Communication Matters

NOVEMBER 2025 VOLUME 39 NUMBER 3

THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

Technoableism - Communication Partners - People with Aphasia - Self-Identity - Catharsis - Parents Report - Local Service - Pseudobulbar Affect - Singing Using Eye Gaze - Self-Identity Across Cultures - Angelman Syndrome - Learning App - Empowering Lives - Communication Club

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COMMUNICATION MATTERS JOURNAL
VOLUME 39 NUMBER 3
November 2025

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CM Member Abdi Omar at the Communication Matters Conference in 2024.

Save the date for CM2026 https://www.communicationmatters.org.uk/conference-2026/!

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

Editor
Emily Campbell & Sophie Nuttall
Email: admin@communicationmatters.org.uk

Design & Production
Kaarin Wall & Emily Campbell

Advertising and Overseas Subscriptions
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Email: admin@communicationmatters.org.uk

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Chair's Report

ANDREA SHARPLES

This year, Communication Matters has seen many changes.

Firstly, our long-standing Chair, Helen Whittle, has stepped down. It is a reflection of how much Helen dedicated to Communication Matters that she is being replaced by a 'Chair Team' made up of myself as the new Chair, Saffron Murphy-Mann as Deputy Chair and Tina Voizey as Treasurer. Helen led the Board of Trustees with humour, reflection, listening to our community at all times, and as such her legacy leaves Communication Matters with a clearer strategy and in a stronger position. We would like to offer our thanks to Helen for her time and leadership of the Board of Trustees. Helen will continue to be involved with Communication Matters and will particularly help with bid writing, so we haven't completely lost her expertise!

Left: Board of Trustees

Below: Helen Whittle

Bottom left: AAC Awards

Bottom right: Conference session

Opposite: Exhibition in Refectory

We were delighted to welcome so many of you to this year's conference at the University of Leeds in September, with the theme of 'Identity'. There were many positive changes at conference this year with many attendees feeding back that this was definitely a year to remember.

We had an increased number of delegates with 472 attending (the highest number yet!) of which there were 39 AAC users. CM were pleased to be able to subsidise 93 places this year for AAC users with their PAs and family members to attend. There was a marked increase in international presence with 75 attendees representing 20 countries. Registration was in the atrium just outside the exhibition, and this proximity helped the organisation of the conference run smoothly.

The exhibition moved to the Refectory, which worked well with attendees reporting more space for the 19 exhibitors, including 2 charity exhibitors. A 'Relaxed Exhibition' on the Sunday enabled people to attend a quieter exhibition with fewer staff and attendees. We would like to thank all the exhibitors for their support.

Meanwhile, Sunday sessions for AAC users on lobbying and mental health ran in the nearby lecture theatre. Many thanks to Annalu Waller, Beth Moulam, Verity Elliott and Gregor Gilmour for facilitating these well attended workshops.

Our plenary and keynote speakers, Bronwyn Helmsley and Alyssa Zisk, gave very thought provoking, interesting presentations. I would like to thank them both for their innovative work, thoughts and ideas on identity and AAC. In the main programme, the quality of the papers presented remained high, and it was very difficult to decide which papers to place into the final programme. While we are still collating feedback, the programme seems to have been received very well with attendees noting a wide variety of speakers and topics.

We hosted the AAC Awards 2025 for 406 attendees at the Royal Armouries in Leeds on the Monday evening. This was a resounding success. We would like to congratulate all the award winners and thank all those who sponsored an award or raffle prize for the evening. Special thanks to Tom Griffiths for hosting and to Oli Cunningham for his DJ skills. Details of award winners and sponsors can be found here: www.communicationmatters.org.uk/awards.

Our Research Matters group led the organisation for our first post-conference Research Study Day. Sessions on AI and AAC were run by Annalu Waller, Rohan Slaughter and Tom Griffiths (University of Dundee), Bronwyn Helmsley, Katherine Broomfield, Jamie Preece and Emma Sullivan. Stephen von Tetzchner and the BAC team led sessions on the 'Becoming an Aided Communicator' research project. These were a well-attended and thought-provoking end to the conference.

Communication Matters will now press on with organising the 2026 conference which will take place on the 13th to 16th September 2026 at the University of Leeds. The theme, keynote, and plenary speakers will be announced soon. The call for abstract submissions to speak at the conference will open in the new year. So, get thinking about your presentation for next year's conference; we would love you to present!

Communication Matters' National Lottery funded project on mentoring in England is ongoing, and we are pleased to report pilot projects taking place in Wales and Scotland. This is a significant step forward as previous funding has covered England only. Communication Matters are contributing to the Wales project, while both Communication Matters and the National Lottery Awards for All are contributing to the project in Scotland.

COMMUNITY FUND

If you are interested in hearing more about this project or feel you have skills to offer, please email mentoringproject@communicationmatters.org.uk.

Communication Matters

Save the Date!

13–15 SEPTEMBER 2026

Communication Matters International AAC Conference

Monday 13 – 15 September 2026

www.communicationmatters.org.uk/conference-2026

Rejoice the Revoice! Exploring the Concept of Technoableism in relation to AAC

JONATHAN TOOGOOD, HILARY KAMBARAMI, JAMIE PREECE, EMMA SULLIVAN, WESLEY TROWELL, DAVID BOYES, CHARLIE MORAN AND ANDREA LEE
Email: charlie.moran@nhs.net

Introduction

The authors listed above are members of an AAC Patient Involvement Group hosted by Barnsley Assistive Technology Team promoting the meaningful participation of users in research (Volkmar and Broomfield 2022). As a group, we observed how frequently the person accompanying the AAC user would repeat **exactly** what the AAC user has said, thus enabling intelligibility by the rest of the group. Naming this strategy revoicing, in the following we explore users' experiences of revoicing and reflect on its recognition within AAC, in relation to technoableism.

Terminology

Technoableism:

Shew (2023) coined technoableism when describing the over reliance on technology in enabling people who are disabled. In her discussion, Shew extends the bias at the centre of ableism that privileges non-disabled ways of being to assistive technology, warning that technology cannot eradicate disability.

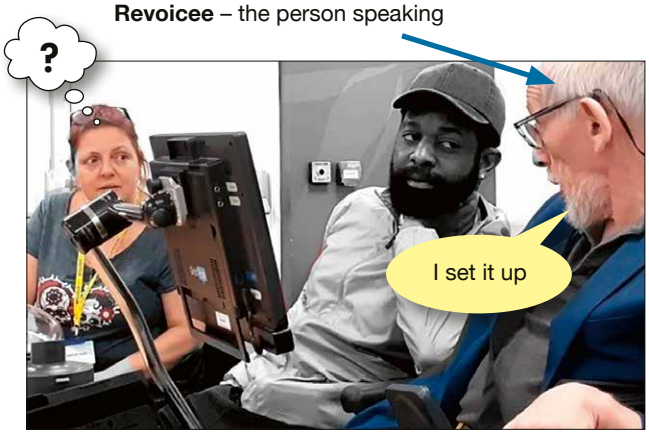
Revoicing:

The term revoicing is defined in the Collins dictionary as "to utter again; echo" (Collins 2014), which reflects how it has been adopted as a term to describe an AAC strategy within the Voice UP group.

Revoicing enables a person to use their voice and gestures at times when unfamiliar listeners may not understand them. With revoicing, there's always a means of clarifying, confirming or rejecting the message that is revoiced; therefore, the person being revoiced is in full control of the output.

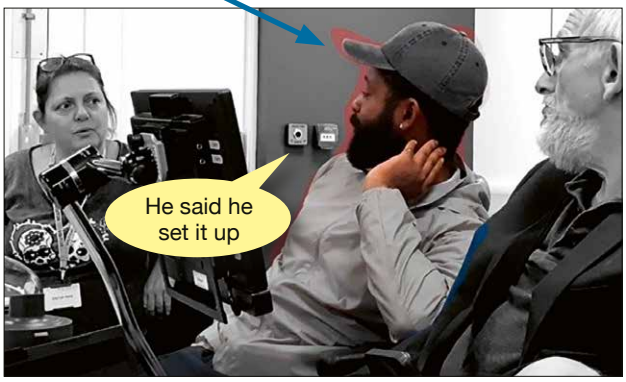
We will use the following terminology:

Revoicee – the person speaking



Communication partner – the person listening to the message but doesn't understand what is said

Revoicer – the person understood the revoicee's speech and repeats the message



Revoice or revoicing – the act of repeating the message

Revoicing is often used with AAC which doesn't have voice output, as in the photos below, when messages require to be spoken by a personal assistant.

Wes is using a Megabee, he spells his message using eye pointing and his personal assistant reads his message aloud for others

DB uses a bliss symbol board, he points to symbols with his toe and his personal assistant speaks his message aloud for others

It is important to note that revoicing is not a facilitated communication technique (ISAAC 2014). We recognise how the dynamic nature of revoicing within social encounters could obscure the authorship of the utterances made by the revoicee, leading to the threat of facilitated communication. For this reason, we recommend that research be conducted to establish good practice, ensuring that revoicing does not stray from the realm of AAC into Facilitated Communication.

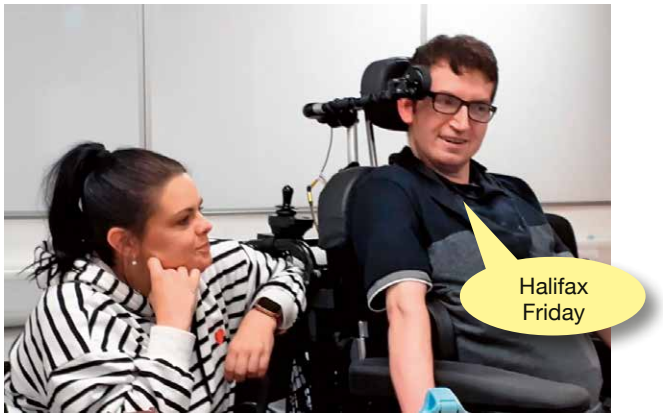
Literature search

Searching the CINHAHL database using the following terms 'revoice', 'revoicing', and 'revoicer' failed to retrieve any articles relating to revoicing in the AAC context.

When is revoicing used?

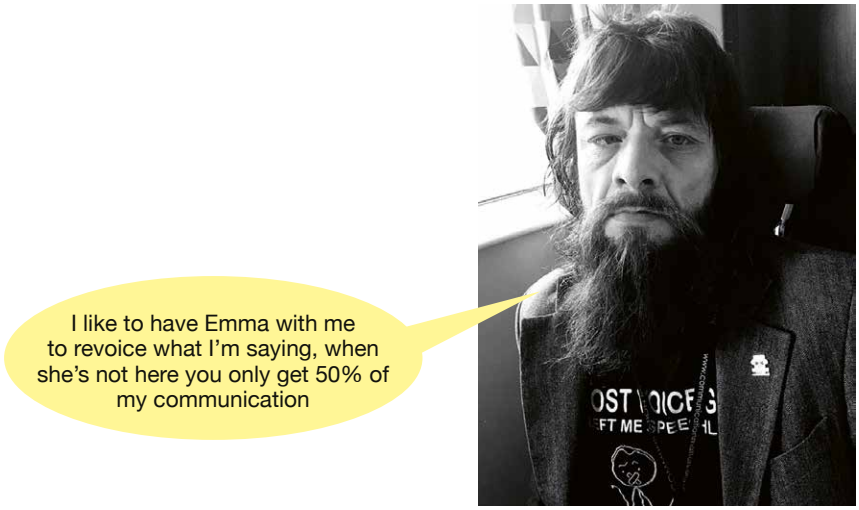
Revoicing can reduce time and cognitive or physical effort for the revoicee. Some examples are:

- When speech is only clear to familiar listeners: A familiar person may have the connection, knowledge and the context which can then reduce the demand on the revoicee to provide all the information



- A long message which has been said but not heard by everyone: Revoicing means that the speaker does not have to repeat what they've said
- Someone has missed the voice output on a device: Revoicer repeats the message rather than the revoicee needing to retype the whole message

- A message that is constructed between 2 people using different modes e.g. speech and gestures which may have taken a lot of time and skill to ascertain the meaning can be revoiced by the revoicer.



Revoicing can be used to approximate the dynamics of a spoken conversation, closer than with other AAC methods, making interactions more responsive and nuanced, helping with conversation timing such as interrupting in a busy meeting, or when responding to questions after training. The revoicer can add timing and intonation expressing the intended humour and sarcasm; being quicker than using other modes of AAC revoicing is better suited to these functions and quick retorts. Revoicing is more spontaneous than having pre-prepared answers or phrases, or can be used when the revoicee might have a message ready but just wants a message tweaking slightly for a specific context.

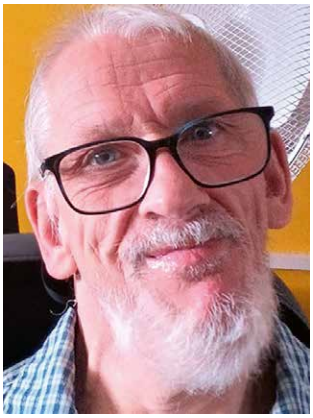
Personal examples of revoicing and technoableism

Jamie shares his views about revoicing in this video clip [https://youtu.be/Vs67joj9J9Q] and how he strongly believes the best AAC is a human. Jamie reflects on the technoableism he has experienced around his choice to use a person to revoice his dysarthric speech instead of using technology to communicate and how internalising this pressure impacted his confidence as a communicator. Jamie calls for people to understand and embrace different modalities and shares how he has moved from a position where he felt he should ask others if it was ok for someone to revoice his speech to a position where he now firmly believes it is his right to decide how he communicates.

Emma's perspective as a revoicer can be seen in this video clip [https://youtu.be/KDNvvY5LLcA]. Emma shares her experience of revoicing an AAC user's speech and the demands, challenges and social communication dilemmas this poses. In her words "Revoicing is demanding and it's ok to be human about this, to feel frustration, to find it hard, to ask for time out. My life is one big game of 20 questions and sometimes I just need to say 'translation mode is off'."

Emma draws on her experience as a revoicer and the power imbalance in the revoicer-revoicee relationship and offers the following advice to others in a revoicing role:

- Acknowledge that it is demanding and tiring and develop a good relationship with the person
- Make sure it is clear to others whether what you are saying is from you or from the person you are revoicing
- Be aware of the power you have as the revoicer but also be honest about your needs.



Jonathan's experience with revoicing and technoableism "Living with partially intelligible speech, I resisted using a VOCA until developments in technology afforded access methods that felt as embodied as physiological speech, making revoicing as an AAC strategy crucial. I now use a combination of revoicing, power chair Joystick, and eye gaze.

For as long as I can remember I have wanted to teach, encouraged through seeing Stephen Hawking being revoiced on the television whilst lecturing, I made it through university. Rather than becoming a lecturer, I went on to pursue disability community activism, in which revoicing played a key role. Co-chairing consultative meetings between the Local Authority and Disabled people alongside someone for whom my speech was intelligible enabled me to chair the meetings through their revoicing. This was never thought of as revoicing, but in retrospect following Voice UP's work on the topic, that was exactly the strategy being employed.

The revoicing by this conversation partner was of such high quality that I was able to deliver

disability equality training professionally. Myself and those supporting me made the technoableist's assumption that technology would enable me as a trainer more effectively than being revoiced. This is not to say that my VOCA was not of benefit to me, both in contexts of delivering training and chairing meetings.

