Communication Matters

AUGUST 2023 VOLUME 37 NUMBER 2

THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

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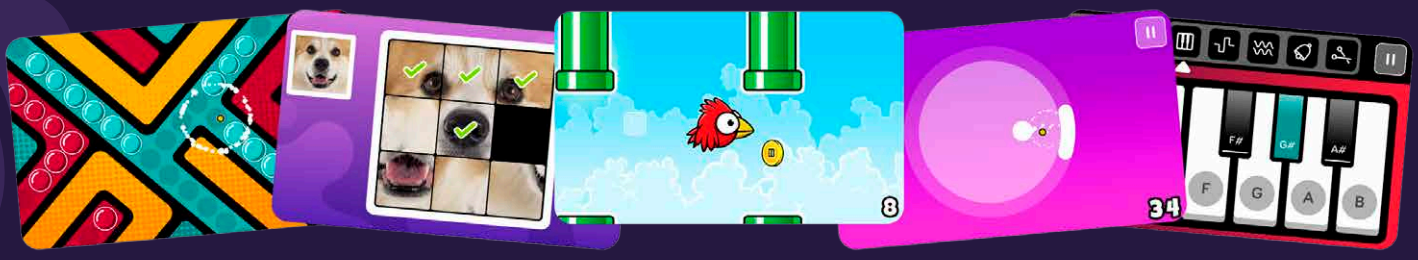

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COMMUNICATION MATTERS JOURNAL
VOLUME 37 NUMBER 2
August 2023

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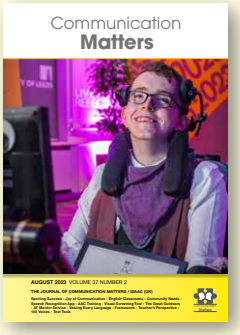

Congratulations to Oli Cunningham, who won the Alan Martin Award at the AAC Awards this March. We look forward to having Oli DJ at the CM Conference in September!

COMMUNICATION MATTERS JOURNAL
ISSN 2756-1011

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Email: admin@communicationmatters.org.uk
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Registered Charity No. 327500
Company Registered in England & Wales No. 01965474

Editor
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Kaarin Wall & Emily Campbell

Advertising and Overseas Subscriptions
Tel: 0113 343 1533
Email: admin@communicationmatters.org.uk

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

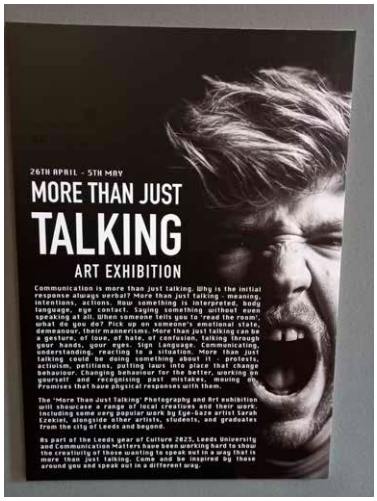
Chair's Report

HELEN WHITTLE

March 24th saw a supplier member Exhibition Day in the Parkinson Building at the University of Leeds. 8 suppliers exhibited, and 125 people signed up to attend. Feedback from the suppliers was great - they were busy and the people who attended were really interested and able to have longer discussions than when attending other exhibitions. During the day, we also held a Mentoring Project Drop-in Session to allow anyone to find out more about the project and how to get involved.

In the evening, the second in-person AAC Awards ceremony took place. 159 people attended, and 10 awards were given out. Subsidised places for the evening and hotel accommodation were available for AAC users and their PAs. These places were made possible by our supplier members paying to attend the Exhibition earlier in the day. A great night to celebrate those in the AAC field.

A "More Than Just Talking" Art Exhibition took place in the University of Leeds from 26th April-5th May. Artists linked with CM and others from across the university took part, including Sarah Ezekiel (eye gaze artist), who has been a keynote speaker at the CM Conference previously. Please see this video link if you missed this inspiring Exhibition.



The last day of the Art Exhibition coincided with Anthony Lowe's last day as Conference and Events Manager at the University of Leeds before his retirement. We were sad to see him go but he said he would still be keeping a lookout for news of Communication Matters.

Communication Access UK is being spoken about and taken up more widely. Communication Matters are involved with this as members of the steering committee. I recently presented at a corporate events conference in Glasgow about making conferences communication accessible and had a stand at a corporate events industry exhibition. It was great to see the interest that the events industry has in making more events and venues become communication accessible.

The National Lottery funded Mentoring Project in England is in its fifth year. We have also successfully run a pilot project in Northern Ireland and have just put in an application for a 5-year project there. We are running a pilot project in Scotland too with a view to putting an application in for another 5-year project north of the border.

On the 8th of June, we held an AAC Information Day in Belfast with 85 delegates and 8 suppliers booked. This was well attended, and again the feedback from the exhibitors was very positive.

Planning for the next CM Conference, 10-12th September 2023, is well underway. The Abstracts Committee have met, and the conference programme is nearly finalised. The conference theme is "More Than Just Talking" with a fancy dress theme of "Back to the Future". We are hoping to have a gaming zone on the Sunday afternoon for AAC users to try out gaming at the same time as registering for the conference. Please register now if you haven't done so already.

I am involved in the Royal College of Speech and Language Therapists (RCSLTs) re-write of the AAC guidance for Speech and Language Therapists. This important work is to produce guidelines to support Speech and Language Therapists when they are working with someone who is/or who has the potential to use AAC.

I would like to finish by saying a HUGE thank you to Professor Annalu Waller from the University of Dundee who is having a "Summer of Madness" to help celebrate her 60th Birthday. She is raising money for 3 charities including Communication Matters. She has already successfully completed a skydive and will have taken part in a Tall Ships voyage as part of the crew by the time this edition of the journal is available. To date, she has already reached her goal of £4,000 which is amazing. In case you missed this and have not sponsored her yet, here is the link: https://www.justgiving.com/team/AnnaluSummerMadness.

Transferring AAC Skills Into Sporting Success

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In September 2021, I was privileged to represent Great Britain in the Tokyo 2020 Paralympics. I can honestly say selection to represent your nation is a huge honour. This came as the result of 17 years of playing boccia and 21 years of dreaming of being a Paralympian. Like all elite sport, representing your nation doesn't happen overnight. It takes years of hard work, resilience, determination, and the support of others.

Research quotes 10,000 hours of training to make it to a world class athlete level. I'd say easily this. Besides competing I was expected to train on court several days a week and attend week long camps. I'd go as far as saying this is similar to my experience of learning to use AAC. I say this because, in my mind, this is on top of the usual social and language exposure any other child gets. Even today my communication is still evolving; I think about it consciously daily. Every day is a learning day, and I'm now 29.

In the run up to going to Tokyo, I was looking at some world class programme paperwork. I realised there were amazing synergies between using AAC and being an elite athlete. It became clear my journey to where I am now as an electronic communication aid user had supported me to be selected for GB. I'd just like to say that this is my lived experience. We are all different, and I recognise that not everyone will want to take up the challenges I set myself.

What I hope you take from this is that each of us has the potential to be many things, and with high expectations we can each fulfil our own potential, whatever our dreams in life. The synergy between AAC and sport is the result of my dreams, hard work, and being resilient.

GB Boccia has a long list of key criteria for selection ranging from strategic and technical skill through to mindset and coachability. I was lucky to be identified as having talent. With their support, sheer hard work and determination, I progressed to competing on a world class stage at the Paralympics, with the opportunity to medal on the podium.

As an athlete or an AAC user, achieving early success dictates your direction of travel, or motivation. Getting to the top in boccia is just like fulfilling your own communication potential. There are assessments, outcome measures, milestones, and goals to be achieved. Growing up goal driven and motivated to succeed as an AAC user meant that I already had transferable experiences for sport.

If we start with the technical aspect of boccia, the very first thing is to have the right tools and resources to enjoy participating. Over the years, my equipment evolved from a borrowed set of balls, to my Tokyo set which cost around £1500. Every ball was different with a different job to do. Then there was the ramp. My very first ramp was a piece of yellow plastic balanced on my knees. With GB, I got a custom-made ramp, designed specifically for the job. It was a really slick piece of technology made of carbon fibre costing around £5000. The synergies here are between the cost of paper and powered AAC.

Next, there was the method to release the ball. I experimented with a head pointer, used a knuckle duster, and various other things. But eventually I settled on a portable telescopic flagpole for high release, and my fingers for mid and low release. All this will sound

familiar. Throughout my time as an AAC user, I have embraced new hardware and software. I've used my finger, a stylus and my eyes to access my AAC.

Next, there is developing and applying tactical knowledge and skills. In sport this is made up of two key attributes: the ability to be strategic, and then applying those tactics in real life. From a strategy perspective, there is a need to have an in-depth knowledge of the game. I learned by being exposed to the highest ranked players in the world. Using AAC effectively is all about knowing how to communicate in different situations. For me, observing 'the greats' at work meant interacting with adult role models at 1Voice and at ISAAC conferences.

Another key skill for a ramp athlete is communication under pressure on the field of play with your assistant. Whilst the athlete can communicate verbally, the on-court assistant may not use any form of communication including eye movement, scratching the nose, etc. Infringement gives away penalties. The result is needing to develop a nearly telepathic playing partnership, similar to the one you have with a familiar communication partner.

Using AAC can be very pressurized. People are waiting for you to input each word. In my case, I sometimes get brain freeze if I am put on the spot. This means I have worked on strategies all my life to deal with feelings of stress, just to give myself a breathing space. I use techniques like a traffic light system of stop, breathe and think, and then respond. I identify with a tiger to help me be strong and in control, particularly in difficult situations. Then, I think in visuals, and visualisation skills have been particularly helpful in boccia.

Game planning is another good synergy. In sport we practice scenarios over and over. Growing up as an AAC user I had plenty of practice of trying things out. There was always modelling at home. In the holidays, I had a teenager come in, and we would share playing together on my device every morning. This might be ordering food in McDonald's, playing teachers or making shopping lists. Mum and I often role-played new situations before they happened which supported being a good strategic decision maker. At elite level, the game is often said to be physical chess with balls, planning 2 or 3 shots ahead yet adapting for constantly changing factors under time constraints.

Sport is of course a physical activity. Even as a BC3 ramp athlete sat in my chair, it has been essential to get right my posture and balance to deliver accurately on the right shot choices, and, when needed, to have the stamina and strength to deal with gruelling schedules. Growing up, I had had drummed into me the importance of sitting well to help me communicate. A reverse benefit has been that my improved posture and balance due to shoulder and core work meant I became a more accurate AAC user.

You may not know that I began public speaking at the age of 12 when I was the then youngest ever AAC user to speak at an ISAAC conference. It took months of planning and preparation to do a PowerPoint. Looking back, I can see that preparation and presentation changed my life. I had loved learning something new, and I had developed a skill that was not the norm for my age. I'd also learned as an AAC user that I needed to take personal responsibility for my learning. There was no-one else who was going to do it for me. When the chips are down, there is only me that can communicate for me. Sport is fiercely competitive, and there is always someone waiting to step into your shoes, so self-motivation is important.

Over the years, I'd learned to recognise and manage the impact of my emotions on myself, others, and on my decision making. Moving away from home to university was probably the biggest challenge, but fortunately I had lots of support from my family and a counsellor. They helped me regulate my emotions and think carefully about what I was portraying to others both through behaviour and the spoken word. This definitely all helped with building my relationship with Christie, my on-court sports assistant. For Tokyo, we were away 22 days. Christie provided all of my care 24/7 which included sharing a room with me and being my on-court assistant. The role of the assistant is recognised in boccia; they medal when the athlete medals. GB may have finished 8th in Tokyo, but in my eyes, we won gold just for what Christie did.

Being in Tokyo was achieved through extensive planning and preparation, hard work, determination and resilience. At the age of 14, I had been to an ISAAC dreams workshop. This was amazing and has provided me with a roadmap for my dreams ever since. We were taught to take our dreams, set effective goals, manage our progress and achieve our desired outcomes. In 2008, I was determined to be in the 2012 London Paralympics. Actually, that was too soon for me as an athlete, but I refined and revisited my goals. To get to my boccia destination, every single facet was broken into steps and goals. For instance, to get seen by a selector I needed first to win at regional competition.

Every single one of those steps needed me to demonstrate my ability to communicate and interact with the boccia staff team and other squad members. Surprisingly, this was not so different to everything that I'd come to expect growing up. By the age of 9,

I was insistent that I attended my annual reviews. I planned each year, and I always had things to say about my progress and what I needed next. So, when it came to working with a multi-disciplinary team of coaches, physios, psychologists, strength and conditioning, lifestyle gurus and nutritionists, I felt equipped to speak up.

I've had, and still have nearly daily, communication setbacks. Like many AAC users, I get patronised, shouted at, talked over and more. When I've got my device, I can tell people I understand them, and they can speak normally to me. I might not like these events, but they set me in good stead for boccia. You cannot change a poor shot or decision. You cannot alter a poor performance by a teammate. You have to deal with the rough and the smooth and remain calm, focused, and professional at all times. Resilience matters.

One of the key things for an athlete is being reflective, to appraise their own performance, look for improvement and take on board coach feedback. I can say the whole of my life has been like this. My mum brought me up by asking me questions: What went well? What might we improve next time? What might we change?

The final attribute that the coaches were looking for in any athlete was the ability to manage themselves in competition, to have the self-belief and deal with pressure. Surprisingly, being a presenter at 7 ISAAC conferences was just the experience I needed. I've grown in self-confidence over the years as an AAC user. Sometimes it isn't easy, but I know I can tackle anything because I have the basics in place. Again, as I travelled up the boccia ladder I learned to be more self-reliant and confident with each new adventure. The key thing I learned is nothing is ever really new. If we break tasks into component parts then it is likely we have experienced elements of it before. That means that we can transfer prior learning and existing skills to achieve success.

It is important that we never underestimate the time and effort it takes to be proficient AAC communicators. Behind every success is a lifetime of work. Every single person, whatever tools and resources they choose, will have developed their own unique skill set. And, that skill set with imagination is transferrable into other walks of life.

Boccia is a Paralympic sport with no Olympic equivalent event. Similar to boules or bowls, played seated on an indoor court, either individually and in teams/pairs. Each side has 6 red or blue balls with which to get closest to a white jack ball. Classified athletes have the most complex disabilities and are usually unable to play another sport.

Joy of Communication

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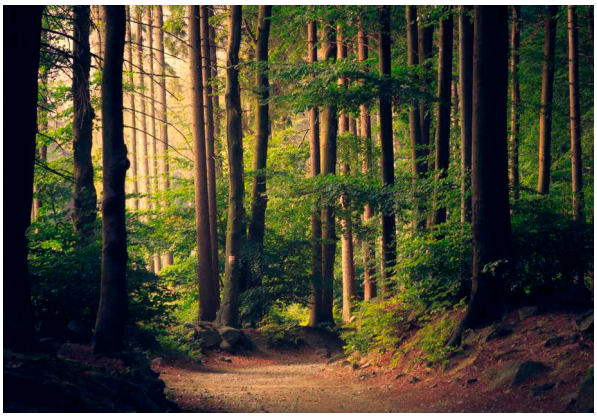
'Experiencing successes' over time was found to be the top reason for overall 'long-term success' with augmentative and alternative communication (AAC) by Johnson et al (2006). Over the years, I've asked people around the world to share their definition of success with AAC. The most typical response is functional use. When I probe a bit more, they list skills such as making choices, requesting needs, correctly answering questions, constructing two-to-three-word sentences, and decreasing behaviors. While we know that these are important skills, sources over the last three decades have a reported rate of abandonment of 30% or more for AAC. It seems to me that something must be missing in our definition of success or the way we are attempting to achieve it for abandonment of AAC to remain so high for so long.



Perhaps, we are out of focus. Maybe, we are not seeing the forest for the trees - like when we can't stop looking at a snag in an otherwise perfectly fine jumper or repeatedly editing one sentence in an overall well-written document. It may be that we are focusing so much on specific skills (trees) that we are missing the forest, which is the sheer joy of communicating.

Joy in communication is in the connection with another human being.

- Sharing exciting news
- Saying silly things
- Expressing your hopes and feelings
- Having a mundane conversation
- Creating beautiful word pictures
- Making someone laugh or laughing with them

Joyful communication is not dependent on language level or mode of communication. It can be accomplished with babbling, waving, making funny sounds, saying *uh oh* or *boo*, pointing to objects in the environment, producing single words on a communication device, or spelling sentences on an alphabet board. The joy of communication is expressing yourself and having it understood by someone else.

In preparing for my presentation at Communication Matters 2022, I found many videos depicting the joy of communication with people using speech but few for those using AAC. Perhaps such moments are not occurring in the daily lives of those who use AAC but, looking back on my own experience as a therapist, it is more likely that they are not noticed or are disregarded as not important. As a result, we are missing out on opportunities that could enhance users' ongoing experience of AAC successes, improve their skills, and reduce abandonment. Yet, such a change will not happen unless there is intention about focusing on the joy of communication, and it must start with us.

I suggest three changes we can make ourselves to prioritize the joy of communication in our interactions and interventions with AAC users, and how to spread this focus on joy to others.

- Remember the joy ourselves
- Use joyful techniques
- Encourage others to look for and inspire joy

Remembering the joy of communication ourselves requires an expansion of our definition of success with AAC. It means moving from concentrating largely on what Light (2014) referred to as linguistic skills to including social and strategic skills, which reflect connection and opportunities for fun as well as potential for being a catalyst in overall progress.

Original Definition

- Make choices
- Request needs
- Correctly answer questions
- Construct two-to-three-word sentences
- Decrease behaviors

Expanded Definition

- Attention to/interest in interactions
- Active participation
- Initiation of interaction
- Variety in communication partners, topics, or environments
- Creativity in communication
- Literacy
- Etc.

As I reflect on my own clinical practice, I realize that my definition of success led me to use intervention techniques that often removed the joy from the interaction like a puncture in a balloon, rather than lifting it to further heights. Today, I would choose different techniques.

- **Teach, instead of test, so that my clients can play, rather than perform.**

  Testing assumes a right answer. Communication is rarely like that. Consider the last time you were asked if you liked something. You probably didn't just say yes or no; instead, you responded with "yes, but…" or "no, and…" Too often in our AAC intervention, we set up correct/incorrect scenarios and, therefore, shut down communication. It is often the unstructured moments of play/enjoyment, the time in between activities, or the mistakes that give us opportunities to build motivation for communication and skills.

- **Focus on personally motivating goals and targets that bring joy to the individual.**

  For most of us, using client interests makes sense simply as a good approach, but it is more than that. There is published evidence indicating that this practice has a positive effect on skills from joint attention (Kryzak et al, 2013) to social interaction (Koegel, et al, 2012) to holistic processing (McKelvey, 2010). After all, we are likely to work harder and persevere when something is motivating for us (Paul, 2013).

