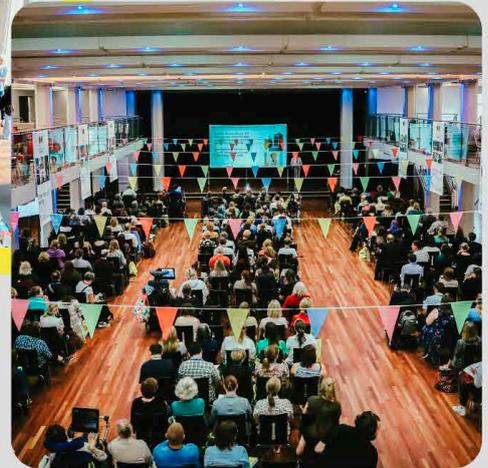


# Communication Matters



**COMMUNICATION MATTERS  
INTERNATIONAL AAC  
CONFERENCE  
10-12 SEPTEMBER 2023  
UNIVERSITY OF LEEDS**



**APRIL 2023 VOLUME 37 NUMBER 1**

**THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)**

**1-Voice Update - Locked-in Syndrome - Core Vocabularies - Brain-computer Interfaces  
- Smartphone Visual Planner - Angelman Syndrome - Social Development - Multimodal  
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We look forward to welcoming you all to the CM Conference 2023 in Leeds. Find out more at <https://bit.ly/cm2023conf>

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# Chair's Report

HELEN WHITTLE

Back in November, we were supported by [Impactara](#) to have a day exploring Communication Matters' (CM) current strategy and how it fits with our aims and objectives. This involved all the Trustees considering what we thought CM should be concentrating on, aiming for, and focussing on in the future. It was a great day, and we achieved so much with the pro bono help of Gerry and Lynne. One thing that will help the Trustees to move forwards with different aims was the establishment of more working groups. These small groups of Trustees will meet between Board meetings and work on certain aspects of business, e.g., Fundraising, Marketing, or Events. Each working group will then feedback to the full Board at Board meetings.

We have some exciting news too regarding staffing in the CM office. As of the 1<sup>st</sup> of March, Emily has been joined by Helen Copeland as the new Administrator. Both Emily and Helen will be attending the AAC Awards evening, so if you are attending, please say 'hello'!

We are planning for a busy March which will all have happened by the time this journal is published. We are holding a free to attend Mentoring Project Drop-in Session and AAC Supplier's Exhibition Day on 24<sup>th</sup> March at the University of Leeds. All the participating suppliers will have paid to attend, and this money will be used to help provide subsidised places for AAC users and their Personal Assistants

at the AAC Awards evening which is taking place that evening. This will be a glittering event celebrating the whole of the AAC field. We were delighted to receive 58 nominations for the awards. It will be a special night. Our Patron Lee Ridley, Lost Voice Guy, will be providing a comedy set, and we will also be joined by Sign Out Loud to help make the evening a memorable celebration.

Following the success of the AAC Information Day in Glasgow last year, we are holding the next Information Day in Belfast on the 8<sup>th</sup> of June 2023. The day will take place at the Girdwood Community Hub in Belfast and will be free to attend with refreshments and lunch provided. You can sign up now to this event here: <https://www.communicationmatters.org.uk/diary/information-days/>

Last but not least, we have also opened the abstract submissions for this year's conference (10-12<sup>th</sup> September 2023). You have until 21<sup>st</sup> April 2023 to submit a paper, so please do so as it will be great to have lots of abstracts to consider and help us to plan the conference this year. The conference theme this year will be "Back to the Future", so get thinking about possible fancy dress ideas! Further information can be found on our website: <https://bit.ly/cm2023callforpapers>.



Communication Matters



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Communication Matters International AAC Conference  
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University of Leeds

# 1-Voice Digital Update

**HELEN HEWSON AND AMANDA HYNAN**

Trustees, 1 Voice

**Email:** 1voice-admin@1voice.info



*Helen Hewson*

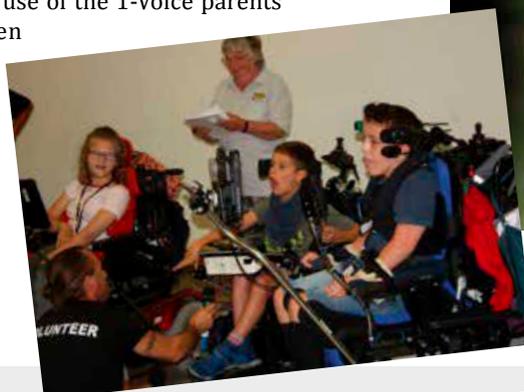
1-Voice Communicating Together is a member led registered charity which was setup by a parent, Katie, and a speech and language therapist, Tamsin, in 2000. Our focus as a charity is to provide networking opportunities and support to young AAC users and their families. Our members are a diverse group of people who all have an interest in AAC (AAC users, siblings, parents, grandparents, personal assistants, carers, teachers, speech and language therapists and a wealth of other professionals). A core principle underpinning our work is a role model philosophy. AAC users are strongly encouraged and supported to share their knowledge and experience with others. This article will report on the presentation that 1-Voice Communicating Together delivered at the 2021 Communication Matters virtual conference. We were keen to report on how we had adapted to run online events during the Covid-19 pandemic, developed new social media groups for AAC using members and their families, started a new role model training programme online and launched our new website.

In 2000, the inaugural 1-Voice event at a hotel in Blackpool offered a chance for young AAC users and their families to get together and have fun. Ever since the success of that first event, 1-Voice has hosted an annual national residential weekend at various venues around England. These national events are always popular and valued for bringing members together to create and maintain social and support networks. The last in-person national event in 2019 was attended by 148 people of which 37 were AAC Users. 1-Voice also has several regional branches which run ad hoc local events throughout the year. We produce a quarterly newsletter so that members can keep up to date with the latest events and initiatives and stay in touch with each other.

We started 2020 in great anticipation of celebrating our 20<sup>th</sup> anniversary at the annual national residential weekend in August. This was going to be our biggest physical event to date, and we were expecting over 150 people. Sadly, it was cancelled due to the pandemic which was so disappointing. Local branch events were also cancelled, including the launch event for the new 1-Voice Southwest branch.

We were determined, like so many other organisations, to rise to the challenge and move our plans online. With careful planning, we were delighted to be able to bring our small and dynamic community together in new and creative ways that we would not have imagined pre-pandemic. However, finding the confidence to get started on these new initiatives and develop new skills was daunting. One of the first things we did in May 2020 was to create a teenage 1-Voice closed Facebook group so that young AAC users could share information and ask questions in a safe online space. We also extended the use of the 1-Voice parents' closed Facebook group. This had been running pre-pandemic, but during lockdown it became a valuable tool for families to share their challenges and experiences.

One of our members, Oli, a teenage AAC user, got the ball rolling on a more dynamic scale by running a virtual event on Zoom that he planned to take



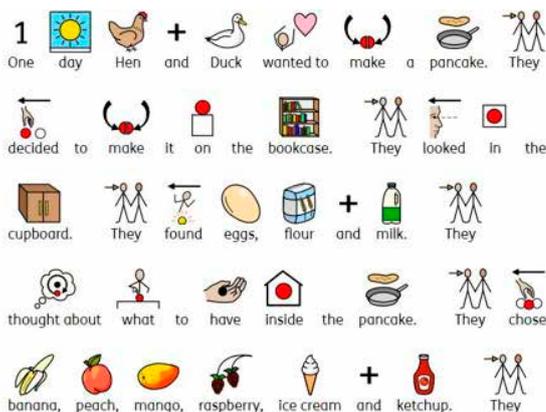
*Left: Eva, Tiago and Oli Teens Facebook group. Above: DJ Oli*

place on the weekend of our cancelled birthday event. Oli is a DJ and uses computer technology to run disco events and had performed live at our residential weekends. He had adapted very quickly to the pandemic and become skilled at running virtual discos online. Although not an official 1-Voice event, many members of the charity attended, and the atmosphere online was amazing. Oli's focus was to bring everyone together to enjoy an online quiz before being treated to his virtual disco. Oli used great videos to support his playlist whilst online audience members danced away having taken time to dress up, set up lights at home, and use fun props on camera. Oli was supported by his parents and a new 1-Voice role model AAC user, Eva, to set up the event.

The success of this virtual event and the example set by Oli inspired us to move forward and organise our own official 1-Voice online events. As a charity, we knew that we had to try and find ways to challenge the isolation that many 1-Voice members reported feeling during the pandemic. Our first virtual event was held in October 2020 to coincide with AAC Awareness month. 19 families joined in a fun quiz, and the online party lasted for 4 hours. At our typical residential events, we run small AAC focused activity groups, so we adapted this approach online and used breakout rooms on the Zoom platform. These smaller groups allowed people to work in quiz teams and have a good catch up and chat. We all came back together as one online group to share the quiz answers, and DJ Oli closed the event in style with another virtual disco.



Above: Jodie  
Below: Pancake day story



The next virtual event was a Christmas party in December 2020 with three activities. Jodie, an adult AAC user and member of 1-Voice who runs inclusive dance workshops, created a fantastic routine that everyone online could learn and then perform. It was a great way to get warmed up on a cold winter's day. The 30 attendees then split into breakout rooms to do Christmas themed activities such as quizzes and joke telling. Sally and Kate (1-Voice trustees) closed the event with a fabulous Christmas Sign Out Loud session. Sign Out Loud is an initiative they created that aims to teach Makaton signing using popular music, and everyone loved joining in and signing along to classic festive favourites.



Our next online event took place during the February half term 2021 and was targeted specifically at members who were less confident about using AAC. Small groups in different breakout rooms with symbol support were encouraged to create stories about making pancakes to celebrate Pancake Day. You can see the stories created by Alex, Benjie, Lucy, Ewan and Finn on our website ([www.1voice.info](http://www.1voice.info)) by following the link for the February half term virtual storytelling session in the news and events section. The website also links to content and news from all the online events reported in this article.

The success of the Christmas event led us to plan another seasonal online get-together for Easter. 14 families joined up for two hours of fun and once again, Sally and Kate got things off to a cracking start with a Sign Out Loud session. Smaller groups then went to different breakout rooms with younger and less confident AAC users doing a 'getting to know you' symbol

supported activity while a more confident group of AAC users went into a presentation group. Eva gave her first public talk, and it was brilliant to hear about her 1-Voice experiences and memories. Her PowerPoint supported presentation was a great success, and other members of the group expressed an interest in doing presentations at future virtual events.

With online events now in full swing, the next date was set for June 2021 when 26 families joined the 'Dream Holidays' two-hour session. Sign Out Loud with Sally and Kate got things started, and Jodie closed the event with a fun animal themed dance session. The structured activity rooms ran once again, and this time less confident AAC users got involved in sharing their ideas for holiday planning. The presentation and chat group for more confident AAC users listened to a fascinating presentation from Lana (right) about her Duke of Edinburgh journey to achieve Bronze, Silver, and Gold Awards. Jemima presented news of her work with Touchdown Care.



Above: Lana

Things we have learned that support planning and running online events are: to limit events to two hours to avoid tiredness and Zoom burnout; create different sessions to cater for those who have differing levels of confidence using AAC; design activities that target and support communication opportunities; do not worry about going 'off plan'; build in plenty of time for catching up and chatting; and ensure you have enough volunteers to support events.



During lockdown, the trustees created a new communications subcommittee to review the overall communication strategy. This targeted focus has led to the creation of a re-designed and improved newsletter to showcase 1-Voice news

and AAC related information, and the launch of a new look 1-Voice website [www.1voice.info](http://www.1voice.info). The new website will continue to develop and is already allowing a more interactive experience and enhanced access to reach as many people as possible.

Another key piece of news that we shared in our presentation was an update on our role model approach. In May 2019, we ran our first 1-Voice role model training weekend in conjunction with Communication Matters. The training was run by Verity Elliott and was a huge success, attended by 6 of our teenage AAC user members. During lockdown, we offered an online course to train more role models and offer refresher training for existing role models. The next step that is underway is the development of a 'buddy' system where AAC users can apply to be paired to a role model to allow them to get to know each other and connect online.



*Helen and Gregor - role models*

During the presentation at Communication Matters, Helen (1-Voice co-chair) shared her perspectives on becoming an adult AAC role model with 1-Voice in 2008. She explained how important the role model approach is for giving support, encouragement and advice to children, younger people, and their families who were just starting out on their communication journey. She described how much she enjoys being an adult AAC role model as she can share her experiences with young people and their families. She has given a variety of presentations which she says has helped her own confidence to develop. She stressed the importance of creating a new younger generation of 1-Voice role models who can continue their involvement with 1-Voice into adulthood, and why the momentum of this work could not be compromised by the pandemic. She reinforced why severely disabled young people need to be supported to have a unique sense of belonging. They must be welcome within a place and community where everyone understands their needs and genuinely wants to communicate with them on an equal footing. Helen

also believes that role models have a key role to support parents and to create a sense of hope and aspiration for their children.

This article can also give a brief update on progress since the Communication Matters conference presentation. 1-Voice has continued to have online events. There was a Halloween special in October 2021 with 19 individuals/families. Some of them took part in spell writing activities, and the chat group shared news from Eva and Lana about the unique voices that they are having created for their AAC devices. A second virtual Christmas Party happened on 4<sup>th</sup> December 2021. It was attended by 30 individuals/families, and we were delighted to welcome new faces. 1-Voice was able to run a small in-person activity weekend from the 20-23 August 2021 at Bendrigg Lodge where 8 AAC users and 29 others experienced the thrill of a variety of outdoor activities. We are currently planning our next residential weekend at Treloar College from 29<sup>th</sup>- 31<sup>st</sup> July 2022.



*2019 1-Voice event at Treloar College*

Thank you for taking the time to read this article and to share our story. As a charity, we are excited and positive about the future. We are delighted that we were able to meet the challenges of lockdown and the pandemic with resilience and energy and are continuing to grow. Since the events reported in this article, Sally Featon and Kate McCallum have stepped down as trustees, and Helen Hewson has also stepped down as co-chair and trustee. We thank them for their amazing support of 1-Voice, and they will be dearly missed. We wish them every success with future ventures.

## References

1-Voice Communicating Together (2022). News and Events. [online] Available from: <<https://www.1voice.info/news-events>>  
Sign Out Loud (2022). [online] Available from: <<https://www.facebook.com/Signoutlouduk/>>



This article can also be watched on video at:  
<https://youtu.be/ruHQhAMiKkY>

# Completely Locked-in Syndrome

## What is it, why do we need to know about it and what options are there for our patients?

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### Introduction

Classic locked-in syndrome (LIS) is rare neurological condition where patients experience complete paralysis of voluntary muscles, except for those that control the vertical movement of the eyes. Patients are awake and conscious, distinguishing them from patients with disorders of consciousness. Executive functions, memory and attention of patients with LIS can be intact or affected, and patients can experience blurring of vision and diplopia.

LIS can have various causes, most commonly basilar artery stroke, traumatic brain injury or a space occupying lesion and has also been described in neurodegenerative conditions.

A lesser variant of LIS is incomplete locked-in syndrome where patients have remnants of voluntary movement other than vertical eye movement.

Patients can also experience an extreme version of LIS, completely locked-in syndrome (CLIS) where there is total immobility which also affects control of eye muscles. These patients are conscious and can think and reason, but are unable to speak or move. It can be difficult sometimes to distinguish whether a patient is affected by CLIS or LIS (Bauer et al., 1979).

Patients with progressive neurological conditions can develop LIS, and if their neurological condition progresses, their LIS can begin to verge on being CLIS (Hayashi & Oppenheimer, 2003). This is especially evident when patients are invasively ventilated as they can survive longer so their neurological condition can progress further. This has an impact on the use of augmentative and alternative communication (AAC) if their eye function is no longer adequate to access eye gaze technology and with no commercially available equipment that can meet their communication needs.

### Methods

We reviewed our patients with progressive neurological conditions to determine which were invasively ventilated. Ability of these patients to access AAC was reviewed, and if difficulties were reported these were explored. The literature was then reviewed to determine what options are available for patients with CLIS, both commercially and research based.

### Results

At the time of this review, the only patients with progressive neurological conditions who were being invasively ventilated were those patients living with MND (plwMND), and these patients made up only 3% of our total MND caseload.

Of these invasively ventilated patients, it was determined that:

- three were reporting problems with their eyes;
- two had died from respiratory problems;
- one transferred to another specialist AAC service and had since died.

### Literature review – what options are available to allow patients with CLIS to communicate?

For patients with LIS or incomplete LIS who have intact eye movements, there are a range of commercially available solutions, and for our patients we explored the use of different eye gaze cameras as an access method for using different software packages.

For patients with CLIS access, methods available are restricted to types of brain-computer interfaces (BCIs). BCIs use brain activity to bypass the patient's non-functioning motor system to control a computer which can then be used to maintain or restore the patient's ability to undertake functions such as being able to communicate.

BCIs can either be invasive or non-invasive. Invasive BCIs involve implanting electrodes into the patient's brain and as such are generally reserved for the most severe patients due to the associated risks. Changes in different parts of a patient's brain waves, which can be manipulated by different tasks, can then be used to enable to patient to communicate using a hi-tech communication aid.

Non-invasive BCIs use an electrode array placed on the patient's head and also use recognisable patterns in brain waves that are elicited during different tasks.

Another type of BCI is functional near-infrared spectroscopy (fNIRS), where oxygen saturation of large superficial cerebral arteries during different tasks is measured (Chaudhary et al., 2021).

