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Conference Delegates Mateusz and Bartlomiej from Poland chatting with CM member Sam at the Communication Matters Conference in September 2024.

Contents

Chair's Report

HELEN WHITTLE

One of the aims of Communication Matters as a Charity is to raise awareness of AAC. In the past, this has involved lobbying and has been successful in helping establish the NHS funding of AAC and AT for those who meet the assessment criteria of the Specialised Services in England. Although the funding systems are different in Scotland, Wales and Northern Ireland, the CM Trustees represent the members in all the devolved nations. The Trustees of Communication Matters (CM) represent you as members in many different meetings across the year and use this to highlight the needs of those who use AAC. However, since the Covid pandemic, lobbying was less of a focus for CM as we concentrated on making sure we were financially secure as a charity.

Now, we are increasingly being asked by Government departments and other groups for our opinion about the latest plans and new ideas in terms of AAC. The Labour Government has just announced the scrapping of NHS England which is involved in many services that directly affect our members. So, it is an important time for us to be able to speak up for our members, in this time of change. As a charity with a small staff and volunteers, there is only so much we can do alongside running the organisation and events, but we have recently become part of the establishment of the Speech, Language and Communication Alliance. We are 1 of 33 organisations that have come together to influence policy makers about the needs of those with communication challenges.

From left to right: Christie Hutchings (Beth's PA), Helen Whittle, Beth Moulam, Tina Voizey, Sarah McPoland (CM Trustees)

The Alliance was launched in February 2025 with a reception in the House of Lords. Four Communication Matters Trustees attended, and Beth Moulam spoke about her lived experience of the importance of a well-trained workforce to support those who need AAC. The other key message was about the importance of early identification of communication differences. Beth spoke alongside others with lived experience of communication challenges, such as selective mutism and Developmental Language Disorder (DLD). Stephen Morgan, Minister for Early Education, sent a video message of support. The event was hosted by Lord Touhig and attended by MP for Lowestoft, Jess Asato, who spoke about her understanding of the need for support for those with communication challenges. She emphasised the influence of communication on their learning, social interaction and emotional well-being into adulthood.

So, this is a good start, and by coming together I believe we are more likely to be heard at a national level.

Communication Matters' basis for lobbying will always be in support of those needing AAC. As Beth Moulam and Helen Hewson have said in their 'Our Futures' project, "Nothing about us, without us". This is very much the stance that CM will be taking in terms of lobbying.

The CM AAC User Focus Group continues to meet regularly and informs the Board of Trustees of the priorities of AAC users. The work on the 'Our Futures' project continues and will be highlighted again at the Peer Support Sharing Best Practice Day on 15th April and at this year's CM Conference (8-9th September).

The conference will be preceded by a Relaxed Exhibition on 7th September to welcome AAC users, conference delegates and members of the public who would like to meet with suppliers and learn more about AAC in a quieter and less busy space.

On the evening of 8th September, we will be hosting our biennial AAC Awards 2025 event which celebrates all forms of communication, the people who use AAC, and the professionals, families and suppliers that support them. Being held at the Royal Armouries in Leeds, we are certain the awards, dinner and dancing will prove to be a fun and exciting night for all!

The conference will be followed by a Post-Conference Research Study Day on 10th September. This additional day is open to conference delegates and others who are interested in research focused strands delivered by an international cohort of researchers and academics.

Registration for the Relaxed Exhibition, Conference, Awards and Study Day is now open, and you have until 16th April to apply to present at the conference - please see our Call for Papers. We look forward to seeing you all there!

Last but not least, we are pleased to be running an AAC Information Day in Belfast at the Girdwood Community Hub on 12th June. This event is a product demonstration day supported and presented by the UK's leading suppliers of communication aids, equipment, software and symbol systems. This free day consists of five presentations which provide information and offer up-to-date knowledge on the range of AAC products available. You can book now at the link above.

A Remarkable Invention

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Above: Aimee and a friend

Left: Aimee playing a game

This article explores how communication aids with computer systems can empower individuals with physical disabilities to work and learn independently, as well as the benefits of gaming on them. It also covers how children can use most devices for imaginative play and strategies for engaging with friends.

To begin, I have Cerebral Palsy, which prevents me from walking, using my hands or arms or speaking. Instead, I use a communication aid called an Accent 1400 to speak. I control it with my eyes, a technique known as eye gaze. This has a computer system which I use for multiple things, such as, gaming. I also use a powered wheelchair to get around with switches which are inbuilt into my head rest. I attended a school for children with disabilities before moving to mainstream schools where I took my GCSEs. I then volunteered for children's services at my local NHS Trust, advising on service improvements. After several years, I pursued a health and social care degree from the Open University. Since graduating, I have begun guest lecturing at universities about my experiences using various health services as a person with a disability. I also hope to set up a business, giving talks in schools about disability.

Communication aids with computer systems can enable people with physical disabilities to work independently in education. This is by having word processing software, such as Microsoft Word, downloaded onto their device and them using it to complete their work. While this might sound straightforward, the benefits might not be apparent. To illustrate these, I will reflect on how I used to do my work for school and university.

At school, my assistants used to write out my work for me, whilst I told them what to put. However, their tendency to predict and correct my responses made my work less challenging and engaging. Because of this, my teachers never knew if I was understanding what they were teaching me until I took tests. This was because my assistants were not allowed to predict or correct me during these times.

However, doing work on my own would have helped me develop two essential skills: how to be independent and how to figure things out by myself.

Yet, as the complete opposite, I did my university work without any assistance. I did my work on the computer system of my communication aid, using Microsoft Word. Working alone allowed me to think more deeply about the topic of my assignments which increased my understanding. Additionally, since I did not have any help with my work, I could feel a sense of pride when I did well. This was unlike at school where I felt indifferent about my achievements due to the help I received.

People, using the computer system on their communication aid, could potentially achieve similar outcomes. Nevertheless, there are some factors which should be considered. Younger children or those less familiar with computers may need help setting up work or using tools, such as to draw tables. Moreover, the process can be time-consuming depending on how people control their device. For example, I took weeks or months to complete my university coursework and needed extra time to write most of it. This is because I was writing everything out myself and had to ensure my work was presented correctly. If I had not got additional time, I would have found it very challenging to fully complete my work. I strongly recommend that people who complete work on their device's computer and control their device slowly arrange to get additional time to complete tasks. Furthermore, I also recommend that people in school and college do not work this way in all their lessons. This is because they may not be able to complete all their work during the lesson itself. Therefore, if they did this, they would have an endless buildup of unfinished work to complete. Instead, they should decide which lessons they would benefit the most from working independently in. Also, they could be allowed to skip a less important lesson to complete remaining work. Note: schools and colleges have frequent tasks, while universities typically have fewer, but longer, tasks.

Moreover, the computer system on communication aids can assist people with physical disabilities to learn and engage with what they need or want to learn about without assistance. This is by downloading relevant apps and accessing digital resources. To illustrate this, maths was a constant struggle before and during my school years, as I found it difficult to understand the things I was learning. Also, maths partly involves children doing physical activities, which I could not do and so my assistant did them for me. This was sometimes under my instruction if the activity allowed for it. However, because I was not doing them myself, I struggled to understand how to do them. For instance, when a child is learning to count and work out simple sums, they often use their fingers or tools, such as number grids or counters. My assistant would help me count on their fingers or use the tools instead.

As a child today, my communication aid could have enabled me to do these activities without assistance. For example, I could have accessed websites or apps, which have interactive activities for counting and basic calculations. When I was in school, using maths websites during lessons was not common. However, I could sometimes use my communication device to do math activities that were similar to what the other children were doing, even if they were not doing digital ones. Furthermore, there are other digital resources I could have accessed to help me with counting and doing basic calculations. For example, I could have used a digital version of number grid and number line, allowing me to use my cursor to count the squares and move along the number line. As I have illustrated, communication aids with computer systems can be a valuable tool to help people with physical disabilities learn independently.

Additionally, communication aid users can play PC games on the computer system of their communication aid. Whilst this is apparent, its benefit may be unclear. I have a major passion for gaming, which I do on my device's computer system. This means I control games with my eyes, which enables me to perform actions quickly and accurately. In the past, I gamed on a laptop, which I controlled by my communication aid. I also briefly tried using head switches to work gaming consoles. However, these methods were often slow and inaccurate, especially when trying to select fast-moving objects. Although I still enjoyed gaming these ways, these challenges made the activity less pleasurable and engaging. It was a major deal when I started gaming on my communication aid's computer system, I did not have these issues anymore, making it more enjoyable.

Furthermore, my favourite games involve creating and controlling a character's life and building and running something, such as a hospital or city. They require players to perform quick actions. For instance, in The Sims, players must quickly decide what their characters do next. If they do not choose fast enough, the game will make decisions for them. This can be annoying, especially when it changes the story players want to follow. I played this on a laptop before doing so on a communication aid.

Additionally, I enjoy competitive games. During these games, players often compete to do something in the quickest amount of time. For instance, I play a music quiz, where players compete to answer the most questions in the quickest time. I used to play this on a laptop and I lost many games, as I was too slow. I might win one or two games out of many. Now I play it on my communication aid, I win much more. I think it would benefit some people to use the computer system on their communication aid for gaming.

Furthermore, children with communication aids can use their devices to create and play imaginative games, similar to traditional pretend play with figurines or play sets. This was a favourite pastime of mine growing up. I did this in a section which normally would be used to store new vocabulary. Most software comes with categories of pictures someone can use to represent new words. Using these was a core part of the games. For games involving characters, I would put their names on the keys in the section. Then, I would use the pictures to represent what they were doing. For example, my favourite game was creating an imaginary family and living out their day-to-day lives. I would use the pictures to represent what they were doing. For instance, if I decide a family I make was going to spend a day at the park, I might put an image of a swing or slide on the children's keys to show that they are playing on them. Also, I might put a picture of a bench to show that the parents are sitting on a bench and having a chat.

Here are a couple of other games I used to enjoy playing. I pretended to go grocery shopping. I used to browse through categories of images of food and drink as they were on sale in a shop, choose what I was going to 'buy', and then put them in a section I imagined was my trolley. I also held horse races. I would put images of horses on the keys in a section with their name above their picture. Then, I would mentally narrate a horse racing commentary, while moving the keys around until I decided which would win. The horse was on the first key in the section was declared the winner. Whilst there are a wide range of toys that children with physical disabilities can play with themselves, there is not any they can use to fully get wrapped up in an imaginary life. Yet, this is a way for those who have communication aids to do this.

Also, people with disabilities should be open about things they could do with their friends' help. I have always done this with my friends and they have been keen to help. For instance, I told my friends from high school and my adult life how to set up my communication aid and put it away. Therefore, they could do it for me when we were together. Furthermore, in addition to my communication aid, I also use signs to communicate. Since I was a child, I have explained them to my friends, so I could use them with them. The heart of friendship is being there for each other and helping one another. Friends will be only too happy to help and make things easier.

Moreover, it can be helpful for people with disabilities to suggest activities they can do with new friends, as they are getting to know them. This is because they will probably be unsure about what they can do. I have taken the lead in proposing activities my friends and I could do together in the beginning of our relationships for this reason. As they got to know me more, they got more involved in suggesting things we could do together.

In conclusion, computer systems on communication aids can enable people with physical disabilities to work and learn without needing assistance. Also, gaming on this system means they control games the same way they control their device. This might help them access the activity better. Furthermore, children can create and play imaginary games on their communication aids. Finally, it is important for people with disabilities to be open with their friends about how they could help them and suggest things they could do when they first are getting to know them. It is incredible how multipurpose some of these devices are, and they can help people in almost all areas of their lives. They really are remarkable inventions!

Developing Voice Banking Technology for a Range of Communication Needs

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Introduction

The term 'voice banking' is used to describe the process of taking a series of voice recordings by an individual and using these to generate a synthetic version of that person's voice (Costello, 2016). The resulting synthetic voice can then be used through "text to speech" technology to convert typed texted into synthetic speech.

For many people who use a Voice Output Communication Aid (VOCA) or Speech Generating Device (SGD), a personalised synthetic voice can be used to replace a pre-installed synthetic voice, allowing the individual to capture part of their identity when spoken communication is not possible.

Historically voice banking was mainly targeted towards people living with motor neuron disease (MND), who knew they would go on to lose their speech as their disease progressed, and therefore had the opportunity to record or "bank" their voice before they lost it. However, if the person's speech was impaired at all, these symptoms would be replicated in the synthetic voice. Additionally, voice banking required an individual to be able to complete an intelligible recording and therefore excluded people with unintelligible speech from creating their own personalised voice.

Background to SpeakUnique

SpeakUnique began as a University of Edinburgh research project, within the Euan MacDonald Centre for MND Research and the Centre for Speech Technology Research. The aim of the research was to develop voice banking technology to be more accessible for people living with MND and other medical conditions that impact speech (Veaux, C. et al, 2013a).

The research project benefited from various sources of funding, including the Motor Neurone Disease Association, the Medical Research Council and Scottish Government. The initial focus was on collecting a "bank" of healthy voice donors that were used to crowdsource the required speech data needed to generate a synthetic voice and reduce the requirement from a single speaker (Veaux, C. et al, 2013b). This allowed the creation of a personalised synthetic voice for someone using only a very short recording of them speaking.