The consequences of the over reliance on technology placed at the centre of technoableism (Shew 2023) became apparent during a training session when the keyguard made contact with the speak pane, causing my device to begin speaking my entire section of the session, interrupting the other trainers. Eventually I was able to stop the speak out of the script leaving me feeling responsible for disturbing the rest of the training. Occurring fifteen years ago when technology was far less advanced than current times, subtle judgements have to be made as to whether technology can effectively replace human support.

Hilary, Jon's PA, shares his perspective: "Building relationships founded upon honesty, empathy, and trust is essential for establishing quality revoicing. These elements build respectful and tactful communication, ensuring that AAC users feel heard, valued, and able to express themselves without fear of judgment. Understanding a person's background and context makes it easier to comprehend and revoice their words accurately.

By learning more about the person, you can better understand their unique communication style and needs, leading to precise revoicing. Words reveal a person's intentions, feelings, and thoughts. Changing their words can compromise their independence and the sincerity of their message, leading to facilitated communication! Revoicing by contrast crucially ensures their exact message is conveyed correctly. Restating their precise words consistently fosters confidence and trust. Knowing that their message will be faithfully received encourages more honest and open conversations."

Conclusion

Despite the lack of published evidence about revoicing in the AAC context, it remains a strategy employed by users. While we join the rest of the AAC community in celebrating the empowerment VOCAs have achieved, Voice UP calls for the recognition that technology can be disabling as well as enabling. In advocating for the removal of disabling barriers, professionals and communication partners need to continue to advocate for users' right to choose which AAC they use, monitoring our unconscious biases towards using technology over strategies such as revoicing. As demonstrated, on occasions human support may prove more effective than technology. We invite readers to reflect on potential bias towards different AAC methods that they may unintentionally be showing in their practice.

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Inspiring New Ways of Thinking About Access to Technology for People with Intellectual Disability

Communication Matters

Study Day - Register Now!

21st November 2025, 9.30-4pm, Irwin Mitchell Offices, Temple, London, EC4Y 0AY

Communication Matters are delighted to partner with a range of leading academic and clinical experts in intellectual disability to host this exciting event.

Following on from our previous Study Day in November 2019 ('Where Next for People with Cognitive Disabilities & Electronic Assistive Technology?), we will offer delegates a range of plenaries and workshops to explore the state of play around existing technology for people with intellectual disability as well as the opportunity to (re)consider how to activate current and future technologies in creative and innovative ways. This is a standalone event and, although drawing on learning from the 2019 event, there is no need for delegates to have attended the previous Study Day to benefit from this one.

Attendance: £100 for non-members, £90 for members and
£75 for AAC users/PAs/family members. Lunch and refreshments included.

Learning objectives, full programme and booking details can be found at
www.communicationmatters.org.uk/what-we-do/study-days/

Register your place now! Registration closes on 6th November

Connecting All Communication Partners

BETH MOULAM AND JOANNA HOLMES
Email: bethmoulam@aol.com / joannaloisholmes@gmail.com

The AAC Connection, a Facebook Group, was set up in September 2023 following the Communication Matters conference. A year earlier we had begun a journey together forged out of our shared passion around the importance of having exceptional communication partners in life. We presented our session and offered participants the opportunity to join us for a continuing discussion about communication partners.

Why Beth and Jo?

Beth is proud to be a Paralympian, a postgrad social policy student, a public speaking nerd, a workshop leader and more. Her advocacy work has led to a few awards including being acknowledged on the Disability Power 100 list of the UK top disabled influencers for two years running and being awarded an honorary doctorate. Beth just happens to use AAC to make this happen.

Jo is a recovering Speech and Language Therapist and in 2014 completed an MSc in Advanced Clinical Practice. It's debatable, and a constant source of reflection, whether these things helped or hindered her in her life as a parent carer for a child with complex disabilities. Since 2020, she has shared her experiences of supporting her daughter's communication through her blog and social media platforms Mummy vs AAC for which she won 'The Anthony Hewson Make A Difference Award' at the AAC Awards in 2023.

How The AAC Connection was born

When we were planning our 2023 presentation, we were exploring the power imbalance between communication partners and how in the main AAC users were often seen to have low power compared to speaking partners. This led to an agreement that the ultimate aim of communication is an equal balance between AAC users and everyone else, as we are all communication partners in our own right. We felt this merited more discussion and the opportunity for AAC users to be seen as equal communication partners in any and every dialogue. Launching The AAC Connection Facebook group, a safe space for anyone in the AAC community to discuss anything about communication on a wide range of topics from training to lived experience to sharing experiences, seemed like a great next step.

We were keen that the group provided something different from other groups. We wanted it to represent the balanced conversation and interaction we're passionate about fostering in day-to-day life.

Finding out what members wanted from the group

Early on we did a survey to find out what people wanted from the AAC connection. Top were strategies to help specific AAC users, general strategies to talk with people who use AAC and being part of an AAC community. Respondents were able to add questions, and someone added one that they joined because they couldn't say no to Beth, and others agreed. This is interesting because we can see in the membership clusters around areas where people have existing networks. Both Beth and Jo are from the Leeds/ York area which has a high proportion of members. There is another cluster of members in Singapore where there is an active community of AAC professionals. Clearly individuals spread the word and influence others to join groups.

One contributor was Gavin, an AAC user, who said:

> *'The concept of the group instantly appealed to me because it brings together such a diverse range of communication partners to create a safe space for discussing all things AAC.'*

What people told us about The AAC Connection

We asked people in the group some questions about the group. Some people responded on email. Three members, Oliver, Anne and Sarah, kindly made videos for us of their feedback which were shared during the session.

We asked the following questions:

- What made you join The AAC Connection?
- Are you in any other AAC groups and what are the differences?
- Have you posted anything in the group?
- What have been the benefits of the group for you?
- Have you learned anything?

What made you join The AAC Connection?

When we asked AAC users why the group, there were 8 themes in the feedback. Most people joined because they were asked or recommended to the group, but other themes emerged too:

- Invitation or recommendation
- To connect with others
- Safe space to discuss AAC
- Give/receive advice and information
- The communication partner dimension
- To get AAC user perspectives
- To support family members using AAC
- To learn about AAC

The things they said they liked were that the group does what it says on the tin. We are all about connections with communication partners. That means they liked that it was a safe space to discuss ideas and thoughts, and they were comfortable to both give and receive information and advice.

Are you in any other AAC groups and what are the differences?

The responses fell into two groups as to whether members were in other AAC forums or groups. For some it was the first time they had interacted with other AAC users, for others they liked the breadth of membership. But overall, they felt they were better connected and receiving quality information.

Have you posted anything in the group?

Most of the detail about this came from the videos and interviews.

One person said they had posted about a range of things related to being an AAC user and sharing their own experience. They stated the responses had been useful and helpful.

Another interviewee, a professional working with families, talked about a post she had made asking for AAC users' perspectives and the useful discussion this created, and it made her self-reflect and gave her a 'wake up call'.

A family member had not asked questions but felt it would be a safe place to ask if she wanted to.

What have been the benefits of the group for you?

When we asked what benefits the group had been to them as individuals there were 6 themes:

- Increased knowledge around AAC
- Safe to ask questions
- Sharing information and ideas
- Connectedness with peers
- Prompted professional reflection
- Learning specific skills to communicate with AAC users

Specific quotes included:

> *'And then you actually, I think you actually grow because I think, um, as you said, the field of AAC is very much more nuanced and, and that diverse, fairly diverse, getting really diverse conversations. Um, I think it's very, it's very useful. Yeah.'* ***AAC Professional.***
>
> *'Um, experience also changes when we spend time together, uh, with her and her mum, it's really good. So, I haven't got to sit and ask all these questions so I can get myself back up to speed with what might be going on. And I can just watch and be with her and let her talk to us in the way she wants to.'* ***Family member.***
>
> *'As an AAC user, I think the biggest benefit for me is included in the title of the group and that is connection. I am loving seeing people from all over the world share their experiences in the group.'* ***AAC user.***

The things they said they liked were that the group does what it says on the tin. We are all about connections with communication partners. That means they liked that it was a safe space to discuss ideas and thoughts, and they were comfortable to both give and receive information and advice.

Have you learned anything?

In conversation, there was an overlap between benefits and learning but the following themes did emerge:

- AAC Terminology
- Gained more knowledge around AAC
- The importance of communication partners
- To reflect on my communication and what I would like to improve

Discussion topics

Topics that have gained momentum include discussion around family interactions, communication partner skills training, practical use of AAC from design issues, mounting solutions and personalizing vocab and layout, to lack of media representation and support for adult AAC users.

So, have we achieved this?

We have 3,000 members and had some good discussions, and we think with a richness not seen in other groups, often with AAC users and professionals and families all chipping in their viewpoints. There have been ongoing discussions on communication rights as Jo feeds in different points from communication bills of rights. We've shared a lot of information and get questions from people outside the UK on what we are doing here and can they join in online.

Managing The AAC Connection

Any group has its highlights and lowlights. Highlights have to have been some discussions around what empowerment means, which was right in keeping with the theme of the CM conference in 2024 where we presented this work, and being shortlisted for an award which came as quite a surprise as everyone else listed was from the States. Challenges have been the path we have trod around use of language, ABA, and facilitated communication. With diplomacy and tact, we seem to have kept most people on board and contributing. We have also tried chats for the group for discussing a book (Home Signs by Joshua O'Reno) and a controversial film (Tell Then You Love Me) that members wanted to post about. We made sure first that as admins we read or watched so we could monitor and contribute, moderate, and eventually close the chats for further comments, but we believe we created healthy debate.

We try to dissuade discussion about devices and sometimes decline posts that are too specific. In the early days as moderators, we were speaking every day about posts and if they met our aims for the group. In the end, we decided rather than letting everyone post everything we needed to moderate each one as it came in. We wanted it to be a supportive and friendly environment, and specifically after an initial rush of people wanting to recruit research participants, we changed the rules so that the AAC Connection did not become a recruitment vehicle. The main reason for this was that we felt we could not control what was good research, nor if there were appropriate ethics in place to protect the membership.

We have also been joined by two additional group moderators, Jenny Herd and Sheridan Forster, whose time and efforts have been invaluable in keeping the group safe and relevant.

Where are members from?

This was interesting because the Facebook analytics allowed us to see where members lived. There were clear clusters of membership in towns, cities, and countries. Clearly individuals spread the word and influence others to join groups. Most members came first from English speaking countries including the USA, UK, Australia, Canade and Ireland with the remainder spread across 25 nations.

Where next?

When we reflect on the journey so far, we've had some great discussions and live sessions with different speakers. We've tackled more topics than we envisaged and have loved the varied interactions. We have more planned for the future to keep the group going.

We would really love you to help us grow more. It would be great if you could encourage others in your networks to join the group either using the QR Code here or by searching Facebook for The AAC Connection and answering the 3 questions on the sign-up page.

Speech and Language Therapist's (SLTs) Perspectives of Their Ability to Support People with Aphasia (PWA) with Using Augmentative and Alternative Communication (AAC): A Service Evaluation

RACHEL CLARE
Highly Specialist Speech and Language Therapist, Electronic Assistive Technology Service (EATS), Lincoln UK
Email: rachel.clare4@nhs.net

Introduction

Aphasia

Aphasia is an acquired language disorder which occurs after damage to the language centres of the brain. This damage can occur due to a stroke, brain injury, brain tumour or in Primary Progressive Aphasia (PPA). Aphasia can affect any or all four of the different areas of language: auditory comprehension, verbal expression, reading comprehension and written expression. It can affect these different areas to different severities.

People with aphasia (PWA) also often have cognitive difficulties, such as impaired working memory and executive function (Purdy & Dietz, 2010; Nicholas & Connor, 2017; Nicholas, Sinotte & Helm-Estabrooks, 2011).

Augmentative and Alternative Communication (AAC)

Nicholas and Connor (2017) report that *'Anecdotal clinical experience reports from speech language pathologists that many people with severe aphasia who need an AAC system find them difficult to use'.*

Grid systems represent vocabulary by graphic symbols and/or written words displayed in rows and columns and organised by semantic categories. Individuals combine isolated symbols to formulate messages. PWA have been found to have difficulties using grid systems and this has been attributed to their language and cognitive difficulties (Petroi, Koul & Corwin, 2014; Purdy & Dietz, 2010; Taylor, Wallace & Wallace, 2019).

Visual scene displays (VSD) represent vocabulary with personally relevant, high-context photographs. These create a conversational support that is shared between the PWA and their communication partner (Dietz, McKelvey & Beukelman, 2006). VSDs are navigated by a visual navigation bar or ring which is visible on each page. Wallace and Hux (2014) found that two PWA were more efficient and accurate when learning to use a navigation ring versus a traditional home page interface.

In a case study design of two participants with non-fluent chronic aphasia, their ability to communicate about a TV show was compared with them using a grid system and a VSD (Brock, Koul, Corwin, & Schlosser, 2017). It was found that the participants' conversational performance was superior in the VSDs compared with the grid display, with a greater number of conversational turns, longer and more complex utterances, fewer instances of frustration and navigational errors and increased question response accuracy. Whilst a study including only two PWA is limited, the findings may indicate that VSDs could be a more useful form of AAC for PWA, compared with grid systems.

Service Evaluation

A service evaluation was completed to explore Speech and Language Therapists (SLTs) experience of using AAC with PWA. The aims of the service evaluation included exploring:

1. SLTs confidence in assessing and implementing AAC for PWA.
2. Facilitators and barriers to using AAC with PWA.
3. Whether the SLTs are familiar with VSDs.
4. What paper-based and power-based AAC SLTs currently use with PWA.

5. What training the SLTs would like to receive and in what format.
6. Whether the SLTs engage with research regarding AAC and aphasia.

Method

Survey

A survey was created in Microsoft Forms. It was shared with SLTs from the six counties which the Electronic Assistive Technology Service (EATS) cover. The survey was shared via email and contained 16 questions. Respondents did not have to answer every question.

Respondents

33 SLTs completed the survey between 23rd January 2024 and 22nd February 2024. 20 SLTs were from Leicestershire, 5 from Derbyshire, 5 from Lincolnshire and 3 from Nottinghamshire.

All SLTs worked with PWA. 45% of the SLTs work in multiple settings, with most (61%) of the respondents working in general community. See Figure 1 for a breakdown of the different settings the SLT worked in.

The number of years worked with people with aphasia ranged from 4 months to 35 years (see Figure 2). Most respondents (55%) had worked more than 10 years.

