Communication
Matters

APRIL 2021 VOLUME 35 NUMBER 1

THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

Teaching Computer Science - Functional Communication Training - ISAAC BUILD - 1Voice Impact Report - Small Grants - Future Vision - Personal Lockdown Stories - Working through the Pandemic

Communication
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COMMUNICATION MATTERS JOURNAL
VOLUME 35 NUMBER 1
April 2021

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Huge congratulations to Nadia Clarke for completing her Employability Skills Level 2 course. Find out how you can gain a qualification here - https://www.communicationmatters.org.uk/what-we-do/projects/mentoring-project/

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Chair's Report

HELEN WHITTLE

I hope you are all safe and well.

As I write this, we are in the midst of Lockdown 3.0. We are waiting to hear the Government's plans for schools and colleges to reopen and a plan for other restrictions to be eased, when appropriate. The success of the vaccine rollout is encouraging but we will all need to be patient, I feel, for things to get back to how they were.

The Trustees and I continue to look for ways to reduce the costs of running Communication Matters whilst still providing as many services as we have in the past. We have had excellent feedback regarding the accessibility of the PDF version of the Journal. We will continue to produce the Journal in this format for the foreseeable future. All Trustees meetings are taking place virtually.

Study Days

Whilst we were unable to deliver any study days in 2020, we have been able to deliver an I-ASC (Identifying Appropriate Symbol Communication) study day together with Manchester Metropolitan University in January and February of this year. As this was a virtual event, we were able to attract delegates from all over the UK, Northern Ireland, Ireland, South Africa and the USA. We will continue to explore options for offering further study days in 2021.

Fundraising

Emily and I will continue to apply for many grants from Trusts that may support our work. We are very grateful for the Coronavirus Community Support from the National Lottery and the Government for the money to fund six months of core costs, this includes wages, rent and auditors fees. This fund was all spent by the end of March 2021. We continue to be very grateful for our members who have raised money for us, donated or use Give as Live or Amazon Smile when shopping to raise money.

The latest idea to come out of the Communication Matters AAC User Focus group has been the Talkathon 3.4 Challenge. This involved 3 hours 40 minutes of chatting and challenges to raise money for CM https://www.justgiving.com/fundraising/talkathon. Challenges held on the 24th March included sing and sign, quizzes, bingo and guess the symbol and they raised an amazing £555 for Communication Matters.

Chair's Report

Running along the same lines was the Communication Matters 3.4 Challenge. This was your opportunity to do 3 sit-ups per day, run 4km each day, or bake 34 biscuits from 21st March to 3rd April. Any challenge that you can think of, really, that included a 3 and/or a 4! A huge thank you to MEETinLEEDS for their raffle of a 34-prize Easter hamper, the Chailey Communication Aid Service team who walked 3.4km each day, Beaumont College for writing 34 jokes and Harriet from MEETinLEEDS who ran 3.4 miles every day!

We are grateful to everyone who is taking the time to raise money for the continued work of Communication Matters.

Conference

This work is even more important as we have just heard that we are unable to hold a physical conference at the University of Leeds for the second year running. This is a huge disappointment, but the decision has been made with the safety of everyone involved in mind.

What this does mean is that we have six months to plan a fantastic virtual event and we will aim, like The CM Sessions from 2020, to give you all a feel for the CM conference you have come to love. So, if you have never presented at a conference before, maybe this could be the year? Go to www.communicationmatters.org.uk/blog to find out more.

You can be sure we will include some social sessions, suppliers' sessions, and opportunities to learn from others about inventive ways of supporting AAC users and families.

Journal

You may notice the layout of the journal looks a bit different this time, with just one column per page instead of two or three. That's because we listened to feedback from the Communication Matters AAC User Focus group, where some members found it difficult to continually scroll up and down the pages to read them. We are sure many of you will find this format easier to read on a screen. If you have any comments on this layout or any aspect of the journal, please do not hesitate to contact us on: admin@communicationmatters.org.uk.

Another new feature of this issue is that some authors have kindly created video presentations of their articles for us. At the end of some articles, you will find links to our YouTube channel to watch these. This was another useful suggestion from the AAC User Focus group, where it was proposed that some people prefer to watch a video presentation rather than read an article to get their information.

Mentoring Project

Finally, this is our third year of funding from the National Lottery Community Fund and we have a wonderful range of qualifications for AAC users in England, including personal and social development, mentoring and employability. This grant can only be used for the purposes of the original bid to do with mentoring courses and therefore cannot be used for any costs related to the running of Communication Matters. All sessions are free and delivered via Zoom or Teams and learners can complete workbooks and activities from their own home. Creativity in Practice will provide 1-1 support and guidance. They can also help with setting up a local peer mentoring project in school or college, or through another service. For more information about any of these opportunities, please contact Verity Elliott on: verity@creativityinpractice.co.uk.

SAVE THE DATES!

Communication Matters

The Communication Matters International AAC Conference will be held virtually this year from Monday 13th - Friday 17th September 2021.

Trustees' News

The CM Sessions – October 2020 (AAC Awareness Month)

VICKY HEALY, DEPUTY CHAIR

I think we can look back on 2020 as a year to remember. For Communication Matters (CM) it was certainly a challenging one - and continues to be so - as we strive to find ways to engage with our members and deliver our message to the AAC community when we have limited resources and no opportunities to meet face-to-face. It's hard to believe that only just back in October 2019, many of us were celebrating together in person at the inaugural AAC awards. What a difference a year makes…

It comes as no surprise that our members, trustees and our wider CM family rose to the challenge and knowing that a face-to-face conference in September 2020 was going to be impossible, we had to find a unique way of delivering the content, uniting the membership and raising some much-needed funds.

And so, the CM sessions came to fruition.

It had to be as simple and cost-effective an event as we could manage, whilst capturing the needs of all our members – from AAC users and their families to professionals in education and health, suppliers and all people working in the field of AAC. Communication Matters relies heavily on income from holding the annual conference and other events, through which we also support our attendees to get the most up-to-date information about AAC. Obviously, it was no coincidence that we held this event throughout October – International AAC Awareness month - and by spreading it across the month we hoped there would be opportunities for attendees to feel as though they were participating together.

We wanted to mirror some parts of our annual conference which would include the academic and social elements that we knew people loved. The recently established AAC users group provided invaluable input into what the members wanted out of the sessions - a mix of research papers, personal stories, supplier updates and social events. Hopefully we managed to capture those requests! And by providing recorded presentations, attendees could watch at a time to suit themselves which we realise has been a bonus for many.

So, here's just a flavour of what you missed if you didn't manage to watch during October, or a reminder for those that did!

We launched the first session at 4.30pm on 1st October - we were mindful of trying to fit in around work/school/college times as people's lives had already been so greatly affected by the pandemic. We were thrilled that Meredith Allan (at the time President of ISAAC) had agreed to record a keynote session to kick off the whole event. As our first social session, we wanted to visit a CM classic, so we were grateful that one of our trustees, Saff, had devised a quiz. Even if you didn't take part "live" on the night, it was fun to do and quite a tricky one too – so well done to Theresa for being the winner!

The whole month was a combination of personal stories, professional experiences and exploration of new AAC products, and we believe it was this mix that gave the sessions the CM conference feel.

We would like to extend our enormous thanks to our distinguished presenters from across the globe who provided us with some thought-provoking subjects in support of AAC. There are some advantages to holding a virtual conference, as we know we would not have secured such a high calibre of speakers in one go at our face-to-face event!

Gloria Soto from San Francisco showed us the importance of a holistic approach to supporting a child's use of AAC, and in particular, how to engage and encourage family participation. Gail M. Van Tatenhove described how she introduces

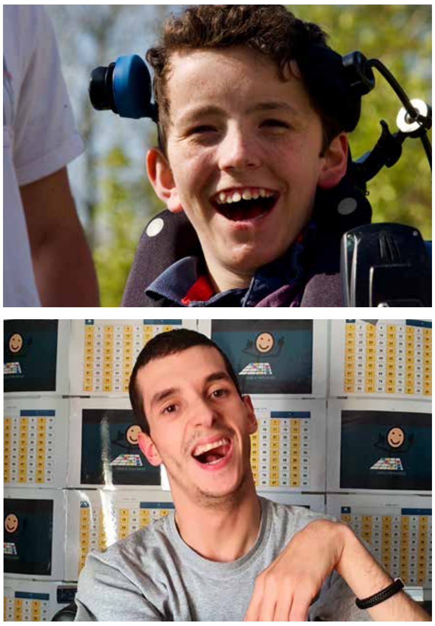
From left to right: Gloria Soto, Gail Van Tatenhove and Catia Crivelenti de Figueiredo Walter and Meredith Allan

Trustees' News

music and songs to support use of functional language skills in AAC, Catia Crivelenti de Figueiredo Walter from Brazil explained how an adapted version of PECS was being used there to support children with ASD, and a second paper from Meredith Allan considered the importance of identity for people with disabilities who use AAC. These were all such pertinent issues, which we hope gave people scope for discussion in their own teams or families. The feedback about our speakers was extremely positive – perhaps a criticism was there could have been more! We really appreciate the time taken by our presenters to record these for CM.

Top: Caroline Gosling, Emily Walsh and Verity Elliott
Above: Samantha McNeilly, Will Wade and Gregor Gilmour

Closer to home, we had Caroline Gosling from The Seashell Trust, Emily Walsh from ATtherapy, Verity Elliott, Project Lead for the Communication Matters Mentoring Project, Samantha McNeilly and Will Wade from the Ace Centre, and Gregor Gilmour from the AT Mentors. Much of what was covered here focused on how working practice has been affected during lockdown, and reminded us of some of the positives we were able to gain from the experience. Again, we are grateful for your time and support and for sharing your professional and personal experiences with us. We are aware that due to limitations with the technical platforms we had available to us, and because we were unable to run these presentations live, there was a lack of interaction and the ability to ask direct questions. However, we were able to share the presenters' details, so hopefully attendees took advantage of this and felt they could contact the speakers afterwards if they so wished.



Top: DJ Oli and Bingo by Alfonso!
Right: Jamie Preece

We knew that the social sessions would be the hardest part of the conference to replicate but we certainly tried, and the bingo session led by Fran and Alfonso proved popular! The winners were Toby and Helen, and we hope they liked their prize. Holding a virtual disco is also quite a challenge, but with Oli's inspiring tunes and light show, how could people not want to shuffle in their seats or dance around the kitchen? Continuing the musical theme, we know many of you enjoyed playing along with Judy King's guitar session. As she has worked so hard to set these up on a number of different AAC platforms, we hope many of you are able to continue enjoying the music…

One of the most inspirational member stories from lockdown came from Jamie Preece, who travelled over 500 miles without his AAC device, raising awareness of AAC and money for CM. He smashed his target and kept on going and did a fabulous job, so Jamie, thank you to you and Emma for your continued support of our charity.

Trustees' News

We are, as ever, grateful to our supplier members, who are facing their own challenges during this time but continue to support the work of CM. Each of them presented short sessions during the October event and many also contributed to prizes for our social sessions. So, we send a big thank you to the following companies…. Abilia, AssistiveWare, EyeControl, Liberator, Liopa, SCandLE, Smartbox, Techcess, Therapy Box, Tobii Dynavox, Voiceonics and Widgit Software.

An ongoing event during the middle of the month was our CM balloon race. It's interesting how competitive you become tracking virtual balloons floating across a virtual sky…. (or perhaps that was just my family?). Congratulations to our winners – Maureen, Simon and Cat and thank you to all who bought balloons. In the absence of being able to run a live raffle, these virtual paid events are essential in helping us to raise funds – so look out for more coming up.

The final session in October gave our AAC users a chance to share their personal thoughts and invaluable guidance for others as they came together as a panel with pre-recorded answers to questions coming from CM supporters. Members of the AAC user group worked hard to compile these, so we thank you for your input. Our finale for the CM sessions was a live singalong with the fabulous Sign Out Loud and we are so very grateful to Sally and Kate for their enthusiasm and incredible singing and signing. There were a lot of hat and wig changes from many of the participants (well done to Sean and Joanne who won the fancy dress competition) and I know that this session could have gone on for many more hours given the chance. It was such a great way to wrap up the month!

It's always good to get the feedback of our attendees to inform how we run future events, so it was helpful to receive a high number of feedback forms. We were delighted that there was so much positive support for the CM Sessions, with a real appreciation for an event that encompassed the normal inspirational and supportive feel of a CM conference.

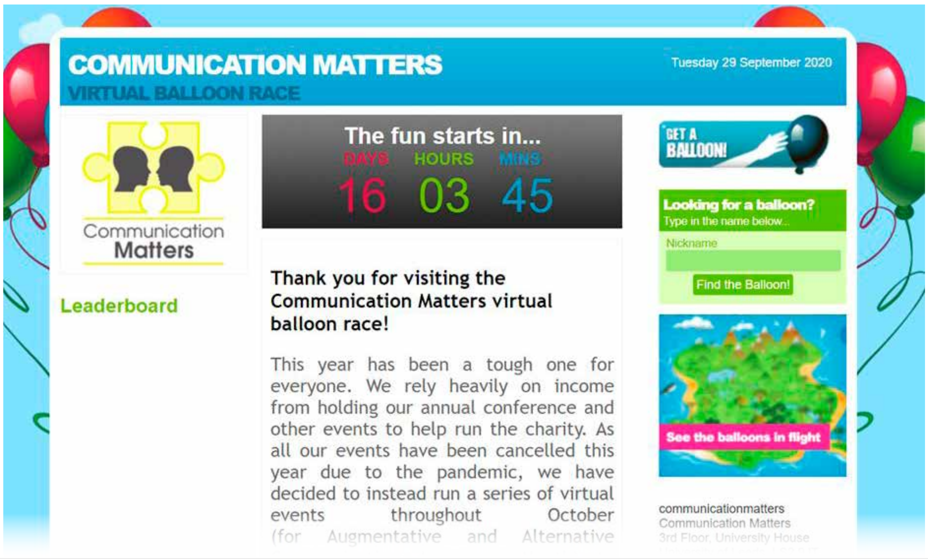
Those that paid to attend made a significant contribution to our funds and supporting our AAC family, at a time when we need it more than ever. The virtual nature of the sessions opened the event up to those who cannot normally attend the conference, suggesting the merit of online events in the future and it not just being seen as a short-term necessity. 95% of attendees said they would be keen to attend more virtual events. In addition, the flexibility of the pre-recorded sessions was welcomed by many who liked being able to watch them in their own time and to stop and rewind talks to make notes. This is something that we hope to be able to incorporate into future conferences or study days.

