

Communication Matters



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People with Aphasia - Remote Consultations - Achieving Independence - Total Communication Environment - Lockdown Learning - Learning Disability - Clinical Practice - Assisted Scanning - AAC Landscape - Parent Story - Overcoming Barriers - Voice & Message Banking - Virtual Equipment - Environmental Factors



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CM member Richard Miles with his two PAs, Alan and Mark, stopped for a photo before heading into the conference dinner. Find out more about the Communication Matters Conference which took place on 11-13 September 2022 at the University of Leeds, in our Chair's Report.

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Chair's Report

HELEN WHITTLE

Hopefully, everyone who attended the Communication Matters Conference in Leeds in September has had time to make use of all the information they gleaned and contacts they made during a very full two-and-a-half days. The conference went really well and the atmosphere was great, as so many delegates were delighted to meet up for the first time in two years. We welcomed 389 delegates from 14 countries (outside of the UK) and 40% of attendees had never been to the conference before. The trustees were delighted with this as when we started planning for this year's conference, we were unsure of how many delegates we would be able to attract.



Following the Annual Meeting of Associate Members, we welcomed some new trustees – welcome to Bob Sagoo, as our new Treasurer, along with Beth Moulam, Sarah McPoland and Michelle Paton. We look forward to working with you all in the future.

The range of presentations at the conference was very varied this year. The number of AAC users attending was the largest ever at a Communication Matters Conference. So much so that we filled all the accessible accommodation at the University of Leeds and had to accommodate some delegates in accessible rooms in city centre hotels. We think this was largely due to gaining grant funding so that we could offer more subsidised places to AAC users, their PAs, and family members.



As people had not been able to meet face-to-face for a while, we hosted many meetings at the conference, for AAC users, for parents, for people working in local or independent services and for those in education. The sustainability theme went down well and, again, led to some fantastic fancy dress on the Monday night! For those of you who couldn't make it, you can view the full conference programme and download a book of abstracts from our [conference website](#). The trustees are looking through all the feedback, and the planning for next year's conference has already begun. Please put the dates in your diaries now for the 2023 Conference, which will be on 10-12th September at the University of Leeds.

Following the success of our first AAC Exhibition Day in Leeds in March 2022, we are holding an AAC Information Day in Glasgow very soon, on the 23rd of November 2022, where there will be seven different AAC suppliers presenting. It is free to attend and you can [book here](#).

On Friday 24th March 2023, we are holding our second in-person [AAC Awards Ceremony](#) at the University of Leeds. Our Patron, Lee Ridley (Lost Voice Guy), will be onstage providing the entertainment for us. And there will be many opportunities to celebrate those involved in the field of AAC across the UK. Nominations open soon so please get thinking about who you could nominate. It promises to be a glittering night, so look out for our social media posts advertising this event.

It has been great to get back to hosting events throughout this year, but the trustees know we cannot stand still and just do things as we always have, and so we are holding a Strategy Day with an external facilitator at our next Board meeting in November. This will give us an opportunity to explore what we as an organisation should be working on and developing in the future. One of the workshops made a start on exploring these questions as part of the conference, and we will develop the ideas generated there to ensure that Communication Matters continues to improve and meet the needs of its members and the wider AAC community over the coming years.

Investigation of Communication Abilities and Quality of Life for People with Aphasia by using Talking Mats in Speech and Language Therapy

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Introduction

Aphasia is an attained neurogenic language impairment characterised by loss in the ability to comprehend and produce language for ordinary communication (Msigwa & Cheng, 2020). Strokes or cerebrovascular accidents (CVAs) are the foremost reason for aphasia in adults (Khedr, Abbas, Soliman, Zaki, Gamea, Abdel and Aal, 2020), but it can also appear as a result of brain tumours, traumatic brain injuries, intoxication or inflammatory and neurodegenerative diseases (Koul, 2011). Anomic, or amnesic aphasia, is the mildest form. Brain lesions which cause anomic aphasia vary in severity and they are often associated with damage in the left angular gyrus (Davis, 2000). Amnesic aphasia is often seen as the final stage in the context of linguistic rehabilitation, having started with Broca or Wernicke aphasia (Davis, 2000), which are more severe. Anomic aphasia can also occur as an isolated syndrome and is associated with minimal to mild damage of auditory comprehension, but grammatically correct and fluent expressions (Nikitha, Darshan, Abhishek & Goswami, 2020). Above all, it is characterised by word finding disorders, which are mostly compensated for through substitution strategies, such as naming generic terms or describing the properties of a word. Phonemic and semantic paraphasias are also typical for anomic aphasia, where a close relationship to the target word (e.g. knife instead of fork) is often expressed. The flow of language usually remains unaffected, while search behaviour and sentence breaks often occur. The sentence formation is mostly correct and comprehension is only slightly impaired (Davis, 2000).

Aphasia can impact on the Quality of Life (QoL) of the person, which is defined by the WHO (2021) as an “individual’s perception of their position in life in the context of the culture and the value systems in which they live and in relation to their goals, expectations, standards and concerns”. Language and communication deficiencies can lead to reduced psychological well-being, poor health outcomes, increased social isolation and overall, a reduced QoL (Mitchell, Gittins, Tyson, Vail, Conroy, Paley & Bowen, 2020). In recent studies, it has been revealed that the severity of aphasia seems to be closely interconnected with QoL, even more than cancer or Alzheimer’s disease, because our modern society depends on fast and effective communication (Bullier et al., 2019). Consequently, detecting and treating impaired language and communication after a stroke is essential to improve the QoL of individuals with aphasia.

Talking Mats Framework

Talking Mats (TM) (www.talkingmats.com) is an interactive communication framework intended to support people with communication difficulties, such as aphasia (Murphy, Cameron, and Boa, 2013). It provides a well-defined outline for the dialogue, the conversation is visible throughout and the communication is stored on a mat (Lauer, 2018). If the attention strays, a person with aphasia (PWA) finds his/her way back any time to the topic without losing energy by trying to recall the conversation; it remains on the mat, visualised by the symbols (Ibid.).

The TM framework can be used both as a low- and a high-tech tool depending on the skills, needs and preferences of the end-user. As shown in Figure 1, it is vital that there is a designated area in which the end-user can communicate his/her thoughts. In low-tech solutions, this can be, for instance, a door mat (hence the name of the Talking Mats framework), or laminated paper. At the top, a visual scale is first assigned on the top of the designated area, at the two ends of which there are the two opposite responses (i.e.

yes/no) and if the person is capable of having a third option, this is also added (e.g. maybe). In addition to this, the topic is also included (e.g. Where you live?). It is important to note that one topic is selected per mat. Options relating to that topic are presented by the communication partner (e.g. clinician, teacher) using open questions to the 'thinker'/ end-user, who then places each option under the relevant top scale to express their view. "Submats" can be used to explore the options chosen in more detail, if desired. The completed mats present a visual record, which can be used for planning, decision making, intervention, conversations with friends and relatives as well as for research (Murphy, Cameron, and Boa, 2013).

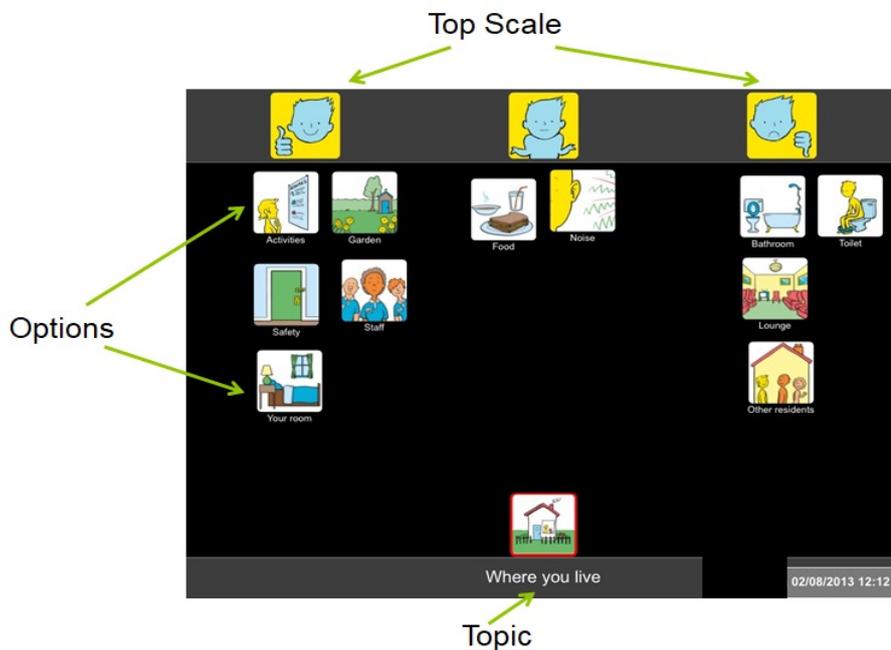


Figure 1: Example of a Talking Mat

Existing literature shows that people with aphasia can effectively use the Talking Mats framework as a communication tool to convey their opinions, feelings, views and thoughts to their communication partners (Murphy et al., 2013). So far, there has been no study undertaken investigating whether the framework of Talking Mats enhances communication abilities and hence, the Quality of Life for people with aphasia beyond merely considering its role as a communication instrument. The current study, thus, represents the first time the effects of using TM in Speech and Language Therapy as a treatment method for communication abilities and Quality of Life (QoL) in a person with aphasia have been explored.

The Research Study

Methodology

The study follows a Single Subject Experimental Design (SSED), which investigates if a consistent intervention with Talking Mats administered by a Speech and Language Pathologist (SLP) over a specific period of time (10 days) influences not only the communication abilities of a person with Aphasia, but also, aspects in the Quality of Life (QoL). The participant in this study was a 34-year-old woman with anomic aphasia, six years post onset and with right-sided hemiplegia (please see Table 1 for inclusion/exclusion criteria). Assessments regarding aphasia and QoL were administered to the participant before and after the therapy with Talking Mats (Figure 2). The therapy itself consisted of 10 consecutive days, in which the SLP followed a specific protocol using the TM framework. One of the assessments was the Stroke and Aphasia Quality of Life Scale (SAQOL-39), which consists of 39 items based on physical, communication and psycho-social fields related to QoL. To measure the level of aphasia, the researchers used the Western Aphasia Battery to examine the patient’s performance on repetition, naming, auditory comprehension and word fluency. This can also diagnose the presence, type and severity of aphasia. During the therapy, the SLP used the Effectiveness Framework of Functional Communication (<https://www.talkingmats.com/wp-content/uploads/2016/07/EFFC-2016.pdf>) to measure communication efficacy in the TM framework. The intervention was undertaken remotely due to Covid-19 restrictions.

Table 1: Inclusion/Exclusion Criteria

Inclusion criteria	Exclusion criteria
Mild, anomic aphasia	Prior symptomatic cerebrovascular accident
Premorbid Greek and English speaker	Neurovegetative or psychiatric disease
Receiving Speech and Language Therapy once per week	Auditory or visual deficits
In the chronic stage of rehabilitation	

The TM interventions were video-recorded and screenshots of the TM mat after each intervention were taken. The results from the SAQOL-39, the WAB and the Effectiveness Framework of Communication scoresheets were captured in MS Word documents and on MS Excel spreadsheets, for subsequent analysis. Visual analysis was used in this single subject experimental design to interpret the data.

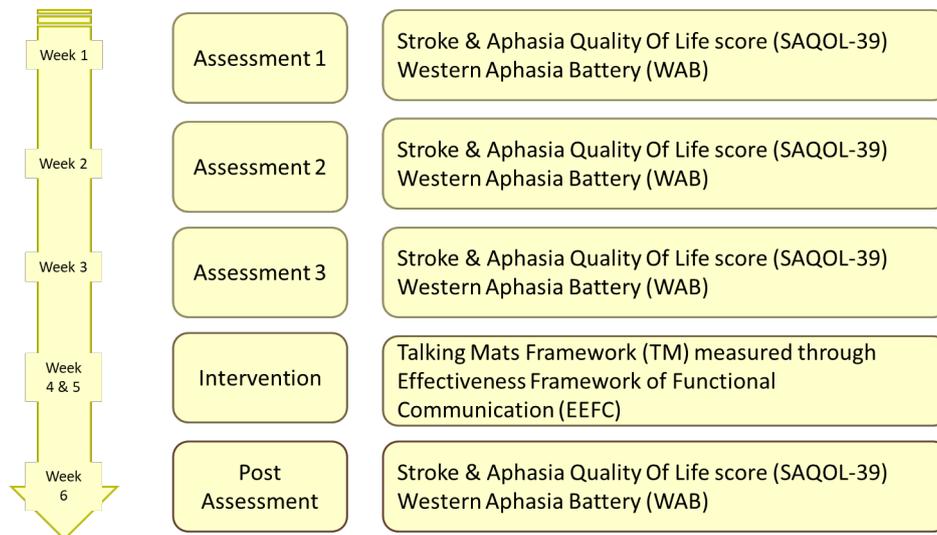


Figure 2: Procedure - AAABA Design

Results

The biggest improvement was captured in word fluency from the WAB by 25.58% when comparing pre-and post-assessments. The mean scores for the baseline levels at the pre-intervention phase rose from 14.33 to 18 at post-assessment, which is demonstrated in Figure 3. Another improvement of 15.15% was witnessed for naming (WAB), when comparing the mean scores before and after treatment. The mean score of 3.30 pre-assessment was enhanced to 3.8 post-assessment. Sentence completion (WAB) improved by 11.11% from means of 9 to 10 at pre-/post-baseline levels. The repetition task (WAB) increased by 8.87%, from a mean score of 8.27 to one of 9 for the pre-/post measurements. Fluency in spontaneous speech according to the WAB increased by 8% from mean scores of 8.33 to 9 when comparing the assessment before and after the intervention. The Aphasia Quotient (AQ) within the WAB increased by 6.36 % with mean scores of 77.83 to 82.8 pre- and post-assessment. The mean scores before and after intervention in the spontaneous speech task (WAB) increased by 5.56%. Auditory word recognition (WAB) dropped slightly with a mean score change of 52.67 to 52 post-assessment.

The physical score of the SAQOL-39 increased by 5.72%, with mean scores of 4.66 and 4.93 before and after treatment. A slight decrease was noted in the overall SAQOL-39 mean score of 0.28 %, falling from 4.50 to 4.46 after treatment. A significant drop in the mean scores from 4.23 to 3.81 pre-/post assessment was found for the psychosocial score from SAQOL-39, with this representing a decrease of 9.86%.

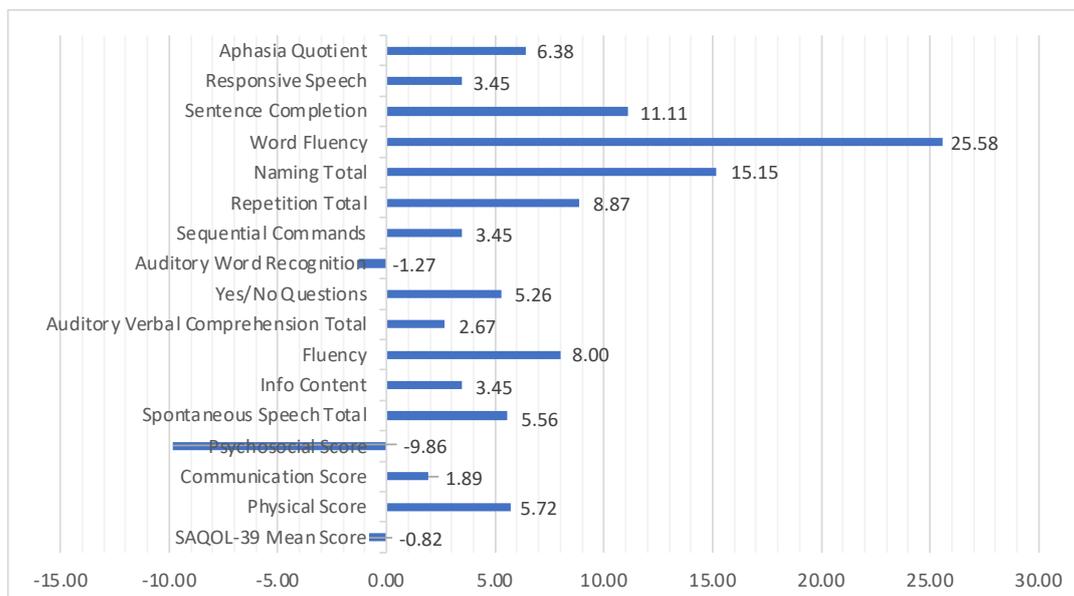


Figure 3: Results after the sessions with the Talking Mats Framework

Conclusions

The outcomes of the study suggest that the TM framework might train vocabulary recall and discourse in people with a mild type of aphasia, such as the anomic form. The clear improvement in communication abilities, e.g. word fluency, naming, repetition, sentence completion, spontaneous speech, and the overall AQ, supports the assumption that the TM framework could be integrated into the therapeutic repertoire of Speech and Language interventions.

Regarding the QoL outcomes, it should be mentioned that the participant was a very sociable person, who met her family, friends and peers on a regular basis. The routine of social interactions played a significant role in her life, but was interrupted by the Covid-19 restrictions. Therefore, it is suggested that a decrease in QoL might be associated with the Covid-19 constraints during the course of this study. However, clear outcomes regarding whether QoL is positively correlated with an intervention with the TM framework could not be produced due to the global pandemic and hence, future research when the pandemic has receded will need to be undertaken. Nevertheless, the results of this single case study might prompt further investigations into how the TM framework could be used in a therapeutic setting.

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Remote Consultations – Feedback from AAC Users and their Supporters, and KMCAT Adult Team Staff

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Introduction:

In response to the Covid-19 pandemic, the Kent and Medway Communication & Assistive Technology (KM CAT) Adult Service has been carrying out remote visits via video and telephone consultations. Seeing service users remotely has become part of a new way of working for the service. East Kent Hospitals NHS Foundation Trust (EKHUFT) IT Department swiftly put systems in place to enable the Team to begin seeing service users remotely by late April 2020. This meant we were able to continue to provide a service throughout lockdown.

This 'remote first' approach was first outlined by NHS England in response to Government guidance (Gov, 2020) and has been incorporated into the team's Covid-19 Business Continuity Plan. Supporting guidance and information was also sought and adapted from the live document 'AHP Virtual Consultation Guidance'.