Future research focused on working with people who might benefit from using a personalised synthetic voice in a VOCA. This allowed people living with a range of communication needs to record at home, compare their personalised synthetic voice with the generic voice offerings and feedback on the experience.

It became apparent that there was a need to offer a solution that catered to people who already had impairment in their speech, or who were not able to complete a recording, either as their speech had deteriorated too far, or they had never had intelligible speech. As noted above, traditional voice banking methods would exclude these individuals and so further refinement and development of the technology took place. This resulted in the ability to "repair" impaired speech and generate a healthy personalised synthetic voice even when only impaired speech was available, and also to create completely bespoke voice by blending together two donor voices.

The feedback from users was that creating a personalised synthetic voice was a positive experience and benefited both the user and their family by allowing them to capture a part of their identity, otherwise lost when natural speech was not possible.

> *"I mean, you are your voice, aren't you? … … it's so your personality as well. …But it's a huge thing to be able to still communicate and people know that it's you that's doing the talking and not a machine really"*

Quote from research participant, 2017

To allow the full potential of this technology to occur, SpeakUnique was launched as a service, independent of the University of Edinburgh, in June 2020.

Tailoring Solutions for Diverse Needs

By creating our services with the user in mind, we have made voice banking accessible to people with many different communication needs; those living with neurodegenerative conditions, including MND, progressive supranuclear palsy, multiple system atrophy, and ataxia. We also offer voices to people with cerebral palsy, autism, and head and neck cancer.

SpeakUnique offers three distinct services designed to meet the varying needs of users:

- Voice Build: For individuals with a medical diagnosis that puts their speech at risk but who have not yet experienced noticeable changes. Users complete a short recording, and we use this to generate their synthetic voice, ensuring their voice is preserved for future use.
- Voice Repair: For users whose speech has already become impaired, our technology can remove the impairment from the recordings, creating a synthetic voice that is clear and healthy, restoring the sound of their voice as it would have been before any changes.
- Voice Design: For those without intelligible speech who still wish to create a bespoke voice. This can either be by using old recordings of someone speaking to recreate their voice, or by blending donor voices to create a completely bespoke voice that doesn't sound exactly like each voice donor, but has the desired characteristics such as age, gender and regional accent

Adapting and Innovating to Meet Users Needs

We take a user-centred approach to improve user experience and meet the needs of our diverse user base.

This includes the development of more accessible recording scripts, such as a "simple script" of common phrases for users with literacy challenges, visual impairments, or those who fatigue easily. Recognising that some users may only be intelligible at the single-word level, we also developed a single-word script for use with the Voice Design service. This enables users to incorporate aspects of their own voice while ensuring the final synthetic voice is fully intelligible and of high quality, with the help of donor voices.

We are also aware that a personalised synthetic voice might not be appropriate or accessible to all VOCA users, however they may still wish to use a voice that more closely reflects the regional accent of those around them. We have therefore created a selection of voices that cover 14 regional accents across the UK. These are exclusively available through Smartbox devices, as part of their software.

New Developments

As well as working collaboratively with VOCA users who come directly to us, we also collaborate extensively with healthcare professionals (HCPs). In response to feedback, we have recently started offering 'Clinician Accounts'. These allow healthcare providers to monitor progress and simplify the management of multiple patients going through the voice banking process.

Our most exciting recent development comes in response to something that we receive a lot of requests for: personalised synthetic voices for young people. There is currently a real limitation in the lack of voices available for young people and this often means many young people are using the same voice.

We've had requests from many young people, who are often very proficient AAC users, and quite rightly feel very strongly that they want a voice that reflects their individuality. We've also heard this from parents who strongly believe that a personalised voice would help give 'ownership' of communication and improve self-esteem, confidence and motivation. To date, we've helped young people living with cerebral palsy and autism use our Voice Design service to create a voice that fits in with their family and their identity.

> *"He has been enjoying his new voice in a much deeper way than we could have foreseen … he connected with it immediately and kept repeating everything that his new voice said, over and over. There are times where he struggles to process information but in this case, he processed it faster than I could. He kept smiling, giggling … He doesn't have the words to tell us yet but it was clear for us all to see by the expression on his incredibly happy face. We were amazed – still are. Probably always will be."*

> Quote from the parent of a SpeakUnique user

To create a Voice Design for a young person, they need to have two voice donors who are willing to record and able to read one of our scripts. This approach will continue to evolve, as our service does, to meet our users' needs. If you have any questions about any of our services, or how to access them please get in touch at support@speakunique.co.uk.

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AAC Implementation Through Joint Working in a Special School

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Background

This article outlines an AAC Pilot Project that was carried out in a Special School for Autistic Children and Young People across an academic year. This project was completed at Drumbeat School in Lewisham. This school caters for autistic students from Reception to Sixth Form. Students attending the school have a range of communication and learning profiles. At the time of the project, the school was based across two sites. The Speech and Language Therapy Team at the school consisted of a school-employed Speech and Language Therapist, a school-commissioned Speech and Language Therapist, two NHS Speech and Language Therapists and an NHS Therapy Assistant Practitioner (TAP).

This project involved joint working between education staff, school-employed and school-commissioned Speech and Language Therapists and the NHS Speech and Language Therapy Team. Historically, AAC support at the school involved NHS and school-employed SLT teams working separately, with occasional informal discussions around low-tech AAC options. There had been a clear division of caseload and at the time, there was no formalised whole school approach to AAC implementation. It was agreed that everyone would work together to support AAC implementation in the school. Everyone was enthusiastic about working together, particularly at a whole-school and strategic level, to improve outcomes for students.

Audit

An audit was completed at the end of the previous academic year, prior to the start of the project. The audit was designed to identify students that required additional AAC support. The audit involved class teachers completing an audit tool for each student in their class. At the time of the initial audit, no high-tech AAC was being used in the school. PECS (Picture Exchange Communication System) was the preferred form of AAC being used in the setting. There was little extension of this system to more personalised robust vocabularies, although some class-based communication boards were used to support play. It was found that PECS was being used predominantly at snack-time and for preferred choosing activities. There was little generalisation of this system to other times of the day. From this process, 10 students were identified as candidates to participate in the AAC Pilot Project for the trialling of high-tech AAC systems. The audit also identified a broader range of students requiring review of their current AAC system. School senior leaders and Speech and Language Therapists also visited other special schools to gather information on AAC apps that were being used most successfully with autistic students.

Project planning and joint-working with school senior leadership

An AAC Working Party was established with senior leaders in the school to drive the project. AAC Specialist, Alice Gallimore (Principal NHS SLT) joined this Working Party to provide clinical expertise and guidance. For the 10 students identified, baseline information was gathered through teacher and parent questionnaires and TOMS measures (Therapy Outcome Measures). The TOMS measure included the "Support" domain which considered the environmental support being offered to AAC users by their communication partners. Objectives were set at a whole school level with the aims of creating an aided language environment and an environment of supportive communication partners. Implementation was planned across Universal, Targeted and Specialist levels. The school senior leadership team were keen to drive this forward and demonstrated this shared goal by focusing on AAC in

the school development plan and staff CPD (Continuing Professional Development) planning. Links were made with the local ACS Hub (Assistive Communication Service) for SLTs to access training and receive guidance in AAC implementation.

Implementation

High-tech and low-tech AAC

The school senior leadership team agreed to provide funding for high-tech AAC. 10 licences for communication software were purchased for students involved in the Pilot Project and 10 further licences were funded for class groups. The high-tech systems that were used were as follows: Grid for iPad - Supercore 30, Supercore 50, and Vocachat which were all used on iPads. The senior leadership also agreed to allow the iPads to travel between home and school.

Whilst the 10 students involved in the Pilot Project were being trialled with high-tech AAC systems, there was a simultaneous increase in the extension of low-tech communication systems across the school for students identified through the audit. A range of different low-tech communication books were developed, trialled and reviewed during the year of the Pilot Project.
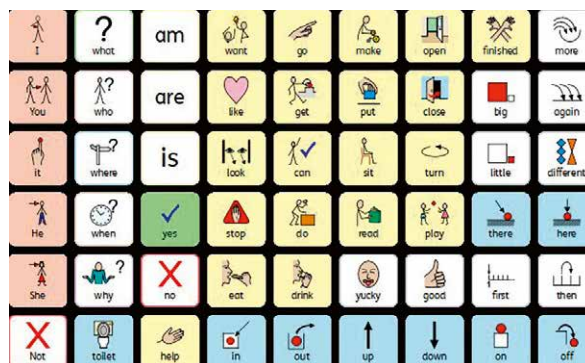

Figure 1: Communication Board with core vocabulary

Universal Level

Smartbox Training Day

Links were made with Smartbox (AAC providers) and a joint staff and parent training session was facilitated by their Assistive Technology Specialist. This allowed staff and parents to practise using the iPads and AAC apps. Parents and staff members learning together was a great success. Access appointments with the Smartbox Specialist, the SLT team, education staff and pupils also enabled further personalised training.

Figure 2: AAC Champion symbol used to advertise role

AAC Champions

The role of AAC Champions was established in the school to have advocates for AAC users and to cascade information within the staff team. The role was advertised to all staff and those interested in developing their knowledge volunteered to access additional training offered by the SLT team. There was an AAC Champion in each class where there was a high-tech AAC user.

Gabrielle Moreton (TAP) designed "*Ask me about AAC*" badges for SLTs and AAC Champions to wear to raise awareness of and visibility of AAC in the school. AAC display boards were created across sites. Reminder notices were posted around the school to encourage staff to support students in having access to their AAC devices throughout the day.

Targeted Level

A weekly Chat Club was set up on both sites for AAC users and key members of staff. The Chat Club was designed to be an informal opportunity for AAC users to meet together and for key staff members to develop their skills in being supportive Communication Partners. The Chat Club on the site for older students practised using their AAC systems in the school café. They organised a party at the end of the term and went to the local shop to buy the supplies that they wanted, allowing them to practise their communication skills in the community.

The Speech and Language Therapists and the TAP spent time in classrooms modelling the use of AAC systems and supporting staff in facilitating AAC use within learning activities. The SLT team also supported class teachers in writing targets that included AAC.

Figure 4: Pyramid depicting Universal Targeted and Specialist levels of intervention

Specialist Level

Direct AAC input from the SLT team was also provided to individual students on a needs-led basis. The SLTs and TAP met with parents to provide training and support. Modelling sessions were also completed with parents/carers and family members.

Case Study

Student C. (7 years old at the start of project) was highlighted through the AAC audit. Prior to the start of the project, he used non-speaking means of making his needs and preferences known. He would, for example, point and vocalise to request. He communicated mainly through gesture and guiding people by the hand. He would also use communication supports accessible in his environment, for example, pointing to symbols/photographs on the wall. C. was set up with Grid for iPad (Supercore 50). His parent attended the Smartbox Training session. His class teacher volunteered for the role of AAC Champion and also attended this training. The TAP worked in C.'s classroom and directly with C. to model the principles of Aided Language Stimulation for staff and to support the use of his AAC system within learning activities and across his day.

Following a period of implementation C. began to combine symbols using his AAC system for a range of communicative functions e.g. "*red I want*"; "*I want swimming next*". He was recognised for positive communication achievements throughout school, for example, telling the dinner ladies that the food was "*yummy*". His mother reported that it is easier to repair communication breakdowns at home. By the end of the academic year, following an application for funding, his iPad and communication app were funded through
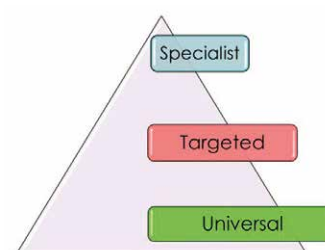
the NHS Tertiary Service – ACS Hub. The success of child C. and others meant staff became much more interested and invested in trialling AAC with a wide range of children and young people.

Outcomes

Outcomes from our project showed success across TOMS measures. Of the 10 students we had 6 sets of complete "pre" and "post" data represented in the graph below.

Graph One: TOMS Scores

The graph below shows the increase in "Support" scores for 6 students. The support domain pleasingly showed the impact of training and support for staff in increasing their skills in being supportive communication partners. The SLT team shared this data with staff to thank them for their commitment to the project and to show them the impact of their hard work. The positive impact was also shared with the school governing body and so future funding was secured.
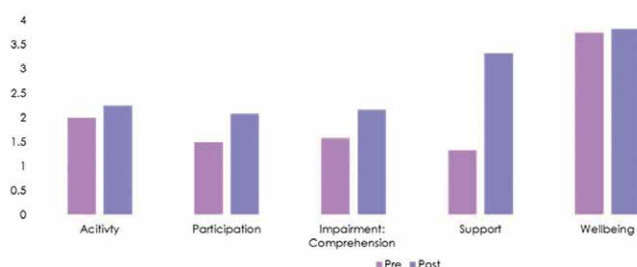

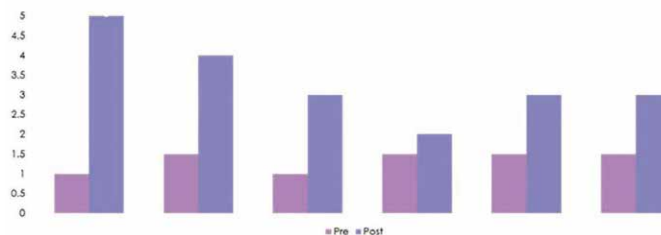
Figure 5: Graph showing increase in TOMS scores

Figure 6: Graph showing increase in Support domain for six individual students

Graph Two: Support Domain

By the end of the academic year, all students included in the project were on track to achieve their communication targets. All students were also making at least expected progress in Literacy and Maths using the school-based progress measures. The number of students trialling personalised high-tech AAC devices had also increased to 14. Of the 10 students in the initial project, 2 went on to receive funding through the ACS Hub within that academic year. In the following year, another student went on to access funding.