Any negative feedback we received mostly surrounded the lack of networking and socialising that is present at a normal conference. This was widely recognized to be unavoidable, and more of a reminder that people are desperate for the CM face- to-face conference to return as soon as possible!

2021 hasn't started in the best way, but there are positives on the horizon. As trustees, we would love to be meeting in person again back in Leeds, but as we still find ourselves in the middle of the pandemic we think this may still be a little way off. As this journal goes to press, we have just learned that a CM face-to-face conference in September 2021 is not going to be possible. The safety of our members is too important for us to jeopardise.

We are currently in discussions with the University of Leeds and MEETinLEEDS to explore all our options for delivering an exciting and safe online conference, and are working with the teams to find the best solution to deliver both the academic and social content to suit our members' needs. We are excited about finding new ways of engaging as many people as we can across the world in a virtual conference.

Keep an eye on the Friday Announcements and the CM website for more details as they develop. If you have any thoughts or suggestions for further conference or fundraising ideas, please do contact the CM office.



Thank you for visiting the Communication Matters virtual balloon race!

This year has been a tough one for everyone. We rely heavily on income from holding our annual conference and other events to help run the charity. As all our events have been cancelled this year due to the pandemic, we have decided to instead run a series of virtual events throughout October (for Augmentative and Alternative

Incorporating Accessibility and Assistive Technology into the Teaching of Computer Science

REBECCA LEEDALE, JAMIE PREECE, SIMON JUDGE, EMMA BARRINGTON, VICTORIA JOHNSON, ANDREA LEE
Barnsley Assistive Technology Team
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Sheffield Hallam University
Email: rebeccaleedale@nhs.net

Introduction

In 2012 a project was initiated by Peter O'Neill, senior lecturer in Computer Science at Sheffield Hallam University and Simon Judge, Service Lead for Barnsley Assistive Technology Team (BATT). The project aims to improve the knowledge of computer science students about Assistive Technology (AT) and accessibility, and to harness the knowledge of Peter and his students to develop apps that are relevant to Assistive Technology and Alternative and Augmentative Communication (AAC) users.

Background

Technology, software and digital content have huge potential to improve the lives of people who have disabilities, but software designers might not be aware of their potential to contribute to this, or what they need to do to achieve it. A recent paper in the UK noted that while there is greater availability of tools and guidance on accessibility, there is no single source of knowledge that software designers use to develop accessibility practice, and that it cannot necessarily be assumed that awareness and implementation of accessibility has increased (Crabb et al 2019).

As well as driving change with existing software designers in terms of accessibility, there is a need to incorporate accessibility and Assistive Technology within the education and training of new software designers, without which there is unlikely to be systemic change. Where accessibility and Assistive Technology are discussed in terms of technology development and taught within computing degrees, this can often focus on the needs of those with visual impairments rather than those with physical, communication or other challenges.

Peter O'Neill worked for 16 years at Barnsley Hospital, and took his PhD in the area of evaluating Assistive Technology provision. Peter knew when he took up his post as a lecturer in computer science at Sheffield Hallam University that he wanted to incorporate Assistive Technology and accessibility into his learning materials. There is a significant and growing need for software that is accessible to all users, and Peter was aware that including this within the degree programme for his students would benefit them in the job market, as well as having potential benefits for future users.

The collaboration

For the past 8 years, Peter has invited a member of Barnsley Assistive Technology Team to give an introductory lecture to his students on methods of accessibility and its importance when creating software. He also feels that the students need real world scenarios as the basis for their final year projects, and therefore encourages Barnsley Assistive Technology Team to suggest ideas for possible projects that stem from the team's clinical practice. Students are then able to choose from these project ideas and develop apps based on them to be evaluated by Barnsley Assistive Technology Team.

The illustration summarises the people involved and their roles.

Who is involved and what we do

Barnsley Assistive Technology Team Practitioner

Gives lecture on accessibility to students. Collates app ideas from the team and provide app specifications. Coordinates feedback

Peter O'Neill - senior lecturer

Organises lecture on Assistve Technology and accessibility. Supports Assistive Technology Team in specification of apps and oversees students' work on the apps

Barnsley Assistive Technology Team Service User Representative Jamie Preece

Trials and evaluates apps and gives feedback to students

Students

Learning from Assistive Technology team. Active participation in designing accessible apps with user involvement in design

Raising awareness of accessibility in software and technology for the students

Teaching on accessibility or Assistive Technology is not necessarily widespread in UK computer science departments, so it is helpful to have an opportunity to highlight accessibility to students directly and explicitly. There is some research on how student software designers' knowledge of accessibility is addressed in the US (Shinohara et al 2018), but it may be an area that needs to be addressed more broadly in the UK.

In providing a lecture on accessibility and Assistive Technology to the students at Sheffield Hallam, the key message is that everybody, whatever their physical or cognitive abilities and needs, might want to access technology and software, so accessibility needs to be built in at the design stage.

Students are given information about what Assistive Technology is and how it can be used by people with physical disabilities for environmental control (EC), AAC and computer access. Different forms of access to technology, such as alternative mice, switches and eye-gaze are explained and it is highlighted that the design of software and websites can affect how these are used. The lecture also emphasises that people might have a range of abilities and needs affecting their motor skills, vision, hearing and cognition, and that these can be related to situations such as the environment, temporary change in abilities or factors intrinsic to the person. In addition, it is highlighted that there are tools and guidelines available to support implementing this, for example the Web Accessibility Content guidelines.

Creating the apps

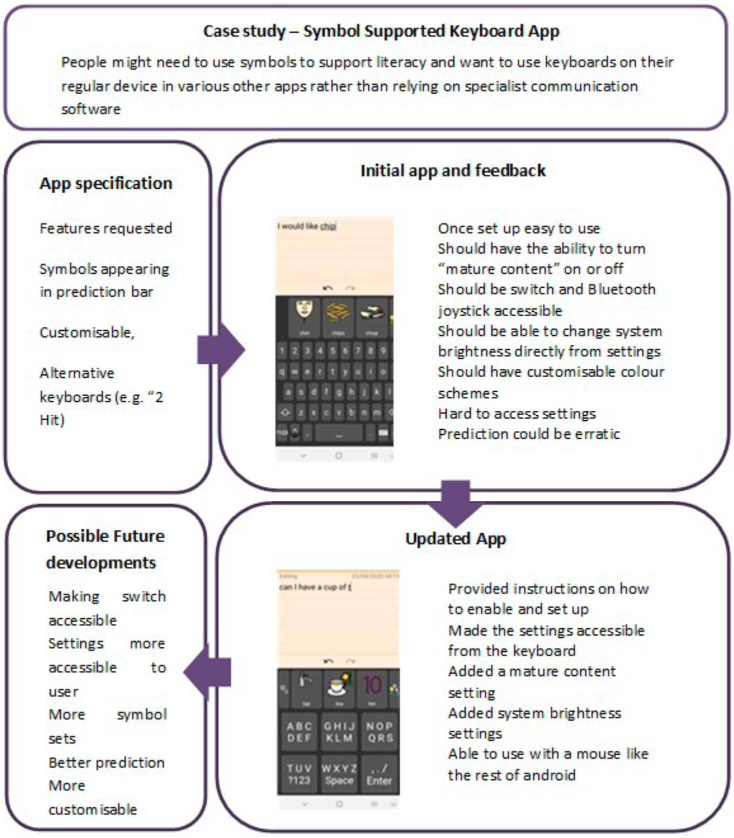
Ideas for apps are generated from Barnsley Assistive Technology Team practitioners and our service users. Situations are identified where the team wish there was a software solution to a particular problem. The service users can have specific needs and goals that are not always met by technology and software that is already available, and they often have ideas about how to address this.

Each year, six project ideas are drawn up into specifications, explaining the rationale and the essential features required. The ideas can be very varied and can be related to AAC, environmental control or access to technology. In the 2018-2019 academic year, specifications included an app with games to practise switch access, a symbol-supported keyboard app for phones and tablets, a yes/no biofeedback app to help people practise their yes/no response and an augmented reality EC app.

Students have 32 weeks to develop an app and are encouraged to contact Barnsley Assistive Technology Team for feedback as they do this.

This part of the process gives the students the opportunity to put their learning about accessibility and Assistive Technology into practice.

The case study illustration demonstrates the process for a symbol-supported keyboard app developed in 2018-2019.



Case study – Symbol Supported Keyboard App

People might need to use symbols to support literacy and want to use keyboards on their regular device in various other apps rather than relying on specialist communication software

App specification

Features requested

Symbols appearing in prediction bar

Customisable,

Alternative keyboards (e.g. "2 Hit)

Initial app and feedback

Once set up easy to use
Should have the ability to turn "mature content" on or off
Should be switch and Bluetooth joystick accessible
Should be able to change system brightness directly from settings
Should have customisable colour schemes
Hard to access settings
Prediction could be erratic

Updated App

Provided instructions on how to enable and set up
Made the settings accessible from the keyboard
Added a mature content setting
Added system brightness settings
Able to use with a mouse like the rest of android

Possible Future developments

Making switch accessible
Settings more accessible to user
More symbol sets
Better prediction
More customisable

Feedback from users

The course teaches that user involvement is an important part of the software development process. There are different ways of achieving this, including participatory design, where users are part of the decision-making process, involved in workshops and prototype testing. (Abelein et al 2013)

User involvement can occur in many different ways, and what determines the success of a system can be hard to define. It can therefore be difficult to measure the influence of user involvement in the design cycle on system success, but broadly, studies seem to show that user involvement is a positive influence (Bano and Zowghi 2013, Abelein et al 2014).

Students are given the opportunity to get feedback from Barnsley Assistive Technology Team practitioners and potential users where possible. It is not always practicable for students to meet specific service users, but the team has a Service User Representative, Jamie Preece, and part of his role is to represent the views of service users when evaluating software, hardware and vocabularies.

Jamie is an experienced user of Assistive Technology and his input means that students are able to meet somebody who may need to use the software they are designing and can give insights that may not come from the team's practitioners. Jamie has noted that:

> ***"It is vital to have user involvement when designing technology – how can anybody make anything without thinking about the user? I have 42 years of experience in using different types of technology and I'm always thinking outside the box so I can give insights that other people may not think of. I'm living the life of an AT user 24/7."***

Impact of the project

The project has not been formally evaluated but anecdotal evidence suggests that it is of value.

Verbal and written feedback given by the students directly and from an online anonymous survey indicated that they had some awareness of accessibility and Assistive Technology, but the lecture and then designing an app broadened this knowledge, helped it become more embedded and made accessibility something they will be more aware of in their future careers. The process of getting feedback from practitioners and the Service User Representative reinforced to them how aspects of software they had not considered or had overlooked could be real issues for users.

When Peter started the project, he was aware that, by participating, students could improve their employment prospects, and this has been confirmed by a number of students, who have reported that their involvement has directly contributed to them getting jobs.

Users of Assistive Technology and AAC have the knowledge to positively influence the quality of software, and the Service User Representative can therefore influence the designers and technology of the future, to create better software.

Barnsley Assistive Technology Team practitioners are focused on how different users access technology, software and digital content and, although there is some ability to influence technology design, especially with specialist companies, the ability to try and embed it in the mainstream feels very positive. Some of the apps suggested had very specific purposes for AT users but these enabled the students to think about accessibility for all, for any purpose. In addition, Barnsley Assistive Technology Team practitioners have developed knowledge of the challenges that can be faced by software designers.

Challenges

There have been some challenges, including the time Barnsley Assistive Technology Team practitioners have available for evaluation and feedback, a lack of specialist resources available to the students, and the fact that sometimes apps are started and appear extremely promising, but are then not fully developed.

All involved feel that this is a valuable project with mutually beneficial outcomes, but it would be of benefit to have some formal evidence of this.

What's next?

In reviewing the project, it has been recognised that there is scope to improve the process, but the project has also demonstrated aspects of collaboration that would benefit Assistive Technology and AAC users, professionals working in the fields of AT and AAC, and computer science students.

One improvement has been to specify that the software be made available for BATT to test and to standardise evaluation methods.

The impact of the project suggests there would be value in this model being adopted by other computer science courses and Assistive Technology teams. This can be challenging in terms of the time available, especially from practitioners, but there may be potential to offer a learning resource and a formal evaluation of the project to contribute to the evidence base that learning about accessibility is effective and important.

A key frustration currently - that some promising apps are not further developed - emphasises the need for the development of a resource to support this. The OpenAssistive website seeks to improve the process of making Assistive Technology software by providing a listing of open source Assistive Technology software and hardware, but there is still a need to improve the process of matching possible projects with people who can contribute. In addition, some developments might not be able to be open, but would still be worth listing to ensure that other projects do not duplicate this. This work potentially highlights a much greater potential to embed and incorporate real accessibility and Assistive Technology development into computer science degrees. A resource, such as the extension of the OpenAssistive website, to support the listing of project ideas and software contributions (by students or others), which could highlight when a project is seeking additional input or other feature additions, could be of benefit, and this has been suggested as a project idea for 2020.

Barnsley Assistive Technology Team and Sheffield Hallam University continue to collaborate on this project.

