

# Communication **Matters**



**APRIL 2018 VOLUME 32 NUMBER 1**

**THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)**

**Topics include: Mentoring Training – Purpose of AAC – Growing Language –  
Conference – Bespoke Communication System – AAC Mentors – Preference Methods –  
Personal Impact – Hub's Experience**



# INTRODUCING THE NEW TELLUS i5:

A communication device  
with integrated eyegaze

## USE EYEGAZE TO:

- COMMUNICATE
- BROWSE THE INTERNET
- SEND EMAILS
- & MUCH MORE...

Supporting the  
needs of people living  
with communication  
difficulties across  
the UK.



**FREE  
LOANS  
AVAILABLE**

Try before you buy

**Our customers choose  
us because we provide...**

- FREE consultations on most types of talking technology (AAC) from keyboard text to speech, right through to more complex eye gaze based devices
- FREE loans – try before you buy
- FREE unlimited telephone support
- Speedy repairs completed in our UK workshop with loan devices available where appropriate

## Tellus i5



### KEY FEATURES:

- Integrated Eye Tech OEM TM5 eye gaze
- 13.3" wide capacitive touch screen
- Turns on with a switch
- Wakes up from sleep using eyegaze
- Includes a webcam & IR environmental control
- A GSM for texting & calls is optional

To find out more...

email: [sales@techcess.co.uk](mailto:sales@techcess.co.uk)

or phone: 01476 512881

Or see us at future Communication  
Matters roadshows.

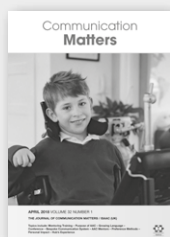




COMMUNICATION MATTERS JOURNAL

VOLUME 32 NUMBER 1

APRIL 2018



*Thank you to CM Member Jo van Berckel, from North Yorkshire, for providing this fantastic photo of her nine year old son, Kit.*

COMMUNICATION MATTERS JOURNAL  
ISSN 0969-9554

Communication Matters / ISAAC (UK)  
3rd Floor, University House,  
University of Leeds,  
Leeds, LS2 9JT  
Tel: 0113 343 1533  
Email: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)  
Website: [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)  
Registered Charity No. 327500  
Company Registered in England & Wales No. 01965474

**Editor**  
Emily Campbell  
Email: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)

**Design & Production**  
Karin Wall & Emily Campbell

**Advertising and Overseas Subscriptions**  
Tel: 0113 343 1533  
Email: [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk)

**Copy submission**  
Preferred text format: Microsoft Word  
Preferred graphics/photo formats: JPEG, TIFF  
Copy deadline: contact editor  
The Communication Matters Journal is the official publication of Communication Matters / ISAAC (UK), and is an ISAAC affiliated publication.

The journal provides a forum for discussion, and views expressed in any section of this publication are the views of the writer(s) exclusively: publication in this journal does not constitute endorsement by Communication Matters / ISAAC (UK) or ISAAC of those views expressed. This is no way affected by the right of the Editors to edit all copy published. Publication of advertisements in this journal is not an endorsement of the advertiser nor of the products and services advertised. Communication Matters reserves the right to reject or cancel without notice any advertisement. Copyright for all published material is held by Communication Matters / ISAAC (UK) unless otherwise stated.

Printed by Swallowtail Print (Norwich)

# Contents

---

- 2 Co-chairs' Report**  
Toby Hewson and Ruth McMorran
  - 3 CM News**  
Toby Hewson, Ruth McMorran and Judith Chapman
  - 6 Level 2 Award in Mentoring training**  
Verity Elliott
  - 8 'AAC is my voice, it means everything to me'**  
**An exploration of the meaning, value, and purpose of Augmentative and Alternative Communication to users and key stakeholders**  
Denise Abraham
  - 12 Tips to Grow Language**  
Jane Odom
  - 13 'We'll meet again at C.M.'**  
Helen Dunman and Helen Quiller
  - 15 Developing a bespoke communication system in secondary school through to college and beyond**  
Lisa-Marie Eastwood and Judy King
  - 20 AAC Mentors**  
Gregor Gilmour
  - 21 Using stated preference methods in alternative and augmentative technology**  
Edward J.D. Webb, David Meads, Yvonne Lynch, Nicola Randall, Simon Judge, Juliet Goldbart, Stuart Meredith, Liz Moulam, Stephanie Hess and Janice Murray
  - 27 Having Pride. Exploring the personal impact of having a speech impairment**  
Simon Stevens
  - 30 A hub's experience of developing augmentative and alternative communication expertise in local speech and language therapy teams**  
Catherine Foy
-



# Co-chairs' Report

## Toby Hewson & Ruth McMorran

So much seems to have happened since we last wrote a journal report!

You may remember that, at the Annual Meeting, we informed you that all the teams based at the Leeds Innovation Centre were moving in Autumn 2018 to the new Nexus Building. Unfortunately, soon after conference Communication Matters was informed that we no longer meet the criteria to have an office within the Innovation Centre. We spent a busy couple of months locating an alternative office and just before Christmas we moved to our new home in University House. That's right on University Precinct, in the middle of the campus. The new office is very slightly smaller than the old one – but we also have access to a small meeting room right across the corridor and to a larger room on the floor below. We're already reaping the advantages of being closer to the MEETinLEEDS team who manage our annual conference.

Towards the end of 2017, we were delighted to secure a grant from the Foyle Foundation to allow us to make major changes to the AACKnowledge website. We will be working on this over the next two years.

In January, Communication Matters was invited to join Leeds CANN (Children with Additional Needs Network). Leeds CANN is formed of third sector, voluntary, community and statutory organisations working with families and carers with children and young people with additional needs, in the Greater Leeds area of West Yorkshire. It has been established so that Member Organisations can share best practice, resources, ideas and opportunities, in order to improve access to information, training and support for families and carers across the Leeds area and the region. Emily Campbell and Euan Robertson will represent CM at the quarterly meetings.



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

The General Data Protection Regulation (GDPR) comes in to effect on 25th May 2018. It is a new set of rules governing the privacy and security of personal data laid down by the European Commission. Emily has been working hard to ensure that we comply with the new regulations. If you are on any of our mailing lists, we will soon be asking for your permission to keep you on them! Please reply as otherwise, under the new regulations, you will have to be deleted. You may also see extra

information about how we store your data appear on our website and bookings forms.

Co-chairing Communication Matters continues to work really well and we hope you all see that too. However, it is important to point out that we are now half way through our 3 years term of office. In 18 months we will be stepping down and The Board is already looking at progression planning.

We were pleased to receive over 50 applications for the post of Admin Assistant. We are pleased to say we have offered the post to Valerie Stephenson-Lewis who will be starting with us before Easter. You will be able to contact Valerie at [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk) or 0113 343 1533. Thank you to Felix Titherley and Matt Masters who have provided temporary cover during the vacancy.

Registration is now open for our 2018 Conference which will be held at the University of Leeds from Sunday 9<sup>th</sup> to Tuesday 11<sup>th</sup> September. We look forward to seeing lots of you then!

## CM News

### Is the Communication Matters National AAC Conference expensive?

Do you want to know where your registration money goes for your conference place? Does it seem expensive?

It may surprise you to know that this 2.5-day event at the University of Leeds takes over 12 months of planning!

So, what do we spend? Well, the university charges us per head, as well as for their own staff costs. On top of that there is the cost of venue hire (and for 90 presentations that's a lot of rooms!) and car parking. Then of course there is the accommodation (lovely, comfy ensuite rooms) and catering (the best part!) - numerous rounds of tea and coffee and lunch is included with every registration and some registrations also contain a fancy 3-course meal and more!

We also have the expense of an online software (known as Ex Ordo) to help with our abstract and review management and to keep in contact with our many presenters. And the boring bit... administration time - the registrations alone use many hours, not to mention all the hours of planning!

Then there's all the small, but vital things... the entertainment, the photographer, the keynote speakers, the advertising, the signage and the travel expenses for all the meetings surrounding the conference! Not forgetting the vast, wonderfully-designed, printed programme.

We couldn't do it all without our amazing sponsors of course, donating raffle prizes and the like! A big thank you to them. In addition to all you delegates who help out by chairing presentations, buying raffle tickets and more!

So... how does your conference fee break down? Take a look at the chart below.

We hope that clears it up a bit! But the general feeling is that our conference is really good value for money, so that's super! We also had lots more feedback from our 2017 delegates which you can read below.

#### CM2017 Conference Feedback

So, what did you lot think of our 2017 conference last September? We had 124 forms returned out of nearly 400 delegates, so we've analysed the feedback forms and crunched the numbers!

Well...

A whopping **98.4%** of you thought the conference was good value for money and looking at the stats above, you'd be right!

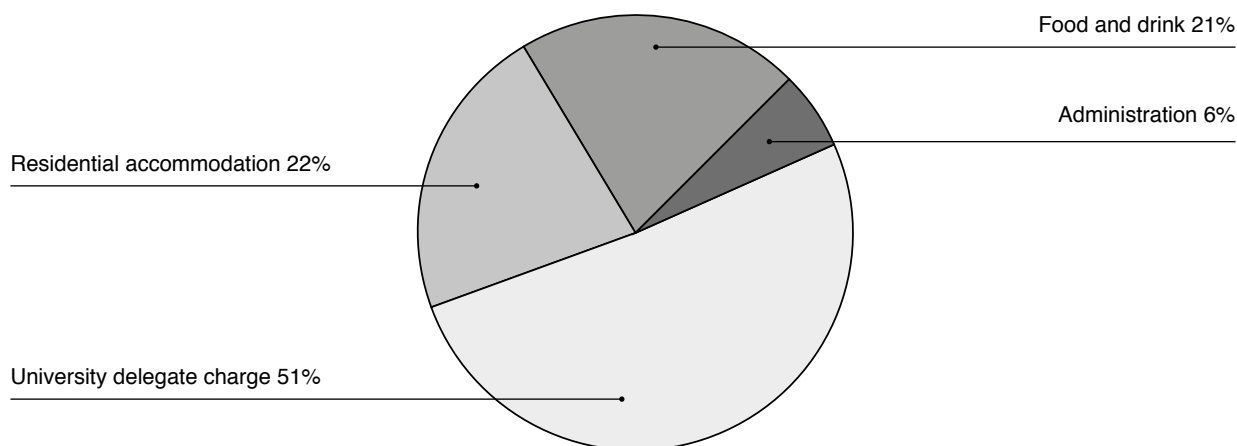
**96.8%** thought the session length was mostly right, with just 4 people finding them too long or too short. This shows that 45 minutes is around the ideal length to listen to a presentation as well as have time to have any questions answered.

**69.4%** felt the number of parallel sessions was mostly right, but 30.6% felt there were too many! It is always difficult to choose which sessions to attend when we have so many fantastic papers submitted, but we try our best to put similar papers in separate timetable slots.

Most of you felt that the sessions you attended overall rated **'Excellent'**

and **100%** rated the Exhibition as 'Good', 'Very Good' or 'Excellent'.

What great news!



Conference delegate fee breakdown

# CM News

There was a mention about the time of year we hold the conference and some people asked if it could be later in the year. As we hold the conference at the University of Leeds we are restricted to dates while the students are away for the Summer. We have the last possible dates in the University's Summer Conference programme - the international students are returning during conference, with other students arriving on the day after we leave. Over the years we have considered the possibility of hosting the conference in a different location i.e. not a university, but this would increase the costs dramatically.

We also had some lovely comments left on the forms too, just a small selection of which are shown below:

*"It's like meeting up with one massive family"*

*"Conference dinner this year was spectacular"*

*"Very well organised and everything clearly signposted"*

*"Good range of topics for adults and children"*

*"Seemed to be a very happy atmosphere - good balance of academic and social programmes"*

*"A good range of informative presentations, friendly staff and delegates, great food and entertainment"*

*"Nice to have a parent presenting about their experiences of having a disabled child who uses AAC"*

*"Really enjoyed the overall experience, opportunity to network and socialise, as well as learn from a wide variety of people presenting such different topics"*

*"I have learnt an enormous amount"*

We wish to take this opportunity to thank everyone who completed a feedback form for us last year. These are so important as they help us to make the conference that extra bit better year on year (or so we try)!

We look forward to the CM2018 Conference at the University of Leeds once again this September and hope to see you all there - both new faces and 'old'!

## AACknowledge Entries

**(November 2017 - March 2018)**

**From Judith Chapman, MMU**

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

## Recent Bibliography Entries

Ahlgrim-Delzell, L Browder, D M Wood, L Stanger, C Preston A I Kemp-Inman, A, 2016. Systematic Instruction of Phonics Skills Using an iPad for Students With Developmental Disabilities Who Are AAC Users. *Journal of Special Education*. 50/2, 86-97

Ahonniska-Assa, J Polack, O Saraf, E Wine, J Silberg, T Nissenkorn, A Ben-Zeev, B, 2018. Assessing cognitive functioning in females with Rett syndrome by eye-tracking methodology. *European Journal of Paediatric Neurology*. 22/1, 39-45

Ainsworth, M K Evmenova, A S Behrmann, M Jerome, M, 2016. Teaching phonics to groups of middle school students with autism, intellectual disabilities and complex communication needs. *Research in Developmental Disabilities*. 56, 165-176

Batarowicz, B Stadsleiv, K Renner, G Dahlgren Sandberg, A von Tetzchner, S, 2018. Assessment of aided language comprehension and use in children and adolescents

with severe speech and motor impairments. *AAC*. 34/1, 54-67

Carnett, A Bravo, A Waddington, H, 2017. Teaching mands for actions to children with autism spectrum disorder using systematic instruction, behavior chain interruption, and a speech-generating device. *International Journal of Developmental Disabilities*, online

Caron, J Light, J Davidoff, B E Drager, K D R, 2017. Comparison of the effects of mobile technology AAC apps on programming visual scene displays. *AAC*. 33/4, 239-248

Dada, S Murphy, Y Tönsing, K, 2017. Augmentative and alternative communication practices: a descriptive study of the perceptions of South African speech-language therapists. *AAC*. 33/4, 189-200

Deliberato, D Jennische, M, Oxley, J Regina d'Oliveira de Paula Nunes, L Crivelenti de Figueiredo Walter, C Massaro, M Almeida, M A Stadsleiv, K Basil, C Coronas, M Smith, M M von Tetzchner, S, 2018. Vocabulary comprehension and strategies in name construction among children using aided communication. *AAC*. 34/1, 16-29

Dodd, J L Gorey, M, 2014. AAC Intervention as an Immersion Model. *Communication Disorders Quarterly*. 35/2, 103-107

Drager, K D R Postal, V J Carrolus, L Castellano, M Gagliano, C Glynn, J, 2006. The Effect of Aided Language Modeling on Symbol Comprehension and Production in 2 Preschoolers with Autism. *American Journal of Speech-Language Pathology*. 15/2, 112-125

