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NOVEMBER 2016 VOLUME 30 NUMBER 3

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COMMUNICATION MATTERS JOURNAL

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NOVEMBER 2016



CM's new logo was released at the beginning of September in time for the conference. We hope you like it!

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Co-chairs' Report

Toby Hewson & Ruth McMorran

We are now two months into our role as Co-Chairs. In the first few weeks after Conference we thought what we have agreed to? However now things have settled down. We've chaired our first board meeting and are getting into a good working routine.

CM 2016 – our 30th anniversary conference - was a great success. Just a few words about something you wouldn't have seen. It was great to be joined for a Mexican Supper on the Saturday evening before conference by the trustees of 1Voice. It was good to see the two Boards working together to select the winner of the Alan Martin award. Jemima Hughes was awarded this and Helen Quiller won CM's Got Talent – both people with strong links to 1Voice. You'll find Helen has written a lovely article for this journal and I know she was very excited to learn that there is going to be a short piece about her in the December issue of the Communication Support World Network Newsletter.

As you will be aware CM has recently appointed a new solicitor, accountant and auditor – all of whom are based in Leeds. On the evening of our first board meeting we hosted a small drinks reception which ensured all members of the board had the opportunity to meet

Mark Honeywell and Lara Jones from Lupton & Fawcett Solicitors and Ian Pickup & Alan Sidebottom from Garbutt & Elliott Accountants.

The review of all our governance documents is now almost complete. The Memorandum and Articles of Association have been updated to take into account the Companies Act 2006 and the Charities Act 2011. We are indebted to Anthony Hewson for his advice and support with this work.

We are splitting the roles of chair between us – sometimes based on knowledge and experience and sometimes purely on geography. We are extremely grateful to trustees and friends who have represented CM at events we have not been able to attend. In recent months, this has included Jenny Herd attending the October meeting of the Communication Consortium; Steven Bloch and Helen Robinson went to the BMA Awards and Janet Larcher was present at the launch of the ChariTable app. Thank you all!

We are excited about being the co-chairs of CM for the next three years. We are keen, with the support of all the trustees and members, to continue taking Communication Matters forwards.



Trustee News

CM welcomes three new trustees

JENNY HERD

Having been involved in AAC issues for almost 16 years as a parent Jenny is pleased to be able to use skills & experience from both her personal & working/voluntary life to support CM. As the parent of an 18 year old AAC user she is a qualified teacher and has worked as a charity advisor (governance and fundraising) as well as for Citizens Advice Bureau. She has also been a trustee of 1Voice and represents them on the Communication Consortium, having been on there for 3 years.

Jenny says "I believe passionately in the right of all people without speech to have access not just to AAC, but also to education, work and opportunities others take for granted. CM has an important role to play in raising other people's expectations of AAC users across a range of settings and as a trustee I hope I will be able to help CM work towards this, and other goals which will benefit those who use or need to use AAC".

Jenny is on several CM working groups - Involvement of PwAAC in CM activities, Conference Abstract Review Committee and Governance (the group that oversees best practice for the Board itself.)

HESTER MACKAY (CO-OPTED)

Hester currently works as a teacher for the Kent and Medway Communication Assistive Technology (KM CAT) Hub Service in Ashford having trained as a mainstream primary teacher & teaching at Foundation Stage for most of her career before joining the CAT service. Now a large part of her job is supporting children and staff in both mainstream and special schools where having the background knowledge of the challenges schools and teachers face has been invaluable. Hester has a particular interest in how literacy is taught to non-verbal children and how best to support children with complex communication needs to acquire the literacy skills that are essential to

open up a world of functional communication. She has seen from her own experiences how much of a difference AAC can make and is thrilled to be working with CM as a trustee to help get that message out there.

Working groups - Literacy and AAC Study Days, increasing OT involvement, others tbc.

EUAN ROBERTSON

Euan is currently an AAC Consultant working at the ACE Centre, providing AAC assessment and equipment via an NHS England Specialised Service contract. He has a background in Speech and Language Therapy & worked in AAC for sixteen years. Euan has held posts within the NHS and also for the National Autistic Society as a Speech and Language Therapist and more recently worked as part of the content development and implementation team at DynaVox Mayer-Johnson.

Euan says "I have relied on the support of Communication Matters in the past and see the benefits it brings to many involved in the field of AAC. As a newer trustee I am excited about the future of Communication Matters and the hard work ahead!"

Working groups - Finance, Marketing & Publicity and Publications.

Key projects for the trustees at present include

Website improvements. Following positive feedback from users & marked increased hits on AACKnowledge in particular, CM is looking to update the research knowledge website and also bring the two websites closer together in function and look.

The Communication Access project now has a coordinator, **Catherine Harris**, who will be starting work in January 2017. The business training pilot will move forward and a more accessible version of the symbol survey that went out at conference, will be circulated in the new year.



From left to right: Jenny Herd, Hester Mackay, Euan Robertson

CM & Conference: impressions of an intern

PETER FUZESI

CM intern June–November 2016

Email: p.fuzesi@lancaster.ac.uk

A few years ago, when I embarked on my doctoral study, I knew little to nothing about AAC. All I knew was that my interest was focussed on the possibilities that new technologies can offer for disabled people. So I started a PhD study in the Sociology Department at Lancaster University. My PhD research investigates the development, delivery and use of AAC and other assistive technologies.

My PhD programme offers the opportunity to gain some practical experience and deeper insight into Assistive Technologies by working with a charity of my choice. Hence, following recommendations from others, I approached Communication Matters as the UK's leading charity in AAC, and I am very happy to have the chance to work with CM, the focus of the internship overlaps with my PhD research, making it an excellent opportunity both to further my understanding of the field of Assistive Technologies, to build connections with stakeholders and to refine and situate my research findings so that it can have the maximum impact.

Furthermore, the internship allows me to advance my understanding in organising and implementing applied research projects and interventions, and acquire new administrative skills and experience through being involved in conference organisation.

I learned a lot since the beginning of the internship in July; and Hilary, Emily and all the trustees, especially Cathy, as Chair, and Ruth, as lead on conference organisation, made me feel welcome.

The annual conference in September provided a great opportunity to meet people



with all kinds of reasons for their interest in AAC and the charity. I could see this event from different perspectives. As a member of the organising team I could see all the work and care that goes into the organisation. I could also meet some of the less known faces of the conference, like Anthony Lowe and his team from Meet in Leeds who support CM so amazingly. It was interesting to see how the CM

conference is an event they know about and look forward to hosting.

It was refreshing to see how the unique selection process of the CM Conference ensures that users, family members, professionals and researchers are all present and there is a balance between expertise, experience and practice. This diversity was reflected in the presentations I attended. I could be at several very

interesting sessions; here I only emphasise a few points that were especially relevant to my subjective interest.

Two presentations were especially enlightening in the way they captured the problem of how technology and use are integrated, a problem central to my own research interest. In different ways, both Kate McCallum and Fil McIntyre's presentation on AAC hacking and Lindsey Paden Cargill's presentation showed that technology always folds into of a larger system of relations. These relations reach far beyond the individual user and include professional standards, economic and cultural norms, and localised arrangements. In this sense, technology is more than a technological problem. Implementation is significant not only for generating positive impacts, but also crucial for making the technology work in the way it is envisaged from the outset.

For a researcher, CM Conference offers several intriguing presentations. One could say that presentations range from practical issues to philosophical and technological problems. In my impression, however, is that in AAC these problems usually come together. It was especially

a presentation from Kim Bates and Kate MacLeod, on the difference between choice making and preferences, that got me thinking about how, in AAC, the most mundane decisions are linked to moral and social dilemmas. And even behind the most abstract problems, there is a face and life that might be affected: communication is central to every culture. While AAC is in the focus of medical and engineering fields, it also holds a huge potential for the social sciences and humanities to critically interrogate and creatively redefine existing notions of human relations.

Listening to Jeremy Briers' presentation on how he communicates showed the way communication really matters: how it makes a difference in the user's and his or her communication partner's lives.

His presentation was a great demonstration of how AAC is linked to the way individuals fulfil their potential, and how technological devices can open the door for personal development.

Last but not least, being at the CM conference meant becoming part of the great community of attendees. The opening Tea Party or the Closing Dinner showed how this is also a warm and personal

event that brings together people from all backgrounds.

It would be impossible to summarise such a diverse event as the Annual Conference. Instead, I would only like to make a single point: technology is about people. Communication Matters and its Conference brings together people, and I am really happy and grateful for all CM members and officials that I could be part of this extraordinary event.

The Chairs, Trustees & CM Office Staff would like to thank Peter for all his hard work for CM. This first experience of hosting an intern has been nothing but positive: Peter has achieved so much, not just through prep for conference but through working on collating data for the Communication Access pilot, visiting further education colleges to network, proof reading outputs, manning the office & telephone, general running & coffee making (of course!!). We will definitely be happy to host another intern soon, possibly from within Leeds University. We wish Peter all the best for the future (and yes, he is still going to volunteer for us while writing up his PhD!)



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1 Voice 1 Day 2016 & more

HELEN QUILLER

(1Voice trustee)

Email: helenquiller@hotmail.com



On the 11th of September we held our 1 Voice 1 Day Event in conjunction with the Communication Matters Conference at Leeds University. This year Communication Matters were celebrating their 30th Anniversary Conference. They were having a big tea party on Sunday afternoon and had invited us to join in this event and celebrate with them, the theme for the conference was the 1980's and we decided to have the same theme. I travelled up on Saturday afternoon and attended a joint Trustee meal with the Trustees of Communication Matters, and all chatted together about both our forthcoming Events. It had been my birthday the Wednesday before, suddenly all the lights went off and someone walked up to me with a cake and candles, everyone started singing Happy Birthday to me. I felt this was very special and it meant a lot to me.

On Sunday morning everyone started to arrive for 1 Voice 1 Day, old friends and new. I began the day with a presentation about what Communication Technology I had and used in the 1980's and talked about how slow it was, compared with the technology of today.

We then split up into our various groups, I was with the adult AAC user group, where we spent sometime discussing what they would like to do in the future with 1 Voice, and what direction they would like 1 Voice to go in. We all came up with lots of ideas, including more residential weekends, possibly at the Calvert Trust, other ideas were a Music,

or Drama workshop. It was then time to test the memories of us older members with a POP QUIZ of 80's music, we then had lunch and fed our brains.

A joint Celebration with Communication Matters

After lunch it was time to go and join in the Tea Party with Communication Matters, where there were lots of surprises and fun entertainment in stall. They had all sorts of giant games for us all to play with, a giant Connect Four, Snakes and Ladders, and other games such as skittles, with lots of people around to help us play. They also had a Clown walking round on Stilts and teaching us all sorts of circus tricks and magic fun. There was also lots of nice food and cup cakes at the tea party, for the adults they also had a Jazz Band playing music.

Everyone had a really great afternoon and enjoyed spending time together with people from CM at this first integrated event.

At the end of our event it was time for the Communication matters Annual Meeting and then, more excitingly, the finals of the Competition CM'S GOT TALENT. I had entered in with my song 'The moment has gone' The final three entries (Robbie Williams, myself & Hollybank School) were played and the audience were all given anonymous voting slips which were counted up at the end. After a few minutes the judges came back in to announce the winner, and my song was the winner of CM'S GOT TALENT! I was very proud and excited about this achievement.



'Everyone had a really great afternoon and enjoyed spending time together with people from CM at this first integrated event.'



I continued to have a good time at the 2 day conference and gave my presentation about 'Independent Living' on the Tuesday morning. It was well received and everyone seemed to enjoy it.