A project was set up in April 2020 to gather and evaluate data in relation to staff and service users' experiences and perceptions of remote consultations. The initial goal of the project was for results to guide how the KM CAT service might be delivered post-Covid-19. For example, whether routine reviews or carer training could be delivered via video call.

Since completing this project, AAC Specialist Services have also shared experiences and ideas, resulting in a best practice guide for remote consultations (Digital Solutions Working Party, 2020), which the team also contributed to.

Methodology

Staff were requested to complete their survey after each remote consultation, and to send the service user link out for their feedback. Surveys went live at the end of April 2020 and were closed on 01 October 2020. Staff discussions and reflection at the KM CAT weekly multi-disciplinary meeting have also been included, to capture additional insights from these conversations.

Staff Survey Questions:

- The purpose of the consultation
- Ease of use with a particular system
- What systems had been used most successfully
- What technical problems had occurred and whether they had been resolved
- Whether the consultation goals were achieved
- Length of preparation time in comparison with face-to-face consultation
- Length of remote consultation in comparison with face-to-face consultation
- Any other pertinent comments/observations.

Service User Survey Questions:

- Ease of use
- Whether the consultation was helpful and its aims were met
- Whether they would be happy to participate in remote consultations again
- Comments/observations from service users.

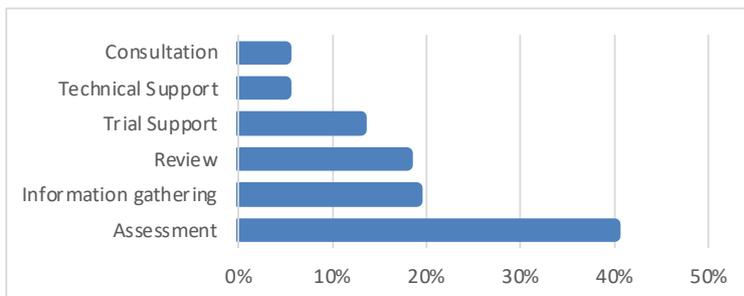
Surveys were sent out via email or text message with a link to complete the survey. Surveys were sent to service users, relatives, carers or therapists (where relevant).

Results

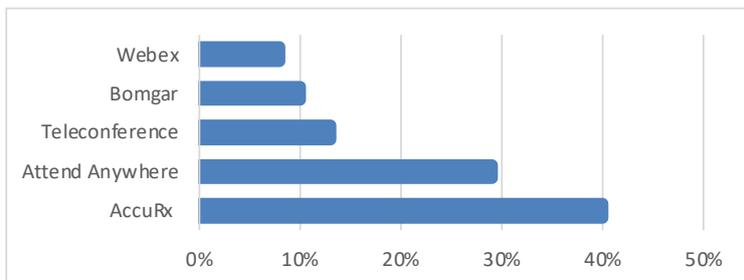
Staff Results

A total of 41 responses during the period were received. It is not known how this relates to the number of consultations completed, but all staff were encouraged to record a response every time a remote consultation was completed.

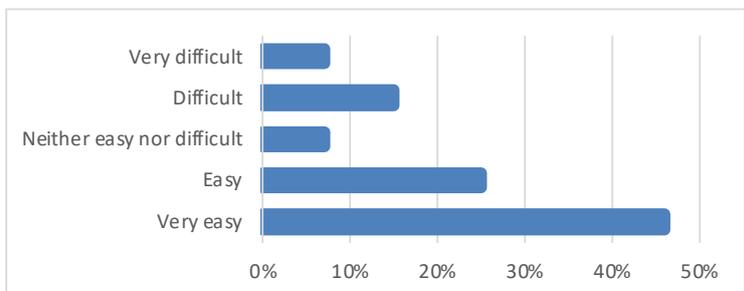
1. What were you using remote access for?



2. How did you connect via remote access?



3. How easily were you able to connect to your service user?



4. Technical issues

63% of staff responses stated they had some technical issues. Of these, the reasons given could be put into 3 categories: connectivity issues, connectivity & audio issues and audio issues alone.

5. Were the goals of the consultation achieved?

56.1% reported that all of their consultation goals were achieved. The remainder, scoring most/some or a few goals being achieved, were asked to expand. These could mainly be classed as difficulties with seeing service user response/ device use.

6. Preparation Time

Staff were asked to rate whether more or less time was needed for preparing for consultations, based on previous experience of face-to-face consultations, with 1 being much less and 100 being much more.

The average response was 52/100 (range 19 to 90).

7. Length of remote consultation

Staff were asked state whether remote consultations took more or less time, based on previous experience of face-to-face consultations using the same rating scales as above. An average score of 43/100 was achieved (range 11 to 92).

8. Comments

17 additional comments from staff were added to the survey.

Service user results

The response rate for service users is not known as there is no log of how many were sent out.

- 80% (12) service users felt it was easy to join the virtual appointment (regardless of the platform used)
- An average score of 93% was given to whether the consultation met the agreed aims at the start of the consultation
- Regarding how useful/helpful the appointment was, the average score given was 94%
- 100% of service users that answered stated they would be willing to use remote means to complete consultation with KMCAT in future.
- 6 service users added to the comments section.

Discussion:

The data from the two surveys, together with information gathered from informal staff discussions, highlight the potential benefits and drawbacks of remote consultations.

Staff survey:

Staff reported they had used remote consultations for a wide variety of purposes. All these activities represent the normal working practice of the Team and reflect that a remote approach, via video or telephone, has enabled service provision to continue.

A variety of remote platforms have been used during the project and these evolved as alternative options became available. 63% of staff reported technical issues around connectivity (10), connectivity and audio (10) or audio (10). These difficulties did not appear to relate to any specific platform and similar issues were reported throughout the project. Filtering responses by date order revealed an increase in technical issues as the project went on. This could be related to the increase in the number of remote consultations as time progressed.

Despite the relatively high number of reported technical issues, three quarters of staff reported their goals for the remote consultation had been achieved. The remainder discussed difficulties such as seeing service users' responses and how service users were using their AAC device as the reason why goals had not been achieved.

Time spent preparing for a remote consultation was similar to preparation time for face-to-face consultations pre-pandemic, although the average length of consultations was slightly less.

Comments from staff could be broadly categorised as:

- **Positive responses** about the remote consultations, such as, "all went well as service user and family have used several times now".
- **Less positive responses** about opportunities to include the service user as much as staff would have liked, for example, "achieved the goals of the consultation, but difficult to gain feedback from service user/direct questions to them using this format, as the person in the room with the camera often takes the lead/is the focus."
- **Frustrations over technical issues** and in some cases how these were resolved so the consultation could continue, for example, "moved to Webex (alternative platform) to resolve the issue which appears to indicate the problem is with Attend Anywhere rather than poor WiFi".

Service user survey:

80% of service users reported that they found it easy to join their consultation and 94% found them useful. This is encouraging when compared with comments relating to connection and technical issues raised by staff. When comments were received about difficulty with connection, in three out of four responses it was stated that the remote consultation was still valuable. As with the staff survey, where there were problems with technology it related to a variety of platforms.

Service users confirmed that they felt that all the agreed aims of the consultation had been met, except one who stated only some aims had been met. All service users agreed they would be happy to take part in further remote consultations. These scores suggest a high level of satisfaction, confirming the technology was enabling productive sessions.

At least three service user surveys were completed by local therapists joining a consultation. Referring therapists are always invited to assessment visits, but rarely join due to time constraints. It is interesting to note that there has been more uptake of these invitations and that they have proved useful.

Limitations

The staff survey was not designed to gather information on how many were entirely remote consultations or combined remote/face-to-face consultations, mainly because this was not happening at the start of the project. This would have been useful because it may have given more observations as to how successful it is to have purely remote versus a blend of staff attending in person and remotely. It may also account for the lower level of technical issues reported in service user survey responses, as there was no need for service users or those supporting them to connect to the call. Only 11 service user completed surveys were received, so this small sample size should be taken into account when interpreting survey results.

Further survey questions would have been helpful to analyse the feedback from both staff and service users in more depth, for

example, how many surveys were sent to service users, so that the response rate could be calculated. It would have been useful to ask service users about technology issues in order for comparisons to be made with the staff survey, and also to ask the role of who was completing the service user survey (service user/carer/therapist).

Conclusion

There were concerns voiced from team members reporting more difficulties building rapport over a video consultation. However, it is acknowledged that there are some benefits to attending remotely, for example being able to resolve straightforward technical issues promptly on the video call. Reports of not being able to see the whole environment have been discussed, with strategies proposed to help, such as asking specific questions about the room and obstacles, or asking for a 'tour' of the space via the video consultation.

It is acknowledged that there is less opportunity for debriefs and discussions following remote consultations (where these have traditionally been done in the car or office). Informal learning opportunities are also less, without peer face-to-face working. This has been noted especially by newer members of the team and students on placement. Therefore, specific case discussion and reflection time has been scheduled via video conferencing, which has helped improve this.

Although there are challenges surrounding the use of technology, these can be reduced with careful planning and preparation. There are clear time and therefore cost savings where remote consultations can be employed.

Those attending remotely can assist with contacting companies or colleagues for support during a consultation, without interrupting the consultation. Colleagues can join the call if they are available where needed. There is also the capacity to offer shorter, more frequent consultations, for example for service users who fatigue quickly or who have reduced attention.

Relatives and additional carers have attended consultations where previously they may not have been able to due to physical distances and time constraints. This has resulted in greater collaboration to help achieve service users' goals. It has also facilitated relatives' understanding of KM CAT's work with their loved one. This has been particularly useful when attendance at care homes has been limited.

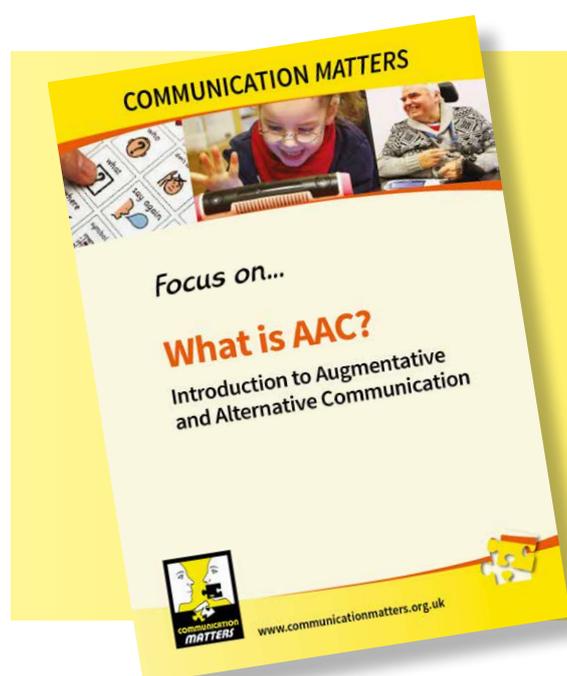
It is anticipated that KM CAT Adult team will take forward the best elements of remote consultations as a choice rather than a necessity, whilst continuing to refine the process to ensure the most effective way to deliver the most beneficial service to AAC users.

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‘What is AAC?’ Focus On leaflet

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CM is very happy to distribute these
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Achieving Independence: The Scandinavian Approach

BRYN MORGAN

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Abilia has had a presence in the UK for nearly 50 years, providing technology solutions to support people's independence.

The origin of the business was to develop one of the first digital communication devices, for people who do not have or have lost the ability to speak.

The Lightwriter SL50 has come a long way over the years but has kept its core values of simple and clear communication for all. Every element has been designed around users' needs, from dual screens and loud clear speakers to the user interface and word prediction - everything is focused on delivering speech as effectively as possible.

Quote from William

"What AAC means to me is that my communication is better, I am better understood and I am able to be independent."

"The ability to be able to contact my family and friends when I want to by mobile phone or text message makes me happy".

Abilia also delivers solutions for people with a physical disability, enabling them to control devices and appliances locally around the home and maintaining their independence.

GEWA One and GEWA Connect are environmental control systems that help users manage equipment in their own homes. Clients are able to control TV, music systems, lighting, bed functions, door phones and automatic doors.

We also have a successful NHS contract delivering Environmental Controls into specialised regional Hubs.

Abilia is also now supporting adults and children across the UK with our range of Cognition solutions, designed to support people who struggle with time perception, starting or planning tasks, memory and problem solving. We support people with Autism, ADHD, Learning Disability, living with Dementia, Acquired Brain Injury & Stroke rehabilitation at home, in education or at work.

We have a range of solutions, both low-tech and digital, that can be tailored to suit individual needs. Our digital solutions offer to family and support workers the ability to remotely support the user 24/7 through our web portal, myAbilia.

"AM began using MEMOplanner through a pilot project in Shropshire around 2 months ago. During the initial assessment AM specified that she wanted to become much more independent at home, whilst out with her friends and also wanted to become much more physically active, particularly when using her mobility scooter that she stopped using whilst in lockdown"

Results after 4 weeks:

AM is much more physically active

AM can now manage her medication due to the alerts

AM is able to manage her time around the house doing chores and reducing friction

AM is now able to see what free time she has to spend with friends outside

Please visit our website: www.abilia.uk for more information or to organise a demonstration.



Journey Towards A Total Communication Environment

LAURA WOOD

Specialist Speech and Language Therapist, David Lewis

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Laura Wood is a Specialist Speech and Language Therapist at David Lewis, a residential provision and college in Cheshire supporting people with complex needs including learning disabilities, epilepsy and autism.

Universal level input is support which is accessed by everyone across a service (Gascoigne, 2015). This level of support from Speech and Language Therapy (SLT) teams involves building knowledge and skills at a community level (Baker et al, 2010), and often incorporates elements such as training, delivery of groups, and other cross-site interventions. Another important element of universal level input is facilitating a good total communication environment – one which ‘values and uses all methods of communication so that everyone we support can communicate, understand and be understood’ (Sense, 2021).

It is widely acknowledged that the supportiveness of an environment can have a huge impact on a person with additional communication needs (Scope, 2004; Goldbart and Caton, 2010), however creating a consistent total communication environment can be a challenge in provision for people with a learning disability. In the SLT team at David Lewis, supporting the total communication environment on site has been a service priority for many years, and in 2019 we embarked on a specific project around this topic, with the aim of offering guidance and encouragement to create more supportive total communication environments across site. In particular, we were keen to focus on practical tips which environments could use proactively, both with support from our team and independently.

Challenges and opportunities

In approaching this project, we were aware that there were several challenges facing us in improving our provision’s total communication environment:

- **The number and diversity of different environments.** Overall we identified 30 different environments across the provision, including residential houses (both on site and in the community), school and college services, and amenities such as the on-site farm, café and shop, each with different staff teams, communication challenges and priorities. The varied environments presented a challenge if we wanted to encourage consistency in approach in every location our service users might access.
- **Existing demands on care staff time.** It was important to acknowledge the existing demands placed on care staff, as this was likely to impact on the success of any additional requests related to environmental support for communication. Any input around total communication environments would therefore need to be as easy and accessible as possible to implement, or risk failure.
- **Staff movement and turnover.** Natural staff changes within a team meant that long-term maintenance of a total communication environment could be challenging; information may not be shared between old and new team members, and responsibilities for maintaining the environmental supports may not be handed over.

Despite the challenges, we also knew that our existing service structure offered a number of opportunities which we could build on in order to promote total communication on site. These included:

- **An existing working party between the SLT team and registered managers.** This had been established in 2018 with the aim of working more closely with executive management on communication outcomes for the service. Having these existing meetings meant that we could work in a top-down way, and discuss plans and resources with staff having already achieved buy-in from their registered manager. It also meant that we could directly influence aspects of environmental support which could only be achieved by those at a management level, for example organising staffing rotas and encouraging attendance at training through supervision meetings.
- **Existing universal level support.** A number of whole-site approaches were already in place at the time of this project, including training packages and two regularly running groups (‘Sing and Sign’ and ‘Jabadao’). We had also completed a number

of single-environment total communication projects in the past, focusing mainly on environmental labelling and establishing specific interventions such as traffic lights. Having these established meant that staff were already familiar with models of universal level support, that all staff had a basic knowledge of total communication as a concept (from SLT Induction training) and that some environments had already made headway towards improving their total communication environment.

- **Existing communication representative programme.** Another aspect of universal level input on site was an existing communication representative (communication rep) programme. This involved identifying a designated staff member for each environment who was given additional shifts to maintain, repair, and replace existing communication aids for their service users. Reps were invited to a meeting with SLT every six weeks to share ideas and access additional training, and maintained closer links with the SLT team across the year. This programme was well-established, with some reps having been in the role for many years and having developed their skills and knowledge accordingly. It was incredibly helpful to have enthusiastic and knowledgeable staff in the environments who could support total communication from the ground up. However, feedback from newly-established communication reps highlighted that they sometimes felt overwhelmed, and shared that they were often 'unsure where to start'.

The 'Journey' document

The primary aim of the Journey document was to break down some initial steps environments could take to make it easier for good communication to flourish. The included steps drew from the principles of total communication (Hansen, 1980), as well as being shaped by Five Good Communication Standards (RCSLT, 2013) and feedback received from staff across the service. We designed the Journey document in a checklist format, providing clear steps to follow and hopefully answering the identified concern of 'I don't know where to start'. We also intended the new document to provide a single point of reference for each environment, meaning that new staff could easily see which steps of the Journey had already been worked on or achieved, and what they could work on next. While the Journey document is acknowledged to only be one part of the communication development of an environment, it allowed us to provide an accessible starting point, and to pursue consistency across all settings at David Lewis.

David Lewis Centre SLT Department
May 2019

david·lewis

The Journey Towards a Total Communication Environment

- Identify a Communication Representative for your house**
A Communication Rep is responsible for supporting the creation and upkeep of communication resources. Having a rep is vital to creating and maintaining a successful total communication environment. If your house has more than ten residents you may need more than one person in this role.
- Assign designated Communication Representative time**
The SLT team run 'Communication Rep Evenings' six times annually which all reps should attend. Reps should be out of numbers during this shift to support attendance between 4:30pm and 10pm. If reps are unable to attend a meeting, they should have access to a communication work shift at another time.
- Allocate a cupboard for communication resources**
Having a designated cupboard for communication resources supports management of risk when things get lost, and provides a space to keep spare symbols where all staff can access them when needed.

Figure 1 – 'Journey Document'

Initial steps on the Journey document focus on identifying a communication rep for each environment, and ensuring they are allocated appropriate time to complete communication work. We felt this was important to include early, as the identified communication rep would be integral to working through the remainder of the Journey document, and time allocated to this role was also key given the time pressures on staff in general. To support recruitment to the rep roles, we created a job description for managers to share, with the focus placed on support given in the role, and the opportunity for development of knowledge and skills.

