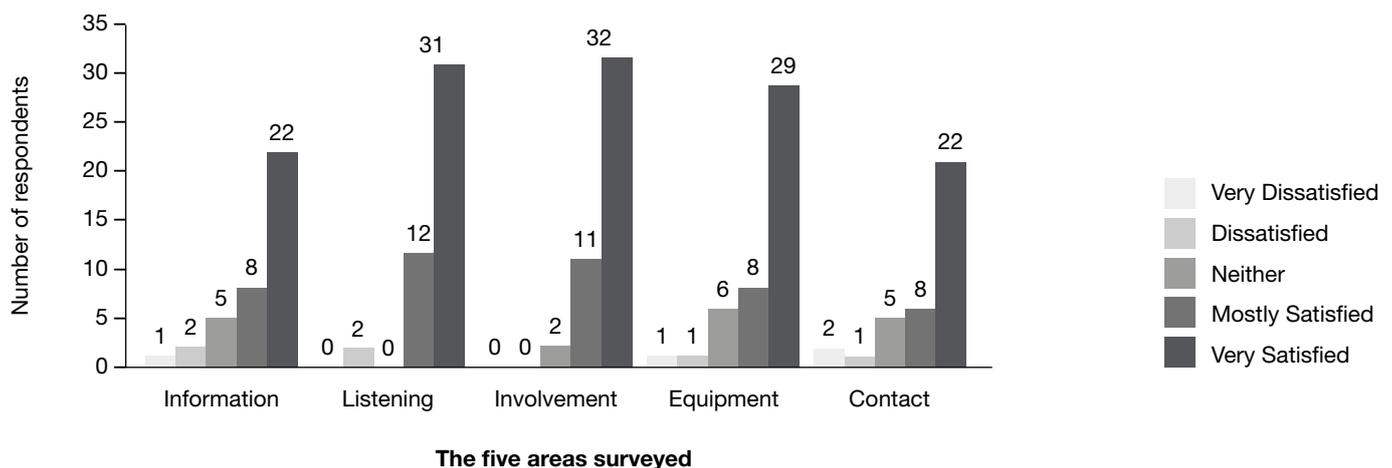
Next Steps

An action plan will now be devised to address the lessons learned.

For Future Research

- Parents of children with equipment were asked to answer on their behalf, what do the children think of ACT?
- Patients who were not provided with equipment were excluded from the sample – is their experience of the ACT assessment process different?

Figure 3: Overview



Pass IT On – reusing computers to change lives

SANDY KERR

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Pass IT On is a charity which collects donated computer equipment, adapts it and gives it to people with disabilities living in the EH (Edinburgh) postcode area. Pass IT On was founded in 2002 by Martha Lester-Cribb and Sandy Kerr, after their long experience of working with disabled people showed that access to computers and technology is restricted for many. We also provide volunteering and work placement opportunities for people with additional needs, allowing trainees to learn skills and contribute to our work; collecting, building and adapting computers for clients.

Imagining life without access to a computer seems unthinkable for many people today. From banking to shopping to social networking or reading favourite newspapers online, much of modern life involves access to computers and the internet. We keep in touch with our friends and families, share experiences and photographs and make social plans online. Yet there are still huge gaps in access to computers, especially for housebound disabled people and others who are not able to take advantage of publicly available IT facilities. Essential adaptations such as special keyboards and switches are rarely, if ever, available in public locations and are very expensive. Meanwhile, each year tonnes of perfectly useable computer equipment end up being discarded when businesses and individuals upgrade their machines.