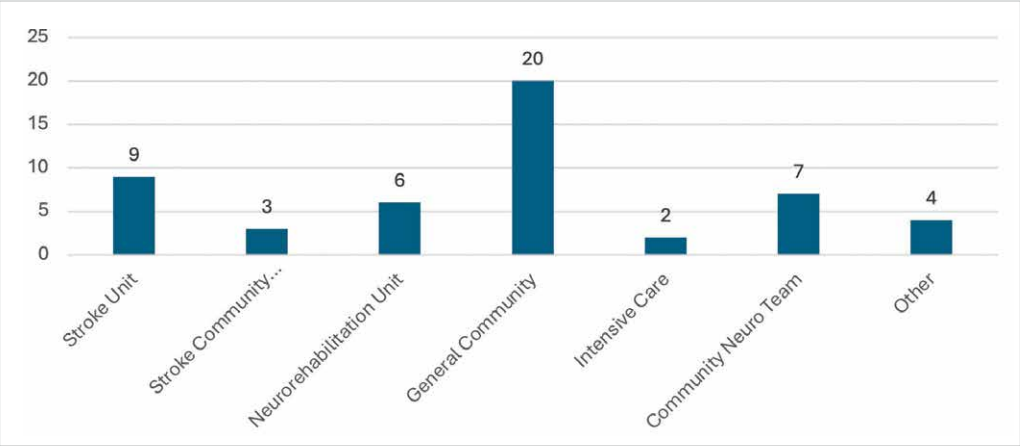

Figure 1. The different settings the SLTs who completed the survey work in.
[NB. The category 'Stroke Community' includes Early Supported Discharge (ESD).]

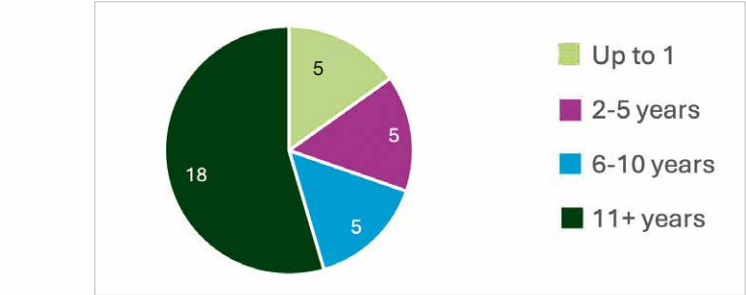

Figure 2. The number of years worked with PWA by SLTs who completed the survey.

Findings

Confidence in assessing and supporting practice of AAC with PWA

One respondent reported they felt 'Extremely Confident' in assessing PWA for AAC and supporting them to practise using AAC (see Figures 3 and 4). No one reported they were 'Extremely not confident' for either assessing PWA for AAC or supporting them to practise using AAC.

For assessing PWA for AAC, 39% reported they felt 'Somewhat confident', whilst 27% responded 'Neutral' and 30% responded they were 'Somewhat not confident'. Thus, 57% reported being 'neutral' or 'somewhat not confident'.

For supporting PWA to practise using AAC, 42% reported they were 'Somewhat confident'. 18% reported they were 'Neutral' and 36% responded they were 'Somewhat not confident'. Thus, 54% reported being 'Neutral' or 'Somewhat not confident'.

What is currently used?

88% of respondents reported using paper-based communication books or picture charts. 36% reported using alphabet charts. Several respondents reported difficulties using AAC with PWA.

Visual Scene Displays

Most respondents reported 'no' when asked if they were familiar with VSDs (see Figure 5). 2 respondents (6%) reported they heard of VSDs and were confident using them.

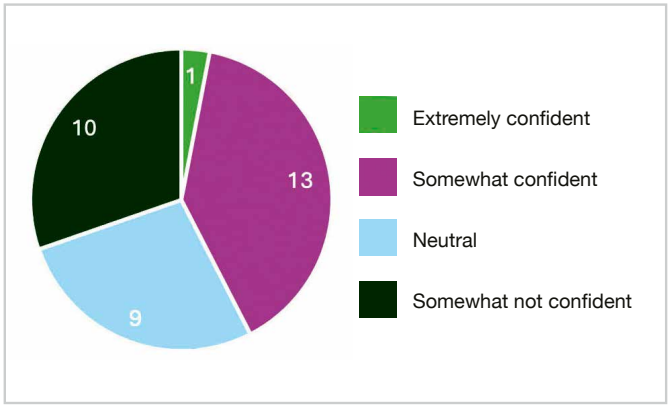

Figure 3. Self-reported confidence by SLTs in assessing PWA for AAC.

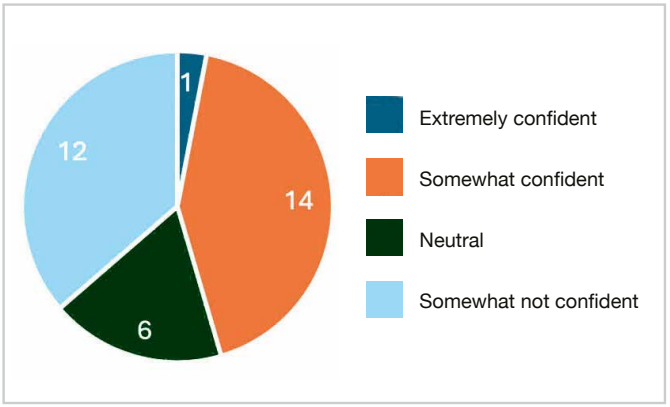

Figure 4. Self-reported confidence by SLTs in supporting PWA to practise using AAC.

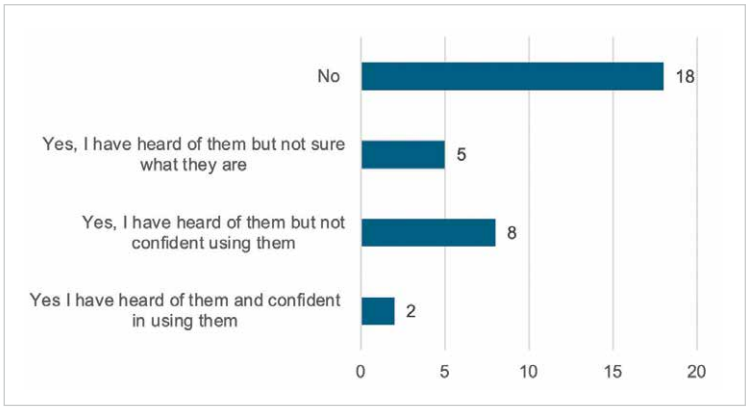

Figure 5. SLT responses when asked if they were familiar with Visual Scene Displays.

What goes well when trialling or implementing AAC for PWA?

There were 28 responses. The following themes were identified:

- Having supportive communication partners (5 responses). The importance of joint sessions and education to others was also highlighted.
- Personalising the AAC to the individual (4 responses).
- The PWA being motivated to use AAC (4 responses).
- The PWA's linguistic and cognitive abilities (4 responses). SLTs referred to understanding the PWA's 'level of comprehension' and 'limitations' to ensure the AAC provided is appropriate.
- Setting functional goals or identifying functional tasks (3 responses).

What difficulties do you experience when trialling or implementing AAC for people with aphasia?

There were 27 responses. The following themes were identified:

- Lack of supportive communication partners and/or a supportive communication environment (12 responses).
- Poor engagement or motivation of the PWA to use AAC (12 responses).
- The person's aphasia impacting use of AAC (7 responses).
- Cognition impacting using of AAC (7 responses).
- Lack of access to AAC resources (5 responses).
- Lack of time (5 responses).
- Lack of knowing what AAC is available (4 responses).
- Difficulties managing expectations of the PWA or families (4 responses).
- Physical access difficulties (4 responses).

What training would you like regarding aphasia and AAC?

There were 29 responses. The following themes were identified:

- Knowledge of what AAC is available (11 respondents)
- Advice regarding implementation and functional use of AAC (9 respondents)
- Understanding the evidence base of AAC for PWA (6 respondents)
- Knowledge of AAC (5 respondents), e.g. benefits of power-based AAC, amount of support required, paper and low-tech options to be trialled prior to considering power-based AAC and how to progress AAC.

Engaged with AAC Research

Most SLTs (55%) reported not reading research about use of AAC for PWA. 33% reported they did. 12% answered 'Other' with comments detailing that they would read research if required for a specific patient or if they were advised to read it by another member of staff.

Discussion

The SLTs identified the following factors as supporting the implementation of AAC for PWA: having supportive communication partners, with the importance of joint sessions and education to others also highlighted; personalising the AAC to the PWA; the PWA being motivated to use AAC; the PWA's linguistic and cognitive abilities, with SLTs referring to understanding the PWA's 'level of comprehension' and 'limitations' to ensure the AAC provided is appropriate; setting functional goals or identifying functional tasks.

The SLTs reported experiencing a range of difficulties with assessing for and implementing AAC for PWA. These difficulties include: a lack of supportive communication partners and/or a supportive communication environment; poor engagement or motivation of the PWA to use AAC; the person's aphasia impacting their use of AAC; the person's cognition impacting their use of AAC; a lack of access to AAC resources; a lack of time.

Over half of the SLTs reported feeling either 'neutral' or 'somewhat not confident' in assessing (57%) and supporting implementation (54%) of AAC for PWA. Throughout the survey, several SLTs shared feelings of under-confidence in supporting PWA and referred to having poor outcomes for this patient group. The majority of the SLTs reported being unaware of and/ or unconfident in using VSDs with PWA.

When asked about what training they would like, the SLTs identified wanting knowledge of what AAC is available for PWA, advice regarding the implementation and functional use of AAC and understanding the evidence base of AAC for PWA. Specifically, it was requested to understand the benefits of power-based AAC, the amount of support required for implementation, paper and low-tech options to be trialled prior to considering power-based AAC and how to progress AAC.

These findings all suggest that SLTs who work with PWA would benefit from support in providing AAC to this patient population.

As most SLTs reported not reading research around the use of AAC for PWA, it may be beneficial for AAC hubs to consider how to support these SLTs to access research, e.g. signposting to key research findings, running a journal club etc.

Limitations

There were no responses from two of the counties covered by the EATS; these SLTs may have different experiences. No responses from these counties may reflect the survey not being shared with the 'right' person to disseminate it or it could reflect a different reason, such as high caseload demands.

The survey was only sent to SLTs; it may have been beneficial to also include Speech and Language Therapy Assistants (SLTA), as they are often involved in the implementation of AAC.

Next Steps

Following the findings from the service evaluation, resources have been created which cover the following topics: an information sheet providing an overview of how language and cognitive difficulties can impact PWA's use of AAC and an overview of research into PWA's use of grid systems and VSDS; an information sheet summarising some key factors to consider when exploring use of AAC for PWA; an example of a paper-based VSD; an information sheet providing advice about what to include when you are making a VSD. These resources can be accessed by anyone via the EATS website.

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If My Gridpad is a Part of My Self-identity, Then Why Do I Choose Sometimes, When I Go Out to Leave It at Home?

PATRICK BATES
Email: pbeyepaint@gmail.com

My name is Patrick Bates, and I live in Coventry with 24hr care support, which I employ myself. I am 57 years old. I have a Gridpad with Eyegaze and a desktop computer with an Eyegaze on.

Abstract

"Everyone knows how vital AAC is to the users to enable us to communicate effectively, but self-choice is a part of self-identity. Sometimes, I choose to leave my Gridpad when I go out with my Carer and just use my low-tech eye board… why, you may wonder? Find out here...."

Introduction

As a nonverbal person, my communication is vitally important as we all know. I can be on my desktop or Gridpad pretty much for 14 to 16 hours per day. You may think that this is brilliant, but I would challenge it, as for the self-management of my mental health and wellbeing, sometimes it is nice not to use my high-tech systems.

How important low and high tech AAC devices are

Before I go forward, as well as my desktop computer and my Gridpad as my high-tech systems, I also have low-tech communication systems, i.e. my eye letter board, my eye pointing and my facial expression, when I am not on my high-tech systems. This is especially true when I am getting up in the mornings and at bedtimes. I think that being able to still use my low-tech communication boards, as well as my high-tech system is extremely important.

Self-identity and self choice

Although self-identity and self-choice are two separate concepts, they share some inter-connections. I think they are merged in my life and for the purposes of this paper I will write about them together mostly. In essence, self-identity is who you are, and self-choice is what you choose your lifestyle to be throughout your lifetime. I know that this is a simplified idea of them.

I will start this by putting the context to how I got my self-identity. From birth, I have always been disabled, so my self-identity has been based around my disability. I had a wonderful childhood - my dad was excellent at communicating and letter writing, planning for events and trips, and my Mum was fantastic at caring for me and having a great sense of humour. Both were straight-talkers, and the phrase, 'a spade is a spade', sums them up. Mum did almost all of my care and I had a ridged routine for my care.

My mum used the low-tech AAC method of spelling with me and she protected me by if I was about to say something controversial, she would stop saying it, and gloss over it, which annoyed me immensely.

Another thing which both mum and dad mistaught me was to keep my small problems in and when asked how am I, the answer is, "fine, thank you", even if it isn't. Therefore, my self-identity has been shaped by both of my parent's attributes.

I made my first self-chosen path at the age of, I would say, 9. I knew I was gay because I was only interested in male focuses. I wonder if I had been able-bodied, if my self-identity would have been different or if it was inherited. I was going to be gay whether or not I had a disability. I came out when I was 25 years old, about 6 months after my dad died. I can remember mum saying that she was pleased my dad did not find out before his death, but she had her suspicions that I was gay.

When I was 17 years old, I had my first communication device, so I joined the fledgling AAC community, so my self-identity started to change. Firstly, when I went to the Star College, where I made some of my own self-choice decisions in choosing what to study, and then to Hereward College. However, since I was using head switches and scanning letter by letter, I didn't think about my self-identity much at all. At home when I was out with my mum and dad, I didn't used my communication device; I still relied on mum's spelling for me. I had a desktop computer at home but that is all.

My mum did not dress me in colourful clothes, and I believe she knew I was gay, but she bought boy's colours, so when I could buy my own clothes, I have bought the brightest colours possible, to subtly emphasize the fact that I am gay.

I would say that my self-identity is a mishmash of everything, intelligence, yes, sometimes, and other times, I do not think the consequences of my actions through. Yet I can plan some physical activities, as I am disabled. I see situations in black and white, and I hold a lot in, until it becomes impossible to, and then, I make irrational decisions without further thought of anyone. Although, I caused numerous problems between myself and my carers, and then I cannot handle the conflict. It is such a strange dichotomy of the self. Before I left home to live on my own, I did not do this, probably because my mum and friends stopped me making awful decisions. I cannot exactly explain how, what, or why I do it.

However, I think as my mum protected me from making any mistakes, probably that had formed some of my self-identity, and time and time again I have made bad decisions and although I do try hard after every time I made bad decisions, after a while, I still managed to make more.

When I got the Eyegaze technology in 2009, my self-identity changed a lot because I could create documents which made it easier to communicate effectively. One sad fact was that, neither my dad or my mum saw the evolution of the Eyegaze technology. It took me several years to get completely comfortable with my Eyegaze, to be able to talk with anyone on my own and to be able to write this paper... No doubt, my self-identity and self-choice will continuously change with the further advancements of communication systems.

Why I think having a time away from my Gridpad is good for me

I know that the Gridpad is fundamentally a communication device for communicating everything from my wants and needs to abstract thoughts. However, with a hot-spot internet connection, the Gridpad turns into a mobile office and social media device. Yes, of course, I can leave my mobile phone at home, thus my Gridpad turns back into a communication device, sometimes it is good to leave my Gridpad at home when I go out locally.

Digital detox for a few hours at a time

While being able to communicate as an AAC user is vital, personally I feel that having some time away from my Gridpad and desktop is important, because I think it rests my mind. When I go out for walks, I call it my digital detox for a few hours at a time, but I will always be able to communicate with my low-tech communication eye letter board and / or if my carer asks me closed 'yes' or 'no' questions, my communication can be effective.

