Communication
Matters

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This super group of CM Conference delegates went all out for our 'Empowerment' fancy dress theme this year!

Contents

Chair's Report

HELEN WHITTLE

We were delighted to welcome so many of you to this year's Conference at the University of Leeds in September. We had 440 delegates which included 40 AAC users. It is great that nearly 10% of attendees were AAC users. CM were pleased to be able to subsidise 88 places this year for AAC users and their PAs and family members to attend.

There was also a fantastic exhibition with 17 companies exhibiting. We are grateful for their support and sponsorship.

As I write this, we are still in the process of collating all the feedback from the Conference, but the initial feedback has been that the presentations were of a very high quality this year and they covered a fantastic range of topics. Thank you to all the presenters. Thank you also to our fantastic Keynote and Plenary speakers, Professor Annalu Waller and Helen Robinson, for bookending the conference with such inspirational messages. We will be using the feedback to help start plan the 2025 Conference.
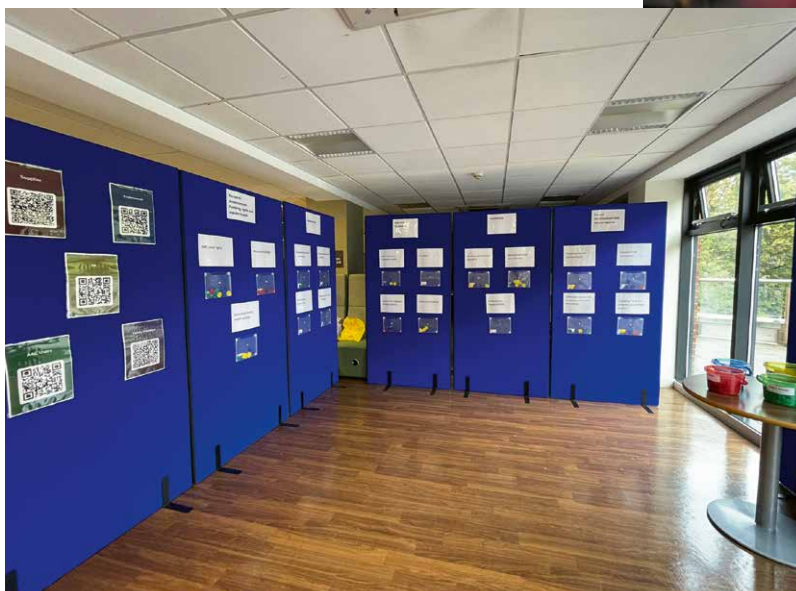
Following the work that CM Trustees Beth Moulam and Helen Hewson started at last year's Conference entitled "Our Futures", the Sunday afternoon activity at registration of CM2024 aimed to continue this work. This activity was well received by delegates who took part enthusiastically. The activity gave each delegate an opportunity to tell the CM Trustees what they needed to empower AAC users to achieve their goals. It gave AAC users the chance

to share what their priorities were in terms of achieving their goals. To allow those who were unable to attend the Conference to have their say, a questionnaire has been made available to all those who follow CM on social media and all members and non-members who would like to have an input. All these answers will be collated and presented by Helen and Beth to the November Board meeting of the CM Trustees. This Board meeting tends to be where we discuss Strategy and make plans for the year ahead. So, watch this space for the feedback and the plans of how we can all work together to achieve these goals.

Earlier in the year, CM became members of BATA (the British Assistive Technology Association). This organisation has been growing its membership gradually over the last few years and is aiming to be more inclusive of a range of disciplines that use technology to support those with disabilities. BATA has a number of Special Interest Groups (SIGs) and the AAC one is starting the academic year off with a presentation by Helen Hewson. Helen will be talking about her use of AAC systems throughout her life, with an introduction to AAC and CM for those new to this area. CM Trustee, Tina Voizey, is co-ordinating this SIG for BATA which is great news for CM.

The National Lottery funded project on Mentoring is going well with the establishment of several Communication Clubs around England. Verity (who co-ordinates the project for Communication Matters) had an exhibition stand at the CM Conference and lots of delegates signed up to receive more information about the support available when setting up Communication Clubs. Please get in touch with Verity if you would like to find out more: mentoringproject@communicationmatters.org.uk.

As a Board of Trustees, we are aware that we are a UK wide charity and currently the mentoring project is only available for people living in England. We have just heard that we have got through to the peer review stage of our National Lottery UK Fund application that is for mentoring project funding to be used in Ireland, Scotland and Wales. Hopefully I will be writing in my next Chair's Report that we have good news about this funding.

Have you started your Christmas shopping yet?

Did you know when you shop online via **Give as you Live**, the retailer will donate a percentage of your spend to us, at no extra to you! You can generate free donations on any online purchases you make at over 6000 stores. Sign up today!

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

If you use **PayPal** then please set us as your favourite charity (charity name 'ISAAC UK') - this means you can choose to donate £1 to Communication Matters whenever you checkout using PayPal. Set us as your favourite charity now! Just click on the heart symbol underneath our name.

https://www.paypal.com/gb/fundraiser/charity/3188321

Your support is really appreciated, thank you!

Model of Support for AAC Communication Partners

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Abstract

The aim of this study was to explore what parents of children who use augmentative and alternative communication (AAC) found the most challenging in their AAC journey. An online questionnaire attracted responses from 75 parents followed by 3 focus groups which were held online. In addition, 18 interviews took place with professionals working in the field. Overall respondents were located in 13 different countries across the globe. Quantitative and qualitative analysis were then conducted. A literature review revealed similarities to our primary research findings. There appears to be an urgent need to re-think the current delivery of AAC support. Our model of delivery targets the barriers found in this research.

Introduction

The focus of this study was parents of children who have complex communication needs (CCN). The utilisation of augmentative and alternative communication (AAC) has been identified as a crucial intervention for individuals with CCN. Creer et al (2016) have reported that approximately 536 out of every 100,000 individuals within the population, representing 0.5%, could potentially benefit from AAC. In reality, parents of children with CCN may not know how to get support in AAC.

The current model for AAC communication partners shows the AAC users support network all working independently.
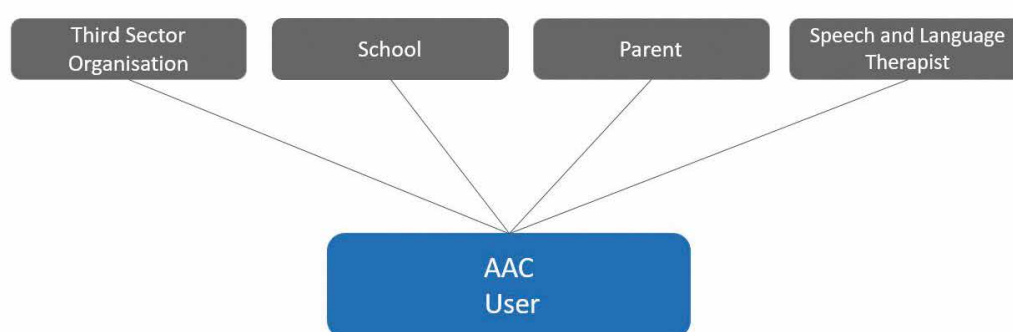
Figure 1 Current Model

Through this study, we aimed to explore our hypothesis that parents face several key challenges:

1. Access to AAC trained speech and language therapists (SLTs)
2. Meeting assessment criteria for AAC supports
3. Procurement of AAC tools and devices.
4. Implementation of interventions at home and at school.

This study also aimed to understand viewpoints of professionals working in the field. This included educators at senior levels in schools and universities, researchers, third sector organisations and SLTs. Their experiences and observations provide a valuable complementary lens through which to understand the challenges faced by them and the communication partners they work with.

Contemporary Literature Underpinning this Study

Kent-Walsh et al (2015) emphasise the pivotal role of partner instruction within AAC intervention plans. Their research suggests that integrating partner instruction "will likely assist in yielding improvements in the communication skills of individuals with complex communication needs".

However, there are pressing concerns regarding access to services. The National Health Service (NHS) in the UK is experiencing a shortage in supply of therapists as well as grappling with a considerable backlog of demand. This includes referrals for children with CCN, as highlighted by the Royal College of Speech and Language Therapists (2022, 2023).

The convergence of these facts underscore the critical need for improved accessibility and efficiency in AAC services. This necessitates innovative approaches to intervention, such as integrating communication partner instruction, to maximise the impact of AAC interventions for individuals with CCN.

Data and Methods

We employed a multi-faceted approach to data collection.

Our online survey was live for 21 days on Facebook pages of special interest and charity groups focusing on AAC supports. Group administrators gave approval to invite parents to participate. Surveys were anonymised with the option to join a follow up focus group. This strategy ensured broad accessibility and inclusivity. In total, 75 parent surveys were completed, spanning across 13 countries, providing a modest global perspective.

We hosted three virtual parent focus groups. This setting facilitated candid discussions and enriched our understanding of nuanced experiences not readily attainable through surveys alone.

We held 18 semi-structured interviews with professionals from a diverse spectrum of expertise. Interviewees worked in education, third sector organisations and SLT within the UK, Ireland and Romania.

The qualitative data gathered from focus groups and interviews underwent a thematic analysis. Through this iterative approach, we ensured a comprehensive understanding of the issues at hand.

Throughout the data collection process, ethical guidelines and standards were strictly adhered to. Informed consent was obtained from all participants, and their anonymity and confidentiality were safeguarded.

Results

Phase 1

Although 75 parents responded, one participant was excluded due to incomplete responses, leaving a final sample size of 74 participants. Table 1 displays the incidences of diagnoses of children as reported by parents.

The three most prevalent diagnoses included Down Syndrome, Angelman Syndrome and Autism Spectrum Disorder (including those with multiple diagnosis).

Table 1 Diagnoses of Children

Diagnoses	Primary Diagnosis	Secondary Diagnosis	Tertiary Diagnosis
Awaiting Diagnosis	2		
Apraxia of Speech	1	3	1
Autism Spectrum Disorder	10	5	1
Cerebral Palsy	8		
Down Syndrome	7		
Rett Syndrome	6		
Syndrome without a name (SWAN)	4		
Angelman Syndrome	16		
William's Syndrome	1	1	
Other	9		

Table 2 AAC Systems Used

AAC System Used	Number
Makaton/Lámh/Sign Language	34
Proloquo2go	16
TD Snap	13
Other	2
PODD	10
PECS	9
Grid 3	7

Table 2 outlines the range of AAC used by the children. Forty parents reported their child used more than one form of AAC. The predominant AAC method was sign language (35), specifically Makaton and Lámh while 17 of them also use a communication aid.

Key challenges faced by parent communication partners

Access to AAC trained speech and language therapists.

- 20% had no access to professional support for their child's AAC needs.
- 53% were dissatisfied with the support they received.

Meeting assessment criteria for AAC supports.

- 2% reported that their child did not meet assessment criteria.
- 70% have access to funded AAC systems.

Procurement of AAC tools and devices.

- 32% expressed frustration with the procurement process.
- 90% had access to AAC, 20% of which were self-funded.
- 8% were investigating options and 2% had no access to AAC.

Implementation of interventions at home and at school.

- 68% identified a gap in training related to their child's AAC needs.
- Participants satisfied with support predominantly received assistance from syndrome-specific organisations or private/independent SLTs.

Dissatisfaction with public health SLT services stemmed from them being under-resourced. This meant delays in appointments exacerbated by post Covid backlog and perceived lack of knowledge of AAC practices.

Table 3 The biggest challenge reported by parents

Communication partner skills	School support	Attitudes towards AAC	Assistive technology
"Using the system as it does not come naturally."	"Getting school to use it with him."	"Attitudes of other people."	"Learning the software."
"Modeling it and moving past requesting."	"Getting school staff confident to use her device with her for learning."	"Finding ways to train PAs to support communication."	"Battery life on the Tobii."
"Motivation to use the device."	"School personnel up-skilling themselves and willingness of teaching staff to deliver	"My child's therapists being rigid about other AAC."	"Bulky would be better on mobile size unit."
"Lack of knowledge on how best to model/get started."	"Getting schools to differentiate all things into grid to enable our daughter to access curriculum and learning as independently."	"Engage communication partners."	"weight of device and since my daughter is mobile it can't be accessible for everything."

This table includes quotes from the parent survey describing their biggest challenge. The headings: communication partner skills, school support, attitudes towards AAC and assistive technology.

Phase 2

Focus groups revealed prolonged delays in support from public health meant their young child missed out on early intervention. This led them to pay for private therapy and purchase their own devices. While private therapists carried out assessments, they did not provide implementation support. In contrast, parents of older children stated a decline in quality of life was a concern when transitioning onto adult services. They worry that staff may not be trained in using AAC, thereby leading to frustration or negative behavioural changes through their young adult not being understood.

Discussion

Overall, the parent surveys suggest a significant gap in professional support for AAC users, with 1 in 5 parents independently procuring AAC systems. Repercussions of the shortage of SLTs were apparent for these parents. The dissatisfaction expressed by over half of the participants underscores the need for improved support services. Satisfied parents reported self-funding supports, sourcing training from assistive technology companies or from third sector organisations.

Phase 3

Educational settings faced challenges releasing staff for continuous professional development (CPD) due to financial constraints and limited staffing resources. The perception of some senior management towards not prioritising AAC appears to be rooted competing demands from educational authorities. Together these hinder the implementation of ongoing professional development in general and specifically for AAC activities.

The availability of relevant and high-quality CPD courses covering AAC topics was a notable concern expressed by teachers. It negatively impacted their ability to enhance their skill set in special education and thereby meet the needs of their students who could benefit from AAC. Highly motivated teachers reported sourcing, self-funding, and attending CPD in their own time outside school hours.

Teaching staff noted some resistance from colleagues when encouraging implementation of AAC practices in their classrooms. This is a typical observation in the management of change (Lewin, 1951). In contrast a positive outcome was witnessed by one interviewee who had returned from teaching in Australia where a paradigm shift had occurred at whole school level. Coincidentally, in the survey two parents responded from Australia describing positive school support.

Young Adult Ambassadors

Encouragingly, researchers in a leading UK university report innovative power sharing for young adult AAC users in their role as consultant-experts in AAC for their peer group. This includes advising on age appropriate expressive language for daily living, influencing future assistive technologies including accessible gaming, challenging attitudes and shaping communication partner development.

Phase 4

The role of third sector organisations was similar in interviews and parent surveys. These included raising awareness, financing AAC devices, syndrome specific training and courses on AAC for communication partners.

The third sector also echoed many of the difficulties cited by educational settings in availing of training for their own staff and volunteers.