### **Invasive EEG speller**

In a study by Vansteensel et al., (2016), subdural electrodes were placed over the hand region of the left motor cortex on the basis of previous work showing that patients with quadriplegia can generate neuroelectrical activity by trying to move their hands. As the motor cortex is possibly affected in plwMND, electrodes were also placed on the left prefrontal region which is activated by mental calculation. A transmitter was placed subcutaneously in the patient's thorax.

The subject controlled the computer by attempting to move the hand on the side opposite the implanted electrodes. The subject made a brain click by trying to move her hand for approximately 1 second. She then had to withhold brain clicks until the correct item was highlighted. For 28 weeks computer tasks were performed to test and improve the algorithms and parameters in the decoding software and to improve her control over her brain signal.

After 28 weeks the subject was able to accurately and independently control a computer typing program at the equivalent of two letters per minute. It should be noted that this patient had LIS and not CLIS.

### **Non-invasive EEG spellers**

For this system the person wears an electrode array which detects their brain waves. These are then analysed with computer algorithms to detect the person's response. One example of an EEG speller is where the person is shown a matrix of letters, and they have to focus on the letter that they want until it is selected. They can then focus on the next letter and so on. There are many studies showing that EEG spellers can work well in healthy control subjects and also in subjects with LIS. Generalising these results to patients with CLIS has not worked though, and there are no studies showing that a person with CLIS can spell (Rezeika et al., 2018).

In 2008 it was suggested that EEG cannot be used by people with CLIS for communication. However, in 2018 a study by Okahara et al., showed that one patient who had learned to use a spelling system when they were LIS was able to use the same system to answer yes/no questions with an accuracy of about 80%. The patient was not able to use the system to spell.

### **Non-invasive infrared spectroscopy (fNIRS)**

Chaudhary et al., (2017) published a promising study, but this was retracted by the publisher as the results could not be replicated. They had reported that 2 plwMND with LIS and 2 plwMND with CLIS were able to use fNIRS to answer yes/no questions. They reported an above-chance-level correct response rate over 70%. The authors maintained that their findings were accurate.

In 2017, Adbalmalak et al., reported a single case report of a person with Guillain-Barré syndrome using fNIRS. The subject was first instructed imagining playing a vigorous game of tennis to verify his ability to successfully perform motor imagery. The experimental protocol consisted of 30 seconds of rest followed by five 30-second alternating blocks of motor imagery and rest for a duration of 330 seconds. Next, the subject was asked three questions confirming his last name, if he was in pain, and if he felt safe. The first question was chosen as a control, whereas the other two open-ended questions were chosen for their clinical relevance. He was instructed to stay relaxed if he wanted to answer "no" to any of the questions or to perform tennis imagery if the answer was "yes." Each question was repeated five times in the same block design of 30-second intervals used for the motor imagery task. The authors commented that there was a lack of a task-driven "no" response. One positive of the study was that no training was needed. The authors also pointed out that an MRI scan would be needed to establish that there is no brain damage that might affect responses.

In 2020, Borgheai et al., reported on a single plwMND with LIS who had fully lost eye-gaze control, suggesting that he was completely locked-in. They used a modified fNIRS paradigm using a visual matrix of letters. The plwMND were asked to do some mental arithmetic tasks for 6 seconds when the line or column containing their letter of choice was illuminated. The interval between letter choices was set to six seconds in order to increase the accuracy of the classification, and the authors reported a good accuracy approaching 75%. This level of accuracy was about 10% higher than they detected using an EEG based speller.

### **Are patients with CLIS able to Spell?**

It has been stressed that results taken from healthy control subjects and patients with LIS cannot be generalised to those with CLIS as it has been suggested that plwMND and CLIS may have BCI illiteracy (Marchetti & Priftis 2015). This is because of multiple factors.

Non-invasive EEG and fNIRS are thought to produce results in patients with CLIS that are too noisy with the wanted signal being buried in the background brain waves (Chaudhary et al., 2021).

It has also been said that paradigms should use auditory presentation, as eyes in patients with CLIS are so vulnerable to damage if the patient is unable to blink. However, it has been shown that patients with LIS were able to perform visual tasks with better control than those with auditory presentation (Chaudhary et al., 2021).

Patients have to learn how to use the BCI for communication, performing the same task multiple times and answering the same questions with known answers and copying the spelling of words. It has been suggested that patients with CLIS do not have the necessary attention to select the wanted target letter, becoming bored so are not attending nor habituating to the questions asked. It has been shown that these attentional problems in patients with CLIS result in episodes of sleep and that these occur frequently during the day for people with CLIS (Malekshahi et al., 2019).

It is possible that the cognitive difficulties that occur in plwMND may have an effect on their ability to use BCI to communicate. However, without BCI we cannot assess a plwMND to determine their cognitive status as all neuropsychological tests require a motor response. It has also been suggested that non-use of language does lead to language attrition in the cortical areas for language and the motor cortex (Ardali et al.2019).

### What is available for CCAS patients who are verging on CLIS now?

Acceptance of my patients that their difficulties with eye gaze access were possibly caused by eye problems as part of MND disease progression, rather than problems the communication device/software/eye gaze camera or medication, was difficult and required sensitive investigation and discussion. Our patients who were verging on CLIS were all very proficient eye gaze users and considering alternative access methods was also difficult as it represented a step backwards to an access method that was not seen as being "as good". These patients were also well read, and much of the literature says that eye movement is retained in plwMND. However, this literature was written without considering patients with a stage of the condition that was never previously possible without invasive ventilation.

I have found no BCI system that is commercially available at the moment. For CCAS patients, it has been a process of evaluating and trialling other access methods. We have tried switches that utilise very small facial movements, for example Brainfingers and the EMG switches, but these have not been successful for our patients.

In the meantime, optimising their current eye gaze systems has been more successful, trialling different eye gaze cameras and sizes of devices. Patients have also found that moving to layouts with much larger cells has also been beneficial.

This area also raises ethical considerations in deciding whether to ventilate plwMND (Magelssen et al., 2018). It is important to ensure that the patient is aware that CLIS is a possibility if they are fully ventilated and that their MND will still progress. The patient needs to be aware that they could become totally unable to communicate. It is important that those around the patient know what decisions the patient wants to make in advance, in case they lose the ability to communicate. These include who is going to make care decisions, what the patient wants and does not want to happen, does the patient want their ventilator turned off at a certain stage of their condition. Also, the support needed by the patient and their family at this stage needs to be determined.

### References

- Abdalmalak, A., Milej, D., Norton, L., Debicki, D.B., Gofton, T., Diop, M., Owen, A.M., St Lawrence, K., 2017 'Single-session communication with a locked-in patient by functional near-infrared spectroscopy', *Neurophotonics*, 4:4, pp.040501
- Ardali, M.K., Rana, A., Purmohammad, M., Birbaumer, N., Chaudhary, U., 2019, 'Semantic and BCI-performance incompletely paralyzed patients: Possibility of language attrition in completely locked in syndrome', *Brain and Language*, 194, pp.93-97.
- Borghesi S. B., McLinden, J., Zisk, A. H., Hosni, S. I., Deligani, R. J., Abtahi, M., Mankodiya, K., Shahriari, Y., 2020 'Enhancing Communication for People in Late-Stage ALS Using an fNIRS-Based BCI System', *IEEE Transactions on Neural Systems and Rehabilitation Engineering*, 28:5, pp.1198-1207
- Bauer, G., Gerstenbrand, F., Ruml, E., 1979 'Varieties of the locked-in syndrome', *Journal of Neurology* 221:2, pp.77-91
- Chaudhary, U., Xia, B., Silvoni, S., Cohen, L.G., Birbaumer, N., 2017, 'Brain-computer interface-based communication in the completely locked-in state', *PLoS Biology*, 15:1, e1002593
- Chaudhary, U., Mrachacz-Kersting, N., Birbaumer, N., 2021, 'Neuropsychological and neurophysiological aspects of brain-computer-interface (BCI)-control in paralysis', *The Journal of Physiology*. 599:9, pp 2351-2359
- Hayashi, H., Oppenheimer, E.A., 2003, 'ALS patients on TPPV: totally locked-in state, neurologic findings and ethical implications', *Neurology*, 61, pp.135-137
- Malekshahi, A., Chaudhary, U., Jaramillo-Gonzalez, A., Luna, A., Rana, A., Tonin, A., Birbaumer, N., Gais, S. 2019, 'Sleep in the Completely Locked-in State (CLIS) in Amyotrophic Lateral Sclerosis', *Sleep*, 42:12, zsz185
- Marchetti, M., Priftis, K., 2015, 'Brain-computer interfaces in amyotrophic lateral sclerosis: a metanalysis', *Clinical Neurophysiology*, 126, pp.1255-1263
- Magelssen, M., Holmøy, T., Horn, M.A., Fondenæs, O.A., Dybwik, K., Førde, R., 2018 'Ethical challenges in tracheostomy-assisted ventilation in amyotrophic lateral sclerosis', *Journal of Neurology*, 265, pp.2730-2736
- Okahara, Y., Takano, K., Nagao, M., Kondo, K., Iwadate, Y., Birbaumer, N., Kansaku, K., 2018, 'Long-term use of a neural prosthesis in progressive paralysis', *Scientific Reports*, 8, pp:16787
- Rezeika, A., Benda, M., Stawicki, P., Gembler, F., Saboor, A., Volosyak, I., 2018, 'Brain-Computer Interface Spellers: A Review', *Brain Sciences*, 8:4, pp.57
- Vansteensel, M., Pels, E., Bleichner, M., P. Branco, M., Denison, T., Freudenburg, Z., Gosselaar, P., Leinders, S., Ottens, T., van den Boom, M., Rijen, P., Aarnoutse, E., Ramsey, N., 2016, 'Fully Implanted Brain-Computer Interface in a Locked-In Patient with ALS', *New England Journal of Medicine*, 375, pp.2060-2066



This article can also be watched on video at:

<https://youtu.be/ruHQhAMikKY>

# My Research Internship: Investigating the Core Vocabularies Provided to People Who Use Symbol Communication Aids

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In 2021 I completed a research internship with the National Institute of Health Research (NIHR). This article will discuss my clinical observations that led to me applying for the internship, what I investigated, and my future research plans.

## The Core Vocabulary Approach

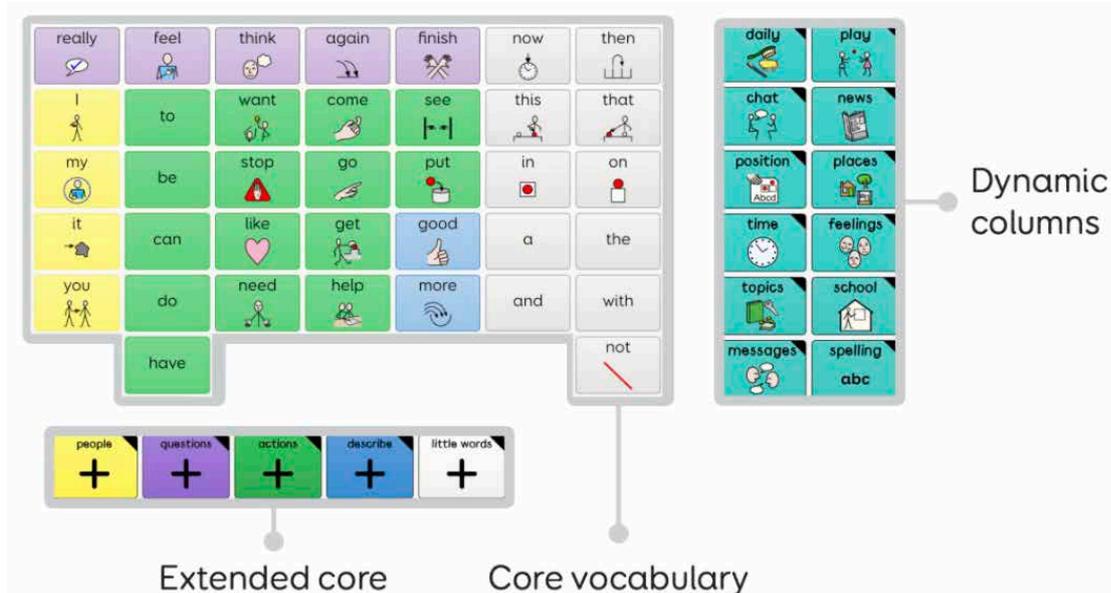
Core vocabulary is the term used within the field of AAC to describe the small set of words that are used most frequently in oral and written language. The Core Vocabulary Approach forms the basis for most of the symbol vocabularies provided on communication aids. Symbol vocabularies are typically comprised of a core word 'home' page with links to fringe or 'topic' vocabulary, as shown in Figure 1.

Vocabulary selection for symbolised communication aid users has evolved over the decades. Historically, symbols that represented preferred items or activities were chosen, creating a noun rich vocabulary often focusing on the linguistic function of requesting. Offering nouns can be particularly motivating and rewarding for early communicators: they select a symbol of a preferred item and can often instantly be rewarded with a tangible object or activity. This too is particularly motivating for the adult supporting the child, and thus historically, concrete symbols (which look like the object or activity they represent) were chosen over more abstract concepts. (Van Tatenhove, 2009, cited in Erikson et al., 2019.)

However, providing only a vocabulary based on nouns can be restrictive when we wish to support the person who uses AAC to communicate language functions beyond requesting, and to move beyond single word messages by linking words together. Light (1997, p.165)

The intention is that symbol communicators will combine core words with fringe words (e.g. 'more cake', 'help socks'). Core vocabulary is intended to provide flexible language which can support people who use AAC to develop their linguistic competence

Figure 1. Super Core Manual (Version 2.0), Copyright 2020, Smartbox Assistive Technology





This seemed to reflect my own clinical experiences which encouraged me to explore this further. I applied for the NIHR Integrated Clinical Academic Programme Internship Scheme so that I could have dedicated time and support to be able to explore my questions. In particular, I was keen to investigate the evidence used to develop core vocabulary symbol systems by their vendors.

I was awarded an internship and began my studies in January 2021. My internship was hosted by Sheffield Hallam University, and my research supervisor was Professor Karen Sage, supported by Katherine Broomfield. The early stages of the internship gave me a much-needed overview of research methods, literature searching and academic writing. Over the next nine months, I further developed my research question and methodology. With the support of five symbol vocabulary vendors, I was able to investigate the evidence used to develop symbol vocabularies which I presented at the Communication Matters conference in September 2021.

### Choosing the right words.

Providing the right words for people who use symbols to communicate is challenging. People who use AAC and have not yet learned to read or write are dependent on professionals to give them systems which provide the words they need in an accessible way. Professionals working in the field of AAC have a significant responsibility when providing symbolised communication aids to those who need them, and decisions about which words to choose and how to organise them has significant influence over the successful use of the communication aid (Erikson, Geist, Hatch & Quick, 2019 and Light, 1997).

Whilst Speech and Language Therapists are likely to have overall responsibility for choosing a communication aid for a person, it is important to recognise the role that the developers of these communication aids play also. Professionals should consider the evidence behind the AAC systems they are providing and evidence regarding how these systems are modelled and implemented. It is essential that those using and supporting symbolised communication aids are consulted both in the development and review of these systems so that, as professionals, our decisions are based on what people using AAC systems want and need.

Symbolised vocabularies provide users with a huge range of vocabulary, giving them the opportunity to communicate about a wide range of topics and for a range of communicative functions. As professionals providing these systems, it is key that we understand the best way to implement them. In other words: which words and when?

### Next steps

I am now interested in taking this exploration further and asking:

1. How are core word symbol vocabularies being used in the real world?
2. What do people who use AAC and those who support them think of core word symbol vocabularies?
3. Should we be developing symbolised AAC systems based on the language of people without speech, language and communication needs?

I am currently writing up my internship project and hope to publish this next year. This paper will explain the methodology that I used during my internship and my results. I shall be applying for the next stage of the HEE/NIHR Clinical Academic Programme which is the Pre-Doctoral Clinical Academic Fellowship. I will look in detail at the language samples of people who use AAC and compare these to the published core vocabulary lists to see if there is a difference. I will also carry out some interviews with parents and others who support people who use AAC to ask their opinions of core word vocabularies.

I would be very interested to hear what people think about the above questions. I was overwhelmed with the response from my conference presentation, and my project has clearly sparked a lot of thought amongst professionals, parents and people who use AAC. I am keen to continue this conversation and invite people to get in touch by emailing [hrobinson8@nhs.net](mailto:hrobinson8@nhs.net) or on Twitter @HelenATSLT.

Thank you to Professor Karen Sage (Manchester Metropolitan University) and Katherine Broomfield (Gloucestershire Health and Care NHS Foundation Trust) for their support with my internship.