See the lyrics to Helen's song here. The link to the Youtube full version is: <https://www.youtube.com/watch?v=0BVRJwNCZYM>

Alan Martin Award

On Tuesday afternoon just before the end of the Conference Jemima Hughes was presented with the Alan Martin Inspiration award for the animated film

that she had made and worked on over the last year (as well as the development of her work over time). You can see the films here: **Imagination** <http://randomacts.channel4.com/post/149327322436/first-acts-jemima-hughes-imagination-a> & **I dream** <https://www.youtube.com/watch?v=kYHm1ZviwJM>

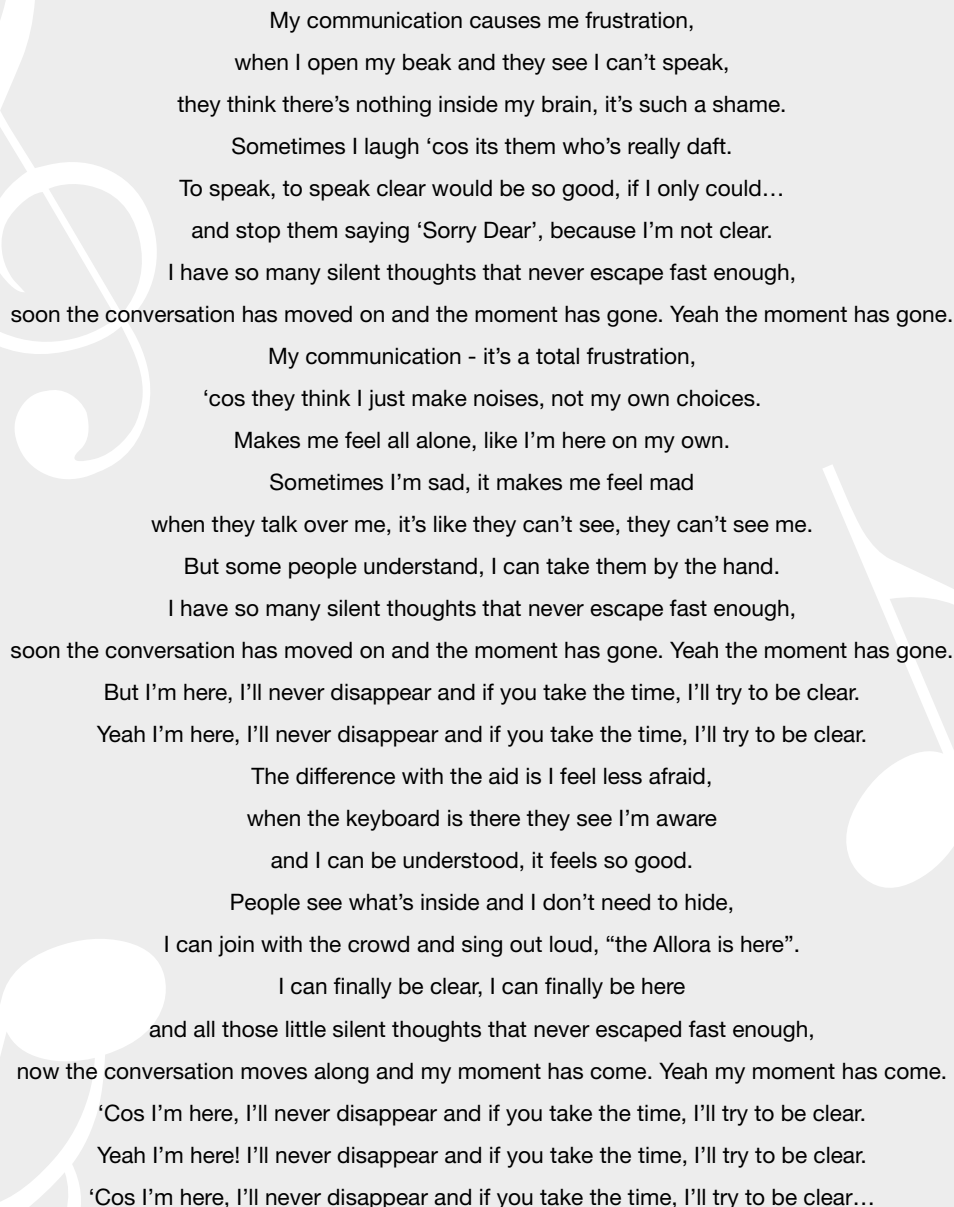
Others who had been shortlisted were also members who had attended 1Voice events in the past, like Simon Judd, who makes films and is studying Film and Media now at Leeds Beckett University. He is full time Liberator user which he and college have linked to an pple Mac

to enable him to use various editing programmes. This particular short is his film BreakDown (capital D in the middle very important). <https://www.youtube.com/watch?v=eCbMukunMnI>

The final nomination was Amy Golden for her musical "Get on With It". The details of how the musical came about are detailed in a feature on the Scope website <https://blog.scope.org.uk/2016/02/10/i-want-to-take-the-musical-about-my-life-to-the-edinburgh-festival/>

All in all, I would say that everyone from 1Voice had a very successful and fun time at Communication Matters this year.

HELEN QUILLER – The Moment Has Gone



My communication causes me frustration,
when I open my beak and they see I can't speak,
they think there's nothing inside my brain, it's such a shame.
Sometimes I laugh 'cos its them who's really daft.
To speak, to speak clear would be so good, if I only could...
and stop them saying 'Sorry Dear', because I'm not clear.
I have so many silent thoughts that never escape fast enough,
soon the conversation has moved on and the moment has gone. Yeah the moment has gone.
My communication - it's a total frustration,
'cos they think I just make noises, not my own choices.
Makes me feel all alone, like I'm here on my own.
Sometimes I'm sad, it makes me feel mad
when they talk over me, it's like they can't see, they can't see me.
But some people understand, I can take them by the hand.
I have so many silent thoughts that never escape fast enough,
soon the conversation has moved on and the moment has gone. Yeah the moment has gone.
But I'm here, I'll never disappear and if you take the time, I'll try to be clear.
Yeah I'm here, I'll never disappear and if you take the time, I'll try to be clear.
The difference with the aid is I feel less afraid,
when the keyboard is there they see I'm aware
and I can be understood, it feels so good.
People see what's inside and I don't need to hide,
I can join with the crowd and sing out loud, "the Allora is here".
I can finally be clear, I can finally be here
and all those little silent thoughts that never escaped fast enough,
now the conversation moves along and my moment has come. Yeah my moment has come.
'Cos I'm here, I'll never disappear and if you take the time, I'll try to be clear.
Yeah I'm here! I'll never disappear and if you take the time, I'll try to be clear.
'Cos I'm here, I'll never disappear and if you take the time, I'll try to be clear...

Round up of arts at the conference



Martin Pistorius presented a keynote but also had a book-signing for 'Ghost Boy'

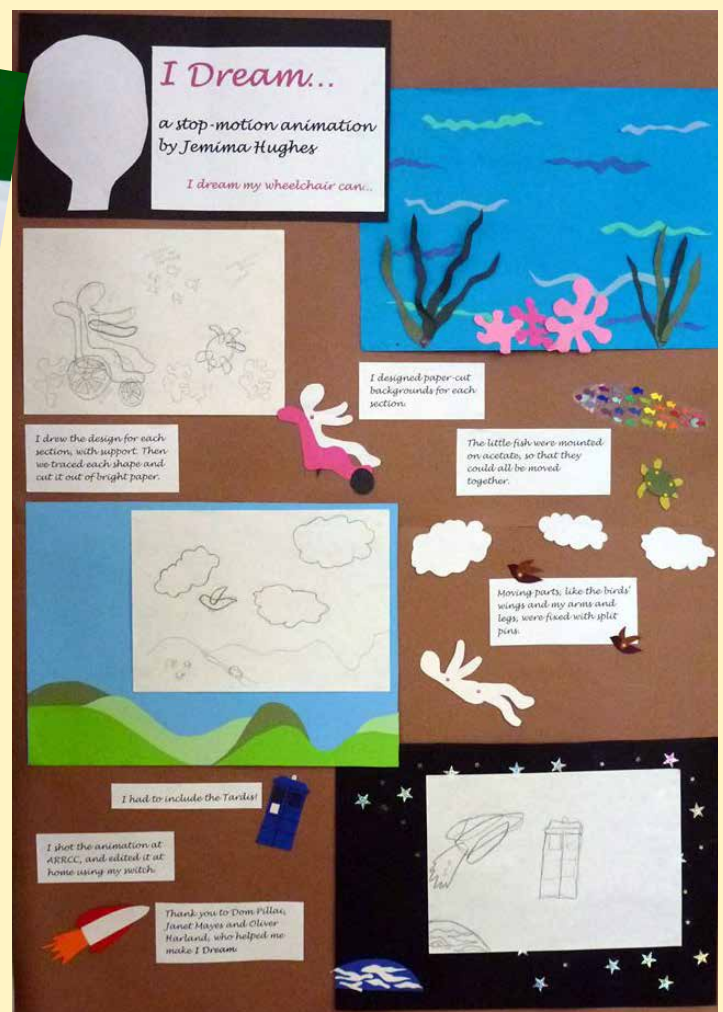


Sam Knapp, 2015 Alan Martin Award winner, was hired as photographer for the event.



ALAN MARTIN AWARD

Animations directed by Jemima Hughes



Round up of arts at the conference



SPEECHLESS

First video showing of Speechless in London!



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SPEECHLESS

An evocative musical theatre performance written by trustee Kate Caryer, which was filmed for future use.

Speechless was written by Kate Caryer, now a Trustee of CM. The performance during conference was supported by fundraising as well as a generous donation from the University of Leeds special fund (Kate is an alumnus of the University, having an MA in Disability Studies). *Unspoken CIC* is now arranging viewings of a film of the performance to raise funds for further development and for CM. The film was funded by the John Ellerman Foundation in order to produce an educational resource. If you are interested in arranging a fundraising evening with Kate please contact her or the CM office.

A breath controlled AAC system

D. KERR, K. BOUAZZA-MAROUF, A. GAUR*, A. SUTTON AND R. GREEN

Wolfson School, Loughborough University

*University Hospitals of Leicester NHS Trust

An estimated 2 million people in the USA and from 0.3% - 1.0% of the total world population of school-age children have a need for an Augmentative and Alternative Communication (AAC) intervention of some kind (Beukelman & Mirenda 2013).

There is a vast range of people with Complex Communication Needs (CCN), from those with chronic or degenerative conditions, those requiring immediate post-surgical intervention, or those suffering traumatic brain injury. Such conditions can also include Dysarthria (disorder of motor speech control), Apraxia (disorder of coordination of motor movements for speech), or Aphasia (language disorder as a result of brain injury or cerebral vascular incident). With such a wide range of conditions, and of the varying physical and cognitive abilities associated with them, it is inevitable that AAC systems have to be carefully tailored to individual needs.

Michael Williams (Williams *et al.* 2008) defines "Five Principles for the next

25 years of AAC". Amongst these, they emphasise the need for systems to be versatile enough to support communication modes that enable participation in all aspects of 21st century life. Further, they specify that users should be fully involved in the selection, training and adjustment of the device or devices they are using, thereby taking ownership of their communication system. However, modern devices still have a long way to go to satisfy some of these principles.

So-called "high-tech" AAC methods use direct selection or scanning interfaces to provide speech output. Storage and retrieval methods are often slow (anything from 3 to 12 words per minute). Narrative conversation is thus very difficult ("normal" conversational speech is 270 wpm). Built-in vocabularies may lack the flexibility required for all but the simplest exchange of ideas. A comprehensive study (Hodge 2007) of AAC users found that one of the major obstacles to successful uptake was the physical interface,

where a user's movement impairments often meant frustratingly slow and inefficient response times. This was compounded by the need for assistance from carers or relatives to pre-programme the machine with chosen words or phrases.

Activation input must be carefully tailored to an individual user (e.g. eye gaze, sip/puff etc.). Sip/puff systems already exist where breath is used to activate a switch (both simple and advanced). A breath-controlled encoding device (Dilbagi 2014) was unveiled at a recent Google Science Fair, and a breath-controlled switch has been introduced to regulate "textual flow" in the Dasher communication system developed by Cambridge University (Tom H. Shorrock, David J. C. MacKay 2004). An example of breath signals we collected using a digital microphone is shown in Figure 1. However, the digital codes produced from signals like this, in order to guide a screen cursor to make fixed selections, are slow, laborious and limited in direct information content.