Phase 5

Speech and Language Therapists (SLTs) faced challenges due to a global shortage in their profession. Currently, their caseloads were high and several SLTs confirmed their region had many vacant posts. This impedes their ability to introduce planned AAC specific interventions.

Newer graduates may have had the option of being trained in AAC, however there remained a significant lack of expertise in the field. This shortage of AAC experienced professionals affected the quality and depth of services provided to individuals requiring AAC interventions and ongoing support.

Speech and language therapy encompasses a broad spectrum of subspecialties. Demand for services has outpaced the available resources.

Discussion

The above findings highlight systemic challenges in the provision of CPD in educational settings, including financial constraints and resistance to change. The global shortage of SLTs is a high level governmental problem. The lack of expertise among professionals, while improving for recent graduates, underscores the need for targeted efforts to bridge this gap.

Limitations

It is important to acknowledge the limitations of this study. The data collected is reliant on self-reporting and may be subject to respondent bias. The small scale time-bound study does not explore potential global variations in support availability and satisfaction.

Conclusion

This study exposed challenges faced by parents of AAC users, highlighting the importance of enhancing professional support services and addressing missed opportunities for communication partner training.

Professionals in education and SLT services have resources shortages. Until these are resolved there is a need for targeted interventions. The identified issues have significant implications for policy and practice in these fields.

Understanding the challenges of both stakeholder groups a unifying innovative service in the form of an AAC consultancy providing communication partner training could alleviate pressures. This can offer a more speedy early intervention.

Recommendations

This new model for AAC communication partners shows an AAC user's cooperative support network. It also creates an opportunity for peer learning between professionals. This underscores the significance of a collaborative approach in AAC interventions. Through educating communication partners in this new way, they become empowered to create meaningful connections with their AAC user.

"This is a great way of learning … and makes the communication journey less intimidating."
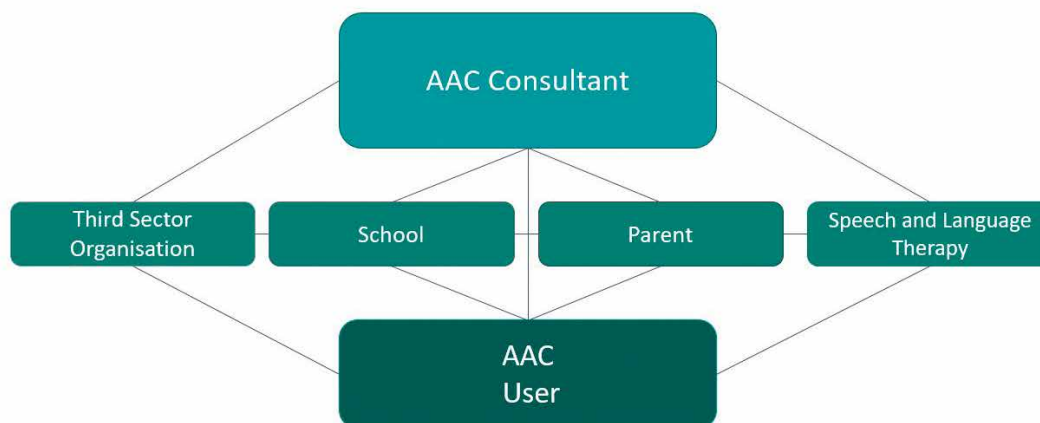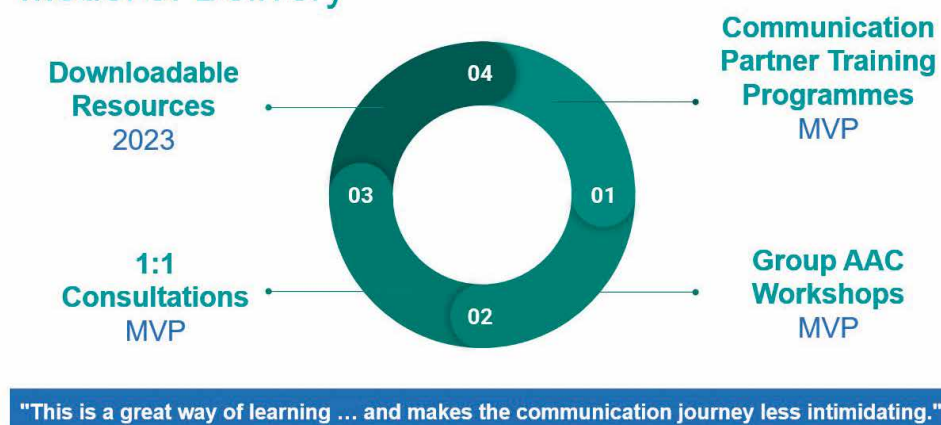
This research was self-funded and conducted by Melanie Boyle and Kathleen Lennon, Mother and Grandmother of an AAC user. Together they run Communication-Angel, an AAC consultancy offering training and support for communication partners of AAC users from family members to school staff and organisations.

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Empowering Individuals to Express Their Views on AAC through Talking Mats

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KATHERINE SMALL
Ace Centre: Ace Centre is a registered charity providing Assistive Technology and Augmentative and Alternative Communication services for people with complex needs. Ace Centre believes that people should be involved in decisions about their communication and AAC.

CLAIRE CARDADOR
Scottish Centre for Technology for the Communication Impaired (SCTCI): SCTCI is a national organisation offering specialist AAC assessment service to both adults and children in Scotland and also provides training and development of AAC.

Background

Research evidence says '*effectively engaging patients in their care is essential to improve health outcomes, improve satisfaction with the care experience, reduce costs, and even benefit the clinician experience*' *(Krist et al 2017).* In the field of Alternative and Augmentative communication (AAC) services, there are added complexities to hearing the voice of the person who uses AAC and thus making their views central to their intervention and care. At the start of their AAC involvement, they might not have a voice. Later, they might have a voice, but there might be other factors that make it hard to express their views, for example, their AAC might not be fully effective and so using it might require great effort. There may be a great dependency on care givers, so giving an autonomous view can be difficult. Improving the involvement of people who use AAC in their care was a key driver behind the development of a Talking Mats AAC resource, and this led on to the development of the AAC Talking Mats advanced online learning module. This work was primarily funded by Ace Centre but the SCTCI also contributed. The work was delivered in partnership with the Talking Mats social enterprise.

What is a Talking Mat?

The Talking Mats framework was originally developed by speech and language therapists at the University of Stirling to help people with communication impairment understand and reflect on an issue and express their views. Various research projects for example, people with learning disabilities (Murphy and Cameron, 2008) dementia (Murphy and Oliver 2013), stroke (Bornman J, Murphy J.2006) , demonstrated that using Talking Mats improves both the quality and quantity of communication.

Each Talking Mat involves a topic to be discussed, a set of options to be placed on the mat, and a top scale which frames the question. In any Talking Mats conversation, there is a "thinker" (the person expressing the view), and a "listener" (the person facilitating discussion). Talking Mats supports the thinking and expression of the thinker by:

• providing a structure where information is presented in small chunks supported by symbols;

• giving people time and space to think about information;

• providing them with well-designed images that support their understanding and expression;

• saying what they feel in a visual way that can be easily recorded;

• building a thinker's confidence by starting with easy topics and moving to more abstract ones.

The Talking Mats process of side-by-side listening gives the 'Thinker' control of the options and therefore supports them to express their views and opinions. The process allows additional thinking time to make, and then review, decisions. Talking Mats is used in conjunction with any existing communication system a person uses, e.g., electronic AAC, signing, a communication book, verbal speech. The origins of Talking Mats lie in the field of AAC, and whilst the framework has developed to have much wider applications, this project has felt like a positive return to its AAC roots, focusing on the development of a resource to enable people to have more easier and accessible conversations about AAC.

The Development of the Talking Mats AAC Resource

Initially, a focus group was held at Ace Centre with AAC practitioners to explore the key issues that they were facing in terms of involving people who used their services.

Two strands emerged:

1. **Improving the referral process.**

    Practitioners felt they were sometimes getting inappropriate referrals. For example, some people being referred did not really understand what AAC was or were not ready to explore its potential.

2. **Finding out what was really important to the person who used AAC** in terms of where, who and how they wanted to use it, and how that related to multi modal aspects of AAC.

The initial focus of the work was on these two strands. Later on, SCTCI joined the work and a topic that explores the effectiveness of an individual's AAC system was codeveloped.

All the resources were developed using the Talking Mats process for developing a communication resource. First, a working group was set up with the experts in the field to identify a cohesive framework of topics for an AAC conversation. Then, the group focused on considering what options needed to be included in each topic. It is crucial to ensure that this is a coherent conversation that will work with the top scale and will answer the question that is being explored. Symbols are then chosen from the Talking Mats symbol bank or designed specifically. It is important that the symbols support the meaning of the option being considered. Once designed, the new Topic Mats are then piloted, feedback given, and changes made. Developing a Talking Mat is an iterative process, and there is an ongoing dialogue between the practitioners, the Talking Mats team, and the thinkers who use the resource.

Readiness for AAC Resource

This was the first resource created. It is designed for AAC practitioners, for example, Teachers, Speech and Language Therapists, Occupational Therapists, with the aim of enabling them to facilitate a discussion about 'Readiness for AAC' with their clients. The time for this discussion will vary from person to person but examples include when AAC is first being introduced, when provision of AAC via local funding is being thought about, when referral to a regional hub for Specialised AAC service is being considered. The resource is in the form of a scripted Talking Mat and is available to download for free on Ace Centre's website: https://acecentre.org.uk/projects/talking-mats-for-aac

The Talking Mats AAC Resource

There are three topics in this resource:

1. **Your communication.** This topic was developed to understand the thinker's communication needs in terms of:
    a. the environment they are communicating in. Examples of options are at home, outside, work.
    b. who their communication partners are. Examples of options are family, staff.
    c. the format of communication they are using. Examples of options are phone, digital writing.

2. **Joining in conversations.** This topic was designed to help a thinker to explore how they feel about their AAC resources when they are joining in conversations. This is a topic that is really focused on activity and participation. In this topic, there are three topic cards which can be used interchangeably with the options. This is because an individual is likely to use a combination of ways to express themselves to support their communication. The three topic cards are verbal conversation, paper support, and powered/electronic support. The options include different communication functions. Examples of options are starting a conversation, telling a story.

3. **How your AAC works.** This topic asks about how your system works for you and includes:
    a. the functional features of the AAC system. Examples of options are charging, saved phrases.
    b. appearance and sound. Examples of options are visual clarity, colour.
    c. the thinker's ability to access their AAC. Examples of options are mounting, access.

Figure 1 (right) shows an example of the How your AAC works Talking Mat – please note not all the symbols in the resource have been used in this example.

Online Module

Once the resource was completed, it was recognised that it would be helpful to build practitioner confidence in using the Talking Mats AAC resource. The modules were designed in partnership with Ace Centre. It has 3 sections:

1. The course begins by explaining the structure of the Talking Mats AAC resource. It explores potential times and contexts that the resource will be helpful for.

2. There is a specific module on access, with information on positioning, creative solutions, establishing methods of confirmation, and the various methods of supporting access, e.g., listener mediated scanning, eye gaze/pointing.

3. The course finishes with a module on conversation dynamics and the advantages and disadvantages of having another person present to support a Talking Mats conversation. Another person may be a great help to support positioning, or because they understand the idiosyncrasies of a person's conversation and can help interpret meaning, but sometimes they may have an undue influence, and this can inhibit the thinker expressing what they really want to say.
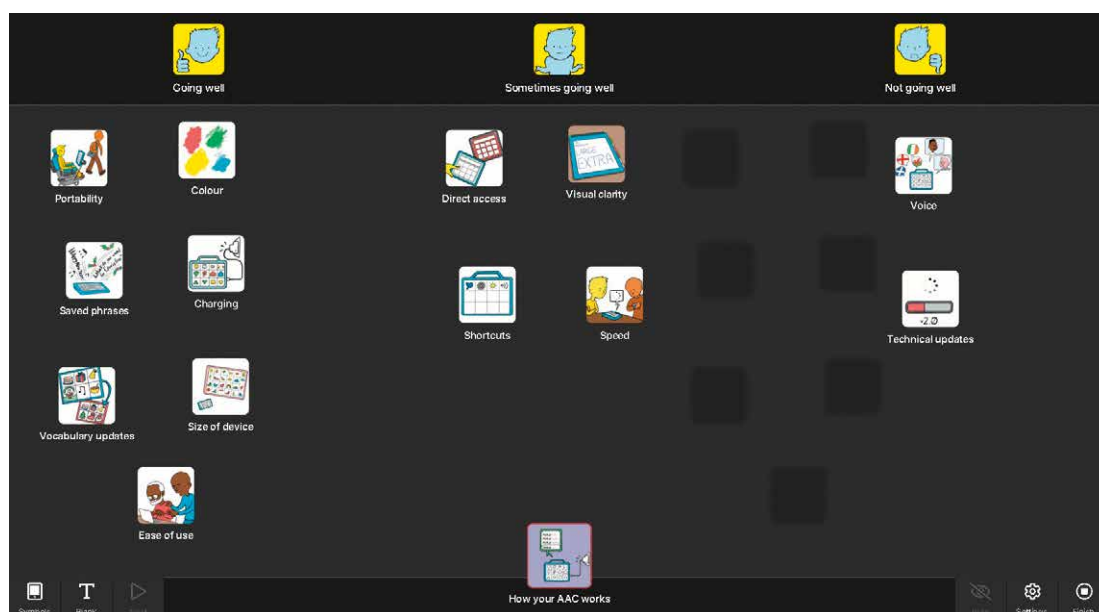
Figure 1

The course is designed to be a reflective practice module and includes information, video examples, interactive quizzes, case examples. It signposts participants to other relevant articles and resources and takes about 3-5 hours to complete.

The final forum allows participants to reflect on how they would apply the learning to their own practice. The practitioner's reflective practice feedback has shown that participants have found it a useful resource to:

1. **reflect on their practice,** e.g., *'Looking back at some Talking Mats I have done with people present I now realise this may have influenced the thinker'* and from another participant '*The course was very helpful in understanding ways to use a communication device alongside the Talking Mat.'*

2. **make changes in intervention and support for the thinkers**. '*The thinker confirmed that she wanted to continue with her current communication options, including using her communication book and her device. At the start of the process this had been unclear. During the Talking Mats session, the thinker had shared that she wanted to use her device with a range of people, but she was not sure about using it with her carers. Staff training was arranged and delivered to 12 carers focusing on:*

   a. *How to charge and set up her device so it is available for her to use.*

   b. *The importance of giving her time to say what she wants to say using her device.*

   c. *How to know when she is eye pointing to use her communication book and how to use the book with her.'*

3. **enable new issues to emerge**. '*From the mat it was clear that her communication at home, school and online with familiar people was going well. However, she was able to communicate about online safety concerns which we will need to address.'*

The submissions in this final module have been very thoughtful and create an online clinical reflective practice resource for practitioners to learn from each other's clinical experience.