Firstly, from a practical point of view i.e., seeing beyond my Gridpad:

Having my Gridpad in front of me blocks my forward vision somewhat, unless I look over it. When I am outside in the bright light, although I know that the Eyegaze is supposed to work in any light, I find communicating virtually impossible. And I find myself concentrating on my Gridpad and not enjoying my surroundings.

Country walks and other short outings with my low-tech communication:

This leads me back onto my self-choice to leave my Gridpad at home when I go out on walks, or should I say wheels, in the countryside, and if I want to communicate with my carer we can use my low-tech methods discussed earlier in my paper.

Leading on to my idea of mindfulness is:

My idea of mindfulness is simply living in the here and now, focusing on that moment in time, and not allowing myself to think about anything else; for me, going on country walks without my Gridpad allowed me to achieve my kind of mindfulness.

Conclusion

Whilst I know how important high-tech AAC is for communicating and self-identity, I strongly believe that I need to find a balance between my high-tech AAC device, and my self-choice not to take my Gridpad out all the time is vital for my mental wellbeing. I think also to keep my low-tech communication board running alongside my high-tech systems is important to do.

Can AAC Be Cathartic?

ALLY KEANE[1] AND PATRICK BATES
[1] PhD Researcher at Newcastle University
Email: a.j.keane@ncl.ac.uk

Introduction

This article discusses a PhD project being undertaken by the first author into the history of AAC, which utilised oral history interviews with AAC users to begin to create a user history of the devices and services, alongside adding AAC user voices into the historical record. The purpose of the paper is to highlight that AAC users should have a space to share their memories and our reflections on this.

The Project

This project focuses on the history of AAC and aims to generate new knowledge around the history of the devices and services, alongside finding experiences of being AAC users throughout the mid-20th century to the present day. The first author came to the project as her dad had MND and used a range of AAC methods (predominantly a high-tech device and no-tech methods, such as blinking), and, since learning about oral history in her History undergraduate degree, wanted to find a way to incorporate AAC user voices into oral history methodology.

There is very little on the history of AAC, particularly within Britain (the few pieces of literature which does exist focus on North America), but the very small amount of source material that exists within the literature and archives is silent on user voices. To ensure this gap begins to close and to democratise the historical record, oral history was chosen as a method to gain access to past experiences of AAC users.

Oral History

Oral history is defined by the Oral History Association (no date) as: 'a field of study and a method of gathering, preserving and interpreting the voices and memories of people, communities, and participants in past events.' Oral history also democratises history, allowing ordinary "everyday" people to have their experiences and opinions as part of the archive, rather than the focus on big institutions and influential actors (the "great white men" of history) such as doctors or politicians.

From an interviewee's point of view, partaking in an oral history interview means undertaking semi-structured interviews. These interviews were life history interviews, which meant the recording of memories from childhood right up to the present day. This can be done over a couple of hours or may require multiple interviewing sessions, especially for AAC users. Communication partners can be included within the interviews too, if the interviewee wishes.

Benefits of Oral History with AAC Users

There were multiple benefits of conducting oral history interviews with AAC users, besides those around adding to the historical record as aforementioned. One of the benefits was that talking about AAC and experiences can be cathartic. Studies from oral history literature do show that most people find that taking part in oral history interviews can be cathartic and rewarding, even when discussing traumatic memories. For example, Alison Parr (2007), who conducted interviews with war veterans, talks about the emotional impact of oral history interviews with people who had previously stayed quiet about their experiences of the war, but felt that the oral history interview was a good way to share these. Throughout the interviews, all interviewees discussed memories which were negative or at times traumatic, alongside happier memories. Of course, throughout this project, interviewees always had the option to say no when answering questions and not share anything they did not want to share. However, the fact that the second author wishes for a space to share these memories live on beyond this project does highlight that memory sharing is a worthwhile endeavour.

Some other benefits have presented themselves when specifically working with AAC users. Firstly, there is the option to talk about things which are important to the interviewee. Whilst the interviews are semi-structured, memories came out of the interviews

which had not been scheduled within the questions, which was great as it shows the importance of these memories to interviewees and ensures the user history of AAC includes experiences which are important to AAC users. Oral history gives space to share these memories in a way which other, more structured interviews may not have the ability to do.

Secondly, oral history always gives the interviewee a right of reply. Some interviewees did not want to pre-write answers (the choice to do or not to do this was always up to the interviewee) as they felt that this was the only space that they had to answer the question. With oral history, this is not the case. Even if answers are pre-written, there is the space to follow up with additional information that may have come to the interviewee in the interview setting or likely another question will be asked to clarify information or to generate a more expansive answer. Interviewees can also jump back to memories and experiences talked about earlier in the interviewee session; there are no strict rules.

Finally, as mentioned above, most of the sources within archives are written sources, usually created by big institutions or professionals. The focus on written sources within the archives does exclude people who are unable to generate written documents, such as those who rely on no- or low-tech methods of communication or who use symbol-based systems. All the interviews were video-recorded so interviewees could use whichever method(s) of communication they wished to use, making the generation of source material more accessible for AAC users, and ensuring their voices were on the record.

Reflections

Some reflections following the finishing of oral history component of the research is that this work in sharing memories may well work better if AAC users interview each other, or communication partners interview AAC users. This will allow for more trust and rapport to be already established, allowing more AAC users to take part in memory sharing outside of the realms of academia and higher education. A group setting where this could happen may work nicely, allowing AAC users to come together and bounce off each other's experiences to create a true user's history of AAC users. Also, if it is based outside of higher education, there will be scope for a project or space to last longer than just the course of a research project.

The time it took to conduct the interviews varied from person to person too, with some interviewees only requiring one session and others requiring multiple. This was a great deal of time that people took out of their lives to tell their stories, something which was anticipated but something which needs to be acknowledged as part of this process. Processes had to be different for each individual AAC user, again, which may mean it may work better with AAC users or those within the AAC community, where this is common knowledge and the time pressures are not as present.

Patrick's Experiences

"When I saw Ally's bit in the Friday Announcements of Communication Matters, I didn't have much idea of what an oral history was or even if I was interested because I would not say I am overly struck with history, but I thought I would try it.

Fortunately, Ally replied to my initial email, and she told me about her project, the aims of the project, and how it would be put into the British Library. I was entirely on board with the project. With Ally's open-ended questions about my AAC journey throughout my 57 years of life, which overlapped with my family and educational experiences, I loved it. Some of the questions even brought back memories I had forgotten about. I can genuinely say that AAC can be cathartic.

I was disappointed when Ally's wonderful project finished, and although I know I could discuss history with my Care Enablers, they would be bored. I would love for C.M. to take the oral history mantle on and turn it into a project for every AAC user who would like to do this. I hope that someone will read this article and see how vital this oral history is to the wider AAC community.

Yes, definitely, AAC is cathartic!!!"

Conclusion

Memory sharing and the process of conducting oral history interviews has been cathartic and rewarding for many of the interviewees, and it is hoped that a space for AAC users to share memories (whether via oral history interviews or other methods) will be created to allow people to share their experiences and opinions. This may work best if AAC users work together to create these spaces and share their experiences with one another, however the spaces should continue to be provided.

For those who wish to watch/listen to the interviews, they will be deposited in the British Library around September 2026.

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What Parents Report on Their Children's Use of Aided Communication and the Role of the Language Environment

ANNA KAWAMURA
MA in Special Needs Education and Research assistant, Department of Special Needs Education, University of Oslo, Norway
KRISTINE STADSKLEIV
Professor, Department of Special Needs Education, University of Oslo, Norway
Neuropsychologist, Department of Clinical Neurosciences for Children, Oslo University Hospital, Norway
STEPHEN VON TETZCHNER
Professor emeritus, Department of Psychology, University of Oslo, Norway
Email: anna.kawamura@isp.uio.no

Introduction

A supportive language environment is of importance for children using aided language, as it for all children. However, one difference between children developing aided language and children developing natural speech is that aided language learning to a large extent is a planned process based on instruction. However, aided language development does not occur only in educational settings. Parents play a vital role in creating a supportive language environment for their children but most parents are not familiar with the use of aided language before their own child needs a communication aid (von Tetzchner & Stadskleiv, 2016). Parents' perspectives on their children's aided language development may shed light on both the children's needs and the families' needs for support in developing aided language competence. Moreover, parents have other experiences to professionals and a deeper insight into the children's lives and needs, thus broadening the understanding of how aided language development may progress.

The purpose of this study is to explore what parents report about their children's aided communication, their children's aided language competence, and the language environment of their children.

Method

The study is part of the project *Becoming an aided communicator (BAC): Aided language skills in children aged 5–15 years: A multi-site and cross-cultural investigation* (von Tetzchner, 2018). This study reports on interviews with 38 parents of children using aided communication. The children – the aided communicators – were 5;3 to 15;10 years;months old (mean age 11;1 years) and 24 were girls. They belong to the expressive language group of AAC users (von Tetzchner et al., 2025), had language comprehension within the typical range for their age, were not perceived by their teachers and/or therapists as having an intellectual disability and did not have a diagnosis of autism spectrum disorder. Almost all (90%) of the children had a diagnosis of cerebral palsy, and the majority (87%) used a wheelchair for locomotion and had limited hand motor skills. The children were on average 4;4 years old when they received their first communication aid, and on average, they had used a communication aid for 6;8 years.

The parents in the BAC project participated in a comprehensive interview, and from this interview, seven questions are included in the present study: the children's ability to express themselves, the complexity of the children's expressions, the parents' comprehension of their child's communication and the occurrence of misunderstandings, and if there were children and adults who did not understand their child. The answers were analysed using reflective thematic analysis (Braun & Clarke, 2020).

Results

Three major themes emerged from the analysis: 1) aspects related to the aided communication, 2) the children's aided language use, and 3) the role of parents and other communication partners.

Key findings relating to aspects of aided communication were a) time, b) vocabulary, and c) availability and accessibility.

Concerning time, it was emphasized that producing aided language takes time, that giving sufficient time is a crucial factor for successful aided language use, and that the time constraints affected the children's communication. Concerning vocabulary, the parents highlighted how the relatively small size of the lexicon in the communication devices increased the occurrences of misunderstandings and affected the children's ability to express themselves efficiently. The parents reported fewer issues pertaining to availability and accessibility, but mentioned how their child's positioning in the wheelchair, different activity settings, and environmental factors such as bright sunlight impacted the children's communication opportunities.

As for aspects related to the children's aided language use, parents mentioned a) aided language competence, b) the child's reasoning skills, c) psychological factors, and d) the effort involved in aided language use.

A key finding was that parents reported that their children varied the length of their utterances depending on the communication partner and the situation. This affected both the complexity of the utterances they constructed and whether they prioritized speed or utterance length. Some parents reported that their child would use brief messages with familiar partners, expecting to be understood, and prioritized longer and more detailed, but also slower, utterances with more unfamiliar partners. Other parents reported an opposite strategy, that their child prioritized a speedier – but less nuanced – utterance with unfamiliar partners, not expecting them to be interested enough to wait for the time it would take for the child to compose a longer utterance.

The children showed their aided language competence quite clearly in situations where the communication broke down or there were misunderstandings. Some parents described their child as creative in finding alternative ways of expressing themselves, using different symbols and combination of symbols if they were not correctly understood the first time. Other parents said their child would struggle with reformulating utterances if their message was not perceived correctly the first time.

There was also variability in how the parents described their child's reasoning skills and ability to solve different communicative challenges. The children's personality and outlook on life were also considered to play a role. Some parents saw their child as eager to communicate, often taking initiatives to strike up a conversation, while other parents described their child as pickier and choosing not to communicate unless the communication partner clearly had the patience to wait the necessary time. Some children varied in how talkative they were, depending on the setting. For example, one child was described as talkative and expecting to be listened to at home, while being the most silent one in his class at school. How children handled not being understood also varied. Some were clearly frustrated when not being understood, while others seemed more resigned and perhaps almost expected not to be understood. The parents often repeated that their children had many things they would want to say but never got to express.

The last point that the parents brought forth in relation to their children's aided language use concerned the physical and emotional efforts of constructing aided language. It was clear from the descriptions that the parents perceived composing a sentence using aided language as a laborious process for their children and that aided communication required the full engagement – both of the child and of the parent.

The third major theme concerned the role of parents and other communication partners. This included aspects relating to a) how familiar the communication partner was with the child, b) the communication partners' competence in communicating with aided language users, and c) the attitudes of the partners.

The parents felt they were good communication partners, as they knew their child better than anyone else. But even though they felt competent in communicating with their child, several parents also reported that they did not understand everything their child wanted to express and that understanding their child also involved some guessing and trial-and-error. Competent communication partners were described as not interpreting the child's intended utterances prematurely, as starting to make inferences too early or just guessing might result in misunderstandings that increased the time use. A competent partner would also know what questions to ask, as well as asking for confirmations. It varied between the parents in how much they encouraged the child to independently express a longer and more nuanced utterance versus themselves taking a more active interpreter role, based on shorter aided utterances with one or a few graphic symbols. Lastly, the parents emphasized how the attitudes of others towards their child also impacted the child's communication. For example, one parent described how unfamiliar partners would ask their child a question but not really wait for and show interest in the child's answer. Other parents described how their child was often misunderstood and his or her cognitive level was underestimated.

Concluding remarks

The parental interviews highlighted how the communicative competence of an aided communicator is not the result of a single factor but of a complex interplay between interrelated factors. This is in line with the model of communicative competence formulated by Light and McNaughton (2014), where children's linguistic, strategic, social and operating skills, and features of the communication device, personality factors, and environmental factors all play together.

The study has implications for clinical practice. Firstly, it highlights the importance of getting the parent perspective. This should be evident, considering the important role of the family in a child's life and in giving the child opportunities to develop and use his or her aided language skills outside of educational settings. However, the study also highlights the importance of getting parents' perspective for understanding the child and providing the support and positive challenges he or she needs in the school setting. There were examples of children who would be perceived as silent and perhaps not so interested in communicating with others in school, being talkative at home. If teachers do not engage with and listen to the parents' experience, they might not tailor the school interventions so that the child's full potential is being realized. Secondly, the study also highlights the importance of providing rich opportunities for aided communicators. They need different communicative partners, communicative access to a variety of settings, and a rich array of topics to communicate about. Thirdly, the study illuminates that misunderstandings were frequent and often had a disruptive effect on the communication process. Providing the children with strategies to both inform their communication partner that they have been misunderstood and strategies for correcting misunderstandings seemed important.

Finally, the study confirmed that although becoming an aided communicator is an achievement, it is also a form of communication that is demanding. It takes time, both to learn and to use, and if costs effort both for the child and the communication partners (Batorowicz et al., 2025). However, these obstacles should not be interpreted as an argument against aided language development. That would deprive the children of their possibilities for communication, interaction, learning and participation – which was so well described by the parents contributing to this study.

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Author declaration

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The Importance of a Local Augmentative and Alternative Communication (AAC) Assessment Service

DELLA CHUBB
Service Lead, Suffolk Communication Aids Resource Centre (SCARC)
Email: scarc@wsh.nhs.uk

VICKY HEALY
Service Lead, Surry Access to communication and Learning Service (ACL)
Email: victoria.healy@surreycc.gov.uk

Introduction

SCARC and ACL are both local AAC assessment services covering Suffolk and Surrey respectively. Both services provide:

- Assessment, identification, funding, monitoring, maintenance, and repair of VOCA (Voice Output Communication Aids).
- Continuing Professional Development (CPD) for a range of Multidisciplinary (MD) professionals.

