

Communication Matters



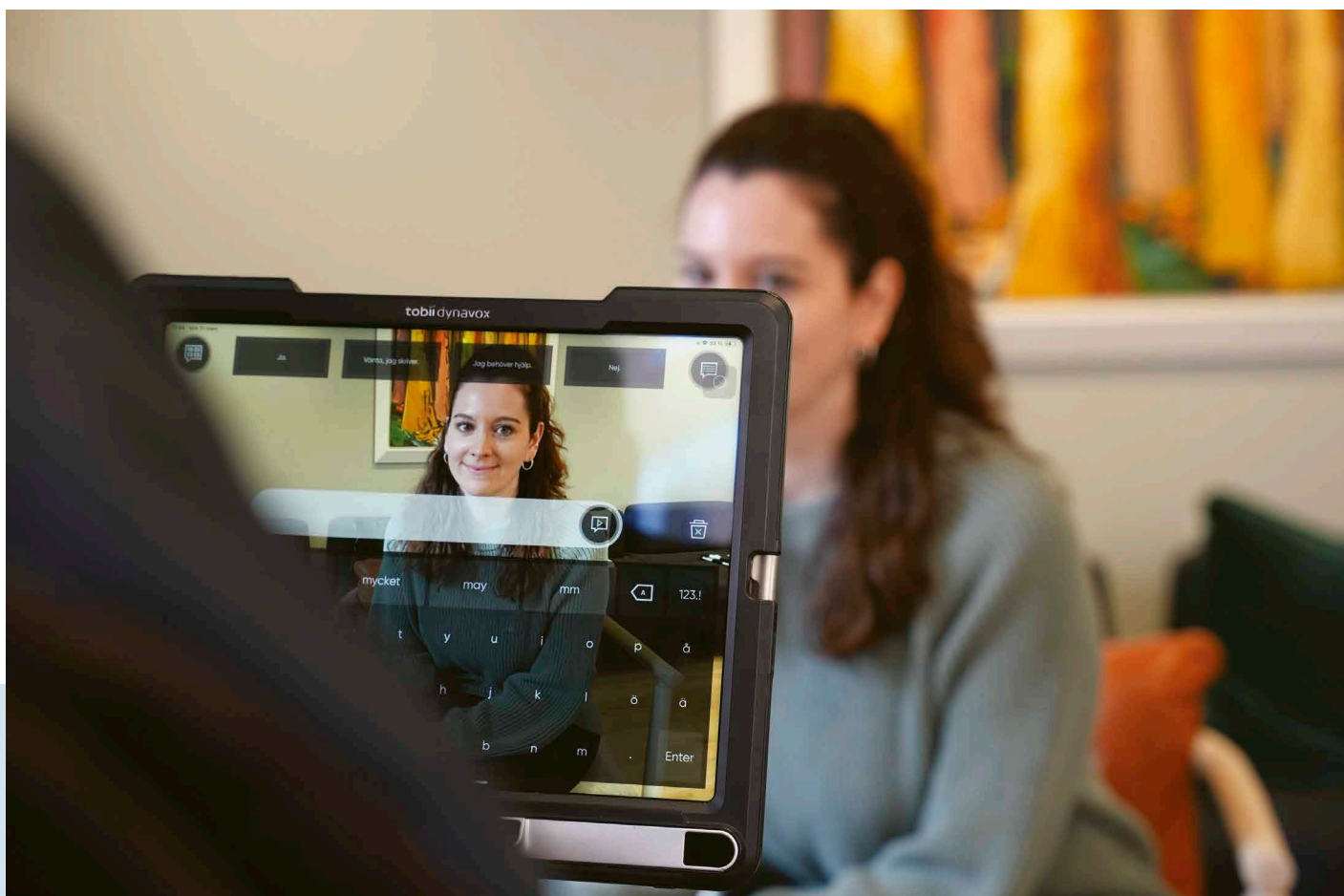
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THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

**Our Futures - Eye Gaze - Multimodal Communication - Provision & Abandonment
- Neurodivergent-Affirming Assessments - Voice Activated Communication Aids -
Research Involvement Network - Identity Within Practice - Adapting Cell Layouts -
Communication Partner Strategies - Service User Involvement**



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CM member Gabriel Davis listening to one of the presentations at the CM Conference. We look forward to welcoming you all back for this year's conference on 8-10 September in Leeds! Find out more at <https://bit.ly/cm2024conf>



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Chair's Report

HELEN WHITTLE

I hope you are continuing to enjoy the printed version of the journal.

Since the last journal was published, Communication Matters has been the Charity Partner for the Medilink Awards in Sheffield. It was a great evening, celebrating some amazing people and their medical innovations. It was also a brilliant way to raise awareness of AAC to people who had never heard of AAC before. Beth Moulam and I did a talk about Communication Matters' work which was well received. The attendees at the awards evening raised over £1000 for Communication Matters, which we are very grateful for. This money will go towards providing subsidised places for AAC users at this year's CM Conference.

We held a successful AAC Information Day in Glasgow on 1st May. There were 9 supplier companies presenting information and up-to-date knowledge on a range of AAC products, and the day was attended by over 100 delegates.

Since receiving another five years of funding from the National Lottery Community Fund in England, we have been working hard on the expansion of the original Mentoring Project to include the mentors who have achieved mentoring qualifications and who may now want to be involved in the running of Communication Clubs. These clubs can take place any time of the day/week. They can receive help in getting started and make use of CM mentoring resources, including risk assessment forms and ideas of topics for the first few meetings. Contact Verity Elliott on mentoringproject@communicationmatters.org.uk if you are interested in running a CM Communication Club for AAC users.

As we ran successful pilot projects in Scotland in 2023 and in Northern Ireland in 2022 with their National Lotteries, we are also making a full application for the expansion of the Communication Clubs across the rest of the UK. We hope we will be successful this time with our application to cover Scotland, Northern Ireland and Wales.

You can find out more about the Mentoring Project on our website:

<https://www.communicationmatters.org.uk/what-we-do/projects/>

Communication Matters continues to be a member of the steering group for Communication Access UK (CAUK). In placing people in hotels in Leeds to allow attendance at the conference, we encourage hotels and other venues to carry out the CAUK training and be added to the website directory as Communication Accessible venues.

The Trustees continue to represent all members of Communication Matters at many meetings, including the AAC Specialised Services meetings in Scotland and England.

Several Trustees have been involved in the rewrite of the AAC Guidance for Speech and Language Therapists and also the public. You can view the guidance here:

<https://www.rcslt.org/speech-and-language-therapy/clinical-information/augmentative-and-alternative-communication/>

This work was co-ordinated by the Royal College of Speech and Language Therapists (RCSLT) and written by an author group led by Professor Janice Murray. This guidance has just been published and was one of the last pieces of work Janice completed before retiring from Manchester Metropolitan University. We wish her a brilliant retirement with lots of time to catch up with other projects.

Following the CM Conference last year when Trustees Helen Hewson and Beth Moulam ran a workshop entitled 'Our Futures', the outcomes of this workshop were presented to the other Trustees and a working group was set up. This work will continue to be developed to ensure Communication Matters looks to develop strategies that support AAC users in their hopes and plans for their futures. Watch out for more developments at this year's conference.

Another exciting initiative that came out of a workshop run at last year's conference is the research working group. This group has produced a video explaining all the different aspects of being involved in research, which can be viewed on the CM YouTube channel: <https://youtu.be/SYbfeG6Ttqw?si=0zJ674z21j11mwBt>. As part of this work, an online meeting will be held by AAC users who wish to be involved in research as researchers and participants. It is hoped this group will meet regularly to discuss and develop their ideas for research. If you like to join the group, please get in touch with friend of Communication Matters, Charlie Moran on charlie.moran@nhs.net.

Professor Janice Murray's Retirement

HELEN WHITTLE

Janice retired as Professor of Communication Disability (AAC) from Manchester Metropolitan University (MMU) at the end of March.

She had a great send off with many people she had worked with over her long career returning to MMU to wish her well. Those who joined Janice for this celebration included colleagues from clinical practice, higher education, AAC users and family members who Janice had worked with, and several researchers some from Norway and Canada who had flown in for the event! They also included past and present BSc, Masters and PhD students, some of whom Janice is continuing to work with while they finish their studies.

Janice had just completed leading and coordinating the author group for the Royal College of Speech and Language Therapists (RCSLT) AAC guidance rewrite. Members of the Royal College attended her celebration as well. Dr Sean Pert, a former student of Janice's and current Chair of College, gave a speech during the retirement celebrations. View the new guidance here:

<https://www.rcslt.org/speech-and-language-therapy/clinical-information/augmentative-and-alternative-communication/>.

Janice was the Chair of the Board of Trustees for Communication Matters from 2009 to 2012, and she worked with the Communication Champion (a government position to investigate AAC provision after the Bercow review) and spoke at a reception at Westminster to raise awareness of the lack of coordinated funding for AAC in England at the time. This work led to the NHS model of service provision that is in place across England now.

Whilst lecturing at MMU, Janice developed and delivered an innovative PGCert in AAC and has also led some influential AAC research projects.

Janice headed up and ran the I-ASC project that was, at the time, the largest funded AAC research project in the UK. The project was a collaboration with Barnsley Assistive Technology service and the University of Leeds. The MMU team had two co-researchers with lived experience who were integral to the development and delivery of the research.

The project focussed on the clinical decision-making process that takes place when choosing an AAC system for a young person. The I-ASC project was also ground-breaking in the way it fully involved people with lived experience of AAC from the very beginning of the project. Read more: <https://iasc.mmu.ac.uk/i-asc-explanatory-model-of-aac-decision-making/>.

Another of the long running AAC research projects that Janice remains involved with is the Becoming an Aided Communicator (BAC) project, which involves researchers from 16 countries mapping language development through aided technologies. This has been led by Prof Stephen von Tetzchner, Norway, the winner of the Communication Matters research award in 2023.

These are just a few examples of her recent work, but there are far too many accolades to list in this short article, which is a credit to all her hard work over the years!

The Communication Matters Board sent Janice some CM-colour-themed flowers to wish her well for her retirement and to say thank you for all she has done for the field of AAC in the UK and beyond (right).



Janice won the Research Award at the inaugural CM AAC Awards in 2019.



Janice at the CM AAC Awards in March 2023 announcing one of the winners.



Janice at her retirement celebration listening to a presentation given by Dr Julie Lachkovic (SLT Principal Lecturer at MMU).

Our Futures: Workshop Findings

HELEN HEWSON AND BETH MOULAM

Email: bkmoulam@aol.com

Background

For many years, AAC users and those who support them have talked together about what happens when an AAC user leaves education. Some of the areas frequently discussed have been the lack of ongoing education, support and training, both during the transition period out of education and then throughout life.

This activity was not a formal piece of research but a way to gain the views of AAC users on how they feel about their own futures and their training needs, and then assess if there were any common themes.

The CM2023 conference was an ideal opportunity to invite AAC users to have a discussion. This was an open session to collect information, and the session leads were clear that this would be the start of a discussion with an agreed action plan as the outcome.

Methodology

The session was developed, written, and led by two AAC users (Helen Hewson and Beth Moulam). The aim was to assess if there were common themes around what AAC users were feeling in relation to their future education, training, and support needs. On the day there were six facilitators (three personal assistants, two Trustees, and one CM member) whose roles were to support AAC users answering each question.

Session Design

The session was planned in 2 parts across two days:

Part 1: To pose 3 questions:

Question 1: What education and training might help you in the short term?

Question 2: What other training might help you in the future?

Question 3: How would you like any training to be delivered?

Part 2: To share the themes generated from the 3 questions, discuss the findings, and agree an action plan.

There were 13 AAC users for Part 1 with an additional 3 AAC users who contributed in Part 2 (n=16). This included the two AAC leads.

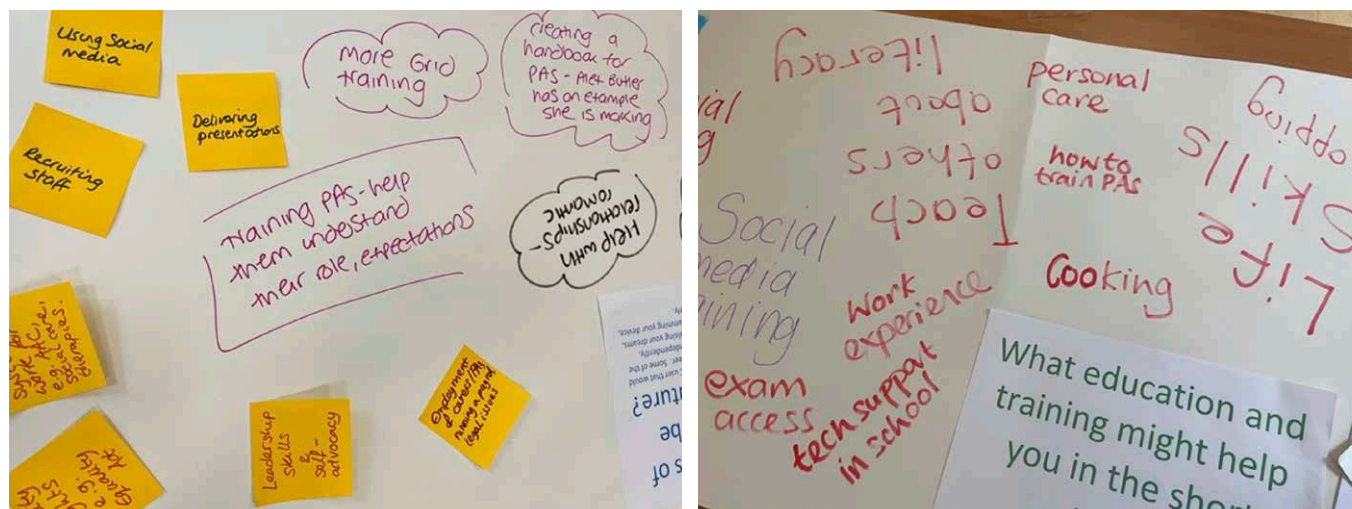
Recruitment

There were 33 AAC users registered to attend the conference (full, part and day attendance). Information was sent to AAC users prior to the event, and when AAC users registered at the conference on Sunday, they received an information pack and had the opportunity to discuss the event with the two AAC leads. By communicating the questions in advance, potential attendees were allowed time to decide whether to attend, process the questions and, if they wished, pre-programme answers.

Data Collection

In Part 1 following a brief presentation by the two leaders, all participants were able to take part by writing (with facilitation if needed) their responses to the 3 questions. Questions 1 and 2 each had two facilitators who changed throughout the session. Question 3 was quicker to answer so there was one facilitator. One facilitator collected demographic information and consent from participants. Each question was written out on wallpaper at a separate table. Around each table there was space to circulate and for the facilitators to speak individually with each participant. Some people used their own personal assistants for contributing, others spoke with the facilitators.

At the end of Part 1, the contributions were photographed for brief analysis/theming overnight. There was a total of 19 overlapping photographs to capture all the information across the 3 questions.



Ethics

This was not formal research; each attendee chose to attend and gave written consent for their input to be shared anonymously. It was made clear in the written and verbal briefings that there were no right or wrong answers and all contributions were equally valid.

Data Analysis

The overnight analysis consisted of writing down every contribution (even if it was duplicated) on a list. These were then themed by one of the AAC Leads into topic areas ready to share back and discuss with participants in Part 2. The prioritisation of themes during Part 2 was done by a simple show of hands.

Results

During Part 2, a short presentation was made outlining the themes. No comment was passed on these during the presentation other than to note the duplication of 4 topics between Questions 1 and 2 (shown in *italics*):

Question 1: What education and training might help you in the short term? 6 Themes:

1. Fundamental skills and education (English, maths, exam access, tech in school)
2. Life skills (shopping, cooking, personal care)
3. *Career development and the workplace*
4. *Leadership*
5. *AAC and technology*
6. Relationships

Question 2: What other training might help you in the future? 5 Themes (those in **bold** are developed below as priority areas):

1. **Career development and the workplace**
2. **Leadership**
3. **AAC and technology**
4. *Relationships (managing relationships, romantic relationships, relationship counselling)*
5. Personal development (funding, mental health support)

Question 3: How would you like any training to be delivered? In order of preference:

1. Face to face
2. Residential courses
3. Day courses
4. Mixture of face to face and online
5. Interactive online
6. Videos

Participants in Part 2 were given the opportunity to discuss the themes. They were then asked to prioritise what support they needed by each having one vote across the topics. The top two areas for support (equal votes) were 'Leadership' and 'Career development and the workplace', followed by 'AAC and technology'.

- **1= Leadership topics included:**

- Recruiting and leading a team, training personal assistants and communication partners
- Managing relationships in the workplace, dealing with staff changes
- AAC user rights
- Creating personalized resources for personal assistants (e.g. handbook)
- Employment requirements, payroll, legal responsibilities, staff rights

- **1= Career development and the workplace included:**

- Careers training, preparing for work experience and the world of work, work experience
- Workplace management course
- Role Model training, Communication Access UK training/opportunities, Mentoring skills
- Public speaking - creating and delivering presentations
- Other opportunities
 - Teaching others about AAC and literacy
 - Working in schools
 - Training in the NHS
 - Volunteering opportunities

- **3rd= AAC and Technology:**

- Access to effective screen readers (most discussed topic)
- ICT training
- Social media training
- 1-1 sessions with my SLT
- Exploring AAC choices
- AAC/technology courses including new ways to operate my device, programming my device, functionality of my device, building and updating AAC vocabulary
- Low tech AAC training/options

Discussion

Without pre-judging any of the themes, it was notable that some of the same topics were applicable to leadership, the workplace, and relationships. These were all communication related topics around self-awareness, self-determination, self-advocacy, in other words knowing yourself, knowing what you want and sharing this with others. These all require an AAC user to be confident in their AAC resources including their technology, personal assistants, and family/colleagues around them.