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Web Content Accessibility Guidelines http://www.w3.org/WAI/standards-guidelines/wcag/

PAPER PRESENTED AT THE CM2019 INTERNATIONAL AAC CONFERENCE, UNIVERSITY OF LEEDS, SEPTEMBER 2019

Evaluation of the Impact of Functional Communication Training on Behaviours of Concern

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Introduction

The prevalence of behaviours of concern within the Learning Disability (LD) population has been well documented (Matson et al, 2011), with population studies stating that 'between 5 and 15% of individuals with ID (intellectual disabilities) show some type of challenging behaviour, like self-injury, aggression, stereotypical behaviour, and other problem behaviours' (Didden et al., 2019). Additionally, studies have found that there is an increased rate of behaviours of concern in individuals who also have a diagnosis of Autistic Spectrum Condition (ASC) (Rojahn et al., 2011). Research has also suggested 'an inverse relationship between level of communicative skill and frequency of behaviour problems' (Carr & Durrand, 1985), supporting the 'communication hypothesis' that behaviours of concern in this population often function as nonverbal communication acts.

Functional Communication Training (FCT) (Carr and Durrand, 1985) is an approach which aims to reduce behaviours of concern by teaching the individual more effective, socially appropriate ways to communicate. Initially, a Functional Assessment is carried out to identify the purpose of specific behaviours of concern. Common functions of behaviour cited in the literature include escape, gaining access to tangible items, gaining attention or fulfilling a sensory need. Analysis of the specific behaviour within a given context, including its antecedents and consequences, is conducted through direct observation and information- gathering from key stakeholders involved with the individual. Understanding the function of the behaviour is paramount to the effectiveness of FCT. The alternative communication method must meet the same need as the behaviour of concern more efficiently if it is to successfully replace it, or achieve a 'response match'.

Once the function of the behaviour of concern has been identified, a suitable replacement communicative behaviour is taught using specific intervention strategies. Durrand and Merges (2001) identify criteria which the trained communicative behaviour should be measured against to evaluate whether it has 'successfully and efficiently produced the desired outcomes'. This is known as 'Response Mastery'.

Although there is a strong evidence base for FCT, the literature focuses on the effects of the approach in a 'test setting' where variables are controlled. This service evaluation aims to look at its implementation in a non-maintained special school setting with individuals with ID, ASC and complex communication difficulties, to evaluate its efficacy in practice and identify the challenges and supports this setting poses.

Method

Students on the author's Speech and Language Therapy (SaLT) caseloads with a diagnosis of ASC who displayed behaviours of concern, with communication acting as a key function of their behaviour, were supported using FCT. A functional analysis was completed by key members of the multidisciplinary team. Following this, a new communication behaviour was identified. Intervention strategies including aided language stimulation (ALS), contingent reinforcement and prompt fading were used to teach the new communication behaviour. SaLT offered training and coaching to staff teams in the chosen new communication behaviour, which included a range of low- and high-tech Alternative and Augmentative (AAC) strategies. Durrand and Murge's (2001) Response Mastery criteria (see Figure 1) were used to evaluate whether the new communication behaviour had been successfully adopted and was meeting the function previously served by the behaviour of concern.

Findings

Response Success

66.6% of new communication behaviours achieved response success. In cases where response success was not achieved, a number of factors influenced this. Some students displayed a strong need to control their communication resources. For example, one student would hide all symbol resources offered in a tent in their classroom. This posed difficulties in staff modelling use of resources, and students therefore building skills in using the communication method. Signing was trialled for some of the students that

Figure 1. Response Mastery Criteria

Criteria	Questions used to evaluate Response Mastery
Response success	Does the individual get the desired response from the trained communication behaviour?
Response effectiveness	Is the trained communication behaviour more effective than the behaviour of concern? Is the new method as easy or easier to produce (including physical and cognitive effort)? Is the new communication behaviour consistently reinforced (while the behaviour of concern is infrequently or never reinforced)? Is the amount and quality of the reinforcement as great? Is the reinforcement immediate?
Response Acceptability	Is the trained communication behaviour as acceptable within the relevant environments?
Response Recognition	Can the trained communication behaviour be recognized by the relevant communication partners?

experienced this difficulty but selection of this communication method did, in most instances, have a negative impact on response acceptability and recognisability. Some of the behaviours of concern demonstrated by students provided sensory feedback that was not provided by any other strategies, and therefore were more challenging to replace with the new communication behaviour.

Response Effectiveness

66.6% of trained communication behaviours required less physical effort than the behaviour of concern, but 100% required greater cognitive effort initially. As a result of this increased cognitive load, some students demonstrated difficulty in adopting the new communication behaviour. In some instances, other behaviours of concern were introduced despite a reduction in the initial behaviour of concern targeted. Students who were already using their AAC for other communicative functions demonstrated significantly quicker adoption of this method for the function originally served by the behaviour of concern. For example, one student had some established communicative competencies using a Voice Output Communication Aid (VOCA). This experience allowed the student to learn to navigate to the target phrase, ‘I want a break’, with less physical effort than the behaviour of concern they had initially presented with to escape from perceived demands. In this case, increased cognitive effort was minimal due to their established skills using the VOCA.

In all cases, delayed reinforcement acted as a significant barrier to development of the trained communication behaviour. This was difficult to address as some students had access to vocabulary on their AAC system that could not be consistently reinforced. For example, one student would often use their VOCA to request their mother outside of visiting times in the residential setting. This led to delayed reinforcement, which decreased the frequency of the alternative communication method and saw the re-emergence of the behaviour of concern to express frustration.

For some of the students who demonstrated self-injurious behaviour, significant challenges were experienced in not reinforcing the behaviour of concern. Staff were supported to not provide social reinforcement in response to this behaviour whilst also maintaining student safety and following positive behaviour support guidelines.

Response Acceptability and Recognisability

These two criteria were evaluated together as there appeared to be significant overlap in the challenges experienced. 100% of trained communication behaviours were accepted and recognised by highly trained expert staff within this specialist environment which strongly advocated for a total communication ethos. However, generalisation of skills was difficult due to less familiar communication partners not being able to interpret students’ messages. Practical issues of high-tech AAC screens being viewed when students were outdoors or voice output being heard in busy community settings also reduced response recognisability. Signing was a method that was introduced following AAC requiring symbols or technology being rejected (as discussed under response success). However, selection of this communication method frequently had a negative impact on response acceptability and recognisability, as those outside of a student’s immediate family or staff team commonly could not interpret the student’s signing or provide a response using this method, leading to communication breakdown.

Discussion

When consistent and specific teaching strategies could be used to implement the new communication method, response success was met. It is vital that the SaLT regularly reviews the new communication method, and takes a creative approach to challenges that may arise which limit effectiveness of teaching strategies. Alternative communication methods had to be sought following barriers posed by the methods originally trialled for 83% of students supported using FCT. This highlights the importance of the SaLT’s role in coaching staff to understand and implement teaching strategies in the most effective way.

In addition, for students for whom the primary function of behaviours of concern was related to sensory processing needs, collaborative working with Occupational Therapists to identify alternative strategies is necessary, as FCT was not effective for these students.

One common barrier to achieving response effectiveness was that students who lacked fundamental communication skills (e.g. initiation) found it more difficult to adopt the new communication method, as they were not able to identify the value in making a communicative exchange. In this case, an ALS approach was required to model this skill prior to students’ spontaneous use.

Furthermore, any delay to reinforcement was a significant barrier to response effectiveness. Providing the student with access to motivating vocabulary which met the 'response match' was relatively straightforward following a thorough functional behaviour assessment. However, challenges arose when items or activities were not always immediately available. This supports findings in previous studies that delayed reinforcement has a negative effect on response effectiveness (Horner and Day, 1991), but is difficult to completely avoid in real- life implementation.

To overcome the challenge of unavoidable delayed reinforcement, the use of visual support to indicate a 'waiting period', such as visual schedules, now and next boards and traffic light systems were used. This appeared to be an effective strategy for 66.6% of students, however this was only when implemented consistently.

Conclusion

In summary, findings indicate FCT to be an effective approach in increasing communication skills and reducing behaviours of concern for individuals with ID and ASC attending specialist education settings.

However, the findings suggest that the intervention is rarely straight-forward and clinicians must regularly review and evaluate all areas of 'response mastery', adapting treatment plans in response to the challenges and barriers individuals may face.

Findings also highlight the importance of a robust and dynamic assessment of students' communication skills, in order to identify the most appropriate communication method for them. It suggests that the identification of appropriate support strategies for when delayed reinforcement is unavoidable is key. The assessment process must take into account the communication partners and environments in which a student will be using the new communication behaviour. Upskilling of communication partners in the new communication method must take place to facilitate successful communication for the individual. Without transferral of the new communication behaviour to a range of environments and a variety of communication partners, the maintenance and generalisation of these new skills will be negatively affected. This increases the risk of the behaviour of concern re-emerging within these settings.

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Communication Matters and ISAAC BUILD Collaboration

An Update since 2015

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Some information about BUILD committee

The chair of BUILD committee is a member of ISAAC Executive Board

- BUILD is a committee, made up of ISAAC members from around the world, focusing on AAC Emerging Countries, finding practical ways to offer them support.
- The BUILD AAC Project supports the development of services in emerging AAC countries by forming collaborative partnerships and distributing information relating to its discussion topics by electronic and other forms of communication.
- At each biennial conference, the BUILD Committee hosts a meeting that brings people together to network, support and learn from each other.

In October 2020, I completed my term of office on the Executive Board as chair of BUILD committee and co-editor of CSWN newsletter. I handed these roles over to Miroslav Vrankic from Croatia - who will be a great asset for ISAAC (with lots of local and international connections). He has also taken over the role of admin of the ISAACBUILDAAC Facebook page.

Introduction to forming collaborations

For the plenary session “AAC around the World” at Communication Matters’ 2015 conference, I was invited to be a co- presenter with Professor Gregor Renner, Germany, President of ISAAC, Dr Janice Murray, UK, chair of ISAAC Council and Aldona Mysakowska Adamczyk, Poland, chair-elect of ISAAC Council and member of ISAAC BUILD committee.

- My role in the plenary was to present examples of my collaboration with Poland, demonstrating practical ways that CM board of trustees and members could also become involved in future developments for Poland and with other AAC emerging nations in Europe.

Postscript after the CM 2015 conference

Communication Matters board of trustees and members agreed to form a collaboration with ISAAC BUILD European sub-committee and are now sharing CM resources and expertise to help support emerging AAC nations in Europe.

- The aim - To form connections with European AAC developing nations to support expanding awareness and use of AAC and AT knowledge and skills, with the potential to benefit people with complex communication needs and other populations with communication vulnerabilities.

Creating awareness of the collaboration

ISAAC biennial conferences have a section for presentations related to Emerging AAC Nations and a regular meeting for BUILD committee members and delegates to share their experiences.

In 2016, at the ISAAC biennial conference in Toronto, Canada, Catherine Harris, Chair of Communication Matters, and I did a joint platform presentation. Our topic was “Model of international collaboration between an AAC developed nation and developing AAC nations.”

We described the aim of the collaboration between Communication Matters and BUILD:

- To form connections with European AAC developing nations to support expanding awareness and use of AAC and AT knowledge and skills, with the potential to benefit people with complex communication needs and other populations with communication vulnerabilities.

and shared an outline of our plan:

Provide resources for translation in the language spoken in the country

Improve and develop connections within each country's education sector

- Involve parents/families and individuals who use AAC in goal-setting and training activities
- Extend the focus beyond education to include healthcare, social interaction and inclusion for people of all ages with communication support needs
- Share knowledge both nationally and internationally

Continuing to create awareness and development of the collaboration

In 2017, at the biennial Eastern and Central European Regional AAC conference hosted in Bucharest, Romania, Ruth McMorran, Co-chair of Communication Matters, participated in the Plenary, with fellow presenters Professor Popovici, Bucharest University, Aldona Mysakowska Adamczyk, Poland, chair of ISAAC Council, and me (Dorothy Fraser) as a member of ISAAC BUILD committee. Ruth showed examples of Communication Matters activities, demonstrating the benefits of collaboration with BUILD.

By attending CM conferences and AAC study days in England and Scotland I have met many people who have generously shared their expertise and resources for me to use abroad.

Networking with European countries

I was invited to travel to each country and worked directly with local professionals.

The start of collaborations involved preparation on both sides.

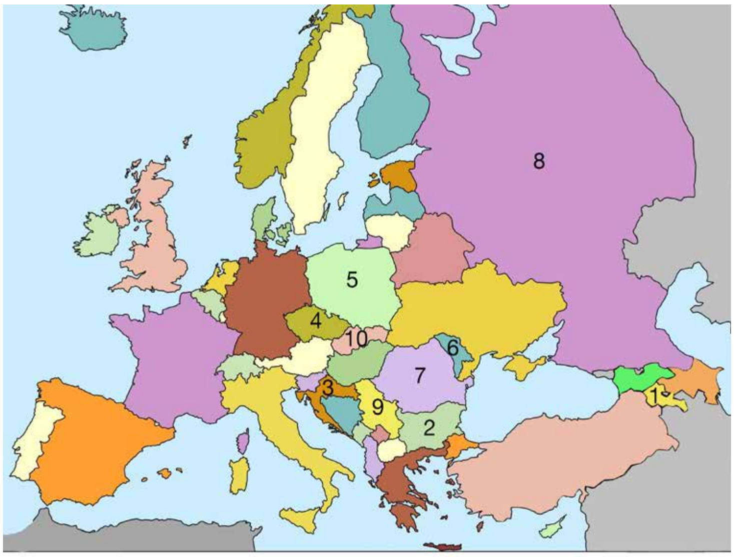
The hosts were eager to learn from the UK how to share, promote and apply up-to-date AAC information and material, including research and practical strategies, ways to overcome existing barriers and how to strengthen their knowledge and build on this with international resources, in education, healthcare and other public sectors, and for the general public.

The success of the projects very much depended upon the effectiveness of understanding and identifying local needs so that each country could be provided with the support they requested relevant to their language, culture, economic and political situation.