- **Respond to all methods of communication.**

  While we may think it is beneficial to prompt an individual to "say it with their talker" it can send the message that the individual's attempts at communication are ineffective and, at worst, unacceptable. Research on responding to all methods of communication reveals increases in client interaction and decreases in passivity (Douglas et al, 2013; Mirenda, 1997) when we respond to all of their communicative attempts. In addition, it allows us to follow the client's lead which increases opportunities for interaction and often motivation to participate. This creates interactions that are collaborative rather than competitive.

- **Demonstrate use of AAC.**

  Known in the AAC community as modeling, this evidence-based technique has been shown to result in meaningful gains in receptive and expressive vocabulary and grammar as well as turn taking for individuals with varying skill levels (Sennott et al, 2016; Project Core). Demonstrating use of AAC throughout our daily interactions and in response to a communicative attempt by the client allows us to show alternate ways to communicate a message and expand on what they say. It also gives us the opportunity to make mistakes which, in addition to being good for a laugh, is an excellent teaching moment.

A new definition of successful use of AAC and use of joyful techniques will impact our intervention, but they must be shared to offer the AAC user the most benefit. We must **encourage others to look for and inspire joy** from the beginning of our interactions with them and throughout the journey.

Beginning with our assessment, we can utilize tools that clearly demonstrate that there is more to successful use of AAC than the skills in our original definition. These resources can also help us write goals targeting the expanded aspects of our definition of success as long as we are confident that they will not become just another item on the checklist. The two examples below introduce an expanded definition of success and can help you facilitate focus on the joy of communication.

- **Communication Success Screening Tool**

  Asks questions focusing on an individual's ability to participate in social interactions and repair communication breakdown as well as express needs and answer questions.

- **Dynamic AAC Goals Grid**

  Offers goals in four areas of communicative competency necessary for successful use of AAC (Light, 2014), not just skills in our original definition.

As we focus on the joy of communication with our clients, we can also inspire teams with stories of AAC success from others. I tend to share items relating to individuals who are at the same level as my client or working toward my client's level. This helps teams not to discount potential for achievement because they view their client as less capable.

Finally, encourage team members to share their moments of joyful communication with the client regularly and you do the same. Discuss any challenges first; it can be difficult to see joy in the face of difficulties. Then, move on to the funny, unexpected, and marvelous moments of joy that will be found when you focus on the forest of joyful communication.

Join me in passing on the message by remembering the joy of communication yourself, using joyful techniques, and encouraging others. Post your videos and stories so the world can hear our joyful voices.

Resources:

Communication Success Screening Tool http://download.mytobiidynavox.com/Resources%20for%20Pros/td-communication-success-screening.pdf

Dynamic AAC Goals Grid

PDF - http://download.mytobiidynavox.com/MyTobiiDynavox/dagg%202%20-%20writable.pdf

Interactive with lesson plans – Pathways for Core First (Available for Windows and iPad) https://uk.tobiidynavox.com/products/pathways-for-core-first

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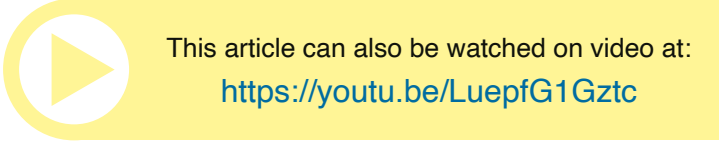

AAC in English Classrooms: Are we modelling?

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Background

The AAC field's prominent Beukelman & Mirenda book, now Beukelman & Light (2020, p. 11), has, throughout its five edition history, contained the quote "***A piano alone doesn't make a pianist, nor does a basketball make an athlete. Likewise, AAC alone doesn't make one a competent, proficient communicator.***" This quote raises two important questions: what is a competent, proficient communicator, and what process does one undertake to become one? In this research, I explore how this relates to symbol AAC users.

The question of competence was answered by Janice Light (1989), who described a proficient AAC communicator as one who has mastered linguistic, operational, strategic and social skills. One can use developmental frameworks such as the DAGG-2 to identify current levels and set achievable goals, but what interventions should we use along the journey?

Aided Language Input, more simply known as modelling, involves pointing at symbols during conversations and other communication events. Modelling has been described as the "gold standard" intervention (Clarke & Williams, 2020, p. 587), and a number of experiments and systematic reviews have demonstrated its effectiveness and social validity. It can be integrated easily into existing routines (such as in the classroom) and, in doing so, increases the recognition and the value of symbol AAC strategies in these environments. One final question: if modelling is so effective at developing AAC skills - is it being used?

Method

A survey asking this question was sent out to all multiple academy trusts in England. The role of the Teaching Assistant (TA) was targeted for a response, as it is the TAs who spend the most time with young people and therefore have the greatest opportunity to implement the modelling strategy into existing routines. The survey asked the TA to consider a young person they worked with who uses symbol-based AAC (excluding picture exchange); the gender-neutral name "Taylor" was used in the questionnaire to refer to this individual.

Results

Participants

Of the 205 TAs who responded, data from 50 were removed as their responses indicated that they did not meet the criteria. Results from the remaining 155 respondents were taken from across England, with a good geographical spread representing all regions. Most of the TAs reported to be confident with their computer skills (85%), confident in finding words and phrases on communication aids (76%), and that enough training had been received to be good communication partners.

AAC Users

The primary cause of the speech difficulties related to ***autism*** (47%), ***cerebral palsy*** (24%), or ***profound and multiple learning difficulties*** (11%). Other aetiologies included ***muscular dystrophy***, ***Rett's***, and ***developmental delay***. All ages had access to AAC, as represented by Taylor's reported current Key Stage, albeit the AAC user was much more likely to be in stages two or three (KS1=16%; KS2=38%; KS3=34%; KS4=12%).

Communication Aids

The students they considered when completing the questionnaire were either primarily ***print-based*** (54%) or ***powered*** (46%) AAC users. Some used both, but of the print-based users, 48% had never tried using a powered system. ***Touch*** was used by 81%, with the remainder using an alternative access method.

All the AAC users were symbol users, with a variety of vocabularies which involved mostly ***core words*** (25%), ***mostly nouns*** (19%), ***mostly phrases*** (4%), or a ***mix of the above*** (50%). Respondents were asked to choose the vocabulary page size closest to that used by Taylor. Most students used a page size of roughly 9 cells (32%) or 24 cells (33%). A single cell page (for example, a BIGMack) was used by 7% of the AAC users.

Use of Modelling

Attendees were asked to predict the amount of modelling when this research was presented at the Communication Matters conference (2022). This group believed that a relatively modest amount of modelling is used by TAs in England (Figure 1)*. This is in contrast to the results of the survey, which demonstrates that 71% of TAs model at least "a moderate amount" (Figure 2). Interestingly, there was no relationship found between the amount of modelling and the type of aid (print-based/powered), access method (touch/non-touch), or time available to the TA. It does appear that the more confident and well-trained TAs provide less modelling than their less-trained counterparts (r=-.171. p=.039. n=146).

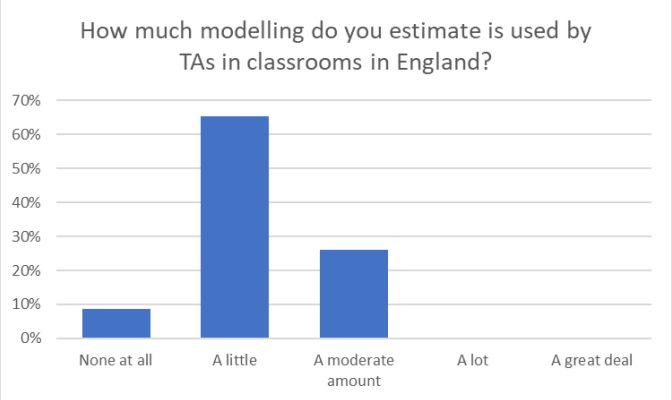

Figure 1

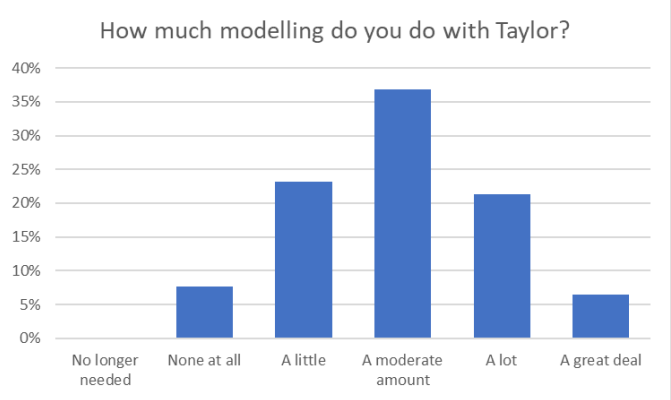

Figure 2

Modelling Style

Teaching assistants were also asked about their style of modelling. Many model either ***most words*** or ***every word*** when communicating (42%), and most use speech while doing so (87%). Expectant pause are used generously by the TAs, with 60% using this strategy at least ***a moderate amount***. On the controversial subject of providing physical prompts, 28% reported that they never used this strategy, but 51% were using physical prompting with Taylor or had used in the past.

Modelling of linguistic functions is more frequent than the other Light (1989) competencies. TAs model requests, emotions and some use recasting to help develop AAC syntax. Social skills such as greetings are modelled well. Operationally TAs model clearing the message bar and navigation but few other operational features such as adjusting the volume or checking the battery. Strategic competencies such as conversation repairs are modelled minimally.

AAC User Competencies

The TAs were asked to report their understanding of Taylor's current AAC skills. Overall, this demonstrated that the students they support have strengths in making requests and navigating pages. Around half combine symbols at least ***a moderate amount***. Fewer students use their AAC aide to make comments, ask questions or make greetings. Only 11% of students use their device to make conversational repairs.

Teaching assistants were provided the opportunity to make comments in the survey. Many of the participants provided statements which were highly positive in nature, for example one participant noted that "***Modelling language is important and it is important for children with speech and language needs to hear adults modelling good communication***" and another "***Although they are hard work initially, they are such an amazing tool to give our pupils their own voice***." However, many more participants used the comments box as a method to explain why modelling or use of communication aids in general was limited in their setting. Most responses concerned the lack of training and support received, particularly from the Speech & Language Therapist, and the resulting impact on confidence and feelings of isolation. Examples that generated these themes include: "***vital to train others around the child on how to model and why it's so important. Also, some people are shy at doing this.***"; "***Limited input, modelling and follow up from SALT within mainstream does not help to embed or develop skills***"; "***Much more training is required***. [We] ***struggle to use*** [the] ***communication aid***."; "***At times*** [the] ***therapist can be confusing.***".

Discussion

Aided language Input is used across England for various ages, disabilities and neurodivergent presentations. In addition to this, modelling is used for both print-based and powered devices and is used equally well for young people using touch access alternative access methods.

The responses of TAs were somewhat surprising. While it is logical to assume that an internet-based, self-selecting sampling method would favour responses from computer savvy and confident TAs, this is in contrast to the qualitative data that indicates a lack of training and limited confidence. This could indicate satisficing as a reason for some of these responses. There is another option: if we expect a student's ability to be able to activate a simple single message device or make a request from a few symbols

then it would be easy to say that we're confident in supporting this. However, if we are expecting every student to be able to select purposefully from a large vocabulary for a range of communicative purposes, then perhaps one might report as being less confident.

Modelling isn't a good or bad thing in itself. As students increase in confidence, we might expect modelling to be reduced and eventually withdrawn. However, the competency data indicate that this level of skill hasn't yet been reached prior to the reduction in modelling. There are also indicators of this in the qualitative statements, such as "***Modelling is generally used the most when introducing new items/phrases to Taylor. After that it tends to reduce."*** and "***As my pupil is still quite new to her voice output device I model when and as it is needed***." This indicates that expectations for these students might be rather low.

Powered AAC systems have the advantage that they can provide access to a lot of vocabulary without the need to carry and handle large books and folders. They are easier to manipulate for those that use touch and have many more access options, including switches, joysticks and rollerballs. Powered systems also speak, meaning that individuals using the aid can communicate with a much larger population - including those that aren't able to interpret the meaning of symbols. While print-based aids do have a place for every child, powered systems often provide more efficient access and provide the person an ability to communicate with a much wider audience. It is therefore concerning that so many young people who use print-based aids have never had access to powered systems.

It was found that a large percentage of vocabularies comprise mostly nouns. It is difficult to interpret whether these systems also have access to a wider range of core vocabulary that is not used to its potential. This is a concern as nouns are rarely high-frequency words for typically speaking children, and core vocabulary can be used repeatedly throughout a range of activities, providing access to more communication events. It may be that TAs are not able to identify core words or their purpose, or that those choosing the vocabularies are unaware of the importance of core words in using and developing language. It was also concerning to discover that the primary communication aid of 7% of AAC users has just a single cell, such as BIGMack. Assumptions need to be made about the use of alternative communication strategies, but for these children they may be unable to grow their vocabulary or learn to combine symbols if restricted to a single utterance.

It is reassuring to see expectant delays, which allow time for the young person to process the language and prepare and deliver their response. The frequent use of physical prompts is more alarming given the impact on the young person's ability to learn to use the device independently and can be interpreted as facilitated communication, something which has been under scrutiny in recent years and is banned in a position statement made by ASHA.

There are many limitations of this study. Primarily, the self-selecting online method of recruitment may have resulted in responses from the most technically-confident TAs. In addition, the respondents were permitted to skip some questions, resulting in missing results in parts. Although the questionnaire was piloted and much consideration was given to language used, it is likely that some questions were misinterpreted or needed further information. It is also true that Likert labels such as ***a great deal*** or ***very much*** used throughout the survey are difficult to correlate to real-world use. Finally, although the respondents were asked to identify the young person's primary communication aid for the purpose of the study, they were not asked if they also used speech or other non-aided methods to achieve communicative functions, such as making conversation repairs, greetings, etc.

Recommendations

Many of the respondents called out for better training and support to ensure that AAC users can benefit from their device. There are many confident modellers who may be willing to be involved in a programme to support the less confident modellers.

The lack of access to powered devices, the use of vocabularies using mostly nouns, and the use of physical prompting are all concerning and should be explored and addressed through better training, processes and resources.

More research is recommended to address the limitations of this study.

* Note that this was an informal Mentimeter survey and not part of the study, therefore did not have ethical approval or methodological rigour.

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Right Place, Right Time: Creating a Local AAC Service That Meets the Needs of the AAC Community

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Background

For many people, Augmentative and Alternative Communication (AAC) is a lifelong tool to supplement and/or replace speech (Beukelman and Mirenda, 2013). The Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016 (part 4) determines that people living in Scotland who require AAC receive the system and the ongoing support to use it in a timely manner.

Following the introduction of the abovementioned legislation, NHS Greater Glasgow & Clyde Health Board commissioned the creation of a local AAC service to meet the needs of the legislation.

Under the legislation health boards must provide:

"(a) communication equipment, and

(b) support in using that equipment, to any person who has lost their voice or has difficulty speaking.".

In February 2020, The CHAT (Communication Help through Assistive Technology) Service, hosted by SCTCI (Scottish Centre of Technology for the Communication Impaired), one of the national AAC assessment services, was created to allow the health board to meet the delivery of 'communication equipment' and the subsequent 'support in using that equipment' for people who use AAC who live within the health board area.

Addressing the challenges

In 2020, The Royal College of Speech and Language Therapists (RCSLT) Scotland office worked with the SLT AAC Leaders Network, members of the AAC Collaborative in Scotland, and AAC users to carry out a survey of both Speech and Language Therapists (SLTs) and people who use AAC in Scotland.

SLTs indicated that they had found it challenging to provide equipment to users in a timely manner. Additionally, concerns were highlighted around providing follow up support alongside other clinical priorities. People who use AAC and their families experienced varied access to assessment and support, with only 50% indicating they felt they received enough follow up support.

From this, the legislation highlighted that specialised AAC services were required at all points of the AAC user journey. In Scotland, AAC services are predominantly provided by NHS services, with existing NHS models of service varying across different areas, and traditionally have focused on assessment services. It was felt that overall specialised AAC assessment was accessible, but the next steps varied depending on the local SLT department. We used this as an opportunity to map the CHAT Service to the existing AAC National Core Pathway (2018). See Figure 1 on the following page.

Stakeholder Views

When having this opportunity to create a new service, we wanted to make sure the service was designed and influenced by the people whom it aims to help. Whilst this was easier said than done, particularly navigating the set up during the initial outbreak of the Covid-19 pandemic, we were able to gather some views from stakeholders. Due to the social restrictions at the time, we used email and video calls to engage with those who were available.

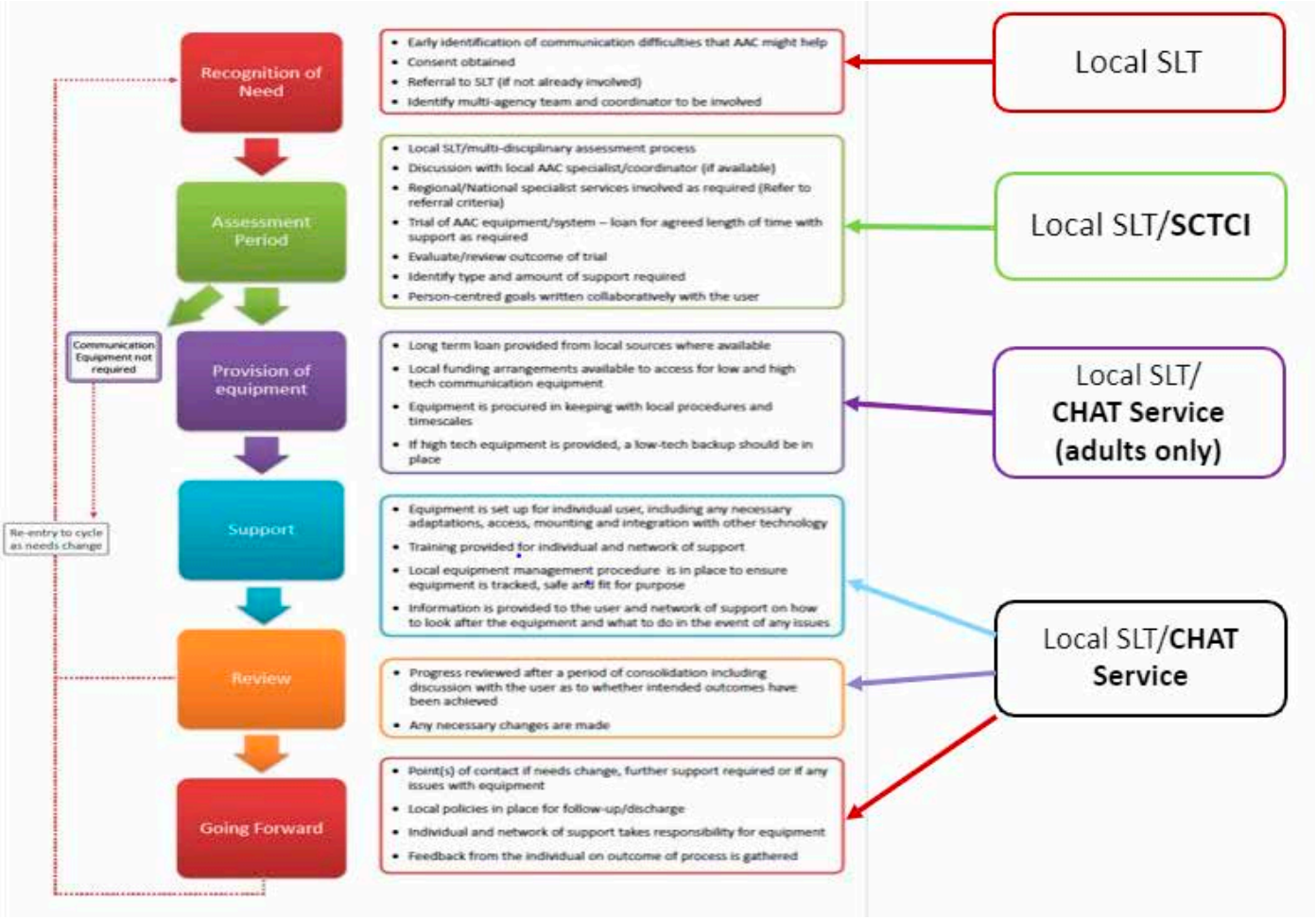

Figure 1. AAC National Core Pathway (2018)

The AAC users we asked told us that they needed the following:

- Someone to contact even if they weren't actively involved with SLT
- To get access to equipment in a timely manner
- To build a community with other AAC users

We also decided to ask local SLTs. Currently the CHAT Service does not have the resource to provide direct support for every AAC user within the area. It was identified early on that the key would be to work in partnership with local SLTs as part of the AAC Team. But we needed SLTs to tell us what they needed help with!