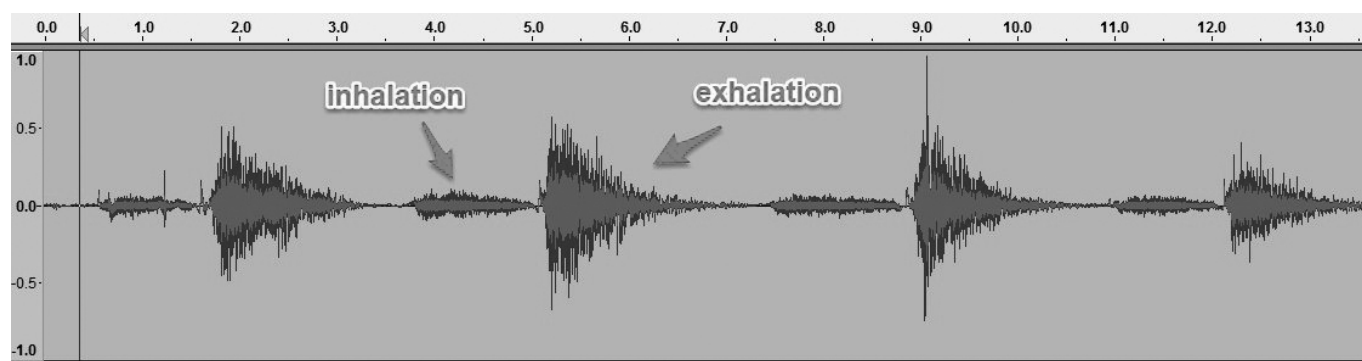


Figure 1 – sound signals recorded by a cardioid digital microphone placed adjacent to the mouth during normal breathing.

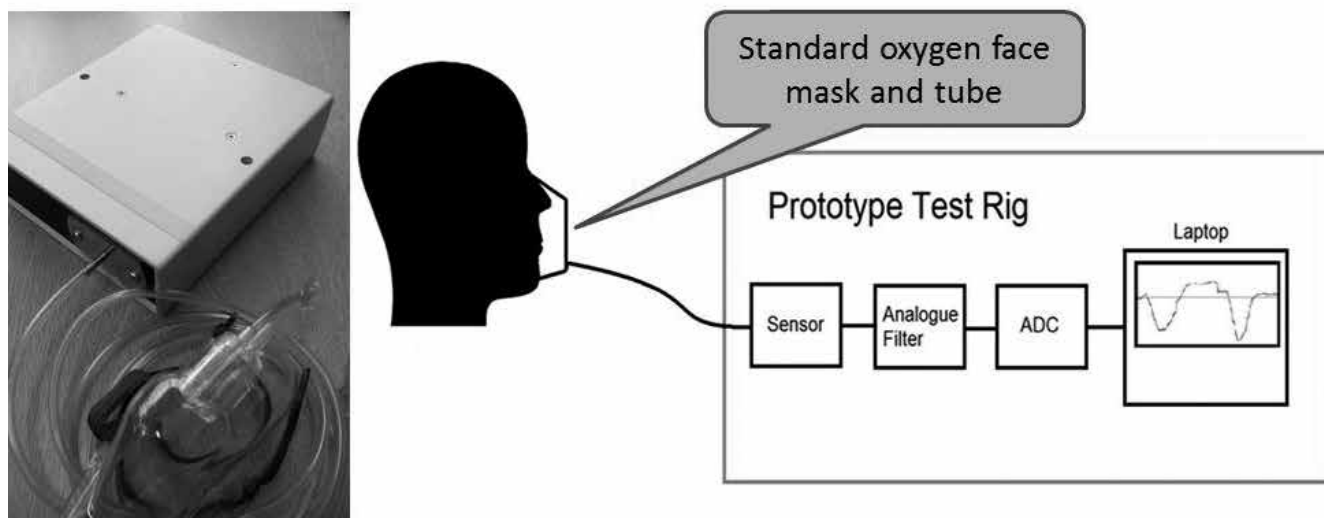


Figure 2 – (left) early prototype data collection system, showing pressure transducer and electronics housing, with breathing mask connected; (right) breath signals are filtered and digitised over a 10 second period, then displayed on the computer screen before data content analysis.

Humans are not really designed to select, think or speak in binary codes!

Analogue methods of encoding are more “natural” and potentially can contain more information. For example, small variations in amplitude can be used to represent nuance, emphasis or emotion. Phase changes might represent grammar variations, such as tense, plurals, or queries. This compares to the semantic compaction methods used in Minspeak and Blissymbols, where such “prosodic features” of language can currently be represented within an AAC system. Greater communication speeds should thus be achievable, thanks to the more rich information content possible. Some analogue signals with differing phases

can be seen in the example of Figure 3. One could for example think of these as past and present tense versions of the same word or phrase.

For this project, we started out to design a simple, needs-driven communication device for patients in a hospital ICU on ventilator support. Later, we sought to extend this more generally to anyone with a severe speech impairment, which may be combined with partial or complete loss of motor functionality. Our starting assumption was that all such people were able to breathe spontaneously; hence we could use breath as an activation method. However, potential users:

- must be able to control breathing rate spontaneously

- must have sufficient cognitive ability to understand how to use system
- in later stages of degenerative diseases may not be suited to the device

A schematic of our device is shown in Figure 2, and some typical breathing pressure/time signals or “patterns” obtained from it are shown in Figure 3. Breathing variations within the user’s mask are detected by a pressure sensor, and then captured as patterns by a computer program and analysed for characteristic features, such as variations in frequency, intensity and phase, as depicted in Figure 3.

The computer-based recognition system then “learns” to understand these

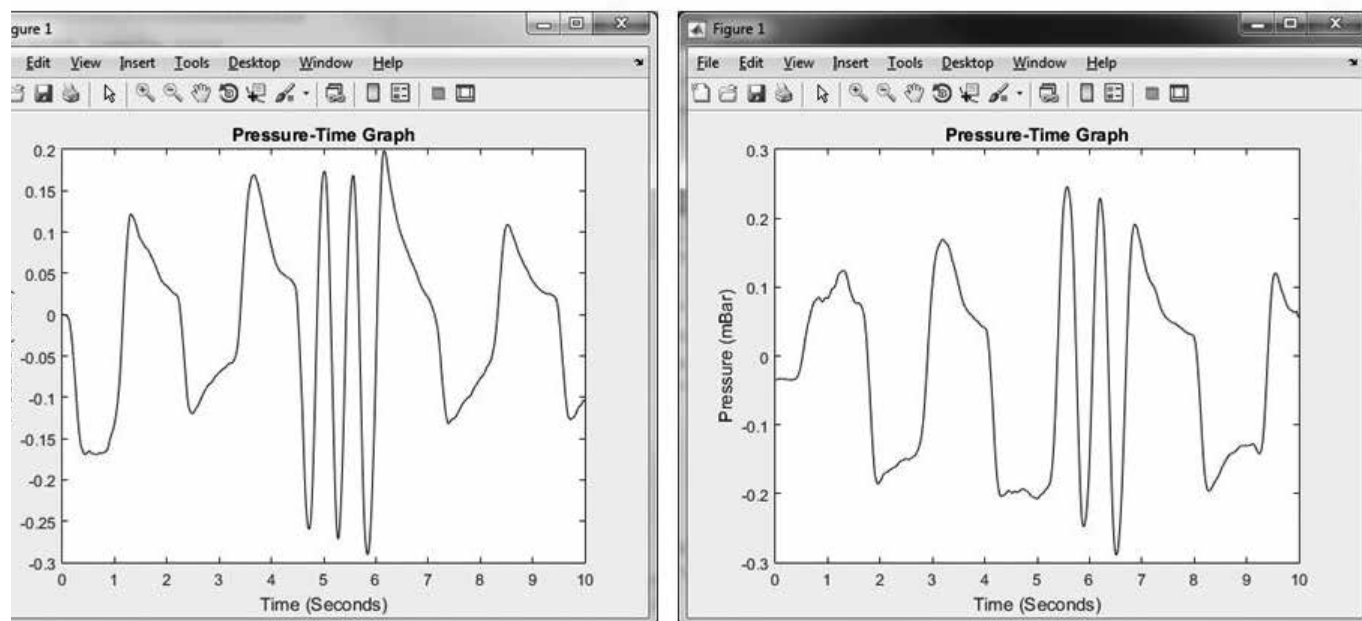


Figure 3 – breath signals collected from a pressure transducer over a 10 second period, showing the differences in signal phase between (left) inhalation at start and (right) exhalation at start.

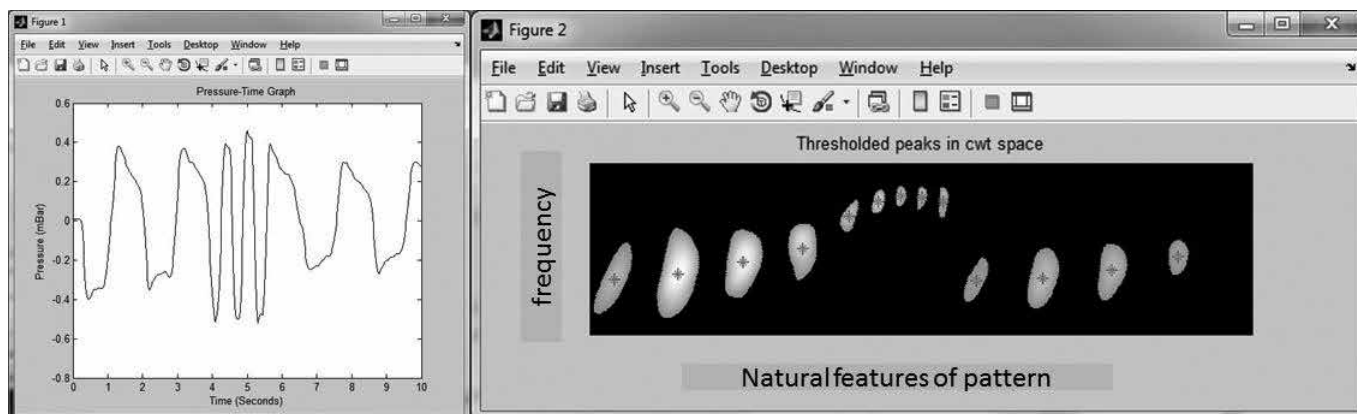


Figure 4 – (left) modulated breath pattern from pressure sensor over a 10 second period, showing variations in breathing rate; (right) data after analysis of breathing rate variations over the same time period. The white patches show how the predominant rates vary with time.

patterns through example and repetition. The data once recognised can be turned into speech using either voice synthesis or pre-recorded playback. Users have to “teach” the system to recognise the breath patterns that they wish to associate with words, phrases etc. There are thus two modes of use.

- Learning mode – user “teaches” the system new words or phrases by providing examples. Vocabulary is built up as required over time.
- Speaking mode – system recognises patterns breathed by user and turns them into synthesised speech, or plays back pre-recorded voice.

We tested our prototype system on 7 healthy people aged 20-22 years, with no speech impairment. Each provided 10 repetitions of 3 unique breath patterns of their choice. After a short period, each was asked to reproduce their 3 unique patterns five times each for the system to interpret. The mean reliability of system interpretation was found to be 90% (values ranged between 73% and 100%)

As the development of our system proceeds, the standard approach of a control interface to some bounded selection set is what we want to get away from. We want to impose as few limitations as possible on what the control interface can achieve in terms of communicating wants, ideas, feelings etc. in the form of narrative communication. We intend to incorporate Natural Language Processing and Generation into our system (to provide contextual data, disambiguate meaning and complete broken sentences, for example).

In the future, we will look at Artificial Intelligence (AI) applications that would allow better interfaces between users and their machines (reducing critical reliance

on family and/or care workers to train and maintain the system). The objective would be an intelligent AAC system that works with its user to grow and develop a means of narrative-enabled communication suited to the individual’s needs and capabilities, without the requirement for constant intervention by others.