The process was a journey of discovery

In addition to sharing their resources for my use, CM members also travelled and presented at AAC/AT conferences in Europe. Attending these conferences was a great opportunity for us to further the expansion of our collaborations, adding resources and discovering more about local AAC requirements in the host countries, and also in other delegates' countries. Meeting members of Communication Matters at conferences in UK and across Europe, forming connections with members of other ISAAC chapters, listening to their presentations and sharing experiences, discussing challenges and finding solutions was an important part of the process.

Map of European countries I have been invited to (countries listed in alphabetical order).



1.Armenia
2.Bulgaria
3.Croatia
4.Czech Republic
5.Poland
6.Republic of Moldova
7.Romania
8.Russia
9.Serbia
10.Slovakia

Taking into consideration, amongst other things, that each European country has its own language, culture and economy, we found that many of the barriers may be the same wherever we are, with similar challenges:

- lack of awareness of AAC
- lack of information about AAC
- lack of skilled professionals as service providers
- lack of access to skilled professional mentors
- limited AAC services
- limited training available for professionals, family members and people who can benefit from AAC services
- limited or no access to AAC materials and technologies
- limited funding for services and/or AAC materials and technologies
- limited access to linguistically/culturally appropriate materials/technologies, and
- uninformed attitudes toward and acceptance of people with disabilities

The aim was to try to get it right for people in each individual country by identifying barriers. Fortunately, we found out that many countries faced similar challenges, which made it easier to suggest solutions and select relevant material from my collection of resources from Communication Matters. It was reassuring for people new to AAC to know there were tried and tested practical ways to overcome barriers they encountered. The 'ripple effect' – if it worked in neighbouring countries, they were more confident in trying it themselves and providing positive feedback to their colleagues.

Material, with examples of theory and real-life situations, was extremely useful for conference presentations and workshops – as a base for discussion and overcoming some of the barriers (from the extensive list) with information for people with varied levels of understanding and experience in implementing AAC.

CALL Scotland was commissioned by NHS Education for Scotland through the Scottish government initiative A Right to Speak , to develop materials to help raise awareness of AAC and ways of providing communication support, aimed primarily at people who have little or no previous experience of communication disability.

Information about A Right to Speak was much appreciated internationally. The material was visually clear, making it easier for people who don't have English as a first language to understand the posters and videos, and also for translators at conferences and workshops to explain the content.

Videos available to download https://www.aacscotland.org.uk/

- **Ways to Communicate**
  An Introduction to Augmentative and Alternative Communication.
- **How many ways are there to communicate?**
  'Collage' showing a number of people using different forms of AAC.
- **A Right to Communicate**
  Made by the Communication Friends Group in Dumfries and Galloway, Scotland.

BUILD activity

Distributing information relating to its discussion topics by electronic and other forms of communication.

Use of Social Media:

- Facebook - ISAACBUILD AAC page (the chair of BUILD committee is an admin). Facebook is a great place to share information quickly, keeping people around the world connected and informed of current news and events related to AAC. We used this as a method of expanding our collaboration with Communication Matters
- Communication Support World Network newsletter CSWN, a 2x yearly online ISAAC publication is co- edited by chair of BUILD committee and chair of ISAAC council.

The newsletters are distributed electronically by ISAAC and also archived, so there is a library of all editions of the newsletter available for free download on ISAAC's website https://isaac-online.org/english/news/cswn-newsletter. Many CSWN newsletters have included AAC information from the UK, with articles, conference news and resource material.

With the 2020 pandemic and restrictions on travel, use of social media became even more valuable as a method of sharing information and resources globally. Widgit symbol software company created more health resources for communication, specifically related to Covid 19, which were translated into many languages. These are free to download: http:// widgit-health.com

The May 2020 edition of CSWN featured material related to the pandemic and we included Communication Matters' posts regularly on Facebook. In October, ISAAC AAC Awareness month, the CM Sessions were made available for anyone round the world to attend and were much appreciated.

A final note and farewell from me

Thanks to the involvement of previous and current Communication Matters chairs, co-chairs, trustees, members and staff. Sharing your knowledge and resources has had a major impact on the ongoing development of AAC and Assistive Technology globally, for people in many emerging AAC countries and in other countries where AAC is more developed.

Thanks to the hosts and translators and everyone I have met for making me feel welcome in their countries. Without you these projects would not have been possible. It has been an honour and pleasure to know you all. I wish everyone a safe and successful life and continuation of your aims towards an inclusive society.

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This article can also be watched on video at:
https://youtu.be/M-LIK_7XEL4

A Report on the Impact of Covid-19 on Young AAC Users

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Background

As a charity, 1Voice supports users of Augmentative and Alternative Communication (AAC), their families and carers. Prior to 2020, this was largely done through social events, such as the annual residential weekend or day activities run by regional branches. However, the Covid-19 pandemic meant our members could no longer access this type of event due to social distancing measures, shielding and safety concerns. Switching to online forums instead to try to continue to offer this social interaction and support, we heard many stories of the significant challenges and difficulties our members were facing.

In Autumn 2020, 1Voice became aware that an All Party Parliamentary Group on SEND was undertaking an inquiry into the impact of Covid-19 and the consequent disruption of education on children and young people with SEND, focusing particularly on the educational transitions they face. In order to contribute to this, we surveyed our members who are in full-time education. This report presents their responses.

NHS England's 2016 guidance report on commissioning AAC services and equipment indicates that around 0.05% of the population require a high-tech powered communication aid. Our survey was completed by 12 parent-carers or the young AAC users themselves, who are aged between 8 and 27. They live mainly in the North West and South West of England and attend a range of educational settings: mainstream primary and secondary; special schools; further education (FE); higher education (HE); specialist residential college and home schooling.

All the young people have complex physical disabilities which mean they are full-time wheelchair users, require full-time support with personal care, communicate using AAC devices and require specialist software and hardware to communicate, interact and access learning.

What They Told Us About the Impact of Covid-19 on Communication And Interaction

83% did not access school between March and July.

67% received no Speech and Language Therapy input during this time.

58% had no care support at home (apart from parents) during this time.

The support needed for these youngsters to interact and communicate, and to develop their communication and interaction skills, largely disappeared. There was an almost complete lack of interaction with anybody but their immediate family. They commented that they were, 'very isolated,' 'extremely isolated', 'had very limited opportunities to interact with others' and suffered from a 'lack of interaction.'

Several families reported a regression in communication and in independence. Many AAC users take a long time to develop the confidence to use their device to communicate independently. The loss of opportunity to communicate meant that some of them stopped communicating altogether. One parent of a Year 11 in a mainstream school explained, 'the only time she would actively use her communication aid was during her speech and language sessions.'

Specialist Speech and Language support by those trained in AAC is a crucial provision for these youngsters to develop their ability to communicate and interact. While 67% had no provision for this between March and July, the remaining 33% reported a massive reduction in this vital support. While one or two still received weekly support, many had just one or two contacts from their therapy service in this time period. This support was sometimes via email or over the telephone.

While virtual lessons were offered to some learners, the pace of these was generally too fast for the AAC user to engage because speaking and building sentences using AAC hardware and software is a slow and demanding process. The pace of online interaction generally meant this opportunity for communication and interaction was also lost.

What They Told Us About the Impact of Covid-19 on Emotional and Mental Wellbeing

> ***"the impact of this on our child and ourselves as parent carers is going to have a lasting effect. We are both exhausted physically and emotionally. We are still in lockdown due to our child's vulnerability…we are both suffering with anxiety and depression."***

50% of our members had not returned to education at the point of completing this survey. The ongoing stress of this is taking a huge toll on emotional and mental wellbeing.

50% have returned to school now but have described the past few months as 'a nightmare.' Although all are keen to return to education, those who haven't been able to make the transition back commented on the stress and fear of knowing whether it is safe to return. For those in FE or HE, in towns further away from the family home, returning to their college means potentially overwhelming complications should they or their care teams have to self-isolate. The risk of parents having to travel long distances to plug gaps in care that could arise from this scenario means a return is too stressful or logistically overwhelming to consider.

Several parents reported their young people suffering with 'anxiety,' manifesting in sleepless nights and compounding mental health struggles. The young people themselves highlighted the strain this extended isolation and dependence on their parents has put on family relationships. While some have accessed online counselling to try to get some support with this, the majority have not.

58% of respondents had no care support at all between March and July. Only 1 respondent had the same hours of support as usual. 22% of those who did still get some care had 'a lot less than usual.' Without additional care support, these young people depended on their parents for everything. The complexity of their physical disabilities means that they need support with feeding, changing, toileting and often facilitation for interaction in online environments. The levels of physical and emotional stress these youngsters and their families have reported is enormous.

What They Told Us About the Impact of Covid-19 on Learning

83% of respondents did not access school at all between March and July.

Although the Vulnerable Children's Act meant that these learners, who all have Education, Health and Care Plans (EHCPs), were entitled to continue to access school, the medical vulnerability and the increased risk they face because of their personal care needs meant that school felt too risky. Respondents reported feeling 'forced to choose' to keep the young people at home and without care support, because the lack of testing meant that risk to life took precedence.

While everyone reported being provided with work, there was a big problem with work not being presented in an accessible format.

54% did not have work provided in an accessible format. A picture emerges from the responses of worksheets and web links being sent home which the learners' physical disabilities meant they could not access. The work 'wasn't adjusted at all' and was 'not in grid or clicker.' The online lessons were difficult for AAC users to participate in.

82% reported that the learning tasks could not be done independently. As well as providing 24- hour care and emotional support, parents were also needed to act as Teaching Assistants (TAs) to enable their youngsters to access learning from home.

While this was stressful, some families reported that they felt their youngsters learnt more over lockdown. Parents used their knowledge of their youngsters to reframe learning materials, re-design activities and re-present the tasks in a way that enabled their youngster to access them and succeed: 'I needed to be able to present worksheets to X in a way that he could access them. Fortunately I was able to do that as I'm a teacher.'

This experience highlighted that the pitch and pace of the learning was often very wrong for these learners. One parent reported, 'the lessons were not aimed at her literacy levels.' Another noted, 'Work was 5 zoom sessions over the entire time period and a package of things to work on that he had achieved at least 10 years before.' Yet another said, 'online, bingo seemed to be the main offer.'

Examples of good practice were reported. One youngster received activities accessible through eye-gaze. One respondent reported always receiving accessible work. One family reported an improvement when TAs who were trained to support their daughter started to offer online intervention which 'worked really well.' These demonstrate that while it is possible to provide adequate support for learning to this group, there are enormous inconsistencies, with the vast majority of provision being inadequate.

40% didn't have the technical skills, software and support they needed to access learning.

As these learners are reliant upon technology, online learning often meant interfacing more than one device and very strong IT skills.

> ***"It was necessary to use another computer to display the work on one screen while accessing the lesson on another, and also trying to access the relevant software to complete the work. It was difficult to switch between screens."***
>
> ***"PC with 3 monitors, intellikeys keyboard, joystick, screen reader, word prediction software."***

The 60% who did have the necessary technical support to access learning got this from a variety of sources: an IT-savvy parent, SENICT, GOSH AAC team and an ICT teacher for instance. Clarity over who is responsible for IT to support learning is lacking and therefore impacted the learning and progression of this group. The responses highlight a huge inequity nationally and a problem which, while compounded by COVID, negatively impacts the learning of this group anyway.

What They Told Us About the Impact of Covid on Their Physical and/or Sensory Needs

75% had no physiotherapy input. The physical disabilities of this group of learners means physiotherapy is vital for avoiding contractures and pain, and maintaining physical health and function.

This lack of provision has had significant negative impacts for these learners. The survey reported little opportunity to exercise in any way at all, physical deterioration resulting in increased pain and surgical intervention.

> ***"our house is too small to use her walker as is our garden"***
>
> ***"Physically, my son has deteriorated."***

Parents have shouldered the cost of purchasing additional items to try to find creative solutions in response to a complete lack of provision or input from statutory services. Parents reported buying spin bikes, hot tubs and ijoy riders out of desperation to keep their young people as fit and healthy as possible. Parents reported 'huge delays' for new equipment, such as leg gaiters, to enable vital physical therapy at home. A lack of space, equipment and support from NHS services means the physical needs of these learners have not been met during this period, except for through the additional efforts of families who have the resources to do this.

The transition back to school has meant that many young people have returned to new classes, groups or settings. Many of these have been unable to train staff to undertake this physiotherapy. Even the 50% who have been able to return to school are not likely to all be getting the therapy they need. Education settings have been keeping out visitors from schools in order to try to ensure Covid safety. This means the numerous experts, services and therapists these young people rely upon to train their TAs and teachers, have not been able to visit. They are therefore still not necessarily able to access physical intervention 9 months later.

What They Told Us Would Have Made It Better

- Regular 1:1 online interaction with education staff trained to help AAC users learn
- Provision of learning materials which were accessible
- Access to priority testing for care support workers caring for AAC users
- Maintained access to vital services like Physiotherapy and Speech and Language Therapy

Conclusions

> ***"The past few months have been a nightmare. It has really highlighted how broken the system was, even before Covid began."***
>
> ***"it is very sad to see that the lives and care of our young people is regarded as so unimportant that the services we rely on for support, such as the community learning difficulty team, were deemed non-essential and closed down for six months."***

Covid has compounded and amplified existing problems in education and transitions for AAC users. A lack of expertise and national standards of provision for AAC users means their educational experiences are hugely affected by a postcode lottery and vulnerable to sudden and dramatic changes in quality. While some areas have expertise at Local Authority (LA) level, or commission specialist services to support their AAC users, other areas do not. A lack of differentiation enabling curriculum access during normal times means that this need is bound to be unmet in crisis time. The lack of funding to adequately train and skill-up school staff around AAC means that each transition, whether change of staff, change of class or change of institution, often sends these learners back to square one. The transition to home learning because of Covid underscored and intensified the existing failure to meet the learning needs of this population.