Action Plan

Part 2 closed with the AAC leads agreeing to:

- Summarise findings and send back to participants for comment
- Continue to engage with participants on how the work might be developed further
- Prepare a presentation for the Communication Matters Board meeting in November to discuss a proposed action plan. This included:
 - Relevance to the aims of Communication Matters (see below).
 - If opportunities already exist for AAC users (e.g. working with the Communication Access UK project, Mentoring via Creativity in Practice, Role Model opportunities via 1Voice) and how individuals might access these.
 - Suggestions for signposting when training was already available elsewhere (e.g. courses in local colleges).
 - How training and support relevant to Communication Matters aims might be supported, developed and funded.

Update

The Trustees were enthusiastic about the findings of the Our Futures workshop. After discussion at the Strategy Day in November, the following actions were agreed:

- The focus for the CM2024 conference would be empowerment.
- It would be impossible to focus on all the areas highlighted by the Our Futures workshop, but these were prioritised in line with CM objectives.
- A new sub-group would be set up called 'Communities' to focus on taking forward plans to develop support for various groups within the associate membership including AAC users, families, and local services. The first action agreed was to survey the whole associate membership with sections in the survey for different community groups including AAC users about what they want from CM for the future. At the time of writing, this work is underway on the proposed survey.
- Trustees to contact AAC suppliers to begin a discussion on how AAC users want to make the most of their hardware/software and what support is available.

Thank You

Helen Hewson and Beth Moulam would like to thank for their input during:

Part 1 and Part 2:

- Kate McCallum, Jess Slater, Lily Ashworth (Personal Assistants to Helen and Beth)
- Verity Elliott (Creativity in Practice)

Part 1:

- Saffron Murphy-Mann and Andrea Sharples (Trustees)

Notes

The participants have not been named as they were promised anonymity. As part of future developments, participants will be asked if they wish to be named on a list (but not have specifics attributed to them).

The full list of anonymised participant contribution can be requested from:

Beth Moulam beth.moulam@communicationmatters.org.uk

Contacts

Helen Hewson helen.hewson@communicationmatters.org.uk

Beth Moulam beth.moulam@communicationmatters.org.uk

Communication Matters/ISAAC (UK) Charitable Objects

- To promote, undertake, encourage and provide facilities for **research** into communication impairments
- To promote, undertake, encourage and provide facilities for the **treatment and rehabilitation** of people with communication impairments
- To promote and protect the **physical and mental health of people** with communication impairments through the **use of AAC**
- To promote, undertake, encourage and provide facilities for the **publication and exchange of information** in relation to communication impairments including development around using AAC
- To advance the **education of members and the public** around the needs of people with communication impairments

Demographic Information Collected (n=16)

Participants had the option to leave questions blank or say prefer not to say.

		No.		No.
Gender (16)	Female	8		
	Male	8		
Age range (16)	16-24	6		
	25-29	4		
	30-39	1		
	40-49	2		
	50-59	2		
	60+	0		
	Prefer not to say	1		
Do you consider you have a disability (16)	Yes	15	No	1
Working pattern (10)	Full time	1	Part time	3
	Volunteer	0	Other	6
In education or training (15)	Full time	5	Part time	0
	Not in education	7	Other	4
Highest level of qualification (16)	Up to and including GCSE	3	A Levels	3
	Degree	1	Blank	9

Learning to Use Browse with Eye Gaze

BETHANY DIENER, MS, CCC-SLP

Clinical Manager, Tobii Dynavox

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Much attention is given to teaching intentional and functional use of eye tracking and rightly so. Once this is accomplished, we tend to assume that the individual will be able to use these skills to do whatever they want. But this is not always the case.

Take browsing, for example. The internet offers many benefits for individuals with physical disabilities for learning, collaborating, and independence. And, gratefully, we live in an age when internet access using eye gaze continues to improve. Yet, browsing with your eyes is different than using touch. It is more closely aligned to using a mouse to browse because of the additional operational requirements to scroll and click. Given this, how do we go about teaching people who use eye tracking to browse?

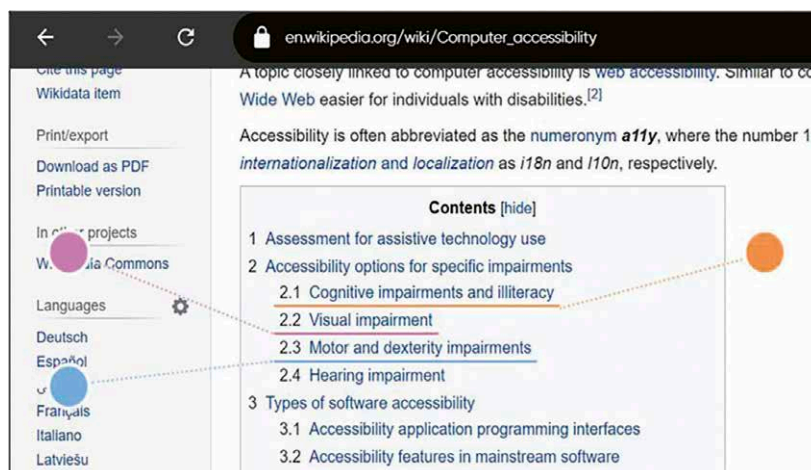
First and foremost, we want to take advantage of the individual's motivations. After all, motivation positively impacts persistence, and effort in the face of challenges. Also, we must take time to understand and implement safety features on websites and browsers as appropriate for the learner's needs.

Next, we will begin by targeting scrolling and clicking as these are the most commonly used functions when browsing and offer the most pay off for the client. Start with the function based on which needs little or no effort on the part of the client for that particular eye tracking app or feature. For example, on Apple's AssistiveTouch with an eye tracker, clicking is on by default and requires no prior selections whereas scrolling is on by default in Tobii Dynavox's Browse with no previous selection required.

After teaching scrolling or clicking, we then turn to the alternate function (scrolling or clicking). For the time being, demonstrate how to switch between the two rather than requiring the individual to do so. We suggest this because of the relationship between motivation and effort. If the individual is highly motivated to switch between these functions immediately, they may have the focus to learn the skill. However, many individuals will need to learn the benefit of both functions to spark their interest in learning to switch. Once this interest is present, teach how to switch between the two functions.

Before we move on, we have a few hints about teaching scrolling and clicking:

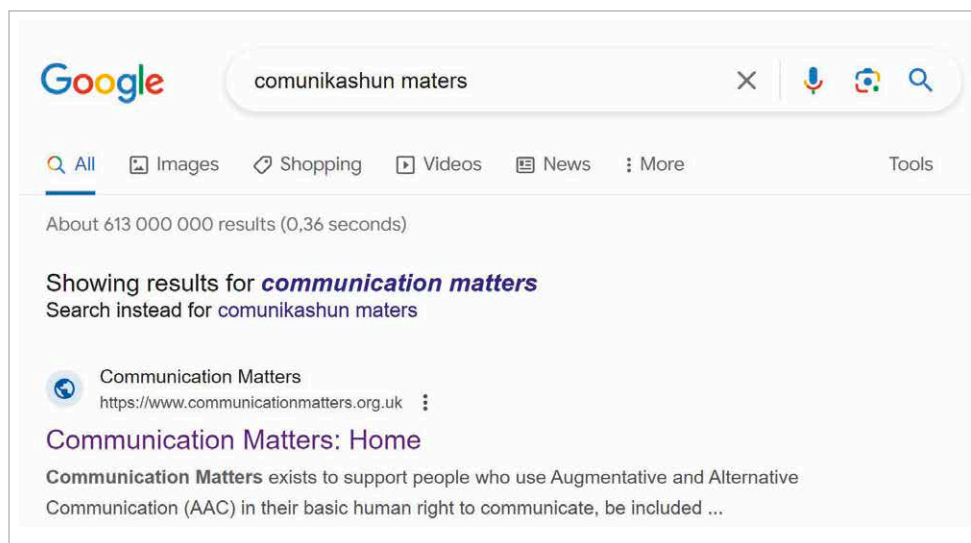
- Set up the eye tracking application to support the functions you are focusing on. Purpose-built browsers (like TD Browse) will likely have this done already. With AssistiveTouch, you might consider including only clicking and scrolling on the AssistiveTouch Menu to start then add functions over time.
- Choose websites that require the function you are targeting to make them interesting for the learner (e.g., content toward the bottom of the page or a click away).
- Teach clicking with large targets first. Searching for images is particularly good for this and can accommodate many interests. On an iPad browser app, that means changing the overall zoom for the browser you are using to make the images larger. For TD Browse, change the zoom for a single page (e.g., Google Images).
- Move to progressively smaller targets as accuracy improves. Perhaps start on an images page with a decreasing zoom. Then, move to non-zoomed YouTube and continue to small links such as those below.



With scrolling and clicking in hand as well as the ability to switch between them, we move on to navigation. Those who are able may want to begin typing keywords, but let us consider the needs of those who are not yet literate. Favourites, top sites, and bookmarks can be a way to provide independent access to favourite websites without needing to type. The options will differ depending on the browser being used as will the process for accessing them. TD Browse provides a home page button on the top bar that displays thumbnails of an individual's top sites. In Safari on the iPad, the tabs along the top of the browser may be challenging for some individuals to access given their size. Further, the only indication of tab content is a text label which may challenge those with developing literacy skills. Consider instead teaching use of the Multiple Pages icon in the upper right corner to see thumbnails of open pages.



It is now time when full browsing can begin. Teach an individual how to use their current literacy skills to type keywords into the search bar as best they can. Show them how to use word prediction, replacements for misspelled words offered by the search engine, and smart search returns to improve returns to search queries. As their interest in browsing continues, they will likely spend more time on the internet. Therefore, it is important to teach how to pause their eye tracker, if they don't already know how.



Now that the individual is browsing with eye tracking, internet safety becomes an issue. Utilise available resources online to teach these important skills. The internet can then become a source of personal and collaborative enjoyment and learning as well as social connection and independence for those who use eye tracking.

Communication Matters Small Grants

Open Now!

Each year the Board of Trustees allocates a set amount that we can offer to members as Small Grants.

These grants are for up to £500 each to applicants who live in the UK. We consider applications on a case-by-case basis but may only award part of the amount asked for.

If you are a member (or about to become a member) of Communication Matters, then you can apply at any time of year while funding lasts.

Trustees look favourably on applications that support the use of all forms of communication for users, families, or professionals. This could be supporting an event, providing play equipment, attending a course, or running a research project, but they are open to ideas.

Tell us what the grant is for, where and when it will be used, and how it will help.

Find out more and download an application form at:
<https://www.communicationmatters.org.uk/what-we-do/cm-grants/>

Multimodal communication: Exploring Factors Influencing Why People Use a Particular Mode

CHARLIE MORAN

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Background

Multimodal communication is about recognising that there are many ways to share a message, not just speech (Iacono et al., 2013). Different ways of communicating can be broken into four categories as shown by the 'The Four P's model' (Robinson, 2022) in figure 1:

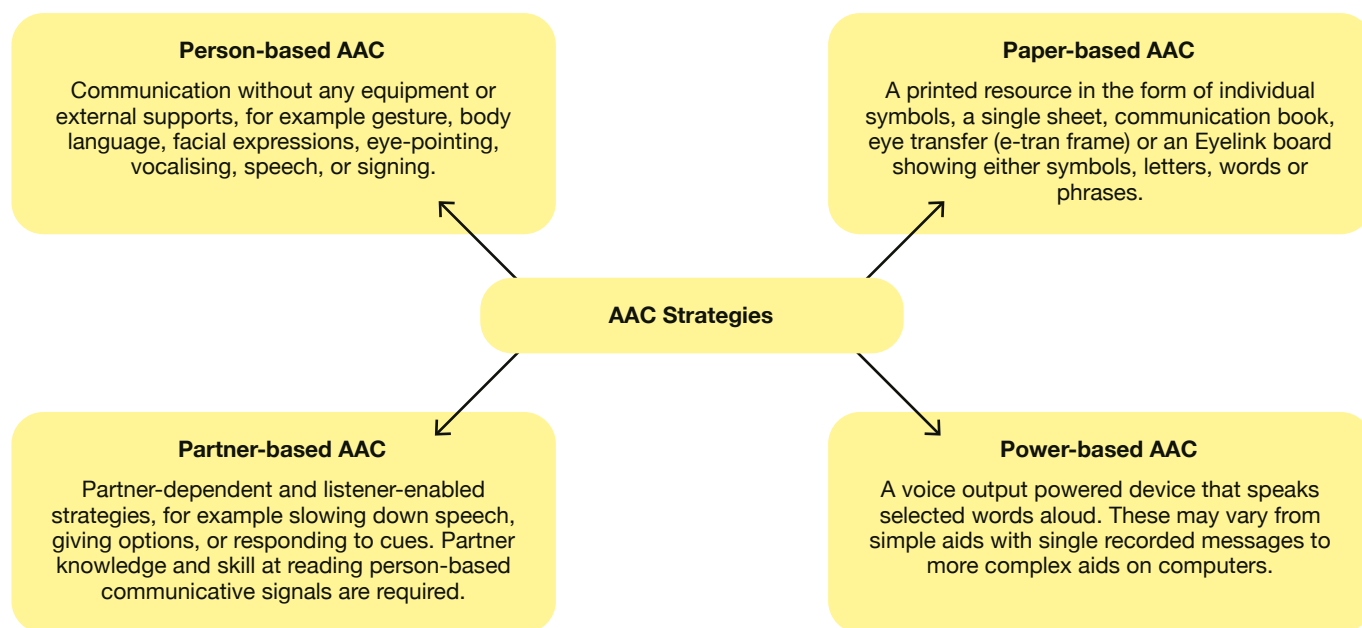


Figure 1. Diagram to summarise different AAC strategies

Person-based, partner-based, paper-based and power-based communication are all equally valid modes to communicate a message, however not all modes are appropriate for all contexts, e.g. most powered AAC devices cannot be used in a swimming pool or someone may not want to use voice output AAC in the cinema. There are no published recommendations regarding how to achieve multimodal communication for people who use AAC (Moran et al., 2023).

Initial Conceptual Framework of Multimodal Communication

A conceptual framework is a visual representation of information - a diagram that shows the networks of interlinked concepts in order provide an understanding of a phenomenon (Jabareen, 2009). An initial conceptual framework of multimodal communication was developed by Charlie Moran (Figure 2), developed by reviewing a number of sources of information:

- Literature review (Moran et al., 2023),
- AAC literature (Beukelman et al., 2013, Light et al., 2003),
- Clinical experience,
- Public involvement (PI) groups. Four PI groups were identified via Stakeholder mapping (Hennink et al., 2020): AAC professionals from the Barnsley Assistive Technology Team, AAC users, parents of AAC users, and local team Speech and Language Therapists.

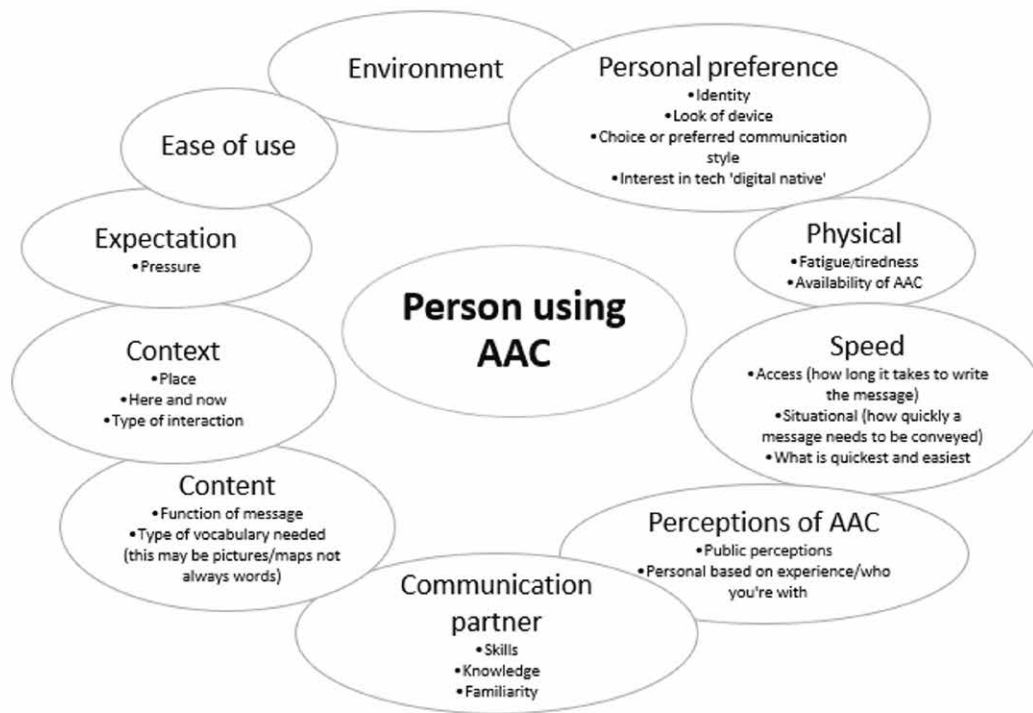


Figure 2: Conceptual framework showing the factors that may influence which mode of AAC chosen

The conceptual framework suggests that a range of different factors may impact an AAC user's choice of mode for an interaction. This is a patient-centred framework; the person using AAC is the main central factor with other influences around them which include:

- Personal preference - preferences in style, identity, device, and interest in tech (someone who is interested in tech may prefer power-based communication).
- Physical - personal physical characteristics, e.g., access methods, tiredness.
- Speed - how long it takes to write the message, the situation, i.e., how quickly does the message need to be conveyed and what is the quickest method to do this.
- Perceptions of AAC - people may change their AAC dependent upon the reaction of others to their AAC, based on previous personal experiences.
- Communication partner skills - the communication partner is the person interacting with the AAC user. A highly familiar communication partner is more likely to understand person-based communication such as speech or signing. Less familiar communication partners may not know sign language or how to set up power-based communication and so other modes need to be used.
- Content - the type of vocabulary needed may affect whether the AAC user is able to communicate with looks, signing or gestures, e.g., the name of a town or city can be difficult to share using looks and gestures alone.
- Context - of the message, e.g., if the message is about the here and now it may be communicated quickly by gesture or looking or pointing to a glass to indicate 'I want a drink'. However, if the message is about something that has already happened, it will be difficult to communicate that you want the same drink that you had yesterday if that drink is not nearby.
- Expectation - an explicit expectation to use a specific mode will mean someone is more likely to use that mode, e.g., in a classroom where the words needed to answer the question sheet are on the device, and the device is set up next to the worksheet.
- Ease of use - people will communicate a message in the easiest way. Using the drink example above, it may be easier to gesture 'drink' than to find a page in a communication book to point to 'drink'.
- Environment - external factors such as the weather. Powered AAC devices may not be appropriate to use in the rain, or paper AAC might be difficult to use outside on a windy day.