The next steps on the Journey document offer practical tips and advice to make creating communication resources (e.g. photos, symbols, objects of reference) as easy as possible, and to make locating spare resources easier too. This includes identifying a dedicated space for resources, and ensuring each environment has easy access to symbol-making equipment. The Journey then builds on this by focusing on environmental visual supports, including labelling of rooms, and the creation of staff, activity and menu boards. The inclusion of this step was helpful as it allowed us to do some information-sharing around the different options for labelling, depending on the needs of the service users accessing each environment, reminding staff that visual support isn't 'one size fits all' and that the right kind of labelling is the one that best suits their service users' needs. These steps align well with Standard 4 from Five Good Communication Standards ('Services create opportunities, relationships and environments that make individuals want to communicate'), by aiming to embed meaningful visual supports into accessible and welcoming environments.



Figure 2 – 'Activity Board'

Building on this, the Journey document also encourages staff to consider using activity sequences to promote independence and daily living skills through the use of visual prompts. Existing symbol sequences (for example around hand washing, tea and coffee making and personal care) were made available by the SLT team and staff, and communication reps were encouraged to consider other activities where clear visual sequences could encourage independence.



Figure 3 – 'Symbol Sequence'

Later steps of the Journey document focus on ensuring staff have access to individuals' communication guidelines (e.g. communication profiles and protocols), and that they are given adequate time to become familiar with them. This also incorporates mention of access to symbol- and photo-supported documentation where appropriate, including accessible communication profiles and swallowing care plans. Encouraging attendance at SLT training is also included at this stage.

The final step in the Journey acknowledges the importance of maintaining of the total communication environment over time. Longevity of communication reps is integral to this, and managers were encouraged to support their existing reps and ensure they had time with SLT and for their communication work. It was also important to highlight that steps on the Journey may have to be revisited in order to support maintenance of the total communication environment.

Once complete, the rollout of the Journey document was planned in conjunction with the SLT/Registered Manager working party, and involved training sessions being offered first to residential managers and communication reps, then to team leaders, then to remaining staff.

Progress so far

Since the introduction of the Journey document to David Lewis, and the associated rollout of training sessions, we've seen initial progress in a number of areas. Numbers of communication reps have increased substantially, with all 30 environments now having an identified rep, and four of the larger houses having two or even three reps in post.

We've incorporated the Journey document into our six-weekly communication rep meetings, during which we encourage reps to share where their environment is up to on the Journey, and access help and encouragement as needed both from SLT and from other reps. Further feedback from managers has also prompted SLT to increase their flexibility around communication rep support, with schedulable slots made available outside of standard communication rep meetings if rota or staffing issues have affected attendance.

The project as a whole has also included us developing our SLT training calendar to best meet service needs, adding a number of new packages, including a 'Top Up' communication revision session and an InPrint 3 training package to promote symbol-creation skills. We also now plan and publish our training calendar for the whole year, to allow managers and staff to more easily plan training attendance in a timely manner.

Future plans

Covid-19 restrictions meant that some aspects of the project had to be put on hold, however with many aspects of input opening up again now, we're looking forward to making more progress with our Journey document project. Our next meeting with the SLT/Registered Manager working party has been scheduled for spring 2022 when we will be reviewing progress so far, and making plans for future project development.

Overall, this project has been effective in prompting us to think practically about how to achieve our total communication goals. Although only a starting point in the process, the Journey document has felt like a positive step forward, and a helpful part of our universal support toolkit. We're looking forward to building on this foundation in the future, working towards a consistent total communication environment for everyone who accesses our provision.

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Lockdown Learning: The ATmentor Way

ADAM LENARTOWICZ, SAM SILLARS

ATmentors

SALLY FEATON

ATmentor Manager

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Our award winning ATmentor Service started in September 2016 and is part of ATtherapy Ltd, which is an independent Speech and Language Therapy company. Our head office is based in the North-West of England, with outreach to all other areas of the UK.

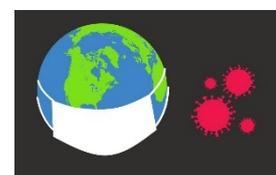


We have a team of highly competent AAC users whose role it is to work alongside our therapists and show mentees what is possible. They can work directly with individuals who use AAC, or they may deliver training to work with the team around that person.

The service has grown significantly over the past few years and the mentor role has become more widely recognised and established due to the positive outcomes we have seen.

Mentoring is a way to give that much-needed time and support to another person to help them make changes to their lives, and it is from someone that has that relevant life experience, who is able to understand from the position of that young person.

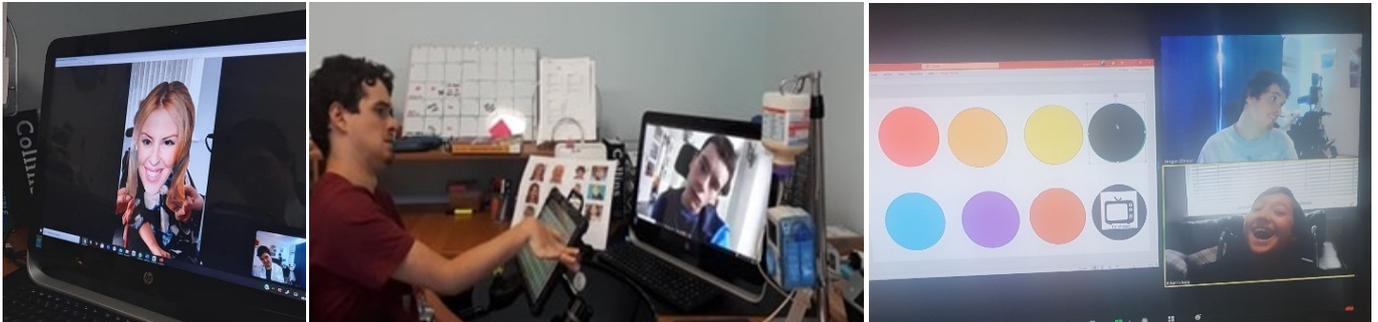
Prior to the pandemic, our mentors would travel to meet with their mentees regularly; maybe for a takeaway, coffee, pamper session or a bowling trip; some even went to a football match and on a trip to Alton Towers.



But then the world just stopped

We moved to remote platforms, such as Microsoft Teams, Skype and Zoom, from March 2020. We weren't able to do face-to-face sessions anymore, due to shielding and local lockdowns. Not only did this affect the mentees, but obviously this affected our mentors as well as they were classed as clinically vulnerable.

There were some mentees that this style of learning worked really well for, so remote working suited them brilliantly; they adapted and were able to progress. Here are a couple of pictures of examples.



Challenges

However, there were others who demonstrated they really disliked chatting on these virtual platforms. This particularly seemed to be true for some of our younger mentees and those with shorter attention spans. There were also challenges for those who were in very remote areas where the internet signal wasn't very reliable or for those who were not very confident in using technology.

Some of our mentees could engage using a remote platform once the ATmentor team had made some adjustments. This included modifying our communication style, clearer camera placements to ensure the mentors head, shoulders and AAC were in shot, and also increasing the volume from the voice output communication aid to improve intelligibility.

Even with these adjustments, it was still too difficult for some mentees and mentors to access and lots of non-verbal communication was missed so we had to think about ways around this. We concluded that there are many access barriers which can make the use of remote platforms difficult. Also, when carrying out mentor sessions remotely, there is a different set of social rules and etiquette which both mentors and mentees had to learn.

Positives

This hasn't all been doom and gloom... and we don't want it to come across that way! We are very pleased to say that, despite Covid and three national lockdowns, we were able to maintain contact with all of our mentees throughout the pandemic; despite the restrictions, the ATmentor team were still very busy! Remote working eliminated the need to travel in all the bad weather, particularly during the high winds, rain and snow in the winter.

We've ensured continued connections during a socially isolating time. We now have a wider geographical spread including London and Ireland and we are making strides to reach out and gain some mentees in Scotland too.

The mentors have connected more as a team, participating in service development and training and have been able to spend more time developing resources for the wider staff team and, more importantly than anything else, everyone in the team has stayed healthy and well.

Last year, Gregor did a presentation about how he had adapted to working remotely through the pandemic through using online platforms to connect to his mentees.

For our presentation this year we presented two case studies focusing on two mentees who had struggled to engage remotely.

Case study One: Luke.

One of the clients Sam has been supporting during this pandemic is 7-year-old Luke. Luke has been receiving support from our services since 2019. He has Cerebral Palsy, Epilepsy and he also uses a wheelchair.

Luke uses a Grid Pad 12 with a PC eye mini; he also uses paper-based communication boards with Supercore vocabulary content.

During the pandemic, ATtherapy felt that Luke would engage best with short videos instead of live sessions over Zoom. This is because of Luke struggling to maintain his attention and listening skills and his seizure activity being sporadic.

Luke's aims were to work on using his AAC more confidently to express himself effectively; this included making requests, asking for help and expressing his emotions.

The first video was shared of Sam sending a video directing questions to Luke about Christmas presents and asking about his pets, for him to respond to.

In a session with his Speech and Language Therapist, he was able to choose what items he wanted to talk about; these were then programmed into his device and filmed to send back.





He wrote a letter (and got messy with glue and symbols), stuck everything down on the paper, and then off the letter went. It was only after he got the next video from Sam – the [Pizza video](#), that these ‘mentoring’ videos started to come to life for Luke. He suddenly saw the letter he’d sent on video and he was so excited.



This inspired Luke to engage in messy play activities and he wanted to create his own video to send back to Sam.



These videos have helped Luke’s involvement greatly in mentoring sessions. It is clear to see the level of engagement increasing through the videos and how confident he is in expressing himself.

He is becoming more confident in using his AAC and it is believed that Sam’s pre-recorded video input has helped significantly with this.

Sam believes that mentoring through videos is a valuable tool as it engages younger children who might struggle with virtual online sessions. Luke has responded so positively to this method of mentoring and always has a huge smile on his face when he responds.

All of these videos have now been programmed onto Luke’s communication aid and he now regularly chooses to watch these over other video options that he has access to on his device.

Case Study Two: E

Adam’s mentee lives in the North-East and is a 19-year-old Autistic young man. He started receiving mentoring support from us last autumn in response to his increasing need to have someone to talk to who was new and outside of his support network.

Due to the nature of his Autism, he finds new environments really stressful and has anxiety about meeting new people. We consequently felt he wasn’t going to cope with having live mentoring sessions over platforms like Zoom.

Instead, we decided on sending in pre-recorded videos of Adam using his communication aid and giving speeches on subjects such as how to increase your efficiency when using saved phrases, or how long it takes to have a conversation when you are using spelling. The latter was to address one of his key aims; developing patience when using letter-by-letter input.



Pre-recorded mentoring sessions allowed him to engage with support at his own pace and slowly gain confidence in talking to Adam.



As sessions continued, E became more confident and participated more in the video content. He has been confident enough to ask questions using his device, his level of eye contact has increased and he is now also able to have live video chats.

Since filming the conference video, there have also been discussions about meeting up in person in a familiar location.

In Conclusion...

So, will we continue to use videos after the pandemic?

The short answer is YES! Even though we are going to be returning to face-to-face, there is still a place for all the different forms of input we provide.

Lots of things have been learnt through lockdown; we've responded well, and we have adapted to the needs of our mentees and we have found new and innovative ways to continue our input with the mentees we work with.

Use of pre-recorded videos has taken away some of the problems that can be encountered online, such as Wi-Fi issues, background noise or the needs of the mentee at a particular time.

The use of videos has helped the mentors to manage their workload and inspired future ideas within the team. The mentors have found them increasingly easy to make; ensuring they are focused and personalised for the individuals whilst keeping them very creative and age appropriate.

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Schematic-taxonomic grid layout in high-tech Augmentative and Alternative Communication for adults with a Learning Disability

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DR JEFF COLLISON

Adviser

Introduction

The use of technology is changing all our lives in countless ways. Yet for adults with Learning Difficulties (LD) the benefits of this through the use of Augmentative and Alternative Communication (AAC) have met with slow uptake and high abandonment rates. For example, research by Stancliffe et al in 2010 showed that less than 1% of LD participants used aided AAC as their primary means of expression. My own work within the adult LD community in more recent times confirms that significant barriers remain to uptake. This article explores one major barrier and proposes a different way of organising information presented to adult LD participants, and evidences how this schematic-taxonomic approach has been used to good effect with several previously non-verbal clients.

Most contemporary AAC systems for adults with LD utilise an information interface based on the semantic-syntactic approach. For example, Proloquo2go (AssistiveWare, 2021), Liberator's TouchChat (Prentke Romich Company, 2021) and GRID 3 Snap Core (Tobii Dynavox, 2021). Such systems combine sense or meaning of words (semantics) within a basic sentence structure (syntactics) to communicate the desire (See Figure-1).

With this design, the phrase "*I want chocolate*" involves the selection of the appropriate pronoun, verb, and noun (syntax) from the visual grid to generate the sequenced output that conveys meaning. Words not readily accessible have to be retrieved through a process of intelligent deduction to determine what category they may be found in (semantics). These systems work very well for many people who lack verbal communication because they mimic natural language processes, and indeed their use with paediatric clients may be doubly beneficial as they also encourage the development of language skills.

This approach, however, raises issues and obstacles when used with adults with LD. This became very apparent to me working with such individuals and was the trigger for me to seek a better approach.

So why is a language-focused approach inappropriate for many adults with LD?

It is widely recognised that language development plateaus in adulthood as the stimulus of the education environment recedes (Rosselli et al., 2014) – this may be particularly so for adults who have had less opportunity to actively engage in conversation. Also, the process of encoding and retrieving the component parts of a communication can be an area of difficulty for many adults with LD (Thistle & Wilkinson, 2013). The distracting nature of this process may indeed result in them forgetting the reason for the communication before it has completed. Problems may arise when the particular word that the individual has in mind is not offered as a choice. Substitution with another word or phrase may represent a problem-solving issue that is beyond the capacity of the individual (Light & Lindsay, 1991), who may simply retreat from the interaction. Even verbal adults with a LD often have issues with sentence construction and grammatical misstatements (Van Der Gaag, 2009). Furthermore, the intelligent predictive nature of many semantic-syntactic AAC systems – aimed at speeding communication – creates a changing and unpredictable interface, too complex for many adults with a LD, who depend on predictable information positioning (Government Office for Science, 2020). All of this begs the question as to whether a language-based approach is appropriate for adults with LD, or whether it introduces additional barriers to effective communication.

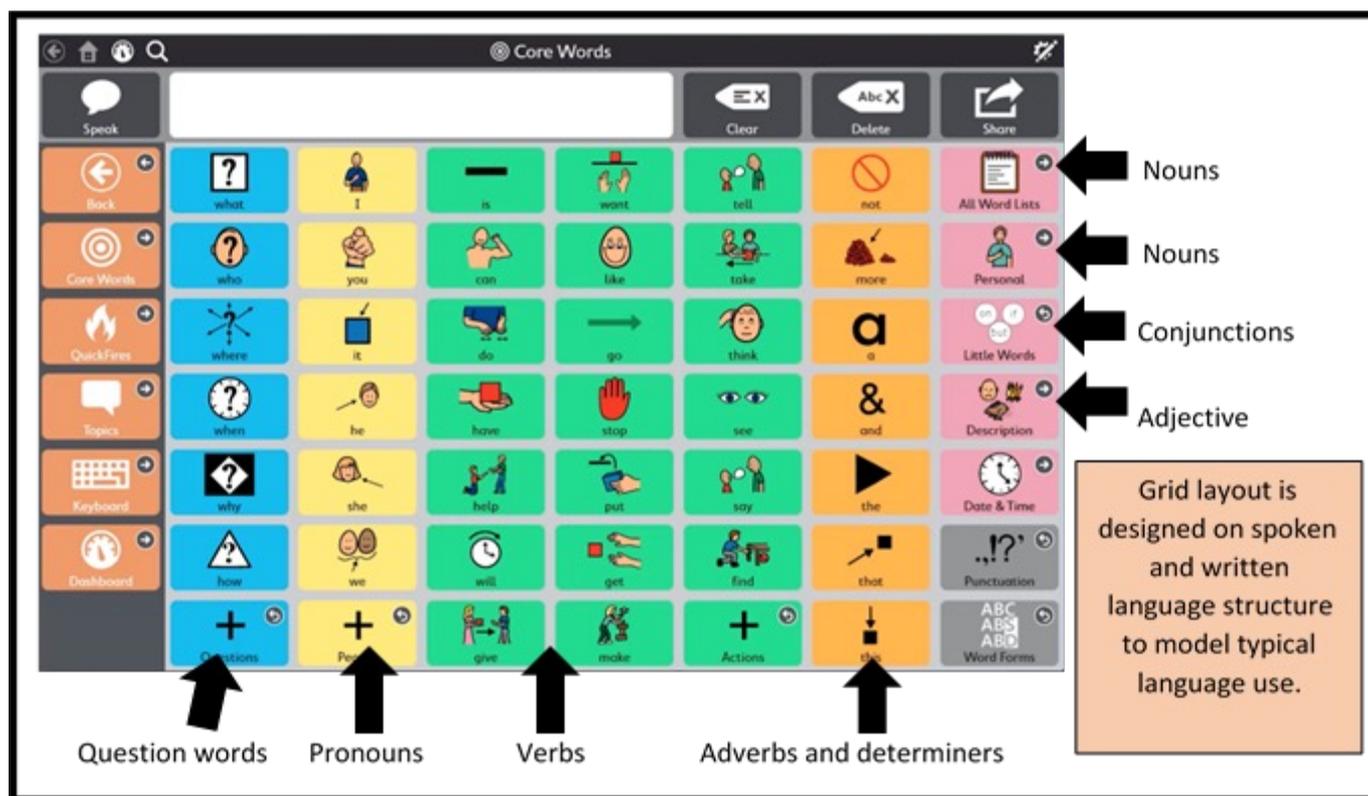


Figure 1: Semantic-syntactic layout of GRID 3's Snap Core first

So where to start in seeking an alternative approach?