# CM News

- Ganz, J B Morin, K L Foster, M J Vannest, K J Genc-Tosun, D Gregori, E V Gerow, S L, 2017. High-technology augmentative and alternative communication for individuals with intellectual and developmental disabilities and complex communication needs: a meta-analysis. *AAC*. 33/4, 224-238
- Genc-Tosun, D Kurt, O, 2017. Teaching multi-step requesting to children with autism spectrum disorder using systematic instruction and a speech-generating device. *AAC*. 33/4, 213-223
- Holyfield, C Drager, K Light, J Gosnell Caron, J, 2017. Typical Toddlers Participation in 'Just-in-Time' Programming of Vocabulary for Visual Scene Display Augmentative and Alternative communication Apps on Mobile Technology: A Descriptive Study. *American Journal of Speech-Language Pathology*. 26/3, 737-749
- Holyfield, C Drager, K D R Kremkow, J M D Light, J, 2017. Systematic review of AAC intervention research for adolescents and adults with autism spectrum disorder. *AAC*. 33/4, 202-212
- Kovacs, T Hill, K, 2015. A Tutorial on Reliability Testing in AAC Language Sample Transcription and Analysis. *AAC*. 31/2, 148-158
- Kovacs, T Hill, K, 2017. Language Samples From Children Who Use Speech-Generating Devices: Making Sense of Small Samples and Utterance Length. *American Journal of Speech-Language Pathology*. 26/3, 939-950
- Lancioni, G E Singh, N N O'Reilly, M F Sigafoos, J Boccasini, A Perilli, V Spagnuolo, C, 2017. Persons with multiple disabilities manage positive leisure and communication engagement through a technology-aided program. *International Journal of Developmental Disabilities*. 63/3, 148-157
- Light, J, 1997. "Let's go star fishing": reflections on the contexts of language learning for children who use aided AAC. *AAC*. 13/3, 158-171
- Light, J Page, R Curran, J Pitkin, L, 2007. Children's ideas for the design of AAC assistive technologies for young children with complex communication needs. *AAC*. 23/4, 274-287
- Lorah, E R Parnell, 2017. Acquisition of Tacting Using a Speech-Generating Device in Group Learning Environments for Preschoolers with Autism. *Journal of Developmental and Physical Disabilities*. 29/4, 597-609
- McNaughton, D Rackensperger, T Benedek-Wood, E Krezman, C Williams, M B Light, J, 2008. Parents of Individuals who use AAC Describe the Benefits and Challenges of Learning AAC Technologies. 24/1, 43-55
- Millar, D C Light, J C Schlosser, R W, 2006. The Impact of Augmentative and Alternative Communication Intervention on the Speech Production of Individuals With Developmental Disabilities: A Research Review. *Journal of Speech, Language and Hearing Research*. 49, 248-264
- Murray, J Dahlgren Sandberg, A Smith, M M Deliberato, D Stadskleiv, K von Tetzchner, S, 2018. Communicating the unknown: descriptions of pictured scenes and events presented on video by children and adolescents using aided communication and their peers using natural speech. *AAC*. 34/1, 30-39
- Østvik, J Ytterhus, B Balandin, S, 2017. Friendship between children using augmentative and alternative communication and peers: A systematic literature review. *Journal of Intellectual & Developmental Disability*. 42/4, 403-415
- Perrin, M Robillard, M Roy-Charland, A, 2017. Observing eye movements and the influence of cognition during a symbol search task: a comparison across three age groups. *AAC*. 33/4, 249-259
- Pilesjö, M S Norén, N, 2017. Teaching communication aid use in everyday conversation. *Child Language Teaching and Therapy*. 33/3, 241-253
- Rispoli, M J Franco, J H van der Meer, L Lang, R, Pimentel Höher Camargo, S, 2010. The use of speech generating devices in communication interventions for individuals with developmental disabilities: A review of the literature. *Developmental Neurorehabilitation*. 13/4, 276-293
- Smith, M M Batorowicz, B Dahlgren Sandberg, A Murray, J Stadskleiv, K van Balkom, H Neuvonen, K von Tetzchner, S, 2018. Constructing narratives to describe video events using aided communication. *AAC*. 34/1, 40-53
- Stadskleiv, K Batorowicz, B Massaro, M van Balkom, H von Tetzchner, S, 2018. Visual-spatial cognition in children using aided communication. *AAC*. 34/1, 68-78
- Trottier, N Kamp, L Mirenda, P, 2011. Effects of Peer-Mediated Instruction to Teach Use of Speech-Generating Devices to Students with Autism in Social Game Routines. *AAC*. 27/1, 26-39
- van der Meer, L Sutherland, D O'Reilly, M F Lancioni, G E Sigafoos, J, 2012. A further comparison of manual signing, picture exchange, and speech-generating devices as communication modes for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*. 6/4, 1247-1257
- von Tetzchner, S, 2015. The semiotics of aided language development. *Cognitive Development*. 36, 180-190
- von Tetzchner, S Launonen, K Batorowicz, B Regina d'Oliveira de Paula Nunes, L Crivelenti do Figueiredo Walter, C Oxley, J Massaro, M Stadskleiv, K Yang, C-K Deliberato, D, 2018. Communication aid provision and use among children and adolescents developing aided communication: an international survey. *AAC*. 34/1, 79-91



# Level 2 Award in Mentoring training

## VERITY ELLIOTT

Director, Creativity in Practice Ltd

Email: verity@creativityinpractice.co.uk

About 18 months ago I first contacted Communication Matters office in Leeds to discuss an opportunity to work together to secure some funding to deliver Level 2 in Mentoring qualification for disabled young people. The aim being that Communication Matters would be an essential partner in identifying young people who would like to complete a recognised qualification along with Creativity in Practice being able to offer all aspects of delivery including, training, assessing and quality assurance.

The inspiration for this came from discussions with disabled young people who had experienced a variety of disappointments and frustrations as recent examples of trying to access higher education highlighted limited opportunities in the educational and professional options available to them.

It was evident that the qualities, skills and life experiences of these young people were hugely relevant to the role and opportunities provided through peer mentoring, and this aligned to the scope to be linked to mentoring roles. A number of factors contributed to this, the most significant of which is new technology and the capacity to mentor in a variety of situations and contexts including face-to-face or via the different forms of social media. Most important was the recognition that disabled children and young people want to be able to network and communicate in order to share different issues, situations and aspirations; peer to peer in preference of perceived 'adult' led advice and guidance.

Awards for All (part of the Big Lottery) awarded a grant for just over £9,000, this enabled us to offer six disabled young people the opportunity to gain a recognised qualification; a Level 2 Award in Mentoring. The funding enabled us to meet for eight taught sessions, provide all the resources, register the young people with the awarding body (NCFE), allocate 1-1 assessment and support and pay for the certificates along with paying travel costs to the young people.

The **Level 2 in Mentoring** qualification allows learners to gain a deeper understanding of the role of a mentor and develop the skills needed to become and effective mentor.

The aims of the qualifications are to help learners gain an insight in to the role and practice of being a mentor, to be clear about mentor/mentee relationships, ensure good practice, develop specific skills and understanding, reflect on own learning and performance, understand the benefits of mentoring and the legal and ethical requirements

The qualification consists of three units:

- **Role of a mentor** – different types of mentoring, who might benefit, mentoring agreements and goal setting with mentees along with the advantages of a mentoring scheme
- **Preparing for the role of a mentor** – understanding the model for a supporting relationship, communication skills, reflective practice, action planning, potential barriers/challenges and legal requirements

- **Demonstrating mentoring skills** – an opportunity to practice and experience mentoring and being mentored, review and reflection of own mentoring and personal development planning

In addition, we included a **Safeguarding Awareness** session.

We delivered the course in Manchester at an accessible venue, The Monastery, which provided a comfortable learning environment; this was important as it ensured the young people felt valued and enabled them to engage in their learning.

The delivery model was very based on a similar programme where Creativity in Practice had worked with another voluntary organisation to provide Level 2 in Mentoring for volunteers working within the family support sector. The same resources were used albeit with some adaptations;

- ✓ **Additional time** – particularly important for AAC users to be able to fully engage in group discussions and prepare short assignments and the workbooks.
- ✓ **Workbooks for each unit** – these were provided both as hard copy for reference during the taught sessions and also electronically to ensure the young people had a choice of how to present their work
- ✓ **Powerpoint slides** for each taught session
- ✓ **Video clips** of mentoring in practice
- ✓ **Scanned notes** from each session



(flip charts) – these were particularly important as the trainer was able to ‘scribe’ and capture key points from whole group discussions linked specifically to a particular unit and assessment criteria, the notes were then shared via email for the young people to refer to as and when needed

- ✓ **1-1 support from an assessor** who provided continuous guidance and feedback; this enabled personalised learning for the young people

The course started in early May 2017 and the six young people have all completed and received their certificates along with their portfolios of evidence for all three units and assessment activities in early August 2017.

The outcomes have been very positive with good feedback from the young people and their personal assistants, for example, in addition to the initial assessment we also included:

Discussing ‘hopes & expectations’ both for this course and for future mentoring roles, this is what the young people said:

- To know more about mentoring
- To learn from other people about different types of mentoring and what people are already doing and what I can do
- Help with my job and to get more experience
- To learn how to mentor
- To help children use communication aids
- To help mentees get some ‘light at the end of the tunnel’, by being a role model

This was reviewed at the end of the last session and all the young people agreed the above had been met and more.

After the first session, the group were asked ‘What had gone well?’

- ✓ Learning all different aspects of mentoring – ‘It was better than I thought it would be’

- ✓ Meeting new people
- ✓ TinyScanner App – good tool for learning
- ✓ Great to learn new skills
- ✓ I enjoyed meeting new people and learning about mentoring
- ✓ ‘I feel like I’m doing something proper, doing the qualification. My manager wants me to feed back when the course ends’

Towards the end of the course, we were required to comply with a quality moderation visit from NCFE external moderator who scrutinised the young people’s portfolios and our delivery methodology, we received an excellent report, below is an extract of the summary:

*“There is an effectively planned programme of learning and assessment. The determination and focus of the learners is inspirational. The assessment practices are exceptionally well planned using fair assessment methods to enable the learners to meet their aims and goals.*

*The learners show themselves to clearly have skills and understanding which achieves securely at this level.*

*The Assessors have made exceptional use of audio/visual assessment methods to ensure that fair assessment practices have been effectively implemented. The care and organisation of the learners evidence and the assessment records is consistent within both the electronic and hard copy folders. Within the hard copy portfolios the learners have provided a good range of evidence types, mind-maps, answered questions, written accounts, plans, feedback records and Assessor observation records. The learners have provided secure evidence across the range of criteria. Thank you for all of your hard work with this qualification. Please congratulate your learners. I wish them the very best for the future.” SM 28.7.17 NCFE*

Five of the six young people have progressed to develop their mentoring practice – for example, one young person

who was already delivering some mentoring in groups, was asked to offer 1-1 mentoring in schools, this was a significant step in recognising the skills and understanding developed as part of the course and he provided more detailed feedback:

*‘The level 2 course has benefitted and helped me to see how to use questions to draw people out, also by learning of their understanding before you advise them, another thing is to listen to the person by showing that you have good eye contact, but most importantly I learn that the main reasons are to help someone. I learnt a lot from the course, these are some of the things I will remember: trust and confidentiality, deep understanding, be patient to see what the other person’s heartfelt reply is. Thanks for a great course and for being a great course leader. You have shown your experience and also had great patience and didn’t rush us especially the people using communication aids like me, but instead you gave us plenty of time’*

Other young people have gained confidence and have shared best practice with their mentoring organisation.

In summary, this was a very successful collaboration and project that provided personal and professional development opportunities for six disabled young people along with the opportunity to socialise and develop friendships. The project had the vision to see this as more than just gaining a qualification as the emphasis was also on ensuring the links with mentoring in practice; continuation and progression.

We are hopeful that Communication Matters and Creativity in Practice will continue to work together with the aim of providing more similar opportunities for more disabled young people. For more information please contact [admin@communication-matters.org.uk](mailto:admin@communication-matters.org.uk) and keep a look out in the CM newsletters and updates – we would welcome your thoughts and feedback.



Shop online through **Give As You Live** and raise free funds for us!

Go to:

<https://www.giveasyoulive.com/join/communicationmatters>

# 'AAC is my voice, it means everything to me'

## An exploration of the meaning, value, and purpose of Augmentative and Alternative Communication to users and key stakeholders

**DENISE ABRAHAM**

Highly Specialist Speech and Language Therapist (Severe and Complex Needs)

Essex Partnership University NHS Foundation Trust

Email: denise.abraham@nhs.net

### Background

Communication is widely acknowledged as a basic human right; it is valuable in that it 'makes us who and what we are and strengthens our human dignity; [it] allows people to feel that they can be treated equally, thereby validating human equality' (Bornman, 2016, p. 235). Augmentative and Alternative Communication (AAC) allows those with complex communication needs to access communication and connection that would otherwise be impossible. However, although AAC has the potential to have a transformative effect on people's lives, this appears to happen in a minority of cases only. There remains significant work to be done in understanding and advancing the usefulness of AAC, so that it can have a greater impact for more people.

It is essential that the value of AAC is demonstrated if it is to remain and rise on the political agenda, particularly within economically unstable environments. A rapidly growing evidence base indicates positive outcomes and benefits of AAC, such as enhancing communication and reducing challenging behaviour (Light & McNaughton, 2015). Nevertheless, despite the growth of the field, AAC is not having the impact that it could (Hodge, 2007). Evidence suggests that only 30-50% of communication devices are accepted and used successfully (Enderby, Judge, Creer, & John, 2013), although

successful use of AAC varies between people and is not a unitary concept (Foy, 2017). Evidence indicates that AAC is under-utilised in schools, as well as by other users, and research reveals more stories of abandonment than success.

It is clear that there is conflicting evidence regarding AAC; that which indicates that it is useful, used, and valued, and that which indicates that it is under-used and abandoned. If we are able to ascertain what meaning, value, and purpose AAC holds for users and key stakeholders, teams will be better placed to support it. Therefore, the question posed in this research is

'what is the meaning, value, and purpose of AAC to users and key stakeholders?' The aim is to establish recurrent themes within and between groups which can guide and influence practice. Knowing differences in team members' priorities can lead to more effective intervention and better appreciation of each person's motivation and values; this can lead to greater potential for long-term success (Johnson, Inglebret, Jones, & Ray, 2006). Also, without commissioners having knowledge and awareness of the impact and value of AAC, its future is likely to be bleak (Bush & Scott, 2009). If the goal of

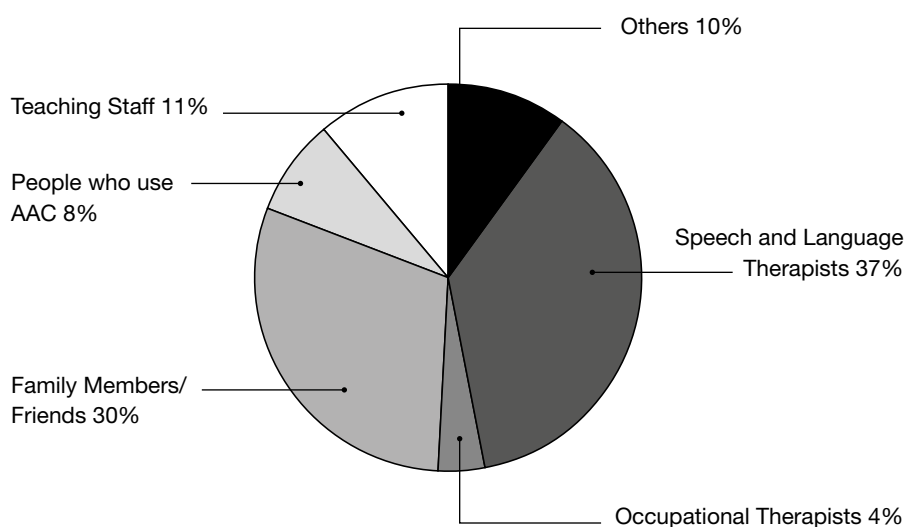


Figure 1: Participants

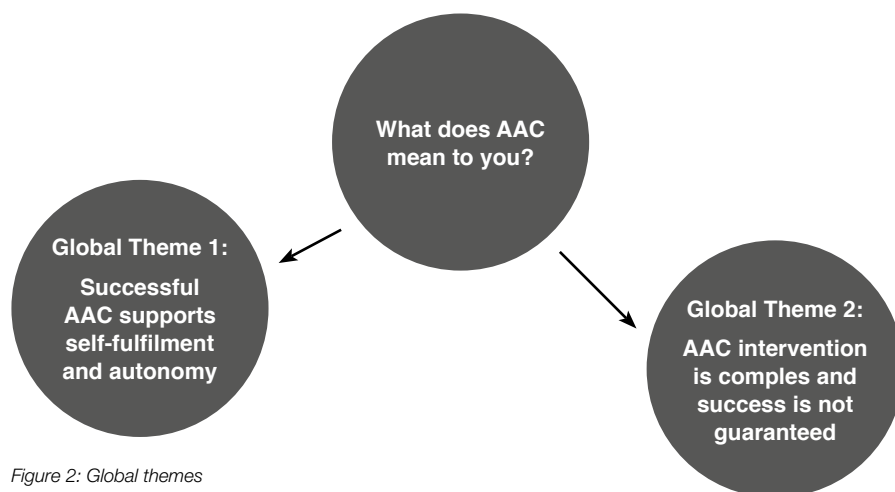


Figure 2: Global themes

AAC is to provide a context in which there is meaningful and authentic inclusion, societal membership, and participation, the elements required need to be known in order to get there (Smith & Murray, 2011).