Investigating Multimodal Communication with AAC users

In order to support clinical work, explore this framework and investigate the ecological validity of it, real interactions were observed and recorded. The authors aimed to:

- Explore the factors that influence how someone chooses the mode they use for an interaction.
- Reflect on the benefits of multimodal communication.
- Consider the role of the support team in enabling and supporting multimodal communication.

Three clients known to the first author from clinical practice are described below. All of the clients had powered AAC provided by Barnsley Assistive Technology Service, were under 18 years old and attended different educational settings. Two of the three clients were visited at home to observe interactions with family members. Natural interactions were recorded during their typical daily activities to explore:

1. What mode they chose
2. What factors from the framework above contributed to that choice

Pseudonym	Rebecca (She/Her)	Ted (He/Him)	Keelie (She/Her)
Diagnosis	Dyskinetic Cerebral Palsy	Neurofibromatosis type 1	Athetoid Dystonic Cerebral Palsy
Age	7	5	17
Setting	Mainstream Primary	Special School	Specialist College
Powered AAC information	Device introduced: December 2021 (aged 5) Device: Gridpad 10s Vocabulary: Supercore 50 Access: Mixed access; direct, stylus and joystick dependent upon tone and position	Device introduced: July 2022 (aged 4) Device: Accent 800 Vocabulary: Easychat 45 Access: Direct access with a keyguard	Device introduced: 6 button, direct access aged 3 / Accent device aged 11 Device: Accent 1400 Vocabulary: Easy Chat Phrases Access: Direct access, either touch or stylus
Summary of Observations	<p>In the classroom the 'expectation' and 'content' of the message largely dictated use of powered-based AAC.</p> <p>In the playground the 'environment' and 'speed' influenced using person-based skills.</p> <p>'Communication partner' was a contributing factor in both situations.</p>	<p>The 'content' of the message and the 'communication partner' affected whether person-based skills or power-based skills were needed to convey his message. At home, with his mum person-based AAC met his communication needs, with less familiar partners power-based AAC was used.</p>	<p>Keelie shared her thoughts about why she chooses a mode. She identified speed and content as the main factors that impact her choice of mode.</p> <p>Communication partner is also a major influencing factor; Keelie is aware of who does and doesn't know signing. At home she uses signing first, and at college she uses a combination of signing and power-based AAC.</p>
Summary of modes used	<p>Person-based first.</p> <p>Other modes directed by support team.</p>	<p>Person-based first.</p> <p>Power-based for school work (more complex messages), encouraged and initiated by school staff.</p>	<p>Person-based or power-based first: the speed and complexity of message are the most important factors in determining person-based or power-based AAC.</p> <p>Has paper-based AAC but rarely uses this.</p>

Observations and reflections

Three common themes were noted when reviewing the case studies:

1. Where I communicate?

More person-based communication skills were used at home, something also observed and noted during clinical experience. Figure 3 shows the factors from the conceptual framework that appeared to be influencing this choice of mode at home versus the educational setting: context, content and the communication partner.

When communicating with the most familiar people, e.g., people at home, much of the context is shared, communication partners may be (or are often) highly tuned in to person-based communication methods, therefore these are likely to be efficient, effective and meet the AAC user's needs.

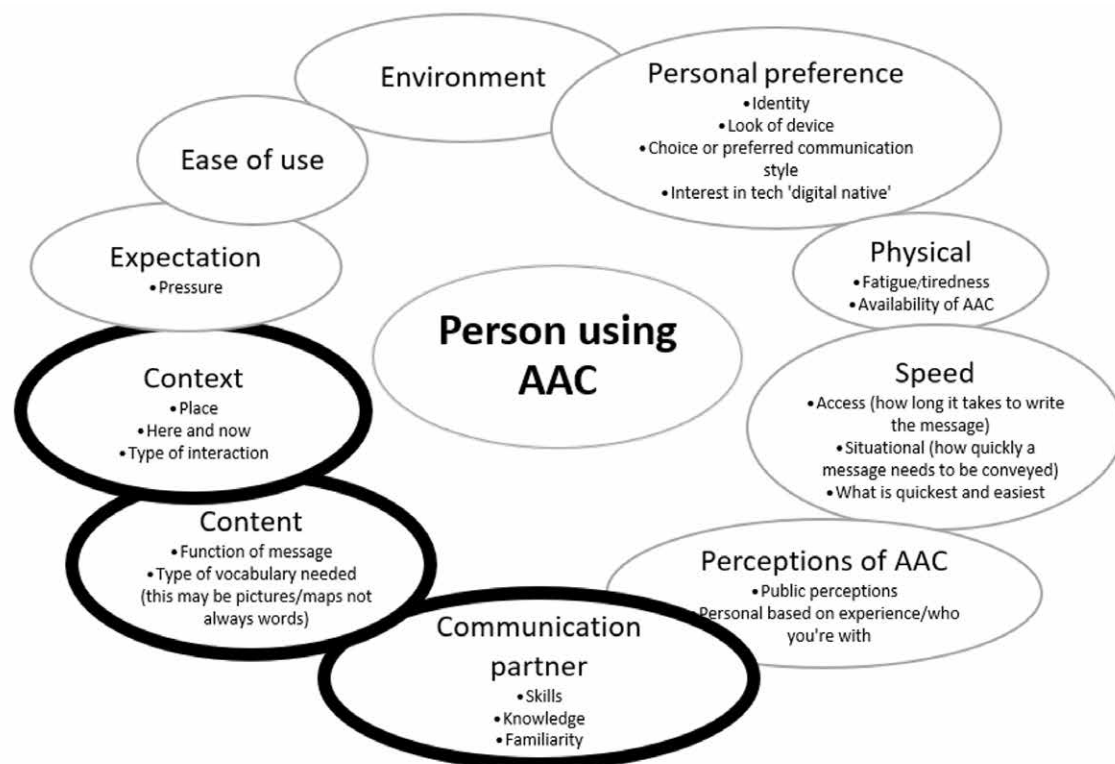


Figure 3: Factors impacting choice of mode: Where I communicate?

2. What I want to say?

In most of the examples analysed, the 'content' was a factor in choosing which mode to use (figure 4). There appeared to be a person-based first preference, weighing up 'can I use person-based ways to communicate my message, for example, a look, gesture, or vocalisation?'. If yes then person-based AAC is used. If not, another mode (power-based AAC for these case studies) is used.

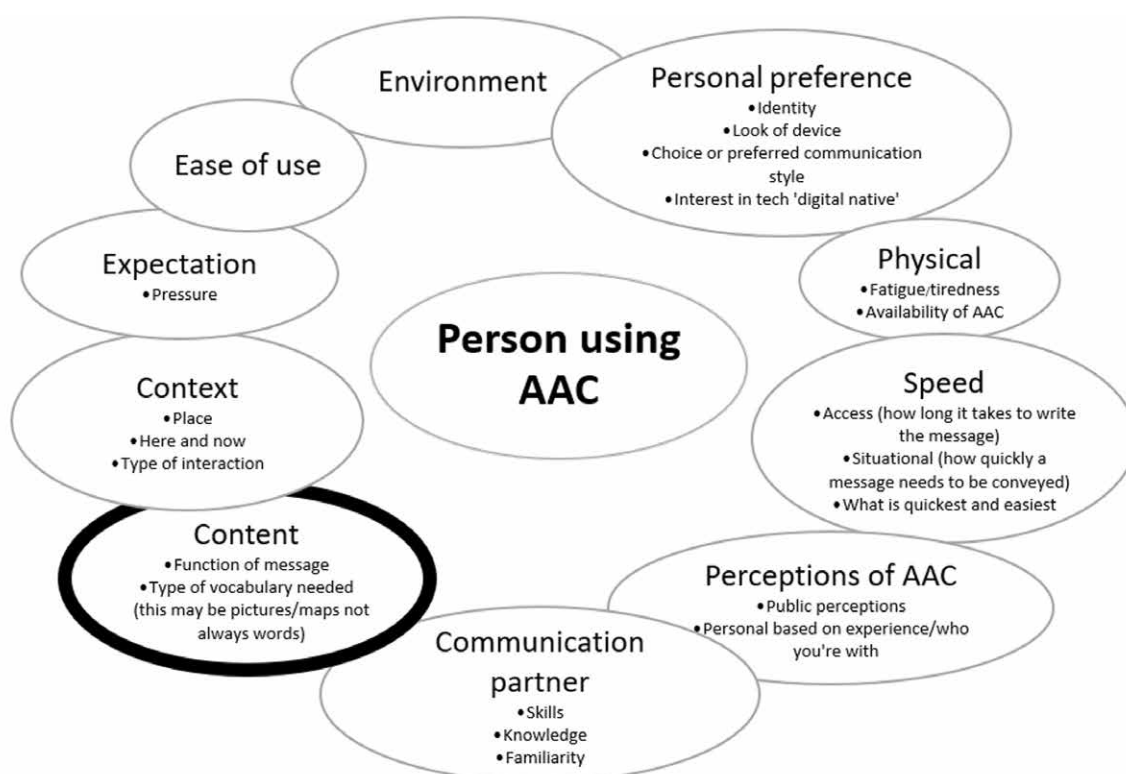


Figure 4: Factors impacting choice of mode: What I want to say?

3. Communication partners – who am I talking to?

Interactions were observed and filmed throughout a morning or most of the day by one or both of the authors. It was apparent that the most frequently used mode of communication was initiated by the communication partner using yes/no or closed questions, e.g., is it this or that? This is likely due to the ease of use, speed and the content of the message as well as the skills, knowledge and familiarity of the communication partner (figure 5). By using closed questions, the communication partner is able to obtain an answer quickly and easily.

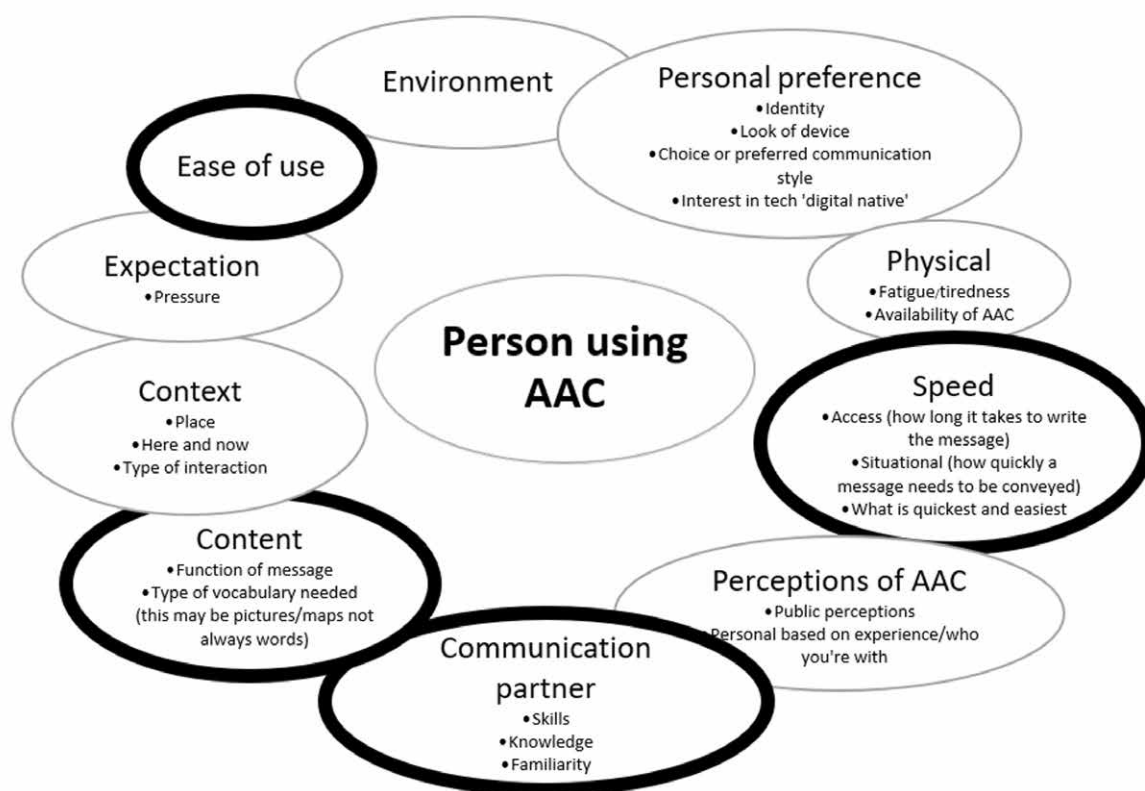


Figure 5: Factors impacting choice of mode: What the communication partner communicates

These common themes highlight that there are some factors that are more important than others when someone chooses their mode of communication: communication partner, content of the message, and also the easiest (or perhaps fastest) way to convey a message. These findings are similar to those presented in Clarke et al (2023), exploring modes chosen by people with partially intelligible speech. They found that choice of mode (speech, aided or unaided or a combination) was based on “the importance of the message; the available time; who they were speaking to; prior experience; personal preference; the environment and situation; and how the person was feeling” (Clarke et al., 2023:116).

Implications for clinical practice

Person-based skills:

These case studies demonstrate the importance of people being able to develop and utilise their person-based skills whilst having access and developing use of other modes of communication as needed.

The team, which includes everyone communicating with the AAC user, need to ensure that they’re knowledgeable about someone’s person-based skills:

- What are an AAC user’s person-based strategies?
 - Gestures, body language, facial expressions, eye-pointing, vocalisations, speech, signing, yes/no – does everyone in the team know what these all look like?
 - Be curious – What is important to communicate quickly? How is it communicated quickly? Do more messages need to be communicated quickly using person-based strategies?

When providing power-based AAC, it would be helpful to have discussions about the different strategies that someone may use, highlighting that person-based, partner-based, and paper-based strategies are all valid. It may be helpful to outline together what someone’s strategies are and discuss preferences for when each one is used. This will impact consideration of what words and phrases need to be available on paper-based and power-based AAC. The following questions should be considered:

- If someone uses quick person-based or partner-based strategies to communicate an important message, do they also need to access this on paper-based or power-based AAC?
- Does a paper-based AAC system need to be used alongside the power-based AAC device?
 - Are there times when power-based AAC is not appropriate but some messages need to be provided on paper-based?
 - Does the whole power-based AAC system need to be provided in an alternative way?

The importance of yes, no, and something else:

- Yes/no or 2 options were observed to be used repeatedly during interactions with Rebecca, Ted and Keelie.
- What happens when someone isn't sure or doesn't want one of the options given?

We need to ensure that we are supporting people with a way to indicate a third option of 'something different' as well as yes and no. It is important to increase the awareness of communication partners to offer 'something else / neither / I got it wrong' as options to choose.

Multimodal communication:

The support team has a crucial role to support people to consider how multimodal strategies can be used to support effective and efficient communication. The team should consider questions such as:

- Do we need to work on developing some quick and easy person skills if they're not already established?
- Does the person have a way to indicate which mode they want to use?
- What key strategies is someone using? Does the whole team know how to support these?
- How is it best to share information regarding communication preferences?

All communication partners need to respond to which mode the person is using at the time, valuing all modes of communication and remember that more than mode can be used during an interaction. Communication is a toolkit; we have many communication tools and we need to use the right one for the job. As outlined by Smidt and Pebdani (2023) we need to move towards a daily choice in use of different modes of AAC.

Conclusion

Communication is fluid and interactive; no one uses just one method. All modes of communication should be considered of equal value. AAC assessments need to take into consideration the fluctuating and changing factors impacting someone's choice of mode. The team also needs to consider communication throughout the day and across different activities to ensure that people are able to communicate effectively in their preferred way at all times.