We would like to see:

- Greater recognition, funding and understanding of the vital part played by services in the lives of this population. Learning disability services, Speech and Language Therapy, Physiotherapy and care support are not additional services but meet fundamental needs. These services cannot be closed down and deny access to the people they support.
- Clarity and national standards regarding who is responsible for IT support to enable AAC users to access learning. This should be detailed in EHCPs and in LA's local offers.
- National standards over the differentiation of learning material and curriculum access for AAC users, to overcome the postcode lottery.

For more info:

For more information about 1Voice - Communicating Together, please go to https://www.1voice.info or contact **Jo Cope** 1voice-admin@1voice.info. 1Voice – Communicating Together, Lymm Business Centre, Lymm Library Annexe, Davies Way, Lymm, Cheshire, WA13 0QW.

For a short introduction to AAC for those who are unfamiliar with what it is and how it is used, we recommend the BBC Ideas short film 'How to Speak When You Don't Have a Voice,' made by 1Voice member Jemima Hughes: https://www.bbc.co.uk/ideas/videos/how-to-speak-when-you-dont-have-a-voice/p07693kc

Communication Matters Small Grants

From time to time, Communication Matters offers small grants of up to £200. Grants are not always for the full amount asked and will be considered on a case-by-case basis. We were delighted to be able to offer the small grant below before Covid-19, but unfortunately, due to the current pandemic and the added financial pressure this is putting on the charity, we are not able to allocate any small grants at this time. Please keep an eye on our website for updates - **https://www.communicationmatters.org.uk/what-we-do/cm-grants/**

Small Grant Award - Feedback

TESS REDDINGTON
Email: contact@purpleumbrella.org.uk

I am delighted to provide feedback about how we have used our Communication Matters grant of £200.

For many years, each month, a group of family members, support staff and people who sign or use electronic speech aids have met together to expand their vocabularies and learn about using high-tech devices. Our group didn't have any formal constitution or insurance, and so it was difficult to market our sessions or expand them. We had been relying on the good will of our local Older People's Club and our own members to teach each other, but neither was sustainable as the Club needed the rent, and we really needed to start to pay trainers. The Communication Matters Grant has enabled us to put our group on a more professional basis.

We have adopted a constitution, opened a bank account and have insurance.

We have introduced a £5 per person membership, but due to Covid and delivering via Zoom we have had to waive the £1 fee for each session.

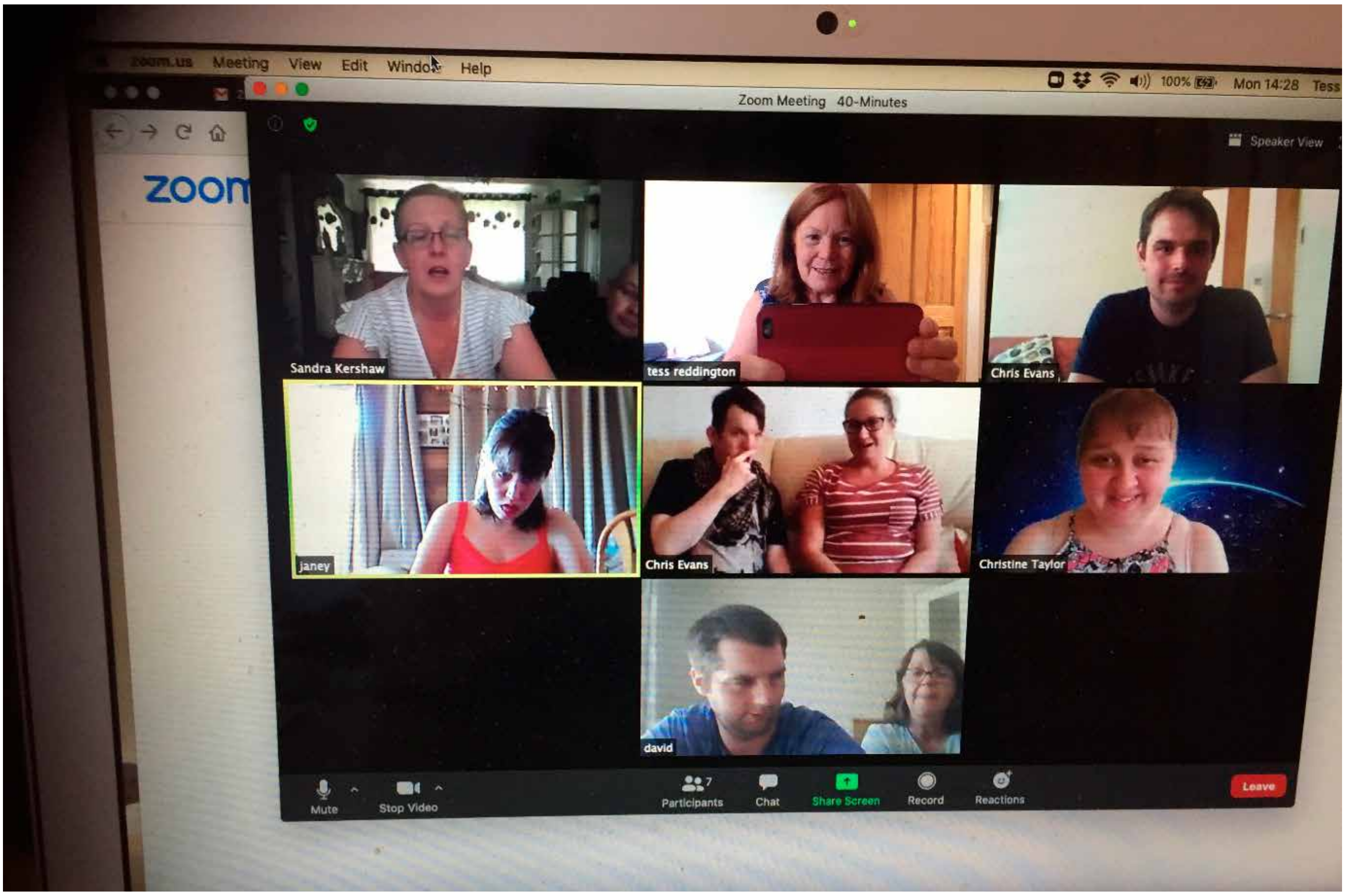
Sessions have been held both in person and via Zoom.

We have held AAC sessions each month as follows:

- 1st June: AAC via Zoom
- 8th July: Mask-erade - a masked ball with signing to help our group get used to wearing masks or visors, and to make meeting up and communicating good fun
- 5th August: AAC in person at Older People's Club
- 2nd September: AAC in person at Older People's Club
- 28th October: Halloween AAC session via Zoom.

Covid has had an impact. Most, but not all in the group, are comfortable working on Zoom, but we have found it impossible to practise using our electronic speech aids via Zoom, so those virtual sessions have just been signing. In-person sessions have limitations (social distancing means we are very limited on numbers), but we have been able to practise and model with electronic speech aids. Two of our new members have been unable to attend due to Covid, and aren't comfortable on Zoom.

We are very pleased, though, with how it's developing. We all feel much more confident, and we look forward to expanding the group further, and particularly to upskilling members and trainers with more external courses, as well as our regular monthly session.



I Think, Therefore I Speak

DR. GEORGE TURNER
Email: opinionator12345@gmail.com

This article looks at a possible future for AAC. Predicting the future can be a foolish game, but it does have two advantages. First, there is a chance (however slight!) that the prediction might come true. Second, even if it does not, such speculation is not a waste of time: it helps to crystalize our thinking about today's problems.

For many AAC users, the problem is that they know exactly what they want to say; it is just that their vocal cords fail to respond. They have a noncompliant body. Usually, the current low-tech solution is some kind of board which, while helpful, is often painfully limited. Alternatively, the high-tech solution usually involves a computer, and a screen that can be scanned. While this system offers more vocabulary, it is laborious and slow.

Mind Control

What is needed is a system which turns any thought instantly and effortlessly into speech. This is the holy grail of AAC. As with all holy grails the question is: does it exist? Well, it might, through - and I hesitate to use this term - mind control. Please be assured I am not talking about brainwashing, meditation or Derren Brown's disturbing TV series. What I am talking about is the miracle that almost everyone performs throughout their waking existence. Most people control their body or, at least, parts of their body effortlessly and almost instantly by simply thinking about it. No one can explain how this happens. How, for example, wanting to move your head can lead to even the slightest movement in the neck. In the 17th century René Descartes believed the mind and body were separate and composed of different substances that interacted through a gland, the pineal gland deep in the brain. Today, most people, certainly most neuroscientists, only believe in one substance, matter. However, as Professor Cobb's recent book on the history of the brain makes clear, after over three hundred years of effort, still there is almost no understanding of how deciding to do X, or to say X, could begin to make X happen (Cobb, 2020). Thus, although researchers know precisely how the vocal cords, the tongue and the lips move when the word 'bad' is spoken, they have almost no idea of how the desire to say that word generates the required impulses.

AAC users can suffer a variety of problems. Sometimes the nerves to the vocal parts are damaged so the required impulses never get through; sometimes the damage is in areas of the brain that control movement, and sometimes the damage is in the vocal parts themselves. However, whatever the problem, many AAC users have a clear idea about what they want to say. It's just that, in effect, these thoughts get stuck in their brain.

The question now becomes whether AAC users could get these stuck thoughts out of their brain, not slowly and laboriously as with current high-tech solutions, but much faster and with less effort. Could they use the everyday miracle of mind control? The signs look hopeful. While it is far too early for AAC users to bin their current machines, progress has been made in three vital areas.

Brain Computer Interfaces (BCIs)

First, effective Brain Computer Interfaces (BCIs) have been produced. So, by wearing a cap over the skull with wires connected to a computer, people can control images of objects on the computer's screen just by using their minds. For example, see Tan Le's (2008) Mind Control Demonstration. If now the BCI is fastened to a robotic arm, it becomes possible to control very precisely objects in the real world. For example, they can be picked up and placed on different shelves (Meng, Zhang, Bekyo, Olsoe, Baxter & He, 2016). Mind control does work and it does not need a compliant body.

BCIs with speech

Second, some progress has been made using BCIs with speech. With thoughts alone, it is possible to move a cursor across a screen and to choose letters and words - something shown on Channel 4's programme Peter: The Human Cyborg (view 22.00-24.00). While impressive, this represents little, if any, advance over existing systems such as eye gaze: it is still slow and tiring. However, a recent article in the prestigious journal *Nature* suggests that it is possible to "read" language directly from the brain (Anumanchipalli, Chartier & Chang, 2019). One of its authors, Edward Chang, claims, 'For the first time, this study demonstrates that we can generate entire spoken sentences based on an individual's brain activity. This is an exhilarating proof of principle that with technology that is already within reach, we should be able to build a device that is clinically viable in patients with speech loss' (Weiler, 2019). Still, before we get too excited, this work used an array of fine electrodes touching the brain's soft surface; it only recognised the electrical activity of sentences the computer had already learnt (although, there were hundreds of these), and it was picking up signals controlling the vocal parts. As Nicholas Weiler (2019) notes, 'The next major test for the technology is to determine whether someone who can't speak could learn to use the system without being able to train it on their own voice and to make it generalize to anything they wish to say'. A YouTube presentation of Anumanchipalli, Chartier and Chang's work (Synthetic Speech Generated from Brain Recordings) shows both how far they have come and how far they need to go.

Progress in Systems

Finally, progress has been made making systems of mind control more practical. Today's headgear seldom consists of hundreds of sensors with large bundles of wires leading to a giant computer, all housed in a laboratory. As Tan Le's demonstration shows, the cap can be fairly discrete, looking like a flimsy cycle helmet, and the computer can be a simple laptop. Eventually, such headgear might incorporate both a miniature computer and a speech synthesiser placed near the mouth. The whole system might look like the equipment that some pop singers wear onstage, with a small speaker replacing the microphone.

How realistic is this vision?

Clearly, this will depend on how much more research is done and on its outcome. In particular, how easy it is to "read" language directly from the brain, preferably without invasive surgery. The good news is there is a strong incentive to conduct more research. This is driven, in part, by the burning desire to communicate with people with locked-in syndrome, people who have become totally paralysed. Moreover, what may finally make speech BCIs a success is not only the efforts of clever researchers using computers that learn, but also the even cleverer plasticity of the brain. Readers who can drive will have had the experience of cringing as their vehicle squeezes through a narrow gap. What has happened is their brain has learnt to treat inanimate metal as part of their living, feeling body. Similarly, the brain can learn to regard any implanted electrodes or any commonly worn electronic headgear, not as a foreign interface, a peculiar add-on, but as part of itself. Whatever scientists create, the brain will subsume and use it.

As noted at the start of this article, even if this particular vision of the future proves a mirage, its pursuit will focus our thinking. It emphasises that the goal for AAC users is easy access to effortless, almost instantaneous speech. As always, the problem is how best to release their locked-in words. If mind-controlled talkers are not the solution, then what is?