Much of the communication experience of adults with LD is organised contextually rather than linguistically (Van Der Gaag, 2009). They are accustomed to pointing or using gestures to indicate desires. These are 'in the moment' actions, the meaning of which is derived from the immediate context. It is these findings and my observations of real but frustrated clients that has caused me to seek a solution for organising the information interface that is heavily context-based, taking its cue from the current location, desired activity or category of interest. This thematic focus is reflected in naming it a schematic-taxonomic approach. In a formal sense, the information interface displays icons that allow the user to access a mix of schematic and taxonomic features: the schematic icons facilitate a particular activity or engage with an environment, e.g. "Getting ready", whilst taxonomic icons access information or vocabulary that relate directly to the selected category, e.g. quick access to food items, objects or people in their environment. From the user perspective, the system enables a richness of 'in the moment' communication that previously eluded them.

It was this realisation that a schematic and taxonomic approach might offer advantage that prompted me to work up a trial system built on Grid 3@ for one of my clients. The capability that this enabled for her encouraged me to expand the use of this approach to two other clients in the following few months. These were all adults with LD in the age range 20 to 30. All were non-verbal at the point of referral, with pointing gestures and the capacity to indicate yes or no. They also embodied a variety of additional conditions, including Down syndrome, autism, epilepsy, head injury and stroke. It is also important to note that these clients displayed a variety of levels of access. One individual was reliant on auditory scanning with a switch due to visual impairment, another had limited movement due to periodic and partial paralysis, whilst the other had good visual acuity and physical dexterity. So, this approach has been trialled across a range of ability and access levels and has worked well for each of them.

What does this approach look like in practice?

Figure-2a shows the typical "Home" screen for a schematic-taxonomic GRID layout, indicating the top-level schema. Take a look at the range of entry point icons available to the client. You can for example start with where you are via the "Locations" option, or something you would like to do, or to eat? Or maybe you would like to talk about yourself via the "About me" option? All of my clients have really enjoyed accessing "About me" and being able to introduce themselves and say what they like. Selecting any of these will display a new group of context-appropriate options.

Next, let's choose "Getting ready". This presents the display shown in Figure-2b.

The options now available cover the range of activities associated with getting ready, including colour choice! Choosing "Make-up" reveals the options shown in Figure-2c. (Icons revealing further options have a triangle in their upper-right corner.) Notice also that there are a set of fixed icons that appear on the right of all the screen layouts, building familiarity with basic functionality.

The options in Figure-2c are all very practical things – for example, there's a directional icon which allows the client to feed back to a carer about positioning of the make-up being applied. All the information and options relating to doing make-up are co-located here. And if there is a need for conversation on the topic, selecting "Make-up conversation" reveals a variety of statements

such as “I need a mirror” which will be spoken by the system when selected (Figure-2d). What a joy it was to see this young client being enabled to make known her preferences or wish to experiment with her make-up for the very first time!

The use of this system is not only functional in its benefits, but relational also. In a further example, a young non-verbal autistic man had shared in Lego building with his dad over a long period, but this was a silent activity. His dad reports that using this system (see Figure-3) has made a phenomenal difference to their shared activity, facilitating conversation about the models they are building together, and developing the son’s language skills in doing so.

A feature that has brought so much pleasure is the “My Lego” icon. This enables selection of photos of models built by himself or with his dad – pictures uploaded from a phone. My client can now take independent control of showing others what he has built! This easy-to-use tool has done so much to change the relational environment within this home. Other features that have been game changers for my clients have been the integration of this system with Alexa© and also with TV control for someone unable to use a normal remote control. For the first time, these clients have been able to select music of their choice (or turn off music that is not to their liking!) or similarly, select their preferred TV channel.

Additional considerations

Ease of maintainability is always a vital consideration in such systems, and particularly so for this approach which relies on up-to-date contextual scenarios. A key feature of this system is that non computer literate parents and carers have found it easy to add additional features and categories, when supplied with a basic system and training. One mother who initially shared that she knew nothing about computers is now independently adding to her son’s communication device with ease. The simple thematic structure means that it is quite obvious where additional elements should fit in the system – e.g. adding pictures of family members or visitors, adding new shopping items or introducing new conversational phrases into an appropriate context. Yet the availability of someone(s) who will periodically update the system content is something to be considered when deciding on this approach.

Another feature of the design of this system is the consideration given to those with visual perception difficulties. High volume of visual content, high contrasts, inappropriately spaced buttons and sharp lines are all features that can disrupt visualisation for LD clients with co-occurring visual processing difficulties (Wilkins, 1995). It will have been noted that the design approach used here offers a reduced level of information loading on any given screen – facilitated by the context-driven approach, greater separation of the individual icons, softening of the icon corners, carefully chosen soft colour palette, and maximising the constancy of location of icons on the screen. To some these may seem minor considerations, but from personal experience I know the difference that careful attention to such matters can make.

Figure 2a: Schematic-taxonomic home page

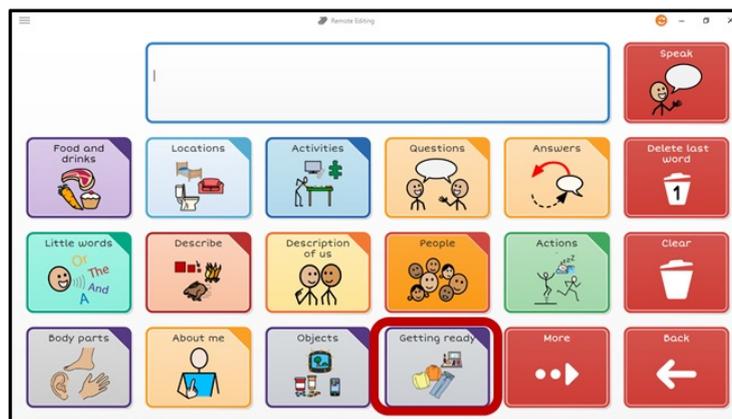


Figure 2b: Schematic-taxonomic getting ready page



Figure 2c: Schematic-taxonomic make-up page

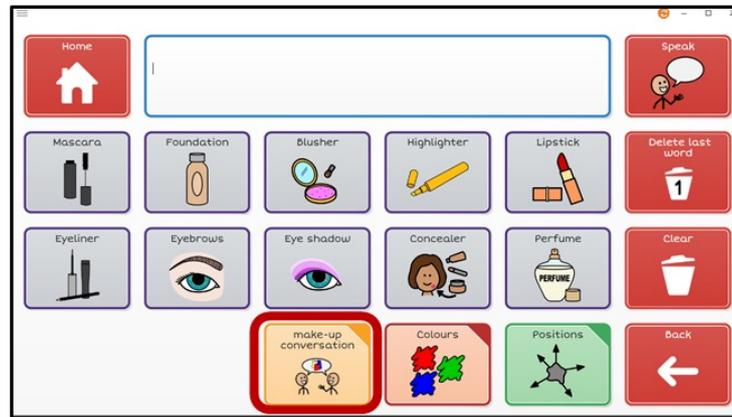
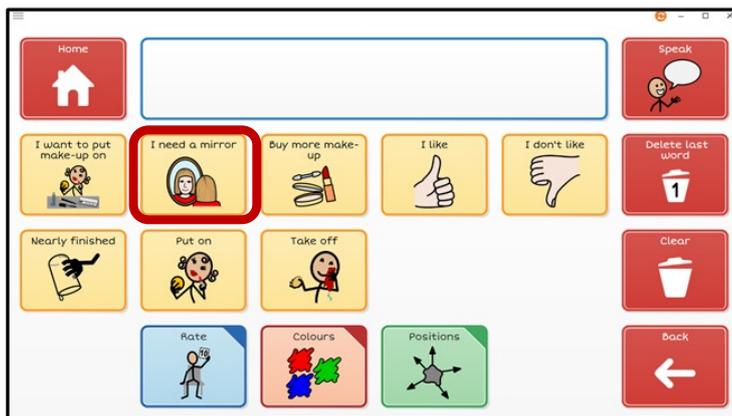


Figure 2d: Schematic-taxonomic make-up conversation page



Conclusion

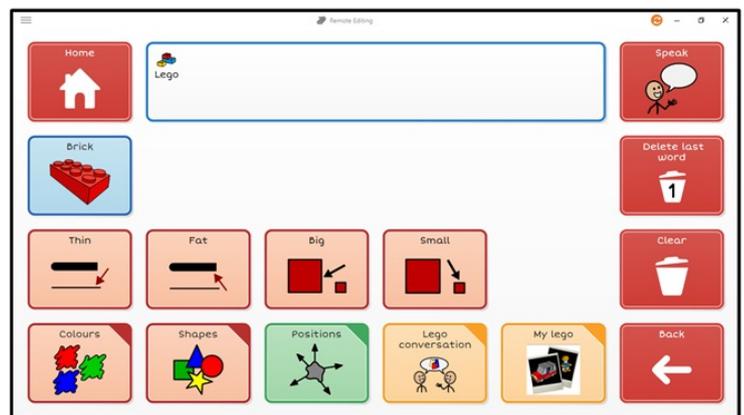
The development of the schematic-taxonomic system approach has greatly enhanced AAC usability for some of my clients and has also hugely enhanced my job satisfaction in seeing new communication flourish. Its distinctiveness lies in being contextually organised, removing the veil of language-based processing that some find obstructive, and in doing so reducing the cognitive demands of communicating. Conversations can be more readily maintained, with more pacy interactions as contextually appropriate sentences are preformed rather than having to be constructed, with benefits to both functional and relational communication, as has been evidenced.

My hope is that the positive results I have seen from adopting this schematic-taxonomic approach will inspire you to actively consider applying it yourself in appropriate contexts.

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Figure 3: Schematic-taxonomic Lego page



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Embracing diversity in clinical practice – Key strategies to support individuals with complex communication needs

STEPHANIE EKIS, MS CCC-SLP

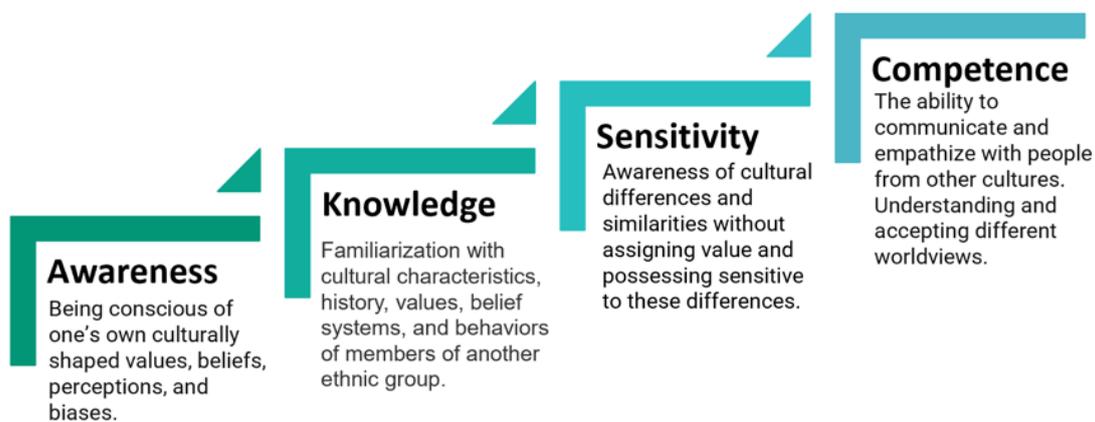
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Individuals with complex communication needs (CCN) who use augmentative and alternative communication (AAC) are particularly vulnerable to a lack of inclusive practices. For Speech and Language Therapists (SLTs) who support individuals with CCN, key considerations related to diversity, culture, and representation should be critically reviewed during the evaluation, treatment planning, and implementation process.

While there is a growing pool of research that supports the use of AAC to support language and literacy development, social skills learning, and academic success, little research is available that addresses the linguistic and cultural needs of this population (Kulkarni and Parmar, 2017). If we consider the shift in recent trends of racial and ethnic distributions of school students (gov. uk, 2021), the importance of understanding the perspectives of culturally and linguistically diverse families becomes even more compelling.

With heightened awareness and sensitivity to the importance of diversity, cultural, and linguistic competency, many SLTs have been compelled to evaluate how diversity is recognised in their own clinical practice. Cultural competence is the ability to think, feel, and act in ways that acknowledges, respects, and builds upon ethnic, sociocultural, and linguistic diversity (Lynch and Hanson, 2011). The process of becoming culturally competent is ongoing and will require SLTs to recognise what they don't know about the diverse communities they serve and to do the work to increase their knowledge in these areas.



Levels of Cultural Competence (Lynch and Hanson, 1998)

To better understand the unique needs of AAC users with diverse linguistic and cultural backgrounds, a group of Speech and Language professionals was pulled together to participate in several roundtable discussions. This group represented the African American, Indigenous, Latino, and South East Asian communities in the United States. The goal was to create a safe space, where participants could discuss difficult topics around race, representation, and clinical practice for marginalized communities. The results included a list of specific considerations.

The following list outlines the lessons learned during the round table discussions:

Lesson learned 1: White should not always be the default.

Examples:

- Common symbol-based and pre-made AAC language systems use symbols that lack diversity.
- Representation of diverse cultures and ethnicities is often not available in commercially available therapy supports and materials.
- Marketing materials (e.g., websites, catalogs, etc.) lack diversity.

Lesson learned 2: Be mindful of the photographs you use in therapy materials.

Examples:

- Avoid photographs that depict marginalized communities in stereotypical ways.
- Children and adults need to feel like they are represented.

Lesson learned 3: Pay attention to subtle negative messages in books and therapy materials.

Examples:

- Racial stereotypes when depicting people of color.
- Marginalized communities always depicted in low paying jobs.
- Dark colors (e.g., black and brown) described as bad or wrong.

The roundtable lessons learned were used to create a set of tangible action items to help SLTs better support diverse caseloads.

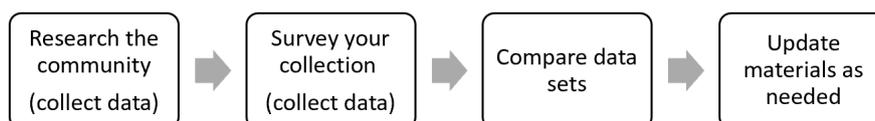
Action 1: Complete a self-assessment to determine your cultural and linguistic competency.

A crucial component of moving toward cultural competence is the ability to self-assess to identify one's own biases. This can help identify and address the inequities that may occur in service delivery (Kinsey, 2013). These types of self-assessments are readily available online. Examples of self-assessment questions might include (Goode, 2009):

- I display pictures, posters and other materials that reflect the cultures and ethnic backgrounds of children and families served in my early childhood program or setting.
- I select props for the dramatic play/housekeeping area that are culturally diverse (e.g., dolls, clothing, cooking utensils, household articles, furniture).
- I ensure that the book/literacy area has pictures and storybooks that reflect the different cultures of children and families served in my early childhood program or setting.

Action 2: Conduct a diversity audit.

Conducting a diversity audit will allow you to review the books, materials, assessment protocols, toys, etc. that are regularly used when providing therapy services. This process is to ensure that you are using materials that truly reflect the communities you serve (Roos, 2020).

**Action 3: Review representation on AAC systems.**

Reviewing the AAC system for cultural and linguistic appropriateness is another important activity to complete when supporting diversity in clinical practice. The goal is to make sure the AAC device content, symbols, vocabulary, etc. truly reflect the person using it.

Problem: The symbols do not represent the AAC user, the people they love, or the things that are important to them (e.g., holidays, food, culture, etc.).

Solution – Some AAC systems have the ability to change skin tone on people symbols. If appropriate communication symbols aren't available, use photographs. Most high-tech AAC devices have a built-in camera or the ability to import photos.

Problem: No access to bi-lingual or multi-lingual vocabulary sets and speech synthesis.

Solution – Many high-tech AAC devices provide the ability to use multiple languages and switch between them.

Action 4: Collaborate, train, and support culturally and linguistically diverse families.

In a survey by Parette and colleagues (2006), it was revealed that families across all ethnic groups want to be involved with professionals in AAC decision-making. However, there may be several barriers that impede success. For example, language and cultural barriers between parents and professionals, communicative limitations of the AAC device, irrelevant vocabulary, culturally inappropriate symbols and messages, and lack of culturally and linguistically accessible, family-centered instruction for device use at home were identified as specific challenges (Kemp and Parette, 2000).

Action 5: Advocate for change and educate others.

Due to recent events and the increase of individuals with ethnic and minority backgrounds on our caseloads, it is necessary for us to move towards higher levels of cultural competence. While many recent advancements have been made to better support AAC users from culturally diverse communities, much work still must be done. Do your part to help!

- Contact AAC device manufacturers to request more diverse symbol sets (or the ability to change skin tone, hair color, etc.).
- Contact commonly used therapy material developers and request better representation of cultural and linguistic differences.
- Request voices that better represent dialect and linguistic differences.
- Ensure that your school or agency is moving toward cultural competence.
- Share what you have learned with others.
- Be an advocate for diversity, equity, and inclusion for all people.

It may be uncomfortable at times, but if we approach the topic of diversity with an open mind and an open heart, we will be able to make a significant difference in the lives of the people we serve.

"Do the best you can until you know better. Then when you know better, do better."

Maya Angelou

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BOOKING NOW OPEN!

Partner Assisted Scanning, Oh My!

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When a person is unable to physically touch the items or symbols that they want to express themselves, it can be difficult and overwhelming to know where and how to start. For people with complex communication needs, alternate ways of indicating their message may be needed, such as scanning through options and making selections by pressing a switch, single message communication device, or indicating yes/no in some way.

In Partner Assisted Scanning (PAS), the communication partner offers options and waits to see how the person will respond. A smart partner reads the person’s communication signals to help problem solve in the moment and support communication development.

Terminology

As we begin to explore Partner Assisted Scanning, let’s define some key terms in scanning.

Term	What it means
Linear scanning	Options are presented one at a time. The partner waits for the person to respond with some form of yes/no before moving on to the next option.
Group scanning	Options are presented in groups. Each group is usually given a name and the name of the group is said to the person. The partner then waits for the person to respond with some form of yes/no before either moving to the next group or saying the items in that group.
Auditory scanning	The partner says the options. There is no visual information for the person.
Visual scanning	The partner points to each option/group and waits for the person to indicate yes/no before responding or moving on to the next option.
Auditory plus visual	The partner says the options and points to or shows symbols/visuals to the person. The partner waits for the person to indicate yes/no before responding or moving on to the next option.
On the fly	The partner offers options spontaneously, often related to what is happening in the moment.
Consistent system	All partners offer options in the same way and order. There is usually a script and directions for partners on how to support the person. The vocabulary is also consistent across situations and activities.
Parallel programming or parallel pathways	There is more than one system of communication, such as a speech generating device and a paper-based system. The two systems build different skills but both support communication.