References

- Beukelman, D. R., Mirenda, P., & Ball, L. J. (2013). Augmentative & alternative communication: supporting children and adults with complex communication needs. Paul H. Brookes Publishing Co.
- Clarke, Z. C., Judge, S., Fryer, K., Cunningham, S., Toogood, J., & Hawley, M. S. (2023). A qualitative study exploring the effect of communicating with partially intelligible speech. Informa UK Limited. 10.1080/07434618.2023.2206910
- Hennink, M., Hutter, I., & Bailey, A. (2020). Qualitative Research Methods (2nd edition ed.). Sage.
- Iacono, T., Lyon, K., Johnson, H., & West, D. (2013). Experiences of adults with complex communication needs receiving and using low tech AAC: an Australian context*. Disability & Rehabilitation: Assistive Technology, 8(5), 392-401. 10.3109/17483107.2013.769122
- Jabareen, Y. (2009). Building a Conceptual Framework: Philosophy, Definitions, and Procedure. International Journal of Qualitative Methods, 8(4), 49-62. 10.1177/160940690900800406
- Light, J., Beukelman David Richard, & Reichle, J. (2003). Communicative Competencies for Individuals Who Use AAC, Volume 3
- Moran, C., Randall, N., Judge, S. (2023). How Do People Who Use Augmentative and Alternative Communication Use Multimodal Communication in Real- Life Situations? A Literature Review. The Journal of Communications Matters, 37(1), 26-29.
- Robinson, H. (2022, October 17). October is AAC awareness month so I thought I'd re-share the four Ps model we use to describe the different types of AAC at @barnsleyAT. I prefer these terms to 'low tech' and 'high tech' as they give equal value to all forms of AAC, which people might use alone or together <https://x.com/HelenATSLT/status/1581965150806212609?s=20>
- Smidt, A., & Pebdani, R. N. (2023). Rethinking device abandonment: a capability approach focused model. Informa UK Limited. 10.1080/07434618.2023.2199859



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Provision and Abandonment of Assistive Technology: an Evaluation of the KM CAT AAC Equipment Provision Service

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The Adult Kent & Medway Communication Assistive Technology (KM CAT) AAC equipment provision service was evaluated in 2019. The evaluation investigated the effectiveness of this service, with particular emphasis on abandonment/suitability of the equipment provided. An abandonment rate of 37% was found, with a number of AAC users identifying inappropriate initial provision or a change in needs as the reason for abandonment. These results highlight the inefficiencies of providing AAC in this way and the need for dedicated local AAC services.

Background

Provision & Abandonment of AAC

Successful provision of AAC relies on a number of factors¹⁻⁴, including but are not limited to: AAC user involvement in the decision-making process; features of the communication aid; perceptions and support of those around the AAC user; availability of technical support; and the knowledge/skills of those providing the AAC. Simply providing a communication aid is not sufficient for a successful outcome. Unsuccessful provision outcomes include rejection, sub-optimal use to total abandonment. Abandonment is defined as:

“when the AAC system is no longer used, despite an ongoing need identified by the professionals involved” (Johnson et al. 2006)⁵

Abandonment is a well-recognised issue in AAC with reported rates of 30-60 %^{3,5-8}. Reasons for abandonment typically mirror those of successful provision: lack of involvement in decision making; features of the chosen communication aid; lack of training; lack of support, both day to day and technical; and lack of professional expertise.⁵⁻⁸

KM CAT AAC Equipment Provision Service

Provision of AAC in England is based on a model of specialised and local AAC services. Specialised services are commissioned by NHS England to assess and provide AAC for those with complex communication difficulties: ~ 10% of all AAC users. Local AAC services are intended to be commissioned locally to serve the remaining 90%, as well as referring and providing continuing support to those assessed by the specialised services. The provision of local AAC services varies significantly across the country.

In Kent, there are no dedicated local AAC services for adults. Provision of AAC and support for the majority of AAC users falls to local teams, with specialised services provided by KM CAT. For these local teams, AAC users likely constitute a minor portion of their total caseload; funding and therapist expertise in AAC may be limited. In West Kent & Medway, local services have to seek funding e.g. charitable or individual funding requests. In East Kent, local adult services assess for and request provision of AAC equipment (non-specialised) via the KM CAT AAC equipment provision service - funded by local commissioners.

The KM CAT AAC equipment provision service effectively operates as a loan bank of non-specialised equipment: local therapists assess, set up, train the user and review equipment; KM CAT provide & maintain equipment. This service has a total budget of £9000, this is designated for equipment only; administrative and equipment management costs must be absorbed by the KM CAT service. Due to service constraints, local services may discharge AAC users without routine review, in some cases, soon after provision. This does not allow local therapists to assess the effectiveness of the provision and determine if the equipment meets/continues to meet the patient's needs.

Service Evaluation

KM CAT performed a service evaluation in 2019 to investigate the effectiveness of the AAC equipment provision service over the period 2013-2017. This evaluation focused on determining the impact of the known limitations of the service and used abandonment rate as a key indicator for effectiveness.

Methods

As the information obtained was not part of the contracted work of the service, approval was required and granted by the Trust's Research and Innovation Department. All data recorded was fully anonymised and contained not personal identifiable information.

A questionnaire was developed to meet the aims of the service evaluation. The questionnaire was conducted via telephone interview, members of the KM CAT team contacted patients/their family members or carers and transcribed their responses to complete the questionnaire. Due to nature of their disabilities, it was not always possible to communicate with the patient directly. Where required, their family members or carers answered the questions either jointly with the patient or on their behalf.

Inclusion/Exclusion Criteria

All patients who had been provided equipment under the KM CAT AAC equipment provision service in 2013-2017 were eligible for inclusion. Of the 291 patients identified, 176 were excluded based on the following criteria:

- Patient was known to have passed away (150 patients)
- Patient had moved out of the East Kent area
- Patient had been subsequently assessed by the KM CAT specialised ACC assessment service
- Patient was identified by local therapist as inappropriate to contact

Results

Response Rate

Of the 115 candidates identified, 57 participated in the questionnaire. Some patients were able to participate directly (22), however the majority of participants were family members (26) or carers (9) answering on behalf of the patient. Responses given by family members of patients who were not known to have passed away prior to the interview were also included.

Representation

The age, diagnosis and type of equipment provided for all patients/participant was evaluated to determine if the participants were reflective of the service.

The age of participants was largely representative of the service, however it was somewhat biased in favour of younger candidates. This could be due to older patients being more likely to be excluded due to passing away.

A number of diagnoses were over/under represented in the sample. Degenerative diseases such as Motor Neurone Disease and Parkinson's Disease were underrepresented, this may be attributed to the increased mortality in these groups. Diagnoses including a Learning Disability were over represented.

The equipment provided to respondents was generally reflective of the equipment provided by the service however, Lightwriters/Alloras were slightly under represented while electrolarynxes and voice amplifiers were slightly over represented.

Abandonment

Abandonment was defined as either total abandonment or continued use of the equipment for purposes other than communication. An abandonment rate of 37% was found with only 25% of respondents reporting optimal use. Of those who had abandoned the AAC equipment, 50% had used it for one week or less and only two had used it for over a year. 26% of equipment which had been abandoned was not returned to the service.

The most common barriers to optimal use reported were: the equipment did not fully meet the user's needs, personal perceptions/motivations and insufficient support/follow-up.

Service Provision

Participants were asked to rate both the service they had received and any improvement to their quality of life (QOL) following AAC provision on a scale of 0-10, 0 being poor 10 being excellent. The service was very highly rated, average rating 8.8 with 50% of respondents rating the service as excellent, 10. QOL improvement was generally positive but ratings were more varied, average rating 6.7.

Participants were also asked if they had been given options when the AAC equipment was provided, if they had received training and if they had received contact details for support. Most respondents reported that they did receive training and contact details (33/54 and 28/55 respectively). However, only 8/54 respondents reported discussing options, the rest were either unsure, 26/54, or did not discuss options, 20/54.

Discussion

Analysis

There was no relationship between the service rating and the QOL improvement rating. This suggests that respondents rate the service on factors beyond the outcome. There appeared to be some correlation between the QOL rating and the use category: respondent who reported optimal use gave a higher rating and those who reported abandonment gave a lower rating. There was however no correlation between use category and service rating, further supporting the suggestion that service rating is not solely based on the outcome. This is also supported by the respondent comments which were overwhelmingly positive: the therapists involved were very good and helpful; equipment was provided quickly; initial training and support was good.

Training, discussing options and being provided contact details for support appeared to have an impact on abandonment rate, service rating and improved QOL rating. Respondents who reported discussing options and receiving contact details for support were much less likely to abandon their equipment, 12% and 18 % respectively compared to 37% for all respondents. Average improved QOL rating was slightly higher than the total average for patients who received training, discussed options and had contact details for support. Similarly, the average service rating was higher for those who received training and had contact details for support.

Limitations

There are a number of limitations to this service evaluation which must be considered when interpreting the results. There were limited responses and not all respondents answered all questions. The data set is not large enough for any meaningful statistical analysis. Additionally, the reliability/accuracy of the data collected is somewhat uncertain as the evaluation was performed in 2019 to cover the period 2013-2017, the responses given are reliant on the memory of the patient & carers/family. Responses were gathered from patients & carers/family, where responses were not given directly by the patient there is a possibility that true opinion of patient may not be captured. There was some ambiguity in questions and responses – some respondents report partial use but also that they are no longer using the device for communication; careful interpretation of the results was required to accommodate these ambiguities.

Future Work

The impact of the Covid-19 Pandemic cannot be ignored and it would be beneficial to explore further. Due to government restrictions and additional pressures placed on services, the support and provision of equipment in this period is likely to have been impacted. A repeat of the service evaluation to capture and define this impact is recommended.

It would also be beneficial to establish the abandonment rate of the specialised service for comparison. Abandonment rates published in literature are wide ranging and do not necessarily compare directly with the KM CAT AAC equipment provision service user population.

Conclusions

Abandonment represents both financial inefficiencies and an unmet clinical need. The abandonment rate of this service was 42%. Beyond this, only 25% of patients reported optimal use, leaving the majority of patients with some unmet need. A number of respondents reported training needs and lack of follow up. The cost of equipment no longer used for communication but not returned to the service was £8,480.77. The cost of equipment which had not been returned to service from patients who had passed away during 2013-2017 was > £ 15,000. Combined, this accounts for >50 % of the total budget for this period. Clearly, this is not a financially viable model. Despite these issues, the service was highly rated and the majority of respondent comments were positive, particularly regarding the therapists, and the speed of provision. Successful provision appears to contribute to improved quality of life.

Following this service evaluation, KM CAT have updated their processes for managing the equipment of patients who pass away, this has led to an improvement in the percentage of equipment recovered. KM CAT have also submitted a business case to the Kent & Medway ICB for a dedicated local AAC service for adults in Kent & Medway. This would replace the KM CAT AAC equipment provision service and go further towards meeting the requirements of a local AAC service as established in the NHS England guidance for commissioning AAC services and equipment⁹. In particular, this service would address the inequalities in non-specialised AAC provision across Kent & Medway and increase capacity for assessment and ongoing follow-up.

References

1. Baxter, S. e. a., 2012. Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis. *International Journal of Language & Communication Disorders*, 47(2), pp. 115-129.
2. Taylor, S. W. S. a. W. S., 2019. 'High-Technology Augmentative and Alternative Communication in Poststroke Aphasia: A Review of the Factors That Contribute to Successful Augmentative and Alternative Communication Use. *Perspectives of the ASHA Special Interest Groups*, 4(3), p. 464-473
3. Majeski KE, Ryan CD, Nadeau B. Finding the right fit: what contributes to the successful use of speech generating devices? *Assist Technol*. 2023 Feb 28:1-8.
4. Moorcroft A, Scarinci N, Meyer C. Speech pathologist perspectives on the acceptance versus rejection or abandonment of AAC systems for children with complex communication needs. *Augment Altern Commun*. 2019 Sep;35(3):193-204.
5. Johnson, J. M., Inglebret, E., Jones, C., & Ray, J. (2006). Perspectives of speech language pathologists regarding success versus abandonment of AAC. *Augmentative and Alternative Communication* (Baltimore, Md. :1985), 22(2), 85-99.
6. Riemer-Reiss, M. L., & Wacker, R. R. (2000). Factors Associated with Assistive Technology Discontinuation among Individuals with Disabilities. *Journal of Rehabilitation*, 66, 44-50.
7. Martin, J. K., Martin, L. G., Stumbo, N. J., & Morrill, J. H. (2011). The impact of consumer involvement on satisfaction with and use of assistive technology. *Disability and Rehabilitation: Assistive Technology*, 6(3), 225-242.
8. Schoonover J, Argabrite Grove R (2015) Influencing participation through assistive technology and universal access. In: Case-Smith J (Eds.), *Occupational therapy for children and adolescents*. St. Louis, MO: Elsevier Mosby, pp: 525-554.
9. NHS England/Specialised Commissioning (2016) Guidance for commissioning AAC services and equipment.

Developing a Neurodivergent-Affirming Assessment Experience for Autistic AAC Users

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In our role as Speech and Language Therapists working within an NHS England Specialised AAC Service (Barnsley Assistive Technology Team), we have spent the past year reflecting on how we might make the way we work more accepting of the differing communication styles of the people referred to our service. This has become known as 'Neurodiversity-Affirming Practice,' born from the Neurodiversity Paradigm in which neurological cognitive functioning (the way our minds work) is seen to be diverse across the population. All ways of being, and communicating, are seen as equal.

Embracing the idea of neurodiversity, along with observing a steep increase in the number of autistic people referred to our team, encouraged us to be proactive in looking how we might improve the experience of autistic people referred to our team for an AAC assessment.

What voices have we listened to?

We are often asked about the best evidence, regarding a range of issues. Typically, the best evidence is seen as that which is peer reviewed and published in an academic journal, more specifically meta analyses, where the findings of multiple studies have been reviewed and trends identified. Consequently, we began our journey with our heads buried in the journals, looking for this evidence.

We also noticed a significant surge in social media content looking at autistic communication styles. Terms like 'Gestalt Language Processing' and 'neurodiversity paradigm' were becoming common in our social media feeds. Messages on platforms like twitter, Instagram and blog posts tended to spread fast and wide. These channels of information exchange allowed a much-needed platform for non-academics to have their voice heard.

In the offline world, we spoke to our colleagues and listened to the experiences of speech and language therapists that were supporting autistic AAC users across our region. We heard their questions and learned from the solutions they had found.

As we gathered information, we realised that a key voice was missing: that of an autistic AAC user. We advertised for someone to review the content of a new training course we were developing and our request was answered by Dr Alyssa Hillary Zisk. Alyssa's opinion has proved invaluable during this journey.

In particular, Alyssa encouraged us to reconsider the value of the peer reviewed studies we had regarded so highly. What were the aims of these studies? Who were the authors? It became evident that much of what is viewed as 'gold standard' research is carried out *without* the involvement of autistic people and so does not align with the premise of neurodiversity. The aims of such research also tended to centre around "fixing" autistic communication: making a person's communication more neurotypical. Following Alyssa's guidance, we began to view this peer reviewed 'evidence' differently. Additionally, Alyssa prompted us to learn from the social media content of autistic people, by spotting the terminology they used and using those words in our searches for evidence. For example, academics tend to use the term 'gestalt language processing' to describe the way autistic people may develop and use language. However, autistic people themselves are likely to use the labels 'echolalia' or 'scripting.' Using these terms in our searches led us to find more work by autistic people.

Changes we have made to our assessments

We consider that people probably learn language either by understanding single words then joining words together and then creating phrases and sentences (analytical language learning), or by learning language in chunks (gestalts), before breaking them down into individual words and then putting those words together to make novel messages (gestalt language processing). Providing people with language that best fits their style of language learning is important, but it can be hard to identify this when working with individuals with minimal speech. We now ask referrers for some additional information, for example:

- Does the person hum, or like songs to be sung to them?
- Does the person like to watch particular videos, or certain parts of videos?

If the answer to the above is yes, it may suggest that the person is more likely to learn language through scripts (gestalts).

Typically, our referrals tell us that the autistic person has rejected paper-based AAC. We understand that for many autistic people, powered AAC is preferred, but paper-based AAC can also be helpful. Sometimes paper-based AAC isn't used because it hasn't fully been supported by those around the person and/or that the language that is important to the individual has not been included. We now ask the following:

- What AAC has been previously tried?
- How has it been introduced and implemented? (what training was given?)
- What language/words were included?

Communication is often dependent on the person's regulatory state. Being regulated means that they are calm and able to participate. Often, our attempts to introduce AAC were unsuccessful due to the person being dysregulated. We now ask referrers:

- What activities are likely to dysregulate the person?
- What helps to regulate them?

We have found ourselves drawn to the work of Chris Bailey who is an autistic academic and was a lead in the 'ruling passions project' (Bailey, 2023). Previously, we would have talked about a person having 'obsessions' or 'special interests', however we feel that *ruling passions* offers a more celebratory description of what is obviously important to the individual. We now ask referrers:

- Does the individual have any ruling passions and what are these?

We are then able to personalise our assessment activities in line with their ruling passions to create a positive connection when we meet.

Adaptations we have made to the AAC vocabularies we provide

We have concluded that there is no single vocabulary that fits best. Instead, we look for vocabularies which support both single words and scripts and have features that match an individual's communication needs. These may include:

- The ability to add phrases/scripts;
- The inclusion of core and fringe words;
- The ability to record audio onto cells;
- The ability to add photos and videos into the pages.

Changing how we write AAC goals

Traditionally, speech and language therapy views communication as being about giving messages to other people, for example: greetings, comments, describing something, making a joke.

We were drawn to Lily Konyon's differing view on communication functions, as shown in table 1.

Other focused	Self-focused
Communicating messages to others	Sensory self-regulatory
Connecting socially with others	Interest based self-regulatory
	Inner dialogue

Table 1. Communication functions (Konyon, 2023).

Re-thinking how we value diverse communication functions has significantly impacted how we judge 'success' with AAC. Previously, we would be likely to measure outcomes based on how well a person communicated messages to others. Now, we place equal value on self-focused communication.

