Communication **Matters**

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THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

CM Conference Reflections - Learning Opportunities for AAC Users - AAC Club - Using Adapted PECS - Bridge School - Mobile App Development - Symbols - EyeTalk - Lockdown Experience - Study Day Feedback - AAC & Literacy Project

Communication Matters

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COMMUNICATION MATTERS JOURNAL
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Contents

CM member, Beth Moulam, competed in Boccia at the Tokyo Paralympics this year. Here she is (left) with her assistant (right) by the iconic agitos logo. Beth presented at the CM2021 conference, and her article will be in the next issue of the CM Journal in April 2022.

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Chair's Report

HELEN WHITTLE

I hope all of you managed a break over the Summer.

In September we successfully held our first ever all virtual conference. Thank you to those who were able to attend — we hope you enjoyed it. The survey for feedback has just closed and you can read more about the feedback we have received on pages 3 and 4.

Thank you to all the Presenters and Keynote Speakers, the Social Session organisers, MEETinLEEDS (particularly Anthony, Corin and Matt), all the Sponsors/Exhibitors, Friends of Communication Matters (CM), Session Chairs, and the volunteer student Conference Helpers – we couldn't have done it without you all! A huge thanks also to Vicky Healy, Brett Walsh and Sign Out Loud for their contributions to the AAC Awards evening. We were also so grateful to all our speakers who had to get presentations filmed and sent to us to allow us time to check them for sound and visual quality. We are glad we did this as three did need to be re-recorded. Thank you to all the Trustees who watched all 90+ presentations in this way during August. We were then able to add the closed captions, which had to be checked for accuracy, and so the Trustees stepped up again to check these. Thank you to them.

Do remember that everyone who registered for the conference has access until 17th December 2021 to watch the presentations they missed. So, unlike a face-to-face conference, you can watch everything you are interested in. Sometimes it is difficult to decide what to attend, but why not take this opportunity to watch a presentation from an area that is not directly linked to your area of work? Sometimes this is a great way to reflect on and learn things that may help our area of work.

We held our first Associate Members meeting since 2019 as part of the conference. Minutes of this meeting can be found in the Members Area of the CM website. We said goodbye and thank you to three Trustees: Zoe Clarke, Nicola Hayton, and Vicky Healy. We also welcomed new Trustees: Katherine Broomfield, Helen Hewson and Tina Voizey onto the Board and co-opted Neil Hansen back as Treasurer. Welcome to you all. The Trustees will be holding a face-to-face Board meeting at the University of Leeds in early November. This will be the first face-to-face Board meeting since March 2020. It will be great to meet in person, especially as we have new Trustees to welcome and introduce to the workings of Communication Matters.

The virtual conference culminated with our second AAC Awards ceremony, which was a wonderful celebration of the AAC community. Thank you for all your nominations and congratulations to the winners! You can find details of all the winners on our awards website here - https://eu.eventscloud.com/ehome/aacawards2021/winners/.

We continue to be on the steering group for the Communication Access UK (CAUK) initiative. On Wednesday 17 November 2021, CAUK partners will jointly celebrate the first anniversary of the training and its associated symbol. Over 4,500 businesses and individuals have already registered for the free training, but with your help, we'd like to encourage many more organisations to sign up. So, to mark the first anniversary, please join us on 17 November to create greater awareness of people's communication difficulties and how this fantastic business tool can benefit everyone. We'll be posting content along with our other partner organisations on social media throughout the day using the hashtag #CommunicationAccess, but we'd love to see your posts too. Find out more at https:www.communication-access.co.uk.

The AAC user focus group for Communication Matters continues to hold monthly meetings remotely to discuss the running of CM and its activities. Please be reminded that if you are an AAC user and would like to take part, then you can contact our Trustee, Andrea Sharples, on andrea.sharples@communicationmatters.org.uk and you will be sent details about how to join in.

Our members have continued to fundraise for us, which is hugely appreciated. One stand-out contribution is from the team at Liberator who celebrated their 30th Anniversary by giving themselves a proper challenge in the form of the "Yorkshire Three Peaks". The team raised money for Communication Matters whilst they walked 24 miles and climbed 1585m, all in 12 hours. They started and finished in the dark! So far, they have raised over £2000 which is fantastic! You can have a look at their JustGiving page here https://www.justgiving.com/fundraising/liberatorltd. A big thank you from us.

Communication Matters Virtual Conference 2021

HELEN WHITTLE

If you attended the CM Virtual Conference 2021, you will have received a few emails afterwards asking for your honest feedback about the conference and the whole online experience.

The questionnaire is now closed and has given us a useful insight into what worked and what we need to improve on for any future online events. This feedback has been useful and will also help us with planning the next in-person Conference in 2022. Thank you to the 80 people who completed the survey.

**367 individuals registered to attend the conference from across 20 countries.
47 of these places were subsidised places for AAC users and their family members.
37 attendees were AAC users, and 32 students attended.**

Most people watched some elements live, and most also made use of the ability to watch presentations later in the day when it suited them. 30% of delegates who responded to the feedback survey said they made use of the Closed Captions available along the bottom of the screen in all presentations.

Many people were familiar with the Communication Matters conference, with 57% having been to a CM event previously. But the conference was a totally new experience to 43% of the people who attended, which is so good to hear.

48% were not members of Communication Matters, but of these, the majority would consider becoming members in the future.

Feedback regarding the overall sessions was generally very positive, with 54% of presentations being rated 'Excellent' and 43% being rated 'Good'. 96% of delegates thought that the conference represented value for money, which is good to hear as it was a clear increase in cost from 'The CM Sessions' in October 2020, but there was so much more on offer this year and we had hoped to gauge this right.

96% of delegates thought that the conference represented value for money

85% of individuals said they learnt something that will change how they do things in the future and 97% would be keen to hear more about future online events.

The questionnaire also had space for delegates to make specific comments about individual sessions. We received lots of these, especially about the keynotes and some presentations that particularly sparked interest in new and innovative areas.

Any negative feedback we received was around missing the face-to-face contact, human interaction and networking elements of a physical conference, or missing hands-on time with AAC devices but we hope to bring all of that back in September 2022! Some people asked for more live sessions and more handouts, but these were limited this time around due to staff capacity. Someone said they, "missed the atmosphere and connection of the live conference, [but] having said that, the virtual conference has lots of benefits." We agree that there are pros and cons to both physical and virtual events.

We agree that there are pros and cons to both physical and virtual events

The virtual event did have fewer costs associated with it than a physical event. Thanks to your registration income, two small grants, and due to kind sponsorship from our supplier members, exhibitors, and from MEETinLEEDS for the conference software and their staff time, we were able to generate income for the charity from this event which will see us through to our next physical conference in September 2022!

Trustees' News

Here are a few of our favourite comments from the feedback survey, when people were asked what they liked best about the conference:

"Thought-provoking presentations; the variety of presentations - clinical practice, research, considerations on various AAC-related topics."

"Opportunity to go back and watch other presentations, when the conference was face-to-face you had to choose and it was always difficult if you had to choose between two presentations that you wanted to see, or you'd choose something that wasn't relevant. Being virtual this didn't matter and you can watch everything!!!"

"I could watch presentations in my own time."

"Being able to view presentations after the set time so it is possible to attend more than one presentation in each session and to rewatch particularly thought-provoking sessions."

"Very well organised. I attended with colleagues and I would highly recommend next time. The variety of sessions was excellent."