Project Legacy

Following the Pilot Project, there was an overall significant expansion in the use of low-tech and high-tech AAC use across the school. A whole school AAC Pathway was developed and formalised through the AAC Working Party and agreed with senior leadership. A shared AAC assessment proforma was also developed. AAC implementation and the facilitation of AAC use became embedded within the school. At the time of writing, over 20 students at the school use high-tech AAC as their main way of communicating, from a variety of funding streams. The year after the project was completed an AAC user joined the interview panel to interview the new Head of School.

The school-employed SLT and NHS SLT further collaborated to write the communication curriculum for the school. This joint working ensured AAC was at the forefront of the pupils' therapeutic education and that linguistic, social, strategic, operational and psychosocial AAC domains (Light and McNaughton, 2014) would all be considered and targeted. Drumbeat staff continue to promote and value all communication methods in school and senior leaders often talk to visitors about the 'life changing' AAC work that continues.

Joint working is now firmly established between school-employed and NHS Speech and Language Therapists and the AAC Working Party continues its work. A key learning from this project was the positive impact of everyone working together to try to achieve the best outcomes for students and their families.

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Enhancing Self-Expression for Autistic Students using Augmentative and Alternative Communication (AAC)

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Self-expression involves revealing one's identity, personality, feelings, thoughts, and opinions. Often, we associate self-expression with the arts, such as painting, creating music, or writing a book. However, self-expression manifests in many ways, including how we move, dress, and style our hair, as well as how we communicate. This article discusses self-expression, its benefits, opportunities for self-expression in AAC (Augmentative and Alternative Communication), and how to promote it.

When considering self-expression in communication, it is evident in various forms: body language, facial expressions, word choice, gesture type and frequency, voice characteristics (pitch, rate, volume, quality, intonation patterns), and conversation topics. These elements evolve over time. Glaser (2016) noted that self-expression might be one of the most important ways for people to connect, navigate, and grow with each other. For AAC users, it is crucial to allow them to express themselves in their preferred manner.

Benefits of Self-Expression

The impact of self-expression for AAC users is interconnected. Individuals express who they are, enabling communication partners to understand them better and know more about them. Consequently, the community gains a greater sense of the capabilities of people with disabilities.

Understanding self-expression involves recognizing the double empathy problem, a concept introduced by autistic researcher Damien Milton in 2012. Milton challenged the misconception that autism involves a lack of empathy, emphasizing that empathy is a two-way street. Both participants in a conversation need to empathize with each other. Research indicates that communication among non-autistic individuals is effective in terms of information transfer and satisfaction, as is communication among autistic individuals. However, communication between autistic and non-autistic individuals can falter due to differences in how empathy and communication styles are expressed and perceived.

Figure 1: Interconnected benefits of self-expression

Communication is a fundamental way we connect with others. We use it to express our wants and needs, share ideas and opinions, advocate for ourselves, and state our preferences. However, autistic and non-autistic individuals may not always understand each other's attempts to connect. It's important to be mindful of these potential breakdowns when considering the implementation of AAC with autistic individuals.

Van Grunsven and Roeser (2022) explored AAC technology's role in promoting empathy towards non-speaking autistic individuals. Positive contributions include enabling these individuals to express their thoughts and emotions and making their inner lives accessible to neurotypical people. The assessment process for AAC needs to understand individuals' unique perspectives, fostering empathy. Challenges include AAC technology sometimes forcing autistic individuals to conform to neurotypical communication standards, undermining genuine empathy. It is crucial to incorporate autistic individuals' interests into the device to avoid this. In addition, AAC users often face the challenge of communicating and convincing others of their communication competence, leaving them vulnerable to being forced into neurotypical standards. AAC design should aid communication while respecting and enhancing autistic individuals' lived experiences.
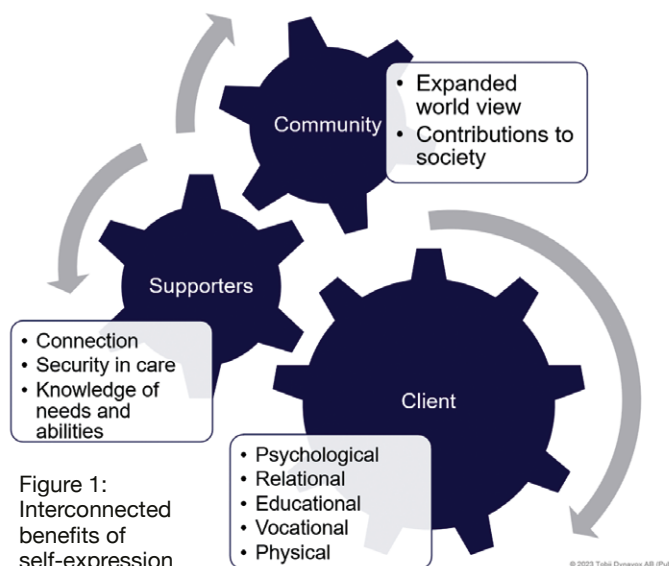
"AAC must attend to the different ways in which individuals and communities can have unique communication styles and recognize that these individuals and communities can lose a part of their identity (or never fully gain it) if the technology upon which they depend for self-expression limits them to 'conventional' communication norms and practices that are in many ways alien to them" (van Grusven, J. & Roeser, S, 2022).

Opportunities for Self-Expression with AAC

There are numerous ways for individuals to express themselves through AAC. Individuals need to be actively involved in these decisions to ensure their preferences are honored:

- Hardware: Options for hardware include decorating wheelchairs, picking out device bags or cases, and choosing device colors. In addition, some individuals may want to apply decorations (e.g. stickers) to the case of their communication device to express themselves.

- Voices: The variety of synthesized voices is expanding all the time. AAC users must be involved in choosing their voice to create the most ownership. Commonly, we change aspects of our voices (e.g., volume, rate, pitch, and intonation) based on the situation, and our interaction partner, AAC users may want to do the same. Some aspects to consider include which voice the individual prefers, do they want a higher or lower pitch, how fast the individual wants the voice to speak, do they want to switch voices for certain phrases or environments, and if recordings would work best to help show emotion. In addition, many AAC apps allow voices to be created based on recordings. This may be important for someone who can't find a voice that has their exact accent or dialect. People can "donate" their voice for a synthesized voice to be created. Intonation can be added in various ways including using recordings or Acapela Vocal Smiley (Acapela).

- Visual representation of vocabulary: Change the visual representation for a word or message based on the AAC user's culture (including skin tone and hair color) and personal representation. Think about using real images or photographs as well. Allow the individual to be involved in the selection process so that their vocabulary is represented by symbols that mean the most to them.

- Vocabulary and syntax: Choose topics that are meaningful and delete topics that are not applicable. Add personalized vocabulary (e.g. favorite foods, people's names). Add slang or current terms that age-equivalent peers are using.

- Flexible communication tools: Allow the use of a whiteboard to draw on pictures or write words or use photo albums to tell stories. Import photographs and create vocabulary around them so that the individual can communicate about what is important to them.

While all of these tools are available in a variety of AAC to promote self-expression, their benefit depends on their being used by the person communicating with AAC.

Promoting Self-Expression with AAC

To enhance self-expression with AAC:

- Understand Needs and Desires: Assess current and potential needs.
- Obtain AAC with Growth Opportunities: Ensure the device can grow with the user.
- Provide Training: Train the AAC user and their team.
- Plan for Ongoing Self-Expression: Create a checklist for self-expression, including preferred voice, special interests, visual preferences, custom vocabulary, and motivating tools.

See the resource section at the end of this article for links to helpful materials to address promoting self-expression. One of these tools is the Dynamic AAC Goals Grid-3 which assists you in writing goals to support self-expression.

Writing Goals for Self-Expression:

Incorporating goals for self-expression in AAC is important. They might come in the form of linguistic goals focusing on learning particularly motivating vocabulary to social goals targeting story telling about favorite activities. Special interests can help keep autistic individuals regulated and should be incorporated into therapy to promote generalization and progress. In fact, Alexa Kelly, an autistic SLP, recommended recasting perseveration as a passion for autistic clients in a recent 2024 article. Instead of trying to prevent the individual from discussing their interest, we can incorporate it into the goal for the skill we are targeting. For example,

an individual who is interested in talking about transportation could have a goal stating, "Client will ask and answer questions regarding types of transportation".

Conclusion

In conclusion, using an AAC device should not limit someone in allowing them to express who they are. There are many options available to allow for self-expression in AAC. "Self-expression for the disabled is just as important and can be just as creative and beautiful as it is for society in general. Social and emotional outlets are needed due to the psychological stereotyping of disabilities and the desire to be so-called 'normal'. Self-expression provides the opportunity to experience a feeling of cultural normality." (Sail, 2020).

Resources

Dynamic AAC Goals Grid-3:
https://www.tobiidynavox.com/pages/dagg-3-resources?refUrl=https://www.tobiidynavox.com/products/dagg-3
Topic Interest Inventory:
Handout - Topic Interest Inventory - Creating AAC Assessment Opportunities for Symbol-Based Communication.pdf | Powered by Box
Identifying Preferences Checklist:
Handout - Identifying Preferences Checklist - Creating AAC Assessment Opportunities for Symbol-Based Communication.pdf | Powered by Box
Let's Talk Together: AAC Inclusion for Kids: https://tobiidynavox.talentlms.com/catalog/info/id:1336

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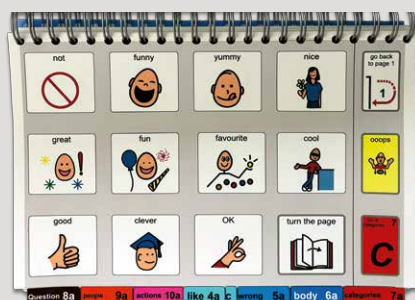https://doi.org/10.1080/02691728.2021.1897189

Five Ceramic Objects to Seed Conversations About AAC Futures

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Between Things is a collection of objects designed to seed conversations about AAC futures. They are five charcoal-coloured ceramic objects, embedded with technological components, connected with colourful cables to acrylic boxes with buttons to interact with the objects directly. Each box contains a microprocessor – a Raspberry Pi, or an Arduino board – which activates speakers, microphones and motors inside the ceramic forms.

These objects are speculative AAC devices. Speculative design is an approach to design where designers create objects for the future rather than for the modern-day market. This could be to explore possible futures in a positive light or critically, or to share narratives and ideas for the future or investigate the potentials for a technology. It allows the designers to speculate on how technology will develop in the future and how we as humans will change as the technology does. Examples of this are Superflux's 'Mitigation of Shock' (2019) which investigates a future where climate change and food insecurity forces a civilian population into cultivating edible plants and fungi in DIY greenhouses inside cramped apartments presented through a live installation, and Dunne and Raby (2004) critically explored energy conservative futures where children raise pet rats to power blood-powered television sets using photography, speculative objects and actors in a project called 'Is this your future?'. A third example, which is closer to Between Things in focus and approach, is Graham Pullin and Andrew Cook's 'Six Speaking Chairs (not directly) for People Who Cannot Speak' (2010) which explores speech technology futures by using chairs to embody different ways of thinking about tone of voice. The Between Things collection is similar to The Six Speaking Chairs in that it gives presence to an abstract issue rather than proposing a specific future. As speculative objects, Between Things aims to explore alternative futures through prompting conversation in a field where technological advance feels both convergent and accelerated.

AAC is a fascinating field through the perspective of technological advancement as it engages with cutting-edge technology: AI models can predict the content of utterances or combine GPS data to create context-aware predictions, for example suggesting destinations when ordering a train ticket based on the AAC user's location, even with the nuance of asking for split-fare tickets (Preece and Lee, 2023). Integration of AI into AAC devices also offers more promising outcomes for brain-computer interfaces (BCI).

While BCI is an exciting technology and promises many advancements in the field, Between Things looks at speculative technologies and AAC through a less medicalised perspective and gives presence to abstract issues about AAC futures. The Welcome Trust funded project 'imagining technologies for Disability futures' in which The Between Things collection was produced, aims to explore how technology, disability and society will change and interact in the future.