Two very interesting developments in AI point towards what might be possible in the future. The Talking Heads Experiment (Steels 2015) was the first large-scale trial in which artificial agents created for the first time a new shared vocabulary by playing language games about real world scenes in front of them. If such machine to machine communication is possible, then human to machine language might also be designed to evolve in a natural way, complete with vocabulary, syntax, morphology, etc. and set within an appropriate contextual basis.

Intelligent tutoring systems, such as AutoTutor (Graesser et al. 2005), developed at the Institute of Intelligent Systems, University of Memphis, are designed to simulate a human tutor’s behaviour and guidance, through a dialogue with the student. The student’s understanding and depth of learning are enhanced and guided by the tutoring system, using so-called “conversational agents” founded on constructivist learning theories. This type of system might be designed to guide the new AAC user through the learning process and the development of the most suitable language structure to suit their needs. The system could thus grow to suit the capabilities of the speaker, and evolve over time as conditions change.

We think that this is an exciting time for AAC development, where a new generation of devices using recent advances in engineering and cognitive science may

one day be possible, that are truly adaptive to an individual’s needs, and that may go even further in satisfying Michael Williams’ five excellent principles.

Acknowledgements

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The potential of Sub Vocal Phonation as Augmentative and Alternative Communication

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What is Sub vocal Phonation?

Capitalising on existing inherent behaviours to facilitate AAC (Augmentative and Alternative Communication) has the advantage of starting with innate competence already available to the individual. A Breath Controlled AAC System (above) makes use of the obvious assumption that all people are able to breathe. Sub vocal phonation also appears to be a phenomenon common to the population generally and occurs as a natural 'unthinking' performance associated with movement of the speech structures.

Sub vocal phonation is often described as silent speech that occurs for normal speakers during silent reading, when the speech mechanisms move in response to the reader's internalised reading but vocal output is suppressed. Metzler (2009) refers to 'mouthed' or sub vocal speech as speech in which "the articulators go through normal production motions except no sound is produced" p.2667

Developing AAC, ongoing research

In order to track sub vocal phonation, electromyography (EMG) uses electrodes placed on the neck and face to read signals from the speech musculature and speech structures Denby *et al*, (2010),

Meltzner *et al* (2008). Becker and Bustelo (2009) were awarded a patent for a method of communication that operates by transforming sub vocal speech signals into synthesised speech or text via electromyography (sEMG) signals. Following experimental work at NASA, investigating the nerve signals that activate the throat and tongue to form words, scientists reported identification of some 'non-verbalised words' via sensors placed on the chin and Adam's apple.

In daily life, sub vocal phonation lacks any communicative significance as it remains inaudible to the listener, below the threshold of normal hearing. In addition, it can occur without any obvious movement of the face or mouth to trigger a communication partner to anticipate a message. However, for those individuals who are unable to produce audible speech, yet still possess internalised language, sub vocal phonation may provide an AAC means to communicate. In a current research project with non-verbal adults, sensitive microphones have been used to capture acoustic signals, hypothesised to be sub-vocal phonation, subsequently amplified via acoustic software, to access any meaningful sub vocal words of the 'speaker.'

Working collaboratively with Dr David Kerr and his team at Loughborough University, the production and

intelligibility of this form of phonation has been examined. Unlike investigations using electromyography signals, this 'light' tech approach uses only the acoustic signals, theoretically attributing sufficient sub vocal movement of the speech structures to produce resonance as acoustic waves. In the longer term, this project seeks to explore both the intentional use of sub vocal phonation where verbal production is lacking or disordered, and the potential of sub vocal phonation to interface with an AAC form of communication, accessed by a communication partner.

A major advantage of this approach is that it capitalises on natural behaviour already available to the individual. It enables the individual to use their own sub vocal 'voice' and their own (existing) vocabulary, grammar, intonation and choice of subject matter. It places ownership of the communication entirely with the 'speaker.'

Present Drawbacks and Future Solutions

A current disadvantage of this approach is the time delay between recording and reproducing the amplified sub vocal samples for the listener to hear. It is not operating in real time. Work is on-going to produce a recording system that amplifies

the acoustic signals immediately and, if required, removes any interference from ambient or environmental noise that may be captured by the initial recording. Listener trials are also required to explore the intelligibility of a range of sub vocal samples, age and gender matched against samples of normative phonation.

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You can find his Facebook page with pictures at this link: <https://www.facebook.com/25in25forLiberators25th/>

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A patient's perspective of the use of alternative and augmentative communication in the acute intensive care setting following acute onset of Guillain-Barré syndrome

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Abstract

Guillain-Barré syndrome (GBS) is a rare neurological condition that occurs when the body's immune system attacks the peripheral nervous system.

This single case study is based on a male, aged 32, diagnosed with a form of GBS known as Acute Motor and Sensory Axonal Neuropathy (AMSAN). It will evaluate the use of a variety of Alternative and Augmentative Communication (AAC) methods during his intensive care stay over a four month period. AAC systems used included an auditory alphabet, high frequency alphabet board, Advocate1 device and a high tech system with Grid software accessed via switches and eye gaze.

Introduction

Guillain-Barré syndrome (GBS) is a rare neurological condition. It is characterised by the rapid onset of muscle weakness which often leads to ascending paralysis, meaning that it travels up the limbs from the extremities towards the chest. The exact cause is unknown. It is called a syndrome rather than a disease because it is not clear that a specific disease-causing agent is involved. GBS is non-discriminative and can affect any person irrespective of age, gender or ethnicity.

Jay, aged 32, was previously fit and well. He was diagnosed with Acute Motor and Sensory Axonal Neuropathy (AMSAN), a severe variant of GBS. Resulting complications included considerable respiratory and bulbar difficulties (causing difficulty with eye movements, double vision).

This case study will document Jay's medical journey and will discuss and reflect on his experience of using different Alternative and Augmentative Communication (AAC) methods during his intensive care stay.

Jay's Story

Jay was admitted to hospital with respiratory failure following a rapidly progressive ascending motor weakness. This required immediate intubation and a subsequent tracheostomy. Initial neurological deficit was extremely severe with loss of all peripheral motor ability, meaning that he was unable to move any muscles throughout his body including his facial muscles. He was effectively locked-in, and was referred to the Adult Speech and Language Therapy Service for support with establishing a means of communicating.

For the first two weeks, Jay was only able to express himself if staff lifted one eyelid open for him and asked closed 'yes-no' questions, which he could answer via

left-right eye movements. It was noted that Jay experienced double vision if both eyelids were opened at once.

SLT Intervention: Assessment of yes-no reliability. The initial aim was to assess if Jay's eye movements were reliable. The outcome of this was that Jay was indeed able to use eye movements to reliably answer closed questions; however fatigue was significant, impacting on his ability to engage. A set of 10 yes-no questions, to be asked hourly, were put in place, providing a consistent and regular opportunity for Jay to express his basic needs.

Jay's reflections: *"It's weird to describe... It's like I'm awake but my eyes aren't opening with me, so it's like I've woken up in the morning and my eyes are still shut. So that's when they started lifting my eyelid up... It was a relief because by them doing that they realised I was actually awake. The thing was though, I didn't have a chance to adapt, all I had was the bright hardened lights and I couldn't close my eyelids and I couldn't say 'bloody hell that's bright' just basically had to wait for them to let my eyelids drop... It was a bit annoying but I'm glad they did it."*

Jay's facial muscles slowly improved and his first reliable movement was to control up-down eye brow movements.

SLT intervention: An auditory alphabet was introduced at this time. The SLT would read aloud the alphabet with Jay stopping on the correct letter by raising his eyebrows. In this way he could spell out single words and short phrases.

Jay's reflections: *"That time I can't say I can remember... I didn't even remember friends coming."*

Muscle strength continued to return slowly and Jay gained some control of muscles in his forefinger and thumb.

SLT intervention: With support from a regional specialist communication service, we were able to assess Jay's ability to access switch devices. As Jay remained unable to control eyelid movements, the advOCate device was introduced as it provides auditory feedback and does not require visual access. The advocate device uses digital recordings to store a selection of speech messages that can be accessed via a switch. We trialled the device with eight saved personalised phrases.

Jay's reflections: *"I don't think I got on too well with it to be honest. It was a bit too simplified almost. It was difficult for my hand it was just making me agitated like I need to get to phrase 3 and I couldn't press the button to stop it... I had to keep it in my hand with a strap so even if I was being moved in the bed I would set it off. If I lost my grip on it, the switch would be put too far up or too far down. Nothing major but little things like that. Annoying that I couldn't move it myself and difficult to say to the nurses 'could you move it or twist it'."*

Eyelid movement then became controlled, with Jay able to consistently and voluntarily open and close his eyes.

SLT intervention: A high frequency alphabet chart was introduced. This is a visual chart with vowels at the beginning of each line, followed by a series of consonants. Jay would use eye blink to initially select the line and then the letter. Jay quickly became very effective using this AAC method and was able to communicate long phrases with relative ease and speed.

Jay's reflections: *"The charts you guys got me, especially the ones with the vowels down the side and the letters across, where you'd say it's a-e-i-o-u and go across, that was probably the thing I found most helpful to be honest, sometimes even more helpful than the machine, because that could have been*

left on my chest and it wouldn't bother me if it was there. No-one had to worry about it breaking or being broken. If it got damaged, worst case, another one could be printed and laminated. With my sister especially it was a great help; it took a while for us to get a system that worked for us but she knows roughly how my mind works and if she got the first two words then she could predict the letters in the next word and would literally go like a rollercoaster. It was the hardest work with the old dear though; she'd hold it too far down where I couldn't actually read it and that was getting me annoyed and her upset. The doctors used it in the proper way and it worked that way too, just made it a bit slower. The nurses only used it on the odd occasion; I think they had a bit of trouble with it. A few of them did get the hang of it though which helped."

Jay's alertness levels and stamina continued to improve and it was clear he could potentially benefit from more high tech AAC. He was also developing improved control of hand movements.

SLT intervention: The team at Smartbox kindly gave up their time and we carried out a joint assessment to identify potential high tech devices. The team then loaned Jay a Gridpad with Gridplayer 3 software which Jay was able to access via eye gaze and switch methods. Their support was invaluable to our intervention.

Jay's reflection: *"The doctor left a sheet of instructions on how to set it up. It was good for the nurses, because they had never seen anything like this before. I think a few were scared to use it; expensive bit of kit and worried it might get broken. And one thing was that, initially, after a few minutes it could start hurting my eyes. Like, after I spoke to the doctors or nurses, if I wanted to lie back and look at the ceiling, I had to say to the nurses 'can you push it away' and the calibration was then difficult when it was brought back. I did get used to it quickly though. The screen didn't get in the way at all; the staff were usually just to the side of it so the machine was in the ideal position for both of us - staff could hear it and I could type quite quickly. I mainly typed out my own things but the stored messages were handy on some occasions. I was using my eyes to type out the words then the clicker in my right hand to speak it out. In the end it was easier to have the switches in the palm of my*

hand to use my three fingers to click it, rather than if it was between my thumb and forefinger. I think if I had needed to use it for a bit longer, I would have been ok with using my eyes, full stop, and I think I would've really got on well with it. By the time I got fast though it was time to get my voice back."

After 108 days in intensive care, Jay's tracheostomy was removed; he was moved to a high dependency ward and was able to use his voice to communicate. Four weeks later he kindly gave us some of his time to reflect on his experiences.

Conclusions

The experience of working with and supporting Jay throughout his ICU journey has clearly demonstrated that any communication device is only as good as the team around the individual being able to use it. For the individual, the really small things can matter but most importantly, a clear and consistent approach needs to be established between all members of the MDT. Jay's reflections are also a valuable reminder that we should never underestimate the value of low tech aids supporting the high tech devices.

The most important learning point for all members of the MDT though, is to get to know the individual. The more you know a person, the more you will understand them. Remember that behind any condition is a personality and person, even if they don't have a voice and cannot communicate in the conventional way.

Glossary

1AdvOCate device is a communication aid that uses digital recording to store speech messages that can be accessed by either direct selection or switch access.

With thanks to Jay for his participation and time for reflecting on his experience

With thanks to Smart Box / EATS for assistance, time, loaning of equipment and support

For confidentiality reasons, we have referred to the patient as Jay throughout. This is not the patient's real name.