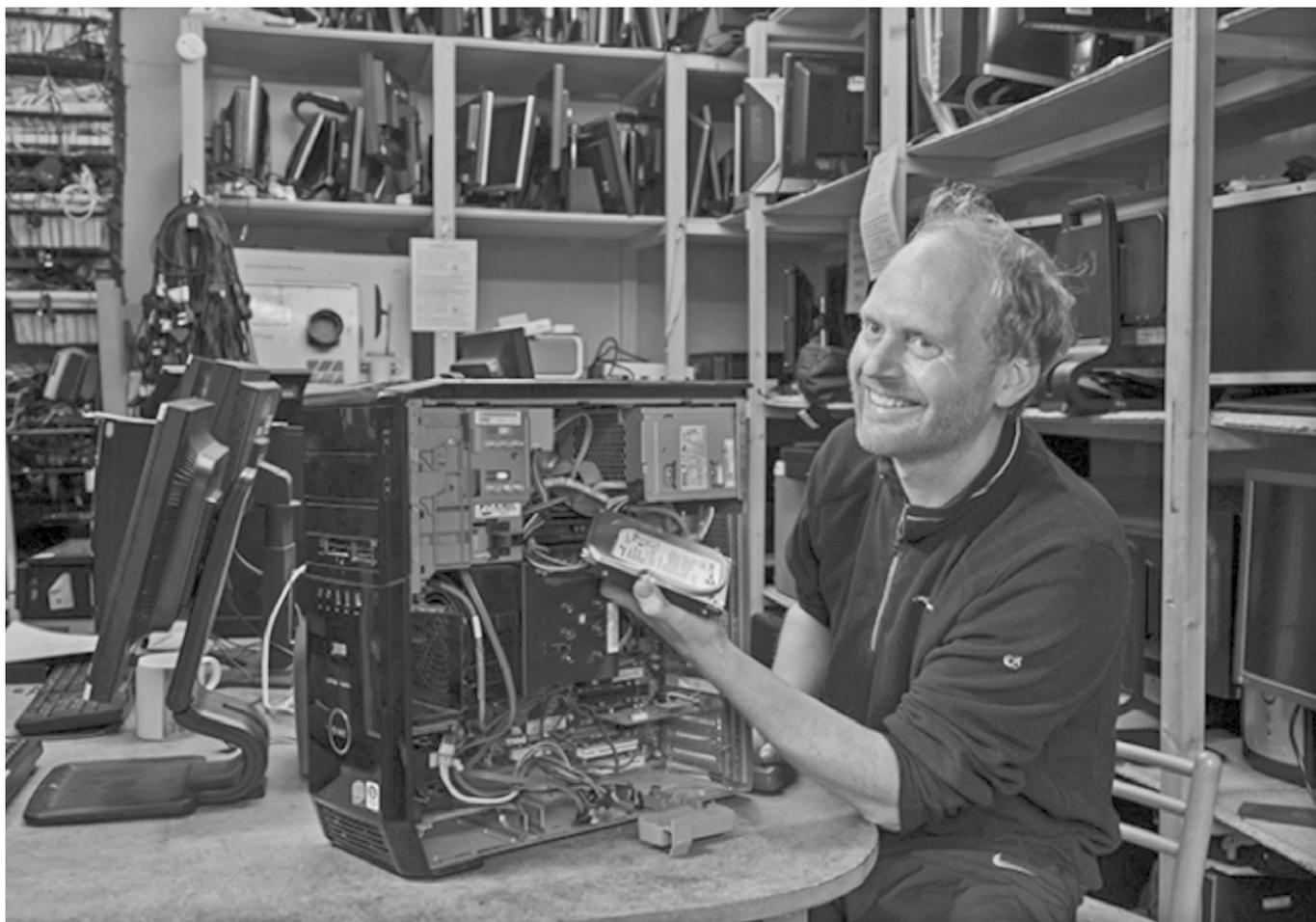
The idea behind Pass IT On is a simple one - that a computer being discarded by one person can be rebuilt and adapted to act as a lifeline to someone excluded by disability or social isolation.



Pass IT On has spent the last 15 years working to make a difference in the lives of some of society's most excluded and vulnerable people. We want technological inclusion to be a reality for every disabled person, not just those who can afford it. If a non-disabled person lacks computer access, they are still able to go to the bank, the library or to the shops in person. A disabled person very often may not have this option. With no statutory provision for computers and adaptations, we fill an essential gap through our provision of computers for disabled people. Our clients have the most to gain from technology, especially in the form of reducing

social isolation and offering sources of empowerment, information, advice and support.

An accessible PC can allow someone who can't use their arms to write a private letter, or someone who can't speak to use it as their voice. It can help someone with a learning disability develop new skills. At Pass IT On, we provide free adapted computer systems to people who are unable to access publicly available computers because of their disability or long-term health condition. We seek out the right equipment and software solutions to suit each individual's needs and interests. All the computers that we refurbish



and adapt are donated to us, which saves resources and the environment. We work with people of any age and with any disability, whether that is a physical or learning disability, a visual impairment, mental ill-health or a long-term health condition. Our only criteria are that the person lives in the EH postcode area and the impairment or health condition makes it difficult or impossible for them to access a publicly available computer (for example in their local library).