### Methods

The study employed a qualitative descriptive design. An open-ended survey was used to collect data from people who use AAC, family members, and health and education professionals. The survey received 189 responses. Figure 1 outlines the percentage of respondents in each stakeholder group. Thematic Networks Analysis (Attride-Stirling, 2001) was used

to ascertain Global, Organising, and Basic Themes which emerged from the data.

### Results

Two global themes, presented in interconnected thematic networks (see Figure 2), were created from the data. The first network (Figure 3) describes the potential that AAC holds for self-fulfilment and autonomy. The second network (Figure 4) discusses the underlying support that is required in order for successful implementation of AAC.

The global theme of the first thematic network is 'Successful AAC supports self-fulfilment and autonomy'. This is comprised of four organising themes. This

network discusses the personal meanings and value that AAC can hold. The volume of responses and themes indicate that there is no singular meaning of AAC. In order for AAC to be implemented successfully, the personal meaning of AAC for each individual/family should be a focal point in intervention, as the real value and purpose of AAC is in self-fulfilment; each person being able to work towards their own life goals.

The organising themes within this network discuss how AAC has the potential to change and transform lives. Respondents reported that AAC offers hope, and increases quality of life, as well as removing barriers and allowing access to opportunities which would not otherwise be possible. Other themes derived from the data highlighted that AAC makes a difference and is worth the time and effort required. AAC is also important in supporting autonomy, contributing to independence, safety, confidence, and control. It is a voice for those who need it, allowing them access to choices and decisions. An important element discussed by participants was that AAC can be empowering, and reveals ability where the world assumes otherwise, allowing people to be heard and respected. The data demonstrated that AAC supports participation, and access to relationships, work, education, social media, and conversation. Respondents also reported that communication and AAC are fundamental human rights, which should not be denied to anyone. Furthermore, AAC was seen as important in contributing to personhood and advocacy.

The global theme of the second thematic network is 'AAC intervention is complex and success is not guaranteed'. This theme was derived from five organising themes. This network discusses the important elements relating to the user, the system, and essential support, which are required for successful implementation of AAC. This network underpins the first network, as without these elements being appropriately addressed, the potential for self-fulfilment and autonomy outlined in network one is unlikely to come about.

This network explores how people see AAC in many different ways, with particular emphasis on AAC as a tool(s)/system(s), and the importance of multimodality. An organising theme within this network discusses how 'AAC can be used but requires skill to use effectively'. This theme indicates that AAC can be

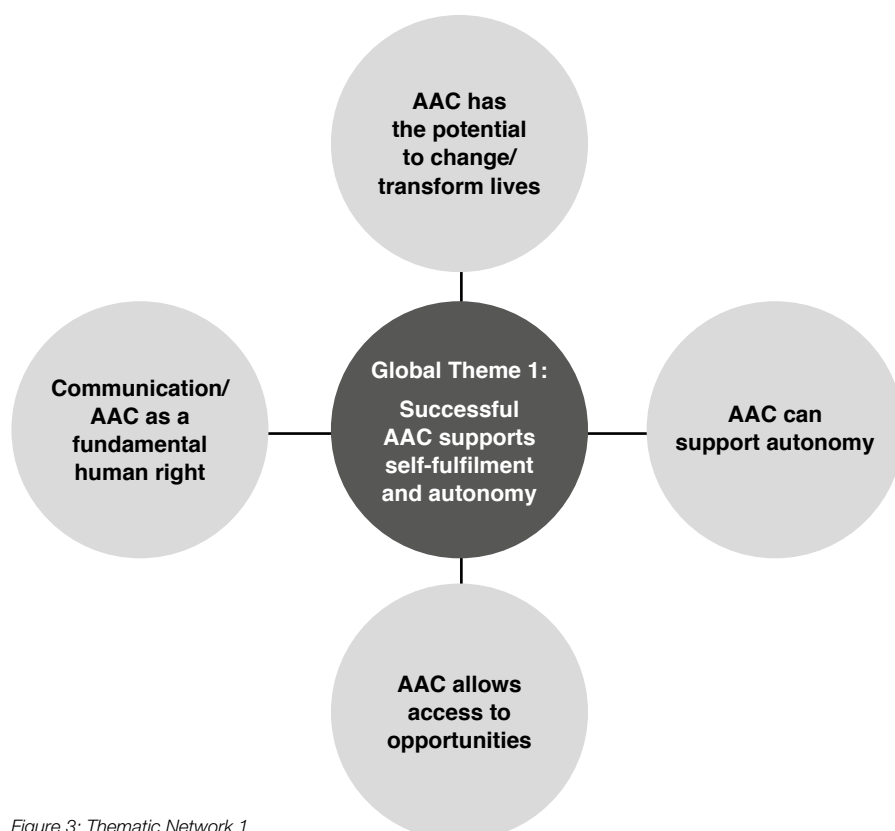


Figure 3: Thematic Network 1

**Table 1: Examples of data extracts related to a selection of basic themes**

Basic Themes	Examples
<b>Offers hope</b>	<i>AAC in its many forms, both low and high tech, to me means hope. Hope that as my son progresses he will be able to articulate more and people can and will see him as I do, an incredibly bright and talented individual with a huge heart and an infectious sense of humour. (Father)</i>
<b>AAC reveals ability</b>	<i>Without AAC, most people would dismiss her as incapable not only of speech but also of thought. (Mother)</i>
<b>Same opportunities as others</b>	<i>The biggest single thing that will provide my disabled adult daughter with independence, choice, control and quality of life, to put her more on equal footing with non-disabled. (Mother)</i>
<b>Importance of AAC</b>	<i>It is fundamental to our daily existence. (Mother)</i>
<b>Allows authentic communication for the user</b>	<i>AAC means I can communicate the things I actually want to say when I need to. (Person who uses AAC)</i>
<b>Needs to be supported</b>	<i>Having appropriate support is key to it working well... without this, it doesn't matter if you have the right device and a motivated individual – it just falls apart. (OT)</i>
<b>Reveals identity/personality</b>	<i>AAC drew back a curtain and revealed my child at the controls, making choices and expressing her personality. (Mother)</i>

used, but is not always used, depending on the person and the situation, and that it takes skill to learn and use AAC effectively. Respondents acknowledged how AAC can reduce frustration, reveal identity, and allow authentic communication, but the hard work, effort, and motivation required are also highlighted. This network also addresses the theme 'AAC systems themselves are complex and multi-faceted'. Within this, participants referred to the careful design required to personalise systems, the importance of assessment, and the challenges of technology, vocabulary, access, and mounting. Skilled and tailored supports were identified as being an essential contributor to success or failure of AAC. The skills required by communication partners, as well as the time, effort, and hard work for families and professionals are discussed. The complexities and frustrations of implementing AAC, particularly with limited resources, are addressed in the data set, as well as the expectations that are often placed on aided communication systems. The final theme in this network discusses the importance of support, motivation, and determination for success with AAC, and conversely how the lack of support, value, understanding, and motivation contributes to failure of AAC.

Some examples of data extracts related to a selection of basic themes can be found in Table 1.

## Discussion

There is no definitive meaning of AAC, demonstrated in the myriad of responses and themes generated. If AAC is not meaningful to an individual, there is no motivation or incentive for them to use the system. However, if the aim of intervention is to fulfil the individual's own

goals, they are more likely to be motivated to use it. The team, with the user and family at the centre, should strive to ascertain priorities in intervention, being aware of potential differences between stakeholders, in order to come up with a tailored and supportive intervention plan that has the greatest potential for success. There is an increased effort required in using aided communication when compared with natural speech (Smith, Murray, von Tetzchner, & Langan, 2010). AAC therefore needs to hold personal meaning, value, and purpose to be worth this effort.

The true meaning of AAC seems to lie in the positive and individual impact it can have, but the bigger picture often gets overlooked in favour of focusing on the foundational elements of network 2: AAC intervention is complex, which, although essential for success, should not be the end goal of intervention. It is important to explore with each person who uses AAC, and their key communication partners, what the meaning, value, and purpose of AAC is and could be for them. The elements of the first thematic network are the potential that AAC can have, but the data indicates that this is not consistently achieved. More work is required to reach the point where this is the norm, rather than the exception.

AAC may currently be under-used or under-valued in that the meaning for the individual has not been fully explored in intervention. In order for AAC to have meaning, value, and purpose for each individual, teams should ask 'what could AAC mean for this person?' as a starting-point to guide intervention.

The presentation of these themes within the networks brings understanding of the inter-connected nature of these elements,

as well as the way that successful use of AAC contributes to a changed life. This perspective could lead to more focused and comprehensive implementation of AAC, allowing the potential for successful AAC to expand. The themes developed in the study provide a useful starting-point for an individual's journey with AAC. The networks could also aid troubleshooting and problem-solving when AAC does not appear to be having the optimum impact.

## Limitations

With regards to limitations, the sample may contain biases, in that the people who feel more strongly and potentially more positively about AAC are more likely to have responded. The number of respondents in each group is different due to the online nature of the data collection, but this is balanced by the fact that most themes were created from responses contributed by all stakeholder groups. There was a reduced number of responses from people who use AAC, which might indicate that they need more support to access online forums. Reduced literacy skills may also have been a barrier for potential respondents. Also, there is the potential that more able users responded, and that the data does not capture the views of less able users, or those without internet access.

## Conclusion

The data has demonstrated that there is no singular answer to the question of the meaning, value, and purpose of AAC, as this varies between individuals and families. There is therefore not one overall solution. Teams can only provide meaningful and effective intervention by engaging with each individual in a personalised, family-centred manner, in



order to meet their needs. The elements and themes arising from the current study can serve as a framework for ensuring that intervention is as comprehensive as possible, with the best chance of bringing about maximal and meaningful change to each person and family in their unique context. To do this, effective and efficient services are required, with appropriate funding for both staffing and equipment, and time to support each family and to interact with society, to make it a more understanding, welcoming, and truly inclusive place for all the citizens of this world.

The data indicates that AAC holds meaning, value, and purpose. The findings show perceptions of more success than failure, more interaction than isolation, more benefits than challenges, more voice than silence. AAC can make a difference, but it requires on-going time, effort, and support. More effort brings more returns, which in turn can lead to increased potential for autonomy, self-fulfilment, and well-being, which should be seen as the final destination in the journey.

### Acknowledgements

Sincere thanks to those who gave of their time to participate in this study. Thanks also to my academic supervisor Dr Martine Smith at Trinity College Dublin, as well as EPUT, particularly the paediatric Speech and Language Therapy Service.

### References

- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, 1, 385-405.
- Bornman, J. (2016). Reflections from Fellows of ISAAC. *Augmentative and Alternative Communication*, 32(4), 233-240. doi:10.1080/07434618.2016.1252947
- Bush, M., & Scott, R. (2009). *No Voice, No Choice: A sustainable future for augmentative and alternative communication (AAC)*. London: Scope.
- Enderby, P., Judge, S., Creer, S., & John, A. (2013). *Beyond the anecdote: Examining the need for, and provision of, AAC in the United Kingdom*. London: Communication Matters.
- Foy, C. (2017). Factors related to high tech AAC use in adults with neurodegenerative conditions. *The Journal of Communication Matters*, 31(1), 9-12.
- Hodge, S. (2007). Why is the potential of augmentative and alternative communication not being realized? Exploring the experiences of people who use communication aids. *Disability & Society*, 22(5), 457-471. doi:10.1080/09687590701427552
- Johnson, J., Inglebret, E., Jones, C., & Ray, J. (2006). Perspectives of speech language pathologists regarding success versus abandonment of AAC. *Augmentative and Alternative Communication*, 22(2), 85-99.
- Light, J., & McNaughton, D. (2015). Designing AAC research and intervention to improve outcomes for individuals with complex communication needs. *Augmentative and Alternative Communication*, 31(2), 85-96. doi:10.3109/07434618.2015.1036458
- Smith, M., & Murray, J. (2011). Parachute without a ripcord: The skydive of communication interaction. *Augmentative and Alternative Communication*, 27(4), 292-303.
- Smith, M., Murray, J., von Tetzchner, S., Langan, P. (2010). A tale of transitions: The challenges of integrating speech synthesis in aided communication. In J. Mullenix & S. Stern, (Eds.), *Computer synthesized speech technologies: Tools for aiding impairment* (pp. 234-256). Hershey, PA: Medical Information Science Reference.

## Jamie's Poem

Jamie Preece

Email: jamiepreece@hotmail.co.uk

*The pen is mightier  
than the sword –  
That's what they say to me,  
But a pen is pretty useless  
to a man like me.  
All my life I went without –  
People talked for me,  
Now all I want  
and all I need is A.A.C.*



### Sales@CandLE (scandle ltd)

Suites 105/107  
Ulverston Business Centre,  
25 New Market Street,  
Ulverston LA12 7LQ  
Telephone 01229585173  
Email sales@candleaac.com  
Website www.scandle.org

Sales@CandLE designs and supplies resources both for communication and educational settings for AAC users who need support with a focus on literacy.

Our ground-breaking program 'Phonics for All' is available in Grid 3. We will soon be able to sell Grid 3 with free curriculum resources to accompany it.



Sales@CandLE also produces an A5 accessible communication book with an optional customisation and update service. We can also supply PODD books for those who have the software but lack the time.

We produce a unique, lightweight, waterproof letter board.



We have developed a comprehensive literacy assessment and development program for students who rely on AAC. Our assessment program works at word, sentence and text level. Our literacy development program includes emergent literacy strategies such as, Alternative Pencils and predictable charts as well as conventional literacy supports. All are tied to the English education system with plans in place for other UK education systems to be accommodated.



Find out more at: <https://www.scandle.org/shop/>

# Tips to Grow Language

**JANE ODOM, M. ED**

Director of Implementation Resources, Prentke Romich Company

Email: jane.odom@prentrom.com

Learning language is a right of passage that every child can experience. Some of us communicate via our voice, or perhaps sign language or gestures. Children with significant speech delays are now, with modern technology, able to use a computer or tablet to communicate. This requires learning the language on that device. As professionals, many of us have never been trained to do this. AAC can seem intimidating at first; but, if we can apply simple strategies, we can be quite effective.

The first step is to learn the AAC system. You can't teach something you don't know. Most manufacturers have ample options for training. Utilize these options. Most are free. You can also take time to explore the device. Learn along with your student. Think aloud while you are learning. For example, say, "I don't know where the word *clean* is on your talker, as in *clean* up. Let's go find it! Let's look under the bathtub, because we get clean in the bath. There it is, *clean*."

We model language to our children when they are young over and over again. This allows for them to discover new words, word meanings, and how to use words in a variety of different contexts. How often do we do the same on an AAC device for our children with language delays? Providing an example of a behavior without expecting a response can be very powerful. There are a variety of ways to model. You can simply use a device to make a comment. You can describe an object or situation. Another example would be to use the device to ask a question.

Core vocabulary makes up most of what we say. In fact, 80% of all of our communication is made up of a small group of 400-500 core vocabulary words. The other words are known as *fringe* vocabulary. Focusing on both is very important. We need to realize that a balance of both is most effective.

Say, for example, you need to teach words to go to a fast food restaurant. You can teach words like soda, hamburger, and apple pie. But, after the student orders, what do they talk about next? They most likely do not really want to talk about the menu, but who won the latest football game or perhaps their favorite toy.

Typically, when a child gets a device, they want to explore. This is great. What may seem like a lot of random hits, may actually be the child learning where words are located. While you are learning the device with the student, be sure to accept all communication as purposeful. This will reinforce the idea of 'why' we communicate.

Allow happy accidents to occur. Be sure your student has access to enough vocabulary. Nothing is worse than a student abandoning a device because they don't have enough words to say what they want to say. One mistake is to only give access to vocabulary we think the student needs, like eat, drink and bathroom. Most kids have so much more to say. We sometimes think it is better to start off slowly, but that isn't always necessary. It may be more comfortable for us, as professionals, but may not be a good idea to limit communication. Always acknowledge any communication attempts. Respond appropriately and give them time to play with language.