SLTs wanted:

- Professional development – CPD opportunities which kept them up to date;
- Networking with other SLTs – two heads are often better than one!;
- Targeted training for those who support people who use AAC.

So using all this information from the legislation and stakeholder views, we decided on the main work streams. See Figure 2 below.

This would be:

Equipment provision - For adults (existing pathways for children remained the same due to joint funding with education – but we have already identified barriers of why a centralised approach would be better).

Support for implementing AAC – Whether directly with the AAC user or their communication partners or indirectly through consultation with their local SLT.

Training – A role for more targeted training for communication partners. As well as training and CPD sessions for AAC practitioners.

Technical Support – We acknowledged that sometimes problems just need solved quickly. Whilst many users can contact AAC suppliers for tech support, sometimes we can solve things locally and quickly without a referral to SLT.

Networking – This was highlighted for both AAC users and their communication partners as well as SLTs.

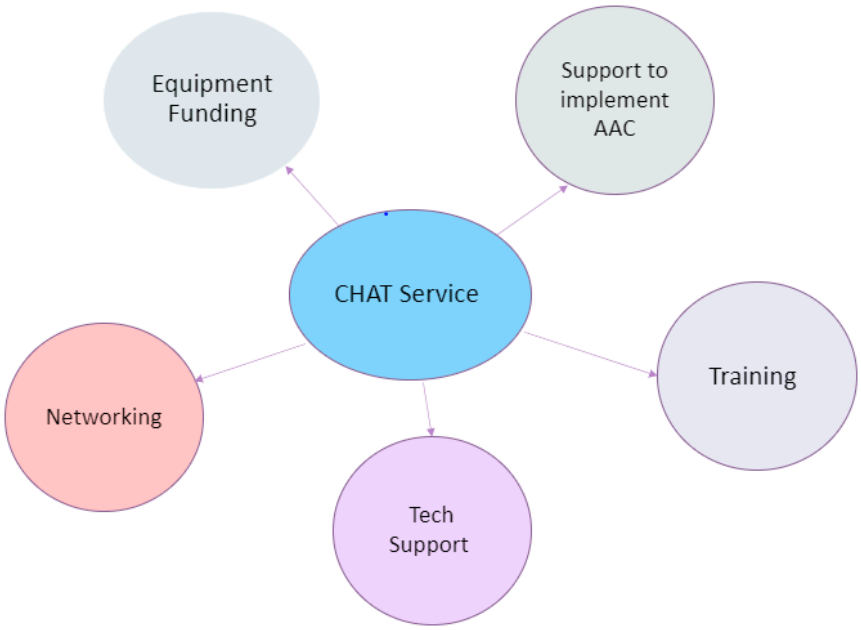

Figure 2. CHAT Service Work streams

Progress so far

Equipment Provision

The service was given a remit to procure and provide AAC equipment for adults within the health board. Due to existing agreements with education, it was agreed that funding arrangements for children's service would remain the same.

From this, following process was designed:

- Availability of Assessment Loan bank to limit barriers to assessment process.
- Application to service from local SLT on behalf of client indicating details of clinical assessment, reasoning and recommendation.
- Clinical governance processes in place to ensure clinical and cost effectiveness.
- Procurement and set up of equipment
- Stock management and audit of equipment
- Initial technical set up support
- Annual review of equipment to ensure clinical and cost effectiveness alongside pre-empting potential known barriers to use such as abandonment and/or obsoleteness of device (Johnson, Inglebert, Jones & Ray, 2009).

Support for Implementation of AAC system

With reference to the AAC National Core Pathway (2018), we realised it would be beneficial to offer specialised input for supporting the implementation of AAC systems for both children and adults.

This work has been generated through referrals, with a focus on establishing the AAC team around the person using AAC. The aim is to then identify personalised goals for use and the steps and support required in order to achieve this.

Whilst there have been common themes, so far there has been no two cases that have resulted in the same style, frequency or approach of support provided, further highlighting the importance of a person-centred approach. We predict that this aspect of the service will continue to evolve based on the needs and wants of our stakeholders.

Networking

When we asked our stakeholders what they wanted from the service, both AAC users and SLTs told us they wanted networking opportunities. So we wanted to make sure we included aspects of this from the beginning. Whilst it started as something from the CHAT Service, we sit as one SCTCI team, and therefore this has allowed the opportunity to build more of AAC community nationally.

Some of examples of this for AAC professionals have been:

Microsoft Teams page – Initially this took time to build, but as the pandemic changed the way we were working it has become a key tool for engagement between SLTs in Scotland. We even have it set up so SLTs can request equipment to loan out.

AAC Pulse/Link Therapy – SCTCI have had a link therapy network between the SCTCI team and representatives from the local areas for many years. Historically, in-person CPD days were held to allow information sharing which could be fed back to local areas. With the introduction of Microsoft Teams, many areas were wanting to open this opportunity to different SLTs in the local area. Whilst this was great, it took away from the back-and-forth nature of the link role. Therefore, we introduced a new CPD session called AAC pulse. This has run a few times now, with the aim of running twice a year. It aims to provide an update of what's new as well as a platform to discuss key topic areas. The aim is for it to be run online so it can be accessed by SLTs across all areas.

Peer Support - We've also started to make connection with small groups of local SLTs to provide peer support and a safe place to discuss cases and queries.

AAC User Networks - In terms of AAC users, this has provided a bit more of a challenge than we would have liked. The AAC users we have spoken to have told us that they would like to have support in meeting other AAC users through social media platforms. Jumping through the hoops of health board IT governance has proven a bit more challenging that we initially anticipated. However, this is something we want to continue to puruse and look at more in person options.

Plans for the future

So we've got this far, what are our next steps?

- Possible expansion of equipment provision. We've created a winning formula that others now want.
- Continue to build AAC community both practitioners and with a focus on AAC users and their families.
- Going digital. Exploring digital tools to ensure ease of access and options for all.
- Different levels of implementation support – targeted training for schools.

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User Experiences of a Speech Recognition App for People with Non-standard Speech

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Speech recognition controlled voice assistants continue to be integrated into an ever-expanding array of devices that we use on a daily basis. In addition to the challenges faced when communicating verbally with less familiar communication partners, people who have dysarthric speech often have difficulty using voice recognition technology such as Alexa, Siri and Hey Google, as these use speech recognition AI/machine learning trained on patterns of standard speech. Aimed at addressing these challenges, the Voiceitt speech recognition app was developed for people with speech disabilities, disorders, or impairments. It uses machine learning to recognise specific trained phrases which it can then either speak out clearly or transmit directly as a command to Alexa voice controlled devices.

In this article, we will reflect on the outcomes of a user experience project undertaken by Ace Centre in collaboration with Voiceitt and funded by the NHS Health Innovation Manchester Momentum Fund. We will discuss the features of the app as experienced by our group of participants, all of whom have dysarthric speech. We will share the participant's thoughts about the Voiceitt app, its benefits, limitations, and their ideas of the functionality they would like to see from this type of technology in the future.

Aim of the Project

The overall goal of the project was to validate the Voiceitt technology and app and determine the extent to which clinical training with Voiceitt can improve participation, independence, and quality of life for people with poor speech intelligibility. The project aimed to comprise 7-10 participants, recruited by Ace Centre. The collaboration would stand for a 12-month duration with participants actively trialling the app for a 3-month time period.

Ace Centre were responsible for recruiting participants, purchasing equipment, onboarding participants with the app and training them to use Voiceitt, troubleshooting, communicating participant feedback to Voiceitt, and gathering photo and video evidence.

Participant Recruitment

To complete the pilot trial of Voiceitt, participants were recruited using the following participant criteria:

- Aged 18+ with dysarthric speech.
- Interested in using technology to increase their independence, socialisation or engagement.
- Have sufficient cognitive ability to express opinions about Voiceitt.
- iOS users or familiar with iPhone/iPads.

Ace Centre contacts who fit the participant criteria were suggested by Ace Centre staff and contacted to participate. Advertisements were also placed on Ace Centre social media. Using these methods and criteria eight participants were recruited with diagnosis of stroke (1 person), learning disability (1 person), and cerebral palsy (6 people). The participants accessed technology using methods such as direct access with a finger, joystick, rollerball and head mouse.

Data Collection

If the participants were not already iOS users or did not have access to suitable equipment, they were provided with an Apple device which they were able to keep at the end of the project. The iOS devices provided to participants comprised one iPad mini, two standard iPads and an iPhone SE with protective cases. The type of device provided was decided in discussion with the participants according to which best matched their access and personal needs. All other participants had their own existing device on which to install the Voiceitt app.

In order to facilitate participants' testing of the Smart Home functions of the Voiceitt app, an 'environmental control' kit was created and sent out to participants who consented to try this function. Four complete kits comprising an Amazon Echo Dot, a Smart plug adapter and a pack of compatible Smart bulbs were sent out, with an additional single Echo Dot and a bulb pack also sent.

Two of the participants received a home visit from Ace Centre staff to facilitate the setup of the app and connection to the Smart Home devices, with the remaining participants either completing setup independently or with the assistance of another person at home. Telephone or email based support was always available at this stage, and a simple printed photo guide was created to assist with the set-up of the Smart Home kit.

Feedback on the participants' experiences with Voiceitt was gained via a continual process, as regular contact was maintained with participants via phone and email to check on their progress with the app and offer any necessary support and assistance. Participation data was also collected and analysed by Voiceitt directly from the user accounts. This data was discussed at monthly meetings which were held online with Voiceitt's Customer Success Manager. This provided an opportunity to pass on feedback and requests for additional features, and to troubleshoot any problems encountered.

A final participant feedback questionnaire was created as an online form. A link was shared with participants for this to be completed either independently or with support as appropriate from either home based support or Ace Centre staff.

Results

Mid way feedback

During the process of trialling Voiceitt, feedback was collected from the participants. Voiceitt has two functions. The first 'Conversation' will speak out a trained phrase clearly for the user. The participants began to use this to talk to family members and while out in the community such as ordering a drink at the pub. The second function is 'Smart Home' which integrates with Alexa to control the environment. The participants enjoyed using this feature for a variety of purposes including turning on and off lamps or lights, asking Alexa questions such as checking the weather, playing music, and turning on an Xbox.

Examples of the feedback that was communicated during the check-ins with participants throughout the project include:

> *"He's really impressed with how well it learns his speech, much better than anything else he has tried. He would like to be able to turn off the motivational awards as they are ultimately annoying and interrupt conversation."*
>
> *"The interface is simple and user friendly"*
>
> *"It was easy to set up Voiceitt with Alexa…I created some short phrases for Alexa commands and compared these to speaking the full phrases to Alexa. Sometimes Alexa did not understand me when I said a long phrase so using a short phrase in Voiceitt was very helpful".*
>
> *"C is using his Echo Dot to play the radio. It's working well and he is able to use much more complex commands. He is using his nose to access the app and finds the big button easy but has trouble with the buttons in the corners."*
>
> *"I have only been using Voiceitt in a limited way recently. I prefer to use Alexa with my own speech rather than through the app. This is partly because it's quicker to speak commands, even though I sometimes have to repeat myself a few times before Alexa understands me".*

Final interview feedback

Five people completed the final interview. This was either conducted over the phone, via video call, or completed by the participant online. The results of the interview are summarised below.

Setting up Voiceitt

Three participants felt that it was easy to set up Voiceitt, while two participants had someone set up Voiceitt for them (see Figure 1). Similarly, two participants felt it was easy to get Voiceitt set up with Alexa while one didn't use Alexa and two had someone set it up for them. Participants described Voiceitt as having a user-friendly interface, straightforward instructions, and quick to get the hang of. Some participants found it a bit confusing and had difficulty connecting to Alexa due to having more than one Alexa in their house.

Training Voiceitt

When training Voiceitt three participants thought that it was easy to understand how to use Voiceitt, one participant found it quite difficult, and one participant needed guidance from someone else to understand the process (see Figure 2). Three participants were able to train their first phrase while the other two required help, particularly with the physical side of pressing the button to record each phrase. All of the participants needed to repeat a phrase between 10 and 20 times before it unlocked. Participants felt that the training was repetitive but manageable. One participant would find it useful if the app would proceed to the next phrase without having to press the button.

Using Voiceitt

When using Voiceitt the participants felt surprised, pleased and a sense of achievement when Voiceitt understood them for the first time. Two participants are able to use trained phrases on the first try while two participants need one to three repeats of the phrase and one participant needed four or more repeats of the phrase for Voiceitt to understand them (see Figure 3).

One person felt that the Conversation side of Voiceitt is the most useful (this participant did not use Smart Home) while four