Getting Started

With the information above in mind, let’s explore more about how to start from the beginning for emerging communicators. When starting PAS, I follow the following steps:



- 1 Determine initiation: How will the person initiate communication? Will partners respond to sounds the person makes, a specific movement, etc.?
- 2 Yes/no response: How the person will indicate yes/no or accept/reject the options presented. We as smart partners may need to watch carefully and respond consistently to behaviours that may be the person indicating preferences, whether they intend them to be communicative or not. Sometimes, there is a change in breathing rate, a change in body posture, a small change in facial expressions, a reach, a smile, a push away, a turn away, or a frown. Other times the signals are clearer, such as the person nodding/shaking their head, pushing items/pictures away, an obvious smile/frown or the person saying a form of “yeah” or “no”. We learn to watch for these cues and respond to them. Over time, they are likely to become more consistent and easier for others to understand.
- 3 Become a smart partner. According to Gayle Porter and Linda Burkhart’s PODD trainings, good communication partners:
 - Problem solve challenges
 - Adjust pacing of scanning
 - Read nonverbal cues of person
 - Interpret movement
 - Use context clues to support understanding of the intended message
 - Adjust the interaction
 - Offer the options for more than one cycle of offering each option and waiting for a response
 - Give the option of “more to say” or “all I have to say”
 - Give the option of “none of these”
 - Are comfortable with silence/waiting
 - Have a white board or paper/pen handy to write down the messages, especially if it takes a while to form so that the partner doesn’t forget
 - Are consistent
 - Limit their own talking to navigating the system or responding to the person while scanning
- 4 Scan type: What type of scanning pattern will be used?
 - Does the person use their vision to gain information? If so, use a form of visual scanning
 - Does the person only rely on auditory information? If so, auditory only may be an appropriate option
 - Does the person understand group scanning? If not, use linear scanning but probe group scanning periodically since it is faster and will be more efficient over time
- 5 Language organization: how should the language be organized? There are many ways to organize language. If the person has a dynamic display communication device, it is often helpful to organize the PAS system to support learning the pathways of the dynamic display system. If that isn’t practical or possible, then stakeholders should look to other systems. It is important that a consistent system be developed over time. When only using scanning on the fly, the person cannot begin to learn the options and is limited to the choices being presented by the partner. Consistent systems should have:
 - Multiple communication functions
 - A consistent organization of words/vocabulary
 - As robust a vocabulary as the person is able to access
 - The ability to support language growth
- 6 Communication growth: how will the system support communication development and autonomous communication? We as stakeholders should be supporting people to communicate what they want to say, where they want to say it, how they want to say it, to who they want to say it (Porter, 2006). That is the heart of autonomous communication. As part of this, it is important to offer, “More to say” and “That’s all I want to say” as options for the person, to help the partner know if they have more to say or not.

Parallel Programming

Following the steps above, you can establish a consistent system for PAS and support communication development. If the person also has a voice output communication device, it is important to plan parallel programming as well. In parallel programming:

- A paper-based system is often set up similarly to a Speech-Generating Device (SGD)
- For people using alternate access methods on the voice output communication device, the paper-based system is often accessed through PAS
- Motor demands are lowered since the systems are used flexibly and responsively
- Learning the pathways on both the paper-based and voice output systems is supported

- Can be used in a wide variety of activities
- There is consistent vocabulary presentation

By using both PAS and a voice output communication device, the person is able to build communication autonomy and independence in a supportive manner. The cognitive and motor demands can be lowered by partners as needed with PAS. The person should also have opportunities to practice their access method for their voice output communication system in low-cognitive and low-linguistic activities to support motor automaticity. By supporting motor learning and cognitive/linguistic learning separately and then together, we can support the skills needed to use a robust communication system.

Summary

Partner Assisted Scanning can be an effective way to support communication autonomy for people who cannot directly touch/select on a communication system and for whom natural speech cannot meet their daily communication needs. Having a consistent system presented in the same way by multiple partners builds the skills needed for autonomous and independent communication. When the person also has a voice output communication system, it is important that the pathways of all systems support each other (parallel programming). They do not need to be identical, and often aren't since the nature of PAS is different than a voice output device. However, parallel programming provides consistency in systems and supports communication development over time.

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iPad...or not to iPad. Has there been a change in the AAC landscape?

MARIANNE DOWLING, ANNE ADDISON, KIM BATES, EMMA DOHERTY

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Introduction

The Augmentative Communication Service (ACS) at the Great Ormond Street Hospital (GOSH) is one of 15 specialised Augmentative and Alternative Communication (AAC) services in England. Our service provides specialist assessment and AAC equipment for children and young persons (CYPs) with complex needs under the age of 18 years. AAC refers to a wide range of techniques, equipment and systems that can aid, supplement, or replace spoken communication. Over the years, we have seen an increased use of iPad for AAC equipment within our service.

In order to explore the reasons behind the numbers, we conducted a service audit on our equipment provision between 2015, when the ACS clinic was first established, to 2021.

Equipment Count

The ACS issued 227 AAC devices to 197 CYPs between April 2015 and June 2021. Our records showed that the clinic has been using more iPads in recent years, with a particularly significant increase in 2018 (Table 1). The number of iPads issued by our service jumped from one iPad in 2015, to 25 iPads in 2018. The number of iPads used remain high year after year. By 2021, 25 iPads had already been issued within the first 3 months of the financial year.

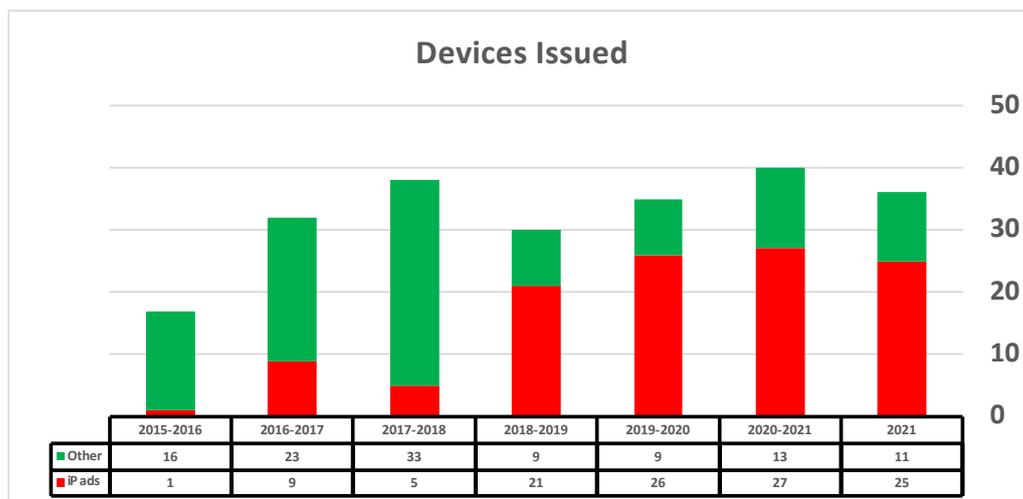


Table 1 – Devices Issued between 2015-2021

Referral Diagnoses

Next, we looked at the diagnoses of CYPs on our caseload. We wanted to explore whether there were changes or patterns of diagnoses which might help us to understand the increase in iPad use (Table 2). We categorised the diagnoses into seven groups: i) Autism Spectrum Disorder; ii) Cerebral Palsy; iii) Motor Disorders; iv) Acquired Brain Injury; v) Neurological Conditions; vi) Genetic Disorders; and vii) Metabolic Disorders. Our data showed that there were fewer CYPs with Cerebral Palsy in 2015 – 2017,

compared to 2018-2021. There was also an increase of CYPs with diagnosis of autism on the caseload in most years. However, we found that these patterns were not very helpful in giving a clear picture of the caseload or the overall profiles of the CYPs. Many CYPs had multiple diagnoses, for example: cerebral palsy and autism, or a metabolic condition with movement disorder. Any two persons with the same diagnoses can present very differently. We concluded that we needed another measurement tool to help us understand the patterns we were seeing.

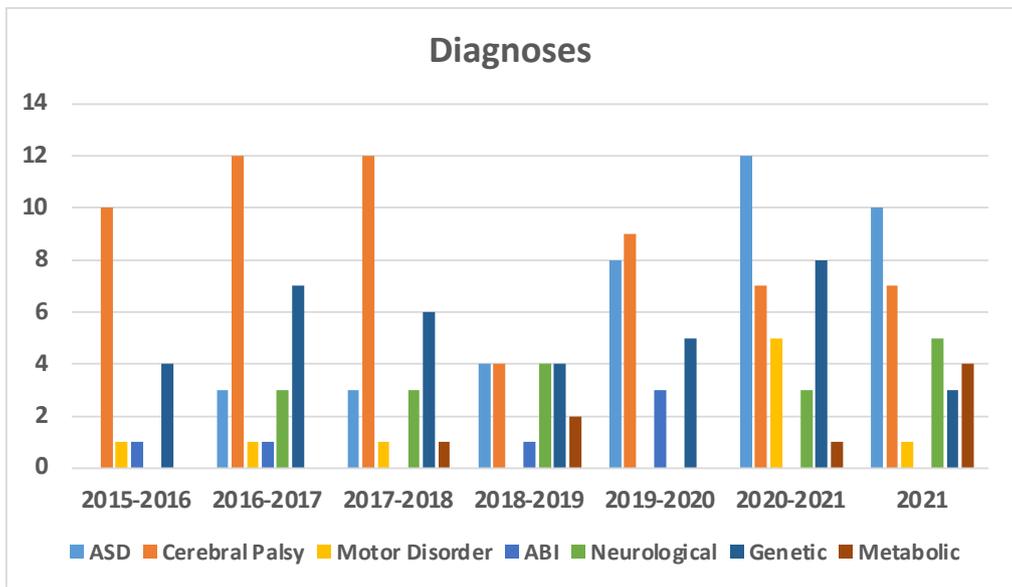


Table 2 – Diagnoses of CYP between 2015-2021

Manual Ability Classification System (MACS)

The Manual Ability Classification System (MACS) was developed to classify how children used their hands when handling objects in daily activities (Eliasson et al, 2006). Although the tool was initially designed for children with cerebral palsy, we wanted to use the classification system as a descriptive tool to categorise a child’s typical manual performance, taking into account the collaborative use of both their hands together (Table 3).

MACS Levels	Descriptor
MACS I	Handles objects easily and successfully.
MACS II	Handles most objects but with somewhat reduced quality and/or speed of achievement.
MACS III	Handles objects with difficulty; needs help to prepare and/or modify activities.
MACS IV	Handles a limited selection of easily managed objects in adapted situations.
MACS V	Does not handle objects and has severely limited ability to perform even simple actions.

Table 3 – MACS Levels Descriptors (Eliasson et al, 2006)

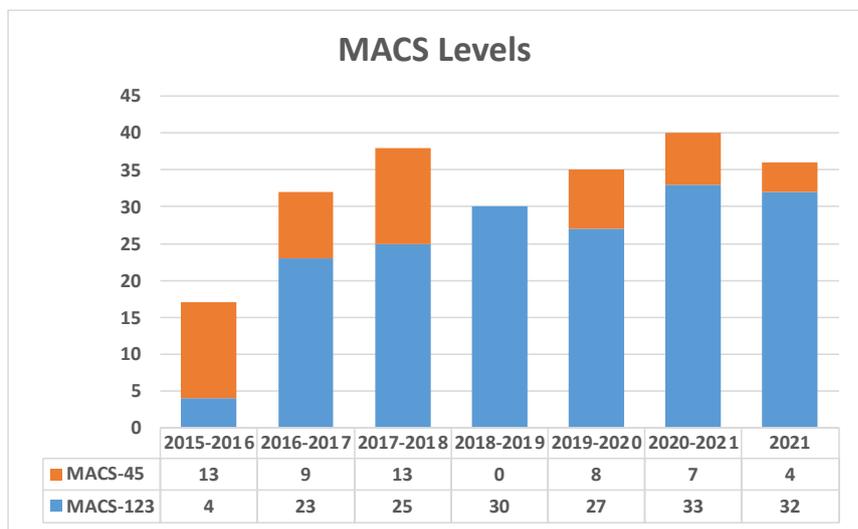


Table 4 – Retrospective categorisation of CYPs by MACS Levels

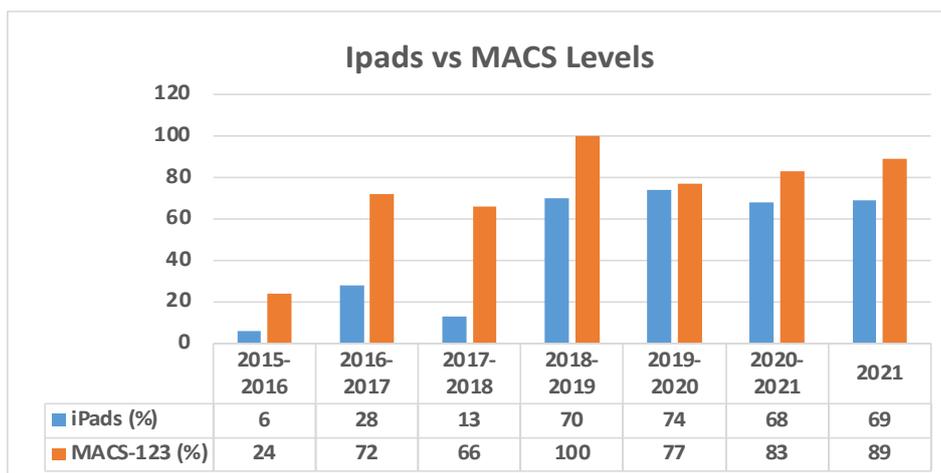


Table 5 –Number of CYPs with MACS 1/2/3 (in percentage of all CYPs per year) against number of iPads issued (in percentage of total devices issued per year)

We assigned MACS levels to every CYP retrospectively, using information from our file notes. Next, we split the caseload into two groups based on their MACS Levels (Table 4):

- CYPs with adequate hand function to operate a touch screen device (i.e. MACS 1-3), and;
- CYPs who would struggle to operate a touch screen device due to more limited hand functions (i.e. MACS 4-5)

We had hypothesised that the prevalence of iPad use might correlate to the number of CYPs with MACS Levels 1-3, but to our surprise, that was not the case (Table 5). Although there were more CYPs with MACS 1-3 compared to MACS 4-5 in every year since 2016, iPads only accounted for a minority of devices we issued between 2015-2018. iPads only became suddenly popular from 2018 onwards.

More iPad Use

There was a low level of iPad use prior to 2018, despite a consistent level of children with adequate hand function to operate touch access devices. A possible explanation to the sudden increase of iPad use in 2018 may be due to the development and launch of more communication apps in the market at that time. Perhaps more children were using iPads because there were more apps available at that time. The shift could also be driven by quality rather than quantity. Recent developments in communication apps had led to more features being available on iPad platforms. Some older models of dedicated communication devices have also been discontinued. The sudden rise of iPad uses might have been influenced by overall changes to the range of hardware and software in the market.

The shift towards more iPad use impacts on how we use our time within the AAC service. Typically, we’ve found that setting up an iPad as an AAC device for a CYP takes more time than setting up a dedicated communication device using other operating systems. The process involves multiple steps: e.g., setting up dedicated email accounts and phone numbers to be linked to the iTunes account, while complying with General Data Protection Regulation (GDPR) requirements. We found that we were also spending more time maintaining and repairing iPad devices. A family might contact us for example, if they were accidentally locked out of their account or device, or if their iPad screen was damaged. They might also contact us if the communication app was deleted, or if they made changes to their settings unintentionally. Technical support requests often fell broadly into three categories: i) hardware, ii) iTunes / Apple related issues, and iii) issues related to specific communication apps. While many manufacturers of dedicated AAC devices provided some form of after-purchase care packages, there was often no equivalent packages for iPads. As a specialised AAC service, we were often asked to provide frontline technical support to families and local teams using iPads for AAC. The provision and maintenance of iPads within our service has impacted on how we have used our clinic time.

More Questions: Preferences and Clinical Decisions

Between April 2018 to June 2021, CYPs who were able to operate a touch screen communication device were more likely to be provided with an iPad (over other touch access devices) by our service (see Table 5). However, the possible reasons behind this pattern are not obvious. Was this trend due to the child’s or parental preference? What were the reasons for this preference? Perhaps there were other factors that influenced the use of iPad over other touch access devices? These were some questions that the current project raised but was unable to answer. It would be interesting to explore these topics further in future projects.

Summary

Has there been a change to the AAC landscape? From our service’s limited experience: yes. The use of iPad has become more prevalent in recent years at least within our service. The rise of iPad use within our service has also changed how we use our time and clinic resources. The reasons behind the shift towards iPad over other devices are not obvious. The factors influencing this trend may be complex and interlinked. A better understanding of these factors could help clinicians to provide a better service to the patients and families on their caseload, and to empower the patients and families to make decisions about their own communication options.

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“...and yet, she talks”

My daughter’s communication path, with us

MARIELLE LACHENAL

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I am Marielle Lachenal. I am a member of French ISAAC, a Makaton tutor, and the mother of Geraldine, who is 30 years old and who is an AAC user. She is said to have learning difficulties and Complex Communication Needs (CCN).

Since she doesn’t speak with her mouth, people think she doesn’t think. I want to demonstrate how through her life, through her will, through all her communication tools, she has shown us that she communicates; we must go beyond the image that she gives of herself. That’s why I like this quote from Galileo: “and yet she speaks”.

I found a concept that I did not know, and I don’t pretend to understand it fully: phenomenology. It’s just watching people live and understanding how they experience the world but without preconceived ideas; just watching how people operate. Indeed, if we look at Geraldine’s communication, she speaks. On the contrary, with preconceived ideas, we could think that she does not think, that she does not communicate.

People who look at her with preconceived ideas think that it doesn’t matter if she doesn’t speak, since she doesn’t have too many behaviour problems. She is quite cute, smiling, they can even say, “Anyway, we are used to her - anyway, she can say *yes* and *no*, so why do you want her to talk?” And, as a mother I am seen as disturbing the peace, asking for my daughter to communicate!

It’s not easy being the mother of a young woman with a communication disability, but we are committed to enabling her to communicate and to live. She is no longer a child, and we must respect her age, but we must also respect her way of being in the world, and her need to talk with us, her immense desire to communicate.