As well as a historical focus on communicating messages to others, speech therapy goals often work towards 'developmental language norms'. We realise now that this is not neurodivergent-affirming and that autistic people may develop and use language differently. Consequently, we have increasingly struggled to set goals for autistic AAC users that are language related. Instead, our focus has turned to the skills of the people around them and to the effective regulation of the person so that they are better able to use their AAC. Some examples of goals we might set are given here:

"Identify times, places and situations within the school day in which 'x' feels calm, safe and focussed"

"Model without expectation, the pre-programmed phrases on 'x's' device that relate to what they are doing in the moment"

We also consider phrases we can use in our goals to ensure that basic good practice principles are being followed, such as:

- "Given a regulating setting..."
- "In an activity of the individual's choice..."
- "From natural models given by the interactive partner..."

Changing how we write assessment reports

We have adapted the language we use when writing assessment reports. The work of McGreevy & Lees has encouraged us to consider the tone and language we use. Our aim is to offer clear descriptions of a person's abilities and describe their support needs, without using deficit-based language.

Training for our region

As a specialised service, our remit includes training and support for teams across our region. We have written a course summarising current best practice, rooted within the Neurodiversity Paradigm, to enable local teams to best meet the needs of Autistic AAC users. The uptake for this course has been overwhelming, undoubtedly as a reflection of widespread interest in neurodiversity-informed practice amongst speech and language therapists.

What questions do we still have?

This piece of work is an ongoing journey. We endeavour to remain updated with current evidence that is based upon neurodivergent-affirming principles and to continue listening to voices outside of the academic space, particularly those who are autistic and especially autistic AAC users. Lots of the information is born from voices in other areas of the world and not only do we need to collate, appraise and understand the information we receive, we need to impose it upon the systems within which we work in the UK. As we do this, more questions emerge and some of those that we are currently considering are:

1. What role do NHS Specialised AAC services have to play in supporting local SLT teams?

Our training offer has been a first step in supporting local teams, but the onward development of knowledge and skills across our region needs consideration. The information surrounding autism and neurodivergent-affirming practice is rapidly evolving. The need for everyone involved in providing support to our autistic AAC users to remain up to date is vital; how should that information continue to be disseminated, what responsibility do specialised services, local AAC specialists and local Autism specialists have to ensure collaborative working and sharing of information? Within individual teams as well as across teams regionally, there are different levels of neurodiversity awareness and implementation – how is such a spectrum of skills and knowledge acknowledged and individual needs met?

2. How do neurodiversity affirming approaches fit with specialised services funding?

The presumption of competence without pre-requisites to use robust powered AAC for our autistic communicators is central to the notion of Neurodivergent affirming practice. This has implications for the provision of such devices for these individuals and the demands upon the NHS funding stream must be acknowledged.

Additionally, in terms of accessing services, we are increasingly aware that there are evidenced reasons why some autistic people do not take up paper-based AAC systems. Evidence of exposure to and use of paper-based AAC systems is needed as part of the referral information to specialist services. If we work within a neurodivergent affirming approach, might we consider the information related to trial of paper-based systems differently, looking for a wider range of information rather than a binary metric of success or failure to ensure autistic individuals receive an appropriate AAC assessment?

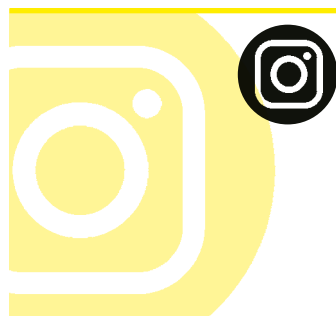
3. How do we use paper-based AAC with people who learn language through echolalia and scripting?

Supporting diverse language learning styles can be challenging to implement in paper-based systems when a variety of language forms also need to be added, e.g. single core words, current scripts that are important to the individual, new phrases that are added to allow the individual access to more scripts and potentially large amounts of fringe vocabulary. What template for our paper-based systems do we use to retain consistency of motor planning and architecture for growth, particularly as the paper system is added to and developed?

We welcome an ongoing dialogue between ourselves, other practitioners, AAC users and their families as we continue our journey to provide a neurodivergent informed AAC service.

References

- Bailey, C. (2023). 'Neurodivergent literacies': exploring autistic adults' 'ruling passions' and embracing neurodiversity through classroom literacies, *Literacy*, The United Kingdom Literacy Association, <https://doi.org/10.1111/lit.12320>
- McGreevy, E., Leeds, E. (2022, Aug 29). Neurodivergent-Affirming Report Writing. *Divergent Perspectives*. www.divergentperspectives.co.uk/post/neurodivergent-affirming-report-writing
- Konyn, L. (2023, 20th-21st June). *Supporting Gestalt Language Processors to Keep Scripting*, [Conference presentation]. AAC in the Cloud Conference, Online. <https://presenters.aacconference.com/videos/UWpFelFUSxo=>



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Incorporating Voice Activated Communication Aids into Everyday Communication

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Introduction

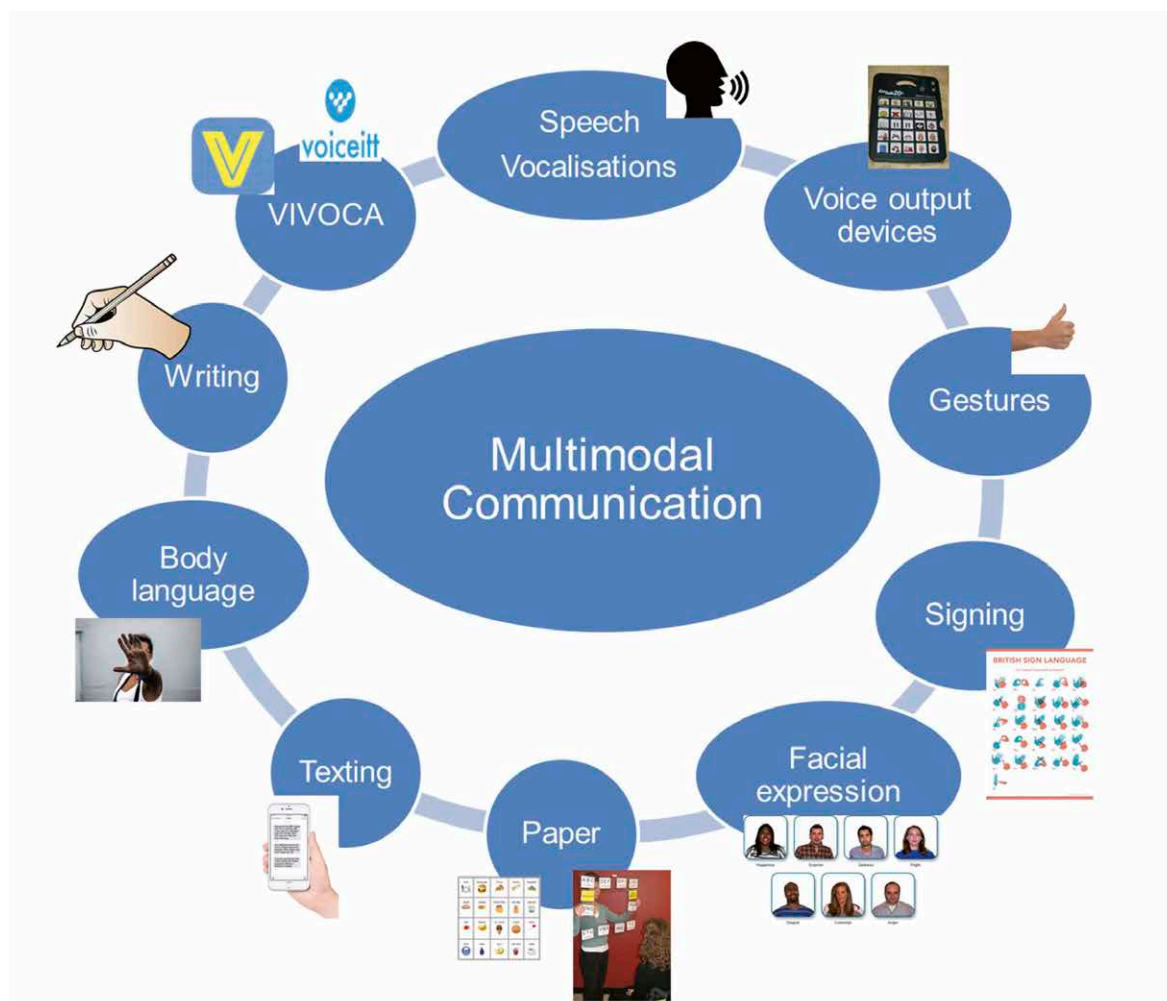
Being able to communicate is an essential part of everyday life, but it can be problematic for many people with disabilities. Dysarthria is a neuromuscular condition affecting 170 per 100 000 of the population, resulting in speech which is slow, slurred or difficult to understand, most commonly caused by cerebral palsy (1). Those with moderate to severe dysarthria experience severely restricted communication (2).

Dysarthria can result in marginalisation in many areas of life, including employment, family and relationships (3). Effective communication is necessary for learning, participation, and self-advocacy in many social and academic contexts and people with communication difficulties are at higher risk of under-achievement (4). This marginalisation may be ameliorated by the use of communication aids, a form of Augmentative and Alternative Communication (AAC) which supports communication (5). Studies suggest that communication aids provide an increased sense of control and independence and contribute to the user's sense of personal identity (6). Our own research also suggests that communication aids can be life changing, "It is like a new life" (7).

There are a range of communication aids currently on the market, and these are provided through specialised and local NHS services. Although communication aids have positive outcomes for many, current methods of using them are intrinsically slow and unable to keep pace with spoken conversation. This is a key factor in some being abandoned or not adopted by users (5). There is evidence that communication devices are abandoned when users don't receive appropriate support (8). In response to this need, there are now apps on the market which can learn to recognise vocalisations of the user, which may be unintelligible to those unfamiliar with the individual, and link these with an intelligible spoken output generated by a speech synthesiser. This technology is known as Voice Input Voice Output Communication Aids (VIVOCAs). VIVOCAs are a relatively new concept, currently clinicians have no or very limited experience of providing or supporting them, and this is likely to be a barrier to uptake. This research aims to identify which participants are most likely to benefit from VIVOCAs and potential barriers and facilitators to NHS staff providing and supporting it.

Our own previous studies suggest that VIVOCAs may be faster for people with dysarthria than their usual form of communication (9). While VIVOCAs have the potential to be a uniquely valuable tool for people with dysarthria, they are a transformational step in technology, being radically different from existing communication aids, and have not yet been widely adopted. We need to understand how the participant benefit from VIVOCAs can be maximised, and how the users should be supported to use VIVOCAs. A guiding principle of the study is valuing multimodal communication, acknowledging that VIVOCAs may form part of a number of communication strategies and finding out the role VIVOCAs can play alongside other modes of communication.

Diagram 1: Multimodal communication: a figure illustrating different ways that people communicate.



There are two VIVOCA apps commercially available, VOCAtempo and VoiceItt. Both apps are similar in their use of voice recognition technology specifically developed to recognise individual dysarthric utterances. The two apps have quite different interfaces: VocaTempo provides visual cues for the user as to which vocalisations they have trained, and what outputs they are connected to; VoiceItt does not have visual cues and therefore relies on semantic connections between the vocalisations and the outputs, and the participants being able to remember the vocalisations or words they have trained. With VocaTempo, listening is activated by a single touch (anywhere on the screen or a switch) whereas VoiceItt listening is activated through use of a specific spoken trigger/activation word or touching the screen (it does not have integrated switch access). Anyone wishing to purchase or download these apps are advised to contact the companies that own the apps in order to check the current support available for users. VocaTempo is owned by Therapy box and VoiceItt is owned by a company of the same name.

We are currently recruiting to the INVITE study, which aims to evaluate who can use these apps, how they use them, and what support they need to incorporate these apps into their communication strategies.

An outline of this study was shared at Communication Matters 2023 as a lightning presentation in order to raise awareness about the study with potential participants or teams who work with people who have dysarthria.

The INVITE study

This study aims to find out who can benefit from VIVOCAs, how they use it, and what support they will need to use it successfully. This information can be used by professionals involved in providing communication aids (CAs) and will help us to plan further research into VIVOCAs' effectiveness.

The study consists of two phases:

1. 20-30 individuals with dysarthria will be asked to use VIVOCAs in their everyday lives for 6 months. We will collect information on whether VIVOCAs improve their communication, and help them reach their goals.
2. Focus groups will be held with professionals involved in providing and supporting people with communication aids to understand factors affecting their ability to provide the support identified as needed in part 1 of the research.

We have a panel of three expert users, all of whom are communication aid users. The team have consulted with them individually, either face to face or using video meet, to discuss our ideas for this project. These discussions were influential to the design of the study, particularly in deciding on outcome measures that were meaningful to users, and deciding the length of time we would need to trial the app for to know if it was successful for an individual user.

The inclusion criteria to be a participant in the study are:

- Over 18 years of age
- Moderately or severely dysarthric
- Minimum of 2 distinct vocalisations over which they have voluntary control
- Able to give informed consent and take part in interviews with appropriate communication support
- Communicates predominantly in English

The exclusion criteria are as follows:

- Significant cognitive impairment and are unable to give informed consent on their own behalf or actively take part in interviews, or are unable to use a communication aid
- No controlled vocalisations
- Dysarthria as the result of a progressive condition
- Not on the active caseload of a local or specialised AAC service (if recruited through informal networks)

Given the complex nature of participants communication, it is essential for the researchers to be responsive to all communication methods. Consent can be either written or verbal, using the participants' preferred communication method, or through use of closed questions. If written, it will be taken using the Participant Consent Form. If consent is not recorded in writing by the participant, then this will be audio or video recorded as appropriate and witnessed by a communication partner of the potential participant where possible. This is necessary as gesture or individualised AAC methods may be used to indicate yes/no. A clear yes/no response will be established with the participant. Each element of the consent form will be read to the participant, their understanding of it will be confirmed (with a yes/no response), and further information provided as necessary, and consent confirmed for each element with a yes/no response.

How We Will Evaluate the Impact of VIVOCAs

The team are ensuring that participants are aware that we do not yet know the level of benefit that these apps may offer. During the study the participants data collection will occur at baseline, 3 and 6 months.

The participants will identify their own goals, and the extent to which participants have met their goals using VIVOCAs will be evaluated with the Goal Attainment Scale (GAS (10)) which has been used clinically to measure the effectiveness of interventions. While goals are unique to each participant, these are scored in a standardised way. This will allow us to evaluate success in a way which is meaningful to individual participants, while also enabling us to make comparisons across cases. The baseline data collection will be used to establish goals, and the 3 and 6 month data collection points will be used to measure progress towards goals.

To what extent VIVOCAs enable the user to engage with a wider range of people, or enter new environments, can be described as pragmatic language and will be measured using the Pragmatic Profile of Everyday Communication Skills in Adults (11). This takes the form of a structured interview which provides a way of establishing a client's own perceptions, placing value on people's own insights into their experiences as communication. The main findings can be encapsulated in a summary. This will give us a picture of how the participant feels about their communication before using the app, and when they have used it for a period of time, and what role the app has played in this. While it is a qualitative measure and will not generate a score, the structured summary will allow us to more easily compare participant perceived outcomes.

We know from the literature that speed and usability are important aspects of the user experience of communication aids, and impact how likely a user is to incorporate a communication aid into their communication strategies. Therefore, the speed of the app will be assessed with measurement of participant's speed in using the app (measuring the time taken to complete communication tasks), at baseline, 3 and 6 months, with an expectation that speed of use will increase over time.

The System Usability Scale (SUS (12)) will be used to measure usability. The SUS contains questions answered with a Likert scale, and provides a quick and easy way of measuring usability, which can be scored and compared across cases. This was used in our previous study and found to be accessible to our cohort. It is also known to be valid and reliable with small sample sizes.

Semi-structured interviews will be conducted at baseline to explore participants' expectations of using VIVOCAs and again at 3 and 6 months to explore the participant's experience of using VIVOCAs, including acceptability, and their reflections on their support needs. These interviews will be video recorded. This is necessary as some of the participant's communication may be non-verbal.

Participant diaries will be used to record the support needs of participants. The research SLT will keep written records of contact with participants throughout the trial period, detailing how often and the type and amount of support required. The participant 'diaries' will be responses to weekly emails sent by the research SLT, to check if any support is needed. This format of participant diary was used in a previous study, and provided useful information about the participant's progress without being too burdensome for the participant. This will provide us with a differential profile of support needs of participants which will help us determine what support will need to be provided as a service level.

Projected Outcomes of the Study

The study will support us in an understanding of the delivery and support context for VIVOCA and this will inform how to implement the intervention in a future evaluation of clinical effectiveness in practice.

The Communication Matters Research Involvement Network: A New Dawn

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Introduction

Communication Matters is a UK-based charitable organisation that exists to support people who use augmentative and alternative communication (AAC) in their basic human right to communicate, be included, and be heard in an equitable society. One of the ways that we aim to achieve this is by encouraging research about AAC. Research is an important way of developing and extending knowledge about AAC devices and the support that will enable people to be included and to be heard.

As an organisation we have been reflecting on how we can encourage AAC research and support people who use AAC to be involved in research. We recognised that it is important to give people who use AAC an opportunity to be involved in research as it offers an avenue for their voices to contribute to the development of new knowledge about AAC devices and services. We also acknowledge the benefits that researchers gain from working collaboratively with people who use AAC, and how much they benefit from having people with lived experience as part of their project teams.