Figure 1

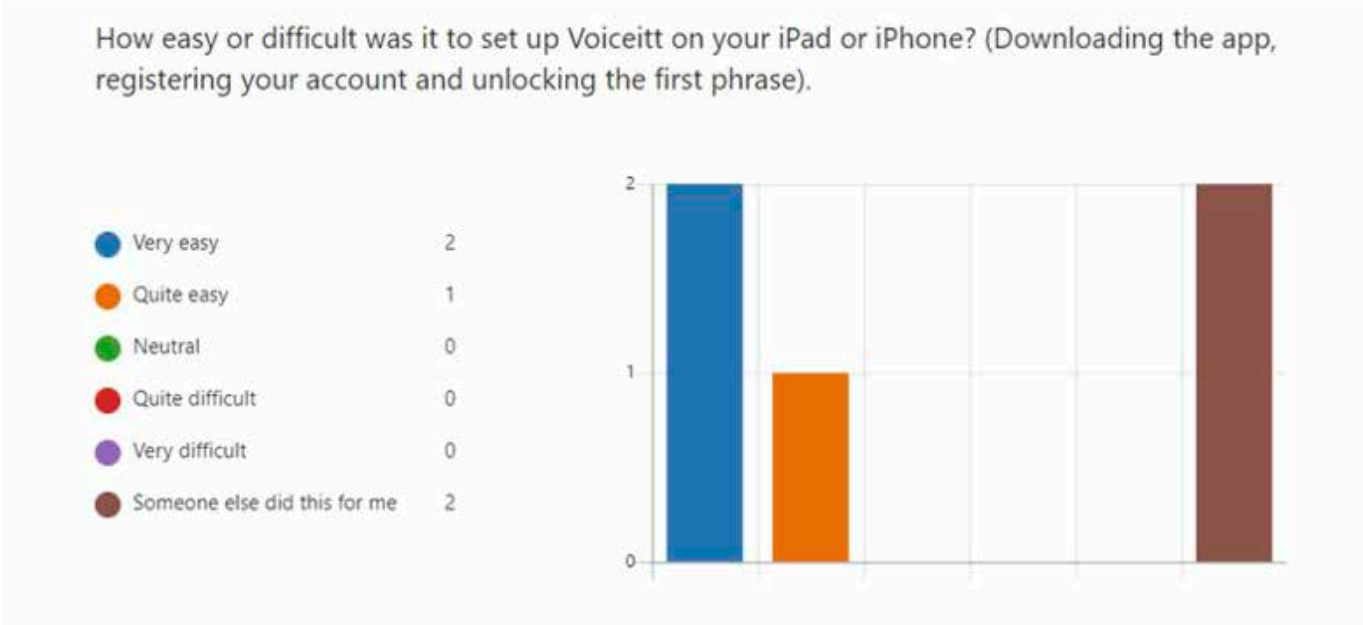


Figure 2

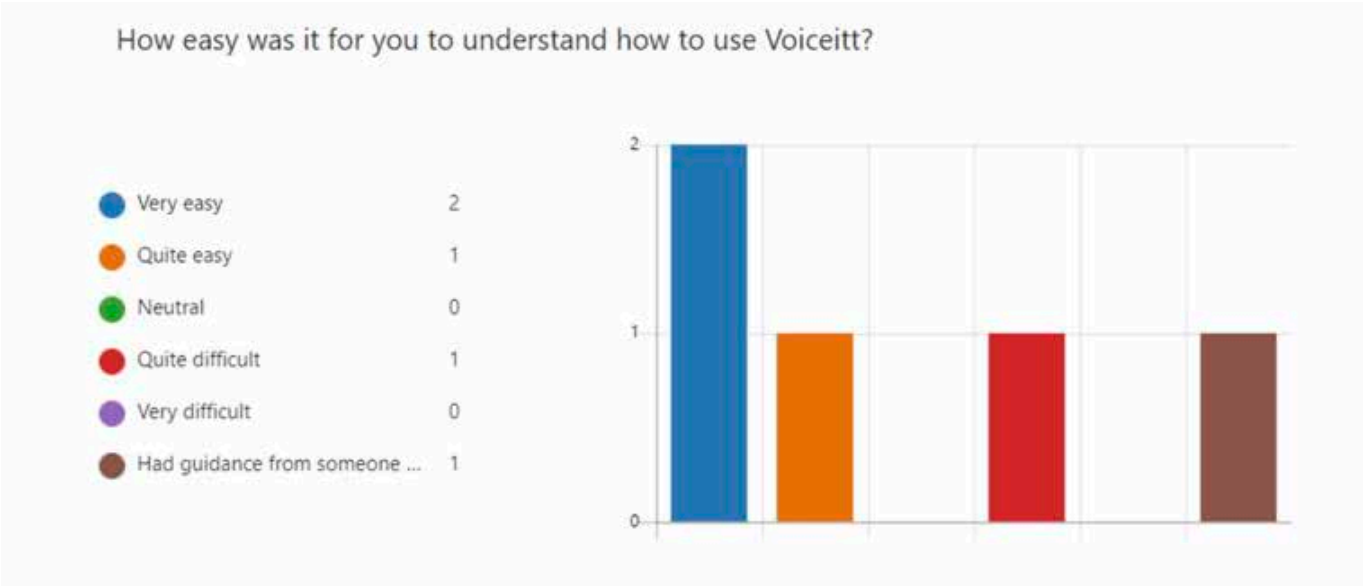
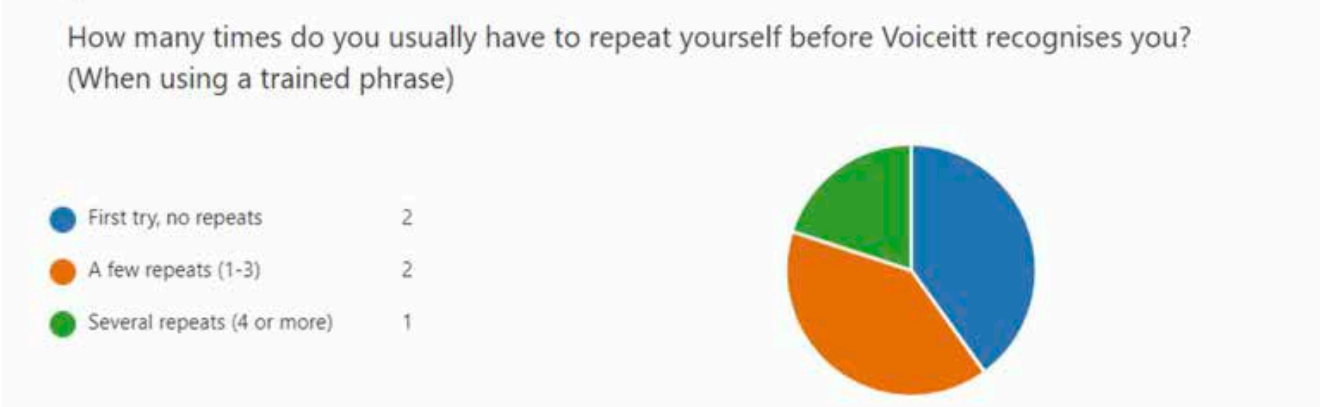


Figure 3



participants found the Smart Home side the most useful. Four of the participants report using the Conversation side less than once a week, with one participant using it 1-3 days a week. Two of the participants report using the Smart Home side less than once a week, one participant 1-3 days a week, and one participant most days.

The participants were asked what they wish Voiceitt could be used for in the future. They identified scenarios such as computer control, dictation, playing video games, unlocking a smartphone, enabling a wake word for a device, and to control household appliances like a washing machine. The participants would also prefer if they didn't have to train each phrase, and it could understand anything they say.

Conclusions

Of the eight participants who trialled Voiceitt, most found it useful and engaged well with the project, however others were less engaged. This was due to factors such as the environment the person was in, the support needed to access Voiceitt, the other tools they already had use of, physical barriers, and whether they felt it was useful in their daily life.

For example, one participant was interested in using Voiceitt to communicate with his family members but found that as they understood him well enough using his natural speech, the effort of using the app was too much for him to use it regularly. Another participant found that it was still quicker to use his own speech to talk to Alexa, even if he had to repeat himself a few times, and so continued to do this rather than using Voiceitt.

Other participants, however, found Voiceitt very useful. The Conversation side of the app was less popular, however one participant said she would use it in busy places where she is more nervous, or her voice is less intelligible. The most popular use of Voiceitt was with Smart Home control of Alexa. The participants who trialled this enjoyed the ability to communicate with Alexa more easily and had a lot of positive feedback. They used Alexa for a variety of tasks such as playing music, turning on/off lamps and lights, controlling the TV, charging their phone with a Smart Plug, and turning an Xbox on and off independently. The participants were also impressed with how well the app picked up their dysarthric speech and expressed a feeling of accomplishment at being understood.

Overall, Voiceitt was not used functionally by every participant in this trial, however those who did make use of the features of Voiceitt were able to successfully improve small moments of their lives, increase their independence, and enjoy access to a variety of things which were previously difficult to use.

We would like to extend our thanks to our eight participants, Voiceitt and the NHS Health Innovation Manchester Momentum Fund for their support of this project. If you are interested in trialling Voiceitt, the project with Ace Centre has now finished, however you can contact Voiceitt directly support@voiceitt.com or visit their website https://voiceitt.com/. The Karten Network can offer additional support for people in the UK and Ireland until April 2023. Please contact liz@karten-network.org.uk if you would like more information.

AAC Users and Nursing Staff's Thoughts and Perceptions of Current AAC Training With Content Considerations for Future Training Interventions

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Introduction

As life expectancy increases, more adults are living with conditions affecting their communication, and many of these will reside within care settings such as hospitals or long-term care, cared for by nurses and health care assistants (HCAs).

The current workload and role of a nurse or HCA is complex and busy, and when caring for a patient who is also an Augmentative and Alternative Communication (AAC) user, they need additional skills and knowledge to be an effective communication partner. Nursing staff also need to undertake the various tasks that an AAC facilitator has to assume, such as high-tech AAC system maintenance - updating software, battery charging, cleaning as well as liaising with companies or therapists for help (Beukelman et al., 2008).

Research has identified difficult and distressing experiences of AAC users within hospitals, and nurses have reported feeling frustrated when caring for AAC users due to a lack of knowledge about AAC e.g. Hemsley et al. (2011). Many barriers to implementing AAC, particularly in hospital settings have been identified, including a lack of staff knowledge and skills (Gormley and Light, 2019). The COVID-19 pandemic's impact on communication function has escalated the need for communication aids and subsequently a nurse's need for awareness of alternative and supportive communication tools and strategies (Altschuler, 2021).

Training nursing staff in inpatient settings is complicated by a need to train a large number of healthcare workers on overlapping shift work patterns, 24 hours a day, 7 days a week. Globally, nurses and AAC users are diverse culturally and linguistically, and training needs to ensure these factors are considered.

In terms of opportunities to support nursing staff, recent research by Barnard et al. (2021) found that most interactions between speech and language therapists (SLTs) and nurses were punctuated by interruptions to the conversations in which SLTs seized moments in between nursing tasks to explain communication needs and strategies.

Compounding these factors, we have a limited research-evidence-base for how we train our nursing colleagues. To meet the demands of the healthcare setting, clinicians and researchers are challenged with the task of developing and evaluating innovative, flexible communication supports and communication partner training (Altschuler et al., 2021).

This article explores current research and practice in this area and describes a research study exploring nurses' and AAC users' views about current and future training.

Current practice and research-evidence-base

As part of this research project a systematised review (adheres to the rigor of systematic searches to appraise and synthesise research evidence, but with only one reviewer (Grant and Booth, 2009), was completed to explore the content and effectiveness of AAC training programmes delivered to nursing staff. In total, the review identified 11 studies published between 2001-2021. The majority of training was provided to qualified nurses (7 papers), HCAs also (2), and student nurses (2). Settings were ICU (6), acute hospitals (4) and one nursing home.

Training sessions cited ranged widely from 15 minutes to 6 hours. The format of training also varied and included online, face to face, practical workshops, and demonstrations. There was a distinct lack of reporting of the training content, but most training was in high and low-tech AAC (7). Most studies investigated nurses' views on the training with few exploring the impact on communication interactions between nurses and AAC users. There was unanimously positive feedback from nurses and HCAs about being trained in AAC.

Research study

This research project commenced in 2017 as part of my part-time PhD at Manchester Metropolitan University (MMU).

Primary objective:

To develop a care staff training programme in AAC based on the views of AAC users and nursing staff in a long-term care setting.

Study setting:

The Royal Hospital for Neuro-disability (RHN), is a medical charity with approximately 220 inpatients for both rehabilitation and long-term care, and we have a number of patients with acquired conditions who use high and low tech AAC. The Compass service is the hospital's assistive technology service and a regional specialised hub. Compass uses a range of methods to support and train nursing staff in the set up and use of AAC, but we have never evaluated these:

1. Photo guidelines (Figure.1)
2. Colour-coded labelling of device parts
3. Adaptation of software to be easier to use and understand
4. Video guidelines saved in patient's folders for nursing staff to watch in handover

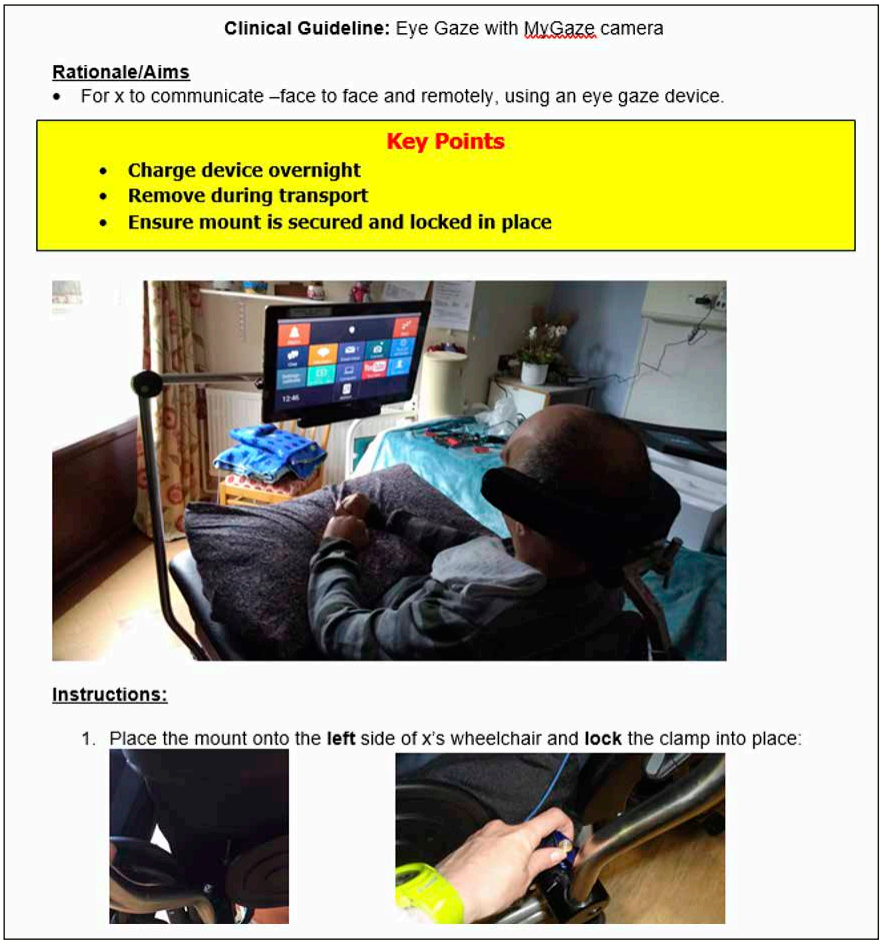

Figure 1. Example of Compass photo guidelines for using AAC

Methodology:

This study uses mixed methods research and is divided into two phases. Phase 1 will be described here.

Ethical approval for this single-site study, based at the RHN, was gained from the UK NHS ethics approval system (IRAS) in 2019. To ensure that the participants had experience of using AAC, purposive sampling was used to recruit 3 AAC users, 9 HCAs and 3 nurses from the rehabilitation and long-term care wards.

The AAC users used a combination of paper-based and electronic AAC and had acquired neurological conditions. They were interviewed face-to-face, with further questions asked and followed up through email. A Talking Mat™ was used with each individual post-interview to confirm their views.

Figure 2. Completed Talking Mat of one of the focus groups with nursing staff

The nursing staff were divided into four small focus groups, each centred around a large, shared Talking Mat as the visual focus for their debate. Talking Mats has proven effective in exploring the views of individuals with and without communication difficulties and diverse health conditions (Murphy et al., 2005). We already know that nurses benefit from peer support when engaging in research and groups are a recommended method to do this (Roxbrough, 2005). The Talking Mats approach was well received by the nursing staff, generating rich discussion and data (Figure. 2).

The questions asked in using the Talking Mats were:

AAC users:

1. How do you feel about the training the nurses currently receive?
2. How do you feel about future training?

Nursing staff:

1. How do you feel about using these different communication aids?
2. How do you feel about the training you have received in communication aids?
3. How do you feel about future training?

The AAC users' interviews were video recorded, and the nursing staff focus groups were audio recorded. These were then transcribed verbatim. The transcriptions were analysed using reflexive thematic analysis (Braun and Clarke, 2022). This approach was taken as it became clear that, as the researcher was also the SLT working with both the participants and the nursing staff, critically reflecting on my role as researcher was crucial in that any themes developed from the data would be hugely shaped by my thoughts, feelings and views.

The Talking Mats were analysed using descriptive statistics to summarise data where scores were allocated to each response to provide a total and these were then summarised visually using a bar chart. Themes from all data were then triangulated, using the Farmer et al. (2006) Protocol for Triangulation of Qualitative health research:

Some key points:

Views on current training (Figure. 3)

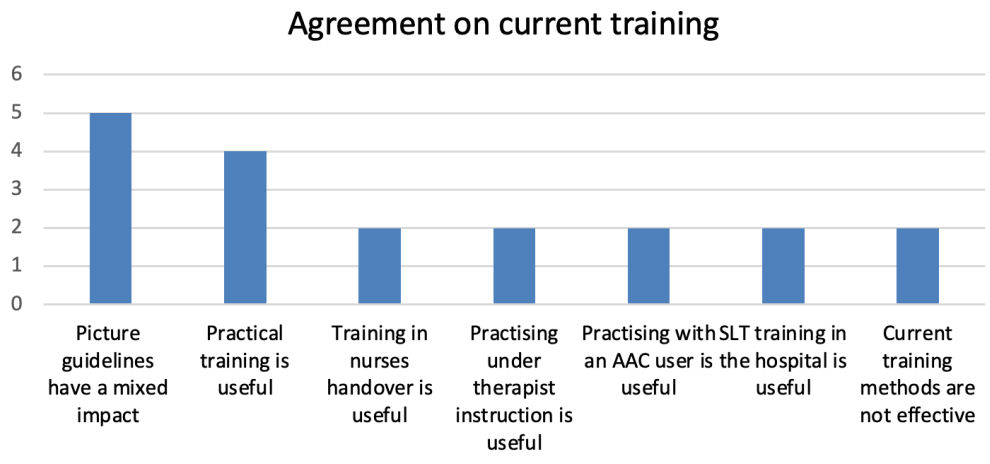

Figure 3. Summary of the triangulated data: Views on current AAC training

- Difficulties with photo guidelines: these are commonly used, but participants reported that health conditions change and guidelines do not always reflect real life. Learning about positioning for AAC from a video is easier.
- Difficulties training during nurses' handover: nursing participants reported this was beneficial as they were all present, but the time pressures in handover meant they could not focus on AAC

Preferences for training: (Figure 4)

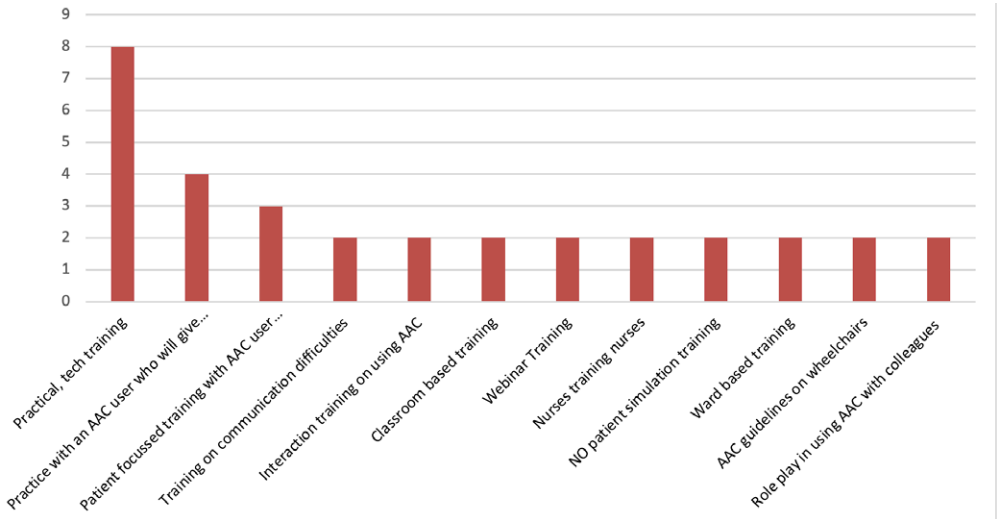

Figure 4: Summary of the triangulated data: Views on future AAC training

- Practical and hands on: participants reported wanting to see and touch devices to understand how they work and how to troubleshoot difficulties.
- Practising with an AAC user who will give feedback: AAC user participants reported wanting to be involved and to provide feedback which the nursing participants also wanted.
- Informative about communication difficulties and the rationale for AAC
- Individual, patient focussed, and not generic.

Examples of quotes from the data:

AAC users-

'*Training must be obligatory at induction'*

'Checklist order of tasks'

Nursing staff-

'The best way to train the staff if you train certain people..then we can train each other we can show each other'

'the role play with a colleague you see someone doing things you tend to remember'

Communication Matters (CM) presentation attendees feedback

A Mentimeter™ poll was conducted at the 2022 CM conference after this research was presented, to ask attendees what they find works well in training nursing staff in AAC.

Forty-four responses were received, with the following results (Figure. 5):

The results paralleled this research with involving AAC users, videos, and in-person, practical hands-on training cited as the most useful.

Discussion

AAC users and nursing staff are often excluded from research due to difficulties communicating or access to and availability of these groups. Yet they have unique insights into the phenomenon of communication through AAC and how they learn most effectively in training. This research has aimed to break down some of those access barriers to explore the views of these marginalised groups through adapting traditional research methods and providing flexibility in data collection. Through combining the views of AAC users and nursing staff, there is a desire for training that is practical, focussed, with AAC user involvement, including videos, role play and feedback.

The data from Phase 1 are currently being triangulated with the literature review and training intervention literature to feed into the development of a nurse training intervention.