When a student is learning new language, we, as communication partners, need to slow down and wait. Give the student time to find things on their own before jumping in to help. As they are forming their message, stop and listen. Maintain eye contact. Give them at least 10 seconds before jumping in to prompt them. Most importantly, be quiet while waiting. Don't have other conversations so the student can concentrate. Students need that time to process not only what they want to say, but where to find it. If they are using alternative

access such as scanning or eye gaze, they will also need to coordinate their body to access what they want to say.

Prompting is very important but over-prompting can be dangerous. Be sure to wait at least 10 seconds before a prompt. You can comment to help them find a word. For example, suggest the first icon in a sequence for them to find. You can also ask an open-ended question. After trying these suggestions, you can gesture and point to the device and then model or show on the device. Finally, if all else fails, the student may need physical guidance.

Some other tricks that can help a student become more effective are the following: Recast, extend and expand. To recast, simply restate the message in a grammatically correct way. So, if the child says '*room messy*', the adult can respond, '*yes, the room is messy*.' Verbalizing an extra word is also an effective way to model and extend. The student may look at their friends and say '*girl*'. The adult can say, '*look at the two girls*'. To expand that message, the adult could also respond, '*same girls*' or '*where are the girls*'.

Finally, be sure to take a person-centered approach. Assume competence. Give the student something interesting to talk about. You can administer an Interest Inventory to find out what really motivates them. Look out for and create fun and motivating communication opportunities. Play, cooking, art projects, science, reading, and games are all good options.

Communication should be fun and functional. There are so many simple things you can to help your student become a better communicator. There will always be good days and bad days. We can all live and learn from those experiences. A little success will lead to more success!

# 'We'll meet again at C.M.'

## HELEN DUNMAN

PSHE Co-ordinator, Chailey Heritage Foundation

Email: [hdunman@chf.org.uk](mailto:hdunman@chf.org.uk)

## HELEN QUILLER

The Vice Chairman of 1 Voice Communicating Together

Email: [helenquiller@hotmail.com](mailto:helenquiller@hotmail.com)

**As we are co-authors of this paper we have decided to each contribute from our particular perspectives.**

### 1. Helen Q.

Our story starts 30 years ago when I was a teenager and a student at Thomas Delarue, a special school in Tonbridge and Helen D was a young care assistant. We worked together for 2 years, then I went off to college and Helen to her PGCE. Fast forward 30 years to last years C.M. when we met up again and Helen immediately knew me, and wanted to come and watch my presentation about my adult life and Independence.

### 2. Helen D.

When I left Delarue I was given a painting that Helen had done with a switch operated airbrush (pictured right), despite all my many moves over the years it survived and hangs in my home. I had often wondered over the years what had happened to Helen and her friends. I was thrilled to go to her presentation last year and hear about her communication journey and her life generally. I was particularly impressed by how Helen talked about how she led a rich life, despite challenges, how she contributed to the wider society and what gave her life meaning. I immediately knew that I had to book her for a workshop with our older students at Chailey, to inspire them as a positive role model for adult life.

### 3. Helen Q.

After my presentation here at CM last year Helen D immediately invited me to go and

deliver a days workshop to her students at Chailey Heritage. My initial thoughts about this were that it was great to know and feel that Helen D had liked and valued my presentation enough to feel that my presentation and adult AAC experiences would be useful and beneficial for her own young students to hear about. I felt a little anxious as well, because I didn't know that much about the age group or abilities of Helen's students. I initially sent Helen a couple of presentations that I had used and given before to the young people who I had worked with at 1 Voice events. Helen chose my presentation about my adult life, and all the different organisations that I'm involved with and work for. This presentation also looks at my leisure time and how sometimes it has been a challenge to find things to do and fill my time with. Helen D felt that this presentation would be the most beneficial for her students to hear and learn about. Helen also sent me a list of questions to work through and answer for the students. Questions such as, What had been my biggest challenges in life? And whether I would do anything differently if I was starting out as a young adult now? I spent quite a lot of time thinking about these questions, because I wanted to show and give the students hopes for their futures, but I also didn't want to make out and pretend that things were always easy and plain sailing as a disabled adult trying to lead an independent and active lifestyle.

At times it was quite a challenge to try and organise a day's teaching and presentation via e-mail, rather than being able to meet up and chat through our ideas



together face to face, and bounce things off each other. We eventually made a plan for the day based around the presentation that I've mentioned above. This included a couple of songs that I'd written about my experiences with my disability and communication problems. The students seemed to enjoy and really respond to my songs and the music.

### 4. Helen D.

The day came and Helen delivered the programme to 17 students. 16 of these students use AAC both low tech and some are beginners at high tech. I introduced Helen and then basically left her to get on with it, only stepping in to go over the key points at the end of a session. At break, Helen hung out in the hall with the students, who wanted to come up and see her and speak to her.

## 5. Helen Q.

On the day when I arrived at Chailey and Helen introduced me to her students, I realised that some of them had quite significant and severe learning difficulties, and I began to worry that my presentation wouldn't be at the right level for the students at all. However I began my presentation and Helen D stepped in to repeat and reinforce what I was saying to the students after each little section. I think we worked this quite well between us, and gauged the really important points to get across to the students. One point we worked hard to put across was how important it is for them to work on and build their communication skills. I was still worried that some of my presentation was going above the students heads and was too complicated for them to understand, for example when I was talking about my work at Birmingham City University.

## 6. Helen D.

I was not worried about this at all! Knowing the students as I do I was impressed by how quiet and attentive they were in this session. One particular student who for various reasons was only usually able to manage 15-20 minutes in a lesson, managed 40 minutes. I could tell that the students were engaged and listening. I also felt that even though Helen's presentation was aimed at quite an adult audience, that when we expect a lot of our young people, they often deliver, behave in a more mature manner and 'up their game' and this is what I saw happening.

## 7. Helen Q.

I discovered and now belong to a group in Birmingham called Musical Connections, we meet up once a month and make music and write songs together. I find that making music and writing songs is another way that I can express my thoughts and feelings without having to verbally say them. For example I can bang a drum

when I feel angry and frustrated, or I can shake a shaker when I feel happy or excited. I feel this allows me the freedom to express myself, without the physical effort of trying to talk and express myself verbally. A couple of years ago I wrote and made a couple of songs, the first one was called 'The Chair' My other individual song is called 'The Moment has gone' We also made a short videos to go with these songs. Which I would like to share this with you in a moment. I had included both of these songs in my presentation to the students at Chailey. They really seemed to like and respond to the music, and all the students showed a real interest and response to my music and songs.

## 8. Helen D.

The afternoon ended with me inviting the students to think of questions that they would like to ask Helen.

It's important to say that my students have severe learning difficulties and take a long time to communicate a single word. I also have 'reluctant' communicators who often flatly refuse to communicate in lessons and also students whose physical disabilities are so severe that they have to be very, very motivated in order to make the huge effort it requires for them to communicate beyond their basic needs. Without exception every student thought of at least 3 questions for Helen, which was a huge achievement for some of our learners. Helen had motivated them!

## 9. Helen Q.

When I reflect on my day working with Helen and her students at Chailey, I found it a really positive and challenging experience. I had always heard a lot of positive things about Chailey Heritage and the work that was done there, so it was really good to be able to visit and see what it was like for myself. I think as I hadn't met the students and didn't know that much about their abilities, the day went very well considering that I wasn't that aware

of their levels of understanding for example. I was delighted when I heard from Helen that the students had done well and managed to be more attentive and focused during my lesson, especially one student who had managed to double his time in the classroom.

I have several ideas about how Helen and I could develop and build on our work together in the future. Yes we could start a day with a small presentation, but then take individual students aside for individual work on their AAC devices with us both, and give them the individual time to watch me asking Helen for simple things with my aid, and getting a positive response from her. For example I could ask Helen for a drink, or to listen to some music that we knew they liked, and then say it's your turn now, which music would you like today? My thinking on this is that if a student saw me asking and getting things that I wanted and liked through using my aid with Helen, then it could really help increase their own motivation to communicate more. I feel that if we did this on an one to one basis and made it fun for the students, and made it a special fun session with our visitor Helen who has a voca like yours, 'let's see what we can all do and say together', this may work well with the students. However I don't know if Helen's structure and timetable would ever allow time for this individual work and time with students? My other thought is whether working over a two day period would ever be possible, and more beneficial for the students, because of their need for time and lots of repetition.

## 10. Helen D.

My reflections. Just the fact that my students could see someone with physical disabilities and AAC running a day's workshop was a very powerful message, in itself. I want to build on the possibility of using Helen or an adult with similar skills as an AAC mentor for identified young people, especially students who need that extra boost of motivation.



# CM2018 International AAC Conference

9-11 September 2018  
University of Leeds

Go to:

<https://www.communicationmatters.org.uk/page/conference-registration>

Registration  
now open!



# Developing a bespoke communication system in secondary school through to college and beyond

**LISA-MARIE EASTWOOD**

Email: lisamarieeastwood@gmail.com

**JUDY KING**

Independent SLT

Email: info@judykingslt.co.uk

Developing useful, functional low and high tech communication systems for a person with complex physical and visual difficulties takes many years and is an on-going adventure!

This presentation looks at one personal account of how a range of communication strategies were developed from secondary school, into college and how we are planning for the future.

Lisa-Marie was looking for a specialist S&LT and discussing it at the 1Voice Chinese Day where she and her Mum met Judy who has been working with Lisa-Marie ever since!

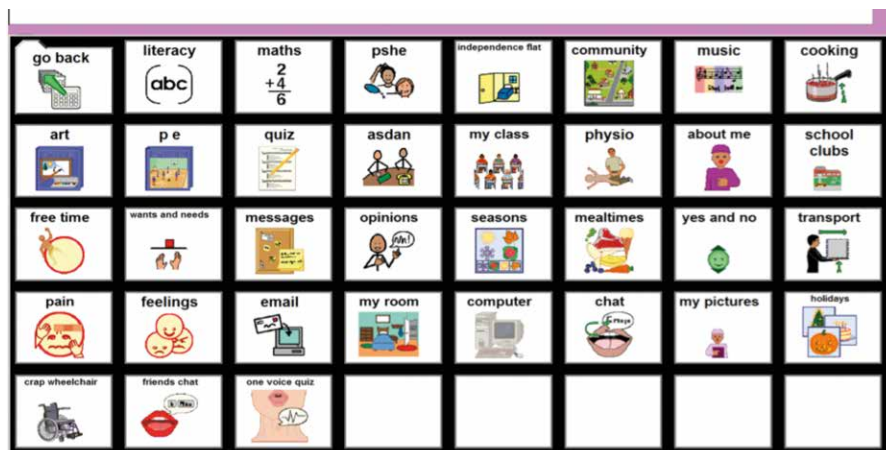
At that point Lisa-Marie was finding switching difficult and had many pages on her DynaVox that she couldn't independently navigate to (Fig. 1). It was a very confusing system that required full



support to select pages for Lisa-Marie and the pages were not in any logical order, so difficult to find. The pages were set up for use in school and school subjects but not for communication and conversation. Lisa-Marie was dependent on her PA to select the correct page and then support her elbow and prompt switching on autoscanning. This was not independent switching or selection of vocabulary and so working on switching skills was seen as a priority.

Lisa-Marie was then 15 years old, however, we took the courageous decision to take a step back to working on basic switching skills using the Big Step. Lisa-Marie enjoyed and still enjoys using the Big Step to select sequences of messages at her own pace. We worked hard on using switches accurately, focussing on pausing and refraining from switching in order to listen to responses. These skills helped Lisa-Marie to create proper conversations with turn taking skills. Lisa-Marie used and still uses the Big Step for conversations in specific settings, presentations and giving sequenced instructions, such as making mulled wine!

We also worked on timed switching on autoscans with an auditory prompt starting with a simple top category page with only 9 choices and 'clear'. We tried different switch positions to give Lisa-Marie optimum success at independent switching, including head switching and different hand movements – lateral /



Above: Figure 1. Below: Making mulled wine. Top right: Judy and Lisa-Marie





Figure 2

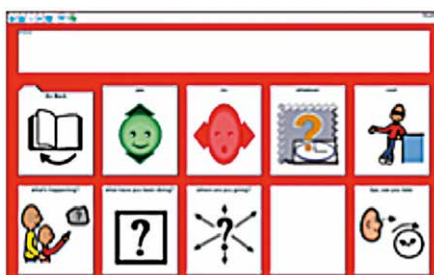


Figure 3

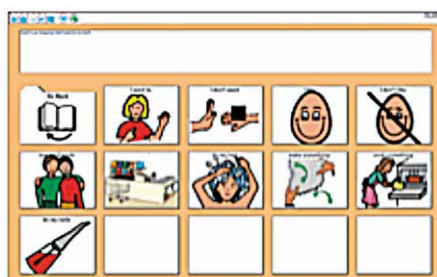


Figure 4



Figure 5



Figure 6

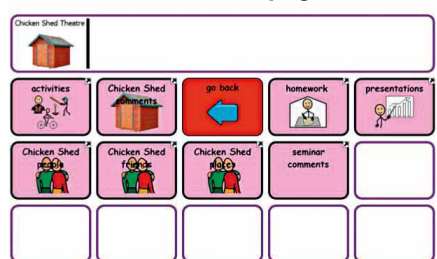
#### People page



#### Activities page



#### Chicken Shed Theatre page



#### Chat page

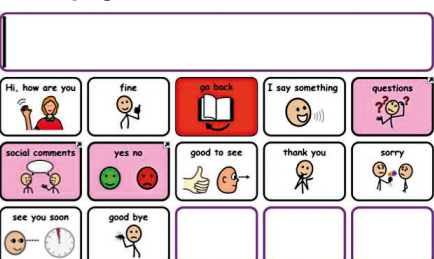


Figure 7

upwards / downwards. We ended up with an angled forward / right position (Fig. 2).

Initially the each category page had just 8 vocabulary items, then we added a few items to make 10 items per page and then eventually 15 (Fig. 3–5).

It was decided that pages of 15 vocabulary items were enough to give a good range of choices, but not too many to scan through on linear scan. We looked at the structure of the pages and decided that having the 'go back' button on the third choice of each page allowed Lisa-Marie time to realise if she had accidentally selected the wrong page without having to wait until the end of 14 choices before being able to 'go back'.

By taking a step back we have progressed to linear auditory scanning on a high tech communication device with 15 choices per page linking to many more pages within pages (Fig. 6).

The system was highly structured but limited at the 8 choice level and has now developed into a complex flexible system at the 15 choice level (Fig. 7).

As each new page was introduced, Lisa-Marie spent time working not just on that particular page but also on navigating to it herself.

Vocabulary selection has been a group decision process between the individual, parents, PAs and therapists. There have been times when too much vocabulary has been added and we have had to pause introducing further vocabulary to consolidate knowledge.

We have regular meetings to discuss what communication is working and what is required. Several situation specific vocabulary pages have been created including going shopping, to a café, going to the library, pub, night clubs and shisha bars! (Fig. 8)

However, Speech and Language Therapy hasn't just been focused on simple and complex high tech and over the years a range of communication methods have been developed for different situations. These now include:

#### No Tech – yes / no:

Lisa-Marie has worked hard to make her yes (head nod) and no (head turn) clearer to interpret.

#### Low Tech:

A Low Tech listener mediated scanning communication book was developed with the words in exactly the same order as on

# NEW: A FREE MULTI-ACCESSIBLE AAC INTERFACE FOR LITERATE USERS

To find out more about Amego and how it works  
with Mind Express call us on 01476 512881

NEW

**Amego**



## THE POWER OF MIND EXPRESS SOFTWARE:



### COMMUNICATION

NEW 'SCORE' Vocabulary Set –  
Making AAC access to fringe and  
core vocabulary as easy as possible.



### EDUCATION

Great new games and  
resources, ask us for  
more information.



### ASSESSMENT

MaximEyes – The all new  
Eye Gaze assessment tool  
from Jabbla

## BUT DON'T JUST TAKE OUR WORD FOR IT...



"Lauren (15) is now able to access a  
complex communication system set out  
in a simple logical way with Mind Express,  
giving her independence, control and a  
better quality of life."