### References

- Erikson, K., Geist, L., Hatch, P. and Quick, N. (2019). The Universal Core Vocabulary (Technical Report). Chapel Hill, NC: *Centre for Literacy & Disability Studies, University of North Carolina* at Chapel Hill retrieved from <https://www.project-core.com>
- Laubscher, E. and Light, J. (2020) Core vocabulary lists for young children and considerations for early language development: a narrative review, *Augmentative and Alternative Communication*, 36:1, 43-53
- Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication. *Augmentative and Alternative Communication*, 5, 137-144
- Light, J (1997) Let's go star fishing: reflections on the contexts of language learning for children who use aided AAC, *Augmentative and Alternative Communication*, 13:3, 158-171
- Murray, J., Lynch, Y., Goldbart, J., Moulam, L., Judge, S., Webb, E., *et al.* The decision-making process in recommending electronic communication aids for children and young people who are non-speaking: the I-ASC mixed-methods study. *Health Services and Delivery Research* 2020;8(45)
- Robinson, H. (2018). Opinion; AAC technology: what's in a name? *Royal College of Speech and Language Therapists Bulletin* March 2018, 11



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<https://youtu.be/XAL1u8O1iZY>

# Brain-computer Interfaces for Communication: Where are We at?

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## Introduction

For individuals with severe speech and physical impairments, who are typically limited in their options for efficient communication, the use of brain-computer interfaces (BCIs) has emerged as a promising tool to increase their quality of life (Zabcikova et al., 2021). This article describes current trends in the application of BCIs to provide Alternative and Augmentative Communication (AAC) and demystifies each use case with descriptive and specific examples. For the target population with severe musculoskeletal, oculomotor, visual or cognitive impairments, non-invasive BCI systems offer tractable solutions for communication, which users can learn to independently control via the use of brain-signals alone (Pitt et al., 2019).

## What is a BCI?

A BCI system is that which converts a biosignal - typically scalp measured electrical activity - into a digital signal for input into a third device. Typically, electrical activity at the scalp is acquired via electroencephalography (EEG), which uses non-invasive electrodes to record fluctuations in electrical activity with millisecond precision, which in turn reflects the spatial and temporal characteristics of underlying changes in neural activity. For the purposes of a BCI, the spatial (i.e. location) and temporal (i.e.

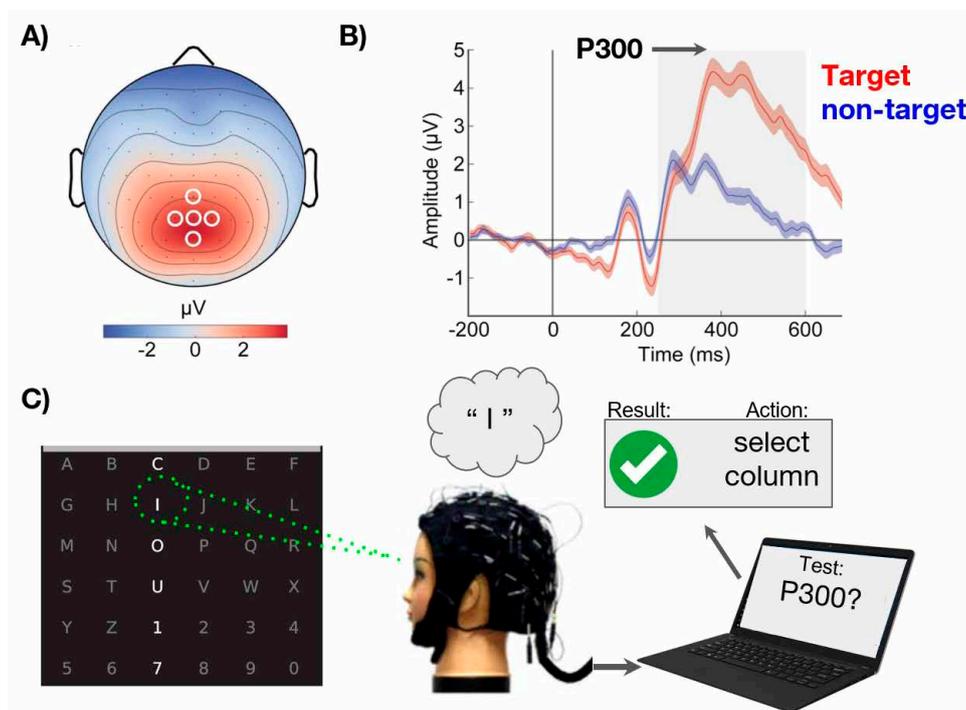


Figure 1. A) Typical scalp distribution of the P300 EEG component. B) Average activity measured over five centro-parietal electrodes (marked in A), for target and non-target sensory stimuli (A-B from Herzog et al., 2021). C) Example of P300 6x6 procedure (adapted from Brumberg et al., (2018). Image copyright Tobii Dynavox). An individual focuses on a target letter, and a BCI infers the relevant rows and columns of focus to select the letter of interest.

frequency) characteristics of EEG can be used to infer the location of a user's attention or intent, which can then power a communication device. Below, we describe the main EEG signals which are used to feed BCIs as communication devices, and provide specific examples for illustrative purposes.

## EEG Signals Used by BCIs for Communication

### P300 Event-Related Potential (ERP)

The P300 is so named as it is a positive deflection in scalp recorded neural activity, emerging approximately 300 ms after sensory stimulation. The P300 is strongest over central and parietal scalp locations and can be recorded following visual, auditory, or tactile stimulation. Attended sensory stimuli evoke the strongest P300, and this feature can help locate the user's attention (Figure 1) (Pitt et al., 2019).

For example, in the P300 speller 6x6, individual rows and columns are flashed in succession, and the timing of the evoked P300 can be used by a BCI to infer the focus of attention. Another type uses Rapid Serial Visual Presentation (RSVP), which consists of presenting large letters in the centre of a screen to evoke a P300. For populations with visual impairments, the auditory P300 can also be used to assist in communication. Typically, the user is presented with two distinct sounds, and the BCI bases selection on the sound input that the user is focusing on (Brumberg et al., 2018). An example of its application in AAC can be a yes/no response, or a switch elimination scanning system.

### Steady-State Evoked Potentials (SSEPs)

Another EEG signal used to enable communication via BCIs is the SSEP. SSEPs are evoked by the continued rhythmic presentation of a sensory stimulus, and the name steady-state reflects their consistent EEG waveform which lasts for the duration of stimulus presentation (Figure 2B). For example, when a rhythmic visual stimulus is presented, EEG responses become entrained at the same stimulus frequency, creating a steady-state visually evoked potential (SSVEP) over occipital scalp locations (Figure 2A). In BCI applications, multiple flickering stimuli can be presented simultaneously, and the relative strength of each flicker in the EEG response is used to determine the focus of attention (Brumberg et al., 2018).

Figure 2C represents an example of an SSVEP system. An individual focuses on relevant options, each flickering at a different frequency. A BCI infers the chosen option via the strength of each frequency in the EEG activity.

### Sensorimotor Rhythms (SMR)

We have seen how BCIs focusing on the P300 and SSVEP leverage the relative timing and frequency content of EEG activity to infer the user's choices. The spatial topography of EEG activity can also be used to discriminate between options on an AAC system. Due to the lateralization of cortical areas involved in the actual and imagined production of movement, BCIs can easily discriminate between imagined use of the left and right hand (for example Figure 3). These SMR-based BCIs typically require the user to perform motor imagery (MI) involving the hands, feet, or tongue, as they recruit a relatively large area of the sensorimotor cortex due to the complexity and regularity of their motion (Xu et al., 2011).

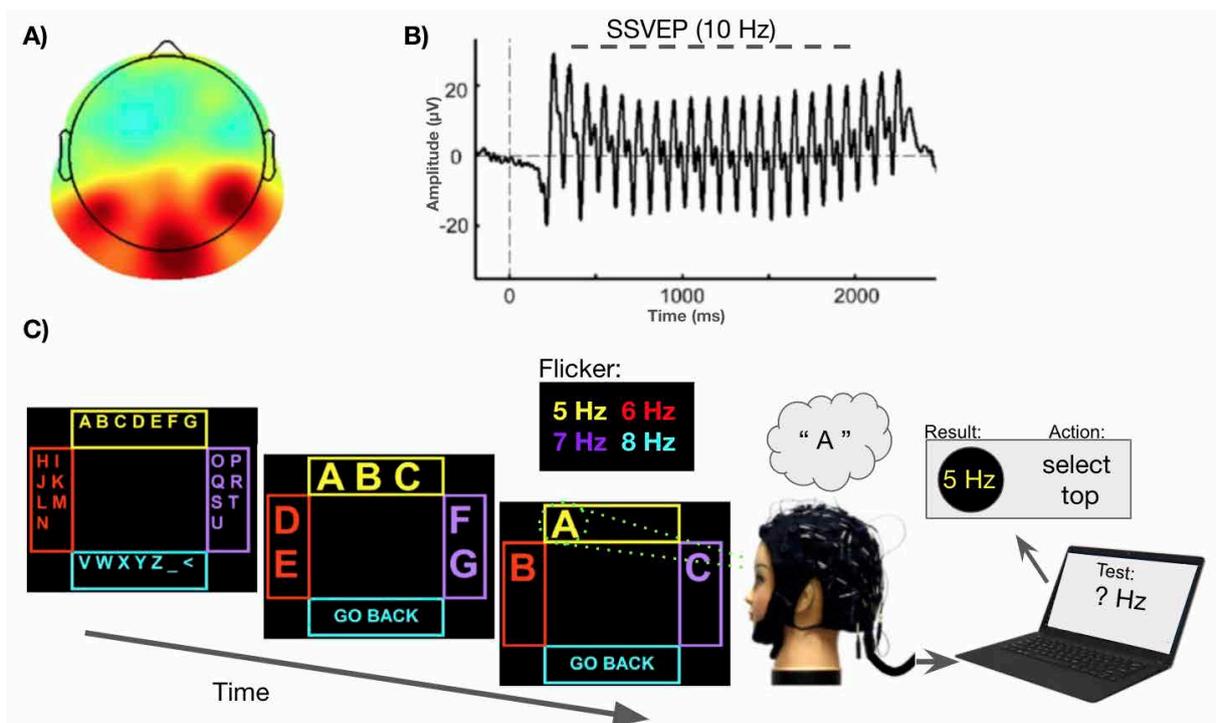
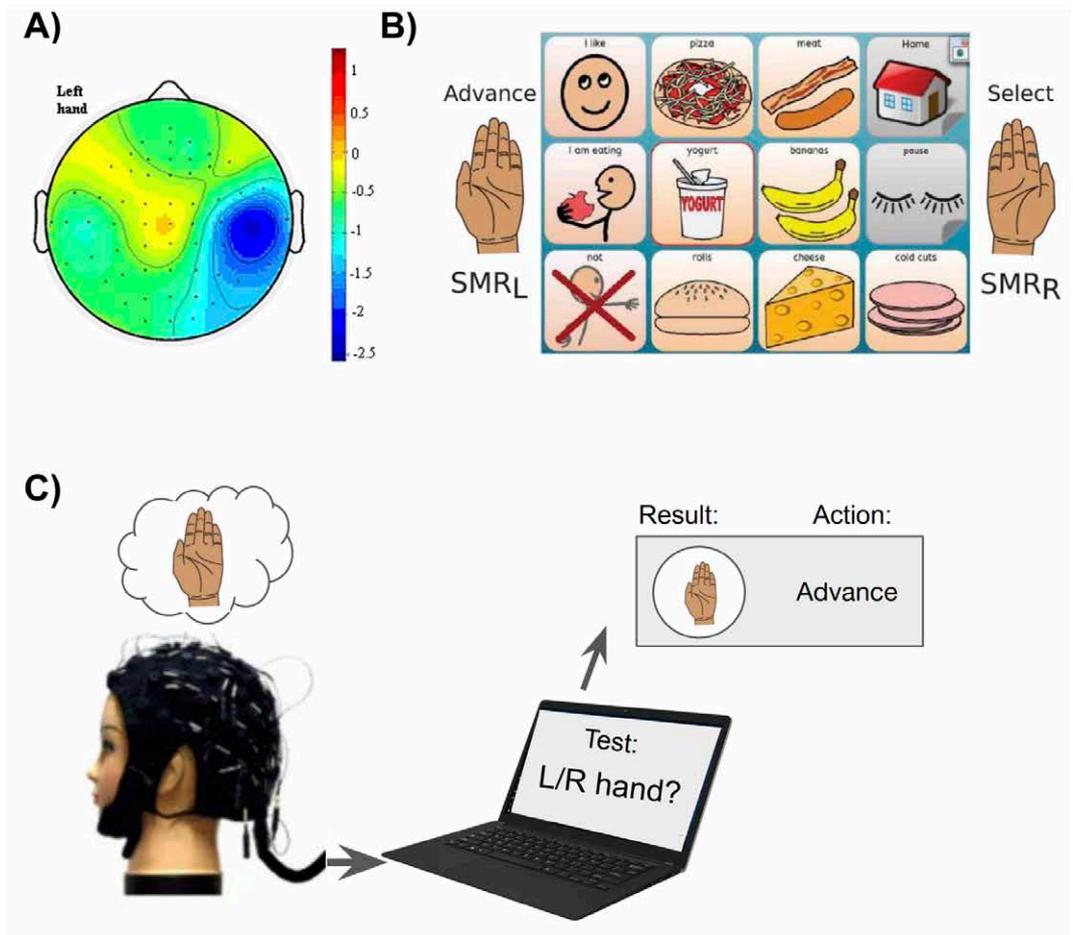


Figure 2. A) Typical scalp distribution of the SSVEP EEG component. B) An example SSVEP measured from occipital electrodes (A-B from Wang & Yuan, 2021). Note the prominent 10 Hz activity, entrained by a repetitive 10 Hz flicker. C) Example layout of an SSVEP grid used for BCI based AAC (adapted from Peters et al., 2020).

Figure 3. A) Example scalp distribution of the SMR EEG component for left hand movement (Xu et al., 2011). B) Example choice options in an SMR-based BCI system (image copyright Tobii Dynavox). C) A user intends to move their left hand. The SMR-based BCI infers an action associated with the left-hand signal, based on EEG signal strength in the respective cortical area; here selecting the "Advance" option.



### BCIs as an AAC Access Method

There are many factors to take into account when selecting an appropriate BCI based AAC. The different techniques we have described must be compared to enable user-centred design. As an example, and among other factors, a P300 visual speller requires high concentration levels and oculomotor control, whilst MI-based BCIs require extended concentration and the ability to perform imagined movements. However, the latter can require multiple training sessions to master the task (Shahriari et al., 2019).

As well as the specific needs, expectations, and capabilities of the individual, a range of quantitative performance metrics are also relevant. These include the accuracy and efficiency of each method - typically quantified in BCI spelling examples as words per minute (wpm). (For an overview of text entry rates across different access methods, Koester Performance Research has created a rich and meticulous database available at <https://kpr.pythonanywhere.com/>).

Table 1 summarises the results from a recent review, focusing on the accuracy and efficiency of the P300, SSVEP and motor-imagery based BCIs. Each row corresponds to a different study, involving non-impaired subjects, subjects presenting with Motor Neuron Disease (MND/ALS) and Locked-in Syndrome (LIS) (Brumberg et al., 2018).

BCI type	Selection rate	Impairment?
Motor Imagery	0 – 2.5 char/min	Yes
Motor Imagery	2 char/min	No
Motor Imagery	2.3 – 7.6 char/min	No
P300	4.3 char/min	No
P300	19.4 char/min	No
P300	1.5 – 4.1 char/min	MND/ALS
P300	3 – 7.5 char/min	MND/ALS
RSVP P300	0.4 – 2.3 char/min	LIS
RSVP P300	1.2 – 2.5 char/min	No
SSVEP	33.3 char/min	No
SSVEP	10.6 selections/min	LIS

Table 1 - BCI-based AAC systems output rates. Adapted from Brumberg et al. (2018).

On average, SSVEP and MI based systems have the highest and lowest average rates of communication, respectively. This is in large part owing to the opportunity to present multiple simultaneous SSVEP options, while MI systems rely on binary discrimination.

In an effort to bridge the gap between research and at home application, Shariari et al., (2019) have highlighted the accuracy of BCI based performance in at-home settings. Table 2 summarises the results of the *BCI-24/7 study*, in which 9 people with MND/ALS used a P300 speller without continuous clinical intervention. A caregiver/family member was trained to set up and run the BCI system and to perform minor troubleshooting. Across their sample, continuous BCI use ranged from 2 - 10 months, and the overall accuracy of the system reached an average of 67%. Accuracy reached as high as 85.5% over a 2.5 month period, evincing the potential and promise of BCIs to augment communication.

User	1	2	3	4	5	6	7	8	9
BCI Use (months)	2.5	5	2.5	2.5	5	2	10	9	5
Successful / Total Runs	62/127 (48.9%)	48/65 (73.8%)	45/52 (85.5%)	39/51 (76.5%)	34/49 (69.4%)	19/29 (65.5%)	29/60 (48.3%)	49/83 (59%)	28/36 (77.8%)
PerformanceRange (%)	0-100	10-100	30-100	0-100	30-100	30-100	0-100	0-100	0-100

Table 2 - BCI-24/7 results (Shariari et al., 2019).

## Conclusions

This article provides a brief overview of BCIs, and common applications in their use as an AAC. Although the scope and appeal of BCIs are wide, two main challenges must be considered in the context of individual users:

1. Technical/Technological: these include the presence of electromyographic (muscle) artefacts in the EEG signal. These may be unavoidable given the clinical profile of the user (e.g. spasticity, tremors) and will impact BCI efficiency, and the motivation of users. Factors such as comfort (e.g. weight, size, use of dry electrodes) and portability are also crucial to improve the user experience (Pitt et al., 2019)

Individually tailored language modelling and integration with mainstream AAC software may also increase the efficiency of output (Brumberg et al., 2018). Although the main technical challenges are broadly common to other AAC systems, some BCIs can also require a large amount of training time. This applies to the users, carers, and system itself (Pitt et al., 2019).

2. Clinical: neurological impairments may also impact upon concentration, attention, working memory capacity, motor imagery, and the sensory system. Impairments on each of these factors may adversely affect BCI operability. For those prone to epilepsy, the techniques used to evoke an SSVEP may also increase the risk of seizures (Brumberg et al., 2018).