Summary and Next Steps

Involving people in their intervention is key to effective care. Making sure you get their views is an ongoing process. This project has produced a resource that supports practitioners to hear the voice of people who use AAC. The online course builds the practitioner's confidence[1] in doing this. Early indications from the course indicates that this is improving AAC practice, but further research is required to look in more depth at the long-term impact of using this resource and training. It would also be helpful to look at the perspectives of the AAC users on their involvement in AAC interventions.

Talking Mats is a social enterprise with international reach. They are aware that AAC knowledge and practice varies in the different countries they work in. As such, it is to be hoped that this AAC online module extends and develops the appreciation for the wider potential and impact of AAC.

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Conflict of interest

The lead author works for Talking Mats social enterprise on a consultancy basis.

Making with Mentors

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Introducing Studio Ordinary

This paper is about collaborative research between designers and people who use AAC. Studio Ordinary is a research centre in DJCAD (Duncan of Jordanstone College of Art and Design) at the University of Dundee*. It was co-founded by disabled and nondisabled researchers in the art school and in the School of Humanities, Social Science and Law, also including Fiona Campbell, Professor of Disability and Ableism Studies – significant because AAC as a field is now beginning to engage with ableism and, at CM2024, technoableism (Lee, Boyes, Toogood, Preece and Moran, 2024).

The meeting of disability studies and design research in Studio Ordinary is applied to numerous disability objects: asking what their design implies about disability and how their design might better reflect different disabled people's attitudes. Our research is characterised by the use of creative methods. We make things. We do this at any and every stage of our process: we build prototypes to test ideas, in the hope of validating them; we also build speculative objects to catalyse discussion and debate; we even make things before we know where a project is going, as a means to starting to think things through. We will come back to the connotations of making later, but first we will consider our working relationship with further disabled collaborators.

Explaining our use of the term 'mentors'

We have come to describe the disabled people that we collaborate with on particular projects, and who are not academic members of Studio Ordinary, as 'mentors'. We realise that the word mentor has other connotations in AAC, so we should explain why we use it in this sense too. It comes from the insightful talk that Colin Portnuff gave about his perspective as an AAC user (Portnuff, 2006), from which we have drawn so much, including our exploratory research around tone of voice in AAC (Pullin, 2011). Portnuff shared a hope for the field: "I'd like each of you... who are engaged in the science of speech and voice development to adopt as your mentor a person... with impaired speech." We really like this term and so we have adopted it.

The importance of spending time together

"Spend time with us. Learn from us, and teach us." was Portnuff's next recommendation. To us, the notion of spending time together implies more than research activities. We consider it important to spend less structured time together in which unforeseen conversations have space to arise and evolve. Our studio is a convivial space in which we and our guests can be in each other's

* Being in Dundee, we are colleagues of Annalu Waller and her team in the School of Science and Engineering. Yet, whilst we have collaborated in the past and plan to in the future, we are not the same group.

Figure 1 Spending time together in Studio Ordinary, right to left: Jamie Preece, Emma Sullivan and Graham Pullin (photo: Fin Tams-Gray).

presence even if not directly working together. "Learn from us, and teach us", also speaks of a principle of mutual benefit and complementary experience (Figure 1).

The design academic Ezio Manzini has written about how a traditionally authoritarian role of design that he terms 'big ego design' has been challenged and dismantled (Manzini 2015). Instead, participatory design involves the communities being designed not for, but with. In these collaborations, designers are frequently expected to be neutral facilitators, a role that Manzini terms 'Post-it design' (Manzini, 2015). This to Manzini is an equally derogatory term, because it squanders the contribution that the designers' experience could bring to the lived experience of the community.

We too are either arrogant enough or generous enough to think that we can contribute not only our skills but also our sensibilities – our own voices if you like – to the voices of our disabled collaborators. In this context, thinking of collaborators as mentors has meaning to us: a mentor is someone to whom you look up, valuing their lived experience and wisdom, their reflections and advice. Yet it is not a mentor's responsibility to tell you exactly what to do, rather to help to frame priorities and decisions.

Imagining technologies for Disability futures

At the moment, we are working with mentors who use AAC as part of a project called 'Imagining technologies for Disability futures'. It is funded by the Wellcome Trust and led by Professor Stuart Murray of the School of English at the University of Leeds who is exploring representations of disability in science fiction film and literature. It feels important to state that this research is framed as medical humanities (not as clinical or technical development) and has not involved funds that would have otherwise been used within AAC.

Our own part of this project is exploring alternative futures for AAC: we say alternative to acknowledge and challenge existing predictions that the future of AAC will necessarily involve brain-computer interfaces and artificial intelligence. Our mentors in this exploration include Jamie Preece, Darryl Sellwood, Kevin Williams, Lateef McLeod, Meredith Allan and Todd Hutchinson. McLeod is

a poet whose poetry includes the line "I don't need a doctor to come up with a cure. I am alright." (McLeod, 2012). This stance directly challenges the medical model on which surgical intervention and undetectable AAC can be based.

We have had conversations online that formed the foundation of a two-hour discussion panel at ISAAC 2023 in Mexico (Pullin, Sellwood, Preece et al., 2023). These conversations were recorded and edited into short films by documentary filmmaker Jared Schiller (Imagining alternative futures for AAC together, 2023). We used these films to structure the panel around three themes: technology, interactions and ownership (Figure 2). This last theme is perhaps the least obvious but the most profound: who will own these future technologies? Not just the devices that incorporate them, but the companies that develop them, even profit from them? Will people who use AAC be in positions of power to decide how and why they are developed further?

Figure 2 A still from the film *'Imagining alternative futures for AAC together: technology; interactions; ownership'* edited by Jared Schiller. Darryl Sellwood is shown talking with Kevin Williams and Katie Brown (image: Jared Schiller).

So, we wish to imagine futures for AAC. But this is difficult. We know this because we tried it once before in collaboration with Alan Martin, whom many CM readers will remember well. We invited people to "Imagine your dream communication device". Alan took the questions to a community of AAC users that he was part of, in order to start a conversation amongst themselves. Even then, the responses were disappointing, if understandable: "something that f***ing works" being not atypical. It seems that frustration with the limitations of current AAC, far from motivating people to imagine something better can inhibit them to engage. Perhaps optimistic speculation felt naive in the circumstances. So, we know that this is a difficult conversation to try to start.

Thinking through making

This where our practice as art and design researchers comes in. In this, making doesn't follow thinking, making and thinking are inseparable. A distinction is sometimes made between 'research into design' (finding knowledge about design processes), 'research for design' (finding knowledge to inform designing something) and 'research through design' (finding knowledge *by doing* design). More often than not, we are practicing research through design.
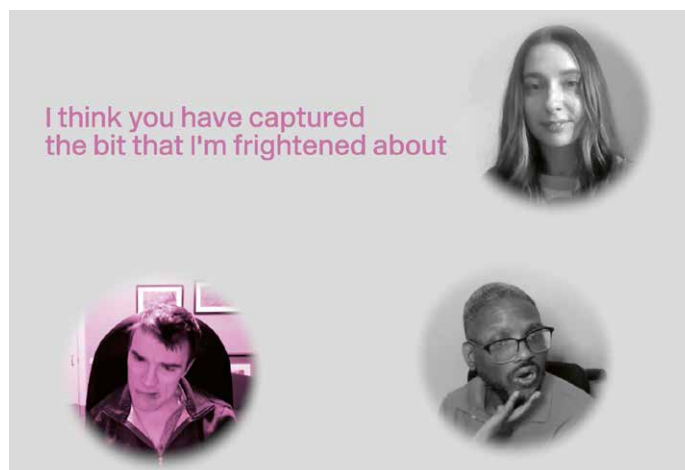

Figure 3 Chair No.6 from the *Six Speaking Chairs*. 17 doorbells are annotated with 17 tones of voice taken from the stage directions to *Pygmalion* by George Bernard Shaw (image: Andrew Cook).

One example of this was the *Six Speaking Chairs*, shown at Communication Matters in 2011 (Pullin, 2011). This was a collection of objects that allowed someone to interact with the tone of voice of synthesised speech in different ways (Figure 3). Yet the six chairs were not prototypes of AAC devices. Rather their role was to embody different ways of thinking about tone of voice in the first place – ways that are sometimes otherwise obscured by esoteric language in different disciplines. The intent was to engage people with a conversation about what is missing and important about tone of voice in AAC (Pullin and Hennig, 2015).

We see ourselves as part of a group of AAC researchers using creative techniques not only to prototype ideas but also to establish equitable working relationships and to support conversations (Volkmer and Broomfield, 2023).

One technique we use a lot is collaging. It can be liberating to explore ideas through images rather than text, but we know that whilst designers are very confident about drawing something, that can be quite intimidating in itself and also inaccessible. So we use collage, both paper-based collage but also online collage. Participants are invited to represent themselves, by pasting a pair of legs in first-person perspective, within a scenario of their choosing. They then annotate the collage with a speech bubble representing how their AAC might sound, the words they might say and the resulting social interaction (Figure 4). We held a workshop at ISAAC 2023 entitled 'Picturing alternative futures for AAC' (Brown, 2023). We have also employed this method public engagement with our research – by which we mean engaging a general public, beyond AAC.
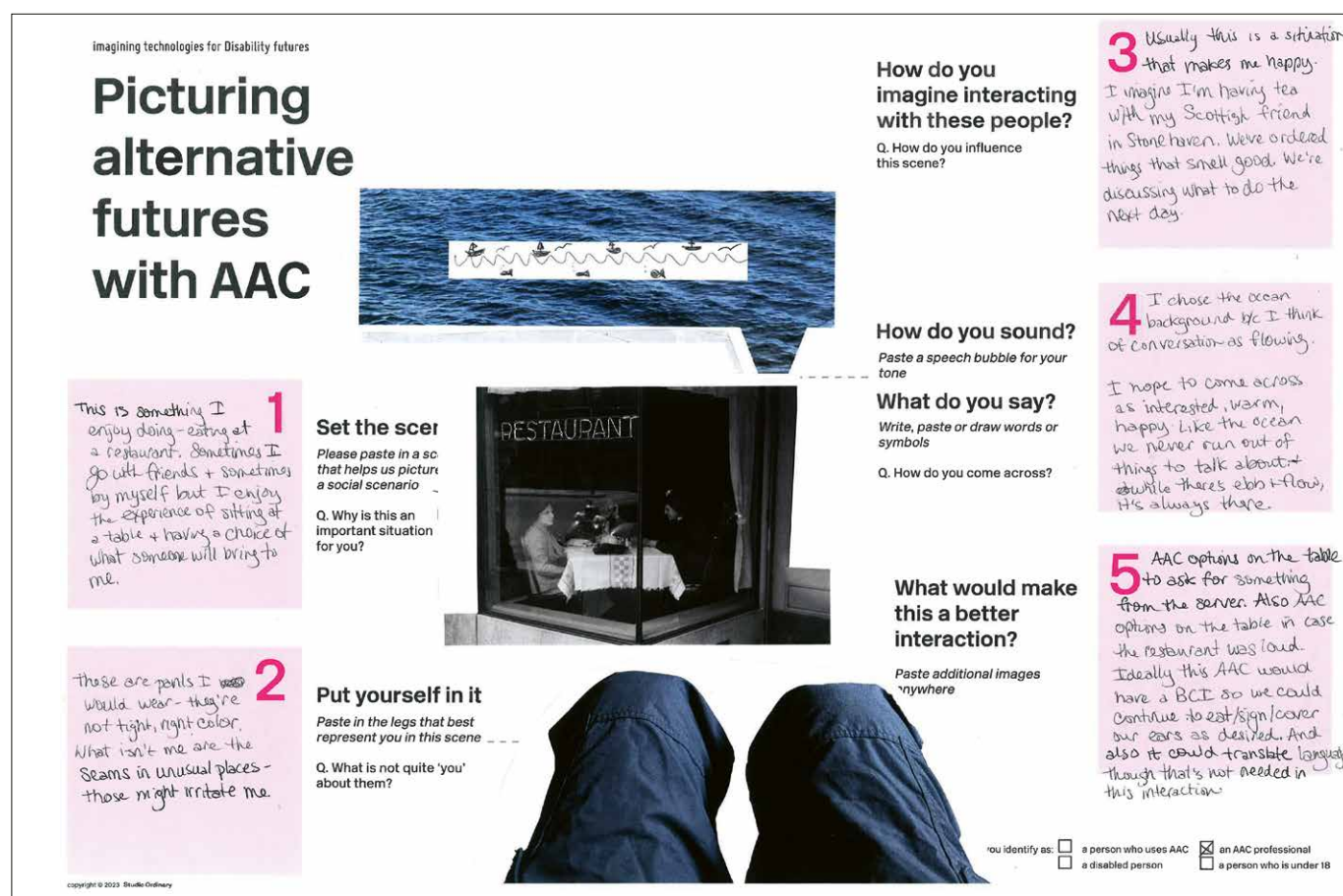
Figure 4 A collage 'Picturing alternative futures with AAC'. Provided images have been stuck down and annotated, in this case by a participant identifying as 'an AAC professional' (Anon).

How to represent non-verbal communication

Johanna Roehr is doing a PhD in Studio Ordinary, as part of the same project. This is exploring the interactions between – the non-verbal communication between – neurodivergent and neurotypical artists in an artists' collective in Norwich, UK. As an illustrator, she is representing those interactions non-verbally herself. So she's not writing transcripts, she's drawing the interactions in a method that she calls sensory ethnography. She also creates risograph prints from them, to give these prints back to the artists. And for those artists, these are a relevant and meaningful outcome for them too. And so this exchange is all part of building the conversation, but also building the value of that conversation to all parties (Roehr, 2023).

How to hold a conversation about silence

On our AAC project, we have also made things in order to elicit reflections. In doing so we consider that we are joining Darryl Sellwood and his invention of the Bummunicator. The Bummunicator is a screen attached to the back of a wheelchair that displays an image of the wheelchair user's (clothed) buttocks, allowing them to participate in flirtation with passers-by. It is a satirical piece, humorous yet with the serious intent of provoking discussion about disabled people's sexuality and sexual agency, the subject of Sellwood's own PhD (Sellwood, 2019). Our work is also related to Seray Ibrahim's use of 'cultural probes' as an art school research method in AAC (Ibrahim et al., 2024).