The aim of a local AAC assessment service is to provide access to VOCA for young people who do not meet the criteria for specialised Augmentative and Alternative Communication (AAC) services (often referred to as the 90%).

Meeting the needs of the 90%

In 2006, NHS England provided guidance for commissioning AAC services and equipment which led to the setup of regional AAC hubs (referred to as Specialised AAC Services).

These provide the funding, assessment, and provision of AAC equipment but only for 10% of AAC users. The remaining 90% is reliant on local AAC assessment service commissioning which is variable across the UK and can be described as a postcode lottery.

Access to AAC for people with Learning Disabilities (LD)

Local AAC assessment services predominantly support young people with LD who would not meet specialised AAC services criteria. Part of the role of a local AAC assessment service is to provide advocacy for people with LD and ensure that their voices are heard in the AAC world. Our role varies in approaches for people with LD, given their access to AAC is intrinsically reliant on effective environmental support and effective communication partners.

Who do we support?

- Those who are neurodiverse with LD
- Those who also have complex medical / physical needs
- Those with Speech Sound Disorder (SSD) / Developmental Language Disorder (DLD)
- Those with environmental / situational mutism
- Those with additional sensory needs - deafness, vision differences

The role of a local AAC assessment service

This includes:

- Assessment and provision of power based AAC
- Ongoing technical support and repairs
- Signposting to resources / suppliers - particularly for parents
- Training for those supporting AAC users
- Clinical supervision for paper and power based AAC, especially related to LD

How can we support each other?

- We are keen to work with and support anyone exploring a local AAC service provision in their area.
- We are keen to work with lobbying services and national commissioning services to promote the need of unified local AAC services across the United Kingdom (UK).
- We are keen to work closely with AAC professionals to support and develop CPD in AAC. This is especially relevant to our Speech and Language Therapy (SALT) colleagues.

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SCARC website - www.wsh.nhs.uk/Services-A-Z/Childrens-services/Childrens-community-services/SCARC/Suffolk-communication-aids-resource-centre.aspx

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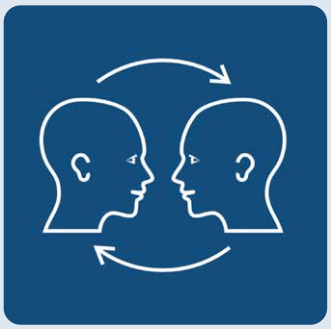

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Fighting Fake Emotions: An AAC User's Plea to Spread Awareness about Pseudobulbar Affect

ÖMER GÜNEY
Email: omer.guney@telenet.be

This article is generated with ChatGPT based on the transcript of my presentation and edited by me.

My name is Ömer Güney. I live in Belgium, and I serve as the secretary of the Dutch-Flemish chapter of ISAAC. In this article that is based on the presentation I gave at the Communication Matters Conference in 2025, I want to draw attention to a condition that is almost absent from AAC literature: the pseudobulbar affect (PBA), and more generally the way AAC users express emotions versus how these emotions are perceived by others. While research on AI in AAC or on technical innovations is abundant, the emotional side of AAC use is underexposed. Yet it matters, because misinterpretations of our expressions can have real consequences in daily life.

Pseudobulbar affect is a neurological condition that causes sudden and uncontrollable laughter or crying without a matching emotional state. It appears as a secondary effect of conditions such as ALS, MS, traumatic brain injury, or cerebral palsy. The cause lies in lesions in parts of the brain that regulate emotional expression, like the prefrontal cortex or thalamus. The result is that a person may cry without being sad or laugh in situations where others expect seriousness. Outbursts can be triggered by small events or appear without trigger at all, and their intensity is often out of proportion. This mismatch makes PBA confusing to outsiders, who assume the expression equals the true emotion.

The impact is more than awkwardness. People with PBA often feel embarrassed, and in some cases may withdraw socially. Misdiagnosis is common; clinicians sometimes mistake it for depression or bipolar disorder, and many professionals are not trained to recognize it. Awareness is low both among patients and healthcare professionals.

I first heard about PBA less than a year ago through a fellow AAC user, Reinier, who had searched online for an explanation of his behaviour. He asked me whether I too sometimes laughed at inappropriate moments. That question started hours of discussion. He describes moments of sudden laughter, especially when something unexpected happens. One evening, when a nurse had trouble removing his catheter and spilled urine, he laughed instinctively. The nurse interpreted this as disrespect and reported him. At a follow-up meeting, Reinier explained that this was not intentional. Discovering the concept of PBA helped him defend himself. He also said that for him, laughter is sometimes a way of showing empathy, for example when someone stumbles and hurts their toe. Reinier will laugh in this situation, but he explained that he will not laugh to mock the person or make fun of them. Through laughing, he empathizes with that person and asks: "Are you okay?"

This story angered me, not because a random bystander misunderstood him, but because a healthcare professional did. If staff working daily with disabled people cannot recognize such phenomena, then the risk of misinterpretation is widespread. While this happened in the Netherlands, I suspect the same lack of knowledge exists elsewhere. It also raises the question of how often AAC users are misjudged for their emotional expressions.

Here I want to emphasize that I do not advocate self-diagnosis. Anyone with symptoms should consult a professional. My use of the term PBA in this article is not a personal diagnosis but a framework; the experiences described by me and by other AAC users resemble what is known about PBA, and that parallel is useful.

To situate myself, I have cerebral palsy caused by hypoxia at birth. Before I had a device, I communicated with iconic gestures that

only close relatives understood. Later I used symbol folders and a letterboard, and at age ten, after a long wait, I received my first speech generating device, controlled with my right foot. Since 2018 I use eye-gaze, which allows me to type about twenty words per minute. This technical path shaped my independence, but for this article the relevant part is how my emotions are expressed and perceived.

Teachers used to describe me as the boy who always smiles. As a teenager, I sometimes felt ashamed of my outbursts, for instance when watching a play. The hall was quiet, I became invested in the story, and I suddenly yelled with emotion. Once the actors even addressed me directly from the stage. How much of this is genuine feeling, and how much is uncontrolled expression? The trigger is real, yet the reaction is excessive. My outbursts are often shouts of joy rather than laughter. Unlike some, I rarely laugh without cause, but I can yell in situations where others only smile. Over time, I accepted this as part of who I am. I also learned some techniques to reduce secondary outbursts after the first one: focusing on the pressure of my seat, my footrest, or on another stimulus. These methods work sometimes, but not always.

The conference theme of identity invites reflection. Do these outbursts form part of my identity? If we define identity as the collection of aspects through which a person connects with others or distinguishes themselves, then yes, my disability is one aspect, and emotional outbursts are part of it. But they are only one aspect. I am also a Muslim, Belgian with Turkish roots, a gamer, a writer. The problem is that society often reduces disabled people to their condition. The media plays a role; disabled persons appear either as objects of pity or as heroes "despite" disability. Both frames center the impairment instead of portraying the person as a full human being.

My own view is shaped by the fact that I grew up with these outbursts from birth. Because CP is congenital, I never compared life "before and after". It was always part of me, and my family never made a problem of it. At a recent hospital visit, a psychotherapist told me that they usually do not warn patients with CP about PBA in advance. The topic comes up only if the patient or relatives mention outbursts. This makes sense for those who develop a condition later in life, the change is noticeable and may be more quickly viewed as problematic. For congenital cases, it may be less discussed unless the outbursts are severe.

Still, outsiders often misinterpret. On the street I sometimes feel that strangers assume I have low cognitive ability. They see my wheelchair, my uncontrolled arm movements, my delayed responses while typing, and if I happen to yell, they conclude I am not competent. I can understand why they think so, but it remains frustrating. For AAC users, the gap between expression and perception is constant.

To broaden this article beyond my own story, I also spoke with friends. Charlotte, whom I have known since kindergarten, also has CP. She now communicates mostly without her device. She told me how, during a walk with her assistant, a stranger suddenly hugged her. Charlotte smiled, partly to be friendly, partly because the stranger smiled at her. But she actually disliked the invasion of her personal space. Only with the assistant's help could she clarify her feelings. Charlotte notes that close friends read her emotions accurately, but strangers often misjudge.

Youssef, another friend, suffered brain damage at age twelve and now uses a speech device. He says he laughs often, even when the timing seems off. Once he laughed at a child pestering its mother. People usually respond positively, seeing him as cheerful, but he himself is indifferent to how they interpret it. Laughing, he says, is simply part of who he is.

Finally, my friend Litania, who also uses eye-gaze, described similar experiences. She sometimes bursts out laughing when thinking of something funny, unrelated to the present situation. Like Youssef, she does not care about outsiders' opinions. She said: "I am Litania, and I don't care about the rest. My friends and family understand my emotions, and the rest should accept me as I am."

These testimonies show the diversity of AAC users' experiences. Some feel embarrassed, others indifferent. Some struggle with misinterpretation, others are shielded by supportive environments.

In conclusion, PBA and atypical emotional expressions among AAC users deserve more attention. In my opinion, further research is needed to raise awareness of unintentional emotional expressions and to support their acknowledgement and normalization within both clinical practice and society.

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Singing Using Eye Gaze Technology: Identity and the Potential for Wellbeing Impact

SARAH DUNN
Parent/Carer of an AAC User and PhD Researcher at School of Music, University of Leeds
Website: https://ahc.leeds.ac.uk/music/pgr/6337/sarah-dunn
Email: mus0sje@leeds.ac.uk

Background

Sarah is a qualified music teacher and parent of two children who love music. Her son, J (10) is disabled with a diagnosis of Cerebral Palsy (CP). He is non-speaking and a full-time wheelchair user. He uses eye gaze assistive technology (EGAT) and switches for communication and music making. Sarah's passion for making music more accessible and inclusive has led her to set up a charity, Accessible Inclusive Music (AIM), which provides musical opportunities to children and young people across the UK, specifically those who are disabled and/or have additional needs. Sarah has a personal interest in how AAC can be used for music making and how breaking down the barriers to meaningful music making can positively impact wellbeing. She recently completed a MA in Music and Wellbeing and is now a year 2 PhD researcher at the University of Leeds exploring eye gaze singing for musical opportunity and wellbeing in disabled AAC users.

This article is a summary of Sarah's journey so far as a parent/carer and musician, exploring how singing might be achieved using EGAT and how this exploration has led to doctoral research. Sarah shared her thoughts on the above as part of a platform presentation at the 2025 Communication Matters conference.

Singing using Eye Gaze: J's story

J's exploration of eye gaze singing started when the music co-ordinator at his school invited him to sing a solo in the summer concert. She asked, "can you make the eye gaze sing?" which led to me exploring how this might be achieved using his Gridpad. We came up with some form of a solution using 'Text Talker' within Grid 3, inputting song lyrics of J's chosen songs and him activating them using eye gaze, however, this sounded more like speaking rather than singing. We explored personalising voice intonation through adjusting tempo, volume and pitch of speech. However, using Text Talker as a solution only really starts to sound 'musical' when the output of the AAC user is accompanied by a musical instrument. Irrespective of the technicalities, J really enjoyed performing in the school concert with one of the teachers accompanying him on guitar. He got so much out of it that he volunteered to perform a 'singing' solo using his eye gaze device, accompanied by me on piano, in a concert I put on for students I taught.

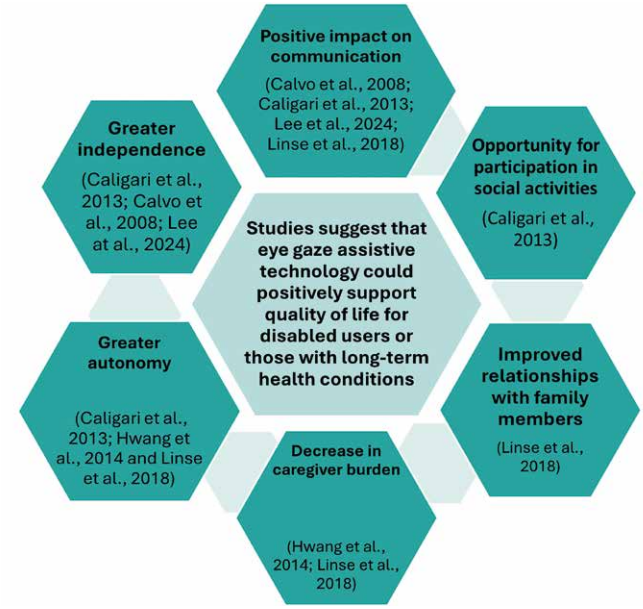
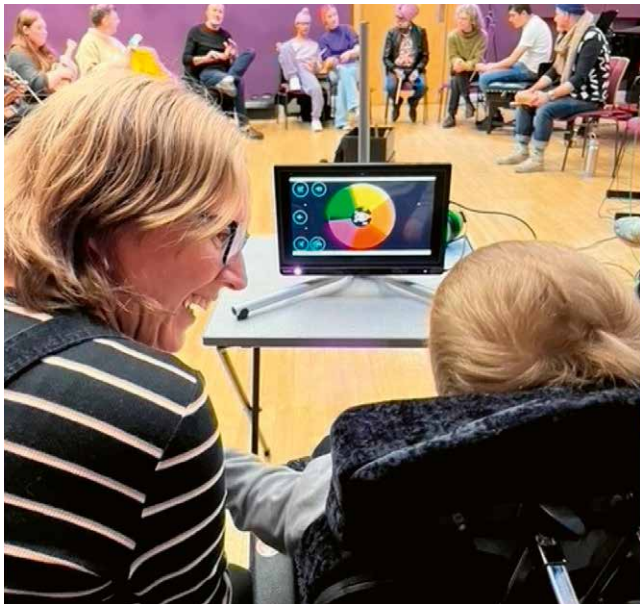


Figure 1. Eye Gaze Assistive Technology and Quality of Life (own diagram)



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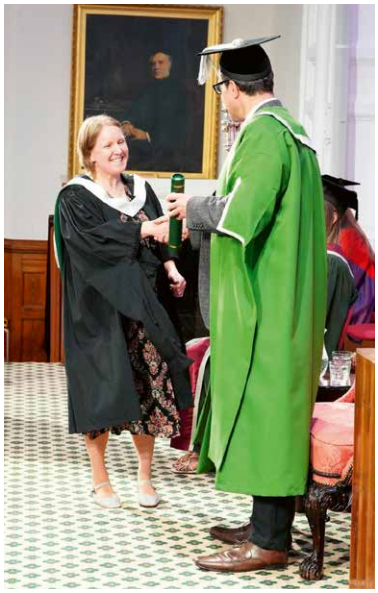
Applying lived experience to research

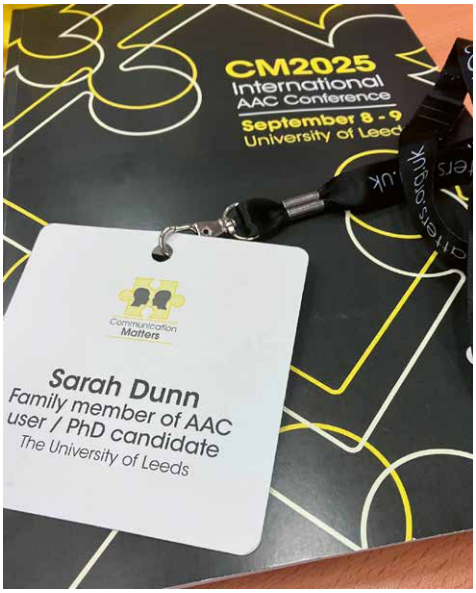
The wellbeing impact that eye gaze 'singing' had on J was certainly positive and performing in concerts using his eye gaze device appeared to be great for his confidence and self-esteem. However, would this be the case for all eye gaze users? How about those not interested in singing? Or for those who could sing previously? Could the emotional impact of an alternative singing method have a negative impact on their overall wellbeing?