The first of the five objects is called No.1 The waiting bowl. The waiting bowl is a large bowl with a circular speaker grill in its centre, a cylindrical base which houses a speaker, which connects to the accompanying acrylic interaction box via a mustard yellow braided cable. The ceramic object is intentionally crafted so that its side profile is representative of a speaker icon. AAC users typically have a profound delay in responding to, for example, a question in a work meeting. In the time it might take an AAC user to compose a response using a digital AAC device, interlocutors may start talking amongst themselves, or the conversation might have moved on to a different subject (Higginbotham, Wilkins. 1999). This influences AAC users' ability to hold the floor – that is, retain an equitable sense of agency and control in a conversation with their interlocutors in such a way that they can feel confident that a conversation won't slip away without them. The waiting bowl focuses on this social interaction by playing a calming yet captivating ambient soundscape which fills the room when interacted with. The aim of this is that the audio will communicate to conversational partners not to continue the conversation without the AAC user.

Figure 1:
The waiting bowl

Figure 2:
The composing bowl

The second object is called No.2 The composing bowl and has a similar yet smaller form to the first object. This object was inspired by a conversation with long-term collaborator on the research project, imagining technologies for Disability futures, Jamie Preece. Jamie is an AAC user and works with the provider of his AAC software, SmartBox. SmartBox has implemented a 'second screen' on Jamie's AAC device, a small screen which faces away from Jamie and towards whoever he is speaking to. This screen can be used to print spoken text in the event that the conversation is being had in a loud venue and it's difficult to hear him, but it also performs the function of showing a parenthesis (…) when he is typing to make this obvious. This status indicator is very useful as often individuals who are not familiar with AAC might not understand that the AAC user is composing a response and might interpret a break in conversation as a lack of comprehension or an inability to respond. The catalyst for the design of No.2 The composing bowl was a conversation where Jamie articulated that in work meetings, or other professional contexts, people often don't see his second screen due to there being many people in the conversation. This object provides a second sensory cue where, when the AAC user is composing a response, the object emits the sound of a vintage typewriter, clearly communicating that a message is being composed.

The third object, No.3 The bookmarking vase, is distinct from the first two objects in form and functionality. Its ceramic form is a tall, conical vase, wide at the base and narrow at its top with a circular speaker grill. The form represents its ability to act as a vessel, capturing and holding parts of a conversation. This object uses a far-field microphone with the ability to capture audio from up to about 10 metres away, and records audio from the conversation to a 'circular buffer' – a method of recording data where only a finite amount of data can be stored. The bookmarking vase is designed so that it records the previous 10 seconds of conversation so that an AAC user can capture a point in the conversation to return to later, bookmarking it. When the AAC user is ready to return to the conversation, they can play that recorded 10 seconds of conversation to (re) direct conversational partners towards the subject of the conversation. This interaction could be compared to the reply feature on messaging applications where a user can show a conversational partner which conversational thread they are responding to, even if it's from minutes, hours or days previously.

Figure 3:
The book-marking vase

Figure 4: The mirroring vase

The fourth object is also a vase-like form but is shorter and wider than the third. No.4 The mirroring vase embodies the casual and everyday interaction of conversational mirroring. This is something that people often do subconsciously as a mode of enquiry, changing intonation to convert the utterance into a question to show that they do not understand. e.g. Person 1: "It won't be that expensive." Person 2: "It won't be that expensive?". The mirroring vase emulates this vocalised interaction by using a microphone and automatic speech recognition software to transcribe the conversation, and when the object is interacted with it will use text to speech software to repeat the previous utterance, intoned as a question in the synthesised voice of the AAC user.

The fifth and final object in the collection is No.5. The deferring object, a simple anthropomorphic form. It is a small cone with a sphere on its tip, with two eye-like features giving it a sense of looking in a specific direction. This object has a motor
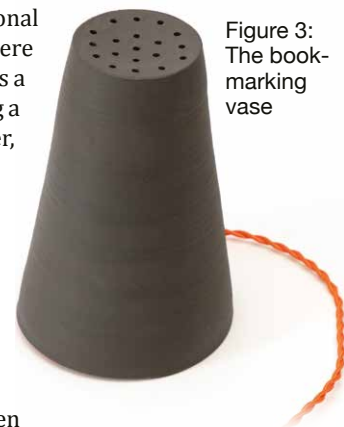
Figure 5: The deferring object

inside it which allows the object to spin on a central axis. The design of The deferring object was influenced from a number of conversations with collaborators and AAC users who pointed out that some non-AAC users unfamiliar with AAC will often focus their attention on the AAC device itself instead of the individual using the AAC. In this way, The deferring object says 'Look at me!' by turning to face the speaker in a conversation, deferring to their body and body language.

The Between Things collection, as speculative design objects, embody conversations about the future of AAC which the author of this paper, and the collaborators and co-researchers they've worked with – academics and non-academics, AAC users and experts in the field – believe should be at the forefront of speculative discourse in the AAC community. The Between Things objects exist as a design collection (Pullin, 2010) which allows each of them to focus a conversation to a specific nuanced conversation about AAC futures, but each object complements one another, highlighting the intersectionality of the field of AAC and of the specific issues these objects explore. Their designation as a design collection also highlights the collaborative and interdisciplinary method of conception and design which these objects underwent, nonetheless conceived as an entity at the time of creation.

The act of designing these objects, prototyping and creating the series as a functional series of objects is representative of a process referred to as thinking through making, where the designer themselves can explore these futures tangibly, as well as creating a series of prototypes providing the opportunity to have these objects between individuals when having a conversation about the future of AAC.

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Belfast AAC Information Day

This AAC Information Day is a product demonstration day supported and presented by our Commercial Members from the UK's leading suppliers of communication aids, equipment, software and symbol systems.

The day consists of five sessions which provide information and offer up-to-date knowledge on the range of AAC products available in the UK. There will also be an exhibition period where you can try out products.

Date	**Venue**	**Cost**
Thursday 12 June 2025	Girdwood Community Hub, 10 Girdwood Avenue, Belfast, Antrim, BT14 6E	FREE to attend! Lunch & refreshments are provided

To find out which suppliers are attending, please visit our website by clicking on the links below:

Read more about AAC Information Days
Request a place on this AAC Information Day
Registration now open!

Exploring Factors Leading to AAC Abandonment

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Introduction

Smartbox carried out a 6-month research project to better understand the reasons why someone might stop using a high-tech AAC device, despite a professional identifying this as an ongoing need. The project was funded through Innovate UK.

Device abandonment is well-known within the AAC industry. With the complexities around living with a disability, it can be hard to pinpoint specific causes. Every individual's need is unique, which makes it difficult to ascertain whether AAC device abandonment is something that we could easily affect.

By gathering feedback from different sources, our aim was to discover the most prevalent causes of abandonment and look at ways that our company could make an impact on this, through mindful product development and process improvements.

Partnership

We co-designed the project alongside an AAC Advisory Group. Co-design is the process of developing a product and involving the end user in design decisions from the offset. The group were encouraged to question our decision-making and rationale and to speak up if something could be improved. We held regular meetings where we explained what we were planning on doing and opened up the floor for feedback. We presented the group with different directions which the project could go in and got a consensus on the correct path.

Our AAC Advisory Group was made up of 5 knowledgeable people from the AAC industry, including 3 AAC users. We also partnered with SpeakUnique, who had an interest in understanding how much of an impact a chosen synthetic voice has on an individual's adoption of their AAC device.

Project set-up

To structure the project, we followed the Systemic Design Framework as outlined by the Design Council UK. This consisted of 5 different phases:

- project set-up
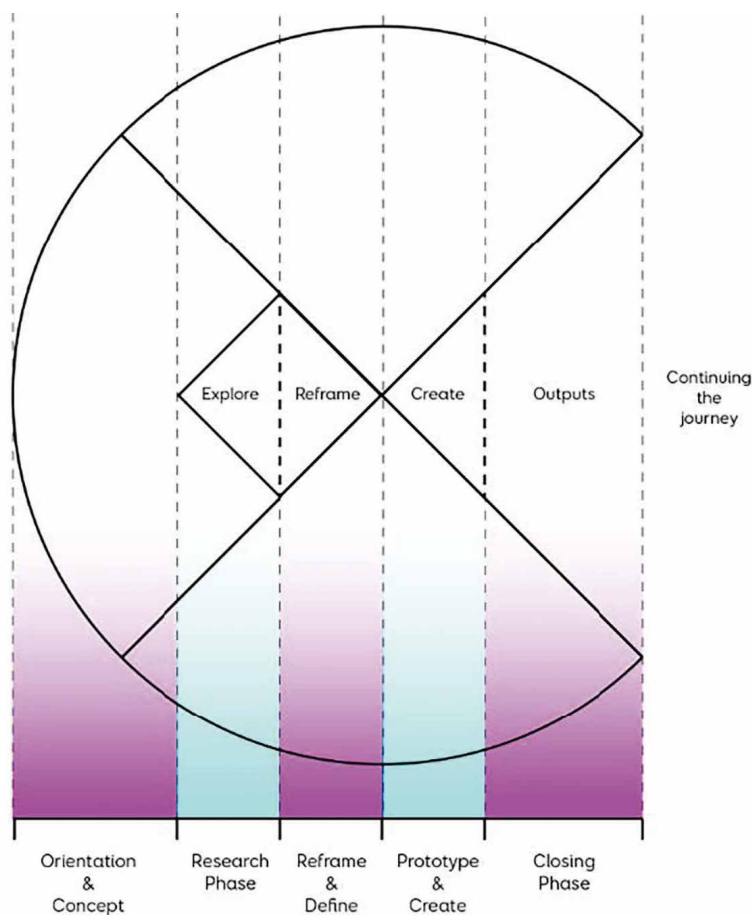- research
- analysis
- prototyping
- final wrap-up phase.

Figure 1: Systematic Design Framework

This approach allowed us to explore the user feedback and focus in on specific reasons for AAC abandonment. We could then zoom out and look at the bigger picture, identifying common trends within those results, ensuring nothing was missed in the research phase.

Research phase

The 3 main areas of research were a literature review, a survey and video interviews.

1) Literature review

The literature review focused on 24 relevant papers which included the key search terms "augmentative and alternative communication" and "abandon", or "accept".

Themes were identified which aligned with the World Health Organisation's International Classification of Functioning, Disability and Health. This framework provided a structured method to organise the data into themes recognised by clinicians and academics.

To learn more about the literature review, including how it was conducted and the results, please follow the QR code at the end of the article.

International Classification of Functioning, Disability and Health

Definitions of ICF Themes

Body Functions and Structures factors – Body functions and structures factors are factors that affect the use of AAC due to motor, cognitive or voice capabilities of the AAC user themselves.

Activity and Participation factors – Activity and participation factors were those related to the activities where AAC was used, or the way in which AAC was used to support the individual to participate in activities or situations. Many of these factors related specifically to the AAC device. A number of other factors related to how the device impacts on an individual's capability, such as their communication skills or independence.

Environmental factors – Environmental factors were the factors most frequently stated in the literature to be facilitators or barriers to long term AAC uptake and use. Environmental factors comprise all factors external to or surrounding the user that directly impact the user's ability to use or access AAC.

Figure 2: ICF Framework

Personal factors – Personal factors include all factors related to the AAC user or family unit itself, for example: motivation, health condition, mental health, etc.

2) Survey

The purpose of the survey was to gather as much initial information as possible in order to see trends. For example:

- typical usage of an AAC device
- what type of support someone receives
- whether anyone had personal experience of an AAC device being abandoned
- opinions on what makes AAC hard to use.

In terms of target audience, we looked for people who might have tried AAC but found that it wasn't the right solution for them.

In total, 294 people responded to the survey:

- 34 AAC users
- 76 Family/Friends of users
- 184 Professionals with knowledge of AAC.

3) Interviews and Focus groups

Once the survey responses were collated, we wanted an opportunity to delve into some of the topics raised in more depth. The interviews allowed a more personal approach, with first-hand feedback on the highs and lows of AAC.

We interviewed 18 individuals in total – 2 AAC users, 7 professionals (6 Speech and Language Therapists, 1 teacher) and 9 family members.

4) Workshops

The project team, comprising Smartbox and SpeakUnique employees alongside the AAC Advisory Group, came together in person for a 2-day workshop.

The aims of the workshop were:
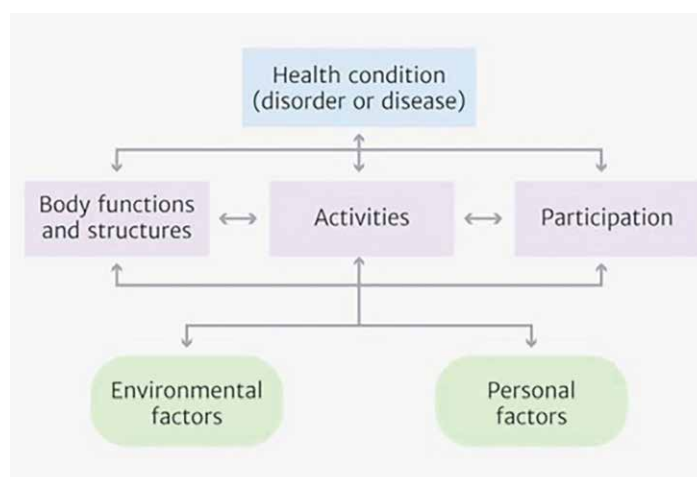
- Organise the large amount of data into key themes
- Identify all factors we can affect
- Prioritise what we want to carry forward and action.