Communication Matters set up a Research Involvement Network in 2011 – a list of people who use AAC and professionals who were interested in being involved in research. This network has not been accessed, reviewed, or added to for a significant period of time. We identified that we needed to revisit how we support and encourage people who use AAC to get involved in research, and what role the organisation should play in supporting involvement in research.

Four members of the Communication Matters Research Sub-Group submitted an abstract to the international conference in 2023 to host a joint workshop. The workshop aimed to address:

- 1) How to make volunteering for research more accessible,
- 2) Identifying ways to connect researchers with people who use AAC,
- 3) Learning what support people who use AAC want or might need to get involved in research.

Methods

Each trustee had a different experience of research, 1 a social policy MRes student with lived experience of using AAC and 3 were speech and language therapists, of which 2 had direct research experience. One also had considerable experience supporting lived experience co-researchers. The team drew on their different knowledge and skills to each deliver a part of the workshop.

The agenda for the session was set at a sub-group meeting. The presentation was then created over several weeks with each person working individually on their section, then sharing back with the group. The 45-minute workshop commenced with a 15-minute PowerPoint presentation about what is research and the opportunities to take part in research. This was then followed by a discussion with attendees at the workshop.

Attendee contributions were captured by one of the workshop facilitators who took written notes. The contributions were then themed and clustered into three main themes that reflected the main topics of the discussion.

Results

Discussion and feedback reflected the range of experience of attendees at the workshop.

From doing research whilst at university, to involvement in AAC specific projects there was acknowledgement that many people, including AAC users, have translational skills and ideas that need to be harnessed in future AAC research. There was recognition that research involvement can at times feel overwhelming and complex. The attendees shared different methods they have had found useful in ensuring involvement in projects was accessible.

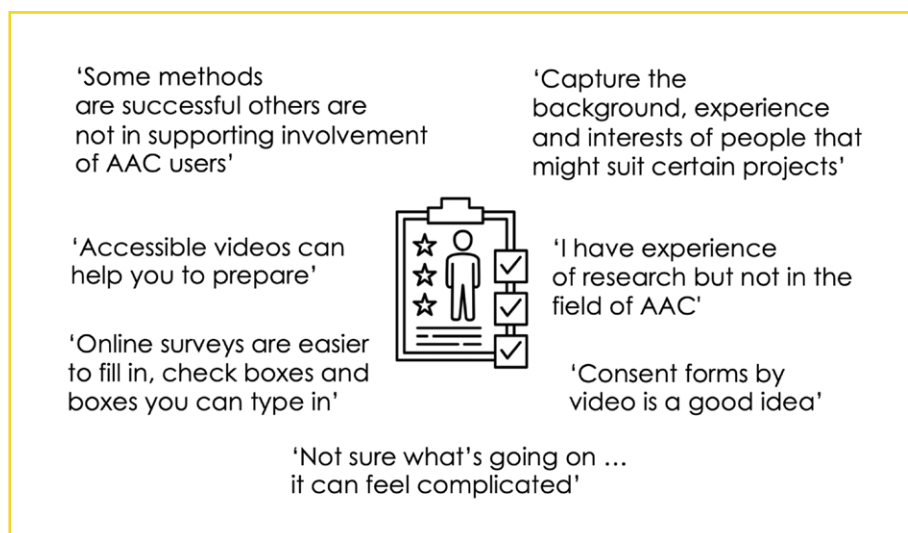


Figure 1: Capturing Previous Experience

The group discussed the roles within research projects and moving away from out-dated expectations of AAC users as participants. It was recognised that there are different levels of involvement, from leading research, to generating topic ideas and co-designing projects, and facilitating others to participate. Involvement can be in person or remote. A key theme running through the discussion was the importance of creating balanced relationships and ensuring authentic and flexible involvement to suit individual need. The group raised the question of how Communication Matters could play a role in increasing and supporting research involvement in the AAC community.

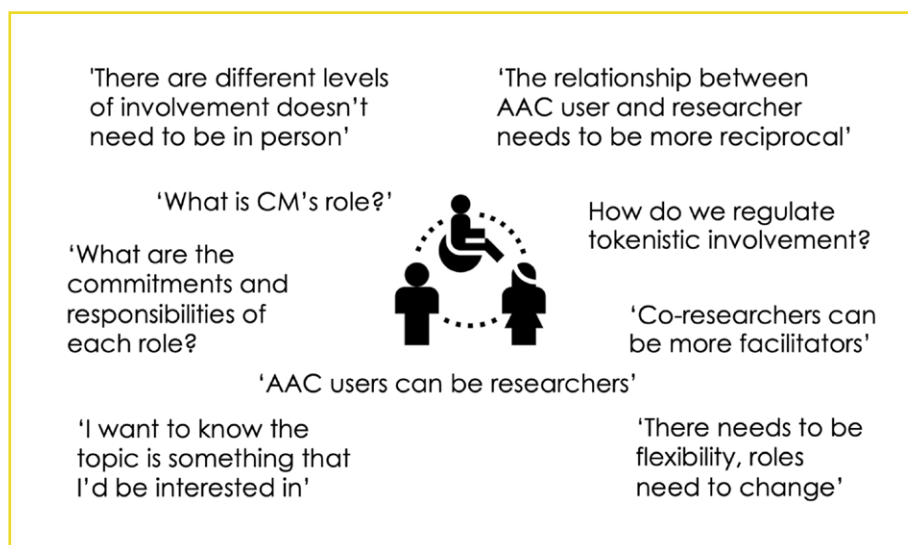


Figure 2: Roles and Responsibilities in Research

From the workshop discussion, ideas for potential next steps were generated. Making research more accessible through the creation of awareness raising materials and providing less experienced AAC users with opportunities to develop research skills were considered. The idea of Communication Matters hosting an AAC user research group to create a network of support and central point of contact was well received.

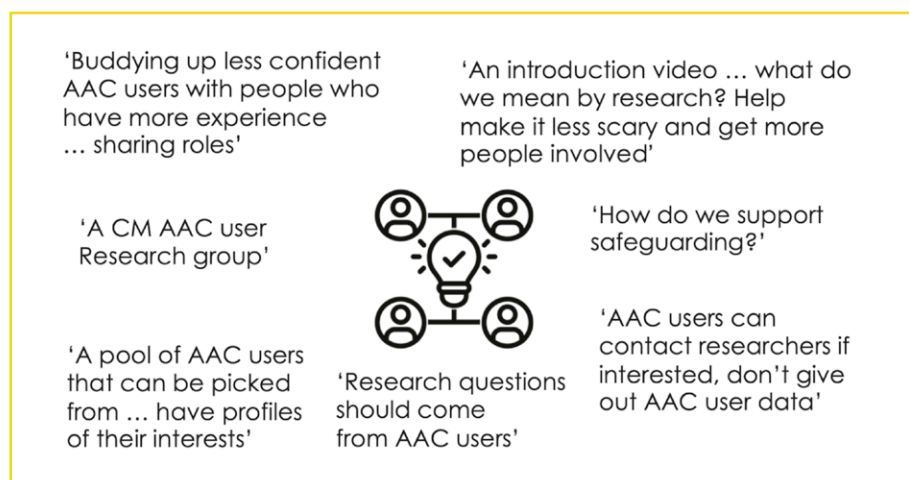


Figure 3: Thinking about Next Steps

Outcomes

The workshop provided the Communication Matters Research Sub-group with some useful information about how the organisation can encourage research. We learnt that there is currently a good appetite for involvement in research amongst the AAC community. We also learnt that there is a need to broaden the range of opportunities available to ensure that everyone who wants to be involved in research. Attendees were able to offer several really useful actions that could be taken in the short term, as well as bringing bigger ideas about how to grow the AAC-research environment and capacity for the future.

Attendees suggested that the Communication Matters website could host some resources about research. The Trustees have responded by setting up a research playlist on the charity's YouTube channel that will host videos about research (<https://tinyurl.com/yau5zjuw>). We will also consider how to incorporate a research resource as we look to redevelop our website in the next 12-24 months.

There was some discussion about how to re-establish the AAC Research Involvement Network. Attendees felt that Communication Matters could act as a conduit between people who use AAC and researchers so that they could share ideas, support the development of research projects but also access support should they want to develop their own research careers. One of the attendees has offered to support the charity to take this action forwards. We are seeking a small number of AAC users who would like to be involved in a working group to consider how to rekindle the research involvement network so that it is more accessible. An online group will be convened to develop this action, and the existing network will be reviewed and re-initiated with those who would like to remain involved.

As the Research Sub-group for Communication Matters, we are considering how to create resources, such as a database for the new Research Involvement Network, to continue to enable more people to get involved in research. If you have any ideas that you would like to share with us, please get in touch – we would love to hear from you.



CM2024 International AAC Conference - Last Chance to Register!

Registration is open for the Communication Matters International AAC Conference at the University of Leeds from 8-10 September 2024.

Over the course of two and a half days, participants will enjoy a diverse programme of keynotes, plenaries, presentations, posters and talks from AAC supplier companies.

The conference provides a unique forum to meet and exchange information with representatives from all disciplines associated with AAC, including AAC users, parents, personal assistants, professionals, and suppliers of AAC equipment. Communication Matters encourages and supports AAC users to attend.

Residential accommodation will be in modern student residences, which is at the centre of the pedestrianised campus. The transport links to Leeds are very good, with a nearby airport and train station.



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Equality, Diversity and Inclusion: A Resource to Support the Exploration of Identity within Practice

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Talking Mats is a social enterprise developed out of research whose vision is to improve the lives of people with communication disabilities by increasing their capacity to think about and communicate effectively about things that matter to them.

Background

This resource grew out of feedback from clinicians and people who use Alternative and Augmentative communication (AAC). They wanted to explore identity and how that interplayed with their AAC systems and support they received.

For example, they thought it important that:

- a communication aid reflects a person's identity;
- personalisation and consideration of intersectionality, e.g., race, disability, culture are recognised;
- it is important to challenge assumptions, ask open questions, listen and learn.

The Royal College of Speech and Language Conference 2021 was titled 'breaking barriers and building better.' Prof. Harsha Kathard from the University of Cape Town gave the keynote presentation and reflected on how '*understanding identity is key to inclusion*'. Secondly, she stressed that if we want to develop better services and support, then '*turning the gaze to reflect on our positionality is central to change*'. Ash R et al (2023), in their editorial for the British Medical Journal, highlight how interventions normally focus on single categories of social identity and '*fail to account for the combinations of, or intersections between, the multiple social characteristic that define an individual's place in society*'. They argue that '*systems of care may consequently overlook overlapping systems of discrimination and disadvantage and exacerbate and conceal health inequities*'.

Development of the Resource

From the outset, it had been hoped that Talking Mats would be a helpful resource that would allow intersectional identity issues to be explored in a safe and supportive way. Talking Mats (Murphy, J., Cameron, L. and Boa, S 2013) is a visual communication framework developed through research at the University of Stirling. Talking Mats supports people with a communication disability to consider and express their views. Although the roots of Talking Mats lie in the field of AAC, its application goes much wider now. It is increasingly used as a tool to support thinking as well as expression. Identity is an abstract topic, and we were unsure at the start of the project whether such a Talking Mat resource could be developed and who it would be aimed at and help.

The Development Group

A group of people worked together from March 2021 to explore how to help explore identity, diversity and inclusion within AAC practice. Communication Matters and AAC networks within the UK advertised the group and 12 people responded. These people came from a range of organisations and had a range of lived experiences of diversity including people who use a communication aid to help them communicate. As has been already stated diversity is intersectional so as well as disability people came from different races, genders, religions and sexualities. The work was funded by the Central London Community Health Trust and Talking Mats Ltd facilitated the meetings and the work. This initial work took place during Covid19 so was conducted remotely. The advantage of this was that it enabled people from different parts of the UK to participate.

A key driver for the group was the recognition that relationships are key to effective support. However, relationships take time and there is an innate power imbalance between the practitioner and the receiver of AAC services. The impact of this imbalance is greater if assumptions are being made. These assumptions are a common experience of those who receive services. Lucia says 'as an AAC user people often assume I can't do things when I can'.

Development of the Resource

The group worked to develop and shape the resource. Its first job was to define what would be included in an identity resource. Mind mapping proved to be a useful tool. Defining the various aspects of identity that should be included took time and was an iterative process. In the end, the group agreed on gender, sexuality, disability, race, neurodiversity, culture, family structure, voice, bilingualism, religion, mental health, personality politics, intimacy, connecting with others and occupation as being the key components that they thought made up identity.

The process of developing the symbols to reflect the various aspects took time. The design process was hugely helpful in unpicking what was actually meant by the various aspects, e.g., voice. The original image for voice represented accents, but the group discussion shaped the image to represent much more than that so the final image included a rainbow flag, a more general sound wave to represent tone, a Spanish word and an image to represent disability. As one group member said '*my cerebral palsy is part of my identity. If I am having a voice I want to reflect that identity – I want a cerebral palsy voice*'. Identity and the issues surrounding it can be emotive, but the focus on the symbols helped contain the emotion and supported group members to listen to the perspective of others.

Developing symbols is a challenge, particularly when you are trying to support understanding of abstract concepts. The group was conscious of resorting to stereotypes in the images or inadvertently missing a particular group out which is always a danger with this type of resource. This was a struggle as we did not want to create a resource that was construed as offensive. For gender, we could not resolve those issues, so we use the standard gender symbol. The group were keen to combine aspects of identity in the images so, for example, a person in a wheelchair is included in the sexuality image. We are aware that we will not have captured all aspects of diversity in all images, but we have tried to capture as many aspects as possible whilst still trying to keep the visual image clear so that it can support understanding.

The whole iterative process of developing the resource and clarifying what the symbols should look like allowed the group to be clear about the individual meanings of these abstract topics. This wider understanding was captured in a glossary to go alongside the resource. For example, identity has the following definition in the resource: *Every person has their own unique identity, just like they have their own unique fingerprint. Lots of different characteristics make up our identity. This is what makes us different from other people. Sometimes we may share some of these characteristics with other groups of people, which can also be part of our identity. Identity is about how we see ourselves and how the world sees us.*

The Talking Mats Resource and the Glossary

The final Talking Mats resource consisted of the symbols set that had been developed with the suggested top scale of 'I considered a lot', 'I considered a bit', 'I have not considered yet'. It was envisaged that this would be used as a framework to help practitioners to think about a case or situation and reflect on their practice. It could be used individually or by a team as a group discussion tool. The glossary is included to allow practitioners to reflect on the wider meaning of the symbols and what the options capture.

Feedback from Practitioners using the Resource

This resource was tested with practitioners working in a variety of settings. Further changes were made to the resource as a result of the pilot feedback. For example, one of the original aspects of identity identified by the development group was politics. Following feedback from practitioners that this was too narrow a characteristic, this was changed to the broader term of values.

Practitioners said using the resource helped:

- understand and reflect on own biases and challenge default assumptions ('*It help me understand and reflect on my own biases and how I am slowly working to be more aware of them and ask the right questions*');
- consideration of wider aspects of identity that were not routinely thought about;
- holistic thinking by encouraging seeing clients in a wider context;
- stimulate ideas about different questions to ask;
- provide a safe platform for staff to open up;
- address your own anxieties as a professional about getting it wrong and fear of "putting your foot in it" ('*This Talking Mat was an eye opener about my worries and anxieties around saying the wrong thing*').

Practitioners commented that it could be used in much wider clinical practice situations not just in AAC. For example, it was used with young people with language delay in schools and with aphasic patients in hospitals. The symbols were well received and even though Talking Mats was being used as a thinking tool, the well thought through images were reported as supporting the discussion.

Case Example

As part of reflective practice, two SLTs used the Talking Mat to explore how they had prepared for an AAC assessment. The client was a Bengali-speaking man in his 40s with a diagnosis of MND. He was becoming more reliant on non-invasive ventilation and his hand function was deteriorating. There were also concerns about his temporary housing. Time and energy was spent in quickly

preparing an eye gaze system in Bengali and option for recording messages in English. An interpreter joined the assessment.

On arrival it was apparent that he was able to communicate effectively with extended family, friends and carers. He could still use his phone and was not ready for or needing alternative access. His verbal communication was sufficient and he was able to maintain his identity as a father/husband through his speech, non-verbal communication and typing on his mobile phone. His priority was support for his wheelchair and bed as neither service provider routinely worked with interpreters.

The Talking Mat helped reflect on how the therapists had prioritised an AAC system without considering or exploring other aspects of his identity, his personality or his values. There had been assumptions and preconceived ideas about needs to communicate in English. The timing of referral was also rushed as professional anxiety around unstable housing and the impact of non-invasive ventilation.



The picture shows the Talking Mats that the practitioners used to reflect on their practice and intervention.

Further Resources

The resource is seen as a springboard to support constructive reflection by practitioners on identity and allows them to consider the different aspects of their patients' lives that may impact on their interventions. The authors have worked on a short video funded by Central London Community Health Trust that demonstrates its use and impact. This can be viewed and used alongside the Talking Mats Equality, Diversity and Identity symbol set and Glossary. This resource is being made freely available on the Talking Mats website for practitioners to use, see:

<https://www.talkingmats.com/wp-content/uploads/2024/04/Equality-Diversity-and-Inclusion-spring-board-tool.pdf>

As the resource uses the Talking Mats framework, it is recommended that, to get the best out of using this resource, practitioners have completed their Talking Mats foundation level training and understand the Talking Mats principles.