'Me and my extended shadow': living independently with personal assistants

BETH MOULAM



When we were trying to come up with a title for the presentation at CM2015 we had a few, some too rude to tell you! Eventually I settled on 'me and my extended shadow'. What I mean by this, is, although I love my own space, I always have someone in the background, 24 hours a day, ready to support me as and when I need them. They are not invisible, but a bit like having an extra long shadow. I couldn't live without my support team, they are invaluable to me in every activity I do on a daily basis from assisting with sport, providing academic support, helping with my care needs and being communication partners. In total I have a team of 8, both part timers and full timers.

I've transitioned a long way and learned a lot in the last few years, and I am still learning. I've moved from a residential school to university halls of residence, into living independently in my own flat. Along the way I have had to learn to work with school staff, manage agency staff, and now run my own team.

My Mum was not intending to be involved when I started at university, it was planned I would get all my support from the university and the agency. What actually happened was a very different thing. Mum is even today still involved with my support in a big way co-ordinating my team and doing the admin support.

Research, carried out by Social Policy Research Unit at the University of York (Gridley et al, 2012), with young people with complex needs found for people

like me, there was a need for holistic support, which needed to be unique to each individual. They also found that staff needed to be dedicated, have the expert knowledge and skills to support each individual, and this included providing emotional and social support as well as personal care. This mirrors what we have found building our my own. Good intention and nice people are not enough to provide effective and consistent support, we discovered that nice people are not always the same as getting people who you can build a rapport with. Being with someone 24 hours a day means needing to have things in common together. Sadly getting it wrong meant we learned a lot.

We decided the key people in the recruitment process had to be me, Mum and the existing team. We have become more discerning over time about deciding who to interview, and decided on a completely different interview process, viewing this as only the start of getting a good team member. Our only criteria to apply are a degree, which is a university requirement, and being able to drive, oh, and being female. We feel we need to be 100 per cent open about the role, and make sure there are no misunderstandings about what was needed, the hours, the commitment, and that working so closely with someone would sometimes be tricky. Personality matters greatly.

As a team we now control the process. Mum now does the pre-screening by phone, she explains the job and gives the candidate chance to ask as many

questions as they like. An applicant is then asked to go away and consider the role and if it's for them, if they want to take it forward we then all decide on who to interview.

We use a range of questions to find out about each candidate, these assess if they can think on their feet and shares with them something about my personality. Their responses need to show they can deal with unexpected situations – for instance I like Harry Potter so one question is "if you had a magical power, what would it be and why?". We have had some really great answers such as the ability to refill things such as a bank account, time and energy. As I'm doing social policy I want an idea of whether the candidates know much about current social affairs. This is always interesting, I feel it important that if someone was going to support me academically, they should at least be up to date with politics, and I can't imagine anything more boring than spending hours supporting me doing a subject that is of no interest to them.

I always ask hypothetical questions about real life situations that have happened to me, such as "what would you do if my chair breaks down?" and "we are going out for the day, how would you go about planning what we take?". There is of course a correct answer which is to ask me, but surprisingly many people say I would phone your Mum. At the end of the interview the candidate can ask as many questions as they like. These questions and their earlier answers are always

revealing about a candidate, if someone cannot look me in the eye and talk directly to me then they are not the person for me.

At each stage we ask the candidate to go away and self select for the next stage of interview, although we sometimes go back and say 'no thanks' before they can come back. Stage 3 is a shadow session with a team member and myself, during this 3 hour session I always get to spend some 1-1 time with the candidate. This has been telling, if they cannot speak to me without another person being present then again they are not for me. By this stage their personality shines through and if we can laugh together and they are engaged then it's looking good.

The final stage they come back and see Mum to do the HR type stuff, asking key questions about background and health as well as getting copies of certificates etc. It's a very protracted recruitment process but we believe it is important if they are to give up another job to work for me full time that we have to get it right for both parties.

The hard work begins once they are recruited. Day one is an induction day when we run through the job, cover key priorities and teach them to drive the van (it has adapted controls). Day two begins with shadowing, I find it's better for a new Personal Assistant to observe than to jump straight in. I have preferred ways of doing things, people have been asking me questions about how I like things done my whole life. Telling the Personal Assistant my way of working eliminates their fear of getting it wrong.

A relationship doesn't just happen, it is something we all need to work at. We need to learn to trust each other, to be companions and have fun together. I love my own company, but sometimes new people think they are there to "look after" me. I like it when people are around, sometimes just in the background. No one has to be with someone all day, every day and I am no different. It's really hard to work with someone, 24 hours at a time. I'm on show all the time. If someone else is tired, or wants some space they make it for themselves. I have to ask to be alone. It can be hard to stop my emotions impacting on the team when they are with me 24 hours a day, however, this is my life and my emotions are very real. My Personal Assistants don't always agree with my decisions, but they do support them and allow me to make my own mistakes, the same way that other 22 year old would.

Like the day we ended up with the Personal Assistant locked outside the flat and me inside unable to open the door.

Having the responsibility of managing a team is not easy. I have been constantly learning as I go. I get help from the team, mum and my counsellor, as I talk to each of them about situations. I can find managing the team stressful at times, especially when I am tired. I don't like upsetting people, and my own voice can sometimes be strident, when I'm trying to make a point, and the Lightwriter has no tone. It's also not easy to direct people all the time, or tell them when they are doing a good job. If you have heard me speak before I often say building a team is like learning to dance. To start you have to discuss every step, over time the movements become unconscious and flow. With team work as we get to know each other, and relax, we can just do what needs doing, without me constantly directing, in a beautiful dance.

The team tell me that just as I can find it not easy to be with them 24 hours a day, they can find it challenging at times too. There is a phenomena called transference which is when our own emotions, attitudes and feelings get transferred unconsciously to others we spend time with. If they have an issue and bring it to work it can affect our day together, and likewise if I have a concern or feel unwell they can be affected too. We all agree it is important for them to try to leave any issues at the door when they arrive at work, but also if our day has been challenging that they leave it at work when they go home. It doesn't always happen but if they need any emotional support then often they talk to Mum, either when we visit home or by giving her a ring.

My family are important, and always will be to me. Mum and Dad provide a stress free zone, with the time and space to discuss anything I want. This ranges from how to build relationships, to concerns about anything, to just having fun together. Normal family stuff. I CAN HAVE LOTS OF FUN SPENDING Dad's money. Living independently doesn't stop me seeing them very regularly, I have the best of both worlds, my own place and a safe haven.

We have clear(ish) role boundaries, each of us knows what is expected of us. I do all the annual appraisals and regular reviews with Mum, in the future I hope to do this alone but for now Mum provides back up. These are opportunities

for the team to reflect on the role and any training needs they have, as well as for me to provide more formal feedback. I try to deal with issues as they arise on a day to day basis, and if I feel I need support will talk to Mum first, or sometimes we have a facetime call with the PA and myself in the flat and Mum at home. Facetime has proven really useful also for training when there has been an unexpected need and Mum cannot just drop everything to come around.

Team building is really important, as is training. One early session together as a team we did a team mission statement which starts with no woman is an island. We work hard together but need to have fun together and we all agreed how we wanted to live our lives, me around the clock and the team when on shift, together we are greater than our individual parts. From a training perspective we have trained in academic support, delivering therapies, supporting boccia (one of my dreams is to represent GB) and supporting me emotionally.

Life does change along the way. Yet, I know the value of long term planning. In 2008 I did a Diane Bryen's dreams workshop at ISAAC in Montreal. I had 5 dreams, we set them out, and I have worked solidly to make them become a reality. These dreams are like a road map for my life, and 8 years on I am still working on them all. I'm achieving towards them all. I'm at university on track for a meaningful career. I live independently, I still dream of a partner and children, but fitting them in at the moment could be tricky. I am well on the road to my boccia dream and I have already represented England. I have long dreamed of going to Australia and now that ISAAC 2018 is to be on the Gold Coast that dream will come true also. That dreams workshop has a lot to answer for! I still dream and use the process I was taught to make things happen. Thank you both Dianne and ISAAC.

In simple terms my personal assistants are there to be my hands, to do the things I'd like to do but can't by myself. It's a strange balance between having a companion, and having to direct what they need to do, all the time. As I said early, over time we become dance partners. I couldn't live my life without my extended shadows. In time most come and go, some even come back, but when they do go they leave a legacy behind of great memories, and I hope I have changed their lives in some small way too.

My communication journey as a person with autism

SOPHIE WEBSTER

Sophie Webster is a 26 year old AAC user with autism, selective mutism and many physical health conditions. She uses Proloquo2Go on an iPad mini with iAdapter case (a mixture of typing and symbols), as well as Makaton, BSL and sometimes verbal speech when she is relaxed. She is passionate about supporting other AAC users and their families and sharing her perspective as a user: she runs her own Facebook support group 'Communication Help and Support for Special Needs'; she is active on the Proloquo2Go Facebook Group for Families where she generously shares advice and screenshots of her customisations, and she blogs at www.aacbrightideas.blogspot.com Here is the story of her communication journey in her own words.

Sophie has kindly written for CM journal as she would find presenting at conference too challenging. It is great to share the experiences of those who use AAC for different reasons: each story is unique. For further information or to contact the author we recommend her social media outlets, above.



Communication at School

When I was at school my way of communication was using a symbol keyring and Makaton which I taught myself and learnt through songs. I was an extremely frustrated young girl at school who couldn't explain what was wrong and why I was getting upset unless it was on my symbol keyring which had basic needs on it such as toilet, drink, teachers' names, snack. It was extremely limited and meant I was unable to make friends and have any voice at school which led to hours of meltdowns and nobody ever knew why! It was complicated by the fact I couldn't read and write back them so nobody could understand my writing when I did try and explain what was making me upset. Because it was so limited on my symbol keyring to what I could say nobody knew

if the bright lights were too much and causing overload. Only way I knew how to cope is to scream and lash out at staff because I didn't have the words or symbols to tell them the problem.

It was the same when I struggled to sit still and couldn't manage a double lesson, I couldn't tell staff I needed time out and why I did all I could say was show them a walk symbol but that didn't tell them my desperate need to move my body and stand up instead of being trapped in a room and on a chair when I physically couldn't hold my trapped feeling in any longer. I needed to move. It isn't just a case of me just being bored it's a burning sensation from head to toe that increases in how intense it is and the more I tried to sit still the harder it became. They never knew that they just thought I was a naughty school child wanting to get out of lessons!

How I Communicate Now

I only started using AAC when I was 21, I got the Proloquo2Go App as a birthday present. What better than a 'voice'? It wasn't so easy to transition from PECS to a device as I imagined. Along with the excitement came fear, I had never had a say or spoken to people outside of my home before and I didn't know where to start! I was completely overwhelmed for 2 years and barely used it, just to ask my mom for things to get me used to it. But then I got a different carer and things were so hard not being able to express what I wanted and needed because he didn't know me as well and I thought to myself I have got to do something about

this! So I went to my iPad and started slowly setting it up more for me to use out in public first time ever!! This was terrifying but I pushed through the fear and then bought a Bluetooth speaker so I could be heard outside!! Luckily by this time my old carer came back and we both plunged into using my device in all areas of life until it became the normal thing to wear each day just like part of a uniform. I packed my bag each day, picked up my 'voice' and off we went for a day out. I can now use my device pretty much anywhere I need and want to and am happy to talk to people now. Knowing I can talk back to them makes everything so much easier!

I mainly use my iPad as a communication device, I have that with me all the time with carers and use it to request things and how I'm feeling. Also to let my carers know when I feel poorly or am about to have a seizure. I can also sign Makaton and BSL quite fluent but not everybody knows what I'm saying which can frustrate me so I use my device most of the time. When I am relaxed in my carer's car I will verbally talk to her in a conversation and sing along to songs in the car

but when we go out of the car my anxiety rises and I'm not able to verbally ask for the toilet or a drink, I will sit and go thirsty all day if I am not given a drink rather than ask out of my mouth.