On day 1 of the workshop, we focused on disseminating the research information to the whole group. On day 2, we focused on prioritisation.

We also did a short workshop activity as part of a presentation of the project at the Communication Matters 2024 conference.

Themes of abandonment

The aforementioned ICF framework allowed us to categorise much of our research findings into sub-themes.

Body Structures and Functions

Cognitive function

Voice function

Motor function

Activity and Participation Factors

Device factors
(Including ease of use, speed of communication, portability, durability and reliability, customisation, communication & independence features)

Improved communication

Multi-modal communication

Interpersonal Interactions

Families Seek Support from other Families

Increasing independence

Feature matching

Technology confidence

Use of AAC across environments

Environmental Factors

Support and training
(Including ongoing support, training for healthcare providers, managing expectations, cooperation & collaboration, training for teachers, training for families & AAC users, managing demands – healthcare providers)

Inclusion of Family in AAC

AAC availability in the environment

Universal AAC

Policies and funding: Access to AAC Services

Policies and Funding: Cost of AAC

Integration of AAC into Daily Life

Attitudes: Professionals

Attitudes: Users, Family and Community

Family Mental Health and Grief

Culture of AAC

Personal Factors

Mental health

Health condition

Motivation

Figure 3: Abandonment sub-themes

Findings

Below are some of the main highlights from the research. We will be posting more in-depth insights on our website later in the year. To be informed when this goes live, please sign up here.

When questioned directly about AAC abandonment in the survey:

- Out of 107 users*, 11 no longer use their AAC device/app;
- Out of 34 users, 11 had thought about giving up;
- Out of 184 professionals, 171 have experience of someone stopping using their AAC device.
  * *combining user and family feedback*

AAC users themselves cited **participation and activity factors** as the most significant reasons for device abandonment, with the following selected most frequently:

- Communication too slow
- Some situations where didn't want to use the device/app
- Couldn't use indoors and outdoors or in different temperatures or weather
- Device/app unreliable.

> *"People don't give enough time for my son to type his message. The conversation moves on. He struggles to use it with time pressure as the dystonia affects his access."*
> Family member of AAC user; from survey

Professionals cited **environmental factors** as most significant, with the following selected most frequently:

- Family / friends / user did not feel confident editing and using the device
- Only offered the device in one place
- Family/friends did not like the device.

> *"You need people who understand and can set up and maintain the device so content keeps up with life changes and experiences. Also they need to know how to encourage the user to make use of it and to try and explain their needs beyond just simple words"*
> Family member of AAC user; from survey

Family and friends of AAC users also cited **environmental factors**, with the following being most significant:

- Communication partners weren't trained
- No support from professionals
- Family / friends / user did not feel confident editing and using the device.

> *"In my experience, caregiver training is crucial to ensuring a person using a communication device doesn't abandon the device. Often caregivers are provided with 1-2 sessions and expected to upend their entire routine to incorporate a new device"*
> Speech and Language Therapist; from survey

Conclusion

High-tech AAC products are complicated pieces of equipment – both in terms of understanding the full potential for individual set-up, but also learning *how* to communicate and learn via a device. Both aspects ideally require a well-trained professional guiding you through the process.

Our research showed that many people receive their device or app without any contact with an AAC specialist or a Speech and Language Therapist. For example, they may download the software themselves or have their device provided through a charity. In this case, we have to be prepared for the fact that people are receiving our devices or app with differing levels of support and guidance.

We need to ensure that our devices and apps are intuitive and easy to start using from the get-go. We need to make sure that both the direct user of the product and those around them understand that there are many background features to individualise the device, while keeping the user experience as straightforward as possible. These customisations should then be easy to maintain and adapt as the user becomes more familiar with the device.

The issue of abandonment should be kept in mind throughout the AAC users' journey, and the factors outlined throughout this project have brought to light that it is rarely one factor that results in the failure of a device to meet the user's needs. It has highlighted that the team around the user must be as committed to the AAC solution as the user themselves.

Furthermore, the knowledge of the device must be shared widely, yet the methods to do this are limited by time, expertise, finance and more. As such, it is imperative that the device and software itself removes barriers and fits into the busy lives of users, their family and friends, teachers and health care professionals.

Our key takeaway from this is to ensure that we build mindful features that support and educate our users and their communication partners. By doing this from within the software itself, we reduce the need for support pages, external training, and the knowledge of others around the AAC user.

We would like to take this opportunity to thank everyone who provided us with their feedback during the project. If you would like to be informed when our literature review and research findings are published, you can sign up via the following QR code:

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Worlds Apart – A Cerebral Palsy Perspective on Learning and Studying in a Second Language

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Introduction

Huiwen Qi describes herself as "just a girl from China". But don't be fooled. This girl from China is no ordinary girl. She knows exactly what she wants her life to mean and is prepared to do what it takes to achieve this goal. Huiwen's dream is to work as a psycho-counsellor with people with disabilities. In September 2023, she set out to make this dream a reality and came from China to the UK as a mature student with cerebral palsy (CP) to study a master's degree in psychology.

Huiwen's story about learning in English as her second language whilst actually learning English as a second language, fitting into a new culture and creating a new career path for herself is one of ambition, sheer determination and empowerment for anybody who wants to achieve their dream. I asked Huiwen about her experiences over the past year.

Here is her story.

Heather Graz and Huiwen Qi

About Huiwen

HG: Could you tell us a little bit about yourself? Who is Huiwen, and tell us a little bit about your cerebral palsy?

HQ: My cerebral palsy (is) just in my fine movement and some vision and sometimes I can't just make myself stable. So it make a big challenge for me, especially when I was young. The Chinese Government don't have so many resources to support me so it was a big challenge growing up, but I try to help myself to make myself better.

HG: What made you decide that you wanted to come to the UK?

HQ: Because I have a chance to go to Disability community accommodation. (I have) a friend (who) just came to the UK and UK Government and the university provided some support for them like some reasonable accommodation. So that's what I need.

HG: Tell us a little bit about the journey that you are wanting to go on. I'm assuming that this relates to the MSc that you are doing?

HQ: I'm a Psychology student at the University of Dundee. I want to be a psycho-counsellor in the future, provide counselling for people with disability. My dissertation focuses on microaggressions and disability. I hope I can help other people with disability.

Growing up with CP

HG: Could you say a bit more about what it was like for you growing up? You were saying you grew up in a middle-sized city. Tell us a little about what that means.

HQ: A disability in a middle city (means) some resources can't (be) provided by the city, so you should help yourself to support yourself. Luckily my parents had good communication skills and they just talk about some my experience and some things that I need to the school and that helped me a lot.

HG: What type of resources did your parents look for, for you?

> **HQ:** As I have bad vision, if I sit far away from the blackboard, I can't see anything. But luckily all my teachers provided me special seat to let me see something clearly.

HG: That could have been a challenge. Were there some opportunities that came out of those challenging situations?

> **HQ:** I met so many nice persons, like my classmates. I could take notes after school or after class from my classmates and it helped me a lot. I also think the teacher was very nice.

HG: Did you find that you developed any helpful skills because of these experiences?

> **HQ:** It's difficult to say because I think it's so complicated. On one hand I needed to adjust to be a nice person, to be an outgoing person. That makes some challenge for me. On another hand it was a good way to improve my communicating skills.

Schooling experiences

HG: I'm assuming that the school system here is quite different from how it is in China. Could you tell us a little about how schooling is set up?

> **HQ:** We have a primary school and a middle school and some people go to high school. Some people after high school go to university, but some people just have a chance to go to the college.

HG: How old are the children in middle school?

> **HQ:** Like teenagers, like 12. When I got to primary school I got there two years later so I was older than my classmates by two years. I was eight years old.

HG: What was the reason why you started school a little bit later?

> **HQ:** Because of my bad movement when I was young I couldn't run and walk so I was not stable. My parents thought it was safer to go to school later.

HG: How old are children when go into high school and when they leave high school?

> **HQ:** About 17 when they go into high school and about 18 years old when they leave. I was 20 years old.

HG: Tell us a bit about the curriculum that you followed and the difference between college and university.

> **HQ:** I went to the college because the Government doesn't provide so much support for my CP. The university has more academic working for the student but the college just focuses on professional things. I attended the university when I graduated from college. I studied management at college.

HG: You are a psychologist at heart. Did you study psychology when you were in China and how did you do this?

> **HQ:** Yes some private institutions provide training for counselling.

AAC and AT

HG: Let's chat a bit about AAC and Assistive Technology. You mentioned just now that speech was a bit difficult for you. Could you tell us about what kind of things you have used in the past and what you use now to help you get your message across?

> **HQ:** Sometimes I use translator software like Google translator to write something, for example when I need to see the GP, I type a word in my phone and show the phone to the GP to let them know what I mean.

HG: So you are using your phone a lot as your main communication support. Other than that, what you tend to be using is your speech? What do you do if people don't understand you?

> **HQ:** What I can do so just speak so slow and then try it again.

HG: That is working for you right now. In the past have you used different methods of AAC or different ways of getting your message across?

> **HQ:** No, but nowadays some Chinese kids use AAC, like looking at pictures in an iPad if (she) want to do something. In China there was a little bit lack of the technology when I was younger.

HG: Would that be why you said that if you wanted to get something done you just had to work harder or you had to find a way of getting around the problem because there wasn't anything to help you that you had access to? Did that help you to develop some creative ways to get things done?

> **HQ:** Yeah. But you have no choice because lack of the resources.

HG: You said you were in a middle city where there was some access to resources. Would things have been different if you were in a different place?

> **HQ:** Yeah. I think that the technology would be better in a big city.

Studying in the UK and learning in English

HG: Moving on to last year September when you got on an aeroplane and you flew over to the UK, it must have been quite a challenge to study in a language that you were learning at the same time. Could you tell us a little bit about how you managed this situation?

> **HQ:** At the beginning when I came here I can't even follow anyone who speak to me. Then I tried to mend that. First, I went to the restaurant to order some food for myself and that helped me a lot to build more confidence. Luckily the School provided a scribe for me. I talked with this scribe often, so it helped me a lot. Next, I use (English) to get some counselling from the local people. It helped me to use more English to describe more about my situation.

HG: It sounds like you knew when you got here that this was going to need quite a lot of hard work on your part. What you did then was to use every opportunity that you could to use English, either listening or speaking. Did you use any other strategies or assistive technology to manage classroom situations where there was a lot of information to cover in a short period of time?

> **HQ:** I followed the recordings of all of the lectures. When I got back to my residence, I looked at my lecture again to get myself back into the knowledge.

HG: Do you feel that things are easier now, a year down the line?

> **HQ:** Yeah. My language has improved more about professional things, I think.

HG: Have you managed to keep up your Mandarin whilst you have been here?

> **HQ:** Because all my roommates are Chinese I can continue talking with them in Mandarin.

Future hopes and tips for people who are planning to live, work or study abroad

HG: To finish off, Huiwen, I have to say to you that you are one of the most positive and practical people that I know. Do you have any tips and recommendations that you could give to any other young people who have cerebral palsy who might be considering going to study, work or live abroad?

> **HQ:** The first thing I want to mention is don't take any limitation of your ability. If you don't have too much space to develop now, then keep waiting until you do and expecting that you will be able to develop.

HG: And so, one last question for you, Huiwen. In an ideal world, where do you see yourself in the next few years? Where is Huiwen going to be in 5 years' time?

> **HQ:** I think I hope I can be a stronger person, and I just want to be a counsellor to provide counselling for people with Disability.

HG: Thank you so much Huiwen for sharing your story with us. We look forward to seeing your dream become reality and watching how people with disabilities benefit from your insights and experiences as a psycho-counsellor.

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

CM2025 International AAC Conference - Registration Now Open!

Registration is now open, but we wanted to highlight some exciting changes and additions taking place this year.

One notable change is the conference being shortened to two days. We will open the main conference on Monday 8th September at 9am and close at 4pm Tuesday the 9th. While this means a slightly shorter conference than previous years, we have worked hard to consolidate the programme to offer better value with events on either side. These include:

• **Pre-Conference Relaxed Exhibition** on the afternoon of 7th September, we will be providing a time for conference delegates and the community who need a quieter and less busy space to meet with suppliers. This is a free optional event for those who wish to add it to their delegate package. Tickets will also be available to people not attending conference.

• **AAC Awards** on the evening of 8th September, we will be hosting our biennial event celebrating all forms of communication, the people who use AAC, the professionals, families and suppliers that support them. Being held at the Royal Armouries in Leeds, we are certain the awards, dinner and dancing will prove to be a fun and exciting night for all! This event is included in the full delegate registration price. It can be added to one-day and exhibition-only delegates at an additional price. Tickets will also be available to people not attending conference.

• **Post-Conference Research Study Day** this additional day on 10th September is open to conference delegates and others who are interested in research focused strands delivered by an international cohort of researchers and academics. This event can be added to all delegate packages at an additional price. Tickets will also be available to people not attending conference.