The process of becoming one of our clients is very simple. People can self-refer or be referred by a carer, family member, social worker, etc. We then send a simple eligibility form to their chosen medical professional. Within 4-6 weeks after receipt of the completed eligibility form, we will assess the client to find out their requirements. Initially we do a telephone assessment, then, if deemed necessary, we will visit the client at home and do a physical assessment. Having

gathered what is needed, we build and adapt a suitable computer and arrange to deliver and set it up. Sandy will then turn up at the agreed date and time, set up the computer (explaining each step to the client) and give basic tuition on how to use it.

For more information go to <http://www.passitoncomputers.co.uk/> or join us on Facebook at www.facebook.com/passitoncomputers/



Search the web and raise funds for free:

<http://www.everyclick.com/communicationmatters>

Invitation to participate – let's talk about talking

ERSIN SINAY

Whittington NHS Trust

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In April 1917, three men met for lunch in New York and made their way to the JL Mott Ironworks, a plumbing supplier on Fifth Avenue, to select a 'Bedfordshire' model porcelain urinal. Once turned 90 degrees and signed as R. Mutt 1917, this has then become the famous 'Fountain' by Marcel Duchamp and started the whole conversation about 'What is art?'

Grayson Perry, in his most recent book, acclaims that, in its simplest summary, art is everything supplied by an artist in a location known as an art location i.e. a museum.

Art has gone through many stages; initially becoming a universal way of communication between people and ages before writing, it was then used as a medium for the Church to deliver its message to the masses. After all the -isms the modern art movement has gone through, contemporary art now claims art for arts sake. We can now see art in golden frames, on

canvases, in museums, on streets, as performances or virtual reality experiences and on our smartphones as an Instagram photo.

This change in our perception of what is art can also be applied to conversation. Regardless of the advances of the internet and our widened connections with people; when it comes to neurodiversity our range of conversation partners is still very limited.

Can we have conversations with people who don't necessarily always follow the same social norms as we do? Can we have conversations with people who don't always maintain eye-contact, ask or share their weekends with us or know exactly what we are feeling when we have not talked about our feelings? Can we have conversations with people who use sign language when we don't? Can we have

conversations with people who use a communication device? Can we look beyond the delay in response when we are talking with someone using a high-tech communication device and be comfortable with that silence? If we don't have small chats or instant replies, can we still find a common ground?

Damian E Milton refers to a 'double empathy problem' as a mutual incomprehension occurring during attempts to communicate between people of different dispositional outlooks and personal conceptual understandings. He sees it as a double problem rather than an empathy problem only consequential of an autistic mind, as both people experience the problem and so it is not a singular problem located in any one person. He recommends that 'if autistic and non-autistic people share in the same sociality



(albeit in somewhat different ways), then the development of shared interactional expertise becomes possible in both directions and the double empathy gap (Milton, 2012) in understanding can begin to be bridged'

In the 'Artist is Present', Marina Abramovic sat in the Museum of Modern Art, New York for a total of 700 hours for six days a week and seven hours a day, across a large number of audiences who queued for hours daily, to sit in front of her for either minutes or sometimes hours without saying a word but seeking to feel a connection.

I would like to use this idea and invite an Augmentative and Alternative Communication (AAC) Device User to join me in connecting and bridging the gap with each other and others around a table in a large social space. Inspired by art and its movement, I would like to start 'a talk about talking' - using gestures, non-verbal communication, a PODD book, an iPad, an eye-gaze device, a PECS book or a comic strip with AAC users and with people who have never interacted with AAC users before.

In a systematic review (Baxter S, Enderby P, Jedge S, Evans P, 2012) it was concluded that as well as the barriers of the communication device itself, i.e. the ease of device, reliability, lack of technical support and limited availability of languages other than English, other people's responses played an important role in AAC users decision-making and continued use of their device effectively in society. The Smith and Connolly (2008)



study identified that the communication partner was the factor most likely to influence use of an aid. In True et al's (2009) report, participants with aphasia note that the audience could make communication more or less challenging.

Having conversations will result in familiarity, reduce anxiety and rally acceptance which in turn will maximise further opportunities and enhance everyone's quality of life.

Meanings are ultimately in people rather than in words. (Kreps and Thornton, 1992)

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Please contact me if you are or know an AAC user who would like to join me on this experience and connect.