My iPad mini with Proloquo2Go has been amazing help to me, it has reduced many, many meltdowns and helps me daily whether it be asking for things from my carer or in a shop to telling the doctor how I'm feeling. It is amazing to be listened, heard and understood for the first time. I spent 21 long years unable to say what was on my mind and just had to sit in the doctor's room unable to verbally speak or even write down anything as I couldn't read and write. I was trapped inside myself and having my iPad has helped improve my verbal speech so so much because I see the words in front of me. I can use them when I don't have my iPad as the symbols are so printed into my head it's like I have a dictionary of words in my head and it's brilliant and so much easier! I feel so much calmer having my iPad and knowing that I finally have a voice and one that will get heard loud and clear by all who meet me.

Advice for Teachers of Children with Autism

I would like to tell teachers don't guess that a child or young person is doing something because they're being naughty. Get the tools to ask the student what is making them do something whether it be a good or a bad thing but don't guess you understand and know them when really you possibly have it totally wrong and that student you think is the naughtiest in the school is actually just desperate for a way to communicate! They may not have the verbal skills to do that so you need to find a way for them to express themselves in other ways instead. This was how I felt at school. I was overlooked by many staff and just thought of as the naughty one. I may have my meltdowns but there is always a reason for them and nobody ever helped me to verbalise what was wrong, whether that would have been showing me symbols, doing a social story, using a communication device, anything so that I could be understood and understand myself too.

Small Grants from CM

From time to time, Communication Matters offers small non-recurrent grants of up to £200 to applicants in the UK.

One area that CM Trustees would consider for support would be for attending an event in a country where AAC is less well developed. One such event coming up next year is the ECE-AAC conference, taking place in Bucharest in July 2017. <http://www.comunicare-augmentativa.ro/ECE-AAC-Conference.html>

If you would like to present at this conference, applying for a small grant to help with associated expenses is something you could consider.

You can find out more here:

<http://www.communicationmatters.org.uk/funding/CM-grants>



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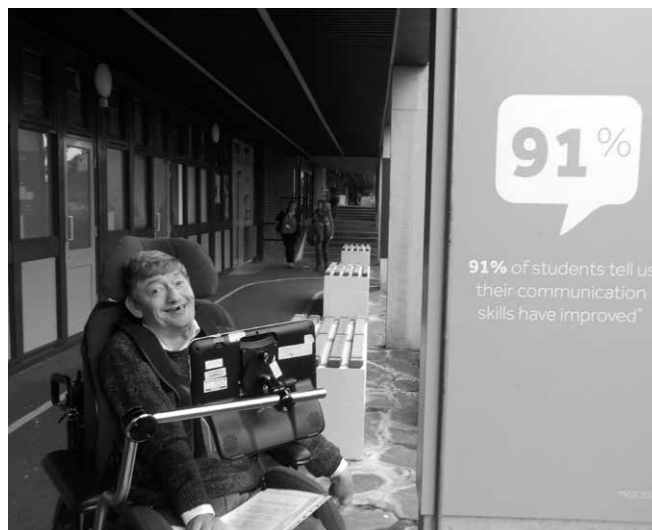
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How I communicate

JEREMY BRIERS

Email: jeremybriers@hotmail.co.uk



Hello everyone, my name is Jeremy Briers and I live in Tavistock, Devon. I would like to talk to you about the different ways I use to communicate. From an early age I used a combination of facial expressions and eye pointing to show my interest in things around me.

From the age of about 3, I would look at things to "tell" Mum what I wanted. Then I started saying "yes" and "no" as well as nodding or shaking my head. At my first school, the staff relied on me to help with the daily register by telling them which children were present.

At 8, I went to a special school in Essex where I learnt to use a Bliss board and operate a Possum switch with my chin.

I moved away from home for the first time at 17 and went to Dame Hannah Rogers School in Devon to continue improving my communication. I really enjoyed life there.

When I was 21, I moved to Kent and used a specially adapted "talker." I was assessed for a Liberator, which led to me to going to Portland College in Nottingham for three years, which was a great experience. I made good progress in Communication, Maths and English and was awarded a prize, which I received from Her Royal Highness Princess Anne at a special ceremony.

I then continued my studies at Hereward College, Coventry for another three years. After staying at home for a short time I moved back to Devon in 2003 to Cornerways in Tavistock, where I still live.

Through a Communication Matters Roadshow, I heard about Tobii Eye Gaze. I was assessed to see if I could use this faster system of "talking" by North Bristol NHS Trust. I now use my own Smartbox with Eye Gaze. At recent birthday parties I have given speeches to friends and relations through my Eye Gaze communicator.

I am very happy at Cornerways and work regularly with the University of St Mark and St John (called Marjon) in Plymouth to liaise with new students on Speech and Language Therapy courses. I enjoy meeting and working with the students and I look forward to developing my involvement with Marjon later this year and I hope this will improve my communication skills and help the students in their Speech Therapy studies.

Since moving back to Devon, I have continued my communications development by joining various local activities such as the "Speaking Up Group" of which I became Chairman. I campaigned with others for wheelchair access to be arranged at a major local hotel in Tavistock, successfully, as a lift has now been installed in what was an old landmark building.

On a regular basis, I join a number of others on a "Walk and Talk" tour of Tavistock. It is a great way to keep in touch with people and bump into other people I know in the town.

Another way that I like to communicate my thoughts and feelings is through Art and Photography and through this interest I have exhibited my work in a local exhibition. I have also started to produce gift and other greetings cards.

One of the most interesting weeks I had was a few years ago when I stayed at the Orpheus Centre in Surrey, the residential music centre created by Richard Stilgoe. I have written music with the help of Richard. I used a series of my own spoken words to "write" the music by telling him to "go up or down" the scales, "loud or soft" or "fast or slow." In the end we created a good sounding military style march, which he called the Jeremy Briers March.

My other interest is supporting my football team, Arsenal. When I do get the chance to watch them at the Emirates Stadium I am certainly able to shout my support for The Gunners or moan if they miss an open goal!

I like to use a variety of ways to communicate. For people who know me, my facial expressions and words mean that I can respond easily to questions that need a "yes" or "no" answer, or where I can get my message across clearly. It is more difficult to use this style when trying to start a conversation and this is where Eye Gaze and other devices are so useful. I am working hard to improve my technique with these technologies as I know this will help me be more independent and able to communicate more effectively.

Finally, I was featured in a short film made by my niece about disability awareness and I was delighted that Communication Matters featured it through a link on their website.

An evaluation of CM's e-learning programme for new support workers supporting adults with learning disabilities

JULIE LOWE

University of Sheffield

This article is taken from an undergraduate dissertation, supervised by Dr Stuart Cunningham at the University of Sheffield. We would like to thank Julie and Dept HCS for working with CM and some improvements have been made to the site based on the findings. Access the website at <http://www.aacelearning.org.uk>. We would welcome more comments to manager@communicationmatters.org.uk.

1. Background

Communication partners are among the key variables affecting the success of communication using an AAC system. There is strong evidence to suggest that providing training from AAC specialists to parents, carers and education staff is effective in reducing perceived barriers to AAC use. One example, McMillan (2008), found that when a training package in AAC systems was provided to educational staff members, AAC use in their setting was more frequent, more effective and staff were more confident communication partners.

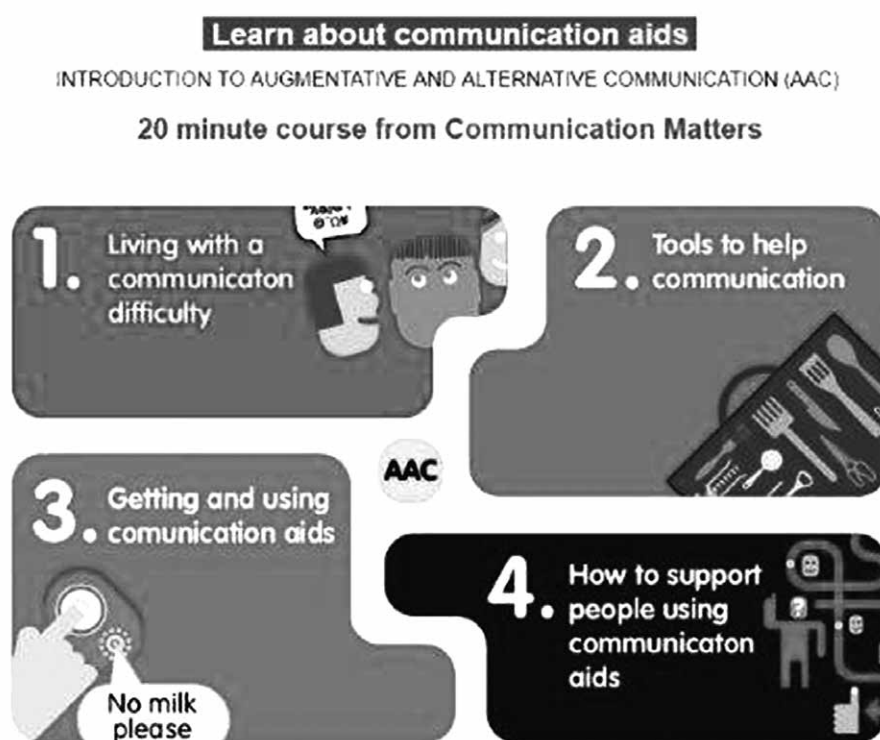
The E-learning Programme

In light of the evidence supporting training for communication partners and the diverse profiles of individuals with an interest in AAC, Communication Matters lead a consultation in conjunction with the Barnsley Assistive Technology Team for the development of a training programme to cover a variety of topics around AAC's theoretical basis, methods and implementation.

During the consultation period, it was decided that the training programme would take the form of a reusable learning objective (RLO). RLO's are commonly used in healthcare training as an efficient tool to deliver training to a larger geographical area and increased number of people than could be reached using traditional face-to-face training (Windle & Wharrad, 2010).

CM's RLO is comprised of four components: 1, Multimedia presentation of the stories, concepts, facts and processes that are central to AAC. 2, Activities that offer engagement with the content in order to better understand AAC. 3, Self-assessment tools so the learner can apply and test their understanding. 4, External resources to reinforce the content of the RLO and support the learning goal or aim.

Figure 1 – Four modules



The programme consists of four modules (Figure 1). Each module is comprised of a tutorial and a quiz. A self-assessment is included within the quizzes of each module.

2. Methodology

The study aimed to evaluate the efficacy of the e-learning programme with a specific pilot group of newly-recruited support workers by a large local care agency, working to support a population of adults with learning disabilities (ALD).

24 support workers were recruited by the agency between February and April 2016, and completed a two-week induction package of training, in which the AAC e-learning programme and evaluation survey was offered as an optional extra. The training package included no other specific AAC theory or training. Participants completed the e-learning course with no obligation to participate in the evaluation survey. Participation was based on consent and strictly confidential; no results were passed on to the care agency provider.

Data Collection

The survey was designed in line with recommendations on evaluating e-learning for healthcare by Braun & Clarke (2006), using a range of question styles from ranking and open-ended comments. The maximum completion time was fifteen minutes and the questions were split broadly into three categories:

- Navigation and accessibility of the e-learning course
- Appropriateness of the information included within the course
- The successfulness of the course in meeting the aims

Results analysis

Owing to the small number of participants, thematic analysis was carried out to inform the results and discussion of this study. Thematic analysis is defined as "A method for identifying, analysing and reporting patterns within data" (Braun & Clarke, 2006 p. 79).

Participants

Twenty participants defined themselves as "no prior knowledge of AAC" (83%) and four participants as "some experience of or informal training in AAC" (17%). Zero participants classified themselves as having "extensive experience or formal training in AAC".

3. Findings

Navigation

Three participants found navigation of the e-learning course 'easy with no difficulties' (13.04%), seventeen participants had 'few or minor difficulties' (73.91%) and three participants rated their navigation experience as 'average – some difficulties' (13.04%). One participant withdrew from this question.