I sometimes have the impression of being a tightrope walker, but the conviction that she can progress is still deeply anchored within us, that she has things to tell us and that we are there to support her. The love we have for her is here to keep us going! And the energy she shows helps us.

We are not alone: she has a great team in the family, and through ISAAC, I have met fabulous professionals and fabulous friends.

How is she living her life?

She is never alone: she has a lot of inner friends to talk with, as children and as we do too. In the past 30 years, among her friends you could find... a blue car from the cartoon *Cars* (“Sally”), who rides on her shoulder, and Elastigirl from *The Incredibles*. And from the cartoon *Ratatouille*, she explained to us that the car, Sally, is like *Ratatouille’s* rat (hidden under the chef’s hat and helping him); Sally talks to her. Geraldine lacks words in her head to be in self-dialogue, to have an internal conversation with herself, and so she talks with this friend whom she puts on her shoulder.

Her inner language

She has true and deep symbolic thought. She made me understand what it is, what language is, to be able to name what is not there: she once had a friend who had been punished and had to stay in the break room. Geraldine took a photo of the break room door and asked me to print it out and laminate it, and she walked around all summer with the image of the door. Behind the door was her friend. The door was enough to be with Christine. I have in mind the French poem by Saint-Exupery, where the little prince asks for a sheep and Saint-Exupery gives him a sheep in a box; the little prince is happy with the box: he knows the sheep is inside. This is language: to have things in mind, and to have names to keep them... the challenge we have with Geraldine is to give her a lot of “sheep” in boxes, that she can name. To give her the world, in boxes of words.

I found in a book the idea of a mangrove. The mangrove is a forest that grows by the sea. It is not the island that allows the tree, but the tree that allows the island: the seed in the water allows the tree to grow and the roots develop and from tide to tide, the roots filter the earth and the island is formed. We do not wait for the island to plant a tree.... I really believe that this is what drives us with Geraldine; we never expected her to show us her capacity to think before giving her language, but by giving her the language we opened her up to the world and she showed us the richness of her mind.

I keep thinking about Geraldine's way of being in the world... I think of *Toys R Us* store. Kids with cortical blindness only see the toys they have at home – they see the toys their brains have learned to see. To allow a person like Geraldine to see the world, she has to be able to name the world. If children are not given words to name the world, they don't see the world and they live in a narrow and empty world.

She supports her thought with images. She has piles of laminated pictures from books or cartoons, and depending on her present feelings, she chooses to take one or another, or stops a DVD on a specific image: sad, or anxious, or angry, or calm. We can learn how she feels just seeing the image-of-the-day. It is important to recognise that prehistoric men, thirty thousand years ago, were doing the same; we too need images to support our thinking.

During the lockdown, she showed us a little of her fragility with images from the cartoon Tintin; the first image where Tintin has collapsed in his bunk, afraid of dying, then Tintin with a mask and finally Tintin who comes back to life. This spanned over three months. During the lockdown, when there were so many people dying, she found Elastigirl and the character of Thor to show that she was stronger than death.

Jacques Souriau is a French researcher on communication for the deaf-blind, who says about Géraldine:

"I am struck by her preference for still images.

Again, I recognize a problem that I have often thought about: when I read, I can stop and think, go back, etc... when I watch a movie, it's the movie that decides my thinking. I am no longer free to think.

Geraldine shows that films give her a stock of stories that help her understand her own life (hence her possibilities to use metaphors).

However, she also shows us that she needs to regain control in order to think, to work with her own intelligence on the connections she can make between her life and the fictions in the film.

She silences the film for a moment, while keeping the element that feeds her thought..."

Her way of speaking

How does she speak? She speaks with her hands – her language is sign language. She can talk about everything and nothing. Important things, or trivial. She talks, she tells, she reports.

In her establishment, because they think she cannot speak, they do not tell us the important things that are happening, or sometimes try to tell us things that are not true, such as an outing to the lake one day, when they told us she hadn't wanted to swim, and she told us they had actually forgotten her swimsuit; in fact when we speak of Geraldine saying "she said" it just means she signed.

A funny little anecdote: we had a visit from a far cousin, and Geraldine took part in the family meal. In the evening, once she was in bed, when we talked about her, the cousin said to us, "Are you sure that she does not talk?" She had such a presence at the table chatting with him that he hadn't realized she wasn't speaking.

She talks to those who talk to her; she talks to the little robot, Peper you might have heard of. She can talk to videos in the museum more than she actually talks to her educators in her center. She feels that objects speak to her more than the living beings she lives with.

Because she needs her story, she needs to know and share who she is, like us. Paul Ricoeur, a French philosopher, says that we have our narrative identity and our digital identity and that what makes us float in life is not at all what is written on our identity card, but our history. It is therefore fundamental to give Geraldine her history; it is one of my great obsessions.

She needs written information and support to remember. She has scrapbooks – we are now at number 55, in 25 years. We too have our photo albums, our external hard drives, our lifeline on Facebook: it's not because she is disabled that she needs this kind of support, it's just because she's human.

And the scrapbooks also serve as a link with the whole family. When her sisters or brothers come home, they are compelled to read the last scrapbook.

And each time it is moving and surprising to see how her anxieties subside as soon as we can write down what she is going to do.

She is multimodal

Over time, new tools arrived: Podd, Proloquo, Talking Mats, which really allowed us to better communicate and give her a real voice. Her expressive language remains signing but by using Proloquo, we manage to discuss, to clarify, to tell better. We especially want her to be able to communicate with people who do not know her signs.

But despite everything we have done, despite all the support we try to give her, the reality of her communication handicap and her intellectual disability remains; there is so much she doesn't understand, there is so much she cannot say, there is so much anxiety that it sometimes leads to behavioural difficulties and sometimes she has even been on the verge of breakdown.

The weight of others' gaze is terrifying. It paralyzes her, and paralyzes me, and I now allow her to get angry, "what if she sets her foot in a dog poop? or if he bumps into a lamppost?" and this helps her to feel better!

There is the terrible pain of her silence: there was a moment when she was watching the movie *E.T.* on television, and froze the film on E.T. in his coffin. And she said, "I'm like E.T., people think I'm dead because I can't speak but I can speak with my hands and with the iPad..."

She often compares herself to a little girl locked in armour, the armour of her silence; when she is better, she finds herself stuck in a spider's web.

With Talking Mats, she can express her suffering around not being able to communicate with other residents, educators, or people she does not know.

But her greatest suffering is not so much not being able to speak, it is feeling she does not exist, feeling she is invisible...

We stay there, by her side.

I finish with a quote from Marie Balmory, a French philosopher:

"My body has experienced an event. But if I tell you, it was "me" who went through it.

If you listen to me, you let yourself write inside you what I am telling you.

And if you keep these things in your heart, I know, I who may have been overwhelmed by what I had lived, that I wrote it in you;

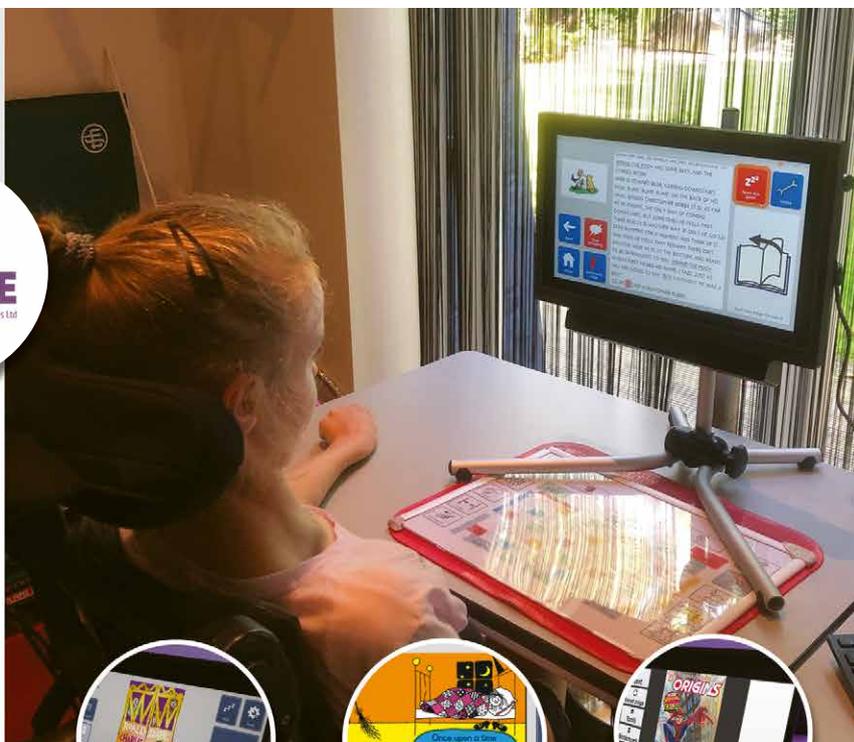
and you left something wrote for us to read together: we are tablets for each other..."

"Candle have loads of books for AAC and will make specific ones if asked..It's been a game changer for him to see and hear the text and to be able to turn the pages via eye gaze." - Parent



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Access to Learning Difficulties often encountered by students who rely on AAC (Augmentative and Alternative Communication) – Overcoming the Barriers

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Much attention in the world of AAC has focused on the development of communication with AAC. This may be, in part, due to a perception that AAC is the domain of the Speech and Language Therapist (SALT) whose skill base would naturally lead to concentration on the communication aspects of devices which aim to support students who have little or no speech.

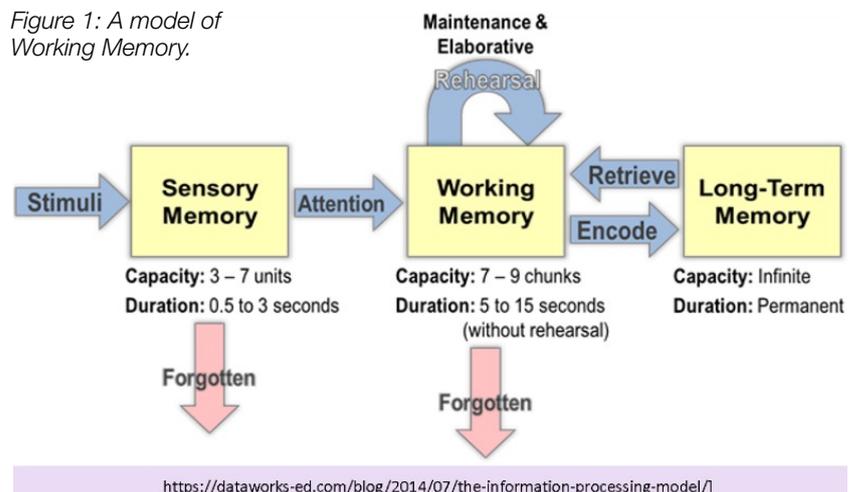
I would argue that there is a need for greater multi-disciplinary joined-up working and thinking in order to bring AAC into wider use, so that the student who relies on AAC has an opportunity to benefit in all areas of their life. In particular, there is a need for teachers to become experts in AAC so that they can bring the learning perspective to the forefront of its use.

The danger of underestimating the learning potential of students who rely on AAC is well documented and, until the balance of professionals who understand the wider implications of using AAC beyond using it as a voice alternative is reached, this is likely to remain the case.

AAC users, by the very nature of their physical access difficulties, will take longer to complete their work throughout their schooling. This can affect the students’ learning in many ways that may not be caused by intrinsic inability to learn. Barriers to learning may include:

- **Neuro Motor Issues.** These are movement difficulties or sensory difficulties that affect the student’s accuracy and reduce their speed to a much slower pace than their non-disabled peers. Compared with speaking rates of between 125 and 185 wpm, aided communication rates fluctuate between 2 wpm (for scanning interfaces) and 8–10 words (for direct selection)
- **Working Memory Compromise.** Working memory is vital for being able to manipulate information in any learning situation. It is the place where we store information temporarily whilst we retrieve another piece of information. The time we have to do this before working memory decays is typically between 5 and 15 seconds. The time it takes to generate a message using AAC will impede working memory (see Figure 1). Sub-vocal rehearsal has been shown to improve the retention of information but is a difficult task for non-speaking students to carry out. Failure to address the need to optimise working memory can present a significant barrier to communication and learning.
- **Emotional Resilience.** Some students who rely on AAC can experience strong emotional reactions to situations. Low expectations from teachers may well, in part, contribute to this as it becomes a source of frustration for the student. Low expectations may result from underperformance on the part of the student because of physical barriers to learning rather than their being unable to learn.

Figure 1: A model of Working Memory.



- **High-order thinking skills.** Complex thinking is something that can be taught but often presents problems for students who rely on AAC. Whilst so much of their thinking time is taken up with physical access to their communication, more complex processing is likely to be impeded. It is therefore essential that we make learning materials as accessible as possible so that the student is able to focus on the cognitive task with minimal fatigue.
- **Bring thinking into everything.** Students need to be supported in three phases of thinking to learn. These are:
 - 1 The input phase.** This is where the student is taking in the question and the information they need to answer it. They need to learn to identify the relevant information and ignore the irrelevant information.
 - 2 The processing or elaboration phase.** The student then needs to manipulate and work with the information they have in a relevant way. They need to be able to compare, remember, give reasons for choices, test out their ideas, see the main point, understand relationships, and plan their answer.
 - 3 The output phase.** Finally, the student needs to be able to show what they have understood by providing evidence, either by writing or making a correct choice. They need to be aware of their audience, be precise, avoid trial and error and impulsive answering, communicate clearly, and translate information without changing the message.

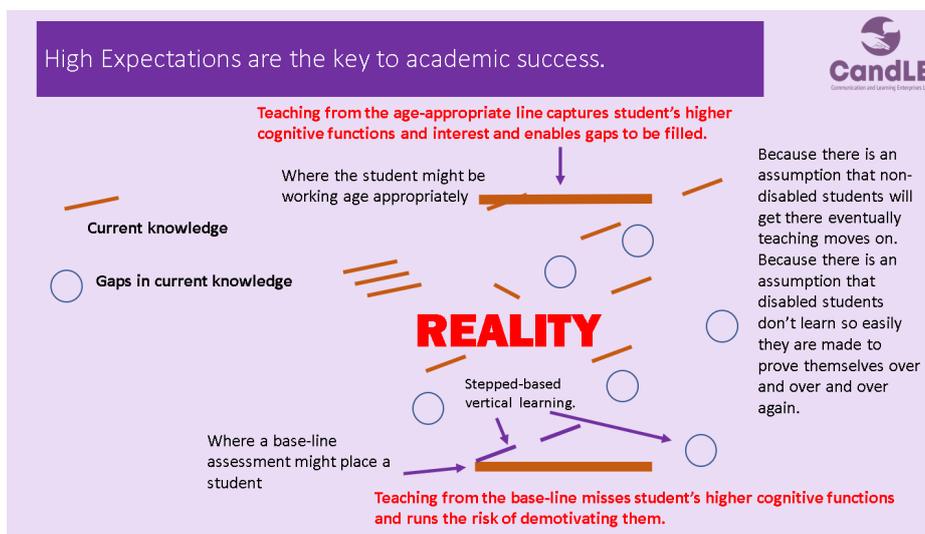
All of this requires concerted action on the part of teachers and teaching assistants to support the student in using their AAC in a way that will support their thinking. We tend to test rather than teach when we are working with students who have complex needs but to do that is to put the cart before the horse. We need to model and support with learning in just the same way that we do with communication.

Historically, AAC users have been offered adaptations designed for other groups of disabled students and not designed for their access needs. For example, a PDF screen reader is still very difficult to open and follow for somebody who is relying on eye gaze and/or switches. Research is emerging that recognises a need for individualised solutions for students who rely on AAC.

AAC users often don't get their access needs even partially met until they have completed a significant part of their education (or until they have reached KS2 or even KS3) so they have effectively missed large chunks of their education. This often results in them being behind their peers in KS2 and very behind in KS3. This does not necessarily reflect their cognition or understanding but rather the pace at which they work, the lack of appropriate software and equipment, and the lack of suitable differentiation and adaptation.

Address expectations by:

- Using dynamic assessment to find and fill a student's learning gaps and measure the rate of their progress as well as their stage of development within each subject area. It is very rare for a student to be working at the level of what is known as a baseline assessment. A baseline assessment will tell you what a student can do but not what they need to learn.
- Enabling routes to academic achievement through activities that support and optimise physical access, working memory and thinking skills so that the student's potential can be maximised. They should be working in the least effortful, most independent and most time-effective way. This may mean that they need layouts that are easier to access than those traditionally used in communication vocabularies.
- For students who have had their education interrupted, it is likely that gaps in learning will occur in patches rather than at a specific level, as demonstrated in the model below:



What we are seeking is to find the student's Zone of Proximal Development. This is the place where the student can achieve success with appropriate help, which can then be withdrawn as the student becomes a more independent learner.

Zone of Proximal Development

This is the area where learning takes place:

- there is enough challenge to keep it interesting.
- What you can do with appropriate help shows what you are capable of.
- It isn't too difficult.

Zone of Proximal Development

Finding the elusive Zone of Proximal Development. ZPD

Where the student might be working age appropriately

Current knowledge

Gaps in current knowledge

Where a base-line assessment might place a student

Expect higher levels and lower levels of ZPD and use scaffolding, modelling and other means to bridge the student's learning where it is needed. This requires recognition that no-one's profile is linear. Often called the 'spiky' profile.

A danger with baseline assessment of students who rely on AAC is that it can lead to predictions of attainment over the ensuing years, often as many as 5 years or more. This can lead to teaching programmes which fail to support the learning potential of the student, because projections made on the basis of the average rate of improvement of non-disabled students are not consistent with the likely increased upward curve experienced by students who rely on AAC, once their access to and adaptation of materials has been optimized. As this model shows, it is highly probable that the student who relies on AAC will have gaps both at their baseline and above but that they will also have abilities that are well above the baseline. These abilities need tapping into and the student supported to use their higher skills to develop those nearer the baseline.

The best way to support a student who relies on AAC to access the curriculum is to utilise the software that they use for communication. This is because they will already be familiar with the software, it will hopefully have been optimised for access and those who assist them will not need to learn to program more than one piece of software. However, you need to offer much more than word lists. The student needs independent access to the information they need to learn, ways to remind themselves of the learning material and ways to provide evidence of their learning.