As with any assistive technology, there is no "one size fits all" in this field. BCIs are constantly evolving and, as awareness of their potential increases, they are poised to become mainstream.

## Acknowledgements

A special thanks to Will Wade (Ace Centre) for his expertise and input on AAC access.

## References:

- Brumberg, J., Pitt, K., Mantie-Kozlowski, A. & Burnison, J. (2018). Brain-Computer Interfaces for Augmentative and Alternative Communication: A Tutorial. *American Journal of Speech-Language Pathology*, 27. 1. doi: 10.1044/2017\_AJSLP-16-0244.
- Herzog, N., Steinfath, T., & Tarrasch, R. (2021). Critical Dynamics in Spontaneous Resting-State Oscillations Are Associated With the Attention-Related P300 ERP in a Go/Nogo Task. *Frontiers In Neuroscience*, 15. doi: 10.3389/fnins.2021.632922
- Peters, B., Bedrick, S., Dudy, S., Eddy, B., Higger, M., Kinsella, M., McLaughlin, D., Memmott, T., Oken, B., Quivira, F., Spaulding, S., Erdogmus, D. and Fried-Oken, M. (2020). SSVEP BCI and Eye Tracking Use by Individuals With Late-Stage ALS and Visual Impairments. *Front. Hum. Neurosci.* 14:595890. doi: 10.3389/fnhum.2020.595890
- Pitt, K., Brumberg, J., and Pitt, A. (2019). Considering Augmentative and Alternative Communication Research for Brain-Computer Interface Practice. *Special Education and Communication Disorders Faculty Publications*, 13, 1-20
- Shahriari, Y., Vaughan, T. M., McCane, L. M., Allison, B. Z., Wolpaw, J. R., & Krusienski, D. J. (2019). An exploration of BCI performance variations in people with amyotrophic lateral sclerosis using longitudinal EEG data. *Journal of neural engineering*, 16(5), 056031. doi: 10.1088/1741-2552/ab22ea
- Wang, M., & Yuan, Z. (2021). EEG Decoding of Dynamic Facial Expressions of Emotion: Evidence from SSVEP and Causal Cortical Network Dynamics. *Neuroscience*, 459, 50-58. doi: 10.1016/j.neuroscience.2021.01.040
- Xu, P., Yang, P., Lei, X., & Yao, D. (2011). An Enhanced Probabilistic LDA for Multi-Class Brain Computer Interface. *Plos ONE*, 6(1). doi: 10.1371/journal.pone.0014634
- Zabckikova, M., Koudelkova, Z., Jasek, R., & Lorenzo Navarro, J. J. (2021). Recent advances and current trends in brain-computer interface research and their applications. *International Journal of Developmental Neuroscience*, 1- 17. doi: 10.1002/jdn.10166



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<https://youtu.be/sz4jwL8krlw>

# What's Next? Development of a Smartphone Visual Planner Designed for Ease of Use by Adults with Intellectual Disabilities and Autism

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## **Introduction**

Visual planners or schedules can be used with people who have difficulties in understanding associated with conditions such as autism spectrum condition (ASC) or intellectual disability (ID). They prompt users about the activities or tasks they will be undertaking in order to help reduce anxiety and confusion and assist users to participate in the activities they are offered. Planners can be realised in physical form for a user to engage with; they can also be realised in computer-based or mobile applications. Symbols, images and text can be used in the user interface, which should be designed for simplicity and clarity in order to make it accessible and comprehensible. Visual information about activities should be uncomplicated, and language used should be clear. The development of a prototype mobile visual planner application for people with ASC and ID is described here.

## **Visual planners**

Some visual planners can be too complex for people with ASC and ID. They can have 'busy' interfaces with many items displayed, e.g., a full day's schedule of activities on one detailed page. Previous activities might remain on display, marked as 'completed', while multiple upcoming activities are listed to show everything that remains to be done. Symbols and icons might be present, with strong colours and contrasts used. The overall effect of such a display can be confusing and over-stimulating for people with ASC and ID.

A project was therefore devised to develop a mobile visual planner application (app) which could show its user what was currently happening and what task or activity should happen next, while minimising visual distraction and over-stimulation caused by excessive information and display content. This paper hence discusses:

- the development of a prototype smartphone app designed to help people with Autism Spectrum Condition (ASC) and Intellectual Disabilities (ID) to follow the schedule of their day;
- trial of the developed technology with people with ASC and ID and their carers.

## **Background**

Visual supports and scene-based systems offer a variety of ways for assisting people with disabilities and communication difficulties (Alm *et al.*, 1998). Visual supports and planners have been shown to be beneficial in helping to reduce anxiety and confusion among users with ASC and ID, for example, while enhancing their independence (Dettmer *et al.*, 2000; Radi, 2017). Visual activity schedules have been shown to be effective with people with ID (van Dijk & Gage, 2019). They can be seen as examples of augmentative and alternative communication (AAC) used to support understanding (Beukelman & Light, 2020). Recommendations have been developed on the design of user interfaces for people with ASC (Pavlov, 2014), including developments for text simplification and enhanced reading comprehension (Pavlov *et al.*, 2016). An interactive scheduling system was designed to support classroom activities for children with autism in elementary school classrooms (Hirano *et al.*, 2010), and user interface design for children

with autism has been investigated in the context of touchscreen assistive technology for the teaching of numeracy and calculation (Kamaruzaman *et al.*, 2016). A tablet-based application for activity schedules was designed for children with autism spectrum disorders; children exhibited increased socio-adaptive behaviours in classroom, with more classroom and communication routines performed correctly (Fage *et al.*, 2014). From such previous work and exploration of other planner and scheduler applications for people with ASC and ID, plans were assembled for the current project.

### **Aim of Development**

The developed planner would enable a carer to create a day schedule with multiple activities for the app user to perform. The user would then see and follow the schedule. The app would avoid overloading the user with too much information, and there would be options available to limit the amount of information on display at one time. The user interface needed to be simple and clear so that the current activity would be evident, followed by the subsequent activity, while information about completed activities would be removed from display and information about upcoming activities would not be shown until needed.

### **Intended user population**

The user participants taking part in these investigations were people who used communication supports and had associated conditions such as: cognitive impairment associated with ASC and difficulties in processing information; intellectual disabilities with difficulties in expressing themselves or understanding others; developmental disabilities and difficulties with communication. They were typically spending time in daycentres, supported by carers, while using paper-based visual schedules. They were known to have difficulty with aspects of touchscreen access such as swiping and scrolling.

### **Key design requirements**

Key design requirements for this visual planner application were:

- ability to show the current scheduled activity
- ability to show the next scheduled activity
- ability to remove from display the previous activity when completed
- facility for adding new activities, including by carers
- facility for adjusting how many activities can be shown at once
- facility for accessing the app without swiping or scrolling
- emphasis on ease of use for both service user and carer
- emphasis on portable (mobile) operation

### **Design and development process**

Low-fidelity prototypes for the visual planner were derived from design requirements. Discussion with clinicians around these low-fidelity prototypes led to high-fidelity prototypes being established for the user interfaces for users and carers, each requiring individual features and facilities.

Given the emphasis on portable (mobile) operation, smartphone technology offered advantages as a platform for this type of application (Jackson *et al.*, 2021) and was therefore adopted. The Android® environment was chosen on grounds of functionality, familiarity, cost, and acceptance. An agile development process was used for the application, with iterations of development and testing being conducted during the implementation in a succession of development 'sprints'.

### **Functionality**

The developed prototype planner app enables a carer to create a day schedule (Figure 1) for a user, specifying a time, date and name for each activity (Figure 2) and selecting a symbol for it from an image or symbol library (Figure 3). The carer completes the activity item (Figure 4) ready for addition to the schedule. Figure 5 shows the activity item as the user will see it, prompting them to do the washing activity. Figure 6 shows the prompt for a subsequent activity (breakfast). The central (grey) button at the foot of Figures 5 and 6 enables the user or carer to change the number of activity items on simultaneous display, in this case to two (maximum). The square blue button beside the activity symbol can be pressed by the user to indicate completion of the activity, whereupon the app will remove the activity from view.

### **Evaluation**

The researcher received specialist training and support in order to familiarise with the needs of people with ASD and ID and interaction with them, including strategies to manage any difficulties which might arise. Inclusive Communication training was also provided. A demonstration of the Talking Mat® method (Murphy & Cameron, 2008) was given with practice and guidance on how to carry out an evaluation with it.

A trial was conducted with four adult users with ASC and ID from three local daycentres. Symbol-augmented forms with simplified language were used with these participants to enhance comprehensibility (Arnott *et al.*, 2020). One carer from each daycentre also contributed to the trial, using unsymbolised forms. The trial activity was conducted within the daycentres. A carer would create a day schedule on the app for a user participant. The user would be given the app and asked to check this day schedule with the carer. The user then proceeded to use the schedule, working through the scheduled activities, with additional guidance from the carer if needed. After completion of the schedules, the users and carers were asked to provide feedback about the app and its operation.

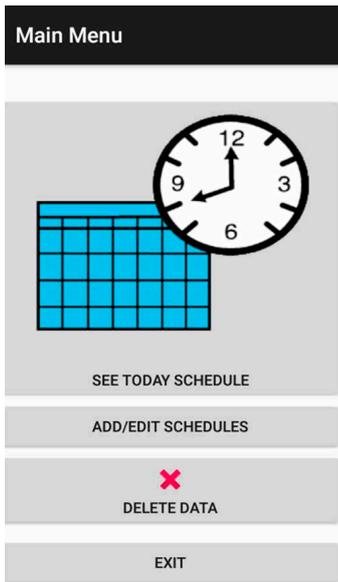


Figure 1: The carer begins laying out a day schedule for the user.

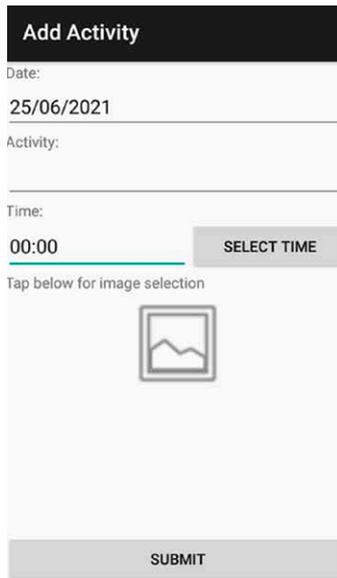


Figure 2: The carer enters date, name and time for each activity.

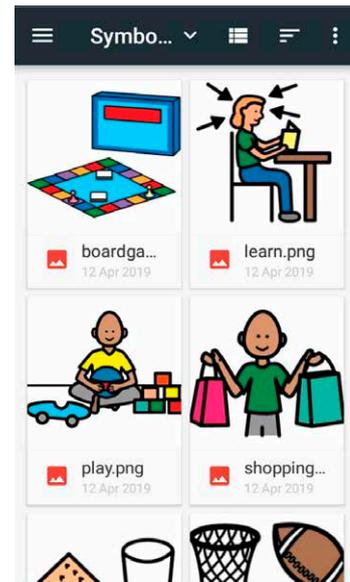


Figure 3: The carer selects a symbol for an activity from library.



Figure 4: The activity page for the carer to review and submit into the day schedule for the user.



Figure 5: Activity page as the user sees it, prompting washing activity. Blue square is 'completion' button.

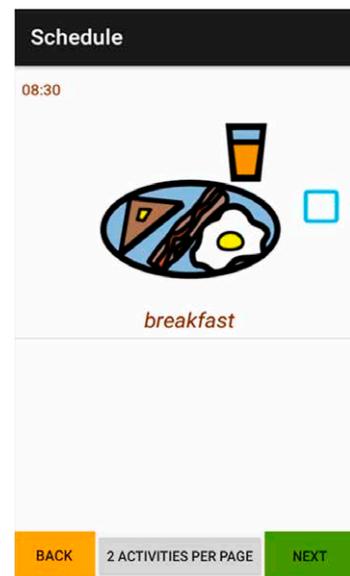


Figure 6: Another page for the user, prompting breakfast activity. (Grey button brings up 2 activities/page.)

**User Feedback:** All four user participants affirmed via questionnaire that they did not feel tired, rushed, or upset through use of the app. One user was positive and the other three neutral about being able to understand what was happening on the app. One felt they had to think very hard when using it while the other three were neutral about that aspect. Thus, *user understanding of what was happening on the app and the mental effort required to use the app* are two areas to merit further investigation and possible further development. Three of the four user participants indicated when asked that they would like to use the app often.

**Talking Mat®:** Two of the user participants completed a Talking Mat® (Murphy & Cameron, 2008). One user was happy about seven (out of eleven) aspects of using the app and neutral about the other four, a relatively positive outcome. The other participant was happy about three aspects but neutral about four of them and unhappy about the rest, a less positive outcome. Both participants liked the screen size and its pictures, finding them easy to see; *knowing what to do* and some aspects of *app appearance* were less favoured by both participants, however.

**Carer Feedback:** Two of the three carers approved all aspects of the app on a workload questionnaire. The third carer reported some time and work pressure in using the app and some doubt over their own level of performance with it, but good outcomes

otherwise. These were considered positive outcomes. There was mainly positive carer reaction on usability aspects of the app.

## Discussion and Conclusion

The user participants showed a good response to the app; their outcomes were mostly positive and encouraging. Further development to reduce perceived effort and improve user understanding could be explored, as well as more practice and training time for the users to enhance familiarisation. Extended familiarisation and training might improve user understanding, which in turn might lessen the mental effort perceived by user participants. On the Talking Mat® session, one user was positive about most aspects of using the app and negative about none, while the other user gave a more mixed response, indicating an opening for further investigation and development. The carer workload feedback showed a positive outcome with only one of the three carers expressing any concern; further work on creating and managing schedules might address this.

A prototype smartphone app has been developed as an accessible and easy-to-use visual planner for use by persons with Autism Spectrum Condition (ASC) and Intellectual Disabilities (ID) and by their carers. It was designed to show its user what activity was currently happening and what activity should happen next, while minimising visual distraction and over-stimulation caused by extra display content.

In trial, users and carers were able to use the planner, the carers to create day schedules and the users to carry them out. Feedback indicated broad approval and some potential for further improvement, following which a fuller trial with a larger group of participants, both users and carers, could be planned. The investigation was viewed as successful and instructive with indications for further enhancement and development of the visual planner application.

## Acknowledgements

The authors gratefully acknowledge the contributions of all participants in the conduct of this work.

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## References

- Alm, N., Arnott, J.L., Murray, I.R. & Buchanan, I. (1998). Virtual reality for putting people with disabilities in control. Proc. IEEE International Conf. on Systems, Man & Cybernetics (SMC '98), San Diego, CA, USA, 11<sup>th</sup>-14<sup>th</sup> October, Vol.2, 1174-1179.
- Arnott, J.L., Munro, S.D., McNaughton, R., Lloyd, G., Malone, M. and Brophy-Arnott, M.B. (2020). Health promotion using smartphone apps for people who use communication supports. *Communication Matters Journal*. 34:1, 16-18. ISSN 0969-9554.
- Beukelman, D.R. & Light, J.C. (2020). *Augmentative & Alternative Communication: Supporting children and adults with complex communication needs*. Edition 5. Baltimore: Paul H. Brookes Publishing Co.
- Dettmer, S., Simpson, R.L., Myles, B.S., Ganz, J.B. (2000). The use of visual supports to facilitate transitions of students with autism. *Focus on Autism and Other Developmental Disabilities*. 15:3, 163-169.
- Fage, C., Pommereau, L., Consel, C., Bolland, E., Sauz on, H. (2014). Tablet-Based Activity Schedule for Children with Autism in Mainstream Environment. Proc. 16<sup>th</sup> International ACM SIGACCESS Conference on Computers & Accessibility (ASSETS 2014). 145-152.
- Hirano, S.H., Yeganyan, M.T., Marcu, G., Nguyen, D.H., Boyd, L.A., Hayes, G.R. (2010). vSked: Evaluation of a System to Support Classroom Activities for Children with Autism. Proc. 28<sup>th</sup> ACM Conference on Human Factors in Computing Systems (CHI2010). Atlanta, Georgia, USA. 1633-1642.
- Jackson, K., Brophy-Arnott, M.B., Whittles, D., Stewart, N. & Arnott, J.L. (2021). Development and evaluation of a mobile app to assist people with autism and intellectual disability to engage in social conversation. *Communication Matters Journal*. 35:3, 22-25. ISSN 0969-9554.
- Kamaruzaman, M.F., Rani, N.M., Nor, H.M., Azahari, M.H.H. (2016). Developing user interface design application for children with autism. *Procedia - Social and Behavioral Sciences*. 217, 887-894.
- Murphy, J. & Cameron, L. (2008). The effectiveness of Talking Mats® with people with intellectual disability. *British Journal of Intellectual Disabilities*. 36:4, 232-241.
- Pavlov, N. (2014). User Interface for People with Autism Spectrum Disorders. *Journal of Software Engineering and Applications*. 7, 128-134. DOI: 10.4236/jsea.2014.72014
- Pavlov, N., Mirchev, K., Gardjeva, T., Krushkova, D. & Rahnev, A. (2016). Responsive user interface for people with ASD. *International Journal of Pure and Applied Mathematics*. 111:1, 105-119.
- Radi, K. (2017). Effectiveness of electronic visual schedules on task completion and independent transitioning of adolescents with developmental disabilities. MA Thesis, no. 2428, Rowan University, NJ, USA. <https://rdw.rowan.edu/etd/2428>
- van Dijk, W. & Gage, N.A. (2019). The effectiveness of visual activity schedules for individuals with intellectual disabilities: A meta-analysis. *Journal of Intellectual & Developmental Disability*. 44:4, 384-395.