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Weiler, N. (2019). Synthetic Speech Generated from Brain Recordings. Available at https://www.ucsf.edu/news/2019/04/414296/synthetic-speech-generated-brain-recordings

George's article **'In Praise of Imprecision'** from the November 2020 issue of the CM Journal can also be watched on video at **https://youtu.be/EbTV1AHq7i0**

Lockdown Poem - The Past Year in Poetry Form, with an AAC Theme

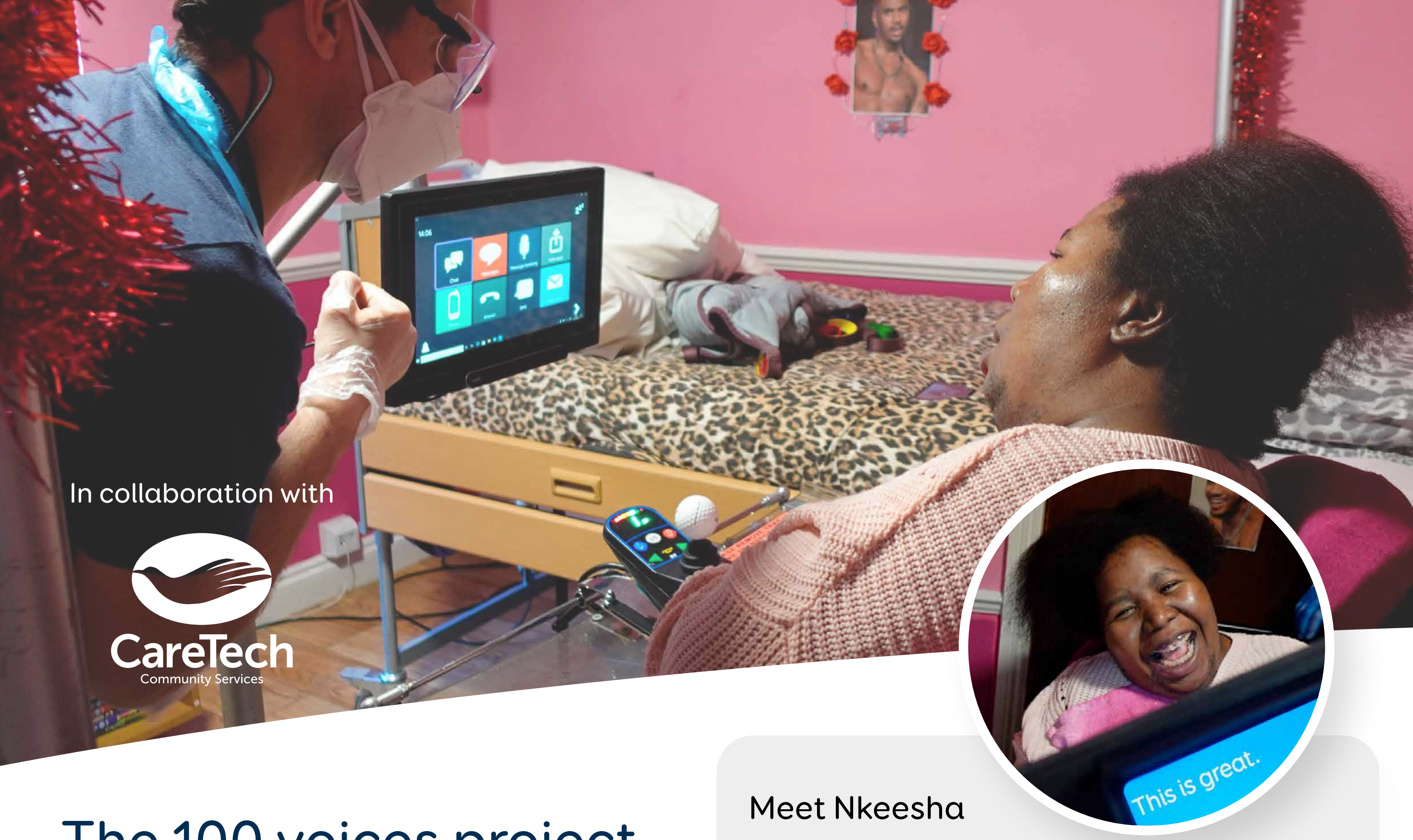
MADDY NORMAN

Stuck with VF for weeks, she is too tired to speak.
Nothing on TV except repeats, AAC freezing every time I use the mouse
Like a house it's slow.

The Powells in Wales can't communicate because of issues.
Haven't seen my boccia gotta mates in months.

Remove the battery from AAC device to make it work,
Yet won't upgrade me because of the iPad type device debakele markele.

Depo injection the nurse needs to wear a mask in case I caught an infection,
I still don't mix because Boris is up to his old tricks.
Communication Matters in trouble, are they going to lose their bauble of funding?



In collaboration with

CareTech
Community Services

The 100 voices project

100 voices is a new joint project between Smartbox and CareTech. Together we will be providing 100 adults and children within CareTech's services with AAC devices to help them communicate.

We will be visiting people in care homes and specialist schools across the UK, trialling different communication aids and methods of alternative access to find solutions that will best suit their needs.

Our team will also provide training for CareTech staff, to ensure that each AAC user is supported throughout their communication journey and able to reach their full potential.

This is our first joint initiative with CareTech and we can't wait to see the difference our technology will make to disabled people in a range of diverse social care settings.

Meet Nkeesha

Nkeesha, 37, is the first CareTech service user to receive a device from Smartbox as part of the 100 voices project. She has cerebral palsy and struggles to be understood by other people.

Nkeesha tried a Grid Pad 15 with eye gaze technology for the first time and was instantly able to interact with the screen. Using Grid 3 AAC software, she explored different types of keyboards and resources for text communication. The predictive features and chat history were a big hit, and she was able to quickly compose messages.

The Grid Pad 15 will give Nkeesha a voice, and in turn help her to live more independently. She is excited to use accessible versions of YouTube, WhatsApp and Facebook, and to use the device to keep in touch with her family via Skype. She is also looking forward to being able to control her TV and change the channels on Sky.

Book your free visit

thinkSmartbox.com/visit

Lockdown with the Hewsons

HELEN HEWSON

Like everyone, I felt quite nervous and tense at the beginning of lock-down when I was listening to the news every day about how many people were becoming infected and dying. Toby and I came back from our skiing holiday in France and almost immediately we went into the national lockdown. I felt quite anxious and scared about what was happening to so many people in the world and I quickly began to realise that this was very different from anything that the world had ever seen before.

At first Toby and I just stayed at home and continued to do stuff on our computers, and email and Facebook our friends. We always went for a walk through our village every afternoon and the spring weather was really nice and sunny. Some days we started playing board games with help from our personal assistants, such as Monopoly and Snakes and Ladders - I usually managed to beat Toby at everything!!! And I didn't cheat that much, honestly everyone.

One of our assistants had the idea of doing some themed days every Sunday, where we dressed up and had a theme for the day and we had food to go with our theme. One week we had an 80s theme where we all dressed up with big 80s hair styles and really bright clothes; another week we had a jungle theme where we dressed up in safari clothes. Liz made a starter in the shape of a lion's face and I found the song The Lion Sleeps Tonight on You Tube and we were all dancing around the living room to it.

Another Sunday, our theme was the NHS rainbow of hope. Liz made a rainbow banner and we all dressed up in really bright colours. Liz had a cake with all the different colours of the rainbow.

Some days and weeks did seem and feel quite long during the lock-down. I missed Mum and Dad and all my family back up in Birmingham; my Dad was very ill for a few months

Missing Birmingham

This article can also be watched on video at:
https://youtu.be/XU4webQTVFQ

and I wasn't able to visit him for nearly 4 months. I'm very pleased to say that he is much better now and back to his usual self and teasing me again.

On the 12th of July, Toby and I celebrated our first Wedding Anniversary and gave each other some presents. Toby then told me that we were going out that evening to a big outdoor drive-through movie and watching Dirty Dancing, which is one of my favourite films of all time. We took a beautiful picnic with us and had our own little roped area outside our car to watch the film. We were all dancing and singing to all the songs. It was a lovely warm evening and so nice to get out and do something different after months of being stuck in at home.

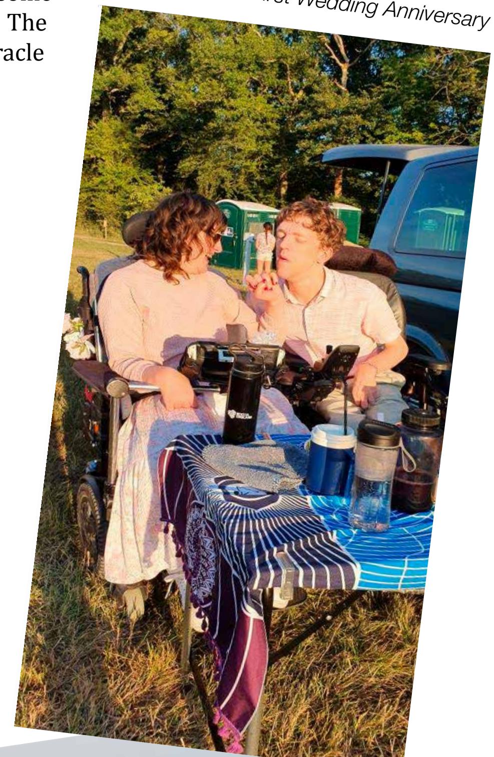
In September, Toby surprised me on my birthday morning and said that we were getting away for a few days in the New Forest. We stayed in a wooden cabin at a place called Avon Tyrell. We went for lots of nice long walks in the forest. At night, we went to a beautiful little pub with lots of little fairy lights outside; the food was absolutely delicious and we all ate far too much.

At the end of September, we went on a short holiday to the Calvert Trust in Exmoor. This was really good and very well organised. We all stayed in our own little bubbles and groups for all the activities. We also had our own instructor who was with us for every activity. They also had plastic screens between the tables in the dining room, so it all felt very Covid-safe.

At the end of October, when I heard that we were going back into a second lockdown, I felt low and scared that things were getting bad again. I wondered what was going to happen next. Luckily, this time I managed to take an overnight trip to my parents just before lockdown, which has made it feel a lot easier to cope with. I also had the sense to go shopping and get all my family Christmas presents the week before, so that I could take them all up with me at the beginning of November. Some days have been quite long and boring this time round, because obviously we can't go out walking in the middle of winter when it's cold and raining. However, I have been able to start returning to some of my work with the Speech and Language Therapy students at Birmingham City University. I was able to deliver my annual Induction talk to the new students during induction week via Zoom. We then had the challenge of working out how we could change my simulation AAC appointment with the students into an online event. This meant some rewriting of the scenario between the tutors and myself, but we got there eventually. The actual day ran well, and none of the technology went wrong or failed, which was a miracle in itself.

My birthday in the New Forest

Celebrating our First Wedding Anniversary



Exmoor

Compass Specialised AAC Service: Working through the Pandemic

JANE BACHE, ALISON HIPKISS AND SAMIA MALIK
Compass Assistive Technology Service
Email: Jbache@rhn.org.uk

Introduction

When the first national lockdown was announced with restrictions on visiting patients in the community, Compass, like many other services, was forced to review its practice. With technology at the heart of what we do, we felt in a good place to offer alternative input to our patients, however the following months were certainly not without personal and professional challenges.

Remote Service Delivery

Compass has always provided remote technical support for patients, and this stood us in good stead for the unprecedented situation we all found ourselves in. Having remote access to devices enabled us to continue providing efficient and effective technical support and intervention, without needing to visit the user in person. In addition, we were provided with a secure video-conferencing package by our IT department which enabled us to continue to offer assessment sessions and observe individuals using their equipment during AAC trials. However, in certain cases, remote working was challenging and limiting. For example, setting up a head switch for someone seems like a fairly straightforward procedure, however it quickly became apparent that we have more skills than we realized, and certain tasks demonstrated the importance of face-to-face interaction! Subtle changes in position and angling of switches, resting a switch against a cheekbone or temple in just the right place, was very hard to describe and demonstrate remotely. We found that some patients' families and carers struggled to manage this work, which was challenging for all concerned.

Sometimes there were more basic problems, such as the patient's supporters not having access to equipment for video calls or not having the technical knowledge or ability to facilitate these sessions. In these situations, there was a need to balance the effort of facilitating a remote session against the risks of a face-to face visit. Some members of the team were keen to do home visits to carry out the required work, and others felt more cautious about visiting and preferred to persevere with remote sessions. Clear policies and procedures were vital to ensure we had a consistent approach to our service input which was effective and safe for both patients and staff.

Face-to-Face Visits

Visits were only considered if they were assessed to be an 'urgent' need and this was a particularly difficult decision to make. We found ourselves trying to marry our belief that communication is fundamental to quality of life with a desire to protect our vulnerable patients. Patients unable to use low-tech AAC options and those with rapidly deteriorating conditions were prioritized for visits. A face-to-face visit risk assessment was created and completed for each patient who required a home visit, with considerations such as the number of people present at the visit, if the physical space allowed for social distancing, the level of PPE required and whether anybody in the household had Covid symptoms. We carried out sessions outdoors, such as on driveways and in gardens, as much as possible and visits were kept short for essential equipment set-up only. We then continued to provide support remotely as needed and whenever possible.

These necessary measures inherently changed the nature of face-to-face visits. On a practical level, it was challenging to don and doff PPE in the community – usually on a pavement, using one's car window as a mirror! Disinfecting equipment before and after visiting and being mindful of what we had touched was an extra consideration during sessions that took some getting used to. Wearing masks obscured everyone's facial expressions, which made communication challenging and more effortful for all involved. The experience emphasized just how crucial facial expressions are during a typical communication exchange. There was one occasion when a member of our team needed to visit a patient who was hard of hearing and relied on lip reading, which was not possible with staff wearing a mask. When keeping sessions short and practical, it felt unnatural to skip the usual informal chat that is so valuable to building and maintaining relationships with our patients. There was a real sense of hurrying through sessions at times, especially initially during the first lockdown when there was lots of uncertainty about the virus itself. It sometimes felt hard to really get to know new patients during this period and build a solid rapport.

Training

As time went on and it was obvious that normal service provision would not resume soon, we considered what other aspects of our service could be adapted to enable ongoing provision. As we could not provide our usual face-to-face training courses to our local referring therapists, we decided to develop and record our content as an online resource which could be viewed at any time. We have received positive feedback from those who have viewed the training videos, but we recognised that we needed to provide an opportunity for discussion and to answer any questions. So, at a later stage, as we became more confident with using online platforms, we held some courses live to support our local therapists.

Moving Forward

The experience of the situation that we were all placed into suddenly, has helped us to introduce changes that we will continue to implement in the future. For example, using video-conferencing facilities to help assess patients, as we have noted that seeing a patient this way prior to a visit is really helpful in planning face-to-face sessions and making them more productive. There have been times throughout this whole experience when we have all been surprised with just how much we have achieved through remote working, both with our patients and as a team. We will also continue to provide some online and remote training as we feel this is often more cost- effective and places less demand on attendees in terms of study leave and travel. Our use of videoconferencing during this period has certainly been prolific and enabled us to maintain team cohesiveness during home working. However, nothing beats a face- to-face coffee and a chat in the office with the whole team, and that is something we all look forward to!