Summary

The authors are grateful to the development group for all their time and willingness to engage in the discussions. Their contribution and time as we worked through the various aspects of identity meant that this resource was developed with rigour. At the start of the process we were not sure where those discussions would lead but the results of the pilot have shown that this Talking Mats identity resource is a helpful springboard for practitioners to mindfully reflect on their practice, allow unconscious bias to rise to the surface, consider all aspects of their client's identity to develop their practice, contribute to reducing inequalities and improving the responsiveness of services. We are aware that the pilot phase of this work has focused on the practice of practitioners, and there is still further work to be done to demonstrate what impact this makes on receivers of services. We would also like to explore whether a similar tool could be developed for people who use AAC to express what aspects of identity they want their practitioners to be aware of and include in their interventions and support.

References

- Kathard H 2021 Keynote breaking barriers and building better The Royal College of Speech and Language conference.
- Ash Routen, 1 Helen-Maria Lekas, 2 Julian Harrison, 3 Kamlesh Khunti1,2023 Intersectionality in health equity research BMJ 2003
<https://www.bmj.com/content/383/bmj.p2953>
- Murphy, J., Cameron, L. and Boa, S (2013) Talking Mats: A Resource To Enhance Communication (second edition) available from www.talkingmats.com

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Conflict of Interests

The lead author is employed by Talking Mats on a consultancy basis.

A Process for Adapting a Large-cell Layout for Russian AAC User

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VOCA Trial

Our user arrived at the Brain Injury Service rehabilitation ward on Royal Hospital for Neuro-disability five months after the onset of a cerebrovascular accident. They presented as anarthric with only a flicker in finger, minimal head movement, generally good eye control (better vertical due to long standing alternating esotropia) and no other movement. They had a consistent yes/no with eyes up/down and were able to use low-tech alphabet chart with this same movements via partner assisted scanning.

Eye tracking technology was the obvious starting point for a high-tech voice output communication aid (VOCA) trial. We trialled the Irisbond (original) and the Tobii-Dynavox PC Eye. Both had stable track status but poor accuracy in use. The Alea also had stable track status with better accuracy. We were able to resolve the accuracy issue by using a larger screen via the Smartbox GridPad18 and by using Smartbox's Grid3 FastTalker LargeCell gridset and by moving frequent targets away from the top left of the screen.

Talking Mat

We used a Talking Mat to explore the user's views on the high tech AAC trial. A Talking Mat is a visual communication framework which supports people with communication difficulties to express their feelings and views (Murphy, 2013). In the authors' experience, a Talking Mat is particularly useful in giving a person agency in the discussion as well as a visual layout in which to display that agency. Figure 1 is a portion the Talking Mat created during a conversation about priorities for their high tech device. The top scale was 'Very important / Important / Not very important'. Note that most of the 'Very important' items are features in FastTalker.

Multilingual Families

FastTalker was quite successful in supporting communication in English on the ward but was unsuccessful supporting communicating with family who spoke Russian at home. This is quite a common presentation for people having rehabilitation at RHN: they speak English when out and about but they speak another language at home. Another common situation is the partner of the person having rehabilitation at RHN will often have parenting and/or workplace duties back at home. Because RHN is a specialist centre for people with complex needs following an acquired brain injury, partners remaining at home can be far enough away to make frequent visits challenging. This was the case for our user, and their primary contact with their family was by email and WhatsApp.

The Russian language uses the Cyrillic alphabet. Whilst there was a Cyrillic FastTalker layout at the time, there was not a Cyrillic FastTalker-LargeCell. So, we made one.

FastTalker LargeCell Efficiency

It would be useful to take a moment to discuss what makes FastTalker-LargeCell more efficient than the typical 'two step' (sometimes called 'two hit') keyboard layouts that are common in AAC software.

The typical strategy for a two-step keyboard is to divide the alphabet into 5 or 6 groups, each group having 5 or 6 letters, allowing for much larger cells. But the larger targets come with a cost: more navigating is needed. The typical two-step layout always requires at least two selections for every letter: the first to navigate to the page where your letter is and a second to select that letter.



Figure 1: Portion of Talking Mat

However, our person did not need the targets as offered by a two-step layout. Splitting the keyboard in half was sufficient for this user. Having the keyboard split across two pages rather than 5 or 6 will reduce the number of selections required, because there will be times that the desired letter can be selected in one step because it is already showing on the page.

One way to reduce the number of selections needed on a multiple page layout is to use a frequency of use keyboard. Frequency of use layouts have been around for some time. According to Bloomberg Originals (2015), Professor Stephen Hawking used a frequency of use layout optimised for block/row-column switch scanning. The advantage of a frequency of use layout is that it has a high potential for to save significant time in a multiple page layout as it is more likely the letter you want is on your first page. But that potential is not immediately obtainable. According to Lewand (2000), the letters in frequency of use order in English is ETAOINSHRDLCLUMWFGYPBVKJXQZ. The user is likely to be slower initially whilst coping with searching this unfamiliar order. And for people with brain injuries, the learning barrier presented by an unfamiliar letter layout could be very high and perhaps so frustrating as to be discouraging or even unattainable.

The FastTalker LargeCell layout gives the user most of the advantage of the frequency of use by including the most frequent letters on the first page and the least on the second. But how it differs from a pure frequency at use layout is that it rearranges the letters on each page into the familiar dictionary order (see figures below).

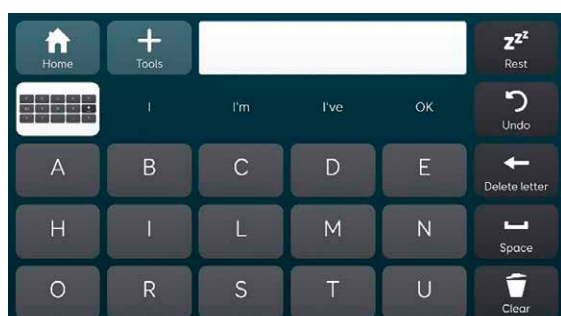


Figure 2: FastTalker LargeCell keyboard landing page

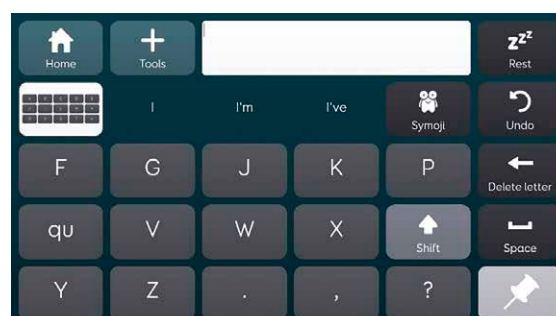


Figure 3: FastTalker LargeCell keyboard second page

With the high frequency letters being on the first page (around 78% of the time on average), the letter you are looking for will be on the first page. FastTalker-LargeCell additionally makes the second page an auto-close page. This saves additional strokes, because it is quite unlikely that after typing a letter on the second page that the next letter is also on the second page. However, in the event the user needs to stay on the second page, there is a pin option which temporarily disables the auto-close feature. These innovations not only have the potential for less keystrokes, but also lowers the learning barrier by presenting the keys in a familiar order.

Recreating FastTalker LargeCell

Design

As discussed above, the two features that make FastTalker LargeCell so efficient is that the letters on the landing page are the highest frequency letters, and they are in dictionary order. Following that model to make a Russian FastTalker LargeCell, we needed two key pieces of information: letter frequency and the dictionary order. This information was readily found. See figures below which show letter frequency from Lăpuşneanu (2020) and dictionary order from Stefan Trost Media (2023).

О	11.18 %	М	3.17 %	Й	1.21 %
Е	8.75 %	Д	3.09 %	Ж	1.01 %
А	7.64 %	П	2.47 %	Х	0.95 %
И	7.09 %	Ы	2.36 %	Ш	0.72 %
Н	6.78 %	У	2.22 %	Ю	0.47 %
Т	6.09 %	Б	2.01 %	Ц	0.39 %
С	4.97 %	Я	1.96 %	Э	0.36 %
Л	4.96 %	Ь	1.84 %	Щ	0.30 %
В	4.38 %	Г	1.72 %	Ф	0.21 %
Р	4.23 %	З	1.48 %	Ё	0.20 %
К	3.30 %	Ч	1.40 %	Ъ	0.02 %

Figure 4 Russian letter use frequency

А Б В Г Д Е Ё Ж З И Й К Л М Н О П
Р С Т У Ф Х Ц Ч Ш Щ Ъ Ы Ь Э Ю Я

Figure 5 Russian dictionary order

It may be an obvious thing to say at this point but it is important to note that the fact that both English (which uses the Latin alphabet) and Russian (which uses the Cyrillic alphabet) use alphabet representations in their written forms. This makes starting with the English FastTalker-LargeCell template a viable possibility when considering a Russian character layout. The same may not be true for nonalphabetic languages.

Implementation

The first snag was related to using the English FastTalker LargeCell as a template. We use the English version as a template, because we knew the cell size worked because of the user's experience using it to speak with hospital staff. The problem though is that the Cyrillic alphabet has seven more letters than the Latin one. The images below show the second pages of the original English version and our Russian version.

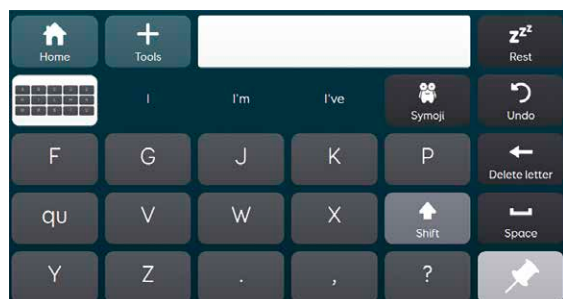


Figure 6: English second page letters

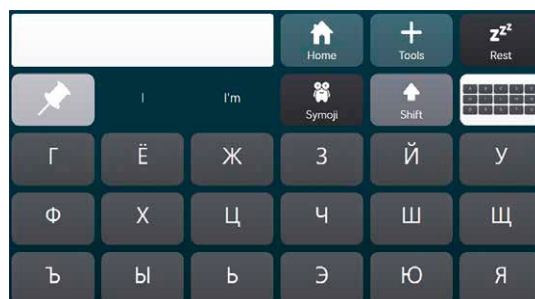


Figure 7: Russian second page letters

You can see we had to get rid of some of the function keys. Whilst this is not so much of an issue in the chat grids, we had to make some difficult choices on the other keyboards such as email and web browser about what to take away to make room for the letters.

The second snag was related to number of keyboards. Not counting number and function keyboards, there are 42 keyboard grids in the English FastTalker LargeCell. It took time to convert 42 keyboards, so we started with ones used most (chat, email and browse). Then we added the others a little at a time.

Please note that the message window was moved to the top left for this user, because they had difficulty with target discrimination in this part of the screen. This is also why the cell for navigating between the two letter sets is on the right.

Letters as WordList

The team also trialled another approach different to the one above. That approach used the WordList feature to display the letters. This had the benefit of being quicker to implement because there is only one page for each keyboard, because the WordList feature automatically creates a more cell and fills the WordList cells with the next group of letters in the list. The main problem however is that the auto-close feature on the second page is eliminated so the user must scroll back to the initial set. This adds keystrokes and is not as efficient as the original design. You may also have to turn off 'speak words as you type', because it speaks the portion of the word in the message window because we put letters into a WordList. The authors felt this method was more about making it easier on staff than making it better for the user. Still, it might for a trial. See Rossi (2023).

Summary

The user of our FastTalker LargeCell gridset left RHN using the device daily and reported they were happy with the outcome of the changes made and with their ability to communicate again with their family. However, the readers of this paper may be more interested in the repeatability of the process.

The process of creating a large cell version a FastTalker standard layout should be repeatable for any alphabet writing system. The process is:

- order letters by frequency of use;
- divide into appropriate number of groups;
- put each group in Alphabet Order.

Keep in mind that it may be better to put the letters into three or more groups if there are more than 28 letters and that it may be a good idea to get help from someone who writes in the language. Also, remember that there are many keyboards in FastTalker that will need adjusting to get the most out of it.

References

- Bloomberg Originals. (2015) Stephen Hawking's Voice and the Machine That Powers It. Available at <https://www.youtube.com/watch?v=OTmPw4iy0hk> (Accessed 22 September 2018)
- Lăpuşneanu, D. (2020) Master the Russian Alphabet Pronunciation. Available at <https://www.mondly.com/blog/2020/03/26/learn-russian-alphabet-pronunciation/> (Accessed 17 April 2023)
- Lewand, R.E. (2000) *Cryptological Mathematics*. American Mathematical Society
- Murphy, A. (2013) What is a Talking Mat? Available at <https://www.talkingmats.com/about/what-is-a-talking-mat/> (Accessed 17 April 2023)
- Rossi, D. (2023) Fast Talker Multi-lingual Large Cell. Available at <https://grids.thinksmartbox.com/en/dante-5/4ad53e9b-ed75-4473-b1ad-4a035c012213> (Accessed 31 July 2023)
- Smartbox Assistive Technology. (2023) FastTalker. Available at <https://thinksmartbox.com/product/fast-talker/> (Accessed 17 April 2023)
- Stefan Trost Media. (2023) Alphabet and Character Frequency: Russian (Русский). Available at <https://www.sttmedia.com/characterfrequency-russian> (Accessed 17 April 2023)
- Viera, M. (2023) FastTalker – LargeCell – Cyrillic. Available at <https://grids.thinksmartbox.com/en/marc-41/be66f73e-f29d-4fe2-ab5c-501174e97ef0> (Accessed 17 April 2023)

Effective Strategies for Communication Partners of Individuals with Complex Communication Needs

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Introduction

Harmonious interactions and a good understanding of each other are the basis of any relationship, including those of individuals with 'complex communication needs' (CCN). With individuals with CCN, we refer to individuals who, due to some form of impairment, are not able to use functional speech as a means to communicate (Beukelman & Light, 2020).

Promoting social and communicative interactions with individuals with CCN is an important task of their parents, caregivers, and teachers. In previous studies, however, parents of children with CCN reported a need for support in the communication with their child (Seligman-Wine, 2007; Walters et al., 2021). A need for support of parents and other communication partners of individuals with CCN became also evident in studies of Fellingner et al. (2020) and Damen et al. (2014) which described that communication partners of people with (dual) sensory loss and cognitive delays struggled with making their communication accessible to them. According to Fellingner et al. (2020), misunderstandings, challenging behaviours, and communication breakdowns can occur when communication partners of individuals with CCN are not able to use those communication strategies that foster accessible and meaningful communicative interactions with them.

Support needs of communication partners of people with CCN may be met by providing training. Several studies showed positive results of training in Augmentative and Alternative Communication (AAC) to parents of a child with CCN on the child's communication skills (Douglas et al., 2017; Ronski et al., 2010). Parents in a study of Senner et al. (2011) also suggested that training communication partners in supporting pragmatic skills of adolescents with CCN, such as in taking initiatives and participating in turn taking, may be beneficial for these adolescents.

For communication partners of individuals with CCN who aim to enhance their competences and for professionals who are offering training to them, it is important to know which partner strategies are relevant to train. The aim of this study was to identify those strategies that are considered effective for fostering communicative interactions with individuals with CCN.

Method

To identify effective strategies for communication partners of individuals with CCN, the study made use of data collected in the project 'Effective Elements', which was aimed at identifying effective elements of communication and language interventions for young children with CCN. The strategies identified in the three research methods of the Effective Elements project were compared with each other. For the overlapping strategies, concrete examples were searched for in a previous study on the effect of a video-feedback intervention for communication partners of an individual with congenital deafblindness (CDB).

Project 'Effective Elements': Data Collection and Analysis for the Current Study

The data analysed for the current study was subsequently collected in a) a systematic literature study, b) a survey, and c) an interview study.

a. Systematic Literature Study

An electronic database search was carried out to find studies of communication and language interventions for children with CCN aged 0 to 6 years. This search produced a list with 5162 publications. The titles and abstract of these publications were screened for meeting the inclusion criteria. The full texts were screened for meeting quality criteria. After this screening, a final set of 28 papers was included. The results sections of these papers were analysed with open coding. The themes and categories relevant for the identification of partner strategies were extracted.

b. Survey

An online questionnaire was distributed to 65 Dutch professionals who provided communication treatment to children with CCN with one main question: how would you describe your ideal communication and language group treatment for children with CCN? The answers were analysed with open coding. The themes and categories relevant for the identification of partner strategies were extracted.

c. Interview

Seven Dutch parents of children with CCN were interviewed with one main question: how would you describe your ideal communication and language group treatment for your child? The interviews were recorded, anonymized and transcribed. The transcripts were analysed using open coding. The themes and categories relevant for the identification of partner strategies were extracted. Subsequently, the overlapping strategies that came out of literature study, survey and interview study were listed.

Literature Study of Video-feedback Interventions for Communication Partners of Individuals with CDB

The overlapping strategies were compared with strategies described in a study on the effectiveness of the high-quality communication intervention, a video-feedback intervention for communication partners of individuals with CDB to find concrete examples of effective application of these strategies in communicative practice.

Results

The literature review revealed four main themes, of which the themes 'Individualized Support' and 'Methods' appeared relevant for the identification of partner strategies. Within the theme 'Individualized Support', two categories described partner strategies. These strategies were: attuning to the interests of the child and attuning to the support needs of the child. Within the theme 'Methods', 11 categories described partner strategies: providing time, eliciting communication, modelling communication, being responsive, rewarding communicative initiatives, providing prompts, providing AAC, expanding communication, creating communication opportunities, using communication around a theme, using repetition.