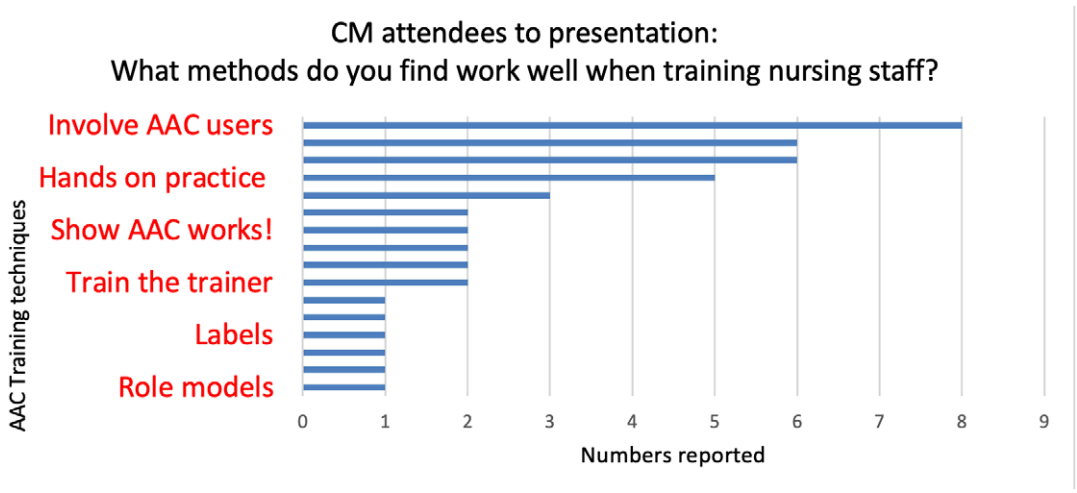

Figure 5: Summary of Mentimeter poll from CM presentation attendees

Limitations

The AAC user participants all had good language and cognitive abilities and not a sample of people with diverse communication needs, and only from individuals with acquired conditions. The nurses and HCAs had volunteered and so likely were more interested in AAC which may have affected their training views and needs.

The Phase 1 data were collected pre-COVID-19 and so results may be different now if we collected data in our post-COVID-19 era which has an increased emphasis on digital learning.

Conclusion

Nursing staff are our colleagues and partners in caring for individuals with communication difficulties and their role is vital in providing and supporting effective AAC.

This small study within a specialised setting does not reflect all settings where nursing staff work. However, the results so far have provided valuable information about what AAC users and care staff feel is useful in AAC training which will now be fed into an intervention of training that could be trialled elsewhere.

Acknowledgement

Thank you to all those who volunteered to be part of this study.

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Audit of a Bespoke Visual Screening Tool Used by Kent & Medway Communication & Assistive Technology (KM CAT) Adult Team

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Introduction

Sight loss affects people of all ages, but as we get older, we are increasingly likely to experience sight loss: one in two people aged 90 and over are living with sight loss (RNIB, 2021). Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population (Gov.uk, 2020). Up to one third of people with cerebral palsy have visual impairment and 10% have a severe impairment (Sonksen et al, 1991). Two thirds of stroke survivors have visual changes after their stroke (Stroke association 2022) and over half have visual field deficits (Rowe et al, 2013). People with Multiple Sclerosis can present with numerous persistent symptoms, with optic neuritis affecting up to 75% of people during the course of their condition and up to 62% demonstrating a range of oculomotor dysfunction (Jasse et al, 2013). People with Parkinson's and Parkinson's related syndromes can experience difficulty with eye movement, involuntary closing of their eyelids, contrast sensitivity, colour vision and seeing movement (Parkinson's UK 2020)

As the statistics show, sight loss is critically relevant to those who may be using some form of AAC. It cannot be assumed that vision has been routinely looked at. Those with the most complex disabilities are less likely to be assessed (Schenk-Rootlieb et al 1992). This is also likely related to difficulties in accessing appropriate services who can effectively accommodate their needs. It is also worth remembering that glasses alone will only address refractive errors. Additional information about a person's visual skills is needed for a comprehensive AAC assessment.

A new system of screening and assessment was introduced for all KM CAT clients at the end of 2017. This was in response to a number of clients who were retrospectively assessed and found to have visual difficulties affecting their use of AAC. The screen covers relevant history related questions such as eye test history, type and prescription of glasses, and any changes noticed by the client. There is also a section based on the Seeability functional vision assessment tool (2019) which requires observation of behaviours. The assessment covers acuity, contrast sensitivity, ocular alignment and control, and visual fields.

It was agreed that all new KM CAT clients should be screened by whoever was first to assess them, and that any clients who scored a 'yes' on any point required further assessment of visual skills by one of the occupational therapists. This was reviewed after 6 months, and the threshold was changed to exclude further assessment for those only needing a new standard eye test as theirs was overdue.

After a period of use with a number of clients, an audit of the screen and a review of visual skills assessment has been completed to see whether the screen picks up those in need of a more in-depth assessment, and whether the assessment covers the areas it needs to.

Methodology

All KM CAT referrals between April 2019 and March 2020 were selected from the Trust information portal. These included all new assessments, transitions, and reassessment clients. Data was filtered to show who was screened, who wasn't, whether further assessment was indicated, and whether any onward referrals or recommendations were made. It also captured whether changes were made to KM CAT assessment or input as a result of information captured in the screen.

All review jobs, planned preventative maintenance requests, and duplicate clients on the system were excluded from the data collection.

Results

A total of 25 clients met the inclusion criteria. These were broken down into 15 new assessments, 5 reassessments, and 5 transition clients (current AAC users moving into area or from the Children and Young Peoples team in Kent).

None of the transition clients were screened. 4 out of the 5 reassessment clients were not screened. This was usually because they had already been screened in an earlier assessment job. One did indicate an assessment was needed, but this was not completed as client declined any further intervention from the team.

See figure 1 for a breakdown of the results for all new assessment clients.

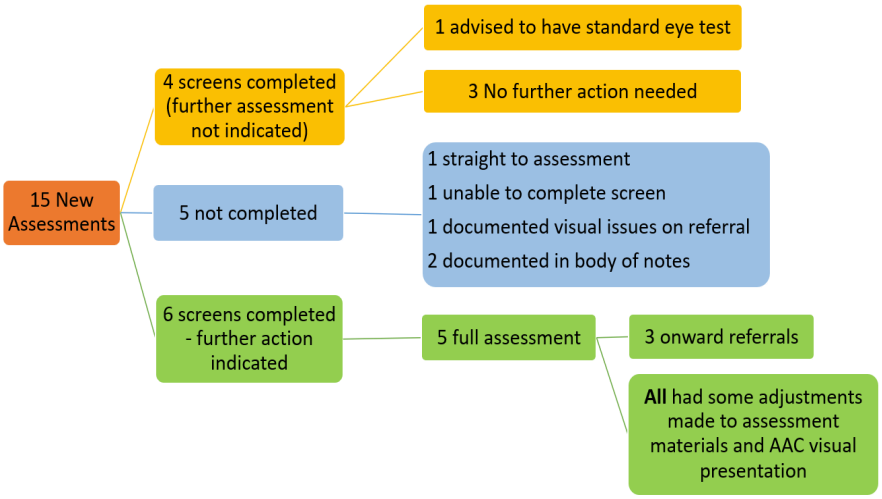

Figure 1 – New Assessment Audit Outcomes

Discussion

A total of 5 new assessment clients had their vision fully assessed by one of the occupational therapists in the team. Of these, 3 were also advised to seek specialist review:

- One was referred back to the neurologist for review;
- One was advised to make an appointment with their neurologist (and possibly an orthoptist if recommended);
- One was advised to see an optometrist for a standard eye test as they had not been seen in the last 3 years and appeared to be struggling with acuity.

Any clients advised to see another professional were given a written report detailing the outcome of the assessment. It was acknowledged that the assessment completed was a gross assessment of functional skills and that the findings of the specialist may differ. Details of how the assessment was completed were also included to aid any other professional in their understanding of the needs of this client group as they may too have to adapt their approach to assessment. This has been recognised as good practice in other areas who similarly adapted their assessment process (Fanning et al 2021).

All clients who needed a full visual assessment had adjustments made to the team's input. This included adaptation of further assessment tools or software, such as increased font size, auditory feedback, change of software layout, alternative resources for language assessment, and adaptations to low tech etc.

No transition clients were screened. It was not done as they were not a 'new' client, they already had a communication aid, and it was assumed that the previous specialised service team had assessed their visual abilities.

Changes made following the audit

It was agreed as a team that a section should be included in the transition referral form to prompt the referring service to pass on any relevant details about their client's vision. KM CAT adult team also plan to ask clients at their first appointment about their vision to ensure nothing is overlooked.

One screen completed was for a client who later required a full assessment because of his condition (MS). On review of the screen, it appears that the guidance relating to when to request a full assessment by the occupational therapists was followed. An additional question was added to ensure all clients who have a diagnosis where visual deficits are a known feature are referred on for full assessment so their problems are not missed on screening.

A more recent update to the assessment, which was not captured as part of this audit but has since been added, is colour perception screening. This was included following some research into this, and the potential for colour perception deficits in conditions such as Parkinson's, dementia and traumatic brain Injury (Parkinson's UK, 2020, Kim et al 2022, Greenwald et al 2012)

This test is based on a non-numeric version of the Ishihara test and has been adapted so it can be used with eye pointing (see figure 2).

Limitations

This audit is based on a representative, although limited, number of clients. It must be noted that all bar one of the screens were completed by an occupational therapist, so there may be a bias in terms of the numbers of screens completed, and those that lead

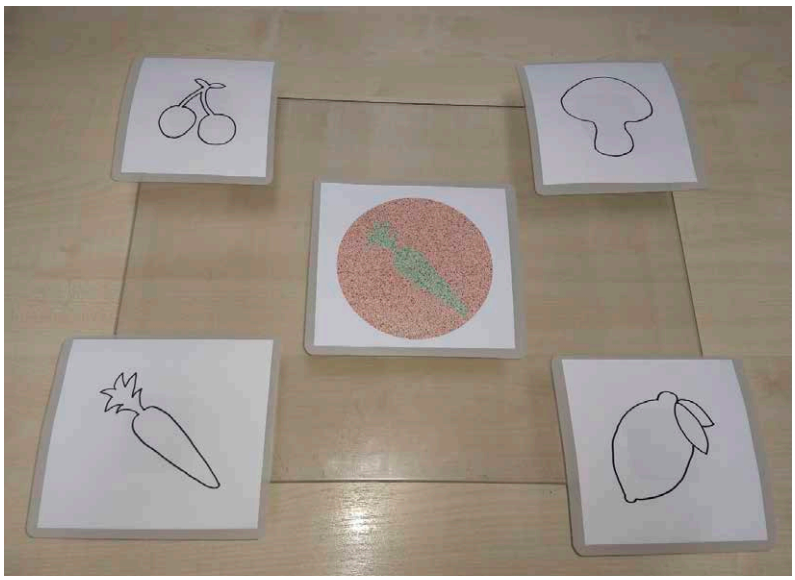

Figure 2 - Eye Pointing Ishihara Test with Fruits and Vegetables

to assessment. A review of staffing mix at the time showed that the team was a speech therapist short so most new clients were initially seen by the occupational therapists.

Four clients had the assessment documented in the body of the notes, rather than on the specific assessment form. This is likely borne out of familiarity with the process by the occupational therapists completing the assessment, having created both the screening and assessment tools. On review of the outcomes from assessment, this does not appear to have affected the quality of the information gathered or intervention received.

Conclusion

The vision screening and assessment process introduced are useful tools to highlight those who may need adaptation to their intervention or further review by a vision specialist.

The screening tool appears to be picking up on those requiring full assessment. With the changes made following this audit to increase its sensitivity, all clients requiring further assessment should not be overlooked. The transition referral form has been updated to allow for relevant information about vision to be included. Clients will also be questioned about their vision on their initial appointment with the adult team. The addition of the eye pointing Ishihara test to the full assessment tool will further enhance the assessment process.

A further review of the process may give a better indication of the sensitivity and usefulness of the tools, particularly if it is being completed by different members of the team.

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Archery, Abseiling and Canoeing AAC in the Great Outdoors

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Bendrigg Trust is a registered charity (508450) with over 40 years of experience. We aim to promote inclusion, encourage independence, and build self-confidence through the safe provision of high quality outdoor adventurous activities for disabled and disadvantaged people. We work with schools & colleges, individuals and families, groups such as charities, and we also offer consultancy.

For many years, Bendrigg has been breaking down barriers to participation by showing people what is possible by inspiring them to achieve their full potential through accessible adventure, offering financial support for our courses, and through some of our inspirational films.

One primary barrier that we hadn't tackled significantly was that of hidden disabilities: those disabilities you can't see and are not immediately apparent. These can include visual or auditory disabilities, sensory impairments, speech impairment, learning disabilities, autism, chronic illnesses and many more. The barriers for people with hidden disabilities can be different to those people with physical disabilities.

Bendrigg's 'Adventure for All' project was kindly funded by the Scottish Power Foundation in 2018 and 2019. The hidden disability project element aimed to address many of these issues through 4 discrete areas:

- **Equipment:** such as portable hearing loops, AAC resources, interactive play panels and safety beds. Allowing people to feel safe, comfortable and in control;
- **Training:** enhance the skills we already have amongst the team and to share our knowledge and expertise with other centers, businesses and individuals. To foster a greater understanding of hidden disabilities and encourage more providers to be inclusive;
- **Information:** such as prior knowledge of the layout of a bedroom through virtual tours, the order of activities or what equipment they might be expected to wear can make a big difference and help people to cope with a visit;
- **Sponsorship:** we all know the cost of living is huge and when you add in the disability price tag, many things seem out of reach. Our sponsorship fund helps individuals and groups make a trip to Bendrigg more financially achievable.

As you can see, the hidden disability project element was enormous, but it has, and is, significantly enhancing our provision for people with hidden disabilities.

This article will focus on AAC in the great outdoors.

One thing we were hearing from guests when they booked was: "They use AAC, but we will just leave it at home. You can't use AAC at an outdoor centre."

NO! At Bendrigg, we want everybody to have a voice, everybody is part of our team, and everybody needs to be listened to, heard and understood. Everybody is valued for the part they play in our team. Without access to communication, we disempower people, and that is not ok.

Bendrigg's staff team is made up of a unique bunch of people from SEN teachers, AAC specialists, sensory impairment specialists, OTs and physios, all with a range of skills in AAC. The diverse skillsets of our team have enabled us to take a truly holistic approach. We are in a privileged position to be able to show the world that AAC shouldn't just be left in a cupboard in the classroom or in a therapy session; it should be part of everyday life in every situation, including in the great outdoors. But we acknowledge that there is work to do.

As a center, Bendrigg's AAC background was limited, but we were not doing a bad job. We have a number of staff with a hearing impairment so there were a couple of people who knew how to sign BSL, and a few people with a little Makaton experience.

We had our 'Bendimen' symbols created in the late 80s by a young man from a youth project. The originals consisted of a person doing one of a selection of 26 activities. These are used during reviews, on activity timetables, and historically as a coloring book/diary for visiting groups. They also formed our logo, the one we still use today.

We began the Hidden Disabilities project 4 years ago following consultation with our staff team and our visiting groups. They are the experts, and we really value what they have to say. Feedback led to us introducing many changes such as eye gaze boards, enabling independent access to the tuck shop.

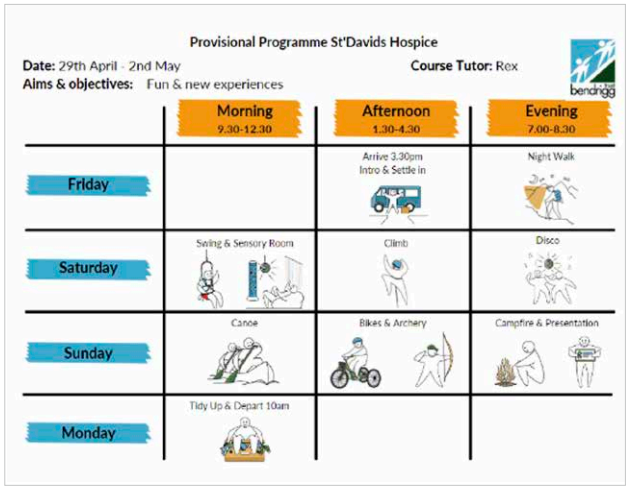
We realise that our staff are our most important resource. We began to expand their skills. This included:

- providing staff with a greater understanding of communication and AAC how we could use it in our practice. What is practical, what is possible?;
- knowledge of communication support strategies, how and when to use them?:
- a 2 day Makaton course enabling staff to boost confidence, refresh skills and learn new ones. We even created a Bendrigg Makaton countdown to Christmas. Our social media nearly exploded when we missed a day; we hadn't realized quite how many people were watching it. Today, we maintain those skills by offering sign a of the week and regular Makaton refresher courses.

The understanding of Makaton has enabled guests to communicate with our staff and vice versa. One tutor reported back that a little boy had used Makaton to communicate to him *'Call Mum, tell I go zipwire'.* Together they video called Mum and told the story of her son's adventures.

So the project got off to a great start until we were hit with the pandemic. 15 months of closure. It was devastating but also very useful as we had lots of thinking time.

Sadly, the funding (with consent from the donor) was reallocated to core costs which helped to keep Bendrigg afloat while we were closed.



Slowly, we began to re-open after lockdown, and we began reviving the project. We put in numerous funding bids. Some were successful, others weren't. But we got there.

The next phase of the project was our Bendiman symbols, they underwent a whole new update and became gender neutral and were renamed Bendifolk.

Their use is extensive throughout the centre, labelling areas as way markers and on our site map, making it more accessible to those with literacy issues. They are used as communication symbols on schedules, helping people understand what's now and what's next, and on communication aids, in downloadable pages, in course reviews and much more. They are placed on our Smooth Talkers loaned from the charity, 1 Voice - Communicating Together. They are a great visual aid to help people with additional communication needs prepare for their trip, use at the centre and to help communicate about Bendrigg once they return home.

The challenge of updating the Bendifolk took about a year, first finding a graphic designer, somebody who understood their purpose and use.

Thankfully our corporate partners, Amphigean, stepped in and have created these Bendifolk graphics as a service in kind. They have been absolutely amazing.

We went through a consultation process with our tutors and guests who told us that they loved the originals, so we didn't want to stray from the original too much as we knew many people were using them pre, during and post trips to Bendrigg.

We consulted with a visual impairment specialist over the design. They suggested placing the colour within the symbols to highlight the activity that's happening. We have them in a variety of formats too: high contrast, inverted, and transparent. We also took advice on how we could use these in a 3D version for an exciting future project.

The next phase involved making the centre more accessible to people with neurodiversity. Coming to a new place is a challenge, let alone taking on new experiences such as climbing, caving, or canoeing.