The Compass Service is one of the National AAC Specialised Services working in West London.

COMMERCIAL ARTICLE BY

MARK STREET
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“Are you there?”, “Can you hear me?”

What a year! 2020 has certainly been a challenging year for many of us, COVID-19 and Brexit both dominating the headlines! My name is Mark Street and I work for Liberator Ltd in the UK. At Liberator, we provide a range of dedicated communication solutions for individuals who are non-verbal or are unable to communicate effectively using natural speech. My role as an AAC Consultant is to support assessments and provide training to those individuals wherever they are (e.g., at home, in school, at their workplaces or residential facilities). This is something I have not been able to do since March 2020 due to the COVID-19 pandemic, but I am not complaining as I acknowledge there have been many people who have suffered financially because of the global pandemic, which makes me extremely fortunate.

Over the last 8 months, I had to adapt and find new ways to reach those with whom I work and previously met face-to-face. I found myself becoming more dependent on existing technologies that I seldom used, and this changed how I worked. I’m sure it changed how we all worked! The phrases “Are you there?”, “Can you hear me?”, “Unmute your microphone!” and “I can see you now” were phrases I quickly began to use on a regular basis as I embraced the virtual world and started using Skype, Teams, Zoom and many other meeting platforms I never knew existed before March 2020!

Given the unavoidable challenge of meeting my clients’ needs remotely, I decided to embrace this opportunity. I created a series of online webinars for Liberator, presenting them live myself and alongside a variety of guest speakers from across the world. The online webinars were a huge success, and we reached more individuals in the UK and Ireland in the last 8 months than we could have ever met in person. Many of the parents, professionals and others who support AAC have been able to adapt to this new way of working, and even when we can “return to normal”, many of us will continue to utilise the virtual technologies with which we have become more comfortable.

Personally, I am grateful for the opportunity to learn new skills. I have been able to share my knowledge and experiences with thousands of people, I have recorded over 70 videos for the Liberator YouTube channel (LiberatorAACVideos) and I have presented to more than 17,000 people live this year alone, hosting more than 200 webinars! I am excited by the technological advances we have all been forced to adapt to, but I am also excited to see this as an opportunity to be able to better the service and support I can offer to those whom I work with, not forgetting the benefits to the environment, too!

So, I would like to say a huge thank you to all that reached out to me over these tough times. I want to thank you for your continued support, enthusiasm and commitment, and I look forward to working with you in the near future. All the best and, dare I say it, “Stay Safe”.

Getting Fluent with PODD via Zoom

KIM MEARS
Independent Speech and Language Therapist, TherapyThread
Email: kim@therapythread.co.uk
Twitter: @TherapyThread

I work with a young man, M, who has just turned 20. M has a diagnosis of autism and he is able to speak a small number of words. He can read, however he has a limited vocabulary and he needs symbols to help him to understand what the words mean. In 2019, we were using a single-page opening PODD (Pragmatic Organisation Dynamic Display) book with 20 words on a page to support his ability to ask questions, comment and give an opinion. In November 2019, I attended an advanced PODD course with Gayle Porter, and the suggestion was made to increase the book size to 70 symbols on a page. The family thought this would work and I set about making a new book. In January 2020 I gave one book to M and made one for myself. I started showing the family and M at home and took the lead (as I would normally) in working on navigation of the book and building partner fluency. Then Covid hit, and suddenly we were working online and I was left wondering how this would work, especially as M found change challenging. I could not have been more wrong. As it turned out, going online was the best thing that could have happened for all of us on the PODD journey. There are many reasons why this was a positive thing, and it was a big learning point for me in how I demonstrate and use the PODD book.

Lesson 1- the balance in control of using the book was transferred to the family. I hadn't realised how much I tended to take the lead in using the book and in demonstrating when I saw him at home. Suddenly the book was literally out of my hands and his family threw themselves into learning how to use it as there wasn't another option. This meant they felt much more confident much more quickly and they started to use the book with other online tutors, which was great.

Lesson 2- I had to massively slow down my navigation of the book! I realised how quickly I can go through the pages, and by having to demonstrate and then wait online, it slowed me down and this was a significant learning point for me.

Lesson 3- less sensory stimulation. This was a really important one for M. He responded well to having some distance from me. With me on screen and mum in the room, it felt that there was less stimulation, and it was less overwhelming. Again, this was a positive effect I had not expected, and it has also been the case with other students I work with.

Working online has thrown up many challenges and is not always ideal, however in this instance it has worked well in supporting the conversation partner's fluency and confidence, and in aiding my reflection on my intervention. M has made fantastic progress over 2020 and I look forward to what 2021 brings.

Having Cerebral Palsy and Lockdown

BARRY SMITH

Who I am

Hello, I am Barry Smith and I am 41 years old, with a physical disable what is Cerebral Palsy. Down to me suffer from this, I am in a power wheelchair and I using a voice output communication aid which is a Lightwriter. I use a SL50, before I use a SL40+. This helps people to understand what I am trying to say to them.

February 2020

About end of February/March I heard on the news some parts of the world were going into lockdown for the first time. I watch the news and thought to myself it never will happen here. A few weeks later the government told us everything must close apart from food shops and pets' shops, and everyone got told to stay at home and support the NHS.

The first thing I did

For once in my life I started watching DVD box sets to take my mind off what going on the world. Then one of my Personal Assistants (PA) say she had a tent - would I liked her to bring it around and put it up out my back door, I say yes because it was what I did with my Dad when I was a boy. My Dad no longer with us now, he died two years ago, but his memory still lived on in me and my big brother.

Then I went online and buy things I needed update in my house and new computer what I use to talk to friends, as well I got a new fire pit for my back door, which one of my PA put on when is good weather.

Then I got a man in to wallpaper my bedroom and paid for it. Just over three years ago I broke off with my Ex man: after he leave I find out he wasn't told the true, and wanted me my house my own again with my cat.

Now I started thinking about the past and it is getting me down a bit. What I do not liked, I was going on holiday in November, but I put it off to next year. What I did not want to put off to next year, but my health come first. Before lockdown happen, I could go out by myself now I cannot without my PA because if I need to ask for help people might have Covid-19 and they might pass it on to me. Will I be able go back out myself, God knows?

Phoning people with communication aids

A few years ago when I use the Connect Lightwright I started to phone people like the Bank and the AWP to sort my benefits out by myself. I was told because it isn't my own voice they couldn't speak to me under date for act 1994. The outcome where they wouldn't talk to me, down to it wasn't my own voice. I told them what I was always being told, that my communication aide is my voice. They told anyone could telephone with a communication aide and say they was you. So I had to ask my Mum to come and make my point, what I don't think personal is right.

Now we are going talk about feelings

Many people who use AAC are happy most of the time, what is nice to see. A few times in my life I start bit the back of my hand, when I am very upset, and say things I don't mean because I don't want people to see me like that.

Exercise

Over the last few years, I find the way I move around was getting harder, down to my age and the bad thing I pick up over the years. Before locking down I asked could I see a physical therapist to help me, at my local hospital. When they got around to see me, we were in lockdown and she could not see me, she gave me and my PA a phone call to talk about what I am look for.

The outcome of the talk was she told me about an online website which is call Giraffe which is a personal fit program, she said I am going to sign you up to do this, there are 8 exercises in the program to do to support you. To do these exercises I got sent out two fitness bands from the hospital. I was told to start on the green band because it was less difficult to start off with, when the green band gets easier, I can move onto the blue one. When I put Giraffe program on, each exercise has video to show you how to do it right, then you can write how feel after doing it, what I personal think is good. All information what I put in is checked by the physiotherapist, and as well I got my bedroom did up, to take my mind off going out.

I am hoping to go back to my power chair football team soon because I am miss see people.

My Lockdown Experience

REBECCA MARRIOTT

I was excitedly looking forward to being bridesmaid for my sister Sarah on May 8th, VE Day. The lockdown announcement changed plans for everybody. Sarah and Simon managed to pull their wedding forward to March 19th. We had three days in which to arrange their BIG DAY. I was very proud to be their bridesmaid. This event was the start of very strange times for me.

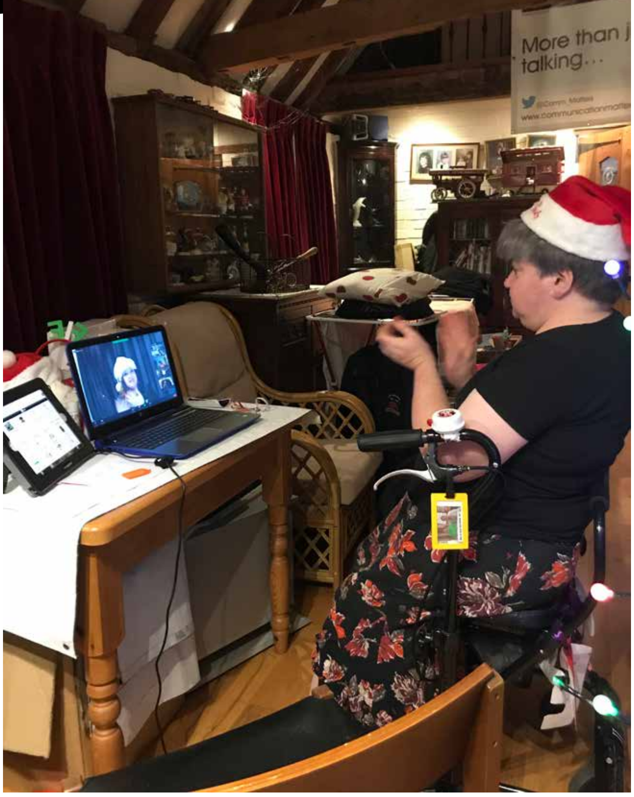
I enjoyed clapping for carers. I played with the pan and spoon, but Fred ran off with the spoon. I preferred playing the old car horn- 'beep beep, parp parp'.

Lockdown for me means being at home with Mum, Dad and my dog Fred. My activities over these lockdown months have been endless. I am lucky enough to have a separate room to escape to, which now resembles a 'Hobby Craft' warehouse.

Fred helped me with exercising in the garden.

My Dad created a display for the NHS with his daffodils.

I enjoyed my Zoom sessions with Communication Matters and One Voice. I was excited to see my friend from Bedford College, Natasha.



My day centre holds Skype sessions twice a week, a quiz or draw-a-thon, or karaoke.

I enjoyed watching a virtual airshow by Aerobility and I watched Cliff Richard live through a Royal Albert Hall link as his concert had to be cancelled.

Mum has organised monthly photo books of my lockdown activities: baking bread; making gingerbread; baking cakes; making jam; latch-hook rug; sewing my own mask; making banners and posters; craft cuttings; sticking and gluing; Easter bonnet making; doing jigsaws; playing dominoes; painting my nails; making hair braids until I could have a lockdown hair cut; birdwatching. Then came the glitter season - I made my own Christmas cards and decorations.

Being autistic and being out of routine in lockdown has admittedly been challenging for my parents. I have missed my friends at my day centre, missed my hydrotherapy sessions, Gateway Club, steam engine clubs and their rallies and road runs, and my gym exercise session, and of course the Communication Matters conference. We have not been able to go on holiday. We telephone Nanny every day as we are not able to see her. But, hey ho, I am lucky to have my family, Fred, and carers to help me through these strange times. Communication is what matters.

Stay safe everyone.

See you all one day.

Rebecca xxx

My Communication is My Communication

BETH MOULAM
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For the most part I accept my communication for what it is, as a part of who I am, in fact I usually celebrate my CP and dysarthria. Every so often I have a blip and frustrations boil over if I'm having a tough time, especially in new situations, and somehow in the first lockdown things were really put into focus, with numerous online communication challenges.

Those of you who have met me know I have some natural speech which is mainly understandable in context to those who know me well. For everything else there is some form of AAC. I got my first device age 4, so I guess I'm a mature multi-modal communicator 22 years later. I'm discounting for this article body language, sign, facial expression and eye pointing just for a moment, because everyone uses these as part of their daily interactions.

I had a half day when I felt everything was hopeless around my communication. Over several weeks I'd had one difficult online conference after another. These were with family who were learning to use digital platforms, and in my sporting life. Fortunately, Mum and my most experienced Personal Assistant were around, and a really long and detailed chat was so helpful.

I resorted to using Talking Mats® to express how I was feeling and to add some qualification to my thoughts. I've always liked this as a tool, not because it's giving choices but because I can rank things quickly without much thought, using my gut instinct; so it's good, but how good? Is it more, or less, important than something else? Or it's something I don't like, but by how much? For those of you who are familiar with the tool, I've created my own additional vocabulary so I'm not reliant on the core words or symbols provided. I guess this plays to my strengths as I am a visual thinker; I like to see the symbols positioned on my iPad screen, and adjust them instinctively if I need.