Sometimes an issue around AAC can be elusive or slippery – difficult to keep a conversation focussed on: for example, the silences that can open up in conversation involving AAC. The problem we have found is that once the time taken to select or compose utterances has been raised, the conversation inevitably turns to how this time can be reduced using prediction, contextual vocabularies and these days AI. Or even eliminated altogether through a brain to speech implant offering 'speech at the speed of thought', which obviously is one frontier of AAC technology research. But this means that we never get to talk about people's experiences of those silences, both AAC users and their conversational partners. And so we don't consider whether and how the design of AAC might make silence less socially divisive; more something that is shared, not just ascribed to the person using AAC.

Between Things is a collection of ceramic domestic objects – bowls and vases – connected to boxes of electronics, that can be used in a conversation between two people. *No.1: The waiting bowl* is a large charcoal grey ceramic bowl that would sit on a table between two or more people. When someone using AAC anticipated a silence, yet wished to maintain their conversational turn, they can trigger the bowl to play ambient sounds, to 'fill' the silence until their next utterance is ready (Figure 5). We are not proposing this as an AAC feature, yet it invites reflection on silences in AAC.
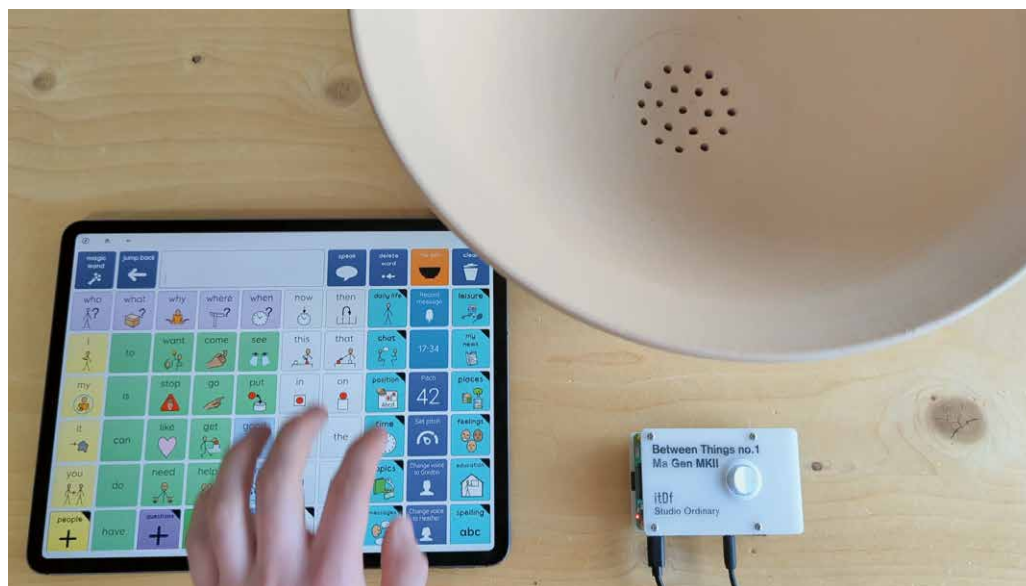

Figure 5 An early version of one of the *Between Things* object No. 1, showing an unfired ceramic bowl by Katie Brown, prototype electronics by Fin Tams-Gray and a modified menu on an AAC tablet (photo: Fin Tams-Gray).

The collection embodies other issues discussed with mentor Jamie Preece, including turn-taking and how AAC might draw attention to body language rather than distracting from it. The poster of the five objects led to many conversations at Communication Matters 2024 (Tams-Gray, 2024).

To conclude, Studio Ordinary is contributing art school techniques and design research methods to AAC research. We would love to hear from future collaborators who might see a role for this contribution in their own practice, research and activism.

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Me and My i13 Journey

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Until a year ago, I was still using the old type of AAC system, a Tobii Dynavox i12, which I have had for a quite a few years and it was getting a bit long in the tooth and had out-of-date software on it.

When I went to the Communication Matters Conference and saw what the other AAC users were using, I mailed my local TD rep and asked him for a trial - let's face it nobody likes to feel like the odd one out.

I had been using Sono Key for years which was a basic communication programme. You had to go to the internet if you wanted to use things like Facebook and YouTube which increased the risk of the Tobii developing problems with hardware. Mr Liddle persuaded me to try the text user programme which has opened up more doors. The next step after the two-week trial was getting the funding for a device though my local communication aid service.

Some of the funding challenges I faced were because the accessible apps were not considered face-to-face communication, so my regional AAC service team didn't think it was a part of their remit. This went back and forth for quite a few years until I played them the funny voice.

My advice to others would be to keep badgering your local NHS trust and don't take no for an answer if they do - just keep fighting.

After a few months, I got my new device. I had gone from a large on-screen keyboard with full colour supporting symbols to something far more fit for purpose. I can now be a part of the AAC User Focus Group without my dad having to do a 40-mile round trip every time. Now I am a part of the AAC User Focus Group, I am able to contribute ideas to the running of Communication Matters and call my friends like everyone else does.

Yes, there are things that I am not too confident on, like editing, but the more I do things the better I am becoming.

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 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/

Using the Silent Voice Inside Your Head to Communicate

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Many children and young people who are considered to have Profound and Multiple Learning Disabilities (PMLD) cannot speak out loud and find access to a range of Augmentative and Alternative Communication (AAC) devices problematic. Difficulties with their visual abilities and their physical movements limit the extent to which eye gaze or switch, screen or keyboard controls can operate, inhibiting their communication responses. However, although they cannot show it, this does not mean that they do not have internal language even if this cannot be verbalised.

Researchers at Loughborough and De Montfort Universities (Woods *et al*, 2023) have used a unique approach to help young people with PMLD to demonstrate their language skills. Twenty children and young adults between 3 and 21 years old who were assessed by the medical profession and their teachers as having PMLD took part in a research project where they were invited to record their comments and opinions by using sub-vocal speech.

Sub-vocal speech is like very soft whispers. The tongue might move a bit, but the mouth and lips do not seem to be speaking. It is as though a person is 'thinking' words inside their head without saying them out loud. If you are not used to listening to sub-vocal speech, you may need to listen for a time to become familiar with this form of phonation as research has demonstrated that with practice, listeners improve their perception of unfamiliar speech (Liss *et al*, 2002)

The recordings, taken over a period of many months, showed that some children with PMLD do have language that can be used in this way. The sub-vocal responses by the children and young people were recorded using sensitive microphones and special sound software on computers. The recordings were then amplified and enhanced so that the children's sub-vocal words and sentences could be heard. Researchers listened to the recordings and wrote down what they thought the children were saying. The words and sentences were read and played back to the children and young people for them to use their sub-vocal voices to tell the researchers if the copy was wrong or right. This response was recorded too, to make sure the researchers had written down correctly what the children and young people said.

What the participants said, and how they put their words and sentences together, showed that they were using real language meaningfully, and it was thus possible to determine their developmental and linguistic levels by matching their words against accepted language benchmarks. If they do have language, it is important to make sure they are being taught and communicated with in ways that match their intellectual needs *and* their language. If they do not have profound developmental delay and can use and understand words, then any attempts to use pre-linguistic communication methods may limit their language learning, rather than develop it further.

Using playback of their enhanced recorded utterances, the participants conveyed messages to researchers and others, responded in question-and-answer sessions and spontaneously commented on subjects of their own choosing. However, this proved to be a slow and difficult process that did not allow anything like an everyday, two-way conversation. Given all the above, it became obvious to us that an AAC device to process and play back sub-vocal speech audibly and in real time would thus be a huge asset.

To date, development of AAC systems for people with PMLD has been very limited. The understanding that they have not developed language has meant that the need for such systems or devices has not been obvious, and their restricted vision and physical skills have made many existing AAC devices too difficult for them to use. However, now that we have demonstrated that language is in fact present, the need for a specific AAC system to enable sub-vocal communication is clear.

The results of our research are vitally important for children and young people with PMLD, as they indicate a pathway towards the use of sub-vocal speech as an AAC intervention (Woods, 2016). The methods we used in the research, however, would be far too slow and inflexible for proper AAC use, as the enhanced sub-vocal recordings are obtained and processed off-line and not in real time. The potential remains however, for using the latest digital technology to overcome this problem. Some early work has already been carried out in this area, for example for hospital patients following an operation on their larynx (Fagan *et al*, 2008).

Direct digitisation of the microphone picking up the sub-vocal speech signals would allow high speed digital processing in real time using dedicated hardware. The enhanced sub-vocal voice could then be analysed by a specially trained speech recognition system using Artificial Intelligence (AI). Finally, language processing software could convert the AI output into synthesised speech, more easily recognisable to the human listener. The key requirement here would be to get the system to respond immediately, with minimal processing delay.

A major problem for children with PMLD is the difficulty that others have in understanding what they are trying to communicate. A communication partner can try to understand what is being expressed but it cannot be certain that they have understood correctly. The assumption that such children do not have language and are at a profoundly delayed level of development has often meant that others speak for them but may not say the right thing (Porter and Ouvry, 2001). In the same way, it is often assumed that the participants could not have abstract thoughts such as ideas, opinions and views (Ware, 2004). Thus, although children have the right to contribute to decisions about their own lives (SEND Code of Practice 2015, Children and Families Act, 2014) others decide for them, because they think they know what is best.

People with PMLD have the right to self-advocacy, to let others know about their wishes, plans and thoughts. One of the most important things that our researchers learned from the children and young people was that they could indeed use their sub vocal speech to self-advocate. They could ask for help with things they wanted or communicate their feelings or worries over things they did not want. They could express their own ideas, opinions and views. They could let others know about what *they* wanted and have their say in decisions about their own lives. The study also provided evidence that participants could use their own choice of words and subject material. When other people choose what words to put on current AAC devices, or select cards, pictures, symbols or objects to help the children to communicate, they may not choose what the children want to say (Van Tatenhove, 2005). Using their own sub-vocal language in a specially developed AAC system, the children would be able to choose subjects that researchers would not have realised they wanted to mention.

Our project was a small study and needs further robust research to check the findings but offers a unique way to find out if children with PMLD are more linguistically and developmentally advanced than they appear. If they do have language, even if they cannot speak aloud, it is essential that they are given a chance to demonstrate their abilities and then to have their needs met at the correct developmental and language level. You can listen to some samples of the sub vocal recordings made during our research by visiting the link:

https://www.sciencedirect.com/science/article/pii/S0891422223002111.

They have been made available with the words written down to help you understand the sounds if they are not clear enough for you. We have made the voices of the children and young people available because they have the right to communicate, to be included and to be heard in a society where we are all equal.

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Coordinating a Multi-Agency Approach to Supporting the Use of AAC in Specialist School Settings

Case study of a Cornwall based pilot project

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The Special Partnership Trust (SPT) is a Specialist Educational Trust with school settings across the South-West. In Cornwall, it has over 500 pupils on role across eight settings. The Trust is state funded and relies on NHS and local authority services for specialist support.

In the academic year following covid school closures (2021-2022), the senior leadership of the four special schools completed an audit of external services input. This audit identified the following:

- Significant cohort of pupils unable to access the universal provision offer in the schools due to the complexity of therapeutic needs.
- Number of pupils unable to access appropriate targeted intervention in school, due to the lack of available training or modelling from specialist services.
- High number of referrals to external services were unsuccessful, often due to the lack of intervention, leading to limited evidence for effective referrals.
- Lack of available specialist support, most notably Speech and Language.
- Some pupils beginning to show a change in presentation and/or deterioration in health/wellbeing whilst on service waiting lists.

Due to these findings, the Specialist Intervention Team (SIT) was commissioned. The team consists of an intervention coordinator in each school, a manager and a clinical lead.

The Intent:
- Provide a **sustainable intervention resource**, working innovatively in SEN schools, across a multi-academy trust, with multi-agency partners.

- Support **early identification of therapeutic needs**, providing personalised outcomes and access to specialist support.
- Develop an equitable offer within the schools, enabling **fair access to therapeutic services.**
- Create **professional career pathways**, supported by expertise. Developing and **retaining highly skilled staff.**

The SIT began by looking at the Quality First Teaching Model, focussing on developing the skills as a team, to fill the gaps that were blocking movement between the pathways.

Between Universal and Targeted provision, key factors were:

- Staff having the knowledge to identify when universal is no longer appropriate, and intervention is needed to support engagement in learning.
- Staff having access to training and knowledge to develop and deliver effective interventions

Between Targeted and Specialist provision, key factors were:

- Staff knowing where to access specialist support and confidently identifying the needs to complete a referral to individual specialist services.
- Having a consistent, "Assess, Plan, Do, Review", evidence collection system, ensuring referrals are accepted to limited services by utilising photo/video evidence.

Moving from Specialist provision back down the pyramid, key factors were:

- Maintaining working relationships with external services (key named professional from each service), information sharing more effectively.
- Increasing accountability for external services and school staff through regular discussions and open dialogue.
- Tracking referrals at a school level
- Sharing recommendations between external services, with access to education as a central focus.
- Developing an understanding of recommendations in therapeutic plans in order to effectively embed them into classroom practice and reduce instances of rereferrals.
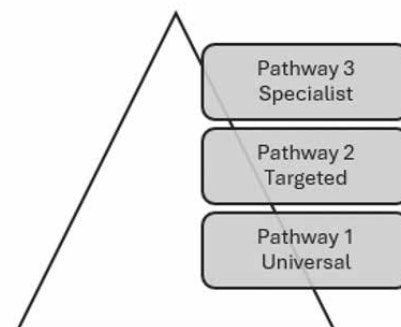
Using the SIT model to support access to AAC across all settings

Step 1: Addressing Communication Provision in the Universal offer

Intervention Coordinators conducted an environment audit at their setting and results were collated to give a Trust wide picture of Universal level Communication provision.

Below are the outcomes of this audit:

- A variety of resources are used consistently to support learners with **receptive** language/ instructions.
- There is limited access to resources that support **expressive** language/pupil voice/choice making.
- Low tech/ paper based AAC is used to support with topic teaching and lessons.
- Some staff are confident in creating symbol resources and have received training and support in the use of appropriate software.
- In some classrooms, with a high number of low tech AAC users, personalised systems are apparent and clearly used. AAC is available at all times.
- Some staff feel confident in supporting low tech AAC users and are seen to model its use throughout the day.
- Few staff are confident in modelling the use of high tech AAC and supporting pupils to access their device appropriately in all situations.
- There were few instances of learners having access to low tech options to request their AAC device when it is not with them.
- Very few classrooms have access to high tech AAC on their classroom iPad, at some schools none did.
- No classrooms have access to high tech AAC on the class whiteboard for modelling purposes

Step 2: Agree trust wide outcomes

Following this audit, there were clear gaps in the universal offer that were delaying skills development and access to high tech for learners within the Trust. Therefore, the following Trust wide outcomes were agreed and made explicit in the SIT offer:

- Total Communication Approach is embedded – including modelling of AAC at **all times.**
- All pupils have a **valued voice** that is identified, responded to and extended by staff.
- **Expressive communication opportunities** are embedded into learning activities/ daily routines and promoted through the availability of communication aids/partners.
- **Receptive language** supports are accessible, appropriate and used throughout the day for generalised purposes.
- **Staff promote the extension of skills from low tech to high tech AAC** where appropriate and understand the steps needed to achieve this.