JUDY KING, INDEPENDENT SLT



"It is difficult for me to communicate verbally,  
but I still think & I love to talk - and that's  
where my Mobi 2 using Mind Express  
comes in. By using it I can say what I need,  
and what I want. My Mobi is my best friend."

HANNAH JAMES

**FREE LOANS AVAILABLE: Find the AAC device that works for you.**



Smart 3



Zingui 2



Tellus 5



Mobi 3



Allora 2



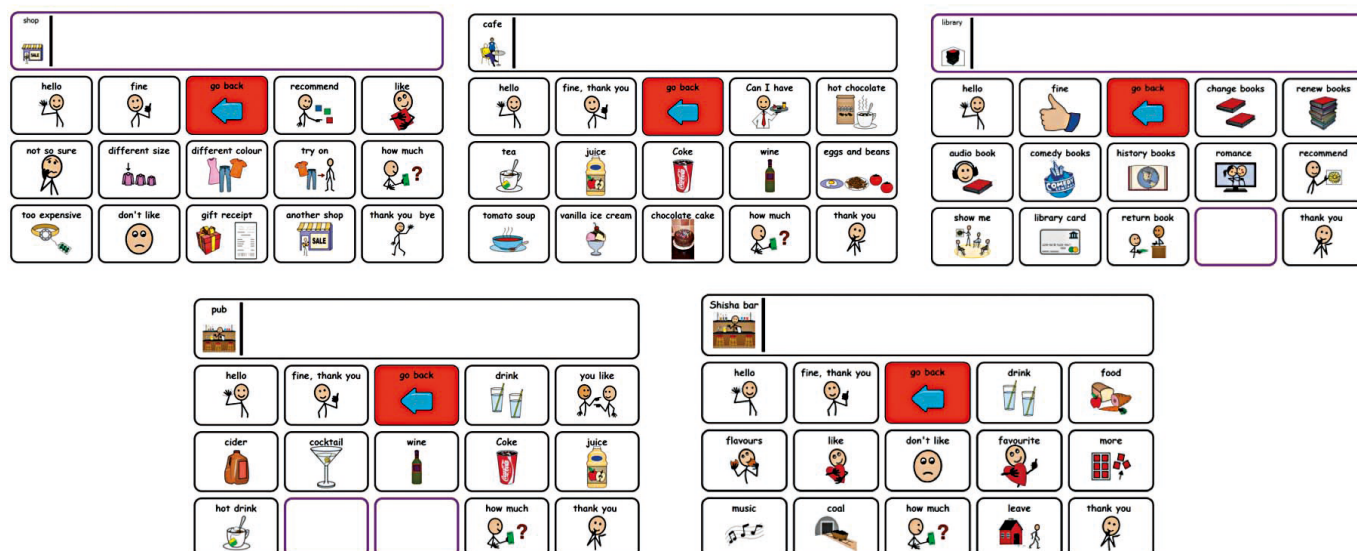


Figure 8



the Mobi to support learning and creating a 'mindmap' of the vocabulary in order to anticipate the words (Fig. 9).

### Simple High Tech: yes / no switches and Big Step

Lisa-Marie uses two 'Big Point' switched recorded with 'yes' / 'no' to allow Lisa-Marie to answer closed questions but also to interrupt or join in conversations in a simple way, to agree or disagree. She can also use them in conjunction with the Communication Book.

The Big Step is usually used in situations when Lisa-Marie is going to take part in predicted conversations and full sentences are needed to keep a conversation

going fast. Sometimes the Big Step is used to 'handover' updates at change of carers or to record lines in a Chicken Shed performance. Lisa-Marie can select the vocabulary via her Communication Book or Mobi2 and then full sentences are recorded in a sequence on the Big Step. Lisa-Marie is always present and agreeing with the recorded messages so she knows what is being said.

### High Tech:

Lisa-Marie worked hard to develop her use of the Mobi2 with single switch auto-scanning access and a linear auditory prompt scan. Once Lisa-Marie got used to the auditory prompt voice, we introduced the speaker so that the voice was a lot quieter. However this also meant a lot more concentration was required.

### Other High Tech:

When Lisa-Marie first got the Mobi2 and was learning to use it, it was felt to be too cumbersome to take out and Chicken Shed were not keen to have it in their sessions. So we set up the iPad with the

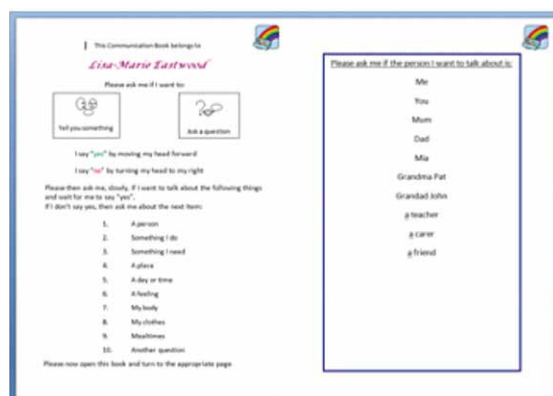


Figure 9

'Go Talk Now' app and the 'APPLICATOR switch box'. The GoTalkNow app was programmed in the same way as the Mobi2 with additional links to music and Lisa-Marie used it in workshops and when out. However, as Lisa-Marie became more proficient with the Mobi2, she used the iPad less and less. Now Lisa-Marie uses the iPad, iPhone and laptop with PA input to research topics and go on Facebook, YouTube and the internet.

Lisa-Marie is now doing a Foundation Degree in Inclusive Arts at Chicken Shed Theatre. The use of the Mobi2 has been invaluable for making independent comments, joining in with workshops and performances and meant that her college



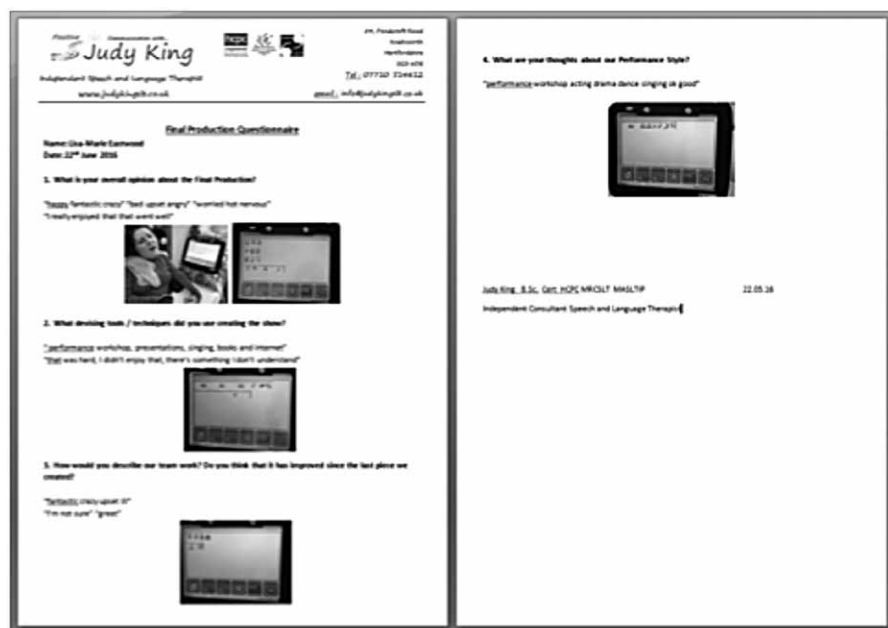


Figure 10

work can be completed independently, clear decisions made, instructions given and conversations initiated, led, followed and closed (Fig. 10).

Lisa-Marie now has a range of different methods of communication that she is competent with and chooses to use in different situations:

When lying in bed either first thing in the morning, during the night or just relaxing, Lisa-Marie uses her facial expression, just the 'yes' switch and her Communication Book. If she's sitting up in bed Lisa-Marie can also use her Mobi with the switch on a Meru mount.

Lisa-Marie is always given the choice of different communication systems and makes the decision of what to use depending of her position and physical well being.

When chilling out and relaxing, sitting in her wheelchair, Lisa-Marie may choose

between her Communication Book / yes & no switches / Mobi2.

Lisa-Marie is also able to use her Mobi2 in her standing frame.

Any coursework that needs to be printed out is done on the Mobi2. However, research is done with PA support on iPad or laptop with Lisa-Marie guiding using her Big Step or yes / no switches.

Lisa-Marie is now starting to use her Mobi in the community in different places using the specific vocabulary pages. When switching is difficult she will then use her Communication Book, yes & no switches and Big Step.

Learning to use the Mobi2 requires a quiet, concentrated environment and can be tiring. Therefore the range of communication systems is important for easy communication, giving presentations, instructions and socialising in different situations.

## The Future

Currently Lisa-Marie's mother helps Lisa-Marie to run her P.A. business liaising with P.A.s about rotas and overseeing finances. The P.A.s are now included in every part of Lisa-Marie's life from ordering medication, updating health and safety procedures, keeping up-to-date with communication and Lisa-Marie's social media. They support her to keep on track with her health targets by doing physio and correct medical procedures. With Lisa-Marie's health and communication on track, she can achieve independent living, her coursework and a social life. Chicken Shed has been a big part of Lisa-Marie's life with workshops, coursework, rehearsals and shows. Lisa-Marie has strong plans to continue her involvement with Chicken Shed in a supporting role to others, give presentations on disability and communication awareness to Health Care Professional and local businesses.

## Advice / ideas

- Go to a S&LT – it's a pain but you have to do it!
- Don't be afraid to go back to basics.
- Have a clear plan of what you want to achieve and how you are going to get there.
- Revisit your plan and update it as life changes.
- Look at Facebook for inspiration! See other people using AAC and their experiences.
- Accept it's going to take a long time – language isn't learnt in a day!

## Comments and Conclusions

We all have good days and bad days but we need to communicate everyday and everywhere!



# AAC Mentors

GREGOR GILMOUR

## What is an AAC mentor?

AAC Mentors are high level, competent AAC users that give support, assistance and inspire developing AAC users. We work with them to show them just what can be achieved if they use their device properly. We support and encourage them to use their devices at home, school and college. We also encourage them to use their devices in the community and for more social purposes like having a laugh with your friends.

It is good for AAC users and their families to meet high level competent AAC users so that they can see just what can be achieved. It gives hope to families and helps them to see a future for their child. In mainstream schools a lot of staff have never met an AAC user before. They are not sure of how that individual is going to cope at school or what they can do to make it easier. Meeting and talking with an AAC users that has been there and done it can be a really useful tool for them.

## How I got into mentoring

I never had an AAC mentor but I think it is a great idea and I would have loved it if I had a mentor coming in to my school to help me. I did however have role models at 1voice. I started going to 1voice when I was about 6 years old, I thought that it was great as it was the first time that I had met other AAC users like myself. Alan Martin was a 1voice role model and a big inspiration, I really looked up to him. I went to 1Voice for many years until I went to Beaumont. I enjoyed seeing my friends and role models.

Becoming an AAC mentor is something that I have wanted to do for many years. When I left school, I did a level 2 college

course in business studies and I did my business plan for the course on mentoring. I then went to Beaumont College for 3 years. When I left I didn't want to just come home and do nothing, so with the help of my mum and PA's we got me enrolled on some courses at my local college to help with my English and IT as this is something I use every day and need to improve on for better communication. I started going back to 1voice but now as a role model and with the help of a few other role models we helped Tamsin to set up 1voice Lancs. I joined lots of sports and social groups but I still felt there was something missing.

I wanted to get a voluntary job but all I could find was charity shops and donation collecting which is not what I wanted. I wanted to find something that was a bit more challenging and would suit my interests. I got talking to a lady at wheelchair football who worked in a local mainstream high school. She was interested to find out more about AAC as they had a girl who had just got her first device and was reluctant to use it. She asked me if I would go into school to meet her. None of the Staff at the school had met anyone else who used a communication aid so it was also good for them. We really got on and it turned into a regular thing. I went every Friday morning for two years until she left. It was great going and seeing her and seeing the improvement that she was making. These meetings were really informal, we would just chat about what she had been up to or she would show me her school work. Anything to get her using her device more and show her that it does not make her different from her friends, but enables her to join in with

conversations with her friends.

Seeing her every week made me realise that this was the sort of thing that I wanted to do more of, but how?

I already knew Francesca from a 1voice disco that she did at Bridge College and she had asked me to go in once to talk about 1voice, so I emailed her to see if there were any voluntary jobs at Bridge that I could do. She put me in touch with the together trust and I had an interview. They offered me a job as an AAC mentor with Francesca as my Supervisor. I really enjoyed working here. I did it for two years but I left this year as I need to focus on my English level 1 Course. At Bridge I used to help out in the VOCA sessions. When Francesca left Bridge College and went to AT Therapy she managed to get myself and Nadia jobs there too as fully paid AAC mentors. This was my dream job. I like going out and meeting clients and mentoring them. I would like to thank Francesca for all that she has done for me and the amazing opportunities that she has given me. I am still learning about mentoring and everyday is different there is a lot more to it than I first thought.

Myself, and 5 others have recently done a level 2 qualification in mentoring which Communication Matters helped us to get started. This was really helpful for us, turning our passion for helping other AAC users into a fulltime career. It gives us as AAC mentors a sense of purpose. We are using our disability to help and inspire others. More and more AAC users are getting involved with mentoring which is great as the more mentors there are the more people we can help. All of us passed the course and now have a level 2 qualification.

# Using stated preference methods in alternative and augmentative technology

EDWARD J. D. WEBB<sup>1,2</sup>

DAVID MEADS<sup>2</sup>

YVONNE LYNCH<sup>3</sup>

NICOLA RANDALL<sup>4</sup>

SIMON JUDGE<sup>4</sup>

JULIET GOLDBART<sup>3</sup>

STUART MEREDITH<sup>3</sup>

LIZ MOULAM<sup>3</sup>

STEPHANE HESS<sup>5</sup>

JANICE MURRAY<sup>3</sup>

## Abstract

Stated preference methods are a way of revealing how people value objects/things/concepts, or components of objects/things/concepts. They are popular in healthcare and social science, yet have not been used extensively in AAC. We give an introduction to two common methods, best-worst scaling and discrete choice experiments, and discuss our experience of using them in AAC research.

## Introduction

Stated preference methods, can be extremely powerful in gaining insight into people's preferences and decision making, and are particularly useful in valuing objects for which no market exists. They rely on hypothetical statements made by individuals, as opposed to revealed preference methods, which are based on observing real life actions.

A simple way of examining peoples' preferences would be to simply ask them. However, more sophisticated methods have been developed to standardise responses, reduce bias, and maximise the usefulness of the information gathered.

Stated preference is commonly used in a range of other fields [1, 2] to help inform decisions by helping understand how individuals will behave when presented with certain choices. It is used, for example, in product design and marketing, and in in planning transport infrastructure. It is also increasingly used to help inform decisions about healthcare resource allocation and in creating tools that support patients' choices about a specific intervention or drug.

Stated preference studies are survey based and present individuals to a hypothetical decision and asked what choice they would make if faced with a similar situation in reality. Responses are usually restricted by only allowing them to pick from a pre-defined set of options. Statistical models of the decision-making process are then constructed from responses.

A great advantage of stated preference is that standardised surveys, often administered electronically, make it relatively easy to collect large amounts of data. The quantitative nature of the data also has

advantages, as statistical rigour can be brought to bear on any conclusions and mathematical models of decision making can be used to make predictions of future behaviour. While it does not capture much of the detail of each individual's situation, which will inevitably be much more complex than can be reflected in responses to a standardised survey, it is excellent at capturing an overall view of the general or average situation in a population.

An analogy to stated preference as a research method is to consider looking at an overhead view of a city. Techniques such as interviews provide a "zoomed-in" picture, with details of individual streets and houses. Stated preference, on the other hand, provides a "zoomed-out" view, giving an idea of the layout of the whole city. It can provide information about whether treatments are acceptable to patients, or be used to design systems of healthcare delivery, or examine how clinicians make prescribing decisions.