Students who rely on AAC need to experience the same learning concepts more frequently than their non-disabled peers. This is not necessarily because they have learning difficulty but may be due to learning access difficulty. A non-disabled student can rehearse and research independently. We may have to manipulate communication software to enable the disabled student to be able to independently do the same. Being verbally taught something is nowhere near so effective as being able to independently learn, yet many students who rely on AAC are expected to learn solely by listening and having a scribe.

When teaching a student who relies on AAC, we must be mindful of the need to develop their vocabulary to a level where they can access the curriculum. This is not possible through the use of symbol-based communication vocabularies with word-lists added to them.

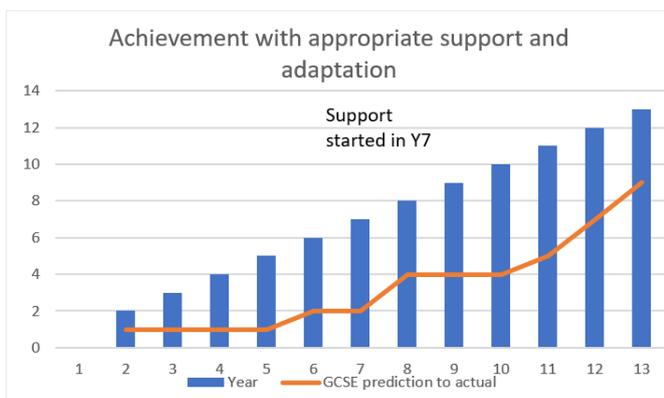
The teaching of literacy is fundamental so that students can explore language through the use of word prediction and through discussion with more knowledgeable others. Beware of the overuse of symbols. There is research evidence that the use of symbols in literacy teaching detracts from the written word.

The student who relies on AAC will need a tailored literacy programme that does not necessarily follow the traditional routes to literacy found in the normal school environment. For further information about the teaching of literacy to students who rely on AAC, please refer to <https://candleaac.com/literacyprogramme/>.

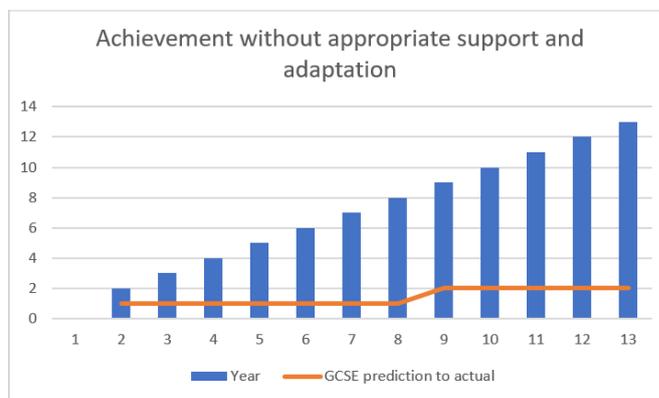
The illustration below (left) shows communication software being utilised so that the student can access a maths lesson. The question is on the page with a quick reminder on a cell if needed. If the student has forgotten the rule, they can go to a page to fully revise (right).



Below is a comparison between two students who rely on AAC showing the difference in attainment curves with and without appropriate support and adaptation.



Student 1



Student 2

Student 1 had support throughout his secondary schooling from teachers and teaching assistants who were knowledgeable in the use of AAC software in order to support learning as well as communication. He came into year 7 with very low levels of literacy but was able to write expansively by the time he left secondary school. The fact that the student had independent access to learning materials that were easy to access through communication software as well as a means to communicate contributed greatly to this.

Student 2 spent his secondary years relying on a teaching assistant reading to him and scribing for him so that he had little experience of directly completing his own work.

We need to be thinking much more deeply and widely about how we give students who rely on AAC access to meaningful engagement with the curriculum. Communication vocabularies are the tip of the iceberg. Students need to learn literacy at as early a stage as possible, and then practise using their developing skills across the curriculum with the assistance and guidance of more knowledgeable others, usually their teacher who should be fully trained in how AAC can be utilised to support independent learning.

For more information and discussion email me at marion@candleaac.com

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The development of voice and message banking options: where are we now and how can things be developed?

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Firstly, an explanation of the difference between voice and message banking. A very simple way of explaining it is to say that voice banking is the process of recording and then creating your own personalized synthetic voice, whereas message banking is the process of recording messages which are then played back in their entirety. Both options allow for the voice/recordings to be used in a communication aid, but the different operating systems and file formats that exist in the world of technology can make this an overly complicated process.

Why do people voice bank? From a study carried out by Richard Cave and Steve Bloch, people with motor neurone disease (MND) and their carers were interviewed to capture their views and three main areas were identified.

Preserving identity

Many people see voice banking as a way to preserve a part of their identity when other parts are being affected or are in effect disappearing. So, although you may lose the ability to move, and you may lose the ability to talk or to eat, if you've got your own voice in a communication aid, that's a part of you which ultimately will remain and will not be taken away.

It also ties in with family and friends, and particularly if there are children in the family. It can be important, even if the person with MND doesn't feel it is critical. If it helps the children to remember how someone sounds then that could be just as impactful for the children as it is for the person with MND.

Keeping control and fighting back

Because MND can affect people in so many negative ways, being able to voice bank can be a positive thing to do. When somebody is diagnosed with MND, there is obviously an awful lot to take in, but with voice banking you can do something positive and you know you're going to get something from it. You may never actually need to use a synthetic voice, but it's there if you do and also gives you something to concentrate on which might take your mind off other thoughts for a time.

Maintaining networks

Although communication aids have generic voices in them, which are perfectly good quality and in many cases can be of superior quality to personalised synthetic voices, they may not sound exactly how the person wants to sound, which can affect confidence and social interactions, so having your own personalised voice can help some people with MND to, literally, leave the house.

An example of this is a lady with MND who lived on the South Coast but was originally from Newcastle, and for a long time had just been using her generic voice on a communication aid. She contacted me and asked if it was possible to create a voice with a Geordie accent. We were able to sort that for her (it was actually donated by a Speech and Language Therapist) and it made the world of difference to her. She informed me that by having her own accent (even though it wasn't her own voice) she started going out more and felt more confident going into shops because she felt like it was actually her speaking.

In the last few years, the MND Association has really tried to push voice banking and message banking. There are positives and negatives for both, detailed in figure 1.

	Voice banking (personalised synthetic voice created from various sentences recorded)	Message banking (standalone recordings of voice)
Positive	Able to speak any word/sentence	Any language possible
	Quick to complete (< 2 hours)	Can include emotion and intonation
	Can be used on all major operating systems (iOS, Android, Windows)	Less need for equipment such as headset microphones/laptops
Negative	Cost incurred	Time consuming (if recording lots of sentences)
	No emotion or intonation	Limited to sentences recorded
	Limited to certain languages	Difficulty in understanding options/ file types/ operating systems required

Figure 1

Voice banking - positives

Voice banking is the process of recording a set number of sentences, which are then broken down. The algorithms are found within those sentences and then in effect, it's all put back together and allows the user to speak any word or sentence that they type into a communication aid.

It's quick to complete (under 2 hours now). That might seem like a long time but consider that the average time to bank your voice a couple of years ago was three months, and now it is closer to 6 days. But if you are committed and do it, at the minimum to get a good synthetic voice it can be as little as 50 sentences. Some services can create a voice with just three minutes of recording, but the basic rule of thumb still applies - the more you record, the better the voice will be.

The third positive for voice banking is that it can be used on all major operating systems. However, there are limitations on which text-to-speech programs can utilise banked voices, particularly around iOS, caused predominately by limitations with Apple programming. Ultimately though, whichever sort of communication aid is prescribed, and whichever operating system it uses, for the majority it should be possible to use a personalised synthetic voice on it, depending on which voice banking service is used.

Voice banking – negatives

There is a cost attached to voice banking. As a charity, we try to provide funding as much as possible so we will fund up to £500 per person with MND. For voice banking, that covers the full cost of the majority of voice banking services available, so the cost incurred to the user is in effect zero if they apply for funding. However, it is still a cost to the charity and is considered negative as voice banking used to be free. This is no slight on any of the voice banking services because they are commercial enterprises for the most part, but it would be lovely if it could become free again somehow.

There is no emotion or intonation, although this is being worked on by many of the services. So, it may not be completely fair to say that there is no emotion or intonation, but generally speaking, it's a robotic voice. However, progress being made in this area is rapid and synthetic voices are becoming more and more realistic.

Voice banking is also limited to certain languages. It is clearly a positive that it is available in more than just English but at the same time it is limited primarily to Western European languages. There are one or two now that are not Western European (e.g., Arabic), but it is still quite limited. In terms of languages, and the problems associated with them, it is not just necessarily with voice banking, but with communication aids generally. In simple terms, with processes in the background of communication aids, they need to be able to understand not just the words but the grammar and construction of sentences in any language to be fully inclusive.

Message banking – positives

Message banking is the standalone recording of the voice, so one positive is it can be done in any language. It is literally just what is recorded that can then be played back on a communication aid, so in some instances this may be the only way to get around the language barrier.

It is possible to include emotion and intonation, depending on how much time and effort is put into message banking. For example, it would be possible to record the same message in different ways to change the meaning of it, as shown in figure 2, where the highlighted word is emphasised.

Figure 2

- I'm*** too hot! (as opposed to anyone else)
- I'm ***too*** hot! (I want to be hot, but not this much)
- I'm too ***hot!*** (I am definitely not cold, if that is what you were thinking)

There is less need for equipment such as headset microphones and laptops when message banking. For voice banking it is recommended that a laptop or a PC with a headset microphone is used for the quality of the recordings. (There are some services that use an iOS app and therefore recordings are made by speaking directly into an iPad or iPhone, which will produce an acceptable synthetic voice, however if a headset microphone is used the quality is likely to be better than speaking into an external microphone.)

With message banking it is arguably about the personality of the recorder and less about the quality of recording, as the resulting output is not trying to pronounce every possible word or sentence. It therefore becomes possible to message bank in a smart phone for instance, or indeed any device that has the ability to record.

Message banking – negatives

It can be time consuming to message bank, particularly if lots of sentences are being recorded. Equally, the person recording is limited to what they choose to record: it would be impossible to record the number of sentences that anybody would use in daily conversation.

There is also difficulty in understanding the options for message banking, particularly around file types and operation systems required. There are options that exist (detailed later in this article) but the opportunity to message bank could still be further improved.

The progression of voice banking from a charity perspective (figure 3)

When I started in the Communication Aids Coordinator role at the MND Association in 2015, one of the first things I was asked to do was investigate voice banking. There were services that already existed, but these were primarily either research projects or would come from a commercial background. So while there were options for voice banking, the awareness of it was very low.

Within a year we started loaning devices because we had enough people with MND wanting to do it, so we added laptops and headset microphones to loan service. The demand that we drove from that meant that in 2017, voice banking was no longer a free option, so this is when we started offering voice banking support grants.

In 2018 we saw more services develop and at that point our loan stock consisted of 75 laptops and 155 headset microphones.

In 2019, we saw the development of deep neural networks (DNN) technology in relation to voice banking and a number of the services adopted this new way of creating synthetic voices from recordings. This is what has really driven down the number of sentences that need to be recorded and the time it takes to do voice banking, while at the same time it has increased the quality of the voices.

More services entered the market in 2020, and as of 2021 there are now at least seven different voice banking options available and our loan stock consists of 240 laptops and 400 headset microphones.

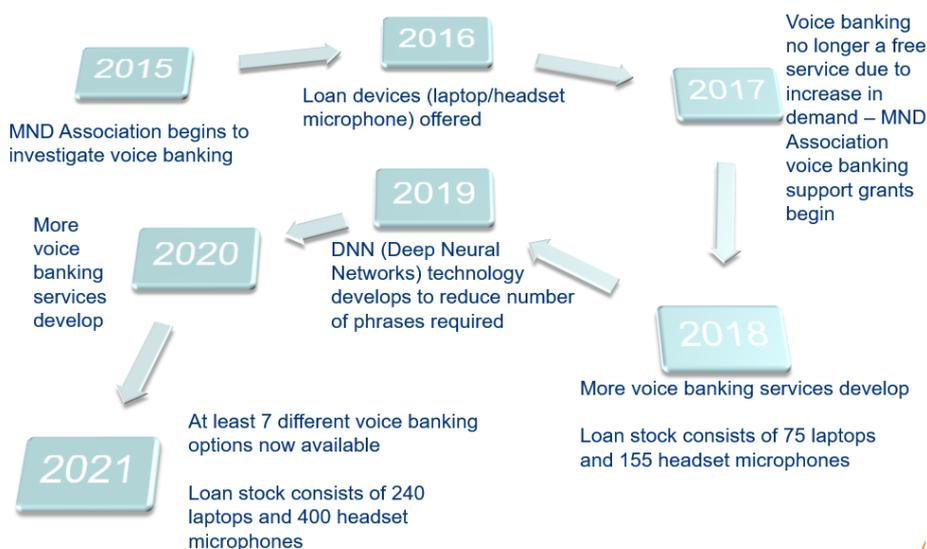


Figure 3

Voice banking options

We have now developed comparison charts (available at www.mndassociation.org/communicationaids), simply because there are now so many options. These charts were developed in conjunction with all of the services, who kindly provided the information and they list aspects such as website contact details, the costs that are incurred, the minimum number of recordings required, the maximum number of sentences someone can record and the equipment needed to do it. In addition, it also shows how to use each service (e.g., online or offline), what operating system the voice is compatible on, the various languages that are supported and also how to apply for MND Association funding.

Message banking options

Message banking should always be considered alongside or as an alternative to voice banking. The following options currently exist but as previously written, more can still be done to improve the process. It can get confusing when understanding which file type recorded messages need to be saved with, as depending on which option is used, there is no industry standard. However, in most instances it is possible to convert files if needed, if you know how to.

myMessageBanking (<https://mymessagebanking.com>)

myMessageBanking is a joint project between Boston Children's Hospital and Tobii Dynavox and is a website that is great for organising recordings, by sorting and transcribing them, which can then provide a .zip file for upload into communication aids. It is arguably the closest service available to a standalone message banking website, but it is not possible to record the messages straight into the site, so it recommends a specific handheld voice recorder is used which will store any recorded messages as .wav files (the file type needed to upload to the website).

Acapela my-own-voice (<https://mov.acapela-group.com>)

Acapela have a custom messages option that can be added to any voice banking account, allowing for up to 300 custom messages to be added to the recording script before starting. An uploaded .txt file will add those messages to the end of the voice banking recording script, and when finished and having installed the banked voice into a communication aid, if those specific messages are typed word for word, it should speak in the actual recorded voice rather than the synthetic voice.

ModelTalker (<https://www.modeltalker.org>)

Alongside the ModelTalker standard voice banking option, it is also possible to have a 'custom inventory'. This is for recording your own messages, people's names, places, anything that the user thinks a communication aid may struggle to pronounce. Similarly, like the Acapela service, having installed the banked voice into a communication aid, if those specific messages are typed word for word, it should speak in the actual recorded voice rather than the synthetic voice.

Predictable app (<https://therapy-box.co.uk/predictable>)

Predictable is a text-to-speech app that has a message banking option within it, so it is possible to record straight into the app and then play the recording back as a set phrase at any time.

Grid for iPad app and Grid 3 (for Windows) (<https://thinksmartbox.com/product/grid-for-ipad> and <https://thinksmartbox.com/product/grid-3>)

Both of these text-to-speech software programs offer message banking within them, so similarly to other apps it is possible to record straight into them and then play the recording back as a set phrase at any time.

Voice recording software (e.g., <https://www.audacityteam.org>)

While not specifically created to offer message banking, a program like Audacity can be used to make recordings and then each recording can be saved as many different file type options. The difficulty is knowing which file type to save the recording as, but at present if each recording is saved as a .wav file and combined with the myMessageBanking service, this becomes a viable option.

Voice Recorder (or similar)

Voice recorder is a catch-all, in the sense that if someone has a device, such as a laptop or smartphone, the chances are it will have some sort of voice recording software on it as standard, allowing the user to record anything and save it on the device. However, the difficulty is then extracting those messages from the device to put them in a communication aid, and while it is not impossible, it can be tricky to ensure each recording is saved as the correct file type in anticipation of it being installed on a communication aid.

Conclusion

Voice banking and message banking have developed significantly in the past six years and continue to expand the options and availability to any person who may be at risk of communication difficulties. It is now affordable to create a personalized synthetic voice even if the user has no voice, meaning that in theory nobody should be without a personalized voice if using a communication aid, if they want it. However, there is still development needed to simplify the process of both voice and message banking, and certainly the inclusion of languages. Further advances are likely in the quality of voice produced and the number of sentences needed to create a voice. Thinking further ahead, could having a personalised synthetic voice become a mainstream option for every person, not just those with a disability or acquired illness? With the advancement of artificial intelligence, robotics and technology anticipated in the future, it could well become a reality.

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Virtual Equipment Issues (a new way – a better way?)

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Introduction

The National Centre of Electronic Assistive Technology (NCEAT), Wales is based in Cardiff, with an additional satellite office situated in Wrexham. The service covers all of Wales, on a lifetime basis, providing assessment, supply and support of power-based environmental controls (EC) and communication aids (CA) to NHS Wales' patients. NCEAT is made up of a wide-ranging multi-disciplinary team including Clinical Scientists (CS), Speech & Language Therapists (SLT), Occupational Therapists (OT), technical and administrative support. The communication aid element of NCEAT is supported by the SLT and Clinical Scientist teams.

The provision is broken down into adult and paediatric services and then by locality, with there being one paediatric SLT in North Wales and one in South Wales.

This report discusses the experiences and findings of remote issuing of CA equipment to paediatric patients in South Wales.

Discussion

Children are referred into the service by their local SLT who remain involved throughout the whole patient journey. Following triage, the typical paediatric pathway for South Wales would be as follows (see figure 1).

Prior to the onset of the Covid-19 pandemic across the UK, all NCEAT services were delivered via face-to-face visits, with appointments being within the patient's locality. From a paediatric perspective, this tended to be at the child's school or in their home. During the week prior to the onset of the lockdown, the South Wales paediatric SLT completed: 17 patient appointments, travelled 421 miles, and had one overnight stay.

On Friday 13th March 2020, because of the pandemic, the service was halted, initially due to schools preventing external visitors from entering the premises. However, this was swiftly followed by the onset of the national lockdown measures on 16th March. The immediate necessary response was to cancel all appointments.