We have a virtual taster available on our website which helps people to understand what facilities we have on offer. We have also created a 360-degree tour of Bendrigg and its grounds.

The Bailey Thomas Charitable Trust funded this project phase which saw the creation of twenty 'activity stories' in order to help ease anxieties before a visit.

Following the same principles as 'social stories', (C, Gray, (1991)). The 'activity stories' provide a step-by-step visual description of an activity detailing answers such as where the activity happens, who is there, what happens and why.

The physical production of the books was an interesting process. After a period of trial and error, we settled on Premium never tear. A plastic printable sheet is not something that we would usually advocate, however it is tough, hardwearing and can take the knocks and blows of its users and the outdoor environment. We are also providing them as a free resource so that people can print them off from our website. We also offer them in an editable format so that if, for example, a client needs more specific details adding, people can add to them.

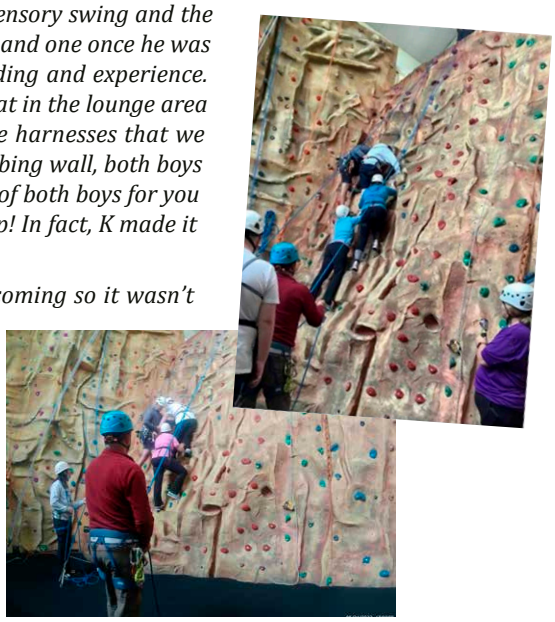
The feedback and effectiveness of the activity stories has been incredibly positive. Hence, we took the concept further and created videos which mirror the activity stories. The videos provide real life visuals in-situ and can be accessed by our visitors at any time before, during, and after a visit via a playlist on our YouTube channel. All have the option of switching on or off the subtitles.

They are also embedded with Makaton signing to support people who need support with receptive language. Each video is approximately 2 minutes to enable the person watching to sustain focus. They follow the same scripted narration as the books. They provide positive feedback and information to develop self-esteem, whilst also providing a way to describe to others what is going to, or has, happened.

Both the stories and videos use gentle and supportive language to present information in a literal, 'concrete' way, with the aim of supporting a person's understanding. The videos help a person to cope with changes to routine and support executive functioning (planning and organising) by informing them of what comes next. They contain coaching sentences which offer support to those who need it, for example, what to do when excited or scared, and how to cope with something new.

The feedback from our groups has been incredible, with some people going as far as saying we should sell them.

One Head Teacher said: *"On our first full day at Bendrigg, we spent time on the sensory swing and the zipline. Two of our young men (R and K), both refused to do either, one completely and one once he was strapped in. Both these activities were far outside the realms of their understanding and experience. Over lunch, both announced they weren't going climbing! After we had eaten, we sat in the lounge area and started looking at the climbing social story. We read it and spoke about the harnesses that we had used in the morning and what would happen. Before we went over to the climbing wall, both boys decided they would try the first step and then come down! I have attached photos of both boys for you to see what happened next! As you can see, neither of them stopped at the first step! In fact, K made it all the way to the top!*



I am fairly confident that the activity story helped both boys picture what was coming so it wasn't a total surprise, and while the stories didn't get them up the wall - that was entirely their own motivation - the stories got them onto the first step!

After that, the group looked for the activity stories and had a read through before we went. They were a really helpful resource that all of our pupils (and staff) found useful.

Thank you for all the hard work you put into them. They are a real asset to the work you all do at Bendrigg."

If you would like to hear more about the project or about The Bendrigg Trust please don't hesitate to contact us.

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C, Gray, (1991) https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-coversations

The Activity videos the article talks about are all available via this link: https://www.bendrigg.org.uk/already-booked/communication-support/

The Role of the AT Mentor Service in Achieving Meaningful but Hard to Tackle Targets: A Range Of Case Studies to Demonstrate and Plans for the Future

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The AT Mentor service was launched in 2016, developed at ATtherapy and originally managed by Fran Sephton, Clinical Manager and highly specialist Speech and Language Therapist, who identified a need for meaningful support and communicative opportunities for not only new and emerging AAC users, but also those who had established AAC systems but were going through times of transition or increased need.

We decided as a team to carry out some case studies to demonstrate our service aims.

Traditional therapy tends to be carried out either in one to one or small group sessions. The AAC user interacts with the Speech and Language Therapist whilst working upon aims based around language and practical skills such as building sentences using their communication system, learning how to scroll through pages or turn the volume up or down. Therapy is often based upon repairing what has "broken" (Lyon 1998).

Interventions and new skills require embedding within the everyday environment, and "AAC interventions need to focus not on the demonstration of isolated skills within labs, clinic rooms, or therapy sessions, but rather on actual communication performance within naturally occurring contexts" (Light, 1989; Williams, Krezman, & McNaughton, 2008). This shows further that we need to be making interventions more meaningful and functional for the users. The turning up and down of the volume may be important, but if the user does not know when to do this within everyday interactions, lacks confidence to do so or is not motivated to do this then it is not a useful skill to have.

This was further backed up when we considered Light's model of communicative competence which suggests that the attainment of communicative competence by individuals with complex communication needs is impacted not just by their linguistic, operational, social, and strategic competence but also a range of psychosocial factors including motivation, attitude, confidence, and resilience (Light 2003).

This led us to the conclusion that the aims of the AT mentor service must target those psychosocial factors that cannot be easily reached within regular therapy sessions. This did not exclude work in other areas but led us to place a focus upon those hard to attain targets, such as being motivated to use a high-tech communication device and having the confidence to do so. If a user, for example, has never met another AAC user then this is going to negatively impact upon their confidence to use their system meaning they may not reach their communicative potential. They are unlikely to be motivated to use their AAC system, just as a verbal communicator would be loath to speak if no one was verbally interacting with them.

The research was considered along with other factors that the mentors reported as presenting barriers and this included:

- No opportunity to meet other AAC users;
- Lack of confidence in using AAC as limited exposure to experience others using it;
- Being ignored/addressed through parents or carers;
- Lack of modelling of AAC system use.

Speaking to the mentors also revealed some things that had helped them:

- Finding someone with the same voice;
- The system itself helping them to express themselves;
- Accessing local AAC social groups.

The aims of the AT mentor service, therefore, take these factors into account and our case studies will demonstrate them:

- For mentees to build confidence using their AAC across environments;
- To improve self-esteem;
- To support and encourage mentees to use their AAC;
- To provide training and support for the team around the mentee;
- To develop opportunities to meet other AAC users.

Case Study 1

K is 10 years old, attends a mainstream school and is seen by Sam Sillars, AT Mentor.

K has Cerebral Palsy and is the only communication aid and wheelchair user at her school. Sam experienced many of the same issues as K throughout her mainstream schooling which enabled her to relate to K quickly.

K was referred to AT Mentor service, because she was starting to notice the differences between herself and her peers. She was becoming more aware of her disability, and she started asking why she is the only one in school who couldn't run, walk or speak. It was distressing for both K and her family. Even weekends had become a time of anxiety rather than fun as K worried about her return to school on Monday.

K's parents and her school wanted her to have access to a mentor who used a communication aid and had experienced the mainstream education system. This meant that K could get emotional support from an adult with similar lived experiences.

K began to participate in 30-minute zoom sessions once a fortnight. These sessions are funded by K's school. K's emotions and any difficulties she is having are discussed with support provided and strategies explored. The look of delight on K's face, not long after they first met, when Sam was able to share a story about similar experiences she had at school, was absolutely priceless. She was amazed and comforted to hear that it was not just her experiencing these things.

The aim for K's mentoring sessions are to build her confidence in herself and her communicative abilities. The sessions have also provided her with that essential opportunity to meet another AAC user.

Every mentoring session has been successful and enjoyable for both parties, and K has fully engaged.

Sam has designed the sessions to encourage and support K to initiate conversation and discussion by having one or two questions to ask her at the beginning and then following her lead. K very quickly took over the discussions to talk about her experiences and how she feels about them.

K's parents and school have been thrilled with the results of the mentoring and are keen to continue, particularly with her move to secondary school next year.

Case Study 2

J has been seen by Gregor Gilmour, AT Mentor, monthly at school. He is 15 years old and uses a Gridpad accessed through eyegaze. Sessions were trialled in several venues initially, however J is easily distracted, and therefore school was the most effective environment.

J was reluctant to use his device and was even loath to take it with him anywhere. He really lacked motivation and confidence to use it.

Gregor started off his mentoring with J gradually to build a relationship. He provided an online training session for J's support team where ideas for encouraging and motivating J to use his Gridpad were brainstormed in addition to general advice about using and modelling AAC.

Gregor was able to see early on that J could use his device as he spent a great deal of time in one session saying goodbye! He obviously wanted the session to end! This showed that he did have the skills to use his AAC but needed to develop his confidence in not only himself but also his ability to communicate using his device and his motivation to do so. Motivation was a big factor for J.

Gregor made activities that were appealing to J, often food related as this is very important to J. Over time, J engaged more in the sessions, building up his acceptance and use of his device. Training of his team, as mentioned above, meant that more opportunities for J to communicate using his device were facilitated, and J was encouraged and motivated to make the most of these.

J's monthly sessions continue at school.

Case Study 3

D is a 12-year-old seen by Laith Richie, AT mentor. He has an acquired brain injury from birth and cerebral palsy with severe dysarthria which affects his speech. D was referred by his case manager who wanted to:

- Build motivation and confidence in using his device;
- Meet other AAC users;
- Provide support for those around him to understand and use his device.

D had a Gridpad that had been kept at school and never brought home. Nobody really knew how to use it so there was no personalised vocabulary for D. He had limited opportunities and reasons to communicate, mainly just to get his basic needs met, and people often asked him yes/no questions to communicate. At the time of writing this, D had met Laith three times: in a bowling alley, at home, and at school.

At D's first session, he looked at Laith with amazement and then began to communicate using his device with support. At his second session, his family were shown the device and, through observing Laith use his own AAC, were thrilled to see how it could be used for D to communicate as they had no idea of the possibilities!

By the third session, D was keen to show Laith the new word he had learnt and used that week on his device and was much more engaged in the session and keen to take part using his device. He will be continuing his sessions with his new mentor, Gregor, to build on the fantastic progress made so far.

Carrying out these case studies allowed us as a team to reflect upon the service and make future plans including:

- Exploring more ways to bring mentors and mentees together;
- Letting more people know about the service;
- Recruiting more mentors.

We are excited to move forward to the future!

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Valuing Every Language: Exploring Best Practice when Working with Multilingual Clients

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Introduction

Research shows that 0.5% of people within England benefit from the use of AAC (NHS England, 2016). Statistics on bilingualism and multilingualism in the UK are less precise, but recent research shows that 34% of children in Britain have at least one parent from another country, and almost 20% of primary school children speak English as an additional language (Office for National Statistics, 2018). However, research into multilingualism and AAC is very limited, and there is little information available beyond anecdotal evidence as to how many people who use AAC speak multiple languages.

However, the options available for electronic AAC in languages other than English are limited. The languages that are served tend to be those spoken by wealthy, Western countries (for example, French, Spanish and German). This means that there are hundreds of languages spoken in the UK for which there is not an off-the-shelf solution for either electronic or paper-based AAC.

At Ace Centre, part of our remit is to provide the NHS England Specialised Service for AAC in the North West and Thames Valley and Wessex areas. When delivering this service, we aim to deliver equitable provision to all clients. However, due to the limitations in off-the-shelf solutions for AAC in languages other than English, we wanted to see whether an equitable service was provided across different clients' languages. To do this, we completed an audit of our service and thematic analysis to evaluate how well we were meeting the needs of our bilingual clients.

Quantitative Results

The first step was to identify how many bilingual or multilingual clients we had seen and to note which languages they spoke. Once this list was compiled, we then worked to identify how well we felt we had met their needs in their second language. Needs were rated as being fully, partially or not met according to the following criteria:

- Fully Met – Full vocabulary provided in both/all languages (OR partial vocabulary provided when this is sufficient to meet their needs e.g. if an individual requires a second language only to access certain phrases such as religious or cultural greetings);
- Partially Met – Partial vocabulary provided in one or more languages, but this was insufficient to fully meet their language needs;
- Not Met – Nothing of substance provided in one or more of the required languages.

Across both of our regions, we found that from the start of the NHS contract in January 2015 until the time of the audit in February 2022, we had seen 3,150 clients. Of these, 127 were multilingual (two or more languages). This works out at just over 4% of our total client population. These clients represented over 50 different languages between them – although there were some more common languages (see graph). 29 of the languages were only spoken by one client. Interestingly, some of the most common languages spoken by our clients (e.g. Urdu, Punjabi and Hindi) are not currently served by any off-the-shelf AAC packages.

Clinicians working with these clients rated their needs as being fully, partially or not met. There were 27 clients who could not be rated – this may have been due for example to the client still being in the assessment process. Of those clients who could be rated:

- 15 clients were rated as their needs being fully met in both languages;
- 21 were rated as their needs being partially met;
- 64 were rated as their needs not being met.

Qualitative Results

With 64 clients not having their needs met at all, we wanted to find out why. Specifically, we wanted to identify what factors influenced whether a client's needs were met or not. To do this, we carried out interviews with clinicians who worked with the bilingual clients. The interviews covered a third of our total population of bilingual clients – this third was split proportionally across clients rated as 'Not Met', 'Fully Met', or 'Partially Met'. The interviews were recorded and transcribed so that we could analyse them for any recurrent themes, using the process of thematic analysis. After carrying out the thematic analysis, we identified four major themes:

- 'Clinicians' Knowledge and Attitudes' – ***factors related to the knowledge and attitudes of Ace Centre clinicians;***
- 'Input and Support From Others' – ***factors relating to the level of support that an individual received from the people around them, including from family, friends and professionals;***
- 'Multilingual Need' – ***information relating to the actual need of the client in both English and any other languages;***
- 'Availability of Resources' – ***availability of pre-existing solutions in languages other than English, including the availability of keyboards and system voices.***

Some factors had a positive influence on provision (i.e., the client was more likely to receive appropriate resources in all languages required), and some had a negative influence (i.e., the client was less likely to receive resources that met their needs in languages other than English).

Positive Influences

Increased knowledge – In general, an increased knowledge and awareness of the issues surrounding bilingualism (both for Ace Centre clinicians and for local therapists) led to better provision in all languages required. We found a positive change over the past seven years in clinicians' reported awareness of bilingual needs - multiple clinicians expressed regret that they had not had this knowledge to support historic clients.

Family involvement - For some clients, the family were very involved in the assessment process and keen to assist with this. These clients were often more likely to receive bilingual provision than those whose family were not supportive of AAC or the assessment process. If a family were involved in the assessment and valued multilingual provision highly, they were able to advocate for the importance of language provision.

Client literacy - When a client was literate, it was often easier to provide a solution. This is due to the availability of standard keyboard layouts in a wide range of languages on commercial hardware such as iPads and Windows tablets.

Negative Influences

Assessment complexity – Through the interviews, it was found that provision in languages other than English was less common if the assessment had other complexities. For example, if the client had complex access issues to be resolved, or a high level of fatigue limiting the length of the session. Additionally, many bilingual clients who had a pre-existing monolingual English AAC system did not receive input relating to additional languages as clinicians were reluctant to alter a setup that was working well for the client.

Off-the-shelf solutions - Many clinicians felt that they struggled to provide suitable AAC resources to a client where there was no pre-existing solution commercially available. As commercial AAC packages tend to cover a small number of languages (i.e. often Western European languages), there was a large number of clients for whom no off-the-shelf solution existed.

Proficiency in English - Clients who were able to speak English at their appointment were less likely to receive AAC in their other languages. This appeared to be due to an assumption that the client would be able to communicate in at least one language, so providing support in another language was less critical. This was in contrast to clients who were monolingual in a language other than English, who often received provision to ensure they were still able to communicate.

Moving forwards

Knowing which factors have a positive and negative influence on multilingual provision means that changes can be made to encourage best practice moving forwards. For example, knowing that assessment complexity has an impact on provision means that care can be taken for these more complex cases in the future to ensure adequate time is allotted for discussions regarding different languages. This is in line with guidance from the Royal College of Speech and Language Therapists (RCSLT) that bilingual clients should be assigned more time than monolingual clients in order to provide an equitable service (RCSLT, 2018). As awareness and understanding of bilingualism seemed to have a strong positive influence, it is also important to invest in training for professionals working with multilingual people who use AAC on this topic to improve client outcomes moving forwards.

Multilingualism is a wide spectrum, and this study highlighted the differences in language need between different individuals. Some clients were fluent in multiple languages, and required a full and robust system in all of these languages. However, there were other individuals who did not require a full system in all known languages. In some cases, the client had no remaining communication partners with whom they used a specific language. For others, their communication partners in a specific language were people who were familiar with them and better able to understand their speech (e.g. family members speaking a home language). This meant that the need for AAC simply was not there in some cases.

For other clients, there was a clear discrepancy in proficiency between the languages used. For example, some clients were proficient in their use of English, with access to a second language for very specific situations such as for communication with a certain family member.

This study highlighted the importance of gathering good quality information regarding clients' genuine language needs, as this will inform the type of provision in each language.

The study also identified areas where more research is needed. One prominent finding was that some clients decline multilingual provision, even when there is a perceived need for it. It is not always clear why this decision is made by the client, and therefore it is difficult to know whether a client has been left with an unmet need. It would be useful to gather more information around the reasons why people decline multilingual provision in order to see if there are any further steps that could be taken by clinicians to meet their needs.

Finally, the findings regarding provision when off-the-shelf solutions are not available again highlights the importance of ongoing product development in languages other than English. As clinicians, it is our job to advocate for the needs of our clients and encourage the development of good-quality resources covering a range of different languages.

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Jacdac - A Framework to Turn Assistive Technology Ideas into Products

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Introduction

How do we get from an idea for a device to enable augmentative and alternative communication (AAC) to a new assistive technology (AT) device? Many people have ideas for new AT devices. How can we make our ideas for assistive technology reality in a safe form that people want to use and that can easily be distributed? The Jacdac project run by Microsoft aims to enable people without specialist engineering skills to create technologically sophisticated devices. A series of plug-together boards can be easily programmed and configured through a web browser interface.