Registration is now open!

Book early to take advantage of the Early Bird discount which expires on 11 July.

See prices and book online **here**.

Piloting a National Specialist Augmentative and Alternative Communication (AAC) service to support the AAC needs of children with Disabilities in Ireland and their Local Team

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Introduction

In response to the evolving landscape of disability services in Ireland, the Central Remedial Clinic (CRC) initiated a pilot program to expand its national Augmentative and Alternative Communication (AAC) service. Traditionally, this service has been focused on supporting children with primary physical disabilities. However, following the implementation of the Progressing Disabilities Services (PDS) program by the Health Service Executive (HSE) in 2016, the CRC's AAC team began receiving an increasing number of referrals for children with neurodevelopmental disabilities, such as autism spectrum disorder (ASD) and intellectual disability (ID). These individuals did not meet the service's referral criteria. This pilot program aimed to assess whether the CRC's AAC service could be adapted to effectively meet the communication needs of these children.

The Changing Landscape of Disability Services in Ireland

Ireland has seen a significant increase in the number of people with disabilities, particularly in the prevalence of autism. Recent research has shown that the prevalence rate of autism in Ireland has increased to 3.38%, up from 1.55% in 2018 (NCSE, 2024). This rise in prevalence highlights the urgent need for services that address the unique communication challenges faced by children with neurodevelopmental disabilities. AAC interventions have been shown to play a critical role in promoting autonomy and improving communication outcomes for individuals with ASD and ID. For example, AAC can reduce reliance on others for communication, thereby fostering greater independence (Gilroy et al., 2023). Similarly, children with ID or developmental disabilities can benefit from AAC interventions, which have been linked to more complex communication functions and improved engagement (Elmquist et al., 2023).

Objectives of the Pilot Program

The primary objective of this pilot program was to evaluate the potential of the CRC's national specialist service (NSS) for AAC to meet the communication needs of children with neurodevelopmental disabilities. The pilot sought to determine whether the existing service model could be adapted to serve these children effectively.

Methodology

To achieve this objective, the CRC employed a mixed-methods approach using a convergent embedded design. This allowed for the collection and analysis of both quantitative and qualitative data.

Inclusion and Exclusion Criteria

The pilot program included children under the age of 18 with a neurodisability who were currently accessing community services. Children with a primary physical disability were excluded from the study.

Data Collection

Participants were referred to the NSS by their local speech and language therapists (SLTs) for an AAC assessment. Although the core principles of assessment remained unchanged, modifications were made to accommodate the needs of children with neurodevelopmental disabilities, such as adjusting the assessment environment and appointment locations.

Quantitative data was collected through clinical assessments and an anonymous online survey completed by parents and SLTs after the assessments. The survey utilized a Likert scale to capture feedback on various aspects of the service. Additionally, qualitative data was gathered from open-ended questions in the same survey. This provided participants with the opportunity to share their perceptions of the service in greater detail.

Data Analysis

The quantitative data was analyzed statistically, while the qualitative data was analyzed using content analysis to identify common themes and insights.
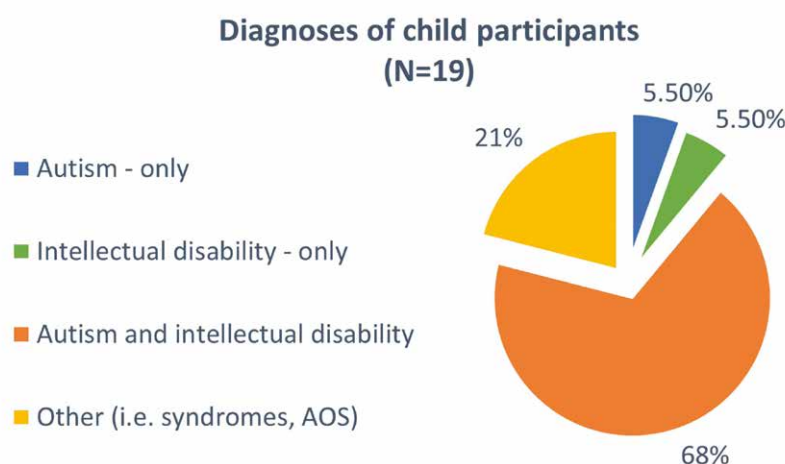
Results

The pilot program saw participation from 15 SLTs and 19 parents, who were invited to provide feedback after the assessments. Of these, 7 SLTs and 5 parents completed the survey, offering valuable insights into the program's effectiveness.

Demographics

Children were aged between 3-14 years old. Children attending the service presented with varying diagnosis.

Figure 1: Diagnoses of child participants

Quantitative Feedback

The survey results revealed several important findings from both parents and SLTs.

Parents generally found the expanded AAC service to be beneficial, with an overall satisfaction score of 4 out of 5. They particularly appreciated the usefulness of the information provided prior to the appointment, rating it 4.6 out of 5. However, the suitability of the appointment location received a lower score of 3.6 out of 5, indicating some dissatisfaction in this area. Parents also rated their child's comfort during the appointment at 3.4 out of 5, suggesting that there might be room for improvement in creating a more child-friendly environment. The clarity of recommendations provided during the appointment was rated 3.8 out of 5, and parents felt moderately included in the AAC appointment process, also rating it 3.8 out of 5.

Feedback from SLTs was overwhelmingly positive, with the service being rated as highly beneficial, scoring 4.83 out of 5. However, SLTs reported a low awareness of AAC prior to attending the appointments, with a score of 2.33 out of 5, highlighting a potential area for further training and education. Despite this, SLTs found the information provided before the appointment to be sufficient, giving it a score of 4 out of 5. They also valued the benefit of face-to-face interactions during the appointment, rating it 4.4 out of 5. The clarity of recommendations and next steps was rated highly at 4.67 out of 5, and SLTs felt well-included during the appointment process, giving it a score of 4.5 out of 5. Additionally, the length of the appointment and the suitability of the AAC system trialed were both rated favorably at 4.83 out of 5 and 4 out of 5, respectively. SLTs also praised the suitability of the assessment environment, the new learning they gained about AAC, and the likelihood of referring to the AAC specialist again, all scoring 4.83 out of 5 or higher.

Qualitative Feedback

The qualitative data provided further insights into the experiences of parents and SLTs during the pilot program.

Parent Feedback: Parents emphasized the importance of the location of the appointments, with several noting that the suitability of the location played a significant role in their overall satisfaction with the service. Some parents found the location inconvenient, possibly due to the distance from their homes or because the environment did not fully meet their child's sensory needs. Additionally, parents commented on the assessment process, appreciating the thorough and structured nature of the evaluations.

However, they also suggested that further adjustments could be made to better accommodate their children's unique needs during the assessment.

SLT Feedback: SLTs reported a significant expansion of their knowledge about AAC as a result of their involvement in the pilot program. They particularly valued the client-centered approach of the appointments, noting that tailoring the assessment to the individual needs of each child was a crucial aspect of the service. SLTs also praised the thoroughness of the assessments, which they felt provided a comprehensive understanding of each child's communication needs. Clear communication was another key theme identified by SLTs, who appreciated the clear and detailed recommendations provided during the appointment.

Discussion

The pilot program's results indicate that expanding the CRC's AAC service to include children with neurodevelopmental disabilities is both feasible and beneficial. Feedback from both SLTs and parents highlighted the importance of centering the appointment around the child's needs. The clear information provided before the appointment was particularly valued by both groups, contributing to a positive overall experience.

However, the feedback also revealed areas for improvement. For instance, some parents expressed dissatisfaction with the location of the appointments, which may have been due to the distance from their homes or the appointment environment not meeting their child's sensory needs. As a national service, addressing these logistical challenges is crucial for enhancing accessibility and satisfaction. Additionally, the low level of awareness of AAC among SLTs prior to the appointments suggests a need for further education and training. By increasing the confidence of local therapists in AAC, the overall effectiveness of the service could be significantly enhanced.

Conclusion

This pilot program has demonstrated the potential for the CRC's national AAC service to adapt and expand its scope to meet the needs of children with neurodevelopmental disabilities. While the feedback has been largely positive, the study has also identified key areas for further exploration, including the suitability of appointment locations, enhancing local therapist knowledge of AAC, and ensuring the service is fully equipped to meet the diverse needs of this growing client group.

Expanding the sample size and conducting additional research into these areas will provide further insights and help refine the service delivery model. As Ireland's population of children with neurodevelopmental disabilities continues to grow, the CRC's commitment to evolving and enhancing its services will be crucial in meeting the communication needs of these children and their families.

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CM International AAC Conference 2025
CALL FOR PAPERS

Communication Matters

You are invited to contribute to the Communication Matters Conference 2025

Presentations should be relevant to the field of AAC and where possible promote the positive role of AAC in the empowerment of the people who use it. This year's theme for conference is 'Identity'. We welcome abstract submissions covering any of the areas this theme encompasses. Topics to cover could include vocabulary, gender, cultural influences, person centred service delivery, self-advocacy, AI, neurodiversity or anything that links AAC to a user's identity.

We are open to presentations from all in the AAC community including professionals and supporters and we especially encourage contributions from AAC users and family members.

The deadline for submissions is 16th April 2025.

Further information can be found on our website:
https://eu.eventscloud.com/website/15994/callforpapers/

Learning Language and Vocabulary as an Adult using AAC

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We all learn new language skills and vocabulary throughout our lives. However, as adults we can all find it more difficult to learn new things as we get older, with challenges of opportunity, time, and memory!

The presentation was worked on for 6 months for the Communication Matters conference, putting together experiences, tips, ideas, and golden rules of AAC language learning as an adult.

As an adult using AAC, I wanted to improve my language skills because I had a habit of not using mature sentences. I also wanted to use a wider range of descriptive vocabulary and verbs.

However, I have had some challenges along the way and continue to do so!

I have been using the Minspeak Application Programme (MAP) called Language, Learning and Living (LLL) for over 25 years. I got my first communication device, a Pathfinder, when I was 17. In the last few years, I wanted more Speech and Language Therapy because it was important to me to improve my communication to say what I wanted to people.

However, I wanted help from a Speech Therapist who knew LLL and how to programme the software. I wanted to make my communication quicker, use better sentences and learn new words. I thought my carers could learn more about communication by joining the sessions and **I also felt that I had something to teach the Speech Therapist!**

The Difficulties

My older body means that head switching can be more difficult; I get more tired, find timing harder, and I may make more mistakes. My older mind means that it is more difficult to remember where new words are stored. All of this affects my motivation and confidence to use and work on language.

As an adult, where I live I am the only person using AAC. I have more than 10 different carers working with me, and the care staff change all the time. I have less opportunities to communicate and often staff do not give me time or stay to listen, so I say "yes" a lot! They are busy 7 days and nights and are only available for 12 hours from 8am to 8pm, so I can't even stay up and chat!

I know that I want to improve my language skills, but I don't know how, so I have a Speech Therapist once a week to assist me. However, there is no one to support my practise and it can be hard to keep motivated.

The Challenges

Print outs of symbol / icon sequences that have been put up where I can see them, get tidied away and put in folders that I can't get to. Staff don't have time to wait, listen and converse with me, and talking to myself could get me into trouble!

I feel frustrated and angry with myself when I can't remember the words; I worry about making mistakes and I know I need more help.

The only time that I meet another person using AAC is at Communication Matters in Leeds, which is why it is so important for me to go there. Regularly meeting up with a group of older adults using AAC would be really good, but I haven't found a group yet!

Language Immersion

Learning communication at school happened throughout the whole day, 5 days a week. This meant lots of practice and lots of new language and vocabulary learning. Everyone around me were AAC users and we were all learning together. There was lots of support. We were immersed in Language, Learning and Living! As an adult, I am now quite isolated.

Tips

- Write down new words.
- Revise new vocabulary regularly.
- Read / immerse yourself in language – listen to podcasts / radio / television.
- Listen and talk to people around you. Learn from context.
- Use it or lose it! Keep Talking!

My Speech and Language Therapist works with me to decide what new vocabulary to learn, and we now have a Communication Practise chart on the wall and update it with new vocabulary.

The words that I am working on are also printed with the symbol sequences, laminated, and are attached to the mounting pole of my Accent 1400.

We have also tried putting reminders on my Alexa Show and an alarm time reminder on my Accent 1400, so I have no excuse to forget!