Information structure

A clear consensus was that the information order was logical with no difficulties following. However in comments, participants indicated that "headings of each section don't exactly match up to the content within, I think it could be a bit clearer". Several participants felt that information was repeated, especially within modules 1 and 2; "the 1st 2 sections was almost the same for information". Further suggestions included a short summary at the end of each module of information learned.

Did you follow the course in order of topics, or use the contents table to navigate? Why?

Most participants responded "order of topics" (95.83%), with just one participant opting to use the contents table to navigate the course (4.17%). Some participants felt the addition of a "home" button to each module would be beneficial in accessing the contents table more easily.

How did you find the length of the e-learning course?

Seven participants responded 'too short' (29%), sixteen participants responded 'about right' (67%) and just one participant felt that the course was 'too long' (4%). In their comments participants offered two clearly different opinions: a large number of participants felt the course could have included more information for the relative length, The remaining group of participants felt that the course was "the right length longer would be boring" and stated that it took longer than the estimated 20 minutes to complete once videos and quizzes were factored in.

Overall, taking into consideration the ease of use, learning material, structure and length of the e-learning course, how would you rate the e-learning course?

Two participants (8%) rated the course as 'average', sixteen (67%) as 'good' and six (25%) as 'excellent'. No participants scored the course as 'extremely poor' or 'poor'.

Was the information included easy to understand? (Rating scale)

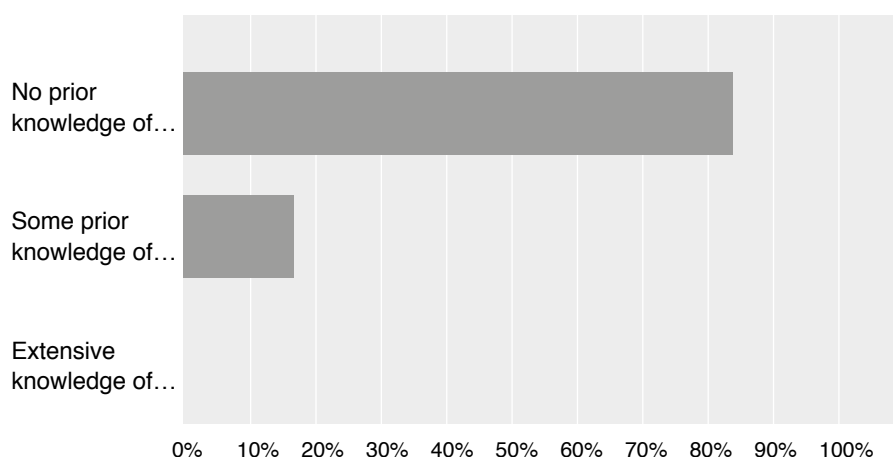
Twenty participants responded to this question, with seventeen (85%) rating the information as 'very easy' and the remaining three as 'easy' (15%).

Figure 2 – Participant Categories

Please choose the category you feel best represents your knowledge of alternative and augmentative communication (AAC) prior to completing the e-learning course.

Answered: 24

Skipped:1



Preferred material within the e-learning course

Among respondents commenting on this question, there was a divide over the value of videos and quizzes used in the course, with some participants commenting that the videos were “really good” and “Videos were great and very informative” and others feeling that there “were too many videos”.

Quizzes were similarly divisive. Some participants experienced difficulties with quiz questions requiring a written response, as the software could not recognise the words. Other participants did not complete the quizzes due to the requirement of having to create a log-in, which was removed shortly after the commencement of the project. Again, this may have affected results. A few participants found it “frustrating” that they could not re-do the quizzes.

Did you understand all of the information given during the e-learning course?

Participants felt that the information included was probably “too simple” and “even for a complete beginner it was very-very basic and maybe not enough information”. Some participants pointed out the difficulty of re-accessing information contained in videos quickly due to the lack of descriptions and transcripts, reducing the ability for the e-learning course to be considered reusable.

Were you able to answer the questions provided in the quizzes?

Twenty participants answered ‘yes – the information provided was sufficient’ (95.24%), one participant answered ‘some – most information was adequate but had some issues answering questions’ (4.76%). Three participants did not record a response for this question.

If the e-learning course was extended and more topics added, what topics would you have preferred to be included?

There was a clear consensus that participants wanted links and access to resources to “find out more”. Several participants also mentioned the lack of low-tech or signing systems within the course, stating that “more examples of signing etc. because that is what we use”. Some participants felt that it would be beneficial to have a longer summary quiz at the end of the course, with requests such as “harder questions” and “longer quiz”. The same participants asking for a longer or harder quiz section generally

added additional comments about wanting certification or proof of completion of the course; two participants suggested emailing out scores upon completion.

After completion of the e-learning course, did you look up any of the information on the course using another medium e.g. google? If so, why?

23 participants responded to this question, with most participants answering ‘no’. Participants that responded ‘yes’ said that they had looked up the charity and/or a method or device named within the course. One participant suggested a short paragraph about Communication Matters should be included within the course, as they had not previously heard of the charity.

After completing the e-learning course, what do you think the aim of the e-learning course was?

100% of participants responded to this question. Participants found the course generally adequate with an overall consensus of “basic AAC education” “basic information for people that don’t know much about AAC, people who might come across it in their job” and “to learn about AAC”.

The aim of the course was to raise awareness of AAC for people with little/no prior knowledge. How do you feel the course achieved the aims?

42% (ten) participants rated the course as ‘fully met the aims and needs no improvements, I am more aware of AAC’. 54% (thirteen) participants rated the course as ‘mostly met the aim but could have some minor improvements’. One participant (4%) rated the course as ‘met the aim at some points but needed improvements’. Comments generally focused on aesthetic and design issues and again mentioning the lack of more commonly-used AAC methods within their setting. Some participants felt that the course was more ‘teaching’ focused than ‘awareness’ focused and one participant wrote that she would have liked to have seen “info on current projects to raise awareness”.

Do you think the content of the e-learning course was suitable for you and other support workers?

With 100% response rate, 96% (23) participants stated that the course was suitable for support workers and just one participant (4%) disagreed.

After completion of the e-learning course, do you know where to look for further information regarding AAC methods and AAC training?

83% (twenty) participants stated they did not know where to look for additional or further information. Four participants (17%), who had “some informal training or experience with AAC”, said that they did know where to look. The overwhelming consensus was that further training and information could be included as an additional module.

Would you recommend this course to other support workers/carers?

Twenty (83%) participants felt they would recommend the course to other support workers/carers. Four participants (17%) felt the course needed improvements before they could recommend.

Overall, how would you rate the e-learning course for carers/support workers? (rating scale).

Good overall result, with nine participants (37%) rating the course ‘excellent’, fourteen (58%) as ‘good’ and one participant (4%) as ‘average’.

Conclusion

In summary, results showed clear patterns across twenty-four participants and some split opinions. Generally, there were key themes emerging across all 21 questions; most notably, the need for information on training and accessing further information to be included within the course. Aside from cosmetic and functional themes other key issues included the lack of low-tech AAC devices shown within the programme, requests for more difficult quizzes, desire for accreditation, considerations for people with English as a second language and the need for more in-depth information about specific AAC-using population groups, e.g. adults with learning disabilities.

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The road less travelled: transitioning to an assessment hub

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In this article we are going to share our experience of transitioning to work within a Specialised AAC (Augmentative and Alternative Communication) Assessment Hub. We work for The Kent and Medway Communication and Assistive Technology (KM CAT) Service. Our service is slightly unusual, in that the service is jointly commissioned by the Local Authority, Kent County Council and the NHS. This means that we have Teachers as well as Speech and Language Therapists, Occupational Therapists, Healthcare Scientists and Therapy Assistant Practitioners. Because our service has been in place for nearly ten years, there are established ways of working. This means that new starters are joining a well organised service. We appreciate that this may not be the case for newer Hubs, who may still be developing their own systems and procedures. The journey for new starters elsewhere may well be bumpier than ours.

We authors have each been with the KM CAT service for over a year. We felt it was useful to share our experiences of becoming AAC specialists, in order to inspire others to join our world, and to enable other Hub services to support new staff. We chose the title of this presentation because being an AAC Specialist could be considered a fairly obscure career move in some professions. None of us planned this at the start of our careers: AAC is something that happened by accident! We were all exposed at some point in our careers to AAC. Some of us went on to develop other specialisms before coming back to AAC. We all agreed that there were interesting links between what we had done before and what we do now.

A Metamorphosis

The transition to working in an AAC hub is a bit like a metamorphosis : whilst we previously identified very strongly with our own professional roles as teachers, SLTs or therapy assistants, these boundaries have now blurred. Whereas before we may only have needed to consider factors related to our individual professions, we now have to consider the other professionals' ways of working to fully understand and meet an AAC user's needs. This is a key factor in becoming an AAC specialist: having individual skills which come together to make us a team.

Because there are so many professions involved, our service has come to understand that solutions take time and there needs to be a level of patience whilst the solution unfolds. There will be uncertainty: solutions unfold through trial and error and through discussion. As AAC Hub employees, we need to learn to be flexible and take things in our stride. In our service we are actively encouraged to think big, to question what we know and suggest ways to help move our practice on.

People come to us as a service because we are the experts and we all found that the responsibility can weigh heavy upon you when you are new. Fortunately, our heads of service are well aware of the vast array of AAC knowledge which you need to acquire and that there are no shortcuts.

We may have had some moments when we panicked. But then we remembered that we were not the only experts – we are a team and there is always someone you can call on to help you out.

One of the many benefits of working in a hub is the opportunity to work in different groups, both large and small on a variety of projects, from planning training, to developing new assessment resources, to creating help sheets for our clients. Time is put aside to ensure that individuals have the opportunity to meet and discuss cases and project work. This helps ensure that all professionals are involved in the decision making process whether it is making decisions about a client or about how to develop the Hub Service as a whole.

Personality Traits

The routes we took to get here were very diverse, although prior to entering this specialist field, we all had acquired the key skills necessary for our individual disciplines. Extensive AAC experience is not essential, however we have found that previous exposure is a huge advantage. Our first-hand experiences enable us to understand the pressures affecting the professionals who are new to the AAC world.

We all agreed that there are certain traits which are helpful:

- **Confidence:** A client who is apprehensive about using AAC is much less likely to use it if those around them show apprehension too. You just have to dive in and give it a go. Being comfortable with making mistakes is essential.
- **Transferable skills:** being able to transfer the skills acquired in previous roles is essential, but you may have to be adaptable to meet the needs of working in an AAC Hub.

- **Flexible thinking:** things go wrong all the time and you have to adapt quickly. Solutions have to be adapted as the AAC user's needs change. For example, a child might progress from a symbol-to text-based package, or access might change from direct touch to eye-gaze in the case of a progressive condition.
- **Willingness to learn:** we are never static in what we do. We are always trying new things and testing the boundaries. Problems arise and solutions need to be found. Working with other disciplines means you need to learn how they work and start to think how they think so you can be a more effective team.
- **Being honest about what you don't know:** don't be afraid to ask questions. Every day someone will use an acronym you may not know, or talk about a piece of software you are unfamiliar with. One of the joys of working in a multidisciplinary team is the wealth of knowledge at your fingertips. If one person doesn't know then someone else usually does.
- **Thinking on your feet:** never work with children or animals should become never work with children or computers – They are two things which you can guarantee will do something you don't expect! Keeping calm, exploring all the settings, and - if all

else fails - turning the device off and on again are all recommended!

- **Have faith:** it is a big change working for a service like ours but it does come together and you will find your way through. You just have to remember that everyone you work with has had to go on the same journey as you to get to where they are today.

Professional Development

Learning on the job is an important aspect of our AAC roles. We needed time to acquire hands-on experience of each device and software package as this cannot be learnt from reading a brochure. You don't get to really know the software until you have actually used it with a client, and it is usually the situations where something doesn't go to plan that help you learn the most.

In the beginning we had the opportunity to shadow our more experienced colleagues on AAC visits. We have also had plenty of opportunities to attend external formal training through attending conferences, study days, events and specific training offered by company reps.