The need

Everybody who uses AT has their own unique set of needs. There are many gaps in what is available from off-the-shelf AT devices to fill all of these needs. Many people who use AT or work with people who use AT have ideas for AT devices to fill these gaps. Until now, knowing how to turn these ideas into prototypes for evaluation requires expertise. Moreover, turning a promising prototype into a reliable and affordable product requires specialist skills, equipment and money. AT devices are often only needed in small quantities, making them disproportionately expensive to develop and manufacture. As a result, many good ideas for AT are never implemented. It is a shame that so much of the ingenuity of the community who are involved with AT is never translated into useful devices.

Even if a working prototype is made and tested, how can the device be scaled to enable all the people who could benefit from the device to obtain it? The traditional method of getting from a prototype to a product is complex and daunting.

The aim of the Jacdac project is to enable people who have ideas for technology devices to be able to create them with a minimum of barriers. One phrase used in the project is 'democratising hardware' meaning to enable people who do not have a background in electronics or programming to still be able to create novel and useful hardware devices.

What is Jacdac?

Jacdac is a system that allows small sensors and devices to be connected in a way that the assembly recognises what is being added or taken away. Jacdac modules are low-cost and low power. Each module has a cheap microcontroller that identifies the board to the main 'brain'. As microcontrollers suitable for this project now cost as little as under 10p each, it is inexpensive to add one to each board. An example Jacdac assembly is shown in Figure 1. The Jacdac brain is the micro:bit in the centre of the figure. A slider, button, ring of RGB LEDs and a rotary controller are attached to the brain. There are a range of other Jacdac brain modules available.

Figure 1: Jacdac modules connected to a micro:bit brain

We take for granted that we can plug a keyboard, mouse or other device into our laptops using the USB interface. Some of us may remember when adding a mouse or keyboard to

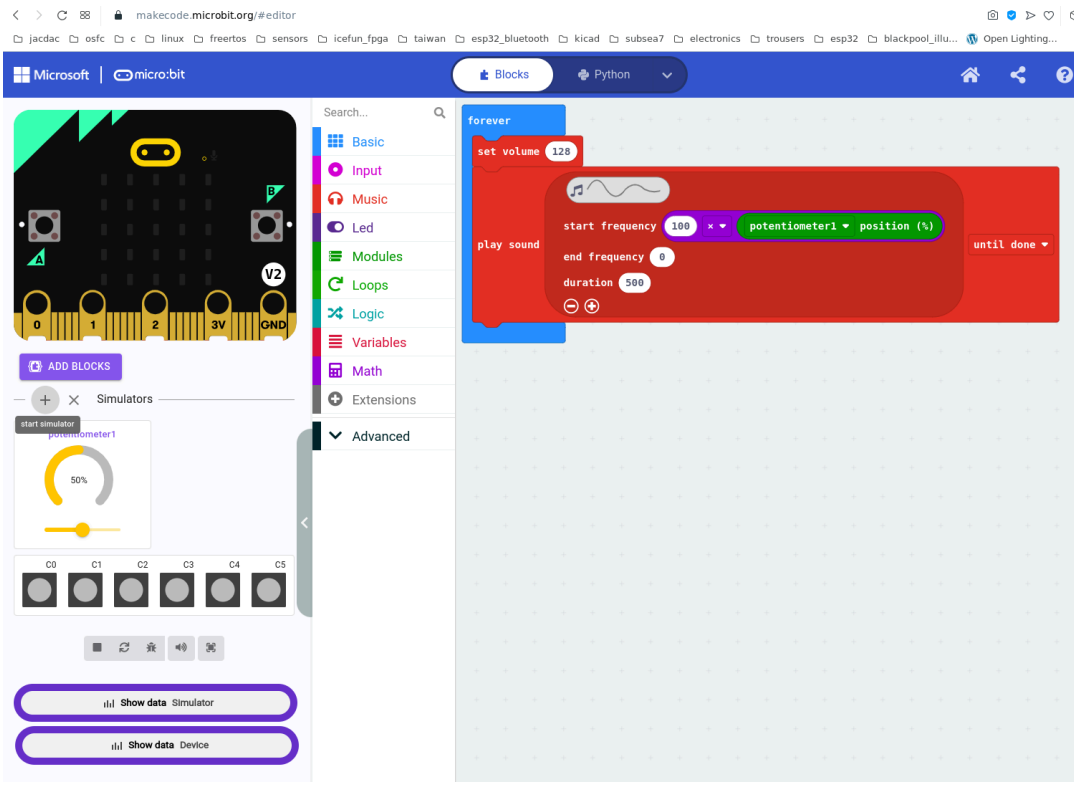

Figure 2: MakeCode interface showing Jacdac blocks with a flex sensor and touch sensors

a PC required that the PC was rebooted to enable the mouse or keyboard to be used. Jacdac takes the USB plug-and-play concept to the embedded hardware world. As we plug together the components of our system, the brain recognises each of the components. If the assembly is connected to the web-based MakeCode (https://makecode.microbit.org) coding environment, the programming blocks for the modules connected to the Jacdac assembly are automatically loaded as the modules are connected – see Figure 2. This integrates the hardware and software development.

Each of the modules in the Jacdac system conform to a standard which means that so long as a module is created to this standard, it can interact with the Jacdac system. The project is open-source and hosted on GitHub (https://microsoft.github.io/jacdac-docs/). Boards can be created using open-source and freely available software such as KiCad. Programming can be done using the free and open-source MakeCode web-based programming environment. MakeCode was developed to help school students learn programming, so is user-friendly.

Other prototyping frameworks

To avoid designing and building at a component level, which requires a specialist skill-set, we often adapt pre-made modules to create a prototype for use in AT. Often, these same modules are incorporated into commercial products that are manufactured in low volume. A high-volume product is more likely to have custom made circuit boards without these pre-made modules due to the economy of scale.

There are many existing technology platforms that offer these pre-made modules. This list of platforms include Arduino, Raspberry Pi, Mikroelektronika and Sparkfun Qwiic. Each of these systems offers a range of boards that connect using a connection system that is unique to that system.

Each of the platforms has their own set of extension boards. Common limitations of these platforms are:

- Initial setup and programming can be difficult without prior experience of programming.
- The systems require the developer to have a detailed knowledge of the hardware configuration of each module and to change the system's software each time that a component is added or removed.
- The assembly quickly becomes bulky.
- The number of boards that can be connected is limited.

For instance, the popular Arduino microcontroller boards have a range of extension boards, known as shields, that connect to the top of the Arduino microcontroller board. These shields add a variety of functionality, such as touch sensors or relays for operating external devices.

To access the shields that are connected to the Arduino, the Arduino needs to be programmed. The programmer needs to have a detailed knowledge of the hardware that was added and know how to configure the assembled system.

Mikroelektronika has a range of development boards for popular microcontrollers. These boards have a range of add on boards known as Click boards - there are over 1000 of these now available. Again, the functionality of these boards is enabled by programming the main controller. Jacdac has an interface board that allows Click boards to be included in a project.

Jacdac features

Jacdac has a range of features that overcome the existing limitations identified in earlier hardware development platforms. These include:

- Automatic recognition of the boards being attached or disconnected to the system.
- Easy to program using MakeCode.

MakeCode features include:

- Easy to use drag-and-drop block-based programming.
- Jacdac modules can be simulated without needing the hardware.

Progress

A successful 'hackathon' was held in 2021 using an early version of the Jacdac system (Devine et. al. 2022). A video of the event can be watched on the Project MakeAccessible website (https://www.microsoft.com/en-us/research/video/project-makeaccessible/).

A second 'hackathon' was held in 2022 using a wider range of Jacdac modules.

There is ongoing development to help automate the design of the Jacdac system, for instance by automating the layout of the components. This research is ongoing at Lancaster University.

Anybody who works to develop new devices will tell you that making a case for the finished device can be time consuming. Automating casing design is one of the areas being looked at by the Jacdac development team. There are two main approaches for automating generating cases - repurposing off the shelf cases or automatically generating design files for 3D printing a case.

With the support of the research group that I work with at Lancaster University, I designed, built and tested a switch adapter board for the Jacdac system - see Figure 3. This allows a Jacdac assembly to either control switchable devices or for a switch to be used as an input to control the Jacdac assembly. The board has two channels. The board has a 3.5mm socket for each of the two channels. If the board is used to control a switchable device, then a double ended 3.5mm plug to plug cable is put in the socket on the board and the other end plugged into the switchable device that we want to control.

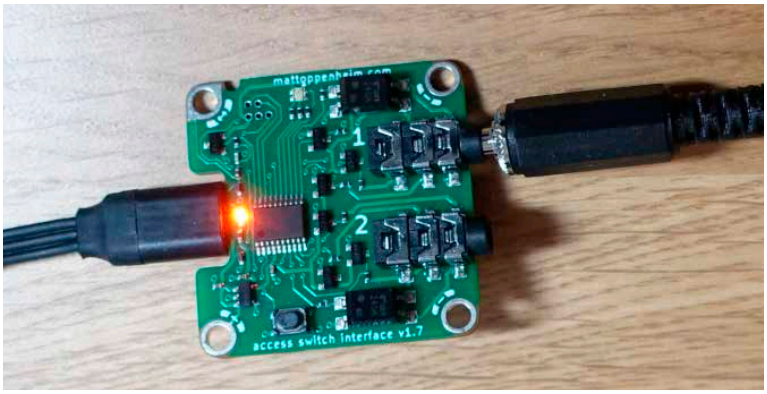

Figure 3: Jacdac access switch module

Kittenbot released a Jacdac kit with a range of Jacdac modules. This is available commercially.

The Jacdac access switch interface board is manufactured and assembled by JLCPCB.com using components from the manufacturer's inventory. The designs for this board are available open-source. If boards are designed in this way with all of the details made available online, then the end user can order the required boards to complete a project direct from the manufacturer on a project-by-project basis. This allows projects to be completed nearer to the cost of manufacturing the components than buying the parts through suppliers. One of the aims of the project is to create an easy-to-use interface to enable all of the parts of a project to be manufactured and delivered.

Discussion

A wider question is how people who use AT and support them will accept if their AT equipment is manufactured using a system like Jacdac. The Jacdac project is aimed at 'democratising hardware' - enabling small scale manufacture of technologically sophisticated hardware outside of large corporations. But will people who use AAC accept their devices made this way? Pullin 2009 makes the case in his book 'Design Meets Disability' (Pullin 2009) that not only should AT be as well manufactured as any other product but that there is no reason why it should not be crafted to the same standard as if made by top designers. Conversations with people who procure AT indicate that, where possible, paying extra for an established product with a warranty and active support is preferable over paying less for a product that does not have a proven track record and that does not have established support.

Links and more details of the Jacdac project can be accessed through the project website (https://microsoft.github.io/jacdac-docs/).

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Megan's AAC Journey: A Teacher's Perspective

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I am currently working for Ace Centre (a charity providing Assistive Technology and Augmentative and Alternative Communication services for people with complex communication needs) as a Senior AAC Consultant. However, I previously worked as a teacher for 10 years, 8 of which were in a special school. During my time as a teacher, I had the pleasure of teaching several learners who used AAC. One of these pupils was Megan. This article documents her journey to receiving a high-tech communication aid and the steps that I followed to reach that point.

Megan is a social butterfly and thrives on interactions with others. Although she has good receptive language skills, she did not have a robust form of communication when she entered my classroom to support her expressive language.

Previous teachers explored different approaches with her, primarily PECS. Megan could use PECS effectively, and it taught her how to initiate conversations, but it wasn't very practical for her. You always knew where Megan had been as there was a trail of symbols behind her! I felt that she had so much more to say than PECS could allow so I started to explore alternative options. I wanted Megan to have access to vocabulary that would give her the ability to chat with friends and family rather than just request things.

I began focussing on core vocabulary. Core words were a breakthrough for Megan, enabling her to say so much more than just requesting, including commenting, questioning, and expressing her thoughts and feelings. This opened a whole new world up for her. Core words make up the majority of what we say and include different word classes, for example nouns, verbs, adjectives, and prepositions. I found the Project Core implementation model was a great source of guidance.

From here, I was then able to create aided language boards and commenting charts for her, combining both core and fringe vocabulary (including those created by Ace Centre). Megan was able to use these well, however these were very context specific. Megan needed access to a more robust communication system as this approach had become too cumbersome for her.

Due to the limitations of aided language boards and commenting charts, I then implemented communication books with Megan. We firstly tried Ace Centre's Developing and Using a Communication Book before moving onto the Saltillo Wordpower60 paper-based communication book.

Megan began combining and stringing words together to build sentences, communicating in a variety of situations with a variety of communication partners. She was able to use a broader range of language functions, including rejecting (showing her stubborn side) and joking with staff and pupils. Her cheeky personality really began to shine! Although the communication book had many positives, there were still some downfalls. Megan is a social butterfly and has many friends she wants to independently chat with, but the book kept her reliant on adults. Due to fine motor issues, she also struggled to turn the pages independently, and the lack of voice output meant an adult would have to read out her messages to mediate conversations. Both caused her frustration when she wanted to quickly get her message across. As with her PECS book, the pages were still falling out and getting out of order. At this point we considered whether a high-tech communication aid would be more appropriate for her. Liberator gave Megan a trial of a high tech AAC device (Accent 800 with EasyChat 60) to see if we could overcome these hurdles. Using the device, she learnt to quickly find and use language that was important to her, for example asking her friends to play with her. She spent time exploring the vocabulary independently as well as chatting to staff who would assign meaning to what she had said. Although Megan was reluctant to let adults touch her device in order to model as a class teacher, we found ways around this, for example having the front page on our lanyards and enlarged under the whiteboard. This enables staff to model throughout the day. Megan was also heavily supported at home and used her device both at home and in the community, including telling doctors that she had a boyfriend after having an operation and talking about them whilst asleep! She followed the example of two other AAC users in my class who were great role models for her. It was great to see her chatting with her friends on her own. Peer modelling was really powerful for Megan, especially during social chit chat, rather than the focus being on learning.

Having an AAC device with voice output also supported her verbal speech. She began to say and combine more words verbally. Her favourite phrase became 'come back'. Due to lockdowns during the pandemic, school and staffing was not consistent. This caused her to become anxious, and she would often ask if members of staff would 'come back'.

Towards the end of the original trial, Megan had a cluster of epileptic seizures where she stopped breathing. Between seizures she reached out to her AAC device to communicate 'help me'. I will never forget how powerful AAC was in that moment. She was scared and frightened but was able to let the paramedics and those around her know she required help.

Following this I made a referral to Ace Centre through their NHSE Specialised AAC Service and Megan was provided with a device of her own. The excitement when she unwrapped it was like all her Christmases had come at once! It was pure joy! She commented on her device 'Like it! I feel very happy today'. The power of AAC was encapsulated perfectly in her comment 'loving say', telling us how she could now say what she wanted and was loving every moment! She ran around the classroom hugging it, verbally saying 'mine'!

Megan's AAC journey has only just begun, and I am very excited to see how she blossoms over time. Her tenacity and drive inspired me to support many more learners using AAC by becoming a Senior AAC Consultant for Ace Centre. My experiences of working with Megan will leave a lasting impact and have shaped me into the professional I am today.

My presentation at the conference was based around a case study we produced a video for which is available here:

https://www.youtube.com/watch?v=aV3my72dJZM&t=15s

This article can also be watched on video at:
https://youtu.be/LjC2_j53pM8

100 Voices: 12 months on

Learnings from delivering AAC into the independent care setting

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The 100 Voices Project began in 2020 and aimed to provide 100 people in care settings with a voice. Throughout 2022, we have continued to deliver support for those involved and gather data to evidence the outcomes.

We are now analysing the data around three key themes identified earlier in the project: Empowerment, Connection with Others and Participation.

Data

Data was gathered from several sources throughout the project to try and provide us with a broad picture of each user's journey and progress with AAC throughout the project. Data collected specific to the user included:

100 Voices Framework

Our framework is a tool adapted from the Pragmatic Profile for People who use AAC (Small & Stevens, 2017). The framework was created as a digital form and completed as a baseline at the very start of the project, then again approximately three months after users had their device and staff had received training.

This provided us with an insight into specific areas of communication and the development of key skills over the time period.

Two key difficulties were acknowledged when we looked at the data gathered from the framework. Firstly, there was the subjective nature of the responses. In some centres, it was noticeable when different members of staff had completed the baseline and the three-month data. Secondly, there was variation in timescale of completion of the three-month data. Teams were asked to complete the data collection at three months, however for some users data was not submitted until nearer five months after receiving their device.

User Voice Survey

From the start of the project, we were keen to make sure that we were able to gather the opinions of users wherever possible. One way we did this was by creating a user accessible survey in Grid 3 software. The survey consisted of seven simple questions each with the same choice of response:

a. Going well
b. Not going well
c. Not sure

The grid set also included information around facilitating the use of the survey and each centre was also offered support from our Clinical AAC Specialist.

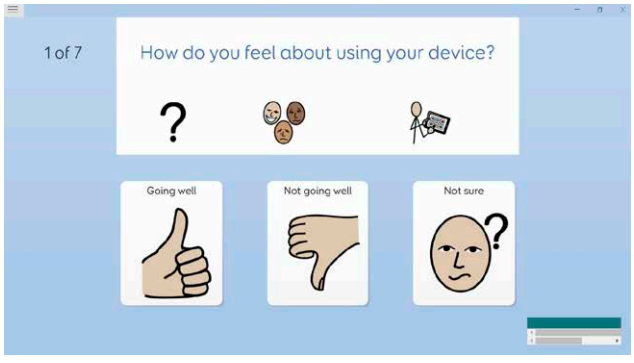

Image taken from the 100 Voices User Survey

One difficulty acknowledged with the User Survey was the lack of engagement from staff teams to ensure that the grid set was made available on devices and that users were supported to complete the survey. For busy teams, this was viewed as adding to their workload, and it was difficult for them to find time to contact our support team and put the grid set on the device during an already busy day. Engagement with the survey was therefore lower than we had hoped but still provided good insight.

Anecdotes, photos and videos

Perhaps some of the most valuable data were the anecdotes, photos, and videos provided by staff which captured their day-to-day use of AAC in care settings. These were able to provide additional, real-life insight into the trends we saw in the data.

Key themes and findings

Empowerment

We defined empowerment as:

'AAC empowering someone to be able to carry out something that they weren't able to carry out before having the device. Enabling the user to be able to have an impact on their environment in a way they wouldn't be able to without the device. The environment adapting to create opportunities for successful interaction which is listened to and respected.'

Key findings here saw an increase in commenting and naming skills as well as an increase in AAC users sharing information about themselves.