The two most common stated preference methods used in healthcare research are discrete choice experiments (DCEs) and best-worst scaling (BWS). Despite their growing use in healthcare and health economics, these methods have never before been used within AAC or Assistive Technology research. This article gives an overview of these techniques and presents our experience of running a BWS

1 Corresponding author: e.j.d.webb@leeds.ac.uk

2 Academic Unit of Health Economics, Leeds Institute for Health Science, University of Leeds

3 Faculty for Health, Psychology and Social Care, Manchester Metropolitan University

4 Barnsley Assistive Technology Unit, Barnsley Hospital NHS Trust

5 Choice Modelling Centre, University of Leeds

**Table 1: Child related attributes and descriptions used in best-worst scaling study. RIS = relative importance score**

Attribute	Description
Access to professional AAC support	Access to professional support such as teacher, SLT or others with knowledge and skills in AAC.
Attention level	Ability to attend to tasks and sustain attention.
Child's determination and persistence	Motivation and persistence to communicate (or not).
Child's receptive and expressive language abilities	Ability to understand and produce language (through aided or unaided means).
Communication ability with aided AAC	The communication functions and roles a child can carry out using aided AAC system.
Educational stage	The child's current education setting and stage.
Functional visual skills	Ability to use gaze to eye point for communication.
History of aided AAC use	What is the child's experience to date with aided AAC systems.
Insight into own communicative skills	The child's awareness and understanding of their own communicative skills.
Level of fatigue	Whether fatigue impacts on aided AAC.
Level of learning ability	Ability to learn and retain information and problem solve (includes the child's developmental level).
Literacy ability	Ability to read and write (aided or unaided).
Mobility	Ability to move independently or with assistance, with or without powered or partner propelled wheelchairs.
Physical abilities for access	Ability to use direct or indirect access methods to control AAC system.
Predicted future needs and abilities	Based on all the information available what are the predicted or expected future needs and abilities of the child that could impact on AAC.
Presence of additional diagnoses	Whether the child has another diagnosis in addition to the condition associated with the need for AAC. For example hearing, vision, epilepsy, behavioural issues.
Primary diagnosis	The main medical diagnosis the child associated with the need for AAC.
Speech skills and intelligibility	Ability to use speech to communicate.
Support for AAC from communication partners	Includes the attitudes, skills and knowledge of people close to the child that will impact on use and learning of AAC.

**Table 2: System related attributes and descriptions used in best-worst scaling study. RIS = relative importance score**

Attribute	Description
Additional assistive technology functions	Whether the aided AAC system supports other assistive technology functions such as offering computer features.
Appearance	Appearance and feel including the hardware and the interface.
Battery life	How long the battery lasts between charges.
Consistency of layout and navigation	Consistency of layout of symbols or text on pages.
Cost	Cost of purchase including warranty or repair.
Durability and reliability	How robust the aided AAC system is, how frequently or easily it stops working.
Ease of customisation	How intuitive and easy is it to add and change vocabulary and customise other features such as changing the volume.
Ease of mounting on a range of equipment	The compatibility of the aided AAC system with different mounting systems and to be used with different equipment (e.g. power chair).
Graphic representation	Type of symbol or text used.
Number of cells per page	The number of cells or locations for symbols or text on each page in an aided AAC system.
Number of key presses required to generate symbol or text output	Number of selections required to generate symbol or text output.
Portability	Ease of carrying or moving the aided AAC system.
Range of access methods	Range of access methods offered to allow control of the aided AAC system.
Size of output vocabulary	The size of the output vocabulary available within the aided AAC system.
Supplier support	Technical and training support provided by AAC device company.
Type of vocabulary organisation	Format used to organise the vocabulary within the aided AAC system for example.
Vocabulary or language package(s)	Preprogrammed vocabulary set(s).
Voice	The type and quality of voice output provided by the aided AAC system.



and DCE study examining AAC clinicians' decision making when making decisions about symbol AAC systems for children.

These stated preference studies were carried out as part of the I-ASC project.<sup>6</sup> The overall aim of the project is to improve health and wellbeing outcomes of children and young people who have little or no intelligible speech and need AAC devices to communicate. In order to meet this aim, we have taken a number of approaches and have gathered data from a range of people in a range of ways. As well as getting the 'zoomed out' data from the stated preference studies described here, we are also 'zooming in' and gathering a large amount of qualitative interview data. The outcome of the project will be the creation of guidance and AAC assessment tools to support future decision making.

### Best-worst scaling

Best-Worst Scaling (BWS) was developed in marketing to find consumers' most preferred aspects of products. It was designed to uncover what features of products were most preferred, for example whether airline passengers valued punctuality more than price. Healthcare researchers then realised that the same methods could be used to examine what features of drugs were most preferred, for example whether patients valued a shorter recovery time over a more convenient way of taking it. In different contexts (including ours) it is more intuitive to think of people stating which aspects of the decision situation are more or less important to them. For example, GPs might decide whether it is more important to treat a patient as soon as possible or to face a longer wait to refer to a specialist.

There are three main variants of BWS: object case, profile case, and multi-profile case.<sup>7</sup> As our study used object case, we concentrate on this.

Individuals' opinions about the importance of attributes could be elicited by simply presenting them with the full list and asking them to rank them in order of importance. However, unless there are

very few items, such a ranking is cognitively demanding. To overcome this in BWS, participants are presented with a few attributes at once, and instead of ranking all of them, they choose only the most important and least important attribute. Individuals answer a series of questions with a different subset of attributes presented each time. Each participant does not rank every combination of attributes and so various statistical methods exist to select how to present the attributes in order to maximize the information gathered from responses [3].

The starting point of a BWS study is a list of relevant aspects, factors or features of a decision-making situation, termed *attributes*. Examples from a transport study might be travel mode or travel time.

Examples from our study are the *size of output vocabulary* and *type of vocabulary organisation* of AAC systems.

In any stated preference study, selecting appropriate attributes is a crucial step and must be done with care. It is important to make sure they are relevant and meaningful to the study population, as well as being understandable. It is also important not to omit any relevant attribute. Best practice is therefore to make extensive use of qualitative techniques such as interviews and focus groups to identify a manageable number of attributes that are the most vital to the study population [4]. It is also important to test any survey before use, for example by running a pilot.

The screenshot shows a survey interface for 'Survey on Augmentative and Alternative Communication'. It includes logos for Manchester Metropolitan University, Barnsley Hospital NHS Foundation Trust, NIHR National Institute for Health Research, and the University of Leeds. A progress bar indicates '11% complete'. The section is titled 'Child factors' and includes a link to 'view as separate questions instead?'. The instructions state: 'Out of the list below, select what is generally the one most and one least important factor relating to children across the decisions you make. Detailed explanations of each factor are shown below the question.' Below this is a table with two columns: 'Most important' and 'Least important'. The factors listed are: Primary diagnosis, Support for AAC from communication partners, Access to professional AAC support, Presence of additional diagnoses, Physical abilities for access, and Speech skills and intelligibility. Each factor has a radio button in both columns. Below the table, detailed explanations are provided for each factor. At the bottom, there are 'Previous' and 'Next' navigation buttons.

	Most important	Least important
Primary diagnosis	<input type="radio"/>	<input type="radio"/>
Support for AAC from communication partners	<input type="radio"/>	<input type="radio"/>
Access to professional AAC support	<input type="radio"/>	<input type="radio"/>
Presence of additional diagnoses	<input type="radio"/>	<input type="radio"/>
Physical abilities for access	<input type="radio"/>	<input type="radio"/>
Speech skills and intelligibility	<input type="radio"/>	<input type="radio"/>

**Primary diagnosis** - The main medical diagnosis the child associated with the need for AAC.

**Support for AAC from communication partners** - Includes the attitudes, skills and knowledge of people close to the child that will impact on use and learning of AAC.

**Access to professional AAC support** - Access to professional support such as teacher, SLT or others with knowledge and skills in AAC.

**Presence of additional diagnoses** - Whether the child has another diagnosis in addition to the condition associated with the need for AAC. For example hearing, vision, epilepsy, behavioural issues.

**Physical abilities for access** - Ability to use direct or indirect access methods to control AAC system.

**Speech skills and intelligibility** - Ability to use speech to communicate.

Figure 1: Example decision screen from best-worst scaling study

<sup>6</sup> National Institute for Health Research, UK Health Services & Delivery Research Project: 14/70/153 - Identifying appropriate symbol communication aids for children who are non-speaking: enhancing clinical decision making.

<sup>7</sup> Also known respectively as case 1, case 2 and case 3.

Once the data are collected, they must be compiled and presented in a useful way. Various modelling techniques exist to do this with varying degrees of complexity. However all of them are based on the principle that the more times an attribute is selected as most important out of a small subset, the more important it is overall, and conversely, the more times an attribute is chosen as the least important out of a subset, the less important it is overall.

For more information on BWS, see [5].

## A BWS study in AAC

Our BWS study sought to find which features of symbol AAC systems and which characteristics of children who would benefit from AAC systems were considered most important when making decisions about symbol AAC systems. We began by conducting two comprehensive literature reviews, running focus groups with 30 AAC clinical specialist stakeholders and having discussions with 20 AAC experts, including clinicians, people who use AAC and relatives and support personnel of people who use AAC. The findings were condensed into attributes by discussion between the authors, resulting in lists of 19 child related and 18 system related attributes (see Table 1 and Table 2). As child and system attributes are conceptually different from each other, we decided to keep them separate and conduct in effect two BWS studies, one each for children and AAC systems, combined in a single survey. We tested the survey on five AAC clinicians using a "speak aloud" technique in which individuals talk about their thought processes while responding. Based on this feedback we revised the survey.

We administered the survey using an online platform. Participants were recruited via email, including the Communication Matters mailing list, invitations to the administrators of service providers, and invitations to authors' professional contacts. Participants were shown 6 attributes at a time and answered 10 questions each on children and devices. An example question is shown in Figure 1.

As this paper concentrates on methodology and our experience, results will be discussed elsewhere.

By conducting a BWS in AAC we have been able to quantify the relative importance to clinicians of a large number of aspects of the decision-making environment

Child B has delayed expressive and receptive language and able to use aided AAC for a few communicative functions. Child B is only motivated to communicate through methods other than symbol communication systems. Child B is predicted to maintain current skills and abilities (plateau).

	System 1	System 2	System 3
<b>Graphic Representation</b> Primary type of graphic symbol used	Ideographic symbols	Photo symbols	Pictographic symbols
<b>Consistency of layout</b> Consistency of layout of symbols on pages, including when navigating through pages to select desired output.	Highly consistent layout	Somewhat consistent layout	Inconsistent layout
<b>Vocabulary sets</b> Pre-determined vocabulary or language package provided	Commercially provided sets without language progression	Commercially provided sets with language progression	Commercially provided sets without language progression
<b>Size of vocabulary</b> The size of the output vocabulary available within the aided AAC system.	More than 1000 vocabulary items	50-1000 vocabulary items	Up to 50 vocabulary items
<b>Type of vocabulary organisation</b> Primary format used to organise the vocabulary within the aided AAC system	Pragmatic organisation	Semantic syntactic organisation	Visual scene display

For this child I would choose: ☐ ☐ ☐

On a scale from 1 to 7, how good a match is your chosen device for this child? (1=very unsuitable, 7=very suitable)

1 = very unsuitable      2      3      4      5      6      7 = very suitable

☐ ☐ ☐ ☐ ☐ ☐ ☐

← →

35%

Figure 2: Example question from discrete choice experiment

regarding symbol AAC systems. It is worth highlighting that we measure *relative*, not *absolute* importance. We believe, based on our prior work developing attributes, that all are important, and we measure only which are considered more important than others.

A major advantage of using BWS is that it can accommodate a large number of attributes. Given the lack of prior stated preference research in AAC, we felt such a study was a vital first step. However, we were also interested in the trade-offs clinicians make when considering devices for children and the interactions between child and system related attributes. Thus we subsequently ran a DCE, which allowed us to address these questions.

## Discrete choice experiments

In a Discrete Choice Experiment (DCE), participants are shown two or more hypothetical items and must choose one. Each item is characterised by a number of attributes (typically five or six) which can take a number of different *levels*. For example, a transport researcher might give participants a choice between different ways

of making a journey, with one attribute being travel time, which could take levels 10 minutes, 20 minutes and 30 minutes. A healthcare researcher might give people a choice between drug treatments, with an attribute being how the drug is administered, which could take levels: pill, injection and intravenous infusion. Items are hypothetical, and the exact combination of levels need not be found in reality. However, they should take realistic values and avoid implausible or impossible combinations so that choices are meaningful to participants.

Individuals are presented with a series of hypothetical scenarios (e.g. treatment A, treatment B, treatment C) each with a different combination of attribute levels. The participants are forced to make a series of choices as to which option they would choose. As with BWS, a variety of methods exist to design the survey to maximize the information gathered [6].

A range of analysis methods exist for DCEs, and generally they will calculate the value individuals assign to the levels of each attribute. It is also possible to calculate the trade-offs participants make

**Table 3: Attributes and levels used in discrete choice experiment**

<b>Child attributes</b>	<b>Levels</b>		
<b>Receptive and Expressive Language</b>	Delayed expressive and receptive language	A receptive-expressive language gap	
<b>Communication ability with aided AAC</b>	No previous AAC experience	Is able to carry out a small number of communication functions using AAC	Is able to use aided AAC for a range of communication functions
<b>Predicted future needs and abilities</b>	Predicted to regress in skills and abilities	Predicted to maintain current skills and abilities	Predicted to make progress in skills and abilities
<b>Child's determination and persistence</b>	Does not appear motivated to communicate through any methods and means	Is only motivated to communicate through methods other than symbol communication systems	Is motivated to communicate through symbol communication systems
<b>System attributes</b>	<b>Levels</b>		
<b>Vocabulary sets</b> (Pre-determined vocabulary or language package provided)	No commercially provided sets	Commercially provided sets without language progression	Commercially provided sets with language progression
<b>Size of vocabulary</b> (The size of the output vocabulary available within the aided AAC system.)	Up to 50 vocabulary items	50-1000 vocabulary items	More than 1000 vocabulary items
<b>Type of vocabulary organisation</b> (Primary format used to organise the vocabulary within the aided AAC system.)	Pragmatic organisation	Semantic organisation	Semantic syntactic organisation
<b>Graphic Representation</b> (Primary type of graphic symbol used.)	Photos	Pictographic symbol set	Ideographic symbol system (with rules or encoding)
<b>Consistency of layout</b> (Consistency of layout of symbols on pages, including when navigating through pages to select desired output.)	Inconsistent layout	Somewhat consistent layout	Highly consistent layout

between different attributes, for example how much they are willing to pay for a journey which is 10 minutes quicker.

Development of attributes and levels is just as crucial a step as with BWS. It is vital to select them appropriately so that the profiles shown to participants seem realistic and plausible, and capture the most relevant aspects of real world decision making. Thus it is also best practice with DCEs that extensive qualitative work is done in attribute development and surveys are piloted prior to launch [4].

DCEs have the advantage over BWS that they give more information about trade-offs between attributes, and also that the response mode in the survey matches real world decisions more closely. However, the number of attributes that can be included is more limited. More than a handful of attributes makes choices too cognitively demanding and encourages "attribute non-attendance" in which

participants ignore some attributes entirely.

For more information on DCEs, see [7].

### **A DCE study in AAC**

Our DCE showed participants a vignette of a (hypothetical) child, then asked them to choose which of three (hypothetical) symbol AAC systems they would choose for that child. Vignettes described children in terms of several attributes. Participants answered four questions for a given vignette before moving to a new vignette with different attribute levels which they answered further questions about. There were four questions for each of three vignettes, making 12 questions in total.

We began by constructing a list of attributes and levels for children and AAC systems by drawing on our previous qualitative research, as well as the results of the BWS. We wanted to ensure that

attributes included in the DCE were considered important by clinicians in the BWS. In planning these studies, we decided a priori to not commit to simply including whichever attributes came top in the BWS survey, as we wanted the freedom to include other attributes key to the research question. Thus, for example, we decided to include graphic representation even though it ranked 11<sup>th</sup> out of 18 in importance. Four child related and five system related attributes were chosen after discussion between the authors, and a list, along with the accompanying levels, is given in Table 3. A final step was to rule out unrealistic combinations such as a system with visual scene based vocabulary organisation and over 1000 vocabulary items.