Supervision can be complicated in a multi-disciplinary team. A balance needs to be found between formal and informal support, between the larger group of professionals and the individual. Different professional groups may have different

appraisal systems which they will need to adhere to. As a result our service has developed a competencies framework document to support new staff and to structure self-directed learning.

One year on, where are we now?

We all feel that we have made a good start. We can understand a lot of what is going on around us! We have started to carve our own path and explore our own interests such as leading on different projects. We have a clearer understanding of our roles and what ongoing experiences and learning we need. Our confidence has increased and this happened more quickly than we anticipated. If we could go back in time, we would tell ourselves to calm down and be reassured that we would pick it up as we went along.

With the internet and social media, global networks are easier to reach, though it is hard to keep up with everything that is happening. We need a balance between the wider perspective and being grounded by informed conversation with our colleagues and feedback from our service-users.

We feel that we are now part of the AAC world. This is not just local, but national and international. We have come such a long way in the first year or so of our Specialist AAC journey, but there is still a lot to explore...



Augmenting Communication using Environmental Data to drive Language Prediction (ACE-LP) project at the University of Dundee

PROFESSOR ANNALU WALLER, LEAD INVESTIGATOR

University of Dundee

Project web site: <http://ACE-LP.ac.uk>

A £1 million research project that aims to change dramatically the way people with no speech and complex disabilities can have a conversation with others has been launched by the Universities of Dundee and Cambridge.

Computer-based systems – called Voice Output Communication Aids (VOCAs) – use word prediction to speed up typing, a feature similar to that commonly found on mobile phones or tablets for texting and emailing.

However, for those with complex disabilities, including for example Professor Stephen Hawking, using typing to communicate can still be extremely slow, as little as 2 words per minute, which makes face-to-face conversation very difficult. Even with an average computer-aided communication rate of about 15 words per minute, conversations do not compare to the 150 words per minute speaking rate of people without a communication impairment.

It is estimated that more than a quarter of a million people in the UK alone are at risk of isolation because they are unable to speak and are in need of some form of augmentative or alternative communication (AAC) to support them with a severe communication difficulty.

“Despite four decades of VOCA development, users seldom go beyond basic needs-based utterances as communication rates remain, at best, ten times slower than natural speech, making conversation almost impossible. It is immensely frustrating for both the user and the listener. We want to improve that

situation considerably by developing new systems which go far beyond word prediction” says Rolf Black, one of the project investigators at the University of Dundee.

Professor Annalu Waller from the University of Dundee, who is lead investigator for this research project, adds: “What we want to produce, for the first time, is a VOCA system which will not only predict words and phrases but will provide access to extended conversation by predicting narrative text elements tailored to an ongoing conversation.”

“In current systems users sometimes pre-store monologue ‘talks’, but sharing personal experiences and stories interactively using VOCAs is rare. Being able to relate experience enables us to engage with others and allows us to participate in society. In fact, the bulk of our interaction with others is through the medium of conversational narrative, i.e. sharing personal stories.”

Professor Stephen McKenna, also of University of Dundee, explains “we plan to harness recent progress in machine learning and computer vision to build a VOCA that gives its non-speaking user quick access to speech tailored to the current conversation. In order to predict what a person might want to say, this VOCA will learn from information it



gathers automatically about conversational partners, previous conversations and events, and the locations in which these take place."

Dr Per Ola Kristensson at the University of Cambridge's Department of Engineering brings his extensive expertise in probabilistic text entry to the project. As one of the inventors of the highly successful gesture keyboard text input system for mobile phones, commercialised under many names such as ShapeWriter, Swype and gesture typing, he adds: "What I find truly exciting about this project is the way it will advance state-of-the-art techniques from statistical language processing to potentially drastically improve text entry rates for rate-limited users with motor disabilities."

"This does not mean that the computer will speak for a person" adds Black. "It will be more like a companion who, being familiar with aspects of your life and experiences, has some idea of what you might choose to say in a certain situation."



The project is named "Augmenting Communication using Environmental Data to drive Language Prediction – ACE-LP" and brings together research expertise in Augmentative and Alternative Communication (AAC) and Computer Vision & Image Processing at the University of Dundee with Intelligent Interactive Systems at the University of Cambridge.

ACE-LP has a number of partners including Capability Scotland and Scope, the two leading charities for people with complex disabilities in the UK, and the ENT at Ninewells Hospital, NHS Tayside.

Industry partners include two of the world leading developers of VOCAs, Smartbox Assistive Technology and TobiiDynavox, as well as Arria NLG Ltd, the market leader in real-time data storytelling, and Edesix Ltd, a leading provider of advances Body Worn Camera Solutions, based in Edinburgh.

The Universities will also work with National Museums Scotland and the leading UK charity Communication Matters to ensure that the results of the research are communicated beyond the science communities into clinical work and mainstream knowledge.

This research project is funded by the UK Engineering and Physical Sciences Research Council (EPSRC).

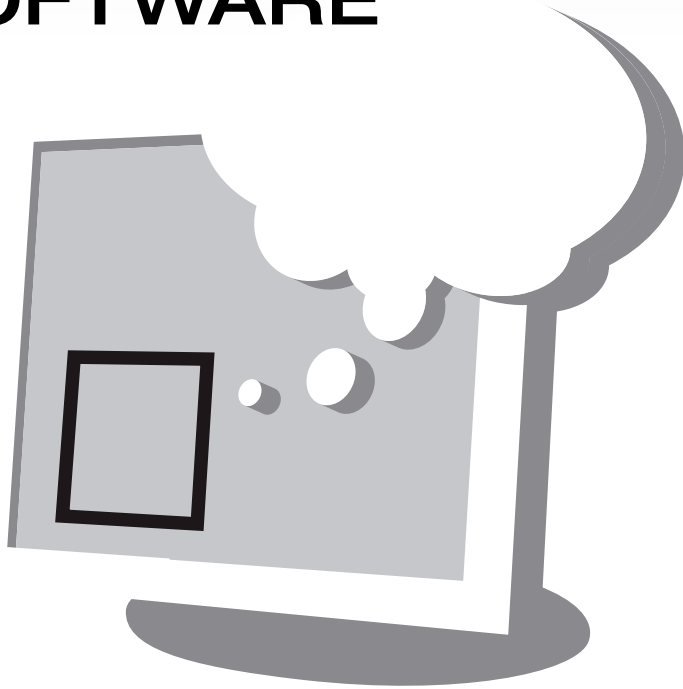
Project web site: <http://ACE-LP.ac.uk>



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'Communication matters to me because ...'

I believe everyone has something to say.

I need to communicate with my child.

I engage with people and it's through engaging with people that I learn and have joy.

It lets me tell people what I think.

We're all important and we all have something to say.

It is the basis for everything I do in life

It is fundamental that every individual has the opportunity and access to participate fully in their own lives through communication.

It colours my world!

Without it we are alone.

It's good to talk.

Everyone has the right to communicate and let themselves be heard.

It enables me to interact with others and my world.

Without a voice you can't be you.

When you are misunderstood it hurts or can accidentally hurt others.

It lets me say "I love you!"

I can tell stories to my children.

EVERYONE deserves a voice!

I can talk to my friends and make new friends.

I have a lot to say.

Without communication we can't learn or form relationships.

My daughter deserves the opportunity to learn a language that she may hopefully one day use.

Memories of Communication Matters celebrating 30 years

Patrick Poon's amazing fancy dress. So many different wigs!

Meeting up with friend's year after year! And also making new friends.
Nicola Bush.

I remember just walking in and feeling at home then getting the support to finding my new communication aid and the feeling of total inclusion. Helen Quiller.

Alan Martin dressed as the Queen. Fantastic!

Always a warm welcome

CM Roadshows. A great way to learn and meet like-minded people.

The barn dances - great fun! The Lancashire hot pot - ?? The shared showers...

As a carer I have learnt a lot about different talkers and meeting interesting people. K. Hirst.

CM2015: Loved it. Inclusive, friendly, interesting &... Sam K winning award! Proud

1 year ago I enjoyed the Sign Karaoke. 3 years ago chatting up student speech therapists! Sam Knapp <3 xx

The Good Communication Symbol from Australia.

Lots of laughs, lots of learning, lots of sharing, a welcoming community.

As a carer have enjoyed watching young people's faces with all the new talkers that are now available.

Every year I have been lucky enough to attend, I have left the conference feeling UPLIFTED

Wonderful to be back in the CM community finally working in a hub after 20 years of waiting! Exciting times. Fab conference.

The unofficial AAC Men's calendar... ? can't remember the year...

CM Memory, Being terrified when I first presented and everyone being really nice about it!

From the 1st conference at UMIST to the friendly atmosphere at Leeds Uni via Portland College, Lancaster and Leicester Unis...CM has really come of age!

Rebecca Marriott's memories: The dance after dinner Lancaster 1997. People communicating with her. Sunshine event 2015 Leeds and Where's Wally 2014.

Seeing old friends.

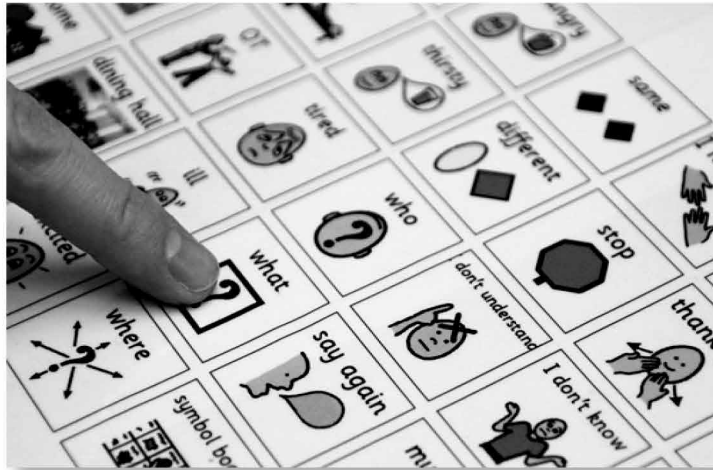
Toby and Brett in conversation. AAC at its best!



Communication Matters

more than just talking

AAC & Literacy Best Practice Study Days

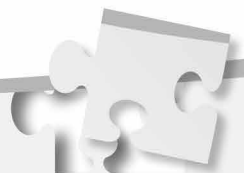


The first of a series of literacy & AAC (/SLCN) days is planned. The days will address the needs of children in special school and mainstream school & kickstart a special interest group with subsequent days planned. The days will be suitable for professionals and family members.

Costs: £65 members, £75 non-members and £40 family members/carers.

Friday 28 April 2017

**The Clare Charity Centre, Wycombe Road,
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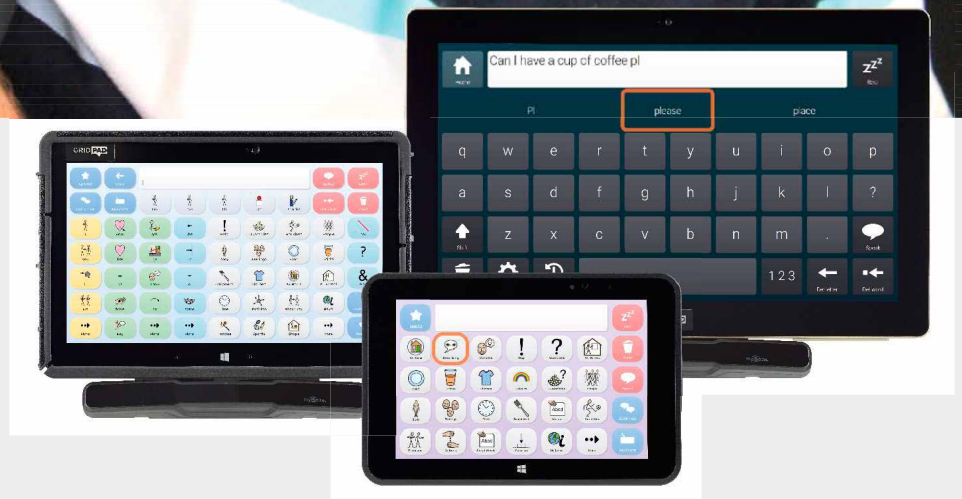
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