The analysis of the survey among professionals who provided communication treatment to children with CCN revealed five main themes, of which again 'Individualized Support' and 'Methods' were relevant. Within the theme 'Individualized Support', six categories described partner strategies: attuning to the child, attuning to the interests of the child, attuning to the developmental level of the child, attuning to the experiences of the child, and attuning to the information processing of the child. Within the theme 'Methods', eight partner strategies were described: providing structure, providing repetition, communicating around a theme, creating an obstruction to elicit a response, adding language, following the child's lead, eliciting shared enjoyment, providing AAC.

The analysis of the interviews with parents revealed six main themes. Of these themes 'Individualized Support' and 'Methods' were relevant. Within the theme 'Individualized Support', four categories described partner strategies: attuning to the development, knowledge, motivation and experiences of the child, attuning to the sensory information processing of the child, involving the child in communication, and providing processing time. Within the theme 'Methods', the following five categories described communication partner strategies: providing structure, providing repetition, providing examples, stimulating self-determination, and offering communication around a theme.

Comparison of Communication Strategies

When comparing the results of our analysis of the literature study, survey and interview study, similarities in the described partner strategies were found. All the sources mentioned the partner strategy 'attunement to the child'. The descriptions revealed that attunement can focus on the interests, motivation, developmental level, support needs, experiences, or on the processing of information by the child. Related strategies to attunement were 'providing time', described in the literature, and 'providing processing time', described by the interviewed parents. Two other strategies, 'providing repetition' (described in all sources) and 'providing structure' (mentioned by professionals and parents) can be considered concrete examples of how to attune to the processing of information and developmental level of the child.

A type of strategy found in all sources was the offering of communication or language to the child. All sources described 'offering communication around a theme' and in both the literature and the survey 'providing AAC' was described. The literature described 'modelling communication' and 'expanding communication'. The professionals mentioned 'adding language', and the parents described 'providing examples'.

Another type of strategy found in all sources was the elicitation of communication initiatives from the child. The literature described 'eliciting communication', 'prompting', and 'creating communication opportunities'. The professionals mentioned 'creating an obstruction to elicit communication' and 'eliciting shared enjoyment' and the parents described 'involving the child in communication' and 'stimulating self-determination'.

In two sources, strategies were described that concerned the responsiveness of the communication partner. In the literature, the strategies 'being responsive' and 'rewarding' were described. The professionals also mentioned 'following the child's lead'.

Concrete Examples from a Study on the High-Quality Communication Intervention

Improving the knowledge and skills of communication partners of individuals with CDB is the focus of the High-Quality Communication (HQC) Intervention. Examples of the implementation of this intervention by communication partners is described by Damen et al. (2014) in a single-case experiment involving Vincent, a 19 year old male with CDB due to Goldenhar Syndrome. Vincent communicated in single sign sentences of which the meaning was not always clear to his professional caregivers. This resulted in frequent misunderstandings and caregivers noticed that the conversations with him had become rigid as they mainly focused on his food and drink choices or daily program. Vincent's caregivers improved the communication with him by participating in the HQC intervention, consisting of four education sessions and eight video-feedback coaching sessions (Damen et al., 2014).

Vincent's caregivers implemented several 'attunement' strategies. Examples of this are choosing a position towards Vincent that enabled sustained physical contact and a better view of Vincent's expressions and waiting for Vincent to respond after taking a new turn. Caregivers also worked on their 'responsiveness' to Vincent; they started confirming his communicative initiatives using tactile imitation. They also started sharing his emotions in a tactile way, for example by caressing him when he was sad or explaining that they noticed that he was laughing, sad or angry in tactile sign language. They also checked with him if they had understood him correctly, by explaining to him what they thought he was trying to tell and then asking if this was correct by making him indicate YES or NO.

Caregivers started 'offering communication' to Vincent in the second phase of the intervention. They 'provided AAC' by using a book with tactile symbols in conversations with him, introduced new topics in the conversation and elaborated on topics he introduced. Caregivers also started to 'elicit communication initiatives' of Vincent. They stimulated him to use his book with tactile symbols and to talk in sign language about past experiences he had enjoyed, e.g., by asking 'AND THEN WHAT?' or asking concrete questions, such as what he had been eating 'VINCENT EATING WHAT?'.

Conclusion

This study identified four main strategies that communication partners can use to foster communicative interactions with individuals with CCN: attuning to the individual, offering communication and language, eliciting communicative initiatives, and being responsive to the individual. Examples from practice revealed that how these strategies can be applied are very specific for each individual with CCN. We recommend supporting communication partners in such application, e.g., by providing them education and communication coaching with video-feedback.

References

- Beukelman, D. R., & Light, J. (2020). Augmentative & alternative communication: supporting children and adults with complex communication needs. In *Augmentative & alternative communication* (5th ed). Brookes Publishing.
- Damen, S., Janssen, M. J., Huisman, M., Ruijsenaars, W. A. J. J. M., & Schuengel, C. (2014). Stimulating Intersubjective Communication in an Adult with Deafblindness: A Single-Case Experiment. *Journal of Deaf Studies and Deaf Education*, 19(3), 366-384. <https://doi.org/10.1093/deafed/enu006>
- Douglas, S. N., Nordquist, E., Kammes, R., & Gerde, H. (2017). Online parent training to support children with complex communication needs. *Infants & Young Children*, 30(4), 288-303.
- Fellinger, J., Linzner, D., Holzinger, D., Dall, M., Fellinger, M., & Fogler, J. (2020). Development of Deaf Adults with Intellectual Disability in a Therapeutic Living Community. *Journal of Deaf studies and Deaf Education*, 25(3), 261-269. <https://doi.org/10.1093/deafed/enz056>
- Romski, M. A., Sevcik, R. A., Adamson L. B. Cheslock M. Smith A. Barker R. M. Bakeman R. (2010). Randomized comparison of augmented and nonaugmented language interventions for toddlers with developmental delays and their parents. *Journal of Speech, Language and Hearing Research*, 53, 350-364.
- Seligman-Wine, J. (2007). Supporting Families of Children Who Use AAC. *The ASHA Leader*, 12, 17-19.
- Senner, Jill. (2011). Parent Perceptions of Pragmatic Skills in Teens and Young Adults Using AAC. *Communication Disorders Quarterly*, 32, 103-108. 10.1177/1525740109351570.
- Walters C, Sevcik RA, Romski M. (2021). Spoken Vocabulary Outcomes of Toddlers With Developmental Delay After Parent-Implemented Augmented Language Intervention. *Am J Speech Lang Pathol*, 30(3):1023-1037. doi: 10.1044/2020_AJSLP-20-00093.

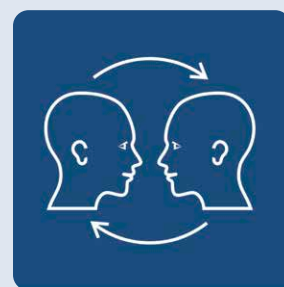
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Service User Involvement in a Specialised Assessment and Provision Service

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Terminology

Service User: a broad phrase to refer to those who use or are affected by services of professionals registered with the Health Care Professions Council

Access method: The way in which a person physically controls their AAC device

This paper is produced by Danielle Diver with Andrea Lee and Jamie Preece. Jamie uses graphic symbols on his communication aid to share his thoughts and ideas, alongside his speech and gesture. The paper was written using messages shared by Jamie during the development stages of the presentation given at the 2023 Communication Matters Conference. The paper describes the processes, benefits and challenges of developing a Service User Representative role within a specialised service. Danielle outlines the importance of involving AAC users in such services and shares hopes for the future opportunities of other AAC users.

Why we need to involve AAC users in service provision and development

Prior to, and particularly since, the development of the Disability Rights Movement and Disability Discrimination Act (1995), the value and importance of involving people with disabilities in social, economic and political policy development has been more widely recognised. This has been expressed more generally as “we best understand what is best for us” (Charlton, 1998), a quote from interviews captured by James Charlton as part of the disability rights movement “Nothing About Us Without Us”. Empowering people with disabilities to shape the decisions that affect them is a Human Right (Equality and Human Rights Commission, 2010).

The lack of involvement of Service Users with communication difficulties has been well documented and discussed more recently. There is consensus in recognising the benefits of involving seldom heard voices in research, which in turn positively impacts service development and the quality of clinical practice (Volkmer & Broomfield, 2022). Frameworks, such as the ‘Different Experiences’ framework published by NIHR (2021) and the UK Standards for Public Involvement (2021), have since been developed for ways to make involvement of people with communication difficulties in research more accessible and collaborative.

Currently, there is an increased interest in involving AAC users as mentors to others who use AAC. There are many reasons why this may be beneficial for people new to using AAC. People who use AAC have skills and direct experience using AAC in reality, have lived experience overcoming communication barriers, can show the value of AAC in their own lives and have personal experience on an AAC journey (Hartman and Sheldon, 2023).

Individuals with complex communication needs hold an intensely personal stake in AAC research and clinical practice. In consideration of this, Barnsley Assistive Technology Team wanted to find a way to better involve Service Users in service development due to the value of their expertise and the benefits of embracing differences. Over the last 5 years, we have been developing the Service User Representative role as part of the specialised assessment and provision service pathway.

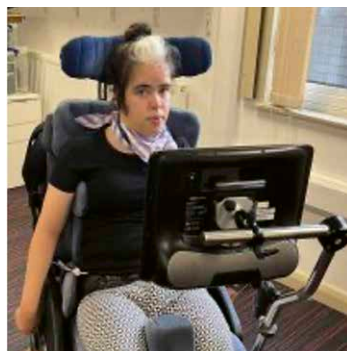
Introducing the Service User Representatives

Jamie Preece and Holly Golborne are honorary Service User Representatives on the Barnsley Assistive Technology Team. Jamie has worked in the team for seven years, helping to shape the role, and Holly joined more recently in 2022.

Jamie says:

"I'm so happy with what we do. I have only had my AAC for 10 years and it has changed my life. I want to help prevent people going through what I went through. I'm glad a service like this is available to those who need it. I want to increase awareness of the service and help make it even better for more people who would benefit from it.

I was the guinea pig for this position!"



Holly Golborne

Holly sees herself more as an Assistive Technology Peer Support Specialist and has decided to pursue the patient contact side of the role, having completed a course about supporting communication aid users. She is also interested in equipment evaluations and research collaboration. Holly sees her role as an opportunity to build up her skills for future employment as a health professional.

Holly says: "I love being part of the team and supporting our clients. I think having an AAC user evaluate software rather than someone who doesn't really use it is really important because we notice problems other people don't."



Jamie Preece

The role can include the following responsibilities:

- Meeting with AAC users and their families
- Working with other professionals across the community
- Evaluating AT equipment and software
- Working with University students
- Participating in training and University lectures
- Resource development and publication

Jamie: My Experience of the Role

"In this role, I share my personal experiences with Service Users and their families who may be at the start of their AAC journey. Service Users have often never met another person who uses assistive technology and may be reluctant, anxious or struggle with feeling different. As a Service User Representative, I can demonstrate first-hand the impact of assistive technology on my life and hope to encourage and inspire Service Users and their families to explore and make the most out of the technology available. I always remember 3 years ago, a 19-year-old lad didn't want to use his AAC. Two hours later he said 'I want to be like you and I want to work for Barnsley'. We talked about beer and ladies and how you don't want your Mum to come on a date with you. My Mum used to text my dates for me. I can show parents that I'm just a normal person, now texting on the road. Parents have told me it is helpful meeting me. Seeing me use AAC has also helped another AAC user to do a job."



Members of the Barnsley Assistive Technology Team



Jamie talking to Speech and Language Therapy students at the University of Sheffield



Andrea Lee with Holly and Jamie at the Barnsley Hospital Heart Awards

“Working with other professionals involves lots of different tasks. I participate in interviews and inductions for new staff in the team. I regularly meet professionals that support AAC users at schools, day centres, care homes or out and about and share the challenges and rewards of using assistive technology. I have made training videos for professionals supporting Service Users and AAC users to demonstrate how their technology can be used in the real world. When Barnsley do device or software training, I come for additional awareness training. I sometimes work as part of awareness raising and training for the Communication Access UK project. I always say ‘you can’t take a dog for a walk without the dog’. In other words, how can you work in an AAC service without an AAC user on the team?”

“Part of the Service User Representative role also includes evaluating equipment. This can include trying new or comparing different devices, software, symbol or text-based vocabularies, and access methods. We also test and give feedback on some environmental control systems, accessible apps or computer control access methods.”

“I collaborate with clinicians to deliver University lectures, work with students on placements, and offer ideas and feedback on projects for University degree courses. I regularly join lectures at Sheffield and Leeds Universities to demonstrate how I use my AAC and the impact it has on my day to day life. By working with Speech Therapy and Occupational Therapy students on placements, I can help them to develop their confidence as well as clinical and communication partner skills. It gives students the opportunity to meet AAC users when they never have before.”

“My role can sometimes involve developing resources for Barnsley Assistive Technology Team, some of which are published on the team’s website. For example, I helped to make and publish a video on the website to demonstrate AAC strategies that communication partners can use to support effective communication. I can help develop and edit AAC vocabularies and give feedback on the importance of personalised vocabularies. I’ve also shown a number of AAC users how to edit their own vocabularies.”

Jamie: My Professional Development

“Working in this role has given me a professional life. It’s given me a purpose. I love helping to shape the service. I recognise myself as an expert AAC user and love how this role helps me share my expertise to inspire users starting out on the journey as well as the people supporting them. I also use this role to make connections, shape research and influence projects by giving my real life, 24/7 experience. I collaborate with Smartbox, an assistive technology developer and supplier, by testing products and offering ideas and feedback to improve them as an ambassador for other AAC users. I’ve had a number of opportunities to participate in research projects both within Barnsley Assistive Technology Team and with external organisations, such as the University of Dundee and the University of Sheffield, and recently presented my work at the ISAAC conference in Mexico. It is really important to me that I am involved in research as I want to be a part of service improvements and helping to shape the future for the next generation.”

Benefits of the role: Impact on the service and beyond

The positive outcomes and wide-reaching benefits of having Service User Representatives working in this role has been recognised by the whole team, other professionals, families, and Service Users we work with and support.

One Service User who met Holly was even more motivated to trial eye gaze for communication and computer access following their meeting and really liked the partner window on Holly’s device. Jamie has visited children using AAC in school with their class teams and met teenage AAC users out in the community to increase awareness of functional AAC use in real life, support confidence building for newer AAC users, and help develop communication partner skills. During an assessment with an adult new to AAC, Jamie helped me to recognise my clinical bias relating to the access method we were trialling and helped to demonstrate an alternative method which was more motivating to the AAC user. Service Users who have met both Holly and Jamie have wanted to use their AAC device for much more, such as using their mobile phone or accessing social media.

The Service User’s perspectives on AAC and communication have been refreshing and have challenged preconceptions or perspectives held by those they meet.

Both our current Service User representatives have complex physical disabilities. Their role and their presence have inspired their line managers and their colleagues to challenge preconceptions about disability in the workplace, to break down barriers and to look for solutions to enable them to make a valued contribution. Through their engagement in this role and their visibility at work, they live out the equality and diversity agenda and promote inclusive employment. They have worked with their team to break down barriers for future employment of people with disabilities. They meet Service Users with similar needs and experiences and inspire them to overcome challenges and to be proud of their achievements.

Challenges and hopes for the future

Supporting the participation of people with complex communication needs and associated disabilities requires varying methods and degrees of support, and Barnsley Assistive Technology Team have worked hard to ensure flexibility in working arrangements for the Service User Representatives to reduce or eliminate any barriers to active employment.

Examples of such support and adaptations include:

- ensuring individual accessibility needs are met, particularly access to IT and physical access
- sharing strategies for more accessible communications
- supporting diary management



Jamie presenting at the ISAAC conference in 2023



Jamie and Andrea Lee presenting at the ISAAC conference in 2023

- matching content of work to the Service User Representatives' personal goals and areas of interest or speciality
- managing requests for Service User Representative input from the wider team to ensure that support needs and practicalities are fully considered
- supporting development of training for the wider team for the Service User Representatives' support needs.

The role is recognised as offering a very different perspective to the role of other team members. Whilst we assure that Service User Representatives have any costs reimbursed and are rewarded for their contributions as described above, there are challenges given the current employment structures around financial reimbursement. Some people with disabilities prefer not to be paid due to complexities around other financial arrangements, such as benefits. Others may not be able to meet parts of the person specification of roles which, for example, often require functional literacy or specify minimum qualifications. The job description and person specification are therefore designed to ensure that volunteers are not being asked to do tasks that paid members of staff would do and that the role is valued for its differences. It is hoped that Service User Representatives may move into paid employment or that opportunities provided through the work will offer them rewards of a different kind.

We hope that sharing our experience and journey in developing this role will inspire or inform others who may consider setting up a similar role within other services.

References

- Charlton, J. I. (1998). *Nothing About Us Without Us*. University of California Press.
- Equality and Human Rights Commission (2010). *The United Nations Convention On The Rights of People with Disabilities: What does it mean for you?* Available at: https://www.equalityhumanrights.com/sites/default/files/uncrpdguide_0.pdf
- Hartman, A. & Sheldon, E. (2023). AAC mentors: Role-models and experts for AAC users. Available at <https://www.assistiveware.com/learn-aac/aac-mentors-role-models-and-experts-for-aac-users>
- NIHR (2021). *Different experiences: A framework for considering who might be involved in research*. Available at: <https://www.nihr.ac.uk/documents/different-experiences-a-framework-for-considering-who-might-be-involved-in-research/27387>
- UK Standards for Public Involvement (2021). *UK Standards for Public Involvement*. Available at: <https://sites.google.com/nihr.ac.uk/pi-standards/standards>
- Volkmer, A. & Broomfield, K. (2022). *Seldom Hear Voices in Service User Involvement*. J & R Press Ltd.

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