The DCE was administered online and an example question is shown in Figure 2. Recruitment was again done by email. Results are not yet available and will be published elsewhere.

## Conclusion

Stated preference methods like BWS and DCE are powerful research tools, yet they are not without drawbacks. For example, individuals' decisions in the real world can be systematically different to their responses in a DCE and attributes present a highly stylised description of often complex objects.

We believe that the results of our BWS and DCE studies in examining the preferences of AAC clinicians in considering choices around symbol AAC systems will add useful findings to the AAC field. Importantly, the findings will also provide a strand of data on which to build resources that can support these challenging decisions. The development of these resources are the next steps of the I-ASC project.

There is much potential for the future employment of stated preference techniques in AAC. For example, it would be possible to study users' preferences for AAC systems, or families' preferences for support structures. It is hoped that this brief introduction will raise interest in stated preference methods in AAC.

To find out more about the I-ASC project, the project findings and the developed resources visit: [www.i-asc.org.uk](http://www.i-asc.org.uk).

## Acknowledgements

This project was funded by the NIHR Health Services and Delivery Program (project 14/70/153). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

We would like to thank Communication Matters for assistance in recruitment and participants who responded to the survey.

## References

- 1 M. D. Clark, D. Determann, S. Petrou, D. Moro, and E. W. de Bekker-Grob, "Discrete Choice Experiments in Health Economics: A Review of the Literature," *Pharmacoeconomics*, vol. 32, pp. 883-902, 2014.
- 2 K. L. Cheung, B. F. Wijnen, I. L. Hollin, E. M. Janssen, J. F. Bridges, S. M. Evers, *et al.*, "Using Best-Worst Scaling to Investigate Preferences in Health Care," *Pharmacoeconomics*, vol. 34, pp. 1195-1209, Dec 2016.
- 3 B. Orme, "MaxDiff system technical paper," *Sawtooth Software Research Paper Series*, 2005.
- 4 J. Coast, H. Al-Janabi, E. J. Sutton, S. A. Horrocks, A. J. Vosper, D. R. Swancutt, *et al.*, "Using qualitative methods for attribute development for discrete choice experiments: issues and recommendations," *Health economics*, vol. 21, pp. 730-741, 2012.
- 5 J. J. Louviere, T. N. Flynn, and A. A. Marley, *Best-worst scaling: Theory, methods and applications*: Cambridge University Press, 2015.
- 6 F. Reed Johnson, E. Lancsar, D. Marshall, V. Kilambi, A. Muhlbacher, D. A. Regier, *et al.*, "Constructing experimental designs for discrete-choice experiments: report of the ISPOR Conjoint Analysis Experimental Design Good Research Practices Task Force," *Value Health*, vol. 16, pp. 3-13, Jan-Feb 2013.
- 7 M. Ryan, K. Gerard, and M. Amaya-Amaya, *Using discrete choice experiments to value health and health care* vol. 11: Springer Science & Business Media, 2007.



## CM Merchandise

Wristbands, Car Stickers & Fridge Magnets - All £1 each

CM Enamel Badges - £2 each

100% of all sales to Communication Matters

*Please contact us on [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk) to place an order.*

Registered charity no. 327500 | Company registered in England & Wales no. 01965474



# Having Pride

## Exploring the personal impact of having a speech impairment

**SIMON STEVENS**

Independent Disability Consultant, Trainer and Activist

Email: [simon@simonstevens.com](mailto:simon@simonstevens.com)

### Abstract

In using the context of my recently published autobiography, *Having Pride*, I explore the impact of having a speech impairment on my life and my work.

Having a speech impairment from birth due to cerebral palsy has, like many AAC users, been my most significant difficulty. This has been in terms of the practicalities of interacting with others, as well as framing my physiological and sociological status in society.

I will explore how I have needed to successfully subvert social norms in order to be integrated, if not included, into many areas of mainstream society. I will explain and discuss how I have altered the common perceptions associated with a 'drooling spastic' to create a proud and confident professional in terms of social branding.

I will also explore the journey from an infant patient of a local mental hospital to a mainstream leader in terms of social media influence, and why we should celebrate the opportunities now available to people with speech impairments of all ages.

I will also explore my relationship with AAC as a part-time user through my life and how technology in general has played a very large and important role in assisting me to overcome practical barriers and achieve a level of opportunity previously unthinkable, and how I have rode the waves of new technology. I will also explore how technology has assisted in my autonomy and question how my autonomy was created in a nature or nurture discussion.

Finally, I will question how my specific impairment has created and retained my internal and external identities, and what lessons SLT professionals can learn of my experiences to assist younger people with speech difficulties to understand and develop their own identities within a world of improved opportunities due to technological and social advances available to them in this century.

### Introduction

During my lifetime, over the last forty years, I have witnessed a gradual and significant change in society's understanding and acceptance of people with impairments, including an improved portrayal in the media. I, however, believe this acceptance has not been universal across all impairment groups. While there is no stigma for someone to use a wheelchair, or have any impairment that does not disrupt the way non-disabled people can interact with them, impairments that make verbal and non-verbal direct communication difficult are still regarded as difficult to fully accept.

Non-verbal communication can be disrupted by jerky and other involuntary movements. This appears strange and unsettling to the non-disabled observer, who may become embarrassed by not being able to understand this unusual body language. Verbal communication can be disrupted by having no speech or a speech impairment, which listeners find awkward and uncomfortable to try to understand as they fear the embarrassment of not understanding.

As someone with cerebral palsy, I experience involuntary movements, and I have a speech impairment. I believe that while my involuntary movements have played a role in how I have formed my identity, my speech impairment, out of all the many difficulties I have, has always played the largest role in my identity and how I have formed relationships with others.

I believe that I have never allowed my speech impairment, or any of my other difficulties, to prevent me living the life I want as a fully autonomous contributing citizen, within the restrictions that are placed upon everyone. The opportunity to have a mainstream education before it was usual to do so, has provided me with the expectations to achieve anything I put my mind to, equal to my peers, despite my difficulties.

The purpose of the paper is to explore how my speech impairment has affected how I have interacted with others personally and professionally, with a sense of pride. I believe that in order to achieve what I had achieved in a mainstream setting, I have needed to subvert social norms to implant myself in places where I do not specially belong such as the committees I attended as a trustee of Skills for Care.

I intend to explore the practical and psychological techniques I have used in my life to overcome my speech impairment and present myself in a professional context. I recognise that while some of my story will be unique to my own circumstances and situation, that other parts of my story are similar to the experiences of other people with speech impairments.

I wish to provide an objective overview of my experiences of managing a speech impairment.

## Background

In order to understand how I have managed the practical and social implications of my speech impairment, it is important to have a brief understanding of my background. More information about my background can be found in my official life story, *Having Pride*, which is available as an ebook on Amazon's website.

I was born in 1974, and my first school was the infant unit of the local mental hospital before it became its own school 'for the mentally handicapped'. After attending the local mainstream primary village school, and another school with a 'physically handicapped', at age 11, I went to the local all boys mainstream school, which was a very big deal, to gain my GCSEs. After doing my A-Levels at the local sixth form college, I went to Coventry University to study BSc Manufacturing and Business Studies.

After University, I set up my own company, Enable Enterprises, which went bankrupt in 2008, and I have remained self-employed since then. During my time since before leaving university, I have made the most of the countless opportunities to work with many organisations in many different ways, to travel widely across Europe and elsewhere, and to experience a wide range of sporting and leisure activities. The details are not important, but it is worth noting some opportunities were as a result of being a disabled person, while others were very mainstream. These were where I was embarking on activities, business and leisure, that were unaccustomed to my needs as someone with cerebral palsy, or had no previous experience of involving someone with a speech impairment.

I believe that my many achievements were as a result of a positive and vehement level of determination that defied the perceived facts of which was possible or not. In order to challenge what is deemed to be possible, I have had to not only overcome the practical difficulties of my speech, but reframe myself with extra effort to overcome the social difference. This means I have needed to create an explicitly extrovert personality that could shine beyond the negative assumptions associated with having a speech impairment. If I had not been so 'in your face' at specific moments in my life, it is unlikely I would have reassured

people of my commitment and ability to perform a range of activities.

## Technology

Technology has played a very important role in my life and has fundamentally enabled me to take up many opportunities that would not have previously been available to me. I have always been an early adopter of new technology. When I started secondary school in 1985, I was provided with an Epson HX20, which I found out much later was the first ever model of laptop available.

My primary method of verbal communication has always been my own speech as in my head I believe I speak normally, despite knowing that this is not the case. I know that with patience and practise, most people can understand most of what I am saying the first time, and there are only specific times I need to use an alternative method. This is where some kind of technology has been helpful.

While I had a Lightwriter for a few years, my technology over the years has been mostly unofficial communication devices, using the mainstream solutions available at that time. The devices I have used have ranged from the Cambridge Z88, a range of Psion devices, the communicator style of Nokia devices and in the last few years, the infamous iPad. I have used all these devices for all their intended purposes, simply using one of its word processing applications to communicate with someone by showing them on the screen.

I have never been keen on people who I am talking with to know I have a communication device available until I feel I need it, as I have found some people will not try to listen to me and insist I use my communication device, which I believe is for my benefit, not theirs!

In recent years, as my energy levels have reduced due to additional health issues, I have been more ready to use alternative methods to my speech. Nowadays, when I have important meetings with anyone, I ask my personal assistant to translate for me as this is easier and quicker than using any form of communication device. Also, when I am presenting and as you will have noticed, I now prefer to read out my speech via my iPad, so I am able to use my full written vocabulary as opposed to my verbal vocabulary, which I will discuss more later.

The best way to overcome my speech impairment is to simply not use speech

to communicate with people, and technology has allowed me to do that on a practical and social level. The internet and other technology have enabled the practical method of communication in written communication in a wide range of methods with emails, text messages, instant messaging and social media. Technology has also solved the original problem of text based communication being hard to communicate emotional meaning with the invention and explosion of Emojis. It is possible to communicate effectively with people formally and informally in a mainstream environment without the use of speech.

What is very interesting is that this ability has made us a less verbal society. We are more likely to communicate with someone by written communication in a formal or informal setting. This means that in the comfort of my own home, I can present myself to the outside world on an equal basis to anyone else. I now only make phone calls, with the assistance of personal assistants, to organisations like banks to deal with technical issues when other communication methods are unavailable. Twenty years ago, I would have spent a few hours a week talking to friends by phone unaided.

Despite the ability to avoid speech, it does not mean I will deliberately avoid face to face communication, that remains an important part of my working and personal life, and therefore my speech still plays an important role in shaping my identity.

## Speech Identity

I believe because I use my own speech as my main method of verbal communication, the vocabulary I use is restricted to some degree, and this has at times made appear to be blunt, rude and even arrogant. I have needed to use words that I believe people will understand and while I do not use them in a formal setting, swear words tends to be the easiest words for people to understand!

This, therefore, means there has been a practical reason that has shaped my speech identity, which then has an impact on how others perceive me. However, my appearance means that many people who do not know me often assume I have learning difficulties, and this is something I need to overcome. What I say and what is understood are the main method I have available to me to demonstrate my intelligence.

To overcome the assumptions that come with my appearance, I require a personality that shines beyond my difficulties. This means I have to have pride in myself and be able to show this to others in a manner that is confident. There is, however, a balancing act to have between appearing naturally confident and forcing my personality onto others. If my personality is not strong enough, then I am more likely to be ignored and patronised, leaving me to be pushed to the background. If my personality is too strong, then I risk coming across as arrogant and so alienating my audience.

My work has meant I have needed to be a member of many committees and my involvement in meetings has been when my unconscious speech identity and skills have been needed the most. Considering my background, and my perceived social role in society as someone with a significant impairment, which is minimal, being able to hold my own in a meeting where most other members are non-disabled middle-class salary paid professionals, I have done extremely well.

There is likely to be a lot about how my speech identity and social verbal skills compare to people without speech impairments that I do not understand because I have always had to deal with my speech impairment. This means I have no other standard I can make any comparison with, and it would require a great detail of self-reflection, watching back videos of myself speaking, in order to begin to make a detailed analysis of my speech identity.

Overall, my speech impairment has naturally developed, based on a sense of pride, to meet the demands I have placed upon myself to achieve as much, if not more, than my non-disabled peers. This drive to achieve, as opposed to being left behind like my many disabled peers, has come with the risk and acceptance that I can appear arrogant and rude to some people.

## Lessons learnt

I believe from experience and observations that the outcomes speech and language therapist and other professionals in supporting people with their verbal communication are much lower than the expectations I have placed upon myself. It often appears that so long as someone can communicate that they need to go to the toilet, other basic needs then job done. These low expectations, which manifest themselves in symbolic communication methods with access to a small range of vocabulary, can actually create poor social skills that reinforce the assumption that someone may have learning difficulties.

I believe therapists should increase their expectations and outcomes of the children and adults they work with. Being able to communicate practically is only half the story, and if someone as a speech impairment that is at a point where they have reached their maximum potential, further therapeutic input offers no useful benefit.

The other half of the story is building social skills to match their speech difficulties and so shaping their speech identity. This means supporting people to develop a bank of techniques available to them in any situation, recognising in what situations unaided speech may be inappropriate, like telling a taxi driver an address, which may be easier in written form.

The problem here is that people with speech impairments, including myself, have taught themselves the techniques they use by trial and error, outside the influence and awareness of therapists, who play no part in their everyday lives. Therefore, the current generation of people with speech impairments should be the teachers of the next generation of people with speech impairments.

## Summary

There is little point having a voice if you are not going to use it to achieve what you want from life. For people with speech impairments to currently be included in society, they require a personality that is larger than life, built on pride and confidence. However, when people are perceived and regarded to be outsiders of mainstream society, this pride and confidence can be frowned upon as being an arrogant speech identity.

However, if I am not positive about myself, no one else is going to be positive of my behalf. While I acknowledge my many difficulties and my disruptive identity, I have to be overly focused on my strengths and abilities in order to cope on an emotional level, leading to a sense of pride on what others may see as very unfortunate.

The skills and techniques I have learnt to manage my speech impairment and how it affects how I am portrayed is about to really be put to test as I start the process of being a local Tory councillor in Coventry. I could therefore become possibly the first councillor with a speech impairment in the country, an achievement that shows how far we have come.

I believe in its important therapists focus more time on the psychological and social impact of speech impairments, as well as the practical need to communicate. Since their knowledge of the skills and techniques available is likely far less than confident and successful people with speech impairments like myself, they clearly need to consult and work with us to upskill themselves.

I believe the whole psychology and sociology of having speech impairments is extremely interesting, and revealing in the many aspects of personhood, and warrants further credible research.



**Search the web and raise funds for free:**

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

# A hub's experience of developing augmentative and alternative communication expertise in local speech and language therapy teams

**CATHERINE FOY**

Speech and Language Therapist, Chailey Communication Aid Service

Email: catherine.foy@nhs.net

## Abstract

Chailey Communication Aid Service was commissioned in 2015 by NHS England as a new regional centre to provide specialist assessment, provision and maintenance of communication aids to adults and children with communication needs, who meet the national criteria in Surrey, East and West Sussex, Brighton and Hove. Prior to the establishment of the service, Surrey and Sussex were acknowledged to have little access to AAC services.

It quickly became apparent that local teams in our area had no access to equipment to assess patients. In discussion with local speech and language therapy (SLT) team leads, it was thought that if teams could be provided with an assessment pack of "basic" high tech equipment this would enable teams to better evidence whether their patients meet the NHS criteria for a specialist assessment. It would also enable them to assess patients not meeting our criteria. The type of equipment needed was discussed and the budget that could be afforded determined. The equipment provided was different for the paediatric, adult learning disability and adult community teams.

Teams were given training on equipment usage and a discussion was had on which patients could benefit from what. The local teams were encouraged to become familiar with the different pieces of equipment and share how they used the equipment with their patients.

We sent a questionnaire to our local teams to ask about their thoughts regarding the

assessment equipment, if and how they had used the equipment, whether it had benefitted their service and how they had navigated the aspects of equipment management.

Local teams said that they found the assessment equipment beneficial, but highlighted the time needed to learn how to use each piece of equipment and difficulties making the equipment accessible across sites and yet safe and accounted for.