Ideas

I put together some ideas for working on language skills, following my experiences of what works and what does not work for me. Being an adult, my Speech and Language Therapist and I worked together to discuss ideas of therapy activities. We regularly review this and come up with new ideas.
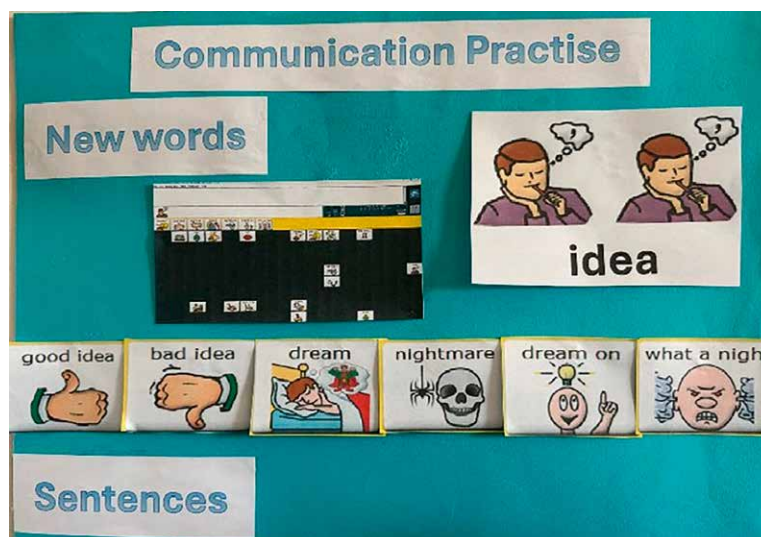
1   **Know why you are doing it. Be determined!**
2   **Find a communication partner.**
3   **Talk to yourself!**
4   **Keep it relevant.**
5   **Have fun with it. Boredom kills motivation!**
6   **Act like a child. Have fun with language!**
7   **Leave your comfort zone. Give a presentation at Communication Matters!**
8   **Listen and watch people talk.**
9   **Don't worry about mistakes.**
10 **Dive in. Go for it!**

5 Golden Rules of Adult AAC Language Learning:

To conclude, my speech and language therapist and I put together these 5 golden rules to support adults who are learning language using AAC.

1. Have a Positive Mindset

- Know how you learn.
- Build your self-motivation.
- Choose resources that interest you.
- Work out strategies that work for you.

2. Immerse Yourself in the Language

- Practise new words and sentences every day.
- Set goals and track your progress.

3. Integrate Active Language Learning into Your Life

- Listen out for new vocabulary.
- Move on from setbacks – don't worry about making mistakes.
- Build great habits. Every day counts!

4. Use the Language to Converse with Others

- Meet other AAC users.
- Talk to people around you.
- Use your communication skills all the time, 7 days a week.

5. Understand that Learning Language Takes Time

- Always keep learning.
- **Be determined! You can do it!**
- **You can always say more!**

Communication Matters is now on Instagram!

Please follow us on Instagram here: https://www.instagram.com/comm.matters/

Don't forget you can also follow us on our usual social media platforms too:

- https://www.facebook.com/communicationmattersuk
- https://x.com/Comm_Matters
- https://www.linkedin.com/company/17974584/
- https://www.youtube.com/channel/UC2UGRtfTqsHgoMT49DckdiA

The Communication Matters Survey 2024

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First, thank you to everyone who responded to the survey in September and October 2024. The Trustees appreciate the very detailed feedback and began discussing the findings at the November 2024 Board meeting.

Background

The survey was last undertaken in 2008. Those findings have been instrumental in supporting the strategic decision making of the charity and fundraising for many years. More recently the Trustees wanted up-to-date feedback on the work Communication Matters (CM) currently undertakes, and what should be future priorities for the charity.

The charity is a membership organisation run by 13 elected Trustees on a voluntary basis supported by 1 full-time and 1 part-time member of staff. This means prioritisation of time and resources is key to achieving the charity objectives. Respondents to the survey were provided with these charity aims to help frame responses. These are to:

- promote, undertake and facilitate research around communication impairments.
- promote, undertake and facilitate treatment and rehabilitation of those with communication impairments.
- promote and protect the physical and mental health of AAC users.
- publish information and research around treatment and support for AAC users.
- educate members and the general public around the needs of AAC users.

The two areas where the Trustees sought feedback were:

- Opinions around:
  What CM does well,
  What might CM improve or change.
- To consider the future strategic priorities of the charity.

The methodology

The online survey was promoted through the annual CM2024 conference, social media, the Friday Announcements, the online AAC forum, and the AAC user forum.

Overall, respondents were a representative sample of the membership. The numbers are rounded throughout so percentages may total over 100 per cent. Participants could identify themselves in as many categories as they felt relevant to them. For example: as a supplier and SLT, or family member and researcher. All respondents were anonymous and written responses that included identifying material were anonymised.

The survey was broken into:

Part 1: Demographic information

Part 2: Universal questions for everyone

Part 3: Tailored questions based on Communication Matters activities

Part 4: Universal summary questions.

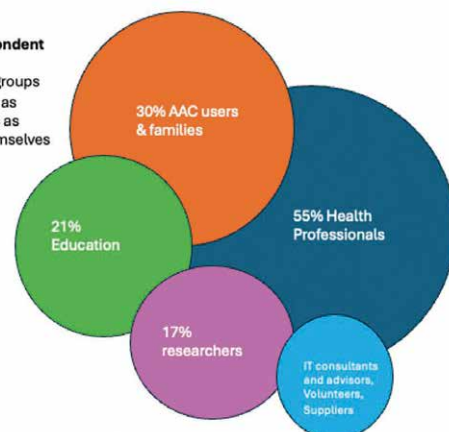Sections 2, 3 & 4 included multiple choice and free choice answers.

Respondents:

	Respondent Type 80 returns	Actual split of membership (Nov 24) 226 members
Individuals	53%	39%
People who use AAC & family members	29%	28%
Institutional members	12%	33%

- 55% of respondents were current associate members
- 36% of respondents were NOT current associate members
- 10% of respondents were unsure

- 20% of respondents have never joined Communication Matters

Type of respondent

Overlapping groups as could pick as many options as reflected themselves

30% AAC users & families

55% Health Professionals

21% Education

17% researchers

IT consultants and advisors, Volunteers, Suppliers

Results

Part 1: What CM does now

CM International Conference:

Do well: Unanimous excellent feedback on organisation, networking, education, exhibition.

Could change or improve: The location not always in Leeds, maybe virtual, or conference recorded to be shared online later.

ISAAC International Conference (All CM members are members of ISAAC):

Do well: Great international networking opportunities, especially for researchers.

Could change or improve: Very expensive conference, most attendees go to present their work and are funded by employers or bursaries.

CM Journal:

Do well: Respondents overall liked the journal focus and content.

Could change or improve: Make it to be more accessible, more articles, more searchable. Because it's not a peer reviewed journal, consider developing it into something that incorporates peer review without losing the wider general interest stories.

CM AAC Information Days:

Do well: Great opportunity to engage with people who cannot come to conference (funding).

Could change or improve: People want more information days, more frequently, in more locations.

Keeping people informed:

Do well: Friday Announcements (email news), the online AAC forum (AAC community discussion board).

Could change or improve: Specific questions around the mentoring scheme, Communication Access UK programme and the Research Interest Group. Mixed feedback, approximately 50% of people by topic indicated they were well informed, and a similar number not well informed.

Part 2: Future Priorities

Respondents prioritised 10 areas of Communication Matters work. The rankings below combined the high and medium percentages. When these scores were equal the high ranking score came into play, e.g. Priorities 2, 3 and 4 were equal on the combined ranking so prioritised by the high ranking.

The priorities free choice feedback was in-depth, every respondent made suggestions. The content was indicative of the passion the AAC community have for AAC.

Ranked priorities for Communication Matters future activities

	% Priority	Ranking High/Med	High	Med	Low
1	Increasing awareness of needs of AAC users & families	100%	84	16	0
2	Increasing awareness of AAC	99%	81	19	1
3	Definitive information resource for AAC and signposting	99%	76	23	1
4	Lobbying	99%	67	32	1
5	Opportunities to empower AAC users including training and networking	98%	75	23	2
6	Education for all AAC community at conferences, study days, information days etc	98%	71	27	2
7	Focal point for research in AAC community	96%	60	36	2
8	Links to government departments etc	92%	46	46	9
9	Education for AAC users at conference, study days, information days etc	90%	63	27	9
10	Workforce development via accreditation of training, networks for clinical supervision, signposting to training	82%	40	42	16

Discussion and feedback from Trustees

"It [CM] supports AAC users and families to be integrated members of the organisation and all its activities. This is to be commended, well done! There may be work still to do but CM is SO FAAaaRR ahead of most other national and international organisations I have ever been involved in."

(Anon, 2024 Survey)

This quote summarised the overall feedback, yet the Trustees are not complacent, there is much to reflect on around priorities, current work, and how these are communicated to the wider AAC community.

Part 1: What CM does now

The CM International Conference has always been residential on a university campus. Some respondents liked the 2021 virtual conference. Delegates were less satisfied with the Leeds accommodation in 2024 (borne out by post-conference feedback forms). The Trustees take this feedback seriously, the location and conference format are under review for 2026 onwards. All other feedback from CM2024 remained positive.

The ISAAC International Conference: Those who responded were advocates for the ISAAC conference and highly rate the conference content. All associate members of CM are ISAAC members with the opportunity to attend all activities.

The CM Journal editors are CM Manager Emily, and volunteer Sophie Nuttall. The Trustees welcomed feedback on making the Journal more suitable for researchers and how to develop the journal in the future.

CM AAC Information Days: There were fewer events recently due to dwindling attendance. Yet feedback from local organisers and potential attendees indicates a local need. This information will be passed onto suppliers who support these events.

CM keeping people informed: The Trustees and Staff keep people informed through the Journal, the Friday Announcements and social media. This is effortful for the small staff team and relies on recipients 'catching' the communications published. The social media visuals were updated in 2024, reflecting a consistent identifiable 'brand' image.

Part 2: CM Priorities from the Survey

Please find below feedback from the November 2024 Board Meeting:

Priority 1: Increasing awareness of AAC users and families. Suggestions included:

- More networking activities for users and families.
- Reaching out to less well represented groups in the membership to increase our understanding of their needs.

There was a high expectation awareness should be achieved through educating the public, training for people working in education, health and social care, and more lobbying. **The Trustees** continue to support initiatives voluntarily. Two specific CM initiatives, with Verity Elliott of Creativity in Practice, included:

- A further 5 years of National Lottery funding for the Mentoring Project.
- New National Lottery funding to establish Communication Clubs locally.

Priority 2 (linked to Priority 1): To focus on public awareness and developing community resources. **The Trustees** noted there are often initiatives on social media and everyone should be encouraged to tag CM. The Communication Access UK (CAUK) project was initiated in the UK by CM but is now the responsibility of the RCSLT to manage.

Priority 3: A desire to see CM as the 'go to point' for AAC information. Suggestions have been summarised under education and training, research, technology and professional practice priorities as appropriate. Many comments suggested the website is outdated, inaccessible, and not showcasing what CM does/stands for. The 'Focus on' leaflets were liked but needed updating. Overall, people liked the Friday Announcements and the AAC Forum. **The Trustees** have been working on developing the website, sadly due to capacity it often takes a back seat with other priorities such as conference. The Trustees have agreed to look at alternative ways to take this forward. The 'Focus on' leaflets are to be added to the website task list for review.

Priority 4 was lobbying, and **Priority 8** links to government: Respondents want basic training around how to lobby and campaign for AAC, and for CM to lobby and speak up on issues affecting AAC users, e.g. provision, continuing healthcare and a national AAC loan bank. **The Trustees** current work includes:

- Being active members of the All Party Parliamentary Group for Assistive Technology (APPGAT) and have regular 1-1 meetings with Policy Connect who manage the APPGAT activities.
- Being members of the British Assistive Technology Association (BATA) who have several members on the APPGAT.
- Contributing to a review of NICE Transition Guidance, the DfE consultation on Higher Education Support, the Mental Health Bill. Associate Members who become aware of public consultations should send information to CM who will endeavour to respond.
- In February 2025, Trustees attended the Speech, Language and Communication Alliance Launch event at the House of Lords. Beth Moulam spoke about the need for a well-trained children's workforce.

Priority 5: Empowering AAC users via conference, study days and information days has been combined with **Priority 9**: Education for AAC users, as many of the responses were similar. There were 3 themes: bringing users and families together, specific training in a range of subjects and supporting AAC users who offer services to get greater profile. **The Trustees** recognise the importance of priorities 5 and 9. Beth Moulam and Helen Hewson ran activities for AAC users at the 2023 Conference (Our Futures project). This

resulted in the 'Empowerment' theme for the 2024 Conference and became a catalyst for this survey. A further activity at CM2024 asked all attendees about empowering AAC users. These findings were discussed at the November Board meeting generating actions and a paper for the CM Journal.

Priority 6: Education for all. **The Trustees** recognise the importance of education, as a thread it runs through all priorities. This continues to be top of mind.

Priority 7: Was for CM to be the focal point for AAC research. The comments included CM coordinating the research agenda, identify gaps for future research and promoting funded research. Several comments reflected the demise of the CM AAC Knowledge database of research summaries. **The Trustees** agree research awareness is an important area for CM and have established the Research Sub-Group a Research Interest Group for AAC users alongside the Research Involvement Network which supports participant recruitment for research. The AAC Knowledge was funded by a National Lottery Award in 2009.

Priority 10: Workforce development was more relevant to a subgroup of respondents, yet the comments indicated significant concerns. The issues raised included the lack of cohesion across local services and hubs with requests for a smoother care pathway. Specifically:

- The postcode lottery surrounding local service provision.
- A growing demand for local provision and limited resources, funding models need reviewing.
- Strategic guidance on how to develop a local service.
- Guidance around identification, assessment and support of non-complex AAC users across lifetime (e.g. not hub assessed).
- Creation of workforce training programmes with nationally recognized qualifications.