E-mails: Ersin.Sinay@nhs.net or ersnsny@gmail.com

**Christmas is coming so get shopping,
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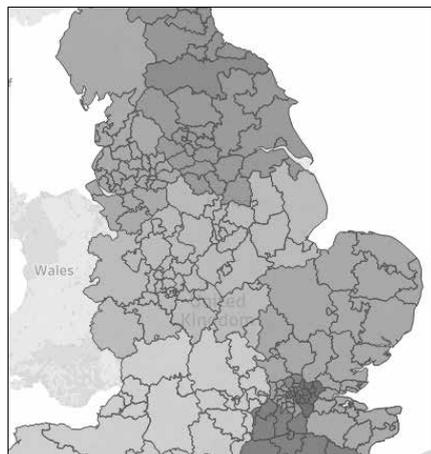
NHS England Specialised AAC Services: an update

JULIE ATKINSON

On behalf of the NHS England AAC Advisory Group
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In April 2013, NHS England became responsible for commissioning services for those people with the most complex communication needs (NHS England 2014). A Service Specification (NHS England 2016) was written defining the remit for these services.

14 centres/services subsequently received funding to set up Specialised AAC Services for England (see map for areas covered).



Specialised Commissioning Region	Service Name
North West	ACE Centre (Oldham)
North East	Regional Communication Aid Centre (Newcastle)
Yorkshire and Humber	Barnsley Assistive Technology Team (Barnsley)
West Midlands	Access to Communication & Technology (Birmingham)
East Midlands	Lincoln Electronic Assistive Technology Service (Lincoln)
Wessex & Thames Valley	ACE Centre (Abingdon)
East of England	Communication Aid Service - East of England (Cambridge)
South West	Bristol Communication Aid Service (Bristol) – including Dame Hannah Rogers Trust
London	Compass Assistive & Rehabilitation Technology Service (London)
	Augmentative Communication Aid Service – Great Ormond Street (London)
	Guys & St Thomas Assistive Communication Service (London)
South East	Assistive Communication Service (London)
	Kent & Medway Communication and Assistive Technology Service (Canterbury)
	Chailey Communication Aid Service (Lewes)

See here for a link to the service contact details: <http://www.communicationmatters.org.uk/page/contacts-assessment-services-hubs>

chaired by Anna Reeves (ACE Centre North) which will develop two toolkits: one for AAC professionals who want to establish or develop a local AAC service and another one for commissioners.

Patient Experience / Quality



Many services reported high referral rates, with variable quality of referral information, initially; this resulted in extended waiting times whilst services were being set up and new staff were being recruited and trained. A ‘Minimum Data Set’ (Contract Monitoring Report) was established, which all services report on their service delivery to NHS England monthly; we are liaising closely with the Environmental Control (EC) services to endeavour to harmonise the AAC and EC data sets as far as practical.

All services report positive feedback from patients, families and referrers who are now receiving support and “have a voice” - see comments summarised above. An Outcome Measurement Working Party chaired by Vicky Styles (Bristol Communication Aid Service) has been

set up and has agreed that the Therapy Outcome Measures for AAC (TOMS-AAC) will be adopted by all Specialised AAC Services; initial feedback from this group was presented at the Communication Matters Conference 2017.

One colleague gave this feedback: “Since NHSE funding has come into being, I feel we can deliver really high-quality assessments with a skilled Multidisciplinary Team who have the time to do a thorough job. We’re no longer dangling carrots of the equipment that would benefit clients without the funding being available. I can see the benefits this has on my clients and my job satisfaction has increased as a result.”

Next Steps

The diagram below shows some of the current challenges reported by the Specialised AAC Services. In addition to the projects that the Working Parties are undertaking, we are also in the process of reviewing Annexes 2 and 3 of the Service Specification in order to better clarify our referral eligibility criteria due to feedback that these are open to varying interpretation. There is also further work planned on standardising discharge and re-referral processes. It

is anticipated that increased clarity will benefit referrers and patients as well as the services.

At our next Specialised AAC Services meeting in December, we are meeting our counterparts from Scotland, Northern Ireland and Wales for national service updates, discussions about cross boundary protocols, and to progress the Working Parties’ remits.

Information about the Specialised AAC Assessment Services can be found on the Communication Matters website <http://www.communicationmatters.org.uk/page/resources/aac-assessment-services> along with the NHS England documentation <http://www.communicationmatters.org.uk/page/national-standards-aac-services>

The NHS England website also hosts useful information about the Service Specification

<https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-d/d01/>

References

- “Guidance for commissioning AAC services and equipment” NHS England (March 2014)
- “Service Specification Complex Disability Equipment - Communication Aids (Specialised AAC Services)” NHS England 2016



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