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# Angelman Syndrome and Lots to Say

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Angelman Syndrome (AS) is a rare genetic condition affecting between 1 in 10,000-24,000 births. Typical characteristics include learning disability, speech impairment, movement disorder and sleep difficulties (Keute, et al., 2021). This article will discuss the communication journey of Leia (15). Leia was diagnosed with AS at 2 years 7 months after concerns were raised about her inability to speak or babble.

Interventions began almost immediately. We began watching Something Special™ the following day, speech and language therapy (SLT) provision began a month later, and she was removed from mainstream toddler and playgroups to attend specialist nursery provision two months later. From the age of three, a home visiting teacher came to the house. This carried on until she went to specialist school at age 5. These therapies were all aimed at fundamental concepts and developing the (perceived) prerequisites for communication. We were also researching ourselves and had bought a communication programme called Tap-to-Talk on the Nintendo 2DS.

Leia picked up a few Makaton signs and developed a nod for yes and a shake for no. She would occasionally point to the symbols on the communication booklet made by the SLT and participate in the educational activities in the expected way from time to time. Although, often she would follow her own agenda, as can be seen on every report! Nevertheless, it was clear, thanks to her relatively good motor skills and her signs and gestures, that she had a good understanding of language. She underwent assessment for a communication device and was recommended a Tobii S32. The Tobii S32 Touch arrived just at the start of school. It was an overlay device; the printed pages were inserted into the device, and pre-recorded messages were activated depending on where on the device you pressed. It had a range of premade pages ranging from single page visual displays to between 2 – 32 symbols per page. Any extra pages or personalisation was done via the provided software. It was an enormous undertaking, especially with a newborn at home, however we worked hard to make it work. Ultimately, after around eighteen months, it was used less and less. It was too clumsy and awkward. There was not only the device to carry round, but also an enormous folder of pages, and it was difficult to find pages when you needed them.

As the Tobii was not working, the SLT was looking for alternative. She had heard of a PODD book and thought it was worth a try. This was towards the end of Primary 2. I was intrigued by the book but never managed to figure out how on earth to use it. Leia did carry it around in a Mr Tumble spotty bag for a full year at school, but at home it sat in a cupboard. She would consistently use it to say, "I want to do what the others are doing" in SLT sessions but not much else.

This carried on for just over a year. Then, in August 2014 when Leia was 8, we went to a conference run by ASSERT (now AngelmanUK), the support organisation for families and people with AS in the UK. They had Mary-Louise Bertram and Erin Sheldon in attendance. Mary-Louise, a teacher from Australia, had a class with 3 boys with AS. She introduced communication and modelling (Aided Language Simulation) to the class and saw improvement in their communication over the school year. Erin was mum to a daughter with AS and, whilst she was at first sceptical of Mary-Louise's claims, she was soon won over and subsequently completed a master's degree in education. The two of them began advocating for better communication for all in what has now been dubbed the "Angelman Syndrome Communication Revolution". For the first time, I understood how to help Leia improve her communication in a meaningful way, rather than expecting Leia to teach herself (McNaughton, et al., 2019).

We began modelling, Leia changed from a PODD with 20 symbols per page to one with 36 symbols, and we got PODD on compass on an iPad funded by education. After we started modelling, Leia started using PODD relatively quickly. I continued to learn more about modelling and communication by attending training courses and conferences, although I did notice that there was only really information for beginners. There was nothing out there to help those of us who had started well but then plateaued, and I knew there were many of us! However, we kept plodding along. Eventually, I decided to undertake a PGCE in Complex Communication Needs at Edith Cowan University in Australia.

This was just one of the changes that occurred prior to Leia making significant gains in her communication, between November 2020 and summer 2021. The most marked difference being in January 2021 where, seemingly from nowhere, Leia changed from a context-dependent to transitional-independent communicator, a jump of 46% to 67% on the Tobii Dynavox Goals Grid. We will look at these now:

### **Understanding of Communication and Multi-Modal Communication**

I completed the PGCE in 2020. Whilst I had already a good knowledge of how to model and help improve communication, there is no doubt that my knowledge was further advanced. One element that surprised me was the confidence that learning about the true meaning of communication gave me. Often when we need to use additional tools or methods to meet communication needs, the tool can become the whole focus. For example, I realised that, whilst Leia very often initiates communication, even if she does not immediately use her talker, the initiation is no less valid, and, more importantly, that this is perfectly acceptable.

It helped me see the value in many of the tools that are used, sometimes badly, by those who are still working on trying to get people to meet prerequisites. Many parents automatically reject the tools, such as visual timetables, big mac switches and GoTalks, when they first understand about modelling and robust communication systems. This reaction often happens as there is no trust left in professionals who have hindered, rather than helped, communication.

### **Video Modelling**

As part of my PGCE in Complex Communication Needs, I had to take videos of me modelling and then analyse them to see what areas I was covering and where I could improve. I was amazed that things that I thought I modelled well, I didn't - especially areas Leia had as targets! This exercise helped me target the areas that we should focus on more effectively. I highly recommend videoing.

### **Understanding Underlying Needs**

Another part of my course covered behaviour through the lens of unmet underlying needs. This led to me to reconsider Leia's behaviour and to question how she gets information she needs and how she questions what she needs to. So, I added additional supports to Leia's talker. This included decision making, what's happening and help pages into Leia's talker, and altering self-talk pages that were already present.

### **OT for sensory regulation**

We were fortunate enough to be part of a project during lockdown that gave us access to an OT specifically for sensory regulation. This gave us space to consider what extra supports Leia required to help regulate her sensory system. We were also gifted a weighted blanket which helps Leia tremendously.

### **Lockdown**

I am undecided if lockdown was good for Leia's communication. We certainly were not great at modelling during that period as we were more on survival mode, but we did spend much more time together as a family. Lockdown has certainly left a mark on all of us, but, as with everyone else, it is difficult to decide exactly what that impact is.

There were certainly a few changes. However, in October 2020 I was recording presentations for Rett UK's communication conference about good modelling, and I was deeply aware that we were not doing enough at home. Things had to change!

### **Family challenge**

In October 2020, we took part in a family challenge to raise money for Leia's school's Parent Council. For 10 days, Gordon (Leia's dad) was to model 100 words on AAC. Aside from helping motivate us all to model more, the monies raised have allowed the Parent Council to buy licenses for Jane Farrall's literacy course. A win for everyone!

### **Change of platforms for PODD**

Leia had used PODD on Compass since she first got her iPad for communication. At the time it was the only one available, but it was old, and editing took a long time. When the PODD page set became available on Snap plus Core First, we changed over. The novelty of it was of course motivating for all of us, including Leia. She also enjoyed the topic pages as she had the opportunity to say more complete sentences with less effort. I know that there is controversy around phrases compared to spontaneous novel utterance generation, but I think the best judge of what is best for an AAC user is the AAC user. I would never advocate for only phrases, but there is no question Leia likes access to them. Another thing we added to the talker was a page known as fun greetings. This has sound bites from TV shows and movies that can be used as greetings. Leia's includes "How you doing?", "May the force be with you", and "So long, farewell, auf Wiedersehen, goodbye". These always get a great reaction.



### Communicate, Educate, Advocate Conference 2020 by Rett UK

Motivation was already increasing in the house, but there is nothing quite like a conference to generate a bit of excitement around modelling, and you always pick up some great tips. Susan Norwell and her pin button so that you can stay on pages that normally close after one word was quite honestly revolutionary.

### Echo Show

I am 99% sure that everything that went before added to the seemingly sudden increase to Leia's communication. I am 100% sure that getting Leia and her family members Echo Shows for Christmas was the catalyst. She suddenly had a way that she could control who she called. They could hear her talker clearly during the call, and of course not being in the same room meant her non-verbal communication was not quite as efficient. Once everyone recognised that she had a lot to say during the calls, they began asking her to talk and to contribute. It had a snowball effect.

It is over a year on since we saw this increase, and Leia continues to use her talkers effectively. She began a literacy class last year, and her literacy has improved too. She can still be a reluctant student but is much happier to spell and get her thoughts out there. If AAC allows you to look into a person's thoughts and personality, spelling is the window cleaner. People continue to ask me if Leia has good understanding. I now like to tell them she spelled "cleptomanc" to describe the thieving grandmother in David Walliams "Gangsta Granny". It seems to stop most further questions. Don't get me wrong - I was as surprised as anyone when I realised what she was writing. But isn't that the amazing thing about children, they continually surprise you with their brilliance. I am so glad that Leia has been given the opportunity to do just that.



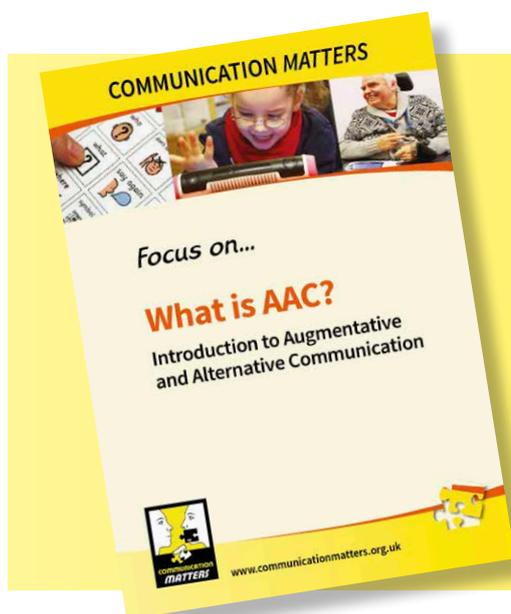
### References

- Keute, M., Miller, M.T., Krishnan, M.L. *et al.* Angelman syndrome genotypes manifest varying degrees of clinical severity and developmental impairment. *Mol Psychiatry* **26**, 3625–3633 (2021). <https://doi.org/10.1038/s41380-020-0858-6>
- McNaughton, D., Light, J., Beukelman, D., Klein, C., Nieder, D., & Nazareth, G. (2019). Building capacity in AAC: A person-centred approach to supporting participation by people with complex communication needs. *Augmentative and Alternative Communication*, Advance online publication. DOI:<https://doi.org/10.1080/07434618.2018.1556731>.



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# From Isolation to Friendship: The role of high-tech AAC in social development and social integration of children with complex needs: case study from a private clinic in Greece

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Friendship and acceptance from peers are significant factors in the social-emotional development and self-esteem of every child/teenager. According to research, children with complex needs present with difficulties in social skills and social communication, which result in limited opportunities for them to develop friendships and be part of a group of peers (Light, 2014). These limitations not only deprive them of the chances to develop self-esteem but also put them at risk of social isolation. When a child is socially isolated then their social-emotional development is also affected (Beukelman, 1992). Therefore, the ultimate goal of intervention should be to develop communicative competence and to enable participation in peer-groups and society.

This paper is a case study focusing on a child with complex needs (Joubert syndrome) referred to a private clinic in Athens, Greece. The child, named S, used only facial expression and screaming to communicate and prior to Speech and Language Therapy input his parents anticipated all of his needs due to severe dysarthria. The child had self-harming behavior and was very negative towards engagement.

The results of his initial qualitative assessment showed that he had high receptive language but very low expressive language. His pragmatic profile from the *Clinical Evaluation of Language Fundamentals – 5<sup>th</sup> Edition* (CELF-5) was also analyzed, and S presented with: difficulty in following conversational rules, participation, giving/asking for information, responding to reactions, and reading cues. The goals set for S were the following:

1. Maintain conversation
2. Initiate conversation
3. Greetings and farewells
4. Read body language and respond
5. Respond to jokes
6. Ask for talker
7. Use strategies to get attention
8. Ask for information
9. Turn-taking

However S responded negatively to engagement and suggestions, was obsessed with computer games, had self-harming behaviours, and he was dysregulated. Due to the cycle shown in Figure 1, aiming at the above goals was impossible.

Interpreting all the above according to Light (2002), S had sociolinguistic and sociorelational difficulties along with a lack of motivation.

Therefore a specialized high-tech system was introduced which followed a relationship- based

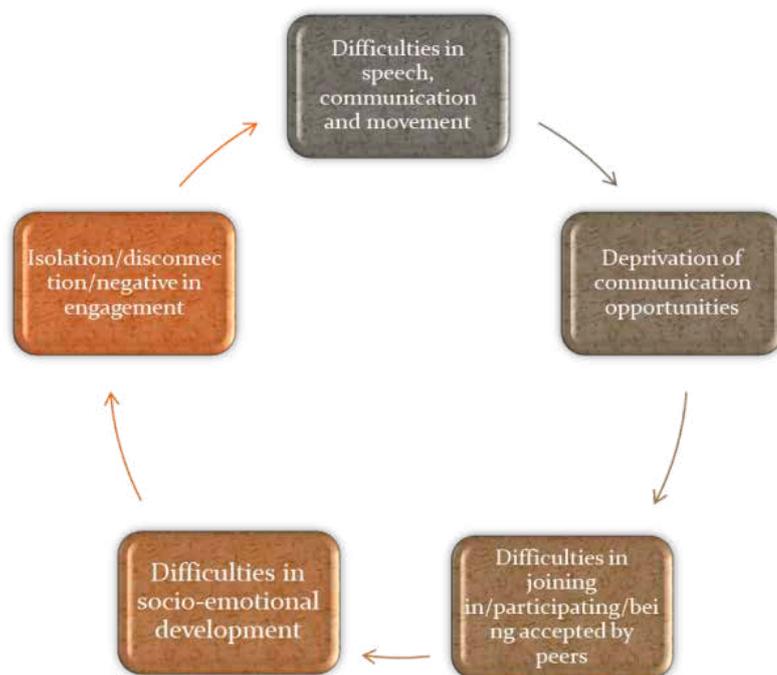


Figure 1

model (DIR FLOORTIME) to support his self-regulation, engagement and communication. The therapist followed his lead without any anticipation for almost 3 months (stage 0) and after that S was able to regulate himself, participate, try new activities and be positive.

However, he was not able to be positive and participate in multiple environments, so a different approach was found. Due to his social skills difficulties, his emotional difficulties and the established isolation, there was a high need for a holistic approach to be followed (Figure 2). For the above reason, the 'circle of 4 socio-emotional stages' was followed.

The main focus of the intervention was functional communication skills, pragmatics and participation, which was achieved with co-regulation and positive engagement. Intervention was divided into four levels starting from 1:1 intervention in clinic and ending in joining in a peer group.

In stage 1, S was in the clinic room with his therapist and they worked on self-regulation and learning new social skills using his pragmatics-based device. In stage 2, S and his therapist invited different therapists into the team's clinic room and they interacted with them at the same time as the therapist was working on his co-regulation. In stage 3, S and his therapist practiced social skills and regulation in the community, and in stage 4, S and his therapist practiced social skills and regulation in the clinic within a peer group. At the end of stage 4, we went back to stage 1 learning new skills in a 1:1 setting, and so the cycle goes on (Figure 3).

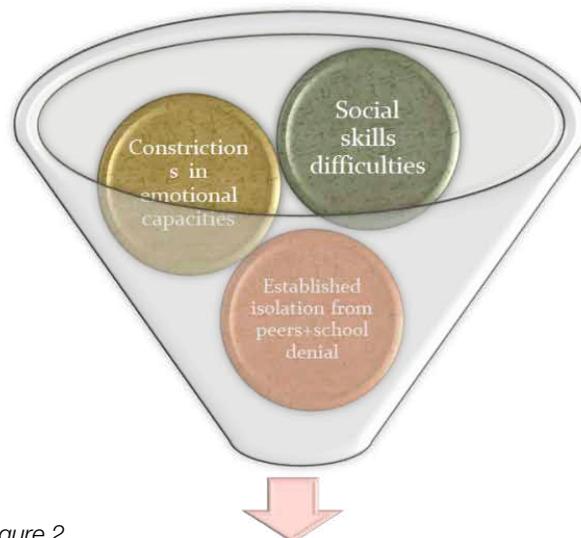


Figure 2

In this model the stable factors are the same therapist (person of reference) and co-regulation, and the changing factors are the people, the setting, and the number of people. Time and skill development are not the criteria to move on a stage. At least 4 sessions at each stage are required. The ultimate goal of the model is for the child to be self-regulated and engaged in positive interaction within different settings and with different people. When all the stages are completed, we start again and move from stage 1-4, making a new circle.

After several circles, S was able to:

- Be engaged in all stages
- Be regulated in all stages
- Needed less prompting in targeted social skills
- Participate positively
- Demonstrate no interest in electronic devices/tablet

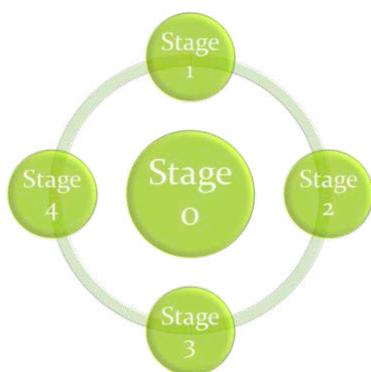


Figure 3

Overall, an improvement in social skills and participation was noted and S was able to stay and participate in a group of peers without self-injurious behavior or isolation. This case study highlights how AAC supported this child to take important steps towards social integration and friendship.

However, further quantitative research is required to be done before we are able to confirm these results.