The Trustees noted these local service concerns. The CM website houses AAC Quality Standards for Commissioners (2011) and Quality Standards for AAC Services (2012). Trustees continue to work on related initiatives, two Trustees are members of the NHS England Specialised Services AAC Group. The current position is not helped by the Local AAC Tools website being down for some time.

Finally, some comments didn't fit elsewhere. First, there needs to be greater transparency around the volunteer Trustee roles, more support for their work, new funding streams developed to employ additional staff. Second, there is an opportunity to raise awareness of the wider benefits of membership outside of attending conference. **The Trustees** role includes meeting legal and financial obligations in managing the charity, as well as running activities. CM must decide strategically how to take the next steps to support the Board, the wider AAC community and maximise membership to increase funding.

Overall CM Trustee Priorities: Like all organisations, the Board have a safeguarding responsibility for Trustees, Staff, Volunteers, and all attendees at events including AAC users and other vulnerable members. In November 2024, current safeguarding practices were reviewed and actions agreed for 2025 to ensure we remain compliant with Charity Commission expectations. Notwithstanding the comments above on priority areas, the focus on safeguarding will continue to be the highest priority for Trustees.

Overall Trustees response

We are delighted the associate membership appreciate the work undertaken by Trustees, friends and staff of CM. This feedback is important for strategic planning. There is an overlap between all the priorities, and we will continue to keep AAC users and families at the centre of our work. The priority is to educate and influence policy and practice around the needs, wants, changing tech, research, provision, training, and support needs of AAC users and their support networks, which includes professionals in the field of AAC. This drives our passion for the work of CM.

For queries contact the CM Office on admin@communicationmatters.org.uk.

Our Futures Update: January 2025

BETH MOULAM AND HELEN HEWSON
Trustees, Communication Matters
Email: Beth.moulam@communicationmatters.org.uk

Background

In 2023 Beth Moulam and Helen Hewson hosted two workshops at the Communication Matters (CM) Conference for AAC users. Workshop 1 was to identify the topics AAC users felt were important to meet their future education and training needs. Following theming the responses, AAC users at Workshop 2 had the opportunity to prioritise their areas of focus.

The responses were themed from day 1 into 7 areas. Two areas were not included in the discussion on day 2 for prioritisation by AAC users. These included life skills development and fundamental education skills (Maths and English). The remaining 5 areas that were discussed were: career development and the workplace, leadership, AAC and technology, relationships then personal development (rights, funding, mental health support).

During the 2023 session, AAC users prioritised the following 3 themes for their future education and training needs as:

- 1= Leadership topics
- 1= Career development and the workplace
- 3rd = AAC and Technology

Whilst relationships and personal development were viewed more important for some AAC users, the overall highest votes went to the 3 priorities above.

At the November 2023 Board meeting, Trustees reviewed these findings. It was clear further work was needed to refine priorities further for future activities and support.

Whilst the original activity was only for AAC users, it was felt useful to ask other 'interested' parties what their views might be on the themes identified by AAC users in 2023. The activity ran at the CM Conference in 2024 was not intended as an activity to override the views of AAC users, instead to show support, or difference, by membership group of what AAC users wanted.

Methodology

This activity was developed by Trustees based on the results of the 2023 workshops. During the CM Conference 2024, Beth and Helen, who both use AAC, were present to encourage participation and answer questions:

Session Design

All 5 themes identified in section 1 by AAC users in 2023 were split out into their component parts (see section 3). These were placed on noticeboards in the registration area of the 2024 conference.

Recruitment

During registration, attendees were asked to participate in the activity which was adjacent to the registration area. There were 102 participants (n=102), including: AAC users (n=13), Suppliers (n=11), Professionals (n=54), Personal Assistants (n=14), and Family members (n=10).

Data Collection

Participants were asked to review the topics previously identified by AAC users in 2023. They were each given 3 tokens and asked to place their tokens separately into 3 pockets that represented what they felt were the most important areas for AAC users' future training and education. Tokens were different colours for the 5 different groups of participants which included: AAC User, Personal Assistant, Family Member, Professional, and Supplier.

Ethics

This was not formal research. Each participant chose to take part in the activity and no registrant at conference was obligated to participate. All responses were anonymous.

Data Analysis

Immediately following the activity, the tokens were sorted by colour and counted by theme and topic. The data was entered onto a spreadsheet by voter group and by theme/topic (see below). This was then summarised for a presentation made on 9 September 2024, updating conference attendees about the Our Futures Project. The timings meant it was not possible to fully analyse the findings from the Sunday afternoon registration activity. Further analysis was conducted after the conference, as below in the results.

Results

Votes by topic

Theme	AAC user	Supplier	Prof	PA	Family	Votes overall
Participants (n =)	13	11	54	14	10	102
Total votes (3 per person) (306)	39	33	162	42	30	
Career development						
Preparing for work	4		9	1	2	16 (5%)
Support in workplace		4	8			12 (4%)
Self-employment	1		8	2	1	12 (4%)
Engaging in CM projects e.g. mentoring	5	3	7	3	2	20 (7%)
Total votes Career Development	10 (26%)	7 (21%)	31(19%)	6 (14%)	5 (17%)	59 (19%)
Leadership						
Working with PAs	3		4	2	4	13 (4%)
Self-advocacy	5	2	30	3	2	42 (14%)
Employer responsibilities	1		2	2		5 (2%)
Total votes Leadership	9 (23%)	2 (6%)	36(22%)	7 (17%)	6 (20%)	60 (20%)
AAC and Tech						
AAC software and hardware	2	2	23	3	3	33 (11%)
IT support	2		4	1	1	8 (3%)
SALT support	2	9	21	2	2	36 (12%)
Social media	3		6	5	2	15 (5%)
Total votes AAC and Tech	9 (23%)	11 (33%)	54(33%)	11(26%)	8 (27%)	93 (30%)
Relationships						
Managing romantic relationships	3		1	2	1	7 (2%)
Managing family relationships			3		1	4 (1%)
Managing friendships	4		8	1	3	16 (5%)
Counselling			1	1		2 (1%)
Total votes Relationships	7 (18%)	0 (0%)	13 (8%)	4 (10%)	5 (17%)	29 (9%)
Personal development and mental health						
AAC user rights			6	4	3	13 (4%)
Access funding	2	11	10	1	1	25 (8%)
Access mental health services	2	2	16	9	2	31 (10%)
Total votes Personal Dev & MH	4 (10%)	13 (39%)	32(20%)	14(33%)	6 (20%)	69 (23%)
Totals by attendee type						
Total people (102)	13	11	54	14	10	
Total votes (3 per person) (306)	39	33	162	42	30	

The numbers of votes are shown as percentages of the total number of votes for that voting group, e.g. 13 votes were cast by suppliers for Personal Development which was 39% of the 33 votes available. Percentages may not add to 100 as each score was rounded up or down.

Priorities by overall theme

Priority by Group	AAC users	Suppliers	Professionals	Pas	Family
Career Development	1	3	4	4=	4=
Leadership	2=	4	2	3	2=
AAC and Tech	2=	2	1	2	1
Relationships	4	5	5	4=	4=
Personal dev and mental health	5	1	3	1	2=

Priorities by Group: Number of votes for individual topics

Priorities by Group: Number of votes for individual topics (3 per participant)

AAC Users: 13

1 = Career Development focus on Engaging with CM projects (5/39)

1 = Leadership focus on self-advocacy (5/39)

3 = Career development focus on preparing for work (4/39)

3 = Relationships focus on managing friendships (4/39)

Suppliers: 11

Personal development focus on AAC users knowing about funding (11/33)

AAC and technology focus on SALT support (9/33)

Career development focus on support in the workplace (4/33)

Professionals: 54

Leadership focus on self-advocacy (30/162)

AAC and technology focus on AAC and software support (23/162)

AAC and technology focus on SLT support (23/162)

Personal Assistants: 14

Personal development focus on access to mental health services (9/42)

AAC and Tech focus on social media (5/42)

Personal development focus on AAC user rights (4/42)

Family Members: 10

1 = Leadership focus on working with PAs (4/30)

2 = Relationships focus on managing friendships (3/30)

2 = Personal development focus on AAC user rights (3/30)

2 = AAC and Tech focus on understanding AAC software and hardware (3/30)

Discussion

If the aim of the activity was to endorse what AAC users want for future education and training needs, then there are some key messages and questions in the findings. However, the very small sample sizes means these results may not be generalisable.

Voter breakdown and observations

AAC users are individuals, they appeared to be very different ages, and at different stages of life. This is an observation as no demographic data was collected. They were voting on their own needs and were not representative of AAC users as a group. In 2023, 15 AAC users took part in the Our Futures workshops, and in 2024, 13 AAC users voted. There is no way of knowing if this group was the same or different. This means the views expressed might be a re-endorsement of their own views or might include some new views.

Personal Assistants are likely to have been attending conference with individual AAC users. Family members will have attended either with an AAC user, or in their own right. On all counts their votes are likely to have been influenced by their own knowledge of the needs of an AAC user in attendance or at home. It is unknown if suppliers and professionals were voting with a specific person or group in mind, or from a more generalised perspective.

Career Development

AAC user's highest equal priority overall was to be able to engage in CM projects such as the mentoring scheme (which was the given example). The activity did not ask for reasons, however, participation in these projects may well give AAC users some of the skills they want to prepare for working, which was their 3= priority overall.

The responses of other groups needed further investigation and raised questions.

- Some suppliers voted for AAC users engaging in CM projects, and support for the workplace.

  Which suppliers are potential employers of skilled AAC users and what skills do they need?

  Which suppliers currently work with AAC users (paid and unpaid) and how do AAC users find out about these opportunities?

- 19% of professionals voted for AAC users to be developing careers. The votes were more or less equally weighted across preparation for work, support in the workplace, self-employment and engaging in CM projects.

  How can professionals help with career development, and what skills do they think AAC users need?

  Self-employment was predominantly seen by professionals as an option, what services do they think AAC users might offer?

- Career development and entering the world of work appeared less important to Personal Assistants and family members.

  Why do families and Personal Assistants think work is less important or, in the scheme of voting, was it less of a priority area?

Leadership

When living independently, AAC users are often leading a team as employers in a workplace, these leadership skills would be equally valid for career development. Developing self-advocacy skills was AAC users 1st= priority, and 1st priority for professionals, receiving the most votes overall.

How does the AAC community develop individual self-advocacy skills?

AAC and Tech

23% of the AAC user votes went to this theme, but they were split evenly across all topics.

By contrast, suppliers voted for greater SALT support of AAC users. Professionals voted this their most important areas for AAC user training and education with 2 near equal priorities. These were for AAC users to have greater knowledge of their systems and software and for greater SALT support. This raises the questions:

Why do suppliers think all training should come from professionals?

Do professionals think the need for AAC users to better understand AAC software and hardware should come from suppliers, or will they provide this through the additional support they think is needed?

Relationships

As in 2023 this was a lower scoring area. Clearly some AAC users wanted support around relationships, but not all. For those that do then this will be important for them, although they do not see it as a topic for counselling. This was a lower priority for all other groups except Personal Assistants (see mental health comments).

Personal development and mental health

The votes by AAC users mirrored the findings from 2023 as a lower scoring area. Again, it does not mean that that those who voted did not see it as their priority. Two of 13 AAC users wanted more information about funding for AAC, and two wanted access to mental health services.

All 11 suppliers voted for AAC users to have better knowledge and information around funding for AAC. Some of the professionals agreed with this but it was not a priority for that group.

The concerning finding might be that 16% of professionals and 64% of personal assistants prioritised the need for access to mental health services for AAC users, whilst only 2 of the AAC users voted for this. Action: This is an area for greater discussion.

Action to date

The report was discussed at the November 2024 Board meeting. Much of these findings also fit within the priorities coming out of the CM Survey.

There was a commitment to continue to take the Our Futures work forward through the sub-groups on the Board and develop a communication plan using social media and the website to keep people updated.

Thank you to the Trustees involved in delivering the activities: Beth Moulam, Helen Hewson, Helen Whittle, Andrea Sharples and Saffron Murphy-Mann.

CM2024 Conference Open Mic Night

MADDY NORMAN

Kids are naturally curious about life,
differences are like a knife.
Race, Religion, Disability. All woven into the fabric of life,
growing like a plant,
wiggling and winding though the earth.
From birth to death.

Whatever language we use,
symbols, Qwerty keyboard, sign language or the spoken word.
We all deserve understanding.
Go out there, explore your talents.
The world is your oyster,
be challenged, be inspired, be empowered,
most of all be you.

Haiku for Poetry Slam

Baked beans. Orange and wet.
Drained so I can eat them.
Sausages in a tin. Smothered in sauce.
I have it every day.

Symbol supported vocabularies for people who have aphasia.

Try it in Grid

Aphasia Duo
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Two symbol supported vocabularies packed with a variety of tools and supports to make communication easier and help with word-finding and daily routines. Included in Grid AAC software, available on Windows or iPad.