- **Staff confidently hold outside agencies to account** for supporting progress towards high tech AAC, ensuring timely referrals to specialist services.
- **All classrooms will have access to ICT devices appropriate for communication**
- **All settings will have access to appropriate high tech AAC software/programmes** enabling frequent modelling of AAC to be embedded into classroom practice, providing increased access to symbol-based vocabulary.
- **Staff can confidently model the use of high tech AAC** within learning environments and as part of daily routines/play.
- Education Health Care Plan (EHCP) and termly outcomes will show **Aspirational outcome setting for Communication and Interaction** (other areas of need as appropriate) to reflect progress for AAC users
- The SIT will provide **increased access to, and joint working with, services supporting high tech AAC use**.

Case study A demonstrates how the SIT supported from the point of referral to obtain a funded device for a learner who now accesses universal provision.

September 2022

A is new to the country and not accessed school provision previously. Initial presentation was one of dysregulation.

October 2022

Referral is made to SIT. Referral to Speech and Language (SaLT) made.

December 2022

Accepted to SaLT.

January 2023

SIT Targeted intervention developed and delivered for 18 weeks, gathering evidence of use of AAC in a variety of settings for a variety of purposes.

September 2023

Universal provision changed to meet need post SIT intervention. No longer accessing a sensory based curriculum due to progress with school iPad as AAC. No further SaLT input at this stage due to long term absence within the team but remains open on SaLT caseload.

March 2024

SIT Intervention evidence used to support referral to AAC West. Discussion with Cornwall AAC team to ensure staff in class were trained to edit class device.

May 2024

AAC West acceptance. Now trialling a mounted device and accessing learning as part of the universal pathway.

Case Study A Challenges

- Limited staff retention and consequent movement of staff between classrooms
- Staff trained in different software to end product
- Home Language not available on device
- 'The Fear!' Staff seeing device as an 'expensive piece of kit'

But…Confident communicator accessing a varied curriculum alongside peers, supported by a variety of teams.

Step 3: Engaging key external services with the SIT offer and raising aspirations

A key team for supporting the implementation of AAC use across the Trust is Cornwall AAC Team. This team offers the following support:

- Work with the NHS to support AAC referrals
- Long term support after a trial resulting in a powered device
- Training for education settings/families
- Technical support for loaned devices
- Education visits

The AAC team have worked closely with SIT to ensure the upskilling of staff and have found that SIT has been beneficial to them, as an external team, because in each school SIT provides a key contact and knowledgeable staff team that aims to disseminate internally. This in part leads to higher levels of staff retention, reducing repetition of training needs and confident modelling of AAC use to school based staff. This has then increased the ability of the school to gather information for effective referrals and enabled staff to access editing training and ongoing support.

Smartbox has also been instrumental in embedding a universal approach to AAC across the Trust. The schools have benefitted from: in class modelling; troubleshooting devices; modelling play based AAC in Early Years classrooms; enthusing and exciting school staff in AAC's potential and supporting them to see immediate success; ensuring school staff and technical support see the process of using high tech AAC as straightforward and promoting multi-agency working. Ultimately, the support offered by Smartbox has scaffolded staff in confidently using high tech AAC as part of their classroom toolkit.

Step 4: Extending multi-agency working to all appropriate teams

Multi-agency partners are needed to ensure an effective and sustainable model that supports AAC use in schools. Supporting the ongoing journey towards accessing AAC across all specialist settings requires:

- Families and Young people
- School staff including tech support, senior leadership and admin
- Trustees/governors
- AAC Team
- Speech and Language Therapy (SaLT)
- NHS Physio and Occupational therapist (OT)
- Trust funded in house OT (regulation focus)
- Smartbox.

Step 5: 'So whats'… from the SIT pilot

Therapeutic skills are no longer held in our schools; there is a lack of in-house therapy support available **so…**

- School staff need to be upskilled to deliver, effective, research led, interventions.

Limited access to targeted support/training for school staff from the SaLTs **so…**

- Work closely with this team to upskill a small group of staff who can disseminate skills and knowledge.

Staff recruitment/retention are low **so…**

- Create roles that offer career progression for highly skilled staff, improving retention and valuing support staff experience.

A multi-agency approach is needed for the complexity of needs **so…**

- Create a robust referral system with clinical oversight that builds a package of evidence around a pupil, speeding up responsiveness of teams and decreasing refusals.
- Provide a consistent point of contact for all external teams.

Delegation and professional boundaries need to be held **so…**

- SIT staff are supervised monthly by both a clinician and an education practitioner.

Step 6: Celebrate and continue to evolve

The SIT roles are funded by the Trust and supported by Trustees and the Senior Leadership Team. This ensures that therapeutic intervention is valued as part of a specialist education model. Due to the success of the pilot, these roles are now permanent, and the team is expanding to work across settings in Devon and Torbay. The SIT model has also influenced the development of a new specialist outreach team, council funded and SPT led offering specialist support in mainstream schools.

The SIT supports the dissemination of AAC skills across the Trust ensuring this knowledge is not held or stalled at a specialist level. Instead, this knowledge and skill sharing is planned and delivered, under supervision, into targeted provision and disseminated through a modelling approach. Staff working on the ground in the schools benefit from this approach as it influences the wider universal provision, reducing the need for further intervention. Part of this change in universal provision is evident in SPT school settings, leading in ensuring a uniform approach to AAC and aligning with other services such as AAC West.

Multi-agency working has increased and improved across the Trust. External teams value the SIT and its links to the individual settings, as well as the wider Trust. This co-working model led by education is supporting children and young people to access specialist AAC teams in a more streamlined and aspirational manner, resulting in bigger communicative success for young people across Cornwall.

Save the Date!

Communication Matters International AAC Conference
Leeds

Early September 2025

Communication Matters

Communication Matters

Case Study: Empowered by the Ripple Effect

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This case study is about a mother, Becci, and her autistic son, Albert aged 6 years. It explores the transformative journey as they learned to use robust Augmentative and Alternative Communication (AAC) with the support of Communication-Angel and how their experience influenced others in Albert's support network and beyond.

Communication-Angel is dedicated to educate and empower communication partners to build meaningful connections with their AAC users. Services include School AAC Coaching, AAC Club for communication partners, communication assessments, 1:1 consultations and workshops.

Through the support and resources provided by our AAC Club, Becci not only changed her own approach to communication, but she was a catalyst for change in a broader educational community.

Beth Moulam's blog post, "The Ripple Effect" articulated the power of grassroots change. Becci's journey succinctly demonstrates this. Beth explains,

> *"each individual AAC user is creating an individual concentric circular disturbance around themselves, imagine dropping a pebble into water." Moulam (2024)*

The pebble creates ripples. The closer the ripple is to the AAC user the stronger it is.

Before discovering robust AAC, Becci was at breaking point feeling no connection with her son. Albert attended an SEN preschool where they used Makaton and Pecs. These did not work for Albert at the time.

A private speech and language therapist (SLT) introduced her to Intensive Interaction. This had a positive impact. However, Pecs remained a chore and had not created the natural connection Becci sought.

She shared her frustrations with another mum who suggested the communication app Proloquo2go. Proloquo2go is a robust AAC app created by Assistiveware and available to download on Apple iPads.

After self-funding the app, Becci began using it based on the methods she had used with Pecs. This again was fruitless as Becci had no idea of how to implement Proloquo2go or where to go for assistance. This became even more frustrating, creating distress for both herself and Albert. Proloquo2go was shelved.

Two years later, Becci joined Communication-Angel's AAC Club. She discovered that AAC implementation focuses on connection rather than compliance. Meeting a group of fellow parents online every week reduced her feeling of isolation. They shared experiences, and she realised that others face similar challenges to her. As the weeks went on, they celebrated success and her confidence and hope for Albert's future grew.

After 1 week, Becci was enlightened by the speed of progress she saw in Albert. Another week Albert amazed everyone when he hopped on to our AAC Club. I modelled a phrase on Proloquo2go. Suddenly off screen we could hear Albert creating the same phrase

on his iPad. He then repeated the phrase using his own mouth words!

Becci has fully embraced AAC. She now feels that by becoming a skilled communication partner she has supported Albert to communicate beyond making requests. Using AAC in natural contexts has opened up a whole new level of connection between herself and Albert. His younger sibling's use of Proloquo2go has proven to be motivating, creating a positive sibling connection too.

Each week, while taking part in AAC Club, Becci shared what she was doing with Albert's teacher. Albert's teacher, Coral, described Becci's advocacy style as STRONG and NICE (*as a parent that's a difficult balance to get right*). Encouraged by Becci's passion and Albert's new found engagement, Coral became more interested in AAC. She began altering her own AAC implementation strategies for Albert's class. Other parents began to seek AAC solutions for their children too.

Enlightenment
- ✓ Community
- ✓ Support
- ✓ Accountability
- ✓ Progress

Connection

The school had created a rich communication environment through visual supports and having invested heavily in Makaton training for staff and parents. They recognised a gap in skills necessary for implementing robust AAC. Through in-service training for teaching staff attitudes towards AAC were reshaped. It was my privilege to deliver this training and together we committed to focus on these key strategies:

- Value Connection
- Share knowledge
- Model without expectation
- AAA (AAC Always Available)
- Initiate AAC Trials

The school also decided to recruit a second SLT who must possess specific knowledge and expertise in AAC implementation. The hope is that more children throughout the school will benefit from robust AAC systems to support their communication needs.

In her professional role, Becci is a school teacher in a mainstream school. She noticed communication and visual supports were being abandoned by staff. Becci shared the theory she had learned from Communication-Angel to support her own SENCO (Special Educational Needs Coordinator). The SENCO took action to improve and enhance how these supports were utilised in classrooms and around the school. Again, the ripple effect in action.

Conclusion

The ripple effect Beth Moulam described shines through in Becci's story. What began as a personal journey to connect with her son, sparked broader shifts in attitudes and practices within his support network and beyond.

I encourage you to follow Becci's example.

Become a communication champion.

Together, we can create meaningful connections through AAC.

Footnote

Near the end of AAC Club Albert became unwell. During this period, he was dysregulated. Daily routines became challenging. At school the main focus was on helping Albert regulate. For communication Albert depended on Makaton which he often used as one of his main communication modes. Becci and Coral respected this choice. They hope that when this period passes, he will resume his AAC journey with Proloquo2go.

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Conn@ct: Development of an Intervention for Communicative Participation with Peers

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Introduction

Within a partnership of AAC specialists in The Netherlands, concerns about friendships and other social relations of post school young adults with complex communication needs were shared and discussed. Despite their high-tech AAC devices, these young adults often have difficulty with communicative participation with peers. Due to limited communication, they have less opportunities to build and maintain social relationships (Teachman et al., 2020). Intervention Conn@ct has been developed to improve communicative participation. This article provides an overview of the Conn@ct research and intervention.

Background

Communication helps in getting education or to be able to work. It makes it also possible to express for example needs and wants. And of course it helps to connect with family and friends, building new relationships like friendship and maintaining old ones. All have impact on the quality of life for individuals with complex communication needs (García et al., 2020; Light & McNaughton, 2015). For building and maintaining relationships it is important that someone can participate, not only physically, but also through communication. Communicative participation takes part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal means of communication (Eadie et al., 2006). Communicative participation can also take place within remote communication such as email and social media.

The research

The aim of the study was to gain insight into barriers reducing communicative participation and to investigate which improvement could be designed and applied within the partnership of AAC specialists. This group consisted of speech therapists, occupational therapists and disciplines like physiotherapy and psychology.

We used practice-oriented research, which means that we wanted to design a solution to a problem and not to investigate the problem itself. It consisted of literature search, interviews, a group discussion and a questionnaire. Using a research model, we looked for factors which could influence communicative participation, like behavior of the young adult, peers, parents and supporting staff but also environmental factors or broader causal factors (Green & Kreuter, 2005). The interviews were conducted with AAC specialists, persons with complex communication needs and supporting staff working in disability support services. Participants were asked to share their experiences with communicative participation between young adults and peers. The results of the literature search and the interviews were very similar. Subsequently a program was designed, selecting interventions that were most likely to be successful and that were within the capacity of the team of AAC Specialists. Attention was also paid to project planning, business case (analysis of costs and benefits), implementation and evaluation.

Factors of reduced communicative participation with peers

There were a lot of factors that had a negative influence on communicative participation with peers. We incorporated these factors into the story about Frank, a post-school young adult of 21 years old. Frank has cerebral palsy, is in a wheelchair and uses a high-tech AAC device. To explain the specific problems of young adults, we first describe Frank's social network at the time he is still in high school (Blackstone & Hunt Berg, 2012). First you see Frank's network circles during school and then his social network circles since he is visiting a day care centre.
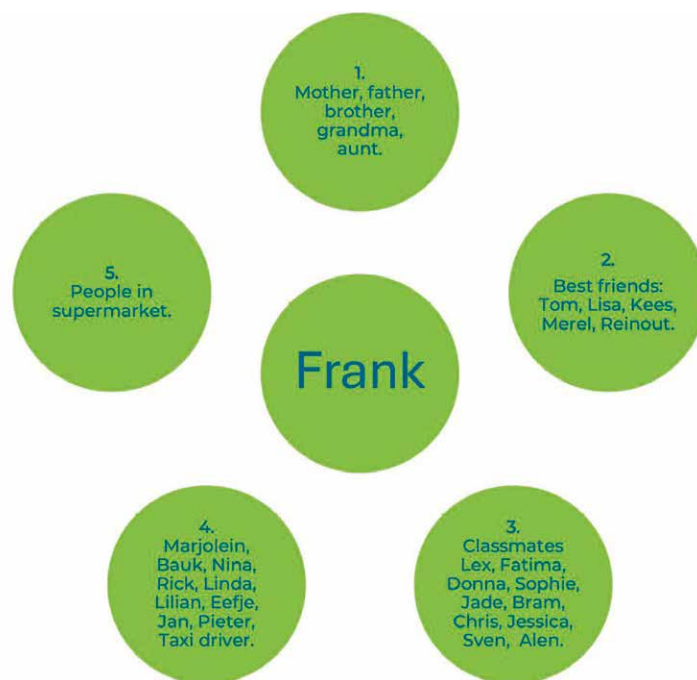
Figure 1 Social network during high school

- Circle 1 shows the family and relatives that Frank often sees.
- In circle 2 are the best friends that Mark has at school.
- Circle 3 shows other children from school. These are acquaintances and not friends.
- Circle 4 shows the professionals, like teachers, therapists and supporting staff at school and the taxi driver. There are often many people in this circle.
- In circle 5 are the partners without a name, people that you can meet in daily life like people in the supermarket.
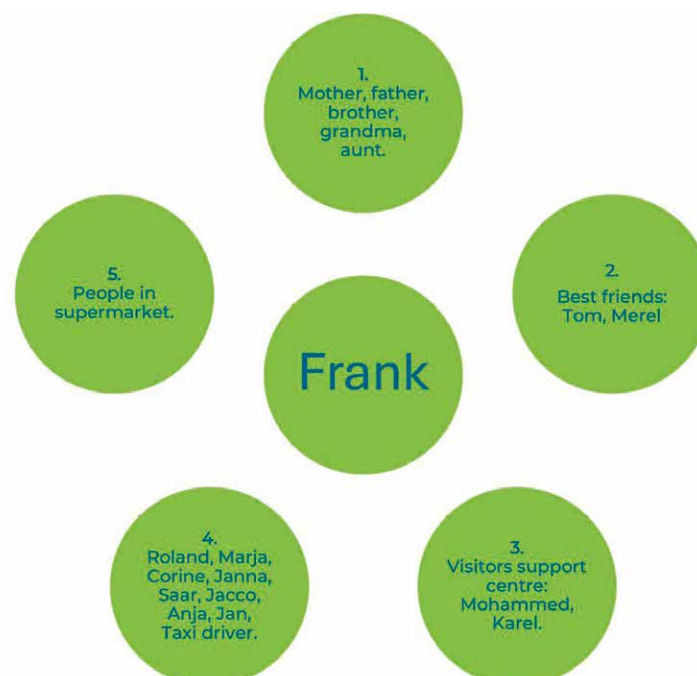
Figure 2 Social network after leaving high school.