**References**

Beukelman, D., & Mirenda, P. (2013). *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (4th ed.). Baltimore, MD: Paul H. Brookes.

Light, J., McNaughton, D., Krezman, C., Williams, M. B., Gulens, M., Galskoy, A., & Uempleby, M. (2007). The AAC Mentor Project: Web-based instruction in sociorelational skills and collaborative problem solving for adults who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 23, 56 – 75.

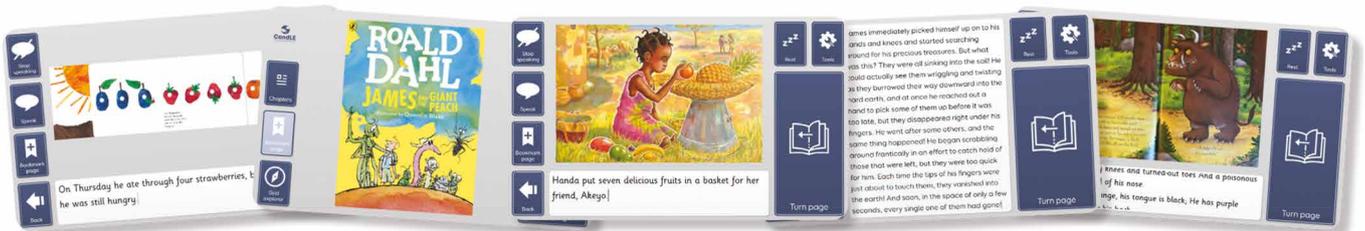
Light, J. C., Parsons, A. R., & Drager, K. D. R. (2002). "There's more to life than cookies": Developing interactions for social closeness with beginning communicators who require augmentative and alternative communication. In J. Reichle, D. Beukelman, & J. Light(Eds.), *Exemplary practices for beginning communicators: Implications for AAC* (pp. 187 – 218). Baltimore, MD: Paul H. Brookes.

Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, 5, 137 – 144.

Light & McNaughton (2014). Communicative Competence for Individuals who require Augmentative and Alternative Communication: A New Definition for a New Era of Communication?, *Augmentative and Alternative Communication*, 30:1, 1-18.

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# How Do People Who Use Augmentative and Alternative Communication Use Multimodal Communication in Real- Life Situations? A Literature Review

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## Introduction

Multimodal communication is a term used to describe the different ways people communicate, for example supporting spoken words with gestures and facial expressions. Everyone uses multimodal communication to add information to what they say, and we wanted to explore what multimodal communication looks like for someone using Augmentative and Alternative Communication (AAC).

In our practice as part of a specialised AAC service, we have observed that people who use AAC use a range of strategies and modes of communication during interactions. For example, someone may combine a phrase constructed on a powered device “I want help” with eye-pointing towards an item to indicate what they want help with. We have also observed that when someone starts to use powered AAC, the use of a paper communication system is often neglected. AAC includes use of signing, writing, letters, pictures, symbols, and Voice Output Communication Aids (VOCAs) and can therefore involve holding and/or operating equipment. We are interested in finding out whether using AAC creates any barriers to multimodal communication.

To help us understand what the existing research tells us about multimodal communication in AAC, we completed a literature review.

## Method

We aimed to answer the research question: how do people who use AAC use multimodal communication in real-life situations?

The databases Pubmed and CINAHL gave a broad spectrum of results using the search terms below, most of which were not relevant. We therefore constructed a search strategy to search relevant journals, *Augmentative Alternative Communication* and *International Journal of Language and Communication Disorders*, for articles with any of the following terms in their title:

- strategy/strategies
- skill
- multimodal/multi-modal
- case

We found a total of 72 articles. These articles were screened at title and abstract level using pre-determine inclusion and exclusion criteria, and 26 were included in this review.

To answer the research question, we then reviewed each article to extract information related to the following:

1. Do people who use AAC use multimodal communication?
2. If people who use AAC employ multimodal communication, what form(s) does it take?
3. If multimodal strategies are used, how are these developed?
4. What should clinicians be recommending in terms of multimodal communication?

## Results and Discussion

We present a brief descriptive summary of the literature below, organised according to the predefined themes of the information extracted from the literature.

### 1. Do people who use AAC use multimodal communication?

There is a consensus in the articles that multimodal communication is utilised by everyone and that there is a benefit for people who use AAC to being able to use different modes of communication. 14 articles noted or commented on the benefits of multimodal communication. Some of these are:

- Some modes are more portable than others;
- Combining or switching between different modes can increase flexibility, improving communicative success and competence;
- A multimodal approach takes advantage of different features of different systems;
- A single mode may not be available in all contexts: different modes are more efficient and practical across different situations.

### 2. If people who use AAC employ multimodal communication, what form(s) does it take?

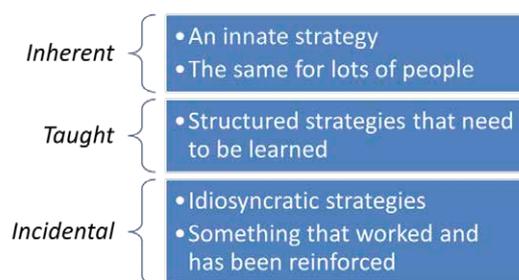
In this review, 7 articles described how people who use AAC use multimodal communication. There were very few examples of multimodal communication being used in spontaneous, real life interactions.

- 3 Studies illustrate that people who use AAC use different modes for different situations: Murphy et al (1996), Sigafoos & Drasgow (2001), Iacono et al (2013).
- 3 Studies outline multimodal communication used during interactions:
  - Batorowicz et al 2014:241: “Parents reported how their younger and older children tried to adjust communication to decrease the effort needed and invented strategies to communicate in the most efficient way...Parents described their child’s multiple modes of communicating: symbols, written words, and gestures; shortcuts and abbreviations; and pointing at objects or moving to a physical location.”
  - Blischak & Lloyd (1996) is a single case study following Cathy’s AAC journey. They report how Cathy uses multimodal communication, a combination of VOCA, signing, and gestures.  
 “ “Jill” <VOCA> + “work” <sign> + office <point>, “Come here.” <gesture to clinician>, (wheeled herself to office), then, “Paige” <VOCA> + <point>.” (Blischak & Lloyd 1996:41)
  - Lasker et al (2005) is a single case study outlining the strategies used by a professor following a stroke: a combination of VOCA, key word teaching and expectant pauses to support word finding difficulties.
- 1 study outlines strategies employed by people who use AAC to name items not on their VOCA: “An average of 87.7% of the answers were produced with the communication aid, while the rest were expressed in different modalities, including pantomimic gestures (e.g. shooting movements to name a gun) and strategic use of gaze or pointing at objects” (Deliberato et al, 2018:8).

A theme that arose through the papers is mode selection. There are different factors that impact on the chosen mode such as physical ability, hearing and vision, cognition, personal preference, environment, context, and the communication partner (Calculator, 1988; Sigafoos & Drasgow, 2001; Dyches et al, 2002; Iacono et al, 2013; Diehl and Wallace, 2018; Blischack et al, 1996).

### 3. If multimodal strategies are used, how are these developed?

The articles that described multimodal communication during interactions did not detail how these strategies were developed or taught. Figure 1 illustrates our theory about how multimodal strategies could be acquired.



Understanding how people who use AAC develop multimodal strategies will impact and inform how clinicians can best support or teach their use:

- If strategies are inherent, they would not need to be taught;
- If skills are taught, consideration needs to be given to how best teach them;
- If strategies are developed incidentally, they will be different for different people, and these will need to be shared with all communication partners.

### 4. What should clinicians be recommending in terms of multimodal communication?

We did not find published recommendations in this literature search about how multimodal communication can be best used by people who use AAC.

## Summary

This review suggests that multimodal communication should be encouraged for people who use AAC, but we did not find information to support understanding about how best to achieve this.

We have found evidence that using different modes supports communication for people who use AAC. However there were limited examples of what this looks like in real-life interactions. The individuals in the articles used different strategies depending on their skills, communication partners and environment. It was not clear how these multimodal communication skills had been developed, whether any interventions could be replicated with other individuals and the impact of these on real-life interactions. There was no indication of how people who use AAC utilise the options of paper, partner, and powered AAC systems together. Recommendations made by clinicians regarding ongoing use and development of paper AAC alongside power AAC and other communication strategies appear to be driven by clinical experience and knowledge that powered communication cannot be used in all scenarios.

## Clinical Implications

This review has not identified guidelines for implementing multimodal communication, however some principles have emerged which should be considered when supporting people who use AAC. Professionals should:

- be aware of the importance of multimodal communication and actively support AAC users and communication partners to use it. This includes placing value on all modes of communication, not prioritising one mode over another;
- be aware that societal influences have led to more attention being placed on powered systems (Iacono et al, 2013) which may act in contradiction to the aim of supporting all modes of communication;
- recognise that the range of communicative modes available to individuals will be influenced by many factors, so AAC assessment should gather information about all aspects of an individual. AAC recommendations should promote a system that works to the individual's strengths, incorporates multiple communication modes, and considers communication across different contexts.

## Future Research

A number of questions still remain about how to develop multimodal communication with people who use AAC. Future research could explore:

- whether multimodal communication strategies are predominantly inherent, taught or incidental and how these strategies might best be developed or taught;
- the interplay between paper, partner and powered AAC. For example, should a paper AAC system be developed alongside the use of a VOCA? What do these systems look like and how are they used together?;
- whether the existing experience and knowledge of clinicians and those who use AAC can be collated to develop more formal guidelines around developing multimodal communication.

## Conclusion

Multimodal communication is of benefit to people who use AAC, but there is little research about multimodal communication in real-life interactions and how best to support this. More research is needed to understand how people who use AAC use, and can best develop the use of, multimodal communication.

## Bibliography

- Baxter, S., Enderby, P., Evans, P. and Judge, S. (2012) 'Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis.' *International Journal of Language & Communication Disorders*, Vol:47, pp:115-129
- Borg, S., Agius, M., Agius, L. (2015) 'A User and Their Family's Perspective of The Use of a Low-Tech Vs A High-Tech AAC System' *Studies in Health Technology and Informatics* Vol:217: Assistive Technology
- Cregan, A. (1993) 'Sigsymbol system in a multimodal approach to speech elicitation: classroom project involving an adolescent with severe mental retardation' *Augmentative and Alternative Communication*, Vol:9:3, pp:146-160
- Cress, C. & King, J. (1999) 'AAC strategies for people with primary progressive aphasia without dementia: two case studies' *Augmentative and Alternative Communication*, Vol:15:4, pp:248-259
- Culp, D. (1989) 'Developmental apraxia and augmentative or alternative communication—a case example' *Augmentative and Alternative Communication*, Vol:5:1, pp:27-34
- Cumley, G. & Swanson, S. (1999) 'Augmentative and alternative communication options for children with developmental apraxia of speech: three case studies' *Augmentative and Alternative Communication*, Vol:15:2, pp:110-125
- DeRuyter, F. & Donoghue, K. (1989) 'Communication and traumatic brain injury: a case study' *Augmentative and Alternative Communication*, Vol:5:1, pp:49-54
- Groenewold, R. & Armstrong, E. (2019) 'A multimodal analysis of enactment in everyday interaction in people with aphasia' *Aphasiology*, Vol:33:12, pp:1441-1461
- Hanson, E. K., Beukelman, D. R. & Yorkston, K. M. (2013) 'Communication Support through Multimodal Supplementation: A Scoping Review' *Augmentative and Alternative Communication*, Vol:29:4, pp:310-321
- Hooper, J., Connell, T. M. & Flett, P. J. (1987) 'Blissymbols and manual signs: A multimodal approach to intervention in a case of multiple disability' *Augmentative and Alternative Communication*, Vol:3:2, pp:68-76
- Iacono, T. & Duncum, J. (1995) 'Comparison of Sign alone and in combination with an electronic communication device in early language intervention: Case study' *Augmentative and Alternative Communication*, Vol:11:4, pp:249-259
- Iacono, T., Mirenda, P. & Beukelman, D. (1993) 'Comparison of unimodal and multimodal AAC techniques for children with intellectual disabilities' *Augmentative and Alternative Communication*, Vol:9:2, pp:83-94

- Light, J., Beesley, M. & Collier, M. (1988) 'Transition through multiple augmentative and alternative communication systems: A three-year case study of a head injured adolescent' *Augmentative and Alternative Communication*, Vol:4:1, pp.2-14
- May, A.A., Dada, S. and Murray, J. (2019), 'Review of AAC interventions in persons with dementia.' *International Journal of Language & Communication Disorders*, Vol: 54, pp.857-874
- Midtlin, H. S., Næss, K. B., Taxt, T. & Veia Karlsen, A. (2015) 'What communication strategies do AAC users want their communication partners to use? A preliminary study' *Disability and Rehabilitation*, Vol:37:14, pp.1260-1267
- Page M J, McKenzie J E, Bossuyt P M, Boutron I, Hoffmann T C, Mulrow C D et al. (2020) 'The PRISMA 2020 statement: an updated guideline for reporting systematic reviews' *BMJ* 2021:372:n71
- Vidal de Thorne (2021) 'Effectiveness of a support based approach to peer interactions of an autistic student in the classroom: A mixed methods study.' *Perspectives of the ASHA Special Interest Groups*, Vol. 6, pp.327-343

## References

- Batorowicz, B., Campbell, F., von Tetzchner, S., King, G. & Missiuna, C (2014) 'Social Participation of School-aged Children Who Use Communication Aids: The Views of Children and Parents' *Augmentative and Alternative Communication*, Vol:30:3, pp:237-251
- Blischak, D. M., & Lloyd, L. L. (1996) 'Multimodal augmentative and alternative communication: Case study' *Augmentative and Alternative Communication*, Vol:12, pp:37-46
- Calculator, S. (1988) 'Promoting the acquisition and generalization of conversational skills by individuals with severe disabilities' *Augmentative and Alternative Communication*, Vol:4:2, pp:94-103
- Deliberato, D., Jennische, M., Oxley, J., Regina d'Oliveira de Paula Nunes, L., Crivelenti de Figueiredo Walter, C., Massaro, M., Almeida, M. A., Stadskeiv, K., Basil, C., Coronas, M., Smith, M. & von Tetzchner, S. (2018) 'Vocabulary comprehension and strategies in name construction among children using aided communication' *Augmentative and Alternative Communication*, Vol:34:1, pp:16-29
- Diehl, S. D., & Wallace, S. E. (2018) 'A modified multimodal communication treatment for individuals with traumatic brain injury' *Augmentative and Alternative Communication*, Vol:34:4, pp:323-334
- Dyches, T. T., Davis, A., Lucido, B. & Young, J. (2002) 'Generalization of skills using pictographic and voice output communication devices' *Augmentative and Alternative Communication*, Vol:18:2, pp.124-131
- Iacono, T., Lyon, K., Johnson, H. & West, D. (2013) 'Experiences of adults with complex communication needs receiving and using low tech AAC: an Australian context' *Disability and Rehabilitation: Assistive Technology*, Vol:8:5, pp.392-401
- Lasker, J., LaPointe, L. & Kodras, J. (2005) 'Helping a professor with aphasia resume teaching through multimodal approaches' *Aphasiology*, Vol:19:3-5, pp.399-410
- Murphy, J., Markova, I., Collins, S. and Moodie, E. (1996) 'AAC systems\*: obstacles to effective use' *International Journal of Language & Communication Disorders*, Vol. 31:1, pp.31-44
- Sigafoos and Drasgow (2001) 'Conditional Use of Aided and Unaided AAC: A Review and Clinical Case Demonstration.' *Focus on Autism and Other Developmental Disabilities*, Vol. 16: 3, pp.152-161



This article can also be watched on video at:

<https://youtu.be/bzqvPMspNn4>

# CM International AAC Conference 2023

## CALL FOR PAPERS



**You are invited to contribute to the Communication Matters  
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We have three topic areas for your presentations:

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Papers can be submitted as either a **Platform** presentation (45-minutes),  
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**The deadline for submissions is 21 April 2023.**

Further information can be found on our website: <https://bit.ly/cm2023callforpapers>

# Mentoring Project Update – New Learning and Development Resources

## VERITY ELLIOTT

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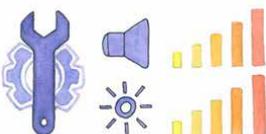


The Communication Matters conference in September was a long-awaited for opportunity to meet face-to-face and to participate in workshops and lots of positive discussions.

The Mentoring Project attracted a lot of interest from AAC users, parents/carers and practitioners. It is evident that the last four years have provided so many opportunities including, but not limited to, gaining a recognised and meaningful qualification, increased use of communication devices, extending and enhancing literacy, and working together.

## New resources

We now have a range of methods for AAC users to complete accredited units and full qualifications. These include a choice between using simple, one-page activity sheet, completing a workbook (either Word or PDF), or presenting information and images using PowerPoint slides with voice notes and short videos. The creativity had been fabulous and as one external moderator observed, 'This is an excellent example of inclusion in practice' (NCFE CACHE July 2022).



## DfE Digital Foundation Skills

We responded to a request from a college to help design some accessible learning resources for AAC users to be able to complete the modules in the DfE Digital Foundation Skills standards. This has been a really worthwhile opportunity and the resources (PDF, Word and PowerPoint slides) are available for AAC users to develop and demonstrate their understanding and proficiency when using a range of digital devices including communication aides, laptops, and mobile phones.