Singing, identity and wellbeing

Research suggests that singing may have a positive impact on wellbeing (Bartleet et al., 2023; Campbell et al., 2022; Clift et al., 2017; Daykin et al., 2018; Dingle et al., 2013; Hendry et al., 2022; Judd and Pooley, 2014). However, it remains unclear as to what it is about singing that leads to positive wellbeing impact. Could it be its role in facilitating communication (Norton, 2015) or developing group identity? (Launay & Pearce, 2020).

Academic literature pertaining to singing and wellbeing is not representative of disabled AAC users, focusing on participants described as 'healthy' (Daykin et al., 2018) or those with specific physical and mental health needs (Dingle et al., 2013). Studies also focus on the impact of group singing which is potentially difficult to access for disabled eye gaze users. The pace of their speech or technology use as a substitute for natural voice may not match the qualities of other singers within the group. Those who are physically disabled may also struggle getting to rehearsals outside the home and therefore, may not have access to the wellbeing benefits of group singing.





Eye Gaze Assistive Technology (EGAT), wellbeing and Quality of Life (QoL)

If EGAT is going to be used to facilitate singing, it is important to understand how it may impact the wellbeing of users. Academic literature examining the impact of EGAT focusses on QoL opposed to wellbeing. Quality of Life (QoL) can be defined as "the extent to which a person obtains satisfaction from life", suggesting that "emotional, material, and physical well-being; engagement in interpersonal relations; opportunities for personal (e.g., skill) development; exercising rights and making self-determining lifestyle choices; and participation in society" are pertinent to a good quality of life (American Psychological Association [APA], 2023, APA Dictionary of Psychology page). Wellbeing can be defined as "optimal psychological functioning and experience" (Ryan & Deci, 2001, p. 142).

Studies suggest that EGAT could positively support QOL for disabled users or those with long-term health conditions. Prevalent themes within these studies included EGAT having a positive impact on:

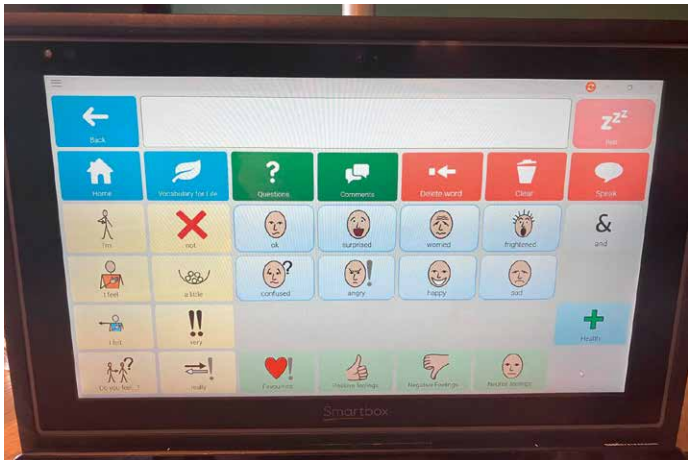
- Communication
- Opportunity for participation in social activities
- Improved relationships with family members
- Decrease in caregiver burden
- Greater autonomy
- Greater independence

Interestingly, some of these themes could be transferrable to singing, e.g. singing for communication or participating in social activities using singing. Singing using EGAT could also be a useful motivation to engage users with this technology, leading to greater use for communication and potentially having a positive impact on wellbeing and/or quality of life.

However, these studies also highlight user challenges that may influence the extent to which EGAT impacts their QoL. These include:

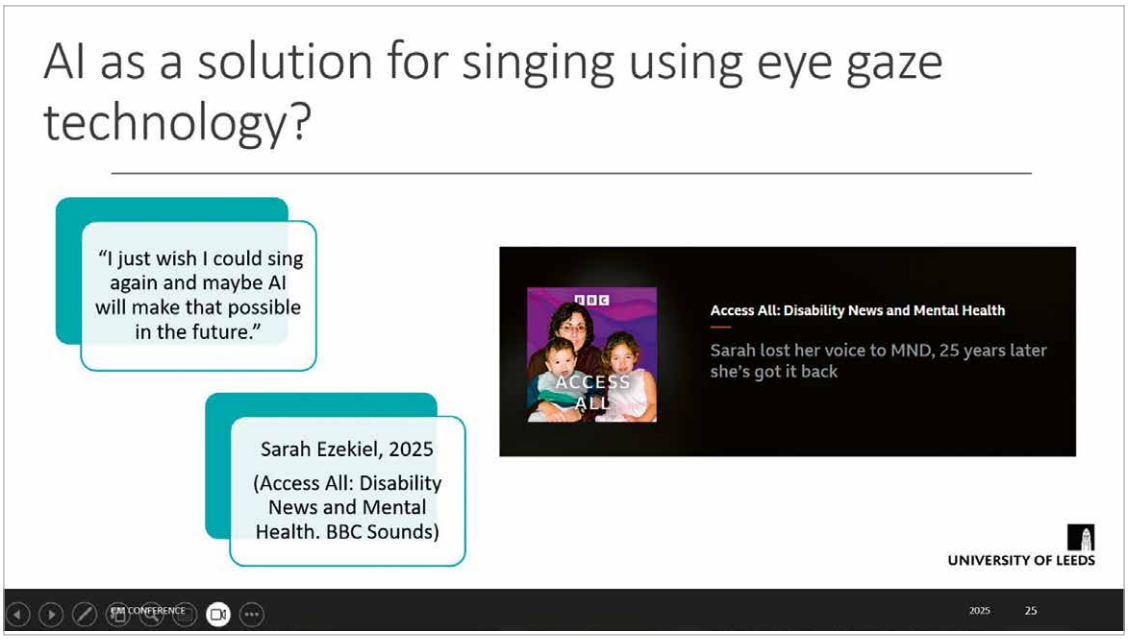
- Obtaining a device due to funding, cost or loan pathways (Caligari et al., 2013; Calvo et al., 2008; Hwang et al., 2014; Lee et al., 2024; Linse et al., 2018)
- Training and support for caregivers/professionals (Borgestig et al., 2017; Lee et al., 2024; Townend et al., 2016) *
- Acceptance of EGAT in daily life
- Perception of how EGAT may impact QoL at a given point in time may be affected by length of time an individual has been using this access method, stage and presentation of their diagnosis (Linse et al., 2018; Londral, 2015).
- Loss of motivation due to technical issues, issues with calibration and uncontrolled head movement (Calvo et al., 2008), uncontrolled eye movement (Hwang et al., 2014), "Tired eyes" (Caligari et al., 2013, p. 548) and portability of devices (Hwang et al., 2014) *.

* At time of publication. There are now training options for parents/carers/professionals, e.g. Smartbox Academy. Technological advancement has led to EGAT being developed to meet the needs of those with physical needs related to head/eye movement. Devices can also be mounted on wheelchairs for portability.



Next Steps…

Given the early stage of my research, I still have many questions to answer. How do those who are disabled and have long term health conditions rate their wellbeing/quality of life? How is individual wellbeing defined? How does singing play a part in leisure time music making? How does voice form part of identity and enable a sharing of self and expression and what is the wellbeing impact for those who are non-speaking/have limited ability to speak? Will AI voice cloning develop into AI singing?



I am looking forward to working with users later in my research to gather thoughts on the topic but in the meantime, I welcome further discussion…

"I just wish I could sing again and maybe AI will make that possible in the future."

Sarah Ezekiel, 2025 (Access All: Disability News and Mental Health. BBC Sounds)

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I Am Who I Am: A Journey of Self-Identity Across Cultures

HUIWEN QI
Psychology graduate with lived experience of CP
HEATHER GRAZ
Independent Speech and Language Therapist
Email: heather@biophys.co.uk

Introduction

Huiwen Qi, a psychology graduate from China living with cerebral palsy, has lived in two very different cultural contexts — China and the UK. This experience of living across continents has generated both opportunities and challenges. It has shown the many facets of multiculturalism and created chances to explore what it means to be a unique individual in each of these cultures. Huiwen's reflections on these experiences continue to shape her self-identity.

At Communication Matters 2024, Huiwen and Heather Graz co-presented Huiwen's experiences of learning English and adapting to a new cultural environment (Graz and Qi, 2025). Building on that work, this article describes Huiwen's lived experience of managing self-identity against a backdrop of different cultures. We present three key themes in this chapter of Huiwen's story. These include:

- Huiwen's experiences of living with a disability in contrasting cultures that prioritise the greater group over the individual, or vice versa.
- The transformation of Huiwen's identity as she has moved between these opposite cultural contexts.
- Emergence of a unique sense of self that belongs to Huiwen.

Here is the next chapter of Huiwen's story.

Living in different cultures

HG: Huiwen, you've had the experience of living in China and in the UK. What's it like being Huiwen in China versus being Huiwen in the UK?

> **HQ:** I feel so different being in different backgrounds and cultures. In our collectivist culture, we want ourselves to be in a group. As a minority, I sometimes feel isolated, especially when I was young. I didn't even have any experience connecting with the disability group. Even when I grew up, my only connection was online. So in reality, I still feel kind of isolated.
>
> But here it's different. Everyone doesn't have such a strong connection with each other. Everybody is an individual, so it makes me feel better. Even as an immigrant, you can join the diversity of backgrounds.

HG: So there are a number of issues you're highlighting. You're talking about your identity within a group versus as an individual, access to diversity, building relationships within that diversity, loneliness, and a sense of belonging—or lack of belonging.

> **HQ:** It's a complicated question for me. The loneliness is different between China and here. Here, I feel isolated because of my immigrant identity. In China, I was isolated because of my disability. So it's different. But in China I felt more isolated because I didn't belong to the group—I didn't belong to "normal" people. That made me very isolated.

HG: And that is the same experience for anybody with a disability in a collective culture like that, where there's no sense of the individual?

> **HQ:** It's related to individual personality, but also the function of the disability. Some people with higher function can join more activities or organisations.

HG: So that's a way of building and developing identity, which isn't available to everybody.

HQ: Yes.

Adapting identity in collectivist vs. individualist cultures

HG: So Huiwen, you've said you see yourself differently depending on where you are living and the context you find yourself in. Can you tell us if there's something you have to do, or a way of thinking, when you realise you're going to a different place and may have to see yourself in a different way?

> **HQ:** Yeah. Different cultures give me many different identities. It can reinforce something like my disability identity. Here I can get more support, so I realise even though I'm disabled, it's fine. Support makes it easier for me to live.

HG: So what you're saying is that it's easier to carry on doing what you want to do every day in this country because you don't have to pretend to be somebody else or try hard to do things in a way you wouldn't want to?

> **HQ:** Yeah, although China also has many supports recently, but in different ways. The Chinese government hopes every disabled person can join society and improve their function, so the focus is on improving disability function.
>
> But here I only need to consider how to achieve my goals. If I want to achieve my goal, I can ask for support for myself. That's the big difference.

HG: Right, so you don't have to rely on somebody else to give you support. You can be proactive and say: "I'm an individual, I know what support I need, and I'm going to ask for it."

> **HQ:** Yes. And I don't feel ashamed to ask for help.

HG: So what you're saying is, in China people get support to do things, rather than to be the person they want to be.

> **HQ:** Yes.

The formation of identity

HG: So what I'm hearing, Huiwen, is that you feel your identity has changed from when you first came here from China. Tell us more about what part of your identity has changed.

> **HQ:** My identity change is that I've got more space to be myself—whether disabled or not. I have more space to explore myself. And I've also built great relationships. I think relationships are very important for me. Even though I am disabled, you and others I meet here treat me as someone who needs support, but we are equal in other ways. That's very important for me.

HG: That's a powerful point—you're saying identity has to do with having space to explore who you are and feeling comfortable doing that, but also having relationships that support you just to be yourself, and for you to support others too. Those two things helped you transition from Huiwen arriving here to Huiwen being here.

> **HQ:** Yeah, I'm so happy to have the chance to explore who I am and be myself.

HG: Well, Huiwen, long may your journey of exploration continue. We're all excited to see where it takes you, because I think you're going to go very far.

> **HQ:** Thank you.

A few reflections

The cross-cultural experience that was unique to Huiwen's life journey may have been the beginning of her journey of self-identity, but it will not be the end. Her journey across cultures shows that identity is not fixed, but can be shaped and reshaped through lived experience. Moving between two contrasting cultures can expose a person to similar-but-different challenges on the one hand, and new relationships on the other hand. For Huiwen, the result of this was a gradual shift in how she views herself as a unique and valued individual and a realisation that she can accomplish more than she thought she could. Now there is a cause for celebration!

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The authors declare that there is no commercial interest associated with this article.

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Angelman Syndrome, My Labels and Me

LEIA CAMPBELL[1] AND TRACEY CAMPBELL[2]
[1] AAC User
[2] Parent of an AAC user, Owner of Tracey Campbell ACT, Microboards facilitator with Microboards Australia and Communication and Education Team Lead at Rett UK
Email: traceycampbellact@gmail.com

Commercial interests: Tracey earns money from working in the field of AAC but has received no money for anything in this article.

Leia Campbell, a 19-year-old with Angelman syndrome, presented for the first time at Communication Matters this year. Below is her talk in which I will explain her literacy journey and how she managed to write her presentation afterwards.

I am by Leia Campbell

I am happy like a gnome and dizzy as a tornado
I wonder why are you happy?
I hear Cara sleeping gold
I see Grandpa waking helpless Gran angrily
I want to go swimming
I am happy like a gnome and dizzy as a tornado

I pretend we go to the lovely caravan
I feel helpless, happy, innocent love
I touch Gabby's eye, it is weerd like a jellyfish
I worry like a guilty duck
I cry when surprised
I am happy like a gnome and dizzy as a tornado

I understand sorry
I say my greetings
I dream I am going to a caravan
I try Glee it may be heaven
I hope to get a puppy, gorilla and an alligator baby too
I am happy like a gnome and dizzy as a tornado

Hello

My name is Leia. I have a dog called Pippa. She is a labrador she is 10. My sister Abbie is 21, she is at university in Dundee. My brother Finn is 14. I like to go horse-riding. I love the theatre, especially pantomimes.

First labels

My first labels were my family roles and my gender. Next, I got labels about my personality. I am told I was content, even though I didn't sleep. I laughed a lot and early. Of course, because of my previous label as a sister there is no video evidence for proof. There are a lot of videos of Abbie. I also had labels from my community. I was a neighbour. I was a member of groups and places.