Figure 2 shows the social network after leaving high school. Frank now daily goes to a day care centre. His family and relatives have remained the same. Again, there are plenty professionals in circle 4. But there are fewer people in circle 2 and 3.

The group of friends has fallen apart because the connecting factor of school wasn't there anymore. Because of the long distance to schoolfriends, Frank has difficulty maintaining his social relationships. He is dependent on his parents for transportation. The visitors of the support service are much older or have less skills than Frank. It is normal that friendships stop after leaving high school. However, Frank does not actively build a new social network by himself. Overprotection by his parents limits Frank from meeting new people.

Both Frank and his peers avoid each other, often out of discomfort. Frank shows passive behavior. He takes little initiative, is quiet and more of a listener. At the support centre, Frank is the only one who uses a speech device and does not get examples from other users. He prefers not to use his speech device and relies on his body language. We often see this with teenagers and young adults, developing an identity and wanting to belong to a group. Frank focuses on contact with the adult health care providers which consists mainly of requests for help and wishes, less on social functions such as telling a story.

In addition, the young adults experience limitations of the AAC device such as the slowness and unnatural voice. Speaking peers are generally not slow and aren't used to this voice. Frank also has difficulty sending emails and using social media due to his limited motor skills. Furthermore, limitations are often present in both groups. Because of intellectual disabilities miscommunication occurs: Frank does not always communicate in grammatically correct sentences and the participants at the support centre cannot always understand this limited language. They are also less able to empathize with Frank and ask him what he means.

Due to Frank's limited communication skills and passive attitude, his support staff underestimates him. The support staff does not sufficiently stimulate social interaction between him and his peers. They are mainly concerned with providing structure and stimulating independence; there is little focus on social communication. Behind this lack of stimulation, many other factors play a role within the support centre, such as staff problems, limited financial possibilities, limited knowledge and a different vision on communication.

The development of intervention Conn@ct

As you can see many factors play a role in this reduced communicative participation, but most of them are difficult to influence such as intellectual or motor disability, staff leaving and patterns that have existed for a long time such as passive behavior or attitude.

Three factors appeared to be influenceable within the context of the AAC specialists:

- Stimulation of social interaction by supporting staff
- The social network of the young adults
- Limitations of technology, however, the AAC specialists cannot remove all barriers.

The literature study revealed several points of attention that were considered in developing the intervention. Autonomy and self-determination appeared to be important among young adults. The interaction seemed to be facilitated by shared interests and the young adults also wanted to use (less stigmatizing) modern technology in addition to the speech device. We combined interventions that were shown to be effective into a multi component intervention which we called Conn@ct.

The intervention

Conn@ct starts with mapping the social network, methods of expression and skills of the individual, current technology use (Blackstone & Hunt Berg, 2012).

Mapping social network, skills, shares interests, how to support

Choose additional technology (social media, photo, film)

Training support staff, digital portfolio

Expand social network

Figure 3 Intervention Conn@ct

Shared interests can be a reason to do something together or to share stories with each other and they are explored with the Talking Mats method. This is a visual framework to support people to express their feelings and views (Cameron & Murphy, 2002). It consists of a mat and symbols which can be arranged in a visual scale. The picture shows the Frank's Talking Mat with the topic at the bottom 'things I like to do' and pictograms that were placed under a scale: like/not sure/don't like.
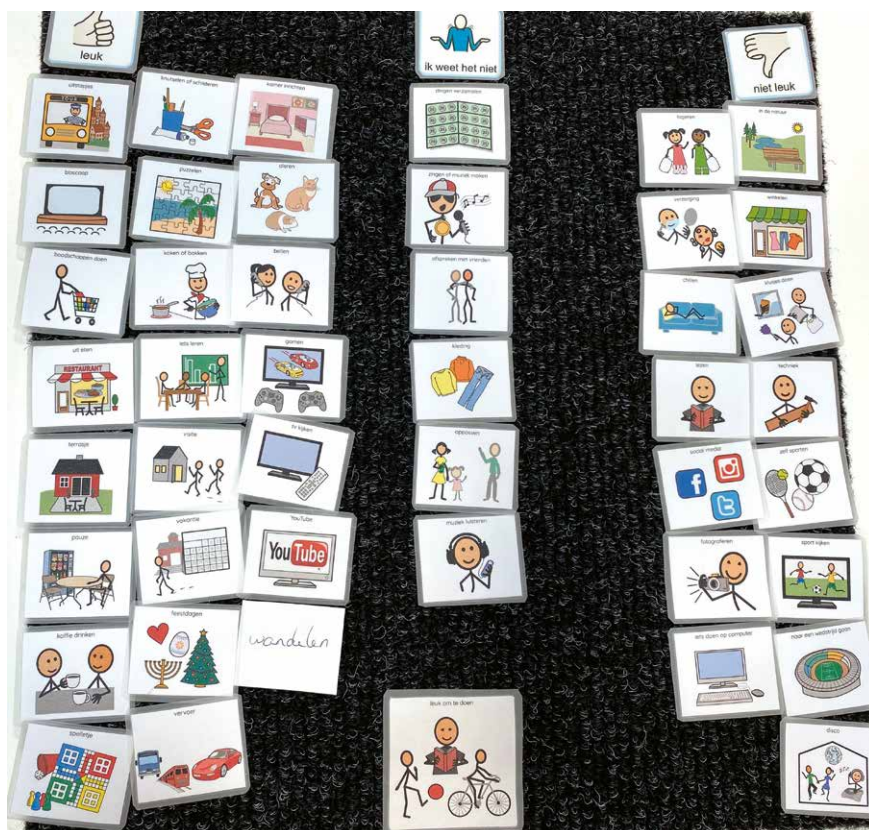
Figure 4 Talking Mats, shared interests

ªCameron & Murphy (2002)

The young adults then choose how they want to use additional technology to make it easier to get in contact. Think of sharing photos and film stories or social media such as email and WhatsApp. Suppose a shared interest is football, then we will for example search for YouTube videos about football, learn to share photos of the local football club or learn to share the football scores and an emoji on WhatsApp. Frank learned to send emails and share photos with his peers. Attention was paid to social communication such as wishing his friend a nice holiday.
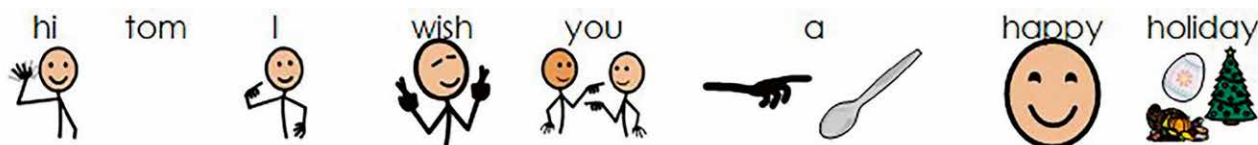
Figure 5 Email with social communication.

Getting in touch more easily can be achieved by applying quick ready-made phrases. Therefore, we programmed sentences for sending mails but also quick phrases for live joint activities. A shared interest with his colleague was making a puzzle. So, we programmed phrases like:

- Which puzzle do you want to make?
- Which puzzle piece are you looking for?
- It's almost done
- Yes! (a funny sound)
- What are you going to do now?

It functioned as a sequence of sentences, like a social script which gave him suggestions to actively participate in communication.

Once the technology works well enough, the supporting staff and parents receive training on how to stimulate social interaction. All advice is summarized in an app with a digital portfolio. In Frank's case, we made categories to structure the information like: how I communicate, my social network, what I like to chat about, the places I often go and how supporting staff can help connecting with peers. In this category, we also use films for example how Frank sends emails.
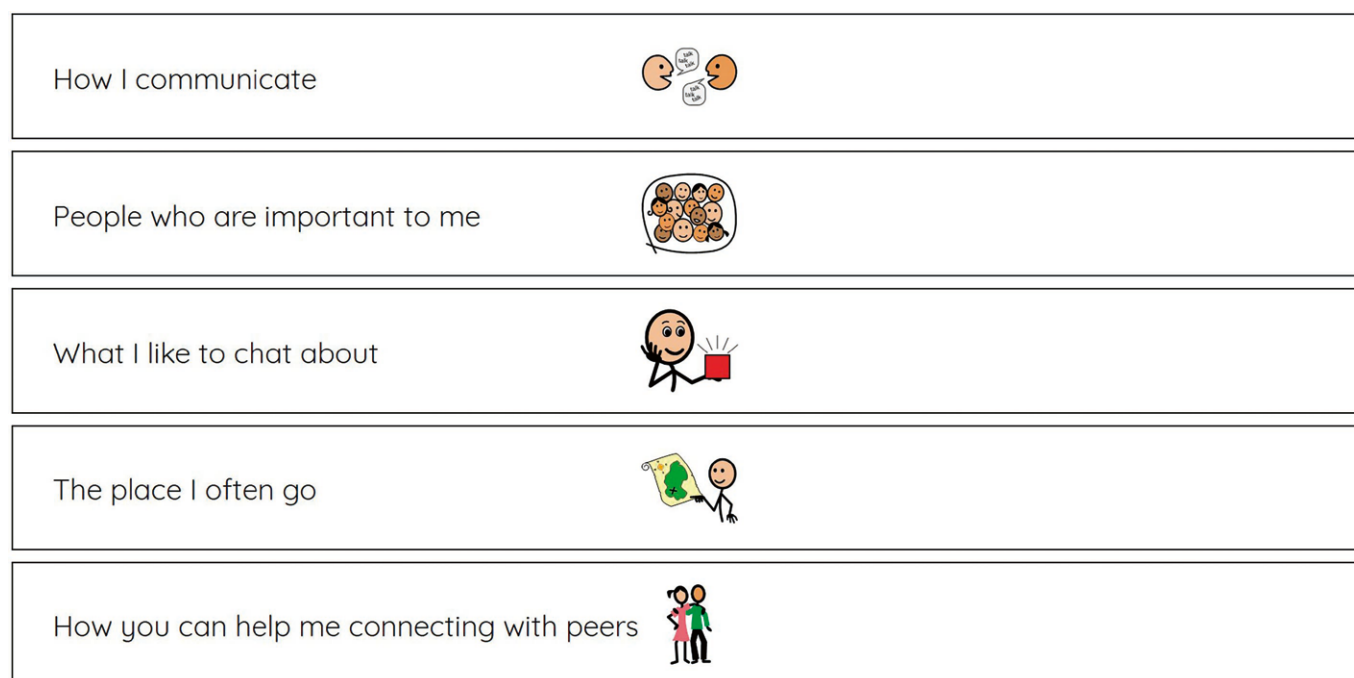

Figure 6 Digital portfolio

Finally, parents, support staff and the young adult are stimulated to explore how to expand the social network, how to start new activities or how to develop social roles. For Frank, a social role was to deliver the coffee during breaks. Frank handed out the coffee but did not much communicate during the activity. Together we brainstormed about the coffee break and came up with suitable ready-made phrases in his AAC device such as 'good morning, can you put the coffee pots on my wheelchair tray, thank you'. Again, like a social script.

Our first experiences with Conn@ct

In the pilot phase that is currently running it has already been experienced that Conn@ct increases communicative participation. The young adults are getting more in touch with peers in circle 2 and 3. For example, Frank was now able to get in touch again with classmates he did not see in real life anymore. It turned out to be important to constantly keep looking at what the young adults want, for example how to share photo or film. Using social media often turned out to be a big concern as well for parents as supporting staff. Questions arose about privacy and knowing how safely use social media. Sufficient attention for digital safety is needed. From an economic perspective there was a risk that the target group was small and so Conn@ct has already been assessed with teenagers. The outcomes within this group are also positive. Instead of offering the Conn@ct intervention from our own therapy practices, we would like to share our knowledge about communicative participation with others so that more people can apply the insights.

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Cornwall Local AAC Service - Paediatrics

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Background

Cornwall AAC Assessment Team (CAACAT) is a multi-agency team established in 2009. We support AAC assessment for voice output only, for young people aged 0-18 in an education setting.

CAACAT is jointly commissioned by Cornwall Partnership Foundation Trust NHS and the SEND Support Service at Cornwall Council.

Jointly Commissioned in 2009

Cornwall Partnership Foundation Trust NHS

SEND Support Service Cornwall Council

- 2 days a week AAC Specialist SALT
- 1 day a month developing specialist SALT

- Full time AAC Advisor
- Full time Technical Officer
- Device provision, management and replacement

Trial Process

Our pathway begins with supervision, where a potential referral is discussed between the Community Speech and Language Therapist (SALT) making the referral and the AAC Highly Specialist SALT. This may include advice on low-tech AAC and battery-operated devices available in the community bank.

If a referral is appropriate, once all paperwork and consent has been received, the referral is triaged in our monthly MDT meeting. We have currently capped triage to 3 cases at a time to ensure we have the capacity for the follow-on work to be completed.