## Mentoring animation

In September, we launched our first animation, and we are delighted with the response received so far. It has been a real 'labour of love' and took a while to get it just right. We are very grateful to the creative team, AAC users, and others at CM as well as freelance artists and the animator who pulled it all together. The animation can be viewed [here](#) and please share to anyone that you think would be interested. We hope to create more short animations to demonstrate the skills and qualities for mentoring.



## Opportunities for 2023

We are pleased to confirm that we still have funding available for any of the short course and qualifications that we offer so please do get in touch to find out more.

For more information about the wide range of learning and development opportunities and mentoring, please contact Verity Elliott: [verity@creativityinpractice.co.uk](mailto:verity@creativityinpractice.co.uk) / 07891 959048.



This article can also be watched on video at:

<https://youtu.be/ID9bleoxJ64>

# Awards for All – Northern Ireland Project Report, October 2022

## VERITY ELLIOTT

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## Introduction

Communication Matters partnered with Mae Murray Foundation who are based in Northern Ireland. National Lottery Northern Ireland provided an Awards for All grant to support seven Augmentative and Alternative Communication (AAC) users to complete an Entry Level 3 Award in Personal & Social Development.

Four workshops run by Creativity in Practice Ltd were held in Belfast on Saturdays between May and October 2022. The workshops were based on themes and topics for each of the units within the qualification. We are delighted that all seven learners achieved the qualification. It is evident that the sessions were not only enjoyable, with the much longed for face-to-face interaction, but that they provided participants with the opportunity to:

- increase the use of communication device;
- develop literacy skills and vocabulary;
- provide opportunities to meet and work together;
- gain confidence.

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

## Participant feedback and comments

During the sessions, the participants told us 'What has gone well'.

A wide range of themes emerged through our discussions:

The participants felt that the **social aspect** was important: *"Getting together again, having a laugh. I enjoyed working in a group and meeting new people."*

Another theme was **increased confidence** in using communication devices. Participants told us having the opportunity to work together encouraged discussion; *"Using my communication aid made me happy. Last week I learned to take my time using my device and asking people to wait. I learnt that I really like this device as people can see what I write on the second screen. I took time to listen to everybody."* Two participants had met up for coffee, outside of the course, with the more advanced AAC user giving confidence to the other to order coffee publicly – a great goal achievement!

Participants also told us how the sessions had helped to provide an **increased awareness of interpersonal skills**: *"Hearing about what everyone wants to work on, venturing into new things. I enjoyed listening to everyone's goals and having the space to stop and listen. There was great patience in the room. I completed the workbook by Zoom with my brother and his girlfriend who joined in the conversation. When having a conversation with friends I have learnt to ask open questions to keep the conversation going."*



On the last day, the group shared how this opportunity (all four workshops and completing a qualification) had helped them:

*"I am better at using my communication aid. Having the confidence to be independent, order food in a restaurant. I can now add words and phrases to my device independently."*

*"The course has helped me to use my device more. Because of what I have learnt, I am excited to help other AAC users. I feel proud of the work I have been doing over the last six months."*



### Consultee feedback and comments

On the last day, the participants hosted a consultation event with family members and Personal Assistants (PAs) to ask for their feedback and any observations in relation to AAC usage since the start of the course.

#### Consultee #1:

*"Since my daughter came home from her first day on this AAC course, this has been a life saver. She was very worried about starting at a new college the following week, yet she came home from AAC and there was a complete change. She felt empowered to talk to new people and said to me 'Mum, I accept the place to go to college'. This course has given her courage and confidence which has lasted from day one. I keep saying this is the best thing ever."*

#### Consultee #2:

*"These sessions have made a massive difference. I have observed more confidence and expression. The interest in supporting each other (during the sessions) has been great. AAC use brings so much potential, thank you."*

#### Consultee #3:

*"This qualification is a big tick; it didn't come easy. I can see how hard all the participants had to work. Confidence has changed so much from week one until now."*

#### Mae Murray Foundation:

*"We've seen everyone come on tremendously in a short space of time, with more experienced device users helping new device users. It's been great to see the confidence growing and just lovely to be in a room with lots of AAC users just chatting away. This pilot is a first for Northern Ireland. Technology is trendy. We can definitely see this group of participants growing their skills and offering peer support to other AAC users in Northern Ireland."*



### Next Steps

Following on from the consultation event on 8<sup>th</sup> October 2022, we will be seeking further funding to continue to offer similar opportunities to more people within Northern Ireland.



# The World of Apps: What Do I Use for Functions Other Than Communication?

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The world of apps for iOS devices has grown exponentially through the years. In fact, a 2021 article reported that Apple approves about 1,000 apps per day every day (Evans, 2021). That is about 30,000 per month and over 350,000 per year. Those numbers are overwhelming and, of course, support Apple's trademarked slogan 'there's an app for that™'. While that is good news for finding an app for a particular function, it can also complicate the decision-making process when we are choosing apps for our clients using iPads, especially for those using alternate access methods such as eye tracking, scanning, and touch with adaptations.

While there is no doubt that we must select appropriate Augmentative and Alternative Communication (AAC) for our clients, we know that clients want to do more than just communicate using their devices (Hemmingsson et al, 2020; McLaughlin et al, 2021). This interest is shared by their families and teams. They want to access social media, news, calendars, education and business tools, games, and more.

To facilitate this access for iPad users, we suggest the following five considerations:

### **1. Client's current ability**

Does the client have the skills needed to use the app already with their access method? Skills might include physical actions such as tap, swiping, or long press as well as device operational skills such as returning to the device's home page, opening apps, and pausing/resuming an access method.

### **2. Upskilling plans**

If the client does not currently have the required skills to use the app, is it a good application to practise skills you want to build? For example, take pictures with a camera app to teach tapping, or practice swiping with a book reading app.

### **3. Motivation**

Is this app interesting to the client? Is it a task they want to do? Does it include content that they especially enjoy (e.g., favorite TV show or character, topic of interest such as cars or animals)? After all, we are likely to work harder and persevere when something is motivating for us (Paul, 2013).

### **4. iPadOS adjustments**

Are there settings in the iPadOS Settings that can help make the iPad more accessible as a whole and the app more accessible specifically? Consider settings related to icon and text size, setup of the AssistiveTouch Menu, and features for specific access methods.

### **5. App choices/adjustments**

Does the application offer settings that may make it more accessible for your client? Based on availability, this might include changing from portrait to landscape, modifying response time or time-out settings in games, replacing complex tasks (Hold and Drag) with more simple ones (Tap), or displaying fewer choices on the screen.

These simple considerations can be applied to choose apps for individuals of varying skills levels and using different access methods as you see in the examples below (see references for downloadable version).

## Child Utilizing Touch

### 1. Current ability

Taps with accidental activations. Understands concept of swipe but does so inadvertently returning her to Home Screen or causing unexpected results in apps. Difficulty holding and dragging.

### 2. Upskilling plans

Improve accuracy of tapping, purposeful swiping, and ability to hold and drag with the goal of full access to the iPad's apps and functions through touch.

### 3. Motivation

Loves anything to do with animals, friends, and peers. Also, enjoys books.

### 4. iPadOS adjustments

Change size of icons and text to increase size of targets (**Settings > Display & Brightness and Home Screen**). Adjust hold time for touch and apply timing for swipe to decrease accidental activations (**Settings > Accessibility > Touch Accommodations > Hold Duration and Swipe Gestures**).

### 5. App choices/adjustments

Changes to iPad Settings were effective in addressing tap and swipe actions so we moved on to Hold and Drag. Choose applications that require Hold and Drag without any time limits or requirement for exact placement (in other words, apps that have a snap into place action when the item gets close to its location).



## Adult Utilizing Scanning

### 1. Current ability

Single switch, group-row-column, automatic scanning in communication software.

### 2. Upskilling plans

Select accurately despite irregular scan patterns. Perform actions beyond tapping. This is accomplished through use of the Scan Menu which provides access to required functions for operational control of the iPad such as Long Hold, Scroll, and Home as well as functions needed for individual apps. Accessing functions on the Scan Menu requires additional switch hits as well as knowledge of the available functions.

### 3. Motivation

Self-advocacy such as scheduling appointments independently and interacting on social media. Searching the internet.

### 4. iPadOS adjustments

Set scanning method and pattern to match that which is currently in use (**Settings > Accessibility > Switch Control**). Adjust scan timing if needed given this new access environment (**Settings > Accessibility > Switch Control**). Set icon size and text size as small as possible to decrease navigation between Home Screen (**Settings > Display & Brightness and Home Screen**). Arrange Home Screen icons with most frequent or most needed in the upper left.

### 5. App choices/adjustments

Native Apple apps appear to cooperate better with iPadOS accessibility options (e.g., scan patterns) and sometimes offer additional accessibility features than third-party applications. Safari, for instance, offers a tiled display of bookmarks as opposed to the list which may be easier to access for many individuals using alternative access methods. Experimentation may be required to learn how to perform functions in apps using the Scan Menu. For example, changing the time in a calendar is not accomplished by scrolling then tapping but by through use of the increment/decrement option in the Scan Menu. Some applications are not accessible using the Scan Menu and will require use of an alternate scanning method available in iPadOS called point scanning. This method allows interaction with targets by 'pinpointing [them] with scanning crosshairs' (Apple).



## Teen Utilizing Eye Tracking

### 1. Current ability

Accurately dwells to select in AAC application most of the time and enjoys cause/effect games.

### 2. Upskilling plans

Expand eye gaze skills and the ability to utilize apps of interest in the iPad with the goal to functionally control the iPad using eye gaze. Begin with Hold and Drag as it is used in many applications then teach Pause/Resume, etc.

### 3. Motivation

Videos, reading, drawing, playing with friends, and controlling the environment.

### 4. iPadOS adjustments

Change size of icons and text to increase size of targets (**Settings > Display & Brightness and Home Screen**). Adjust dwell time if needed to accommodate for possible differences between eye gaze in AAC

and eye gaze with AssistiveTouch (**Settings > Accessibility > AssistiveTouch > Dwell**). Customize the AssistiveTouch Menu to include the actions on which you want to work (**Settings > Accessibility > AssistiveTouch**).

### 5. App choices/adjustments

Play or music applications are a great place to begin. Be sure they are accessible with tap only and without any timing requirements so that the individual can acclimate to eye tracking in the iPadOS environment. iPad native apps such as Photo Booth, Camera, Photos, and Flashlight are good options. Book reading apps and websites like Tarheel Reader, Google Images, and YouTube can be great ways to teach pausing and scrolling.

The stories of these three individuals underscore the importance of the following considerations when selecting apps to improve access, target goals (e.g., education, social, language), or meet needs (e.g., daily living, social, education, entertainment).

1. **Current ability** – Know current skills so as not to frustrate.
2. **Upskilling plans** – Systematically plan what you will teach.
3. **Motivation** – Use what interests the individual to facilitate perseverance.
4. **iPadOS adjustments** – Create a baseline environment in the device that works for the user.
5. **App choices/adjustments** – Use apps creatively and tweak them as you are able.

They also remind us that use of an iPad through an alternative access method may require teaching and practice. It is important to prioritize skills thoughtfully based on client motivation for the best results. And remember that ‘there’s an app for that™’.

## References:

Tobii Dynavox. (2021). *Choosing the best apps for your TD Pilot – Quick Guide*.

Note: This handout focuses on eye tracking but is applicable to all access methods.

Apple. (n.d.). *Use Switch Control on iPad*. iPad User Guide. <https://support.apple.com/en-in/guide/iphone/iph8de250c54/ios>

Evans, J. (2021, September 6). *Apple approves 1,000 new App Store apps each day – report*. Apple Must. <https://www.applemust.com/apple-approves-1000-new-app-store-apps-each-day-report/>

Hemmingsson, H., & Borgestig, M. (2020). Usability of Eye-Gaze Controlled Computers in Sweden: A Total Population Survey. *International journal of environmental research and public health*, 17(5), 1639. <https://doi.org/10.3390/ijerph17051639>

McLaughlin, D., Peters, B., McInturf, K., Eddy, B., Kinsella, M., Mooney, A., Deibert, T., Montgomery, K. and Fried-Oken, M. (2021). Decision-making for access to AAC technologies in late stage ALS. In Billy Ogletree (Ed.), *AAC Challenges and Solutions: Improving Everyday Service Delivery*.(pp. 169-199) Plural Publishing.

Paul, A. (2013, November 4). *How the power of interest drives learning*. Mind/Shift. <https://www.kqed.org/mindshift/32503/how-the-power-of-interest-drives-learning>



# Msc Educational Assistive Technology: Training a New Professional Group

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## Introduction

The MSc Educational Assistive Technology (EduAT), (University of Dundee, 2022) is relevant to Communication Matters (CM) members due to the valuable contribution that the emerging assistive technologist profession can make to the assessment, provisioning, and ongoing support of AAC and allied AT (Assistive technology) systems. It is fitting to document the creation of the MScEduAT in the CM journal due to the pivotal role the CM conference played. At CM2014, Trevor Mobbs and Rohan Slaughter (first author) presented on the Dart project (Slaughter & Mobbs, The Dart Project, 2015). Following this presentation, Professor Waller (second author) discussed the assistive technologist training method, known as 'the Dart curriculum'. Based on that initial conversation at CM2014, development of what would become MScEduAT began.

This article follows the presentation given at CM2022. It points to a definition of the assistive technologist role and considers how MScEduAT was developed. The article continues by considering how this MSc fits into a wider AT training ecosystem, noting whom the MSc is for. This is followed by an overview of the curriculum developed to train assistive technologists, concluding with a summary of what has been learned over the two years that the MScEduAT has existed, alongside summarising research plans.

## Defining a new professional group

The name 'educational assistive technology' was chosen to differentiate the MScEduAT from AT courses for rehabilitation engineers and clinical scientists, both of which have established professional routes available.

In late 2020, the first author established the EduAT competency framework, based on work done to define the Assistive Technologist role in the ESCO (ESCO, 2022) database. The author collaborated with Natspec TechAbility colleagues to support the creation of the ESCO 'assistive technologist' definition. Whilst this does not have any power to make the 'assistive technologist' a protected title, it is useful to point to this definition, clarifying about what the role is, and what it is not.

The AT elements in the EduAT framework map to the TechAbility Standards (Natspec, 2022). The assistive technologist role has previously been defined in CM journal article (Slaughter, Connect to Control, 2014).

## Developing MScEduAT

The Dart Project (Maudslay, 2015) was funded by LSIS (Learning and Skills Improvement Service) and Jisc 2010-2015. As part of Dart, a curriculum was developed to train assistive technologists. The Dart curriculum has inspired the approach taken in MScEduAT and has been expanded upon considerably.

In 2014, attempts were made to create the MSc; these did not progress. In early 2019, a small group gathered at the top of the University of Dundee's (UoD) Tower Building to consider core module scope and structure. By the end of 2019, the first author had drafted the core modules. During 2020, the modules and the programme specification were scrutinised internally and approved mid-2020.

The first author was appointed as Senior Lecturer in late-2020 to begin the development and delivery of the MScEduAT. Professor Waller took on the role of Programme Lead for the MScEduAT as director of the UoD AAC and AT Research Group. The programme team are fortunate to have support from colleagues interested in AT from across the education sector and academia who formed the MScEduAT advisory group. The purpose of this group is to function as 'critical friends' to the programme team.

The first cohort of students started in January 2021, the second cohort began their studies in January 2022, and the third cohort will start their EduAT journey from January 2023.

### AT training ecosystem

The EduAT team does not believe that everyone working to support AT should have an MSc. Rather, a range of training is required at multiple levels for people in different roles, and at different stages of their careers, in a range of organisations. This includes:

- advanced courses for those wishing to become AT specialists (e.g. MSc EduAT);
- advanced level courses for professionals (e.g. masters level modules);
- CPD (continuing professional development) level training opportunities for teaching assistants, teachers, therapists etc.

All teaching, learning, and care support staff should have some AT knowledge. To support this, Ace Centre, Natspec TechAbility, and the UoD have partnered to produce a CPD course: **Understanding the Benefits of Assistive Technology** (Ace Centre, 2022). This is a short, free online course, providing a basic introduction for all staff to what AT can achieve and which learners will benefit from AT.

To meet the needs of professionals' CPD, the EduAT team are planning to offer some MScEduAT modules 'stand alone'. In addition a **partnership between Ace Centre Learning and the UoD** will deliver accredited masters modules from Ace Centre starting April 2023. This includes options for students to exit with a PGCert (60 credits) in **Specialist Assistive Technology** (Ace Centre, 2022). This includes the 'AT unit' and either the 'Access unit' or the 'AAC unit'.

### The MScEduAT curriculum

The MSc EduAT has six core modules:

1. The educational assistive technologist
2. Introduction to AT systems
3. Mainstream and specialist AT
4. Assessment for AT
5. AT in educational programmes
6. AT partner relationships

In addition to 100 core module credits, students take 40 elective credits and choose a 40-credit project dissertation, totalling 180 credits required for an MSc award.

The first module uses a guided tutorial to undertake a supportive gap analysis using the EduAT competency framework. Based on identified learning opportunities, the team suggests elective modules from education, computing or IT and health or therapy to address relevant parts of the EduAT competency framework.



Figure 1: Members of the MSc EduAT programme team and students in the Geddes Quad, UoD, June 2022.

Module one establishes the nature of the role, how it can change for different contexts and shares context and background of relevance. Modules two and three cover the broad spectrum of available AT. Module four provides the AT assessment theoretical basis and includes a range of different examples of AT assessment, inclusive of AAC, DSA (disabled students allowance) and EAT (electronic assistive technology). Module five provides students with the tools to embed AT within taught programmes, and the final core module covers the professional context of the role and making referrals to various parts of the system. More detail can be found on the MScEduAT website (University of Dundee, 2022).