Angelman syndrome

I was diagnosed with Angelman syndrome aged 2.5 years. Wikipedia says 100% of people with Angelman syndrome have:

- Functionally severe developmental delay and learning disability
- Speech impairment – no or minimal use of words
- Movement or balance disorder – mild to severe
- Behavioural characteristics

Learning disability and me

I do have a learning disability. It is not severe. I feel better when people support me. School didn't support me, so I made a Venn diagram to show them the difference between the support I got in school compared to my online literacy class. They didn't listen to me. I did not go back to school after that. Pippa still helps me learn.

Speech impairment label

I don't understand why Wikipedia says that we have no words. I have a Level 1 award in Communication. I feel proud and excited about it. I sign to the spider to go away. I have a fat and loud vocabulary. Reading makes me feel good and excellent.

Balance, movement label

I like to go on Grandpa's X-trainer. I also like to work with my new Personal Trainer. Horses help make my core strong. Dancing with Ruth helps to improve my balance and movement.

Behavioural characteristics label

I often feel merry and happy. I have a short attention span. I flap my hands when I communicate excitement but also worry. I have a short attention span. I find sleeping difficult but have medicine to help, with support through the night. I have a short attention span.

Me and my family

I am happy at home. Abbie helps me communicate. Dad makes me feel better. I love Mum, she uses a microscope to examine what is happening in my life. Gran takes me to Lamont farm. Finn gets me stuff. I like going to Gran and Grandpa's house.

Me and society

I like the cinema, theatre, circus, and pantomime. I have faced public. I heard it echo my feelings. Thank you for Jorden. Cara coming to the pantomime is like a present.

Character

Me and my family have lots of fun. I am massively empathetic, but this ignores my like of fun. I am brave I recently got bloods taken.

Labels and me

I feel better when I believe in you. I need people to believe in me so I can believe in them. Labels are unbelievable.

The eejit Zeze by Leia Campbell

Katie's jacket the clown Zeze
Ignored the feeling of dizzy
Erratic is the clown eejit
A female hoax, my jewellery

Aligned I think, very glaikit
Gagged, bleeding, nervous
Keep it from Gran
Find greatness

A good idea that Zeze, cool eejit
I went through my quotes
I have affiliated with Katie
Versions of the quotes and cheeky coats

Link to presentation https://youtu.be/Bm_79hK-wVM?feature=shared

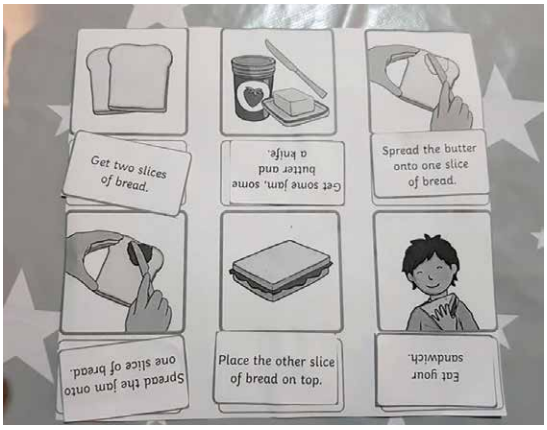
Leia's literacy journey

Like many children, Leia's literacy journey began with bedtime stories and being read to. However, the journey wasn't entirely conventional. Leia was hyperactive; books would be destroyed or thrown so she got less access to them. She didn't have a way of communicating her thoughts so couldn't ask questions or comment on books. She also didn't have the motor skills to engage in meaningful mark making or scribbling with pencils. In her favour, Leia did always have a good understanding of spoken words and could respond using a consistent yes and no. She also liked sticking things and was able to pick things up and place them where she wanted to.

Leia had some input from a home teacher pre-school. They mainly worked on teaching concepts such as "in", "on", "under". She had phonics instruction at school but it was hard to know if she knew the letters when she couldn't write or say them and a lot of the time she liked to "follow her own agenda" as countless report cards said.

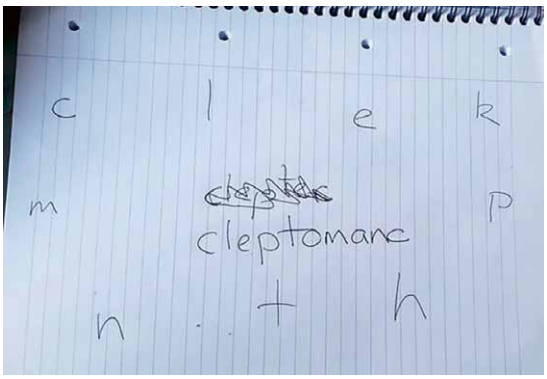
When Leia was in Primary 4, I attended a conference which led us on a life-changing journey. We learned how to introduce communication in a way that was most likely going to lead to success and the Four Blocks methods of literacy instruction. We introduced guided reading, alphabet and phonics instruction and using an alternative pencil to write letters. At the time Leia had a great team in school, and they implemented the same methods.

Leia made good progress early on, but she became stuck at a transitional level for a long time. It was very hard to say if she knew most of the letters most of the time. After a change in school team, we decided to get a tutor at home. Leia was able to show that she could read by sticking the correct sentences underneath pictures.



This was 4 years after we had begun our journey in earnest. We were still struggling with consistent spelling. Like many people with AS and other disabilities, Leia was consistently inconsistent. She wrote QRAYZ to describe her brother and then nothing for a long time.

I went back to university and studied a PGCE in Complex Communication Needs in which one of the courses was specifically on literacy. We had lost the great tutor but had started an online literacy class. So whilst Leia wasn't getting great input at school, we were still trying to improve literacy. Then one day I noticed that she had chosen all the letters for the word Scotland, but not in order. After this we began to put the letters she was choosing round in a circle, and she could very quickly choose them in the order she wanted to. She wrote the following to describe Gangsta Granny (a jewellery thief) if you are not familiar with the story. This was now 7 years into our literacy journey:



She remains at her online literacy class and has produced some great work. Until earlier this year, she was still using an alphabet flip chart but she was not enjoying the process. I cannot remember why I tried doing this, most likely sheer desperation as literacy class isn't always a harmonious time, but Leia makes choices by us assigning the choices to a particular finger and then she chooses the finger she wants. I combined this with her spelling and she was suddenly much more engaged and faster when she was writing. She would more often spell in the correct order too. We also introduced using the predictions on her talker keyboard as I was now more convinced that she was spelling in the correct order and it wouldn't get it frustratingly wrong for her.

We first offer 5 fingers representing a,e,i,o and u and then the corresponding letters such as i,j,k,l,m and n. Leia either kisses or points to the finger she wants.

There is still work to be done. It would be ideal if Leia could become more independent with her typing and finding suitable keyboards is our next task.

How Leia wrote her presentation

We first discussed the structure of the presentation, and I gave her a few options. Leia chose this structure. Leia chose to bookend the presentation with two poems she had already written as they explain a little about her personality. Dizzy is the word she uses for the thoughts whirring in her mind. The first poem was written using a structure, and she used a combination of spelling words and her talker.

Leia chose the design of the presentation and the first pictures. She wrote the first slide "Hello" using phrases that were already in her talker. For the slides from "First Labels" to "Angelman Syndrome", we Googled different labels, and Leia chose the types of labels that she wanted to write about. She then ordered the labels, and I offered some options of sentences. We did a similar process for her personality as a baby, as when I asked her about this, she used her talker to say "I don't know" which seems very fair. She also said she wanted to talk about Abbie's videos as she loves watching them.

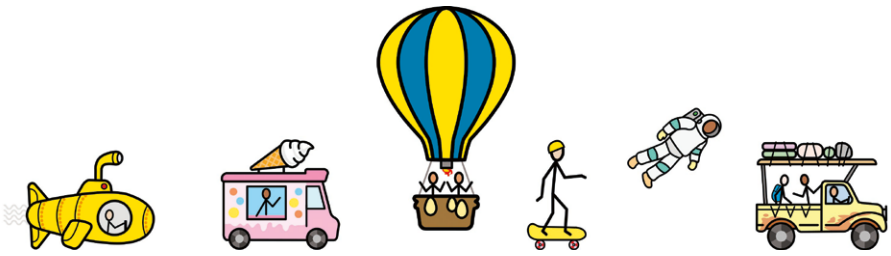
From the slide "Learning Disability" onwards, she used a combination of her talker, signing and writing. We reviewed the grammar together. As we were tight for time, we mainly did this with me (or other communication partners) offering suggestions.

The final poem "The eejit Zeze" Leia wrote every letter. Leia is still working on writing independently on her keyboard, so she relies on a communication partner. The letters are grouped into 5 with each new group starting with a vowel. Leia selects which group she wants and then the individual letter. She does this using an alphabet flip book, or an object or finger that has been assigned a particular letter. After three letters, it is put into her keyboard and Leia is offered the predictions. She often prefers to spell the full word though. We are researching different keyboards to make her more independent in her writing.

It is not a quick process, and determination and patience are needed in equal measures. She wrote her poetry and presentation with 5 different communication partners across multiple sessions. This is both a positive and a negative; she works differently with each partner and each partner has their own approach which can lead to inconsistency for Leia to manage. However, it is also very important that several people can help Leia communicate which reduces the risk of that person leaving Leia's life. The Zeze poem alone took 12 weeks to complete but the sense of pride and purpose she achieved on completion was well worth it!

Symbla - Widgit's New Learning App

JAMES ATTREE
Product Manager, Widgit Software
Email: james@widgit.com



Abstract

Symbla is an activity-based App designed for language stimulation and early literacy development which can help to build knowledge and reinforce learning.

Symbla contains ready-made exercises that follow a clear progression through vocabulary, phonics, early reading and writing development. Exercises include sorting, matching, memory games, spelling, true or false, find the meaning, and more. They can be played directly or assigned to users who can then play them offline.

You can also create and customise new interactive exercises using Widgit Symbols with custom vocabulary for the individual needs of each user or profile. Symbla accesses the entire Widgit Symbol set, with the same customisation you can expect from other Widgit products. This includes Smart Symbolisation, changing skin tone, swapping to black and white Symbols, editing the colours of a Symbol, choosing the Symbol line colour and changing the Symbol text.

Developed initially for use in Sweden, through extensive research into pedagogy, we will discuss the application of Symbla in the UK for practitioners, parents, and in school.

Commercial Interest and Authors

This publication was written by James Attree (james@widgit.com), a Product Manager at Widgit Software. This discusses a new product, that uses Widgit Symbols, with the aim to introduce and explain how the product works.

Widgit Software and Symbols

At Widgit, we believe in the transformative power of Symbols to enhance communication and understanding. Our mission is to break down barriers, empower individuals to express themselves, and ensure that everyone has the right to understand and be understood. Through the use of Symbols, we strive to create a more inclusive world, one where no one is left behind. This is the purpose that drives us.

What is Symbla?

Symbla is a tablet app that aims to help language development and early reading and writing by strengthening vocabulary and knowledge of the world. It contains a large variety of ready-made activities that can be adapted to capture an individual's interest and desire to learn. The activities provided have a clear progression of early reading and writing. You can also create activities from scratch to meet the very specific needs and interests of each individual, which we all know is so important to acknowledge.

It can be used in a number of different ways, supporting curricula such as Early Years, Primary, and Special Education. Any vocabulary you want to work with, you can create an activity to help.

You'll see the same familiar Widgit Symbols, enhanced with subtle animations as you move between pages. While these animations don't aim to add communicative value, they introduce a playful and engaging element designed to make the experience more enjoyable while doing an activity.

Replacing Widgit vocabulary apps

Symbla replaces all current Widgit Vocabulary Development apps, which offer limited activities with unflexible vocabulary lists. The vocabulary in these apps has been recreated in Symbla as new Topics, with more flexibility to modify and extend for your own needs.

Who is it for and how can it help?

Symbla works well for whole-class activities using a whiteboard, or more targeted one-to-one sessions. SLT practitioners can create truly bespoke activities tailored to individual needs. And for parents, it's a great way to reinforce what's being learned in school, all wrapped in a friendly, game-like interface that is enjoyable.

The app shines in several key areas: it helps build vocabulary knowledge and concepts, supports continuous provision and independent learning, and acts as a reinforcement tool. It can even be used for ongoing assessment, helping you track progress over time.

Symbla can offer a really engaging and motivating experience for learners and even limited use can add real value in supporting language development, understanding and learning.

Symbla isn't a replacement for any schemes of work. It is a support tool, especially useful for learners who need extra practice or reinforcement.

Examples of use

A special needs school in northern Sweden has a group of four students that have worked with Symbla almost daily during the last school year, their teacher has been able to use Symbla to create and tailor activities to fit each student's interest and make the various subjects more accessible and engaging. Before using Symbla, they were instead using a variety of different apps with limited possibilities to adapt to their own content. The power of Symbla for these students is how flexible and adaptable the App is for their own needs.

A speech and language therapist in Finland is working with Swedish speaking aphasia patients and has successfully used Symbla with several patients to create training material for word recognition and sentence building. In this example, they've disabled the Symbol animation feature and the more, let's say, "childish" elements of the App. This shows the use case of Symbla outside of "in the classroom", for more than just reading and writing, and not just for a younger audience.

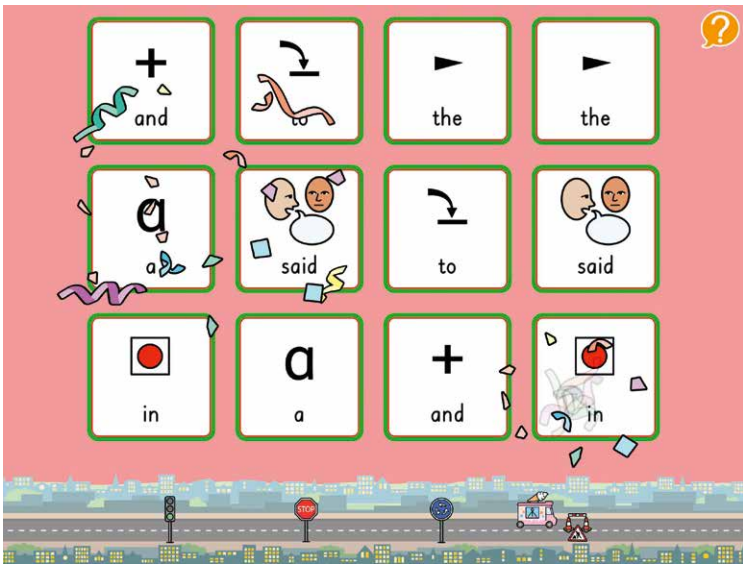
What are the key features and exercises?

Terminology

Symbla consists of three main concepts:

1. Topics
2. Activities
3. Pages, or Exercises

A **topic** is a collection of activities, e.g. "Core Vocabulary". An **activity** consists of multiple pages or exercises. A **page** is a single **exercise**, e.g. "Build a word".