It was concluded that any devices recommended for trial would have to be issued remotely. A primary concern around providing equipment in this manner was raised by the SLT's previous observations and experiences of many family's anxieties and reluctance to integrate the device into their lives, even when well supported with face-to-face involvement. In addition, well-documented issues are highlighted within the literature regarding families struggling to implement AAC within the home environment (Johnson et al, 2009), with reasons ranging from lack of support through to capacity of and demands upon the parents (Moorcroft et al, 2019). An initial hypothesis concluded that remote or virtual issues could increase these anxieties and create further barriers to successful implementation.

The sessions were to be delivered via Attend Anywhere, a video consultation (VC) platform that was rolled out nationally by the Welsh Government (WG) via Tech Enabled Care (TEC) Cymru. A PowerPoint presentation was written to be delivered through screenshare during the VC session. This included screen shots of the device to show various parts to help the family recognise what was being discussed, along with YouTube videos of aided language stimulation strategies and from the device developer around implementation of the specific equipment being used.

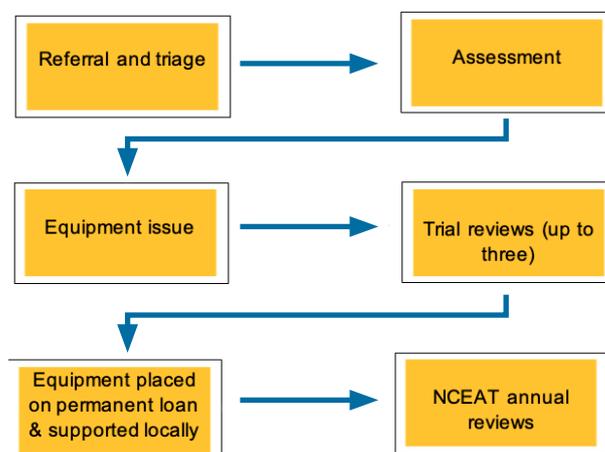


Figure 1: NCEAT paediatric patient typical journey

During the first session being delivered, the parent attending stopped the appointment it in its tracks and asked several questions that made clear he had been exploring the equipment and had gained some robust knowledge prior to the meeting, which made most of the planned presentation irrelevant. This behaviour set the scene for every subsequent session that took place. Families were joining the appointments with a confidence and breadth of knowledge around the equipment that had not been experienced pre-covid, during face-to-face appointments.

During discussion with one parent, she likened receiving the equipment to being in an ‘unboxing’ video on YouTube. These videos show a person filming themselves opening a parcel they have received and sharing it on the video platform. They are excited and go into rhapsodies over whatever it is they are opening. It was this general comment that started the realisation that receiving the equipment first was a game-changing experience for families.

Prior to the pandemic, all families were first introduced to their child’s equipment during a face-to-face appointment, usually at school and in a room full of professionals. Unsurprisingly, even with lots of support, in this environment they tended to sit back and encouraged the training to be directed at the teaching staff, using comments like, ‘I’ll look at the device tonight when I get it home’. The equipment would then go with the teacher back to class and not be seen at home until the end of the school day. Then home life was busy, the device would be put in a safe place and the family would lose momentum. Whereas now, the equipment was being received directly in the family home. They could look at it in their own time, explore it without anyone watching and start to get a feel for it without being under pressure or worrying about what people would think of them.

Results

Every virtual session was delivered within a change management model of a plan, do, study, act cycle (Crowfoot & Prasad, 2017) which created the opportunity to plan the process and encouraged reflection by asking 3 questions after each session to promote ongoing change and improvement (figure 2).

The project plan for the first session can be seen in appendix 1. This process has allowed the delivery of the VC sessions to react to the changing lockdowns as they occurred, and collate evidence along the way of the impact of these changes. As the early pandemic lockdown restrictions have been lifted and virtual sessions have reduced, the advantages of patients receiving equipment prior to face-to-face training in schools have continued to be identified and the indications are that the families continue to significantly benefit from receiving the equipment in this manner.

Data collated and analysed by Tec Cymru identified that participants included every patient that had specifically gone through the AAC pathway in Wales who did not already have AAC equipment. All of the patient notes were written by one highly specialised Speech and Language Therapist. Participants were from many health boards in South Wales including:

- Aneurin Bevan University Health Board (ABUHB)
- Cardiff and Vale University Health Board (CAVUHB),
- Cwm Taf Morgannwg University Health Board (CTMUHB),
- Hywel Dda University Health Board (HDUHB),
- Powys Teaching Health Board (PTHB),
- Swansea Bay University Health Board (SBUHB)

100% of visits prior to Covid (controls) were conducted face-to-face and 100% of all visits during Covid (cases) were conducted via video consultation.

Tec Cymru also ran a chi squared test of independence between the notes of controls cases. This revealed a significant difference between the cases and controls for satisfaction, $X^2(2) = 10.353, p = .006$, cases reporting they were more positively satisfied with the appointment than controls.

The engagement with the EAT technology prior to the equipment issue appointment was explored for cases and controls. Tec Cymru’s results demonstrate that cases were more likely to engage with the EAT technology prior to their appointment than controls, OR = 4, 95% CI[1.415 to 11.310]. A chi squared test of independence revealed a significant difference between cases and control for engagement, $X^2(2) = 7.169, p = .007$. Cases engaged with the equipment prior to the appointment more than controls.

Furthermore, the post-session feedback collated from the parents began to highlight that, far from receiving the equipment first being a negative experience, families were benefitting and making the most of the time before the session, by exploring, learning, and engaging with the equipment. Additionally, analysis of themes collated from the SLT’s own reflections highlighted 4 areas of benefit (figure 3).

Figure 3: SLT thematic analysis from session reflection.

EMPOWERED	OWNERSHIP	CONTROL	ENGAGEMENT
Parents leading school sessions	Talking about their device	Having a pre-thought agenda for sessions	Using device at home for general conversations
Parents having prepared questions for training session	Editing device on own terms	Having expectations of school staff to follow their lead	Expecting schools to follow language models and not to use for just lesson work.

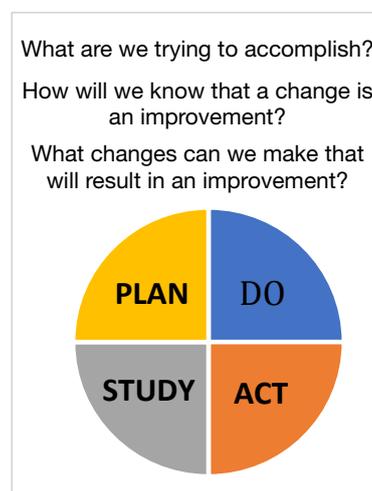


Figure 2

Limitations

This work was completed with a paediatric caseload, usually supported by families who were computer literate and able to follow both written and verbal instructions. The adult SLT team found this process was not as successful for them: their patients also tended to receive the equipment and instructions directly but the very nature of their need sometimes prevented them from being able to engage with the process in the same way.

The training sessions were only successful when the equipment was with the individual being trained. Therefore, there was potential for duplication of work once children were back in school and face-to-face appointments were not possible, as two sessions had to be delivered, one to home and then one to school. However, the recording of VC sessions also allowed staff who were unable to attend at the time of the appointment the opportunity to receive the training later.

Conclusion

As has been highlighted above, rather than families being negatively impacted upon by receiving their equipment before training, it became a positive experience that put parents and carers at the heart of the process and created better engagement. Using a plan, do, study, act cycle during the change process allowed for regular reviews and early identification of any advantages and negatives of the amendments, which aided speedy resolution. The recording and analysis of themes through the process highlighted the ongoing benefits to the family, and as such, issuing equipment before training will continue to be implemented now sessions are returning to a similar form to those prior to the onset of the pandemic.

Appendix 1

<p>AIM: What do you want answered with this test: To successfully change provision of equipment and support to the paediatric caseload in South Wales from face to face to video consultation within 3 months.</p>			
<p>Describe your first test: Complete first equipment issue and VC to obtain benchmark to develop from.</p>	<p>Person responsible: Michelle Thole</p>	<p>When to be done: Monday 4th May @13:00</p>	<p>Where to be done: Attend Anywhere platform</p>
<p>PLAN: List the tasks need to set up this test of change: Pre-delivery phone calls Arranging courier and paperwork to accompany device Write up presentation of training Create post session feedback form</p>	<p>Person responsible: Michelle Thole</p>	<p>When to be done: W/E 24/04/20</p>	<p>Where to be done: Office</p>
<p>DO: Run the session.</p>			
<p>STUDY: Describe what happened when you ran the test? Dad had explored device fully, followed instructions sent and used the device manual. He knew how to do some basic editing and had started using the device with his son. Some of the prepared presentation was not needed Describe the measured results and how they compared to predictions and what you learned about the cycle. Post session survey provided very strong qualitative evidence that receiving the device first was not the issue originally thought. Both SLT and Dad felt the presentation was too formal and it was better when able to see each other on the screen.</p>			
<p>ACT: Continue to issue equipment first Stop using PowerPoint. Deliver session 'face-to-face' via VC. Family to use device alongside SLT during session.</p>			

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Environmental factors supporting writing for children and youths with physical disabilities who use AAC: practice implications

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Introduction

For children and youths with a speech impairment and a physical disability who use Augmentative and Alternative Communication (AAC), the journey towards functional literacy is often more challenging than for other children and youths who use speech for communication. The specific reasons are not fully understood, but are likely a combination of personal and environmental factors. The Unified Theory of Development (Sameroff, 2010) emphasizes that this interaction and transaction between the person and the environment is critical to the child's learning and development. The Integrated Model of Social Environment and Social Context goes further, by explaining the relationship between environmental influences and children's experiences (Batorowicz et al., 2016). This model acknowledges that the environment affects children through the availability and the provision of opportunities, supports and resources. Social contextual factors are understood as five key elements: people, activity, place, objects, and time.

Some of the acknowledged personal factors contributing to the development of literacy among children and youth include cognitive, linguistic, sensory and motor abilities and limitations (Dahlgren et al., 2010; Smith et al., 2009). Less is known about environmental factors which are related to and important for conventional writing for children and youths who develop literacy and use AAC. We reviewed up-to-date research evidence on environmental factors supporting writing for children and youths with speech and motor impairments. The literature search was guided by the writing model developed by Flower and Hayes (1981), as well as Nystrand's social interactive writing model (Nystrand, 1989). The first was used to define the cognitive components of writing, and the second to define the social interaction components of writing.

The research evidence suggests that people in the child or youth's environment need to create writing opportunities, and offer appropriate support and resources (objects), across a variety of activity settings (places and activities). In this paper, we discuss the implications for AAC practice based on our review findings.

Family and communication partners as creators of opportunities

Families were found to play the role of an advocate for their child's literacy instruction or expectations at school (Johnston et al., 2009; Lundt, 2001; Myers, 2007). Advocacy activities included: ensuring that the child or youth received appropriate assessments (e.g. cognitive, visual, language and literacy); institutional supports; and frequent opportunities for written composition at the school (Myers, 2007). Other family members such as siblings were also influential to the child's or youth's literacy-related outcomes (Blischak, 1995; Carpe et al., 2010). Families' involvement in reading and writing activities, access to print and writing materials, and access to AAC systems at home may be related to improvements in literacy skills such as reading comprehension, word identification (Erickson et al., 1997) and writing (Blischak, 1995; Erickson et al., 1997). Furthermore, both case studies described literacy experiences which were provided in social interactions with parents, peers or siblings, such as frequent book reading (Blischak, 1995; Erickson et al., 1997).

To illustrate the above points, we present a case scenario. Lucy is a seven-year-old girl, diagnosed with cerebral palsy. Her mother programs the vocabulary on Lucy's device for regular school activities, and participates in goal development for Lucy's educational planning. Lucy's mother provides a home environment which is rich in print, by placing written words on many objects in their home (e.g., fridge, drink, piano, play). Prior to visiting new places, she makes sure that Lucy's device is updated with any relevant new vocabulary that contains picture symbols and their corresponding written words. Lucy's AAC team, consisting of a Speech

and Language Therapist (SLT) and an Occupational Therapist (OT), frequently involve Lucy's sisters in her therapy sessions. Furthermore, her mom encourages Lucy's sisters to play games with her, using recently learned printed words.

Positive outcomes were also related to communication partners' supportive behaviours. Several studies indicated that children and youths with physical disabilities had limited writing opportunities as compared to reading opportunities (Koppenaver et al., 1991; Light et al., 2009). Yet children with physical disabilities benefited from frequent writing opportunities, and from discussing their written work with others (Blischak, 1995; Myers, 2007; Staples et al., 2012).

Multiple researchers reported the critical importance of communication partners remembering to provide sufficient time for the child who uses AAC to write and explore writing (Blischak, 1995; Erickson et al., 1997; Howery, 2018). Howery (2018) conducted a phenomenological investigation into the use of speech-generating devices in a school setting. Her primary finding was that children who used AAC had a difficult time keeping up with the speed of communication of others' in their environment. However, when they used texting, there was less pressure for an immediate response, lessening the time constraints. Howery (2018), stated, "Can we allow our students with SGDs [speech-generating devices] to talk, not by making them enter into our talk time, but rather by demanding of ourselves and other children that we enter into *their* conversational time, text time?" (p. 47). Furthermore, she suggested that many educators were moving to online communication, where students were allowed to use "backline chats" during class time, which may allow for more reflection time prior to participating in discussions during the class for all children, and may benefit children with physical disabilities who use AAC to be able to fully express their ideas (Howery, 2018).

Supports and resources: appropriate assessments, systematic instruction, providing access to writing aids, and training in how to use AAC systems

Studies which focused on factors that supported writing reported the following facilitators: detailed assessments in school (addressing cognitive, visual, language and literacy abilities) (Blischak, 1995; Erickson et al., 1997), and provision of institutional supports, such as partnerships between all of the stakeholders or accessibility to the AAC system (Carpe et al., 2010). Research evidence suggested that low expectations of teachers or students could be a barrier to writing (Koppenaver et al., 1991; Lundt, 2001), and high expectations could be a facilitator (Carpe et al., 2010; Mason, 2016). Erickson et al. (1997), conducted a longitudinal case study of the communication and literacy of an 11-year-old boy with speech and physical disabilities related to cerebral palsy. In this study, authors described the number of language and literacy assessments, which revealed that Jordan "had literacy skills (and perhaps language skills) beyond the team's expectations" (p. 146). The detailed assessment results improved the team's expectations of Jordan's literacy skills. His fourth grade literacy goals were increased to include silent reading time, and books were programmed into his Dynavox in order to allow him to read independently. Words were pre-programmed into his Dynavox, so that Jordan could independently spell words which were similar (six sets of words which varied by one letter only). He was encouraged to start writing using the words he encountered in his silent readings, and to use invented spellings (where he created his own messages, even if they were not spelled correctly). In the fifth grade, the focus increased to reading and writing connected text, where all children in the class began the day with a full hour of writing time.

From the evidence, we have learned that children or youths always benefited from access to their writing aid in all of their settings, and when the writing aid was in functioning order (Carpe et al., 2010; Lundt, 2001; Sturm, 2012). The child or youth who uses a writing aid may require assistance from the teacher, peer or parent, in order to help them have access or to initially set up their writing aid. Parents, teachers and clinicians played an important role to help the child or youth with their physical set-up on their wheelchair, to set up and start the computer, to open up the email or social media, and to provide access to the writing aid in multiple settings. (Carpe et al., 2010; Erickson et al., 1997; Koppenaver et al., 1991; Lundt, 2001; Myers, 2007).

It is important to offer support and information to the person who uses an AAC system about how to use their AAC system; how to use the device features; how to use other software; and to provide them with refresher training (Blischak, 1995; Bryen et al., 1995; Carpe et al., 2010). Families reported that they did not receive sufficient training in how to use AAC systems, and the youths did not remember all of the training they initially received (Carpe et al., 2010). Yet children and youths who used AAC often relied on online apps or the internet for social interactions (Bosse et al., 2020; Carpe et al., 2010; Rasid et al., 2015). They also used their writing device to complete their homework, and they often needed support with software compatibility and help in how to use various social media (Carpe et al., 2010). In an article by Carpe et al. (2010), one child said, "I went through it [training] a little bit at [the center] but when I got home I had completely forgot it so I had to teach myself" (p. 93), and one of the OTs stated training should also "focus on functional applications of the software, and not solely on the operational features" (p.93). Myers (2007) reported that when technology was too cumbersome, frustration mounted, and participation and motivation for writing would decline.

Opportunities and resources across a variety of activity settings: home, school, and online

The research points to the importance of parents, clinicians and educators encouraging independent writing activities. The level of independence can increase over time (Erickson et al., 1997; Myers, 2007), including strategies such as silent reading time and invented spelling (Erickson et al., 1997). In some studies, the independence of choosing your own topic was found to be a motivating factor for writing, supporting genuine authorship (Bosse et al., 2020; Millar et al., 2004; Sturm, 2012). In a study by Sturm (2012), a writing workshop consisted of mini-lessons, followed by independent writing and then by "author's chair", where the writer could share their work with others. The mini-lessons could for example, focus on building self-confidence as a writer; participating in choosing a topic, or using eye-contact when sharing their story. The independent writing activities may include writing on a given topic, increasing the number of letters in writing, communicating ideas in writing, etc. Lastly, the sharing of children's writing with others may involve, for example, giving a presentation to peers, or asking questions and making comments about a peer's presentation on their written work. The adults can provide individual supports as needed (e.g. offering the child a choice between three photos, or presenting them topic areas on their communication board, which will determine their topic, etc.)

Studies about written communication outside of school or leisure settings were mostly about online activities. Children and youths who used AAC, like other children, were found to benefit from communicating online (e.g. email, social media). In addition, for these children and youths, written online communication could reduce the time pressures of face-to-face communication (Bosse et al., 2020; Howery, 2018). An online community was reported to be especially important for children and youths who used AAC, and allowed them to make social connections and friendships (Gosnell et al., 2017). To write online, the children and youths who use AAC may need to rely on parents or friends. This may include helping them with the set-up or with the navigation, which may minimize the privacy of their communication (Bosse et al., 2020). Hence, it is important for any person who is helping with this set-up to try to respect their need for independence and privacy whenever possible.

Conclusions

To date, research for the most part has focused on personal factors related to writing, however emerging evidence points to environmental factors that are also important to consider in the development of writing for children and youths with physical disabilities who use AAC. This article focused on the practice implications based on the research evidence, and discussed the opportunities, resources and supports we can create for children and youths who use AAC to become better writers.

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