- 33% of users increased their commenting skills
- 33% of users increased their naming skills
- 41% of users increased sharing information about themselves

The anecdotal evidence from staff teams also provided further evidence to support the findings. Below are some quotes:

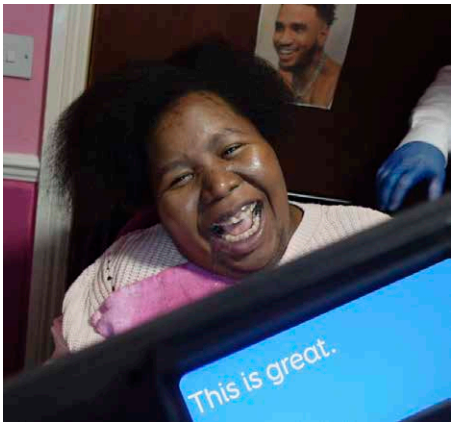

Image of participant, Nekeesha demonstrating her new commenting skills

"He uses it lots at school, appropriately pressing words and finding it a useful tool when he can't be understood"

"In a therapy session, he used the 'core' and 'next word prediction' to ask for space. He was showing frustration up to this point"

"He ordered himself a drink in Costa Coffee independently using his device. Staff helped him practice using the device in a 'set-up' setting in the home, so he knew where all his words were once in the setting"

As a project team, we were pleased with the findings. In just a short period of time, we have seen progress for our AAC users and evidence that they are becoming more empowered through communication and interaction.

Connection with Others

We defined Connection with Others as:

'Connecting with family, friends and professionals is recognised as being essential to wellbeing, health and fulfilment. The introduction of AAC in a supportive environment can help foster relationships, build friendships and access to vital services'

We also recognised the importance of this theme in view of the lack of connection many people felt during the Covid-19 Pandemic.

Key findings here saw an increase in AAC users being able to repair conversational breakdown. This might be if they were not being understood, or if they were not understanding others. We also saw that some users were beginning to use their device for remote communication.

- 30% of users increased their conversation repair skills when they did not understand someone
- 33% of users increased their conversation repair skills when they were not understood
- 8% of users began using remote communication such as email, WhatsApp, Facebook

The anecdotal evidence from staff teams also provided further evidence to support the findings related to connection with others. Below are some quotes:

"She said her support worker is the best support worker and that she loves her, completely independently. She's composing her own messages on Facebook and WhatsApp too"

"She is very quiet, but the device has given her/staff a reason and a method of communication"

"He is more communicative in general – even trying to speak more, and then when not understood using the device. Before, he would not even try to communicate with anyone not familiar with him through fear of not being understood"

The project team were pleased that the findings for connection with others showed a positive trend. We noted that the percentage of users increasing their skills was similar to those looked at for empowerment. The team did not expect users to have started to use remote communication so early on and were therefore delighted to see that some had started to use remote communication to connect with others.

Participation

We defined our final term participation as:

'AAC enabling someone to take an active part in the community around them. To contribute to the wider community as an individual, sharing thoughts, ideas, and opinions.'

Key findings here saw an increase in requesting skills, rejecting skills and asking questions. The increases were in line with increases we had seen in other themes.

- 40% of users increased their requesting skills
- 33% of users increased their rejecting skills
- 21% of users increased asking questions

We also had more anecdotal evidence to support what we saw in the data collected from the 100 Voices Framework. Below are some quotes:

"We had students use their Talk Pads to tell us what activities they would like to take part in and have been able to plan these for them."

"One user used her device to find any and every symbol that involved swimming and water to tell her team that she wanted to go swimming, it was amazing! We never knew there were so many ways to communicate that you really wanted to go swimming: beach, swimming, swimming pool, swimming costume, river, water. Water play, rain, goggles! She has now been swimming."

Again, the project team were encouraged by the findings, showing that within a short time frame there had been a positive increase in communication skills, and this had impacted on their participation.

iii. A participant playing with a train toy after request

User Voice

As acknowledged previously, the engagement with the user survey was low. There may be a number of factors for this. However, the data we have still provides us with an insight into the thoughts of the AAC users who took part in the project. Below is a summary of the findings:

Question How do you feel about…	Going well (%)	Not going well (%)	Not Sure (%)
Using your device?	43	14	43
Using your device to get something?	43	21	36
Using your device to talk to family?	43	0	57
Using your device to talk to friends?	43	7	50
Using your device to talk to people who work with you?	72	14	14
Using your device out and about?	36	14	50
Using your device to share your thoughts?	43	14	43

Firstly, the most notable number in the data above is the relatively high number of users (72) who responded with 'going well' under 'how do you feel about using your device to talk to people who work with you?'. This provides evidence that the introduction of AAC devices is making an impact on how users connect with staff in the centres and other professionals who may work with them which is a positive outcome for AAC users. We can also see that consistently over 1/3 of the users who completed the form responded with 'going well' in all of the seven areas they were asked about. The number of users who replied 'not sure' was similar in trend to those who replied 'going well'. From our closed question survey, we could not infer the reasons for which a user had not yet used their device for the function asked about, e.g. the user had not yet used their device for the function asked in the question, or that the use for each function had varied success. Responses for use of the device 'not going well' were consistently lower. Although the response of not going well indicates the need for additional support around AAC, it was useful that AAC users were able to identify this and share it.

Conclusions and Next Steps

When we look at the trends in the data, we can see that consistently around 1/3 or more of the AAC users in the project increased their scores in key communication skills, and the anecdotal evidence supports this. We can also see this reflected in the user survey, where again around 1/3 or more of the users who responded indicated 'going well' as their opinion.

What the 100 Voices project has provided us with is a greater understanding of how technology, care, and education can come together in the independent care setting and make a positive impact for individuals. As a project team, we now know so much more about how to work closely with care settings, what the challenges are, and how to support staff and individuals in these settings to provide the best opportunities for successful AAC.

Going forwards, teams within CareTech are developing new pathways in education and care settings to make sure the provision of AAC is looked at for individuals entering each setting. Staff are working with local authorities to increase awareness of AAC and demonstrate the impact that it can have for service users in the care setting. We are working with teams to continue to raise awareness of AAC amongst staff more widely and look at how they can make AAC part of the 'everyday' rather than being an add on. After the positive impact AAC has had, CareTech now want to make AAC central to their offering and are committed to supporting more individuals to access AAC.

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Developing Adapted Friends & Family Test Tools For Non-Verbal Children

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Background information

The NHS Friends and Family Test (FFT) is a key way that NHS services gather feedback about their services and respond to user experience. Listening to the views of patients and service users helps identify what is working well and what can be improved.

Using patient feedback to improve quality is important in all services, however there are additional challenges in meaningfully hearing and responding to the voices of the children and young people. There have been concerns about this raised within Special Educational Needs and Disability (SEND) inspections across the country, and it is also a theme from the NICE Guideline for Children and Young People with Severe and Complex Needs (NICE, 2022).

Following on from a SEND self-evaluation carried out by NHS providers across North Yorkshire and York, this project was launched. The self-evaluation identified a gap in enabling children and young people with complex communication needs to provide feedback on services. Despite efforts to include children with SEND in feedback, existing tools were not able to capture the voice of non-verbal children (and those with the most complex needs) without adult support. This project was commissioned by the Clinical Commissioning Group (now ICB) to develop tools to enable children and young people who have complex needs and/or are nonverbal to have a voice and give feedback on their experience of NHS services.

Project aims

This project aimed to develop an adapted Friends and Family Test for children and young people with complex SEND, specifically those who do not use speech as their main form of communication, to ensure they are heard as part of the routine NHS feedback process. We wanted to develop tools to give a voice to the children and young people who are historically marginalised due to their Alternative and Augmentative Communication (AAC) methods.

Identifying populations

It became obvious very quickly that our identified population of children and young people with complex communication needs/non-verbal communication preferences was a diverse group and would be unlikely to access a single tool. To try and capture the communication needs of the majority of children and young people, we considered the possibility of multiple tools:

1. A word-based survey with emojis accessible to cognitively able children/young people;
2. A simplified word-based survey with visual supports (Widgit symbols) for children with moderate learning disabilities/limited reading comprehension or preferences for images over words;
3. An observational based survey completed by a carer observing the child/young person in an appointment. This would be for children/young people with profound/multiple learning disabilities.

Developing the tools

Starting with the NHS standard Friends and Family Test (FFT), we considered which elements would be meaningful for the children and young people who use health services.

Survey 1:

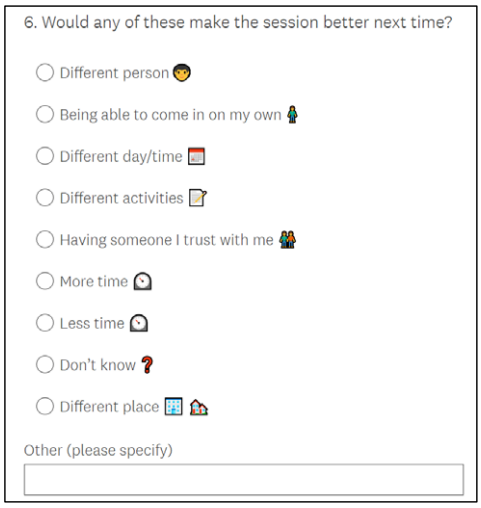
For survey 1, our first trial involved piloting a series of questions adapted by the authors from the core Friends and Family Test. These questions were trialled with neurodivergent adolescents, a SEND user group and young people who use Specialist Children's Services (SCS) within our NHS trust. Key messages from the first trial included the benefit of adding emojis, having a mixture of free-text and multiple-choice options.

Trial 2 involved asking young people to generate a word and emoji pool, based on both positive and negative experience of using health services.

Trial 3 engaged children/young people who use Specialist Children's Services to refine the word/emoji pool and to establish a shared understanding about which words/emojis were interpreted in positive neutral or negative ways.

Learning point:

Several autistic young people who helped us develop the word pool of response options struggled to identify words like "stressful", "boring", "sad" as either negative or positive.



Survey 2:

Initial scoping with Speech & Language Therapists and Learning Disability Nurses to establish what kinds of images would best support the simplified questions of Survey 2 led to the decision to use Widgit symbols. Widgit was determined to be the most accessible symbol support for this adaptation of the Friends and Family Test, as it is used throughout SEND provision locally.

In trial 1, a simplified (paper-based) version of the NHS Friends and Family Test questions was drafted and shared with young people accessing SCS, as well as clinicians. The content was then revised based on their feedback.

Trial 2 involved the evaluation of a website-based version of the questions, accessible from any mobile device or tablet/computer. The survey was again revised, based on feedback from children, young people, and carers.

Learning point:

Colourful Semantics colour coding was added to the response sets to increase accessibility for children and young people who used this system in school.

Survey 3:

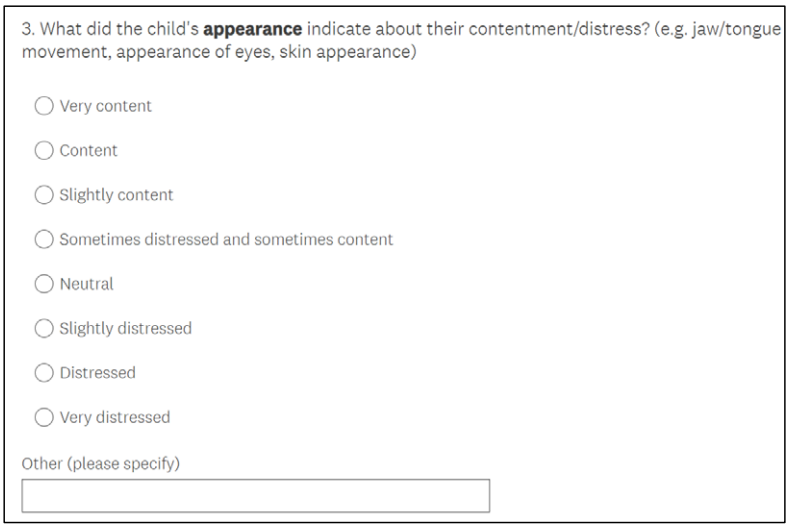
Rather than rely on parent/carer feedback, we were keen to access the voice of the child as far as possible. For children and young people with profound and multiple learning disabilities (PMLD), asking questions (either verbally or using visuals/objects) about their opinion of an experience in a standardised way wasn't possible. We recognised that children and young people with PMLD communicate primarily through their body – how they move, changes in facial expression and vocalisation, and how they respond to events around them. We decided to use a recognised tool for observing these changes, based on the observations of the people who know a child best. The DisDAT is a well-established tool for assessing comfort and distress in people with PMLD.

The DisDAT allows for the nuanced and personalised interpretation of an individual's experience, reportable in a standardised way. It recognised that each individual has their own unique vocabulary of comfort, enjoyment, distress and pain, and that this is best understood by their key carers who support them daily. For example, one young person in our service laughs before a seizure, and this behaviour was initially understood as a sign they were enjoying a session. When their carer 'translated' for the young person, the clinical team were able to adapt their approach and respond more sensitively to the child's unique communications.

Survey 3 was developed based on the key domains of the DisDAT and then refined based on feedback from a group of parents and carers in health and education. There were a number of clarifications of the wording of questions and the structure was refined in 2 ways.

Learning point:

A wider scale of response options based on feedback about the need for more options, neutral response and a response to indicate variance over a session.



Feedback so far

We learned not to make assumptions e.g. what emojis mean to young people. Young people used very different words when 'translating' emojis for us, and so it was not appropriate to assume that 🥺 meant "scared/emotional" to all young people – one thought it meant "cute". Using ambiguous words/emojis could leave services with feedback they cannot interpret.

It was important to allow children and young people to co-develop the word pool for responses. When we asked them to come up with their own words, there was some overlap with the clinician-generated word pool, but a lot of variance within and between the groups. Some of the young people involved in the project struggled to classify words like "stressed, scared, happy, excited" into positive and negative description words, and neurodivergent young people in particular seemed to find the emotion words (e.g. "scared/happy") more challenging than the more concrete words (e.g. "helpful"). Refining these long lists of words into common themes/most often used words, and least often misunderstood words helped refine the words to use in the final survey.

Getting the balance right between too few and too many options in response sets was crucial: the list of choices after each question had to encompass the likely range of responses without being overwhelming.

Next steps

We have piloted and refined all three tools, based on input and feedback from children, young people, carers and clinicians working in Specialist Children's Services. We have engaged young people in the area to design us an engaging character to help bring the feedback process to life (right): Jif will feature on stickers and on the hand-held tablets that children can use in clinic to give feedback.

We now aim to incorporate these tools into our routine feedback mechanisms across Specialist Children's Services in our NHS Trust, and to share with colleagues across the ICB who offer support to children and young people with SEND/complex communication needs. Ultimately, we hope that these tools prove to be a useful addition to the suite of Friends and Family Test tools and could be available beyond North Yorkshire and the Humber region.

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DisDAT Disability Distress Assessment Tool, 2006 Northumberland Tyne & Wear NHS Trust and St. Oswald's Hospice

This article can also be watched on video at:
https://youtu.be/hFl6YJriJxA

tobii dynavox

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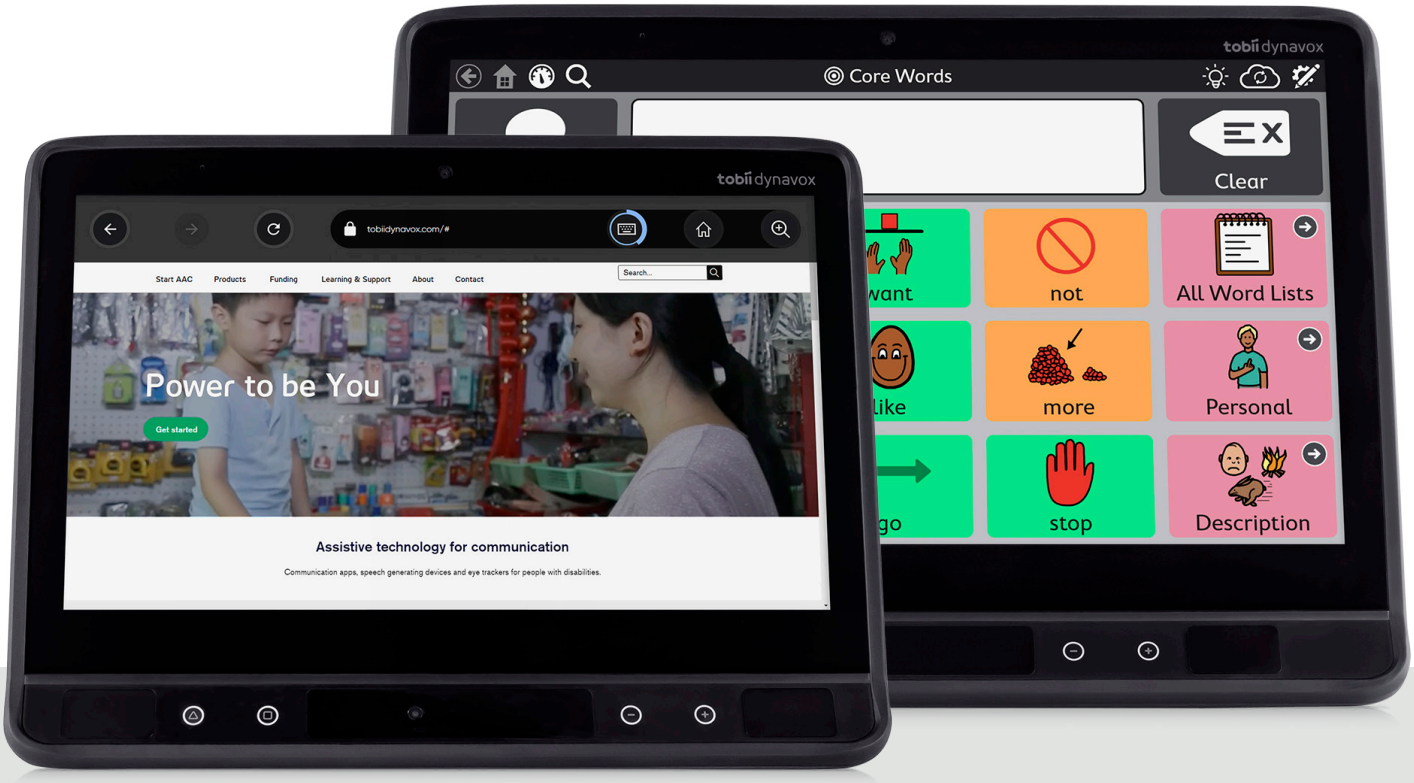

TD Snap
A symbol-supported AAC software offering a choice of solutions, complete with tools and resources.

TD Control
A way to control Windows with just your eyes on a TD I-Series or PCEye device.

TD Browse
A way to browse the web intuitively using just your eyes on a TD I-Series device.

TD Talk
A speech generating app that empowers people to talk with just their eyes or fingers.

TD Phone
A way to text and call using just your eyes on a TD I-Series device.

Communicator 5
An AAC solution designed to help literate individuals with language disabilities communicate more efficiently.

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