Features

Practitioner and participant modes

There are two modes in Symbla:

1. Practitioner – A way to **create** and assign activities
2. Participant – A way to **play** activities

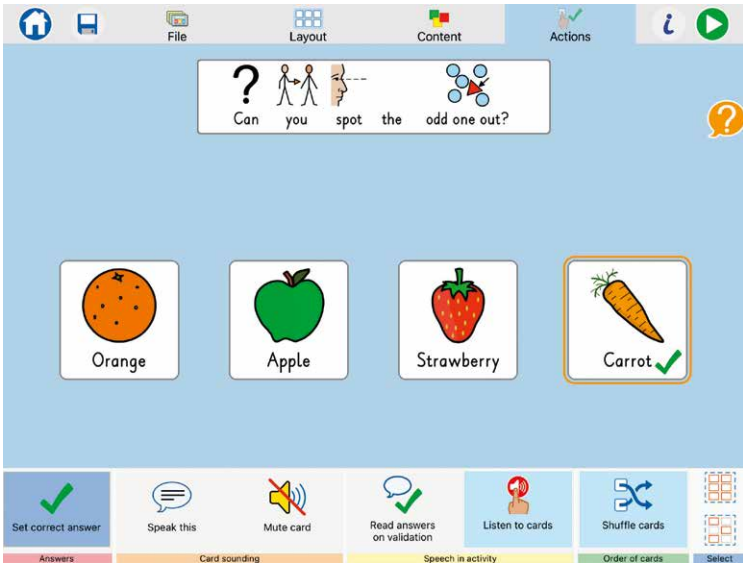
When you first open the App, you will see a list of profiles, or be able to create a new one. A practitioner can access the practitioner mode from this screen too, which gives them access to finding and creating activities and App settings.

Profiles and playing activities

Participants can set up a profile, where activities can be assigned by a practitioner. Profiles can be set up for individuals or for specific tasks. Profiles have a name and a symbol avatar.

When an activity is assigned to a profile, from the participant view, it appears in the profile to unbox and play. Once an activity is downloaded, it can be played with or without an internet connection.

Progress of activities is saved and shown, if you do not complete an activity. When going back, you will start where you left off. Activities can be played once and then reassigned to a profile to be played again.



Find activities

There are over 170 pre-made activities that a practitioner can download and use from the Find Activities tab. When you log in, as a practitioner, select the Find Activities tab at the top of the screen and look through all the topics and activities on offer, such as Phonics, Colourful Semantics, Core Vocabulary, and more.

Download a set of activities, which will appear in the My Activities tab, where you can use or modify for your own needs.

My activities and creating your own
Downloaded activities will appear here, along with Topics and Activities you create yourself. You can search and filter activities on this screen.

When you create a new Activity, you can choose from 13 exercise types, each with many options, detailed in the following section.

Widgit Symbols and Smart Symbolisation
When creating activities, you have the full power of Widgit Symbols, always evolving over time. New additions to the Symbol Set will be available without needing to update the App.

Smart Symbolisation allows the correct symbols to be returned, contextually, for the sentence, e.g. typing "Can you spot the odd one out" selects the correct symbols for "Can" and "Spot", based on their context within the sentence.

You also have full control over the Symbols, such as changing the text, symbol colours, skin tones or replacing the symbol with a picture or image.

Formatting and layout
For existing Widgit Customers, the UI is similar to Widgit Online, with familiar actions and icons. You can manage how your content is displayed, such as Text or Symbol only, Text and Symbols, Text Above or Below. You can change the border, background, corner radius and thickness for each frame.

Instead of starting your exercise from scratch, you can quickly amend an exercise by adding additional frames, or removing frames, from the Layout tab.

Full control with Actions
Exercises have internal logic, such as preselected items, choosing which elements are correct or match a specific category. You can also set what sounds are heard when you click on frames or when the exercise loads. You can replace the spoken text for a frame with additional text-to-speech, or record your own spoken instructions.

You can manage all of these settings from the Actions tab.

Managing Symbol Animations and Sounds
Symbla comes with Symbol Animations and Sounds to help create an engaging atmosphere when playing through activities. These can be disabled in the Settings menu to help provide as much flexibility as possible.

Exercises

Below are a list of exercises that Symbla comes with, including a brief description of what they are and how they can be customised.

Build a sentence • Build a sentence by dragging words or phrases to form a correct sentence. Sentences can be text only or feature symbol support.

Arrange • Drag the cards into the correct sequence order. The template is available both with and without symbols and with different numbers of elements to arrange.

Build a word • Build a word from a selection of letters. The level of difficulty can be adjusted by placing letters at the outset or by adding a number of extra letters to act as distractors.

Connect the cards • Draw lines between the cards. Creators can choose different layouts for the pairs (e.g. Symbol to Symbol, Text to Symbol) so the template has many uses.

Clip cards • Find the correct answer for each clip card. The large cell contains the question while the smaller cells have different possible answers. You can swap the text and symbols to ask a question and have symbols as the answer.

Drop cards • Drag the correct card to the correct statement. The level of difficulty can be increased by adding extra incorrect answers as distractors.

Find the cards • Find the cards that meet your criteria. When creating this activity, use one of the many templates to select how you want your criteria to be met, e.g. a question, sentence, category, and then choose how many options you want. Select the correct answers in the Actions tab.

Label the cards • Drag the correct word to label the correct card. Creators can also choose to add distractors here too.

Memory • Play memory. Creators can choose difficult layouts for the pairs as well as different but matching content, e.g. the template could be used for rhyming activities, animal to habitat, matching, or antonyms.

Multiple Choice • Choose the appropriate option under each card. The template is available both with and without the addition of Symbols and different numbers of questions and answers.

Sort the cards • Sort the cards into the correct boxes. Creators can choose different numbers of cards and two to four boxes.

True or false • Click the correct option next to each statement. These templates can be used to frame yes/no, true/false, or comparison questions.

How can you get it?

Symbla will be available for iPadOS and Android (releasing later in 2025) on the App Store and the Google Play Store. For more information, please contact info@widgit.com.

Celebrating Individuality, Empowering Lives: The Via Range by Liberator

MICK DAVIES, AAC CONSULTANT MANAGER, LIBERATOR LTD
Email: Mick@liberator.co.uk

In a world where communication is the cornerstone of connection, expression, and identity, the ability to speak one's mind is not just a privilege, it's a fundamental human right. For individuals with speech and language impairments, this right can feel out of reach. Liberator, a pioneering force in Augmentative and Alternative Communication (AAC), is changing that narrative with its innovative Via range of AAC devices. Through thoughtful design, personalised technology, and unwavering support, Liberator is not just providing tools, it's empowering lives.

The Via range: personal style meets practical design

Liberator's Via range is a fusion of functionality and personal flair. Available in three distinct sizes: Via Air, Via Mini, and Via Nano. These devices cater to diverse lifestyles and mobility needs. Whether someone is on the go, in the classroom, or at home, there's a Via device that fits seamlessly into every day.

But it's not just about size. The Via range offers colour options that allow users to express their personality. These devices are lightweight, durable, and portable. Designed to withstand the rigours of daily life while reflecting the uniqueness of each user.

Express your personality with Via

Vocabulary that speaks your language

Communication is deeply personal, and Liberator understands that one size does not fit all. That's why the Via range supports a variety of vocabulary systems tailored to different communication styles and developmental stages:

- **TouchChat with WordPower**: Ideal for users who benefit from symbol-based communication with robust word prediction.
- **LAMP Words for Life**: Designed for those who thrive with motor planning and consistent access to vocabulary.
- **Unity AAC**: A versatile Minspeak system that supports both beginners and advanced communicators.
- **Dialogue AAC**: Simple AAC for literate users.
- **Open Access**: For users who prefer third-party AAC apps, the Via range offers full compatibility.

This flexibility ensures that every user can find a system that resonates with their cognitive, linguistic, and motor abilities.

Access that works for you

Liberator's commitment to accessibility is evident in the range of input methods supported by the Via devices. From touch access with optional keyguards to switches and headtracking, individuals can choose the method that best suits their physical capabilities. Custom-made keyguards are available for third-party apps like Grid, Proloquo, and TD Snap, ensuring seamless integration and ease of use.

Voices that reflect identity

A voice is more than sound; it's a reflection of identity. Liberator offers a rich selection of regional and personalized voices, including:

- **Amalgu**
- **Acapela**
- **Apple**
- **Cereproc**
- **The Voice Keeper – AI**
- **Acapela My Own Voice**
- **Apple Personal Voice**

These options allow users to select voices that match their age, accent, and personality, fostering a sense of ownership and authenticity in communication.

Technology that adapts to you

The Via range is not just smart, it's intuitive. Features like split-screen multitasking and app launching directly from the Liberator vocabularies streamline the user experience. Individuals can share text from their communication app with compatible iOS apps, enhancing interaction across platforms and making everyday tasks more efficient.

Support every step of the way

Our dedication doesn't end with the device. We offer comprehensive support services, including:

- **Free Assessments**: Ensuring the right fit for each individual.
- **Free Device Trials**: Allowing users to test before committing.
- **Free Training and Support**: Empowering users and caregivers with knowledge.
- **App Partner Program**: Facilitating collaboration and innovation.

This holistic approach ensures that users are never alone on their communication journey.

Peace of mind with warranties

Durability and reliability are critical when it comes to AAC devices. Liberator provides a comprehensive warranty with each Via device, including accidental damage claims (contact us for further information). A dedicated UK-based support and repair team ensures quick and efficient service, giving users and families peace of mind.

Real voices, real impact

The power of AAC is best understood through the voices of those who use it. Liberator Ambassador Abdi Omar captures this beautifully:

"Imagine being a child who understands everything, has thoughts, dreams, personality, but can't express any of it. Communication changes lives. I know this, because it changed mine."

Abdi's words are a poignant reminder of the transformative impact of communication. Through AAC, individuals are not just given a voice, they are given the power to connect, to express, and to thrive.

Conclusion: a celebration of individuality

Liberator's Via range is more than a product line… it's a celebration of individuality. It's a testament to the belief that everyone deserves to be heard, understood, and valued. By combining cutting-edge technology with compassionate support, Liberator is redefining what it means to communicate.

From Club to Community: Building Inclusive Communication in Northallerton

Insights from starting a grassroots AAC club in rural Yorkshire

TOM MCDONALD[1] AND VERITY ELLIOTT[2]
[1] Facilitator, Northallerton Communication Club
[2] Project Coordinator, Communication Matters Mentoring Project
Email: mentoringproject@communicationmatters.org.uk

Introduction

In the summer of 2024, I attended a Communication Matters webinar about the mentoring project. Verity Elliott explained how CM had received some National Lottery funding for AAC users to achieve a range of Level 1 and 2 accredited courses to become mentors, and how funding could support anyone wanting to start a communication club. Communication Matters has enabled us to start the group and has covered some of the essential costs: venue, travel and any resources we might need. There is more information about the CM Peer Support & Mentoring Project at the end of this article.

I had wanted to set up a local group for disabled people for a long time but wasn't sure what the focus should be. Part of that came from my own family. My son has disabilities, and when I looked around locally there wasn't much for him to join. Another part came from my late mum, who ran a weekly leisure club for disabled young people and adults for many years. I wanted to do something in her spirit – a space that gave people not just an activity, but a community.

My background is in teaching children with special needs before moving into assistive technology consultancy. I've been involved in disability groups since I was a teenager, and before that my family ran trips and clubs in Keighley, West Yorkshire, where there was once a thriving network of groups. Over the past 15 years many have disappeared. When I moved to Thirsk it struck me how few existed here at all. Things are starting to change. My son can now join activities like football and theatre, but I wanted to build something grounded in my own expertise: communication.

Getting started

The first challenge was finding a venue. I asked in local SEND groups online and received a few suggestions. A past colleague, Julie Tarn, got in touch and offered to help. We visited the Mencap Hub in Northallerton. It was ideal: wheelchair accessible, with a Changing Places facility, kitchen, car park and plenty of space. We booked it for December 2024.

Neither of us expected much of a turnout for the first session. To our surprise, six AAC users arrived with parents and carers. Straight away we could see the need for a club like this.

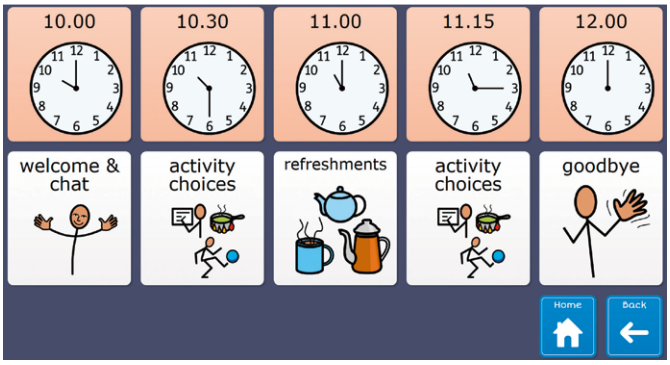
Who the club is for

We never advertised an age range. At that first session, we had everyone from teenagers to adults in their 60s. For now, we've kept it open to that group, knowing that younger children will need something else.

How the club runs

The club meets on the first Saturday of each month from 10am to 12pm. We start with a themed vocabulary scavenger hunt. The idea is to give AAC users words that go beyond making requests – vocabulary that sparks conversations. Themes are broad enough to work for different levels. For example, when the theme was summer, one AAC user combined two words to ask "Where go?", while others built longer sentences.

After a short break, members choose what they'd like to do. There are board games, activities and lots of conversation. My favourite has been adapting *Guess Who* for AAC. Free gridsets online gave us a starting point, and we made our own tweaks. I have also made paper-based core boards for things like Lego and pool so there is the chance to model or find related vocabulary for the activities. The second hour is my favourite part of the club: time to sit and chat with AAC users, learning about their lives and interests.



What we've learned

In the early days we over planned – printing resources that weren't touched. We've learned that less structure works better. The atmosphere is relaxed, with no pressure, no targets, and plenty of space for things to develop naturally.

There's still work behind the scenes. Safeguarding, GDPR and child protection policies need to be in place. I also have to make flyers and share these on social media. We ask members for photo permissions so we can share what we do more widely. Running an informal club still means managing risk, insurance and admin.

The impact so far

The most powerful part has been watching confidence grow. Parents tell us AAC is being used more at home and in public. Friendships are forming, and families feel less isolated.

One parent said:

> *"It is hard to find social activities for older children with disabilities – not only does the group provide this, but it encourages interaction and communication. My daughter used her AAC only at school... but now she lets me join in. That's started to spread to home. This could be life-changing for our family."*

Another AAC user described the club as:

> *"a great way to meet other AAC users and to communicate on a level playing field... It gives me a reason to use different vocabulary as I do different activities, expanding my skills."*

We've also seen individual journeys. One young man came to the club quiet and anxious. Over time, he began to join in more and more, with a highlight being the day he ordered his first ever cup of tea. For him, that was about more than tea – it was about confidence, communication and independence.

Looking ahead

We're already thinking about what's next. We'd like to start a separate club for younger AAC users, develop accessible gaming and music-making sessions, and create symbol-supported resources for families. We're also wanting to build partnerships with libraries, youth groups and community events, and hope to grow a team of volunteers.

Conclusion

Starting the Northallerton Communication Club has shown me what true inclusion in communication can look like: a space where AAC users meet as equals, try things out, and connect with others. For some people, it's a chance to practise. For others, it's simply a place to socialise. For all of us it feels like being part of a community.

For more information:

NORTHALLERTON COMMUNICATION CLUB:
Tom McDonald & Julie Tarn – aac.northallerton@gmail.com
CM PEER SUPPORT & MENTORING:
Verity Elliott – mentoringproject@communicationmatters.org.uk
https://www.communicationmatters.org.uk/what-we-do/projects/mentoring-projects-2024/

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