The course is 'blended', with the majority of delivery online as students are UK-wide. Most students work full time and undertake MScEduAT within their working contexts. There are no exams, all assessment is coursework, designed so that students use work they are conducting in their employment as a basis for academic work. This makes the assessment relevant to students' working contexts and more achievable overall whilst working full time.

One on-campus teaching and conference week is undertaken per year of part-time study. Entry requirements have been kept as flexible as possible to support a diverse range of students to join the course.

This course is for anyone who wishes to become an educational assistive technologist (EduAT). Students could be:

- Teachers, teaching assistants
- Therapists, therapy assistants / technicians
- Technologists from a variety of backgrounds.

Most students have prior AT experience, are employed in a suitable AT environment, inclusive of education, social care or third sector organisations, in a role that requires the post holder to support the use of AT. Where a student is not employed in a suitable context work placements may be identified.

### What has been learned?

Students are employed in a range of different organisations:

- Membership bodies
- Specialist and mainstream schools and colleges
- Charities, third sector and care organisations
- Higher Education
- Private AT or AAC practice and therapy services
- Local authorities (advisory teachers / electronic AT specialists)
- NHS services

Cohort one includes people working in AT mature organisations. This is to be expected as several people in the cohort are developing their skills, addressing learning opportunities and validating their existing skills and knowledge. The second and third cohorts are drawn from a diverse range of organisations. Overseas students have been made offers for 2024 entry, and the EduAT team are developing AT placement opportunities.

Some students are fully supported by their organisations; they have leadership buy-in and ownership of AT as a core part of the organisations' offering. This leads to improved AT training and development and active engagement in improving the wider AT service. It is not always straightforward as there is huge variance in organisations' AT maturity and very different expectations of the AT role. This can be variable in terms of budget support, ability to buy assessment equipment, and limited budget for additional staff as the AT service scales. The EduAT team have seen occasional concerns with other professionals or groups around accepting the need for a 'professionalised AT role' in the unfounded belief that this may encroach on existing roles.

More experienced colleagues are in part taking MScEduAT where they want to improve recognition for a professional AT role within their own organisation. For those starting out with AT, the course can provide knowledge skills and understanding to undertake assessment, provisioning and ongoing support of AT in a range of organisations.

There is now a 'formal' route into AT training for those who wish to train as an assistive technologist. This means students can develop as an assistive technologist or embed AT skills into another role such as teacher, technologist or allied health professional (primarily SLT or OT).

The EduAT team have seen a wide range of examples of how AT is implemented in the UK. In some organisations, our student may be the only person who is working to support AT, in others they can be part of a wider AT team. There is also variation in where AT is located in organisational structures, sometimes within education teams, therapy services, IT or within a dedicated AT or a broader technology team. In some organisations, we see good management buy-in, and in others this is very difficult. The EduAT team have supported students and their management teams to embed the AT role and have signposting to other services inclusive of Natspec, Jisc, TechAbility and others.

A useful feature of the course has been peer review and development through an active learning student body. The programme team plan to encourage alumni to remain engaged within this community upon graduation.



Figure 2: Suppliers exhibition at the June 2022 on campus teaching and conference week.

## Research plans

The AAC and AT Research Group at the UoD has a long history of innovative AAC and user centred computing research (Waller, 2018). The group plans to develop new projects as well as renewing some of the group's previous projects into replicable 'products' that the community may benefit from.

### New research

#### AT assessment tool development

- Building a web-based software tool to support qualified staff to undertake high quality needs-based assessment.
- Useful for multiple educational stages, levels, ages, transition points, and outputs useful reporting and guidance materials (e.g. AT or AAC passports).

#### Modelling the impact of assistive technologists

- Reviewing the impact of the AT role on organisations.
- Considers data such as destinations, achievement rates and, where possible, exam or course pass rates, alongside stories or case studies can bring a richness to the lived experience of individuals, it will be important not to represent these stories as data.
- A 'social return on investment project' to inform evidence-based policy making.

#### AT training framework and discovery tool

- Improving discoverability of AT resources and training through design of an AT training framework that identifies what training is needed by people in a range of roles, in different organisational contexts and at different stages of their AT journey.

### Renewing UoD research

To 'productise' research projects in order to ensure that the outputs are directly useful to people who may benefit.

#### Productising ACE-LP (AAC research group, 2022)

- This is a novel word, sentence and phrase predication method that also uses geolocation and AI (artificial intelligence)/ML (machine learning) scene analysis.
- The potential exists to radically improve word, sentence and phrase prediction and therefore text entry speeds in AAC systems and beyond.

#### A modern implementation of 'How Was School Today'

- A revised 'How was school today' project using 5G or IoT (internet of things) technology, instead of Bluetooth beacons.
- Through utilising current technology, this project can be scalable and sustainable in ways that the original project was not.

### MSc AAC renewal

Of potential interest to CM members, the UoD already offers the research focussed MScAAC. The group would like to consult with CM members on three possible options for renewing MScAAC:

- Maintain the research focus of MScAAC, retain as on-campus one-year, full time;
- Align MScAAC more closely with MScEduAT, including becoming a two-year, part-time majority online, 'practice based' MSc;
- Offer additional MScEduAT modules creating a practice and research 'hybrid' MSc that is taught on-campus and online.

If you have views on how MScAAC might evolve, please contact [MScEduAT@dundee.ac.uk](mailto:MScEduAT@dundee.ac.uk)

## References

- AAC research group. (2022, 12 07). *AAC Research Group*. Retrieved from ACE-LP project: <https://aac.dundee.ac.uk/ace-lp/>
- Ace Centre. (2022, 12 07). *Ace Centre*. Retrieved from Ace Centre Learning: <https://acecentre.org.uk/learning/understanding-the-benefits-of-at>
- Ace Centre. (2022, 12 07). *Ace Centre Learning*. Retrieved from Ace Centre Assistive Technology for Complex Communicaiton, Physical and Learning Needs: <https://acecentre.org.uk/learning/atu>
- ESCO. (2022, 01 27). *Assistive Technologist*. Retrieved from European Skills/Competencies, qualifications and Occupations: <https://ec.europa.eu/esco/portal/occupation?uri=http%3A%2F%2Fdata.europa.eu%2Fesco%2Foccupation%2F4e82464b-e9d7-4d51-9116-294ab40c5169&conceptLanguage=en&full=true#&uri=http://data.europa.eu/esco/occupation/4e82464b-e9d7-4d51-9116-294ab40c5169>
- Maudslay, L. (2015). *Assistive technology in further educaiton organisations*. Bristol: Jisc.
- Natspec. (2022, 12 07). *Natspec TechAbility*. Retrieved from TechAbility Standards: <https://www.techability.org.uk/techability-standards/>
- Slaughter, R. (2014). Connect to Control: How we can do the 'bells and whistles'. *Communication Matters, Volume 28*(Number 1), 11.
- Slaughter, R., & Mobbs, T. (2015). The DART Project - Improving Assistive Technology provision in Further Education. *Communication Matters Journal, 29*, 24-26.
- University of Dundee. (2022, 12 07). *MSc Educational Assistive Technology*. Retrieved from University of Dundee: <https://www.dundee.ac.uk/postgraduate/educational-assistive-technology-part-time>
- Waller, A. (2018). Telling tales: unlocking the potential of AAC technologies. *International Journal of Language and Communication Disorders, 54*(2), 159-169. doi:10.1111/1460-6984.12449



This article can also be watched on video at:

<https://youtu.be/kLqIBeqEMbQ>

# Metamorphosis

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***Because of the CM guidelines, the full comprehensive version of this article cannot be printed here. However, I have made it available, in full, on my website here <https://talksense.weebly.com/metamorphosis.html>***

I am a disabled man in my sixties. Over a year ago, I had a stroke that put me in hospital for weeks. The stroke left me with a left hemiplegia, paralysed completely down my left-hand side and weak core muscle strength.

The stroke also affected my speech and talking became something of an effort with limited results. If I am emotional, or in pain, or my throat is dry, or I am not feeling well, I cannot speak at all and have to resort to using my single-handed version of Makaton (because my left hand is not functioning) sign language that I call Maka-One. I found myself having to cope with lengthy periods of pain and poor post-hospital provision.

All my working life, I was involved, in one way or another, with **People Of Disability (POD)** and or learning difficulties. I also was involved in the provision of training for professionals and support workers. I worked alongside gifted therapists, as well as many talented teachers and support staff in many different countries. The focus of the training I provided concerned good practice in education and support provision for staff working with individuals experiencing special needs. It now seems somewhat ironic that I am in need of that support myself! The irony is not lost on me.

I had become an I.R.O.N. (*Individual totally Reliant on Others for Needs*) P.O.D. (**Person Of Disability**). A stroke can take away the power of speech. My stroke left me with very poor speech. On good days, I can just about make myself understood, but on bad days, I have no speech at all. I have worked with AAC (Alternative and Augmentative Communication) throughout my working life. I have taught AAC, designed and developed AAC, marketed AAC, and lectured on AAC all over the world. After the stroke, I became a consumer of AAC. I am probably the only person in the world to have occupied each of those roles. The irony of becoming a user of AAC is not lost on me.

While in hospital, I used a combination of very poor natural speech, Makaton signing, and writing in a notebook at various times in order to communicate and get what I needed to say across to others. Makaton signing is tailored for use with two able hands; I only had one functioning upper limb following the stroke and even that was not very able. I had to use Makaton creatively, adapting signs made using two hands into a single-handed form. It would not have mattered if I had the use of my left hand, however because none of my nurses knew any Makaton. I had to teach them some signs by signing a single word and then writing down its meaning in my notebook. A very slow way to communicate - communication matters!

My lack of effective communication let me down on several occasions both during my time in hospital and during the year afterwards spent at home. A few of those experiences are detailed in this article. I continue to have communication difficulties nearly a year post-stroke. I guess I will have them for the remainder of my life. Silence is not golden. I am already beginning to notice subtle differences in the way I am treated by others. Others are not comfortable with silence and, as I take longer to respond to communication from other people, will 'jump in' and continue communicating in what, I presume, is an effort to ease the discomfort that I must be feeling not being able to communicate effectively. There have been other, some very noticeable, changes too (full list available on my website).

**Asking a question and then immediately asking more questions without allowing me the time to respond to any of them**

One morning the carers asked me a question. By the time I had the chance to answer in sign, they had already asked several more questions. I signed "I don't know". The carers hadn't got a clue what I was saying. They would have not known, to which of the questions they had asked, my signing was the response, because they had moved on so far beyond the original question: "*Where's it hurting?*", "*Is it your leg?*", "*Do you want me to get the doctor?*", "*Do you want us to move you?*", "*Are you feeling sick?*", "*Do you feel hot?*", "*What can we do to help?*"

*"STOP asking so many questions all at once!"*

### The use of age-inappropriate language

For example, “*Good boy*” is not appropriate for an adult male many years your senior. When I am eating, I usually have a tea towel across my chest so that if I accidentally drop any hot food, it falls onto the towel and not my bare flesh. Once, the carers arrived before I started my lunch, but after the towel was in place:

1st Carer: “*Oh! You’ve got your bib on ready for dinner.*”

Me (struggling to speak): “*Don’t call it a bib. I am an adult.*”

2nd Carer to 1st Carer: “*What did he say?*”

1st Carer to 2nd Carer: “*I haven’t a clue*”

The carers then started the normal lunch visit procedure with no attempt to ask and clarify my statement.

### Reluctance to relinquish control

Carers like to be in control. Early in my first period in hospital following the stroke, I had to call a nurse to look at my catheter bag, which was full. The nurse said, “*Oh Christ!*” and hurried to get a disposable bottle in which to empty it. I then asked the nurse for the bed control. She gave me a quizzical look and asked, “*What do you want that for?*” I explained that I wanted to raise the top of the bed. She asked, “*Do you want to sit up?*” and using the bed control herself proceeded to raise the top of the bed saying, “*Tell me when.*” I protested, “*No, give the control to me.*”

My speech was very poor, affected by the stroke. The nurse just carried on, in control, saying, “*Too high?*” and began lowering the top of the bed! I repeated, as clearly as I was able, “*No, give it to me.*” This time, the nurse appeared to understand me and passed me the control stating, “*Fine, do it yourself.*” She was not pleased as she walked away. Carers like to be in control. It is not the carer that needs to be in control, it is the client. The goal is control. Give the client, the patient, the learner the means to take control. Control of the carers, the clinicians, the environment, over the gadgets in the environment, over my own being, over everything. Control is empowering. Take away control, and you take away dignity. Loss of control is demeaning and handicapping in the true sense of the word.

Another time, while in hospital, I found myself with no access to a nurse call button. I could not shout, as a result of the stroke I could hardly speak and, when I did manage to speak, it was barely intelligible. Needing assistance, I improvised and used the bed control pendant to bang on the bed frame. The unorthodox communication technique worked in that it got attention, but I was scolded (banging was *‘inconsiderate of other patients’*), and I had the bed control taken away and moved out of my reach! However, the nurse did give me the nurse call button, but it was at the cost of losing my bed control. Ensure the client always has an acceptable means of summoning assistance. Never punish a client by removing control. The removal of a patient’s control is the removal of a patient’s dignity.

When hoisting, ensure the hoist is in good working order (Health and Safety Executive 2011; Bainbridge 2019). If the client is capable, put control of the hoist in the client’s hands. Give control of the hoist to the person to be hoisted. The carers can ensure that hoisting is undertaken safely even when they are not directly holding the hoist control. If the individual is physically and cognitively competent, the role of the carer is to empower the client and enable him/her to do it for him/herself. If there is no other option but for carers to operate the hoist, it is important that they allow the client to take charge of the situation by asking the person to give instructions on what actions to take and when to take them. Client instructions need not be verbal. Sign or gesture are equally as good; these modes of communication still allow the client control of the situation.

Do not take control away from the client, allow the client gradually to take control away from you. The goal is control - client control. Who is in charge in such situations? (Haug & Lavin 1981; Veatch 2008) A Carer entered my room while I was watching a film. She took the TV remote off my bed and paused the film without asking. I was somewhat annoyed! Her actions implied that she was in charge of the situation, and now that she was present, I was subject to her will. The question of who is in ultimate control of a situation can be contentious. If a client is saying one thing and the client’s spouse (or significant other) another, and the carer’s belief is yet a further option, whose rule is correct? Sometimes this can be problematic. As a general principle, the client should always have the guiding voice, although it may prove very difficult to ignore the spouse! Suppose the client is not cognitively competent, should the spouse’s wishes prevail? The answer is not a simple ‘yes’. The client’s wishes should always be a priority, but another’s wishes may overrule a client if the client’s wish is **D.U.B.I.O.U.S.**:

1. **Dangerous**
2. **Unreasonable** (impartial others would judge it to be so)
3. **Bad** (for the Client), (who decides what is bad for the Client?!)
4. **Impossible to undertake**
5. **Outside your remit** (there may be rules that do not permit Carers to perform specific actions. This includes any directive written into the Client’s Care Plan)
6. **Unintelligible or Unworkable**
7. **Specialist** (requires a professional – a person specifically qualified for that role)

If any of the above are a ‘dubious’ feature of the Client’s request, it may prove necessary to follow an alternative path. The goal is control unless control is *dubious*.

Choice is a voice. Always give the client a choice (Dixon, Robertson et al 2010; Mulley, Trimble, & Elwyn 2012) but don’t constrain the client to choices that Carers find acceptable Don’t ask, “*would you like tea or coffee?*” rather ask, “*would you like tea or coffee or something else?*”.

Adding 'or something else' makes possible a choice that puts the client in control. Of course, multiple options within a single question posed to a person without any means to communicate is, in itself, problematic. It is easily solved by presenting the options, one at a time, allowing the person to respond 'yes' or 'no' to each. If the person responds affirmatively to 'something else', you have the further issue of discovering which of all available drinks the person wants. However, that task is not so arduous as it might appear. The person is in a room within a building, and there will be a finite number of drinks available. Once you get to know a person, you will also get to know the person's preferences. Presenting personal preferences prioritising previously picked options will likely quickly reach a choice. Provision of real choice puts the individual in control and gives the person a voice.

References available on website.

## Belfast AAC Information Day

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

**Date:** Thursday 8 June 2023

**Venue:** Girdwood Community Hub, 10 Girdwood Avenue, Belfast, Antrim BT14 6EG

**Cost:** FREE to attend! Lunch & refreshments are provided.

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

**Read more about AAC Information Days:**

<https://www.communicationmatters.org.uk/diary/#information-days>

**Request a place on this AAC Information Day:**

<https://www.communicationmatters.org.uk/diary/information-days/>

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## Grid in the classroom

Oasis Academy Long Cross is an inclusive primary school in Bristol, supporting a diverse group of children with complex learning difficulties. Over the past two years they have integrated Grid into their day-to-day school life.

Grid is used in every lesson at Oasis Academy, supporting students to make choices, comment on what is happening around them, and to work towards their communication goals.

The range of resources within Grid ensures a variety of content is available to support every student. From early cause and effect tools in Interactive Learning, to research based symbol vocabularies with Voco Chat and Super Core.

“

“The simplicity and effectiveness of Grid and the ability to engage with Smartbox for support, have made this transition towards ‘high tech’ communication, so much simpler.”

Tom, Grid Lead at Oasis Academy



Explore how to involve Grid in your classroom  
[thinksmartbox.com/classroom](https://thinksmartbox.com/classroom)