Talking with my family I understand that EVERYONE experiences some of these issues. They are common communication issues. Everyone:

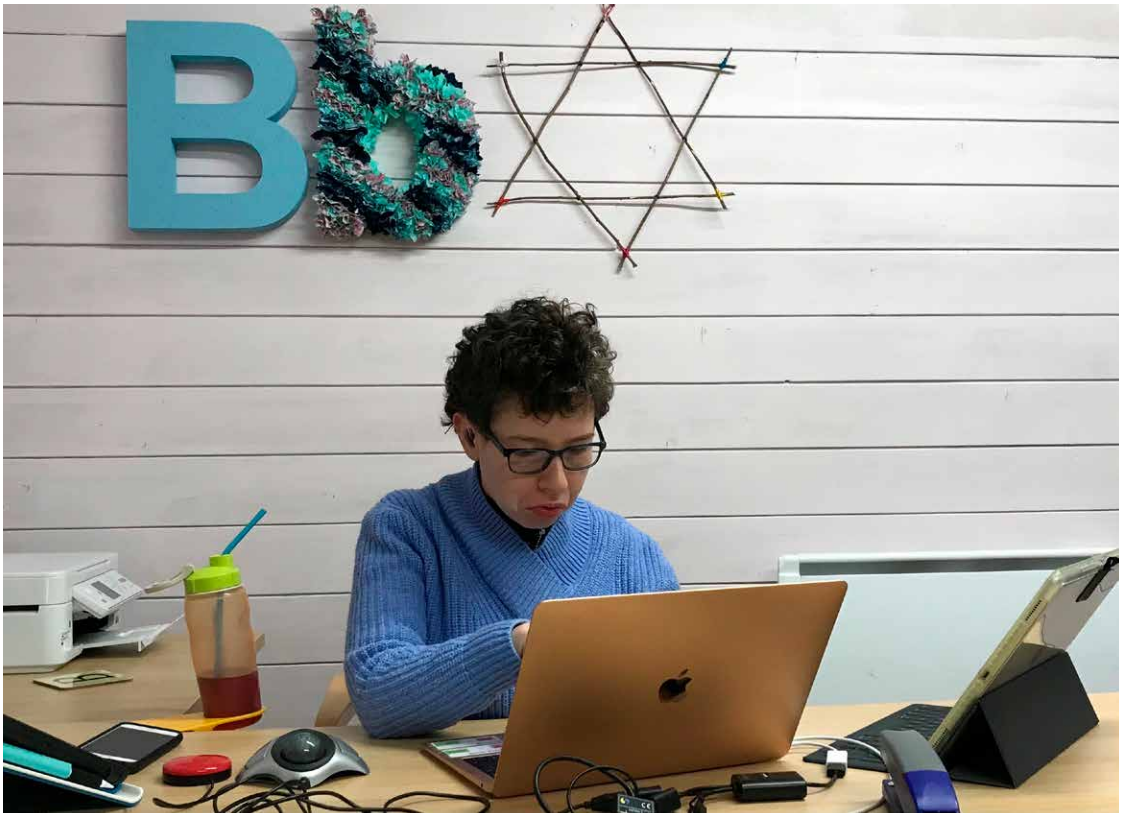
- gets talked over at times, so even as a communication aid user this is normal
- meets people with strong opinions who shout down others, or interrupt
- finds there is always someone who wants to finish off their sentences
- has challenges sometimes getting a word in edgeways
- comes across people who are rude, patronising, are unable to listen or just don't understand things.

What I think is the difference now is that these examples were more in my face due to constant video conferencing. I also now recognise these things have been a constant in my life, particularly in groups, when I have plenty to say but find I cannot always be as spontaneous as I would like.

The pandemic and our first lockdown brought many more opportunities to reflect on my communication than I would have thought possible. This year has given me plenty of time for thinking and whilst I guess I knew all this, I have had the time to consider things, talk to people about these challenges and share information with key people in my life (plus the opportunity to blog about some of it on my website).

For me:

- Written communication is effective and more detailed for discussions outside of home. It allows me thinking and preparation time, consequently, my responses appear more spontaneous, detailed and considered than using AAC face-to-face.
- During group video conferences I've been able to work on protocols so I can interact more effectively with team mates at boccia - ideas are in one of my blog posts (link below).
- Some psychology activities for boccia made me realise how I needed to communicate with my coach and support team more generally eg. discussing feedback from match performance and motivation, and what I need in return from them.
- Reflecting on what works best for me in all types of situations has led to some tweaks in how I program my AAC, which devices I have available, and when it might be pertinent to have a back-up device eg. when delivering something pre-programmed but still wanting to be able to communicate spontaneously, for instance when I'm delivering training or a workshop.



- Repair strategies are ever important, but the ones I use most when verbally communicating and face-to-face don't always work for video conferencing, so I have had to have new strategies.
- Revisiting some of my lesser-used communication resources, I've renewed all my alphabet boards and actually now find in some circumstances spelling is quicker with someone familiar when we are one-to-one.

It's also important to remember that communication is not a one-way street. In every interaction there is the communicator and the listener. Having identified I was struggling I realized I needed to both understand why and let other people know too. Sharing with people who have your best interests at heart lessens the load, and simple things can make a huge difference.

One thing I also like about video conferencing is that I can lip read what someone is saying, but people need to be sat close enough to the screen in good light for me to see their faces, and I need to have the right screen set up. Sadly, I've discovered some people don't want to have their video on in more public forums, like university lectures, so I miss out on some of their contributions, but on the whole this has been good.

All the online stuff has shown just how important it is that I understand the impact of my hearing impairment, as well as letting other people know what they need to do. Sometimes at home when I'm tired I don't wear my hearing aids, to give my brain a rest, but I really do need them online, even if the platform in use has a text or subtitle facility (because 'they' often caption the videos with gobble-de-gook, and somehow they think dysarthric speech means swear words).

Ultimately, what the pandemic has taught me is that sharing makes things better and brighter. Talking through my perceived issues with those I know have my best interests at heart helped to put them into perspective. Then, by unpicking each area of concern, it's made me review my 'practice', what I do on a daily basis, and subsequently refresh and update my ways of communicating. What I know now is my communication is continually evolving with new situations and circumstances, and this has to be a good thing. Going back into lockdown in November, and then January, was not something anyone would wish for, but I knew I was in a better starting place than back in March 2020 because of what I'd learned.

Further thoughts on being a multi-modal communicator can be found on my website at https://www.bethmoulam.com/ and my blog at https://www.bethmoulam.com/blog/

This article can also be watched on video at
https://youtu.be/qmzxxt1eVhc

Tips to Support Patient Safety in a Virtual Environment

ROSLYN IRVINE
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In response to the COVID-19 pandemic, many of West Park's health care services have been modified to be provided virtually by connecting with patients via telephone appointments, video visits, and messaging. Virtual care visits bring safe and convenient health care directly to patients and their family members, reducing the need for travel to and from the hospital.

The Augmentative & Alternative Communication (AAC) Clinic had to quickly adapt during the Covid-19 pandemic to provide most of their service in a virtual environment.

Roslyn Irvine, Clinical Coordinator for AAC, said that the team was prepared for the challenge noting, "we were already familiar with using remote platforms such as Team Viewer for supporting clients' technical needs, and we started to use Zoom Healthcare to conduct assessments, training and interventions with clients and their caregivers." As part of their learning journey, the AAC clinic shares a few tips on safely and effectively delivering virtual care below.

Tip 1: Understand the needs and preferences of the client

An important question to ask yourself as a clinician - is virtual care the best approach for your client and their family? The AAC team suggests you try to spend some time before seeing the client to discuss with them (and/or their caregiver), the pros and cons of in-person vs. virtual care, to find the best fit for each phase of assessment and intervention. This involves discussion of the risks and benefits of both modes of service delivery to ensure informed consent.

> ***Quote from client: "Initially we thought that we would have to put the eye gaze [assessment] on hold but after discussing our options with the AAC team, we decided to try a virtual care approach to our daughter's training. ... She officially started her sessions in July and it has been a success.... Between virtual appointments and email correspondence, the virtual care that our daughter has been receiving has been great. Her training sessions have been convenient and more frequent because of the flexibility of scheduling."***

Tip 2: Plan and Prepare Before your Virtual Session

The AAC team found that planning and preparation before the virtual sessions began was integral to their success. Consider training the caregiver/support staff before working with the client, to ensure they are able to operate the videoconferencing system and enable different views of the client, their equipment and the environment. This will ensure accurate clinical observations and confirm that the AAC equipment the client is using (e.g. a speech generating device with wheelchair mounting) is set up safely. This training can be done by emailing cheat sheets with photos or video tutorials to the caregiver/support staff, and having the clinician observe the caregiver/support staff safely set up equipment through videoconferencing.

> ***Client quote: "The staff worked quickly to ensure that all the paperwork was completed and through emails and phone conversations, our daughter received her eye gaze device via courier. We were also sent very detailed instructions on how to put the device together which was quite easy to do"***

Tip 3: Ensure service is being provided safely

The AAC team found that they were able to translate many of their clinical indicators to the virtual environment. Catherine Monchesky, an Occupational Therapist in AAC noted, "as masks do not need to be worn in the session, we are able to closely observe the client's communication, including facial expressions, to ensure that use of the equipment is not creating any physical strain or eye fatigue". Should the client experience any health issues or medical emergencies, the pre-agreed upon emergency plan can be initiated.

Overall benefits of virtual care for patient safety: AAC Perspective

Virtual care has allowed the AAC clinic to schedule appointments at times which integrate into the daily routines of their clients. This creates a natural and functional learning environment for maintenance of skills. Sessions can also be scheduled more frequently and at different times of the day.

> ***Client quote: "A major benefit to virtual care is giving our daughter the opportunity to use her communication device in the comfort of our home with real life situations.... our daughter would access her eye gaze with activities such as eating a snack, reading books and choosing a TV show that she would like to watch after eating or reading."***

Multiple clinicians can participate safely in an appointment without risk of transmission of infection. As masks do no need to be used, it facilitates clear communication, especially in terms of reading facial expression and hearing unclear speech. This is essential for the delivery of effective AAC care.

Irvine says that virtual care has, "enabled the AAC clinic to continue to provide high quality service to our clients, many of whom have compromised health, in the safe environment of their home. It has challenged us to implement processes to ensure that service is provided safely as well as efficiently".

Call for Papers!

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We are looking for both pre-recorded and live platform presentations, as well as poster presentations and lightning talks.
We particularly welcome contributions from AAC users and family members.
We would also be interested to hear your experiences of telehealth this year.

We have based our topic areas on the three aspects of evidence-based practice:

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Again this year we will be using an online submission programme.
You will be asked to login and submit a simple form with a title and a short summary about your talk (maximum 300 words). The deadline for submissions is 23 April 2021.

Further information and guidelines can be found on our website:
https://www.communicationmatters.org.uk/what-we-do/conference/

If you have any questions or would like to discuss the opportunity, please email admin@communicationmatters.org.uk

COMMERCIAL ARTICLE BY

SUE WHITE
Senior Education Specialist, **Widgit Software**
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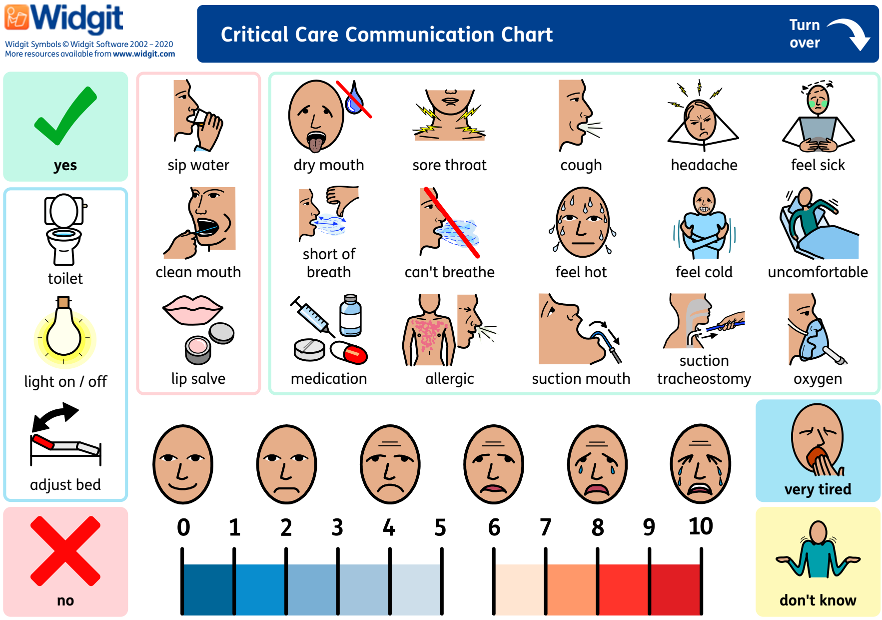
My Personal Experience During Lockdown

As with everyone across the industry and workforce in general, lockdown initially caused concerns about the validity of my job within the Widgit Team, as I spend most of my time in ‘normal circumstances’ out on the road demonstrating our software in schools, at events, conferences and exhibitions up and down the country.

However, it soon became apparent that despite the inability to get out and about, there were plenty of projects to keep me occupied! The most important of these was the work that Widgit Software did in collaboration with the Speech and Language Therapy (SLT) team at Weston General Hospital in producing a critical care communication chart to support patients who had difficulty communicating when they were unwell due to COVID-19.

The Critical Care Communication Chart (https://www.widgit.com/products/health/covid19-communication-chart.htm), which is a symbol board, assists medical staff to communicate with patients who are critically ill due to COVID-19 (or other conditions). It can make communication possible, even if the patient is being ventilated or has a tracheostomy (but is alert).



The chart includes symbols for immediate care needs as well as messages the patient may want to pass to family members. Patients simply point to items when they are either too fatigued or otherwise unable to talk.

Working collaboratively with Emma Shah (SLT) and a senior designer within the Widgit team, the initial design was agreed, prototypes were checked, layouts discussed, items added and taken away and consideration given to symbol size and so on.

It was then decided that we should translate the chart into as many languages as possible (currently over 60), and with the help of Emma Shah and her contacts in Communication Therapy International (a Royal College of Speech and Language Therapists Clinical Excellence Network) and CPLOL (the organisation for national Speech and Language Therapists’ associations across Europe), translations were received, and I spent many hours placing these into the charts.

Feedback from translators has been that Widgit symbols are very accessible to people of all ages and cultural backgrounds – the skin colours have been varied for different ethnicities. Receiving this feedback and knowing that the chart has made a difference to so many in such a large number of countries, made all the hard work worth it!

Once the free pdf downloads had been completed, I then decided to create an online talking version where the patient, or a member of their care team, taps a cell on the board and their choice is spoken aloud. These have proved very popular too, and are available in 24 languages.

As Covid-19 and various levels of lockdown continue across the world, I am proud of the contribution that this chart has made in supporting communication amongst the most vulnerable, and proud that I was able to play a part in this work.

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