## Introduction

In 2015 Chailey Communication Aid Service (CCAS) was commissioned as one of 15 NHS England funded hubs in the UK to provide an assessment, provision and maintenance service for the most complex patients requiring Augmentative and Alternative Communication (AAC) living in East and West Sussex, Brighton and Hove and Surrey. Historically, prior to CCAS, patients needing AAC had to rely on local stocks of equipment, individual funding requests to health, social care, education and charities and self-funded mainstream technology such as iPads and apps. Neither Surrey nor Sussex had an adult in-county assessment centre. This was recognised in the parliamentary report, "Condemned to silence - Inquiry into access to communication support for people with Motor Neurone Disease", compiled by the Motor Neurone Disease Association just prior to Chailey coming into existence in 2015, which highlighted the service provided to patients in Surrey and Sussex as poor.

Baxter et al., (2012) conducted a literature review to examine the facilitators and barriers to AAC, identifying limited availability of technical support, service provision and staff training as barriers.

Iacono and Cameron (2009) found a wide variation in the knowledge and skills of paediatric SLTs regarding AAC. Marshall (2004) found parents reported that professionals working with AAC often did not have enough experience or expertise in the area. Insufficient training of education staff was also identified as a major barrier to successful implementation of AAC.

Baladin and Iacono (1998) found that Australian SLTs' knowledge and expertise in AAC was affected by: the person's professional background; their current clinical caseload; their location and employment status; their knowledge and use of aided low and high tech AAC, as well as their opportunities to access information and training in AAC. Matthews (2001) found a similar pattern of factors in the UK. She highlighted that SLTs need to be able to access different pieces of AAC equipment in order for them to develop expertise and skills, which in turn enables them to assess patients with the equipment and then recommend equipment and support the user and their communication partners. More recently, Morgan and Colman (2017) interviewed five AAC users and found that they felt that SLTs lacked technical knowledge and in-depth experience of equipment. However, they thought that the general knowledge SLTs have, of a range of devices, enabled them to make informed choices.



In "Guidance for Commissioning AAC Services and Equipment", (NHS England/ Specialised Commissioning, 2016) it says that local teams should provide assessments of people's needs and a loan bank of AAC equipment and resources. The report states that this would enable the local teams to carry out pre-referral assessments of AAC skills and provide comprehensive referral information to the specialised NHS England hubs. This report also sets out that local teams should have an AAC budget to enable staff to: access professional development opportunities to develop and maintain the required level of expertise; provide and maintain assessment equipment and resources for the local AAC service; provide and maintain AAC equipment and resources for those children and adults who do not meet the eligibility criteria for referral to specialised AAC services; and allow staff to have access to short-term loans of higher-cost equipment for assessment. Additionally, local AAC funding is needed to enable staff to work with and support the complex patients who are provided with equipment through NHS England. However, access to a local AAC budget within our area is variable, with some teams having access to resources and others not.

## Methods

The need for local assessment equipment was initially highlighted at a pan Sussex AAC meeting encompassing SLT team leads working with children, adults and adults with learning disabilities, to which therapists from CCAS were invited to attend. It was identified that many teams had no or little AAC equipment. Without such equipment, when assessing patients who did not meet the NHS England service specification (so do not qualify for an assessment with CCAS) it was difficult to evidence why such equipment was thought to be successful for an individual. Initially it was identified that, due to lack of experience and knowledge about AAC, therapists were requesting eye gaze technology as they were not aware of other access methods. Therapists were also not evidencing why a patient was eligible for our service or fully completing the referral form with all the information required. CCAS experienced a number of unsuitable referrals, of which the referring therapist was aware, but rationalised that as they had no access to AAC equipment and funding to source equipment, an assessment by CCAS was the only option they had.

In August and September 2016, CCAS provided assessment kits to local community teams in East and West Sussex, Brighton and Hove and Surrey who were working with children, adults and adults with learning disabilities. Teams working with the three patient groups received slightly different sets of equipment, spanning from low to high tech.

Careful thought was given as to what equipment was provided. For example, the adult teams were not provided with switches because the point at which a patient needs switches generally means that they are eligible for a referral to CCAS for a complex assessment. The adult learning disability and paediatric teams were provided with switches as they work with clients who are using switches to access communication software at a lower level, meaning they are not yet eligible for a referral to a specialist hub (see table 1).

In addition, teams were provided with a training handover session on how to use each piece of equipment. Teams were encouraged to think of ways they could use the equipment with specific patients on their caseload, and to become familiar with how it could be used.

In March 2017 we asked for feedback from the local teams to whom we provided equipment using a questionnaire. We asked questions about what equipment teams had access to before the assessment kits were provided, whether they had used the equipment provided, and if so, which pieces and with whom, as well as difficulties they experienced with the equipment and what else would have been useful.

## Results

We received 29 questionnaires (15 working with adults, 5 working with adults with learning disability, 9 working with children), of whom 23 were SLTs (14 working with adults, 4 working with adults with learning disability, 5 working with children) who had used the equipment provided in the assessment kits.

### Therapists seeing patients with AAC needs

Where AAC was needed in paediatric teams, some community teams had therapists who had more knowledge and expertise in this area and would see these children for their AAC needs.

Adult therapists tended to see their own patients who needed AAC, rather than having specialists on the team.

### Prior access to AAC

- One therapist describes using her own iPad on which she has loaded apps.
- One team had access to an Etran frame, which they had to share across 3 sites.
- Lots of adult teams had aging Lightwriters which were no longer fit for purpose and which they had to use in the absence of anything else.
- Some schools had access to iPads, Big Macks, switches, Go Talks and Boardmaker. Often only if schools have funded it themselves.

### Most used pieces of equipment

All teams were using a range of the equipment provided not just the tablet and iPad.

**Table 1. Equipment provided**

Adult equipment	Adults with Learning disability	Paediatric equipment
Etran frame	Etran	Etran Frame
MegaBee	Talking Tile	Talking Tile
Voice Amp	Big Mack	Big Mack
Microphone headset for completing Modeltalker	Talking Photo Album	Talking Photo Album
Allora	Story sequencer	Go Talk 9
iPad + software	Range of switches	Range of switches
11" Windows tablet + software	Switch interfaces	Switch interfaces
	iPad + software	iPad + software
	Prox Talker	Prox Talker
	11" Windows tablet + software	11" Windows tablet + software

## Patient groups assessed

- Adult teams – Motor Neurone Disease, Multi System Atrophy, Multiple Sclerosis, Progressive Supranuclear Palsy, Parkinson's disease
- Adult Learning disability teams – Cerebral Palsy and non-verbal Autistic Spectrum Disorders
- Paediatric teams – Cerebral Palsy, complex needs, Autistic Spectrum Disorders, Specific Language Disorders

## Difficulties experienced

- Accessing the devices for therapists who worked over different sites
- Booking out the equipment – often multiple therapists want to borrow same equipment
- Making sure that equipment is returned with all parts, is clean and charged
- Prioritisation of dysphagia and lack of time to see communication patients

## Was equipment beneficial?

Able to make referrals more specific

More skilled using the technology

More impetus to explore low tech AAC where high tech is not suitable

- Able to determine if child is able to move on with AAC and what might work
- Can determine if a child needs a referral to CCAS or to SCAMP (The Specialist Communication Access and Mobility Potential). The SCAMP clinic is a multi-professional service for children and young people who have complex needs, including physical, sensory and/or learning disabilities
- Better able to advise families about AAC, e.g. can advise families who want to buy an iPad whether this is suitable or not

## What else would be beneficial?

- More equipment
- Keyboard and mouse
- More training of local therapists
- Reflection on case studies and equipment to use
- Training in nursing homes around specific patients and their AAC
- Replacements/maintenance if equipment breaks
- Central funding of Clinical Commissioning Group /Environmental Control Service and CCAS equipment

## Discussion

We found that providing assessment equipment to local teams was universally identified by the therapists who replied to our questionnaire as beneficial, even if they had not used the equipment.

Therapists identified that access to up to date equipment has allowed them to become more confident using this equipment to assess and make recommendations to patients and also to make referrals to CCAS that are more specific and relevant. This finding is in line with that reported by Baladin and Iacono (1998) and Matthews (2001).

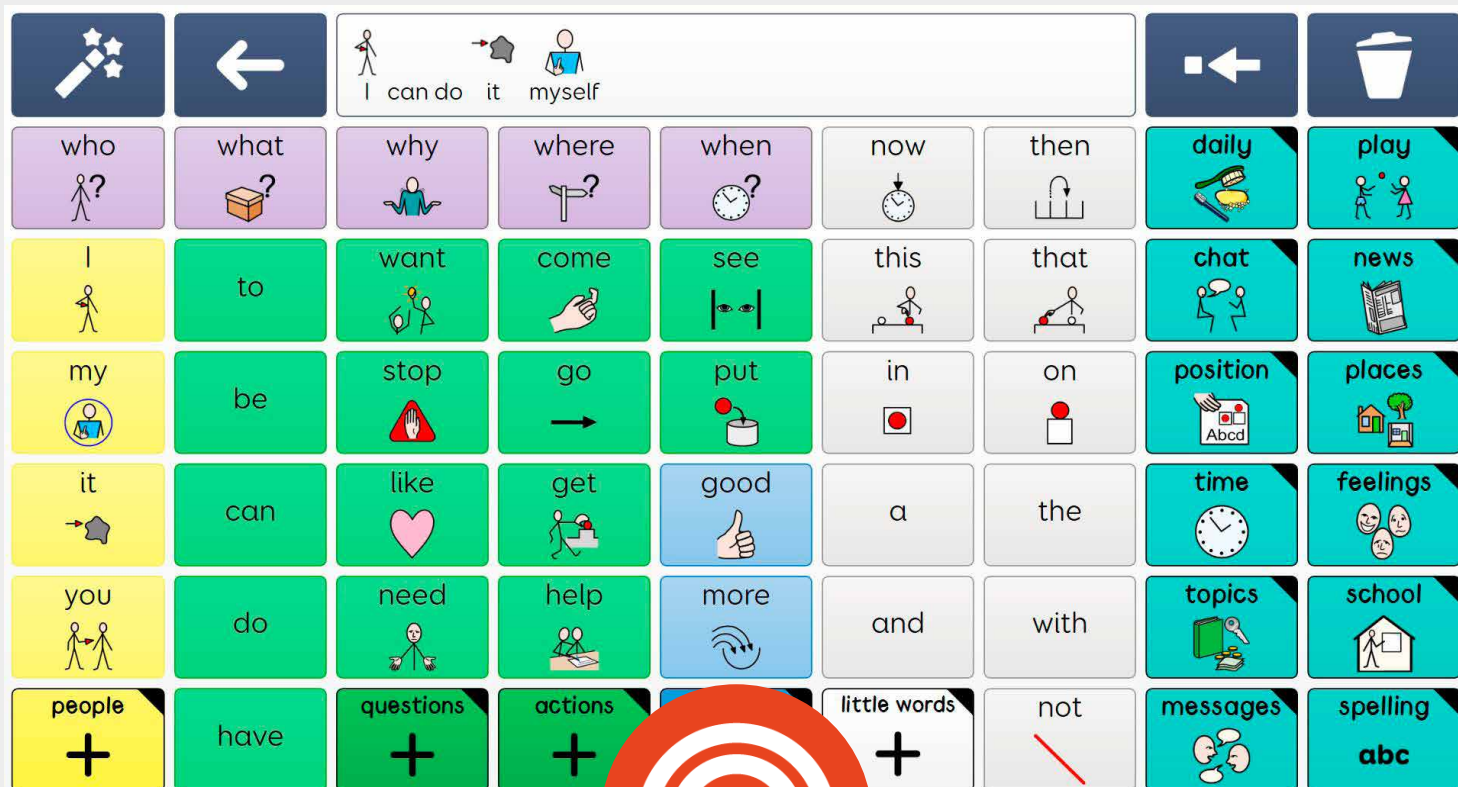
Although teams report that their skills and expertise have increased since receiving the assessment kits, more training on how to use the equipment, how to edit software and also training on who to use which equipment with was identified as a need. As a service we have developed training to meet this need and it is being run out in 2017/2018. A lack of training was identified by Baxter et al., (2012) as being one barrier to the use of AAC.

What happens when equipment breaks, is lost, or becomes obsolete has not been addressed. CCAS undertook funding of the assessment kits as a one off and would be unlikely, in the face of growing numbers of referrals and demands on our funding, to repeat such an exercise. Local teams, we know, have little funding for

equipment, as evidenced by their access to AAC equipment prior to the provision of assessment kits. Some adult teams were able to obtain funding from the MNDA, following a donation from the Wolfson Foundation, to fund AAC equipment for use with people with MND, but this too will all too quickly become obsolete.

## References

- Baladin, S. & Iacono, T. (1998). AAC and Australian speech pathologists: Report on a national survey. *Augmentative and Alternative Communication*, 14, pp. 239-249.
- Baxter, S., Enderby, P., Judge, S. & Evans, P. (2012). Barriers and facilitators to use of high technology augmentative and alternative communication devices: a systematic review and qualitative synthesis, *International Journal of Language and Communication Disorders*, 47 (2), pp. 115-129.
- Morgan, J. & Coltman, A. (2017). Establishing a local AAC service. *RCSLT Bulletin*. Volume 784, pp 18-19. <https://www.rcslt.org/docs/bulletin/2017/august2017.pdf>
- Iacono, T. & Cameron, M. (2009). Australian speech-language pathologists' perceptions and experiences of augmentative and alternative communication in early childhood intervention *Augmentative and Alternative Communication*, 25 (4), pp. 236 - 249.
- Matthews, R. (2001). A survey to identify therapists' high-tech AAC knowledge, application and training. *International Journal of Language and Communication Disorders*, 36 Suppl, 64-69.
- The All Party Parliamentary Group on Motor Neurone Disease (2015). "Condemned to silence inquiry into access to communication support for people with MND". Available from <https://www.mndassociation.org/wp-content/uploads/appg-report-condemned-to-silence-full.pdf>
- NHS England/Specialised Commissioning (2016). "Guidance for commissioning AAC services and equipment". Available from <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/guid-comms-aac.pdf>



## Get started with symbol AAC

Brand new research-based core vocabulary, designed to make it easier to get started with symbol communication.



- ✓ Provides a full and consistent core vocabulary
- ✓ Combines core words with activity-specific language
- ✓ Focuses on everyday routines and play to keep learning motivating and fun!
- ✓ Easy to learn for both the learner and people supporting them
- ✓ Grounded in research and developed by Smartbox SLT Daisy Clay (MSc Cert MRCSLT)

Try Super Core for free today: [thinkSmartbox.com/supercore](https://thinkSmartbox.com/supercore)



# Great AAC software doesn't just happen

Some fun facts about how we made Snap + Core First



The clinical content team who designed Snap + Core First and the ecosystem of resources which surround it are made up of **7 SLTs, 3 teachers and 3 technical content developers**



Over **1000 books and articles** were reviewed



**35 years** of development, from **two world leading brands**, added to the design of the language and ecosystem of Snap + Core First

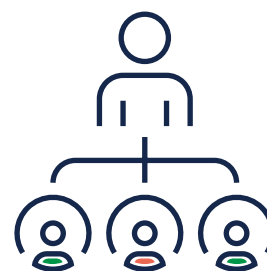


Each member of this team has between **15 and 30 years of direct experience** in the field of AAC



Development of Snap + Core First is **based on scientific evidence, clinical expertise, and user/parent/caregiver perspective**

User testers wore Tobii Glasses to get eye tracking data to gain feedback on the usability of Snap + Core First— **an AAC first!**



There are **7,436** core and fringe words in Core First in addition to **3,836** pre-stored messages and over **250** days of lessons in Pathways for Core First, the free app for Windows and iOS created to support your AAC journey



Eye tracking was used to gain feedback on usability. **38** people were eye tracked during the trials performing **26** unique tasks each to insure simplicity and transparency of the system

Want to hear more about Snap + Core First? Please visit [tobiidynavox.co.uk](http://tobiidynavox.co.uk) or contact us at 0114 4810011 or [sales.uk@tobiidynavox.com](mailto:sales.uk@tobiidynavox.com)

**tobii**dynavox