At triage we determine whether CAACAT support at a local level, through skill building with a trial device, or if we refer straight to our local specialist hub, AAC West.

The pathway continues at a local level with an AAC technical officer visit in school to complete the AAC Genie screening assessment and explore different software options with the young person, gathering their voice to inform the assessment. At this stage, we

request personalised vocabulary ideas from key people around the young person and ask them to sign a user agreement and risk assessment as well as set up Dropbox to allow for remote editing and future backups.

Following this, we hold an initial casework meeting with the young person (if appropriate), parent/carers, and the education setting where expectations are shared, the young person's communication is discussed, trial device and software agreed with targets set for the start of the trial.

The loan of the trial device begins shortly after this meeting, dropped off at school and shown to parent/carers, teaching staff and the young person with a small amount of training given. The device will have personalised vocabulary.

A block of SALT intervention by a SALT or SALT assistant, is carried out alongside the assessment trial to support implementation strategies and working towards targets.

Trial meetings with key people are held every 2 months to review progress and update targets. Trials typically last 6 months.

Technical

The devices we loan are iPads or iPad Minis plus there are some iPods still in circulation. We use older devices in our training, and we are able to loan these to settings on a short-term basis to support adults to model alongside the young person. In 2022, a Mobile Device Management (MDM) system was introduced. This allows devices to be accessed remotely by the council IT team and locks down the software available. We only install the communication app; there is no access to the camera or the internet including education apps. This was put in place as a safeguarding measure but also prevents settings using the device as an education tool rather than the young person's voice. Since installing the MDM, we have had feedback about young people increasing their use of the communication app, rather than other features of the device.

Impact

In August 2024 there were 77 young people on our caseload:

Trials ▪ **Long Term Loan** ▪ **Specialist**
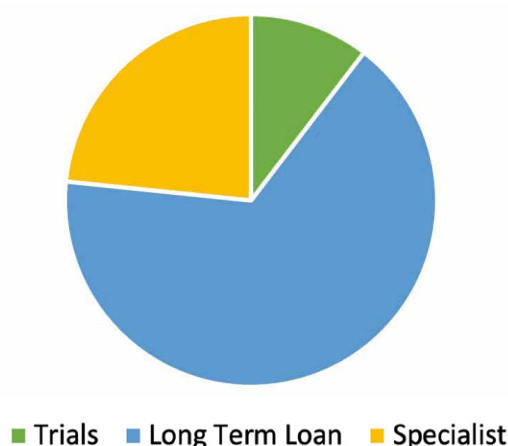
- Trials – 8 young people on AAC trials with CAACAT
- Long term loan - 51 young people with long-term loans from CAACAT
- Specialist – 18 young people with an AAC loan or trial from the Specialist Service

During the academic year 2023-24 we delivered:

- Inset training for 7 schools to support transition or new staff in special schools.
- AAC Assessment for 13 young people using DAGG-3.
- Training (full day) for 35 people supporting a young person with a trial or loan device including family members, setting staff, SALTS and assistants.
- 63 editing training sessions, face to face editing training for key communication partners in small groups (max 3) delivered over 2 or 3 sessions. This was largely made up of teaching staff due to staff changes since the original trial.
- Termly AAC TA Network meeting offering peer discussion and a CPD focus.
- Termly AAC Newsletter received by parents, carers and professionals.
- AAC Family Coffee Morning during the Easter holidays.

Future Projects

We are also introducing an 'AAC online Student event', supporting young people to meet other AAC users. This event will take place in October to coincide with AAC Awareness month and we are really pleased with the positive response we've had.

In response to the increase in requests for supporting young people who have privately funded devices who are not on our caseload, we have extended our training offer. For the academic year 24-25 we will be introducing 'Communicating with Symbols', a full days training on best practice for any form of symbol communication.

Authentic AAC: Embracing Diversity in Communication

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The Oxford English Dictionary defines authentic as 'genuine, not feigned or false.' It is a word which has been used a lot in recent years, particularly within the speech and language therapy profession and within our National Health Service. We have seen Equality, Diversity and Inclusion (EDI) high on the agenda for many companies and services. The workplace, and society more broadly, is less likely to bat an eyelid at rainbow coloured hair or heavily tattooed bodies compared to the previous decade. These things are gradually becoming 'normal.'

What exactly is *normal* though? And why does normal equate with acceptable? In their book, Empire of Normality (2024), Robert Chapman explains that for centuries, there was no concept of 'normal', until the age of enlightenment gave rise to capitalism and the need to not only be as good as each other, but better than. Any variation from the norm was seen as divergent. Physical and mental difference quickly came to be viewed through a pathologising lens, where individuals were seen as broken and needing to be fixed. People were ranked, rated, compared and then labelled. This medical model gave rise to a whole range of treatments and therapies with the goal of fixing what was deemed to be broken.

The medical modal has influenced Augmentative and Alternative Communication (AAC) practice in many ways:

The design of graphic symbol vocabularies

AAC users who use graphic symbols to communicate are dependent on AAC product developers to choose the concepts (words) that are included in graphic symbol vocabularies. These choices are influenced by research which is primarily based on the language samples of children and adults without communication differences (Laubscher and Light, 2020). The AAC product developers also choose how to represent and organise these words. Again, these decisions are based on the language development of children who do not have communication differences.

The criteria for AAC assessment and support services

A further impact of the medical model is seen in the pathways and acceptance criteria for AAC assessment services. If a person is communicating in a way that is judged to be not good enough, or not matching neurotypical communication styles, they may not be eligible for assessment and be denied the opportunity to use AAC.

Therapy goals and outcome measures

Therapy interventions are guided by 'developmental norms' of speaking children. Goals are set and progress is measured against checklists developed using speech samples of white, middle class children without communication difficulties or differences (Brea-Spahn and Bauler, 2023). Furthermore, goals are often set and progress is measured by so-called 'experts,' without consulting the AAC user and/or their families (Broomfield *et al.*, 2019, 2022).

Climbing the AAC staircase

The belief that a person must climb what could be called 'the AAC staircase' (see figure 1), is ingrained within AAC culture. We see an expectation that someone will start their AAC journey without technology and have to prove their worth through paper and battery powered devices before being rewarded with the prize of a high-tech communication aid. This idea reinforces the idea that AAC strategies do not hold equal value, and there is a 'right way' to use AAC, and a path to follow. For some people, they may never reach the top of the stairs, which can leave them and their loved ones feeling a sense of failure (Robinson, 2018).
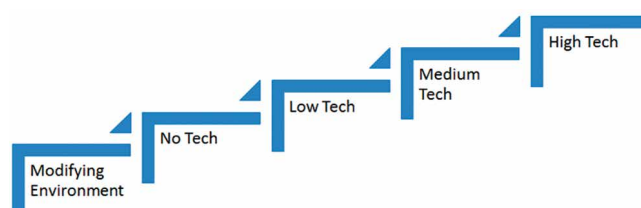

Figure 1 The AAC Staircase

Perhaps instead of the AAC staircase, we might listen to the preferences of AAC users and select a range of AAC tools accordingly. These tools might be used some or most of the time, in one context and not others, as shown in figure 2. The individual's AAC tool kit will be unique to them and reflect their preferred way of communicating.

Viewing AAC through a neurodiversity lens

The Bridges Learning system is web-based organisation that produces resources to empower the autism community. Their handout 'Reframing Autism Using the Neurodiversity Paradigm' shows how we might view the medical model's representation of autism as something requiring fixing through a neurodiversity lens. In doing so, we see autistic traits as part of human diversity, and perhaps can begin to consider accepting and embracing different ways of communicating (figure 3).

Autistic communication differences

Prizant (1982) and Blanc (2012) have proposed an alternative route for learning language, which some autistic individuals might use, termed 'Gestalt Language Processing.' This theory proposes that some children acquire language in 'chunks' known as Gestalts, as opposed to building up single words (referred to as 'analytical language processing)'. There have been recent calls for further research to be done looking at this theory (Hutchins, Knox and Fletcher, 2024).

Figure 2 The Preferences strand of The Positive AAC Framework (Helen Robinson, 2023)

Speech and language therapy roots itself in the sender receiver model, where one person communicates a message to another. However, people such as Lily Konyn (2023) have encouraged us to consider a wider range of communication functions. As well as using communication to greet each other, comment, ask questions and make jokes, we might use communication to connect socially with others, for example, through photos, links to funny videos and memes.

For autistic people, self-focused communication can be important. An individual might use communication to self-regulate, by saying a word or phrase over and over again because they find the sound, intonation or rhythm soothing. They might list words relating to their interests, again, for the purpose of self-regulation. Another function might be that of the inner dialogue, where non-autistic people might rehearse conversations in their head, or silently repeat a shopping list or phone number, autistic people might do this outwardly through speech or AAC.

AAC use, some of the time but not all of the time.

Autistic people may be able to use speech sometimes, but not always; often referred to as 'semi speaking.' The amount of energy used up by completing daily activities could mean that the individual loses the ability to use speech. The additional stressors placed on the person, such as flickering lights, loud noises or routines being disrupted can also impact their communication skills. We need to support those individuals who might be semi-speaking and need AAC some of the time. Another consideration is how the type of AAC someone uses might need to adapt depending on the context. It's possible they could use a keyboard to type sentences in one moment, and require graphic symbols in another.

How might AAC use differ for autistic people

- Autistic AAC users may need:
- lots of vocabulary about a small range of topics;
- access to phrases which are highly personal to them;
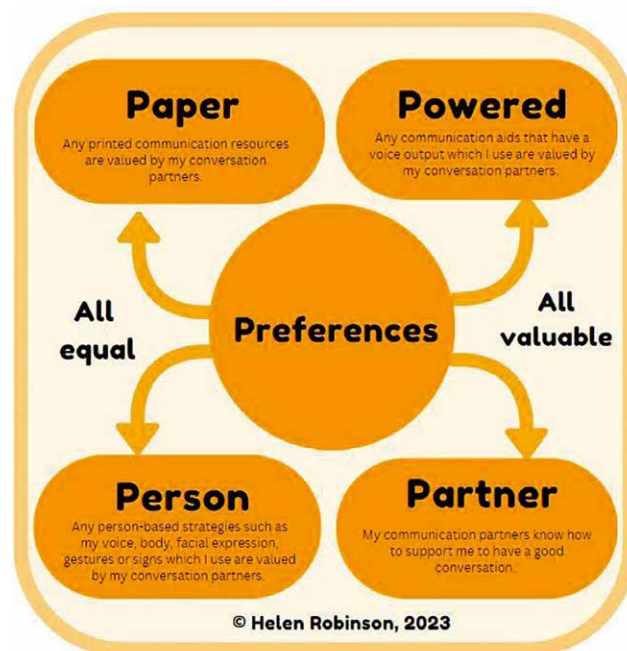- to hear a recorded voice rather than a synthesised one;
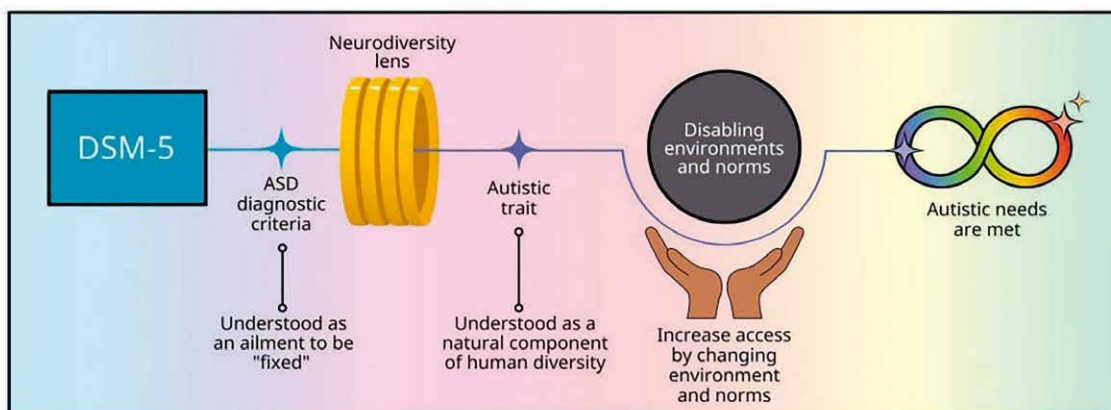

Figure 3 Reframing Autism Using the Neurodiversity Paradigm (2021)

- to use AAC 'part-time';
- AAC systems that also support regulation alongside communication;
- access to the alphabet, written phrases, graphic symbols, visual scenes or video;
- access to other apps to support with regulation and/or communication (e.g. music, YouTube, maps, photos).

It is important that we provide people with access to all of these things and consider that these features might also be helpful for non-autistic AAC users. Importantly, rather than choosing the type of AAC based on a label or diagnosis, we should be assessing the individual's strengths and needs and using these to select the features required from AAC.

Ideological rocks

Despite knowing that autistic AAC users might need certain features in their AAC and might use AAC is a way that is different to non-autistic AAC users, as practitioners we can find it challenge to actually influence change. Brea-Spahn and Bauler (2023) encourage us to explore the 'ideological rocks' which anchor our beliefs about communication.

> "Assumptions about idealized or "normative" ways of knowing and learning, ways of communicating, and ways of existing and behaving act as the sediments that form most ideological rocks. These unquestioned assumptions define who owns privilege and power, that is, who has access to rights such as due process under the law, which types of people belong in linguistically sustaining learning spaces, and which category of individuals sharing a geography gets to participate actively in cultural democracy (Darder, 2016)" (Brea-Spahn and Bauler, 2023, p. 2).

Brea-Spahn and Bauler (2023) urge us to take a critical inquiry stance, through which we first name the problematic dominant perspectives and question where they come from. Next, we must attempt to disrupt these by reflecting on the evidence we have in support or opposition to these beliefs. Then, we might reflect on alternative viewpoints and actions. Finally, we can reframe these problematic ideologies so that they represent marginalised communities.

So, to take a critical inquiry stance with AAC might involve asking ourselves the following questions:

- Are we providing AAC tools that support different ways of communicating?
- How could those who design and sell AAC products improve their offer to reflect a wider range of communication styles?
- How could we better support AAC users to set communication goals which are meaningful to them?
- Are we asking the views of AAC users when designing and choosing AAC tools?

Moving forward

As we reflect on the dominant beliefs that influence how we design AAC tools, who we deem suitable to use them, and how we measure their success in using them, some of us can feel lost and unsure of how best to support, or even perhaps what our role is at all. Sharon Carpenter, Speech and Language Therapy Assistant, offers this suggestion:

> "My role is to find the interest, find the fun. Break all the rules, be there with the child, in the moment, see what happens." (Comment taken from an in-person training session).

Another quote we might turn when considering communication and what is 'typical' and 'non-typical' comes from the television programme The Addams Family, spoken by the character Morticia Addams: "Normal is an illusion. What is normal for the spider, is chaos for the fly" (Charles Addams, cartoonist).

So, let's be brave and challenge the beliefs about 'normal' communication and allow AAC users to use it on their terms, in their way, and aim to look through the neurodiversity lens when we support them to set goals and celebrate their achievements.

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Communication Matters – Communication Clubs

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The CM Communication Clubs are an exciting new development of the Peer Support & Mentoring Project (England) funded by the National Lottery for the next five years (2024-2029).

Whilst the Communication Clubs aspect of the project is in the early stages of development, we have had a lot of interest from schools, colleges, a range of speech and language services and individuals, and we have created lots of useful resources as well ongoing support and guidance.

Having had considerable experience over recent years with delivering the first part of this project, we have a host of units and qualifications at Entry Level 2, Entry Level 3, Level 1 and Level 2, that can be accredited (awarded by NCFE) or non-accredited. These include topics relating to personal and social development, mentoring and employability skills and qualities. We are in the process of creating new resources that complement the DfE Essential Foundation Digital Skills. We are also developing AAC Communication resources: a set of PowerPoint slides with discussion points and related activities for use by individuals as well as in the Communication Clubs. We are also able to design and facilitate other topics and workshops, for example, Introduction to Safeguarding, Mental Health Awareness, Coaching, Being Assertive and others. The National Lottery funding includes the cost of resources, support and accreditation.

As part of the CM Conference 2024 in Leeds, I facilitated a workshop to present more information and more importantly, the opportunity to have a conversation with AAC users about their views and aspirations. It was so useful and thank you to everyone who contributed to the discussions.

The conversation consisted of an activity with three key questions. Participants were divided into three groups with everyone having time to consider each question and then share their top priorities. The three questions were:

1   What is the key purpose of a communication club?
2   What would you like to do in a club/group and why?
3   What support would you need?

The information below includes the statements made by the participants along with a summary and context.

Question 1: What is the key purpose of a communication club?

>*'Bring AAC users together – community and sense of belonging'*

>*'Inspire the next generation – role models, offer support'*

>*'Share knowledge and experiences – peer to peer learning, educational trips, invite guest speakers'*

>*'Feel valued – build confidence, reduce isolation, support mental health'*

This is an important consideration when thinking about communication clubs/groups. It has been evident for some time that people who use AAC value the opportunities to get together, to socialise and to be able to provide and receive valuable peer support. Whether the club is new or there is already an existing group, we can provide a range of useful resources along with guidance for AAC users who wish to co-facilitate and be actively involved in leading the session. We have created some resources for communication clubs/groups that include 'Top Tips', 'Risk Assessment' and 'Planning and Review', as well as activity sheets and

discussion points relating to different aspects of communication. The aim of the project is to encourage group interactions, whether in person or remotely or a combination of both, and we want to create a 'community of communication clubs' to share ideas and make connections.

Question 2: What would you like to do in a club/group and why?

It was evident that the social aspect and connecting with others was high on the agenda:

'Socialising and making friends, build a community – help improve confidence, mental health and emotional support, reduce social isolation'

'Sharing experiences and stories, sharing the positive and negatives'

'Doing interesting activities, trips out together'

Opportunities to engage with others also provided additional benefits:

'Troubleshoot technology, problem solving from an AAC user perspective'

'Navigating ways to make sure that policies are fit for purpose for the individual'

'Developing social communication skills'

This discussion highlighted the key benefits and opportunities that a communication club/group can provide: having time to share challenges and problem-solve, identify the particular needs of individuals as well as the overall needs and interests of the group, as a vehicle to address some aspects of mental health and emotional wellbeing, to help tackle everyday problems and challenges or signpost to sources of help.

Question 3: What support would you need?

This activity highlighted some of the practical aspects:

'Accessible venue – enough space of a group of wheelchair users with toilets'

'Volunteers and PA support – some training and perhaps a facilitator/group leader'

'Social contract/group agreement'

'Enough time, energy and momentum'

'Use social media to advertise'

'Some money, funding'

All three questions link together and overlap. The evidence is clear: AAC users really value having time to connect with others, to share experiences, and to share learning, alongside opportunities for self-development. This activity only took 30 minutes and was so useful, perhaps this is something you could do if you are thinking about setting up a communication club or group and together, prioritise the purpose, the activities and who to involve. It is also a useful exercise to do in an established group to review and refresh. There is a lot of scope to be creative and make your communication club fit the needs and interests of AAC users. In addition, keep a look out for the first 'sharing best practice' days which we are in the process of planning for early Spring 2025. The aim is to share what works, to help address some of the challenges, create new ideas and meet with others including AAC users, practitioners, parents/carers and PAs.

With regard to funding, we do have a small grant of up to £600 for clubs to apply for to help cover the cost of travel, venue and some resources. Applications are considered on an individual basis and are subject to available funds.

We have a wonderful opportunity to continue and develop this project with thanks to the National Lottery.

For more information, visit:

https://www.communicationmatters.org.uk/what-we-do/projects/mentoring-projects-2024/

Whilst this funding is for England only, we are working hard to secure funding to work in Northern Ireland, Scotland and Wales so that this project can be delivered across the UK.
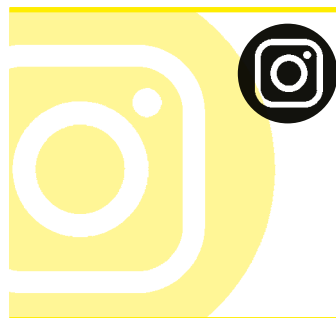
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https://www.youtube.com/channel/UC2UGRtfTqsHgoMT49DckdiA

Opportunity Barriers and Challenges for Older Adults with Cerebral Palsy Using AAC With Eye-gaze Access: Themes from a Case Report and Literature Review

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Introduction

Community-dwelling adults with multiple disabilities including complex communication challenges may rely on multi-purpose augmentative and alternative communication (AAC) for all activities of daily living. For individuals with paralysis, speech-generating devices activated by eye gaze can be essential. However, there are opportunity and participation barriers in many settings that make communication with high-tech SGD systems even more challenging for individuals with mobility and device access needs. We present a literature review and case report of an older adult navigating a broad sphere of participation utilizing an eye-tracking SGD for communication and activities of daily living. We aim to highlight barriers and facilitators for developing and meeting participation goals for older individuals with similar profiles and complex communication needs.

At age 60, JJ, an individual diagnosed with quadriplegic cerebral palsy who has never communicated with oral speech, sought speech-language pathology services in Texas, United States, to support his professional and academic goals with training and programming of his eye gaze accessed speech generating communication device. His previous primary communication mode was partner-assisted verbal alphabet scanning with eye blinks to select letters and spell words. JJ provided clinicians with goals for therapy along with input from his family and aide. His goals focused on functional use of the device for increased access to conversation, to send electronic communication, and to draft professional documents.

Literature review on AAC with eye gaze access

A literature search was conducted by clinicians to assess current research activity on effective implementation of AAC with eye gaze access. Search terms pertained to assessment, intervention, maintenance, progress monitoring, clinical training, challenges, and recommendations for eye gaze AAC irrespective of population of users. The search was conducted using databases Web of Science, Academic Search Complete, ASHA Wire, and CINAHL Plus. Additional forward citation searches were conducted using Google Scholar.

Themes from the review indicated that clinician knowledge and skills are critical to achieving person-centered goals of effective communication with eye gaze AAC. While any AAC assessment must evaluate individuals' cognitive, sensory-perceptual, physical, language, and motor domains, critical factors in feature-matching particular eye gaze AAC systems to appropriate users include precise assessment of vision and physical status including subtle eye movement differences and anomalies such as atypically dilated pupils or mild hypotonia (Chen & Oleary, 2018). Progress monitoring with language sampling (Van Tatenhove, 2014) and evaluating skill development according to four domains of AAC competence (i.e., linguistic, operational, social, and strategic; Light, 1989; Light & McNaughton, 2014) are frameworks to measure success. Family and community involvement (Kovach, Moore, & Frisbie, 2015; Thistle & Fosco, 2013) are key contributors to positive outcomes, and more recently, working closely with device and software manufacturers to improve user experiences is increasingly recommended (Townend, 2016).

Although there are mixed views on intervention focused on increasing rate of speech for eye gaze AAC users, person-centered care standards and use of a biopsychosocial model in speech-language pathology mandate clinicians to consider client priorities in determining therapy goals. JJ aspired to a faster rate of speech to chat with new conversation partners in casual settings, such as his neighbors using public transportation.

Challenges to supporting this form of high-tech AAC were noted to be communication breakdowns related to the pace of conversation, disruptions to intersubjectivity or shared understanding related to temporal expectations, environmental factors

including ambient light conditions affecting infrared eye tracking capability, personal and positioning considerations such as the use of glasses, monitor mounts at sub-optimal distances, and barriers to family involvement and training (Chen & O'Leary, 2018; Engelkea & Higginbothamb, 2013; Fiannaca et al., 2017).

JJ's experience

A case report of JJ's experience in twice-weekly therapy was synthesized according to the CARE case report guidelines (Rison et al., 2013). The CARE guidelines are a recommended framework for clinicians to report to peers at professional gatherings and for researchers to develop clinical guidance from individual experiences. Data was collected from outpatient speech and language therapy sessions and review of video recordings by a licensed speech-language pathologist AAC specialist and three Speech, Language, and Hearing Sciences undergraduate students. JJ provided consent to share information about his experiences.

In 32 weeks, JJ met four of six communication goals with skill gains and made significant progress on the remaining two goals to expand his sphere of participation. While his utterance time fluctuated considerably from week to week, his perceived ease of communication improved considerably with use of predictive text and structured practice. Clinicians provided semi-structured conversation with least-to-most prompting and use of yes/no clarifying questions for navigation and typing practice.

Barriers to participation for JJ were consistent with the literature. Eyeglasses and positioning challenges consistently interfered with eye tracking and required frequent recalibrations of eye gaze settings. Needed software updates and glitches required technical troubleshooting an average of once per two weeks. Despite improvement in all domains of competence, JJ attended at least ten medical appointments outside of speech therapy during the 32-week period where providers' time constraints restricted JJ's use of his device to fully communicate with the health care team. Unexpected health care visits resulted in missed sessions at the speech clinic and loss of skill gains at times.

Facilitators of success included clinic use of family-centered standards, interprofessional collaboration with the device manufacturer, and self-report of growth in competence as an essential factor in progress monitoring. The latter is a key takeaway from the literature and JJ's experience—perception and confidence matter and must be used to guide this type of AAC practice (Kovach et al., 2016). JJ reported his perceived self-efficacy with keyboard typing using a 1-10 scale each week. Although his rate of speech did not continuously trend towards a faster pace of utterances as JJ hoped, he reported self-efficacy increases from a rating of one in his first week to a rating of nine in week 32. JJ's comfort with producing utterances at a rate that is typical for typing with eye gaze increased considerably with support and active listening.

Conclusion

Gaps in the literature and clinical guidance for supporting efficacy with eye gaze AAC can be addressed with input from individuals using this mode of communication. JJ shared with clinicians his frustration with the limitations of the technology he uses to communicate (e.g., software issues, infrared eye-tracking glitches, practice disrupted by the need for medical care, time demands of typing with eye gaze) and asked about opportunities to share them with others in the field.

This brief case report attempts to convey some of his story of focus and persistence to make communication gains with a challenging AAC tool. JJ will return to twice-weekly therapy sessions for another semester, this time focused primarily on skills to send emails and draft documents such as essays and blog posts. He will continue to self-assess his efficacy with rating scales and conversations about strategic practice. He plans to enroll in a class at the University when he has met his two remaining goals. He hopes this will give him the preparation and confidence he needs to pursue the higher education opportunities he has dreamed of for a very long time.

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Suffolk Communication Aids Resource Centre (SCARC)
The Importance of a Local Augmentative and Alternative Communication (AAC) Service

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Introduction

Suffolk Communication Aids Resource Centre (SCARC) is a local Augmentative and Alternative Communication (AAC) service providing Voice Output Communication Aids (VOCA) for young people aged 0-25. SCARC provides:

- Assessment, identification, funding, monitoring, maintenance, and repair of VOCA.
- AAC Continuing Professional Development (CPD) for a range of Multidisciplinary (MD) professionals who support those young people using AAC.

SCARC is made up a of clinical team (including Speech and Language Therapists – SLT and an Occupational Therapist – OT) who clinically assess and identify VOCA. SCARC has an equipment and training team (Communication Aids Practitioner – CAP and Communication Aids Assistant – CAA) who set up VOCAs and train those supporting young people with AAC in how to programme and support VOCA in the young people's environments. SCARC additionally has an administrator with oversight for Administration and day to day running of the service, alongside SCARC's service lead.

Why do you need a local AAC service?

In 2006, NHS England provided guidance for commissioning AAC services and equipment which led to the set up of regional AAC hubs (referred to as specialised AAC services). These provide the funding, assessment, and provision of AAC equipment but only for 10% of AAC users. In experience, this effectively removes access for young people with Learning Disabilities (LD) meaning their access to potential VOCA is limited. SCARC serves to support the 90% gap and 90% of its service users have a diagnosed LD. The

90% of AAC users who local AAC services aim to support are under-represented in relation to AAC, and opportunities for access to VOCA are both variable and inequitable. This is often because they do not fit a typical assessment framework and require significant adaptations to ensure that they can shine and demonstrate their communication skills.

What are the issues with local AAC services?

Whilst regionally AAC services have been centrally commissioned and set-up via NHS England, this is not true of local AAC services. Recommendations were made both by NHS England and Communication Matters for a hub and spoke model, but these have not been universally applied. Funding streams are often varied (SCARC is both funded via Suffolk County Council – SCC and local Integrated Care Boards – ICB). Some are just school based, meaning that AAC

equipment is not available across all environments and some only cover paediatrics, meaning that adult services are often unable to access effective AAC equipment and advice to support their service users.

What do we need?

SCARC is keen to share its experience of managing and supporting a local AAC service and is keen to work with other local Speech and Language Therapy (SALT) service to look at local AAC service commissioning. This is with a view to develop a local AAC service in each area in the UK, providing unified access to AAC equipment and support for anyone who requires it.

Next steps

- SCARC is exploring a business case to explore removing age restriction to make the service accessible to all (regardless of age).
- SCARC is keen to work with and support anyone exploring a local AAC service in their area.
- SCARC are keen to work with lobbying services and national commissioning services to promote the need of unified local AAC services across the United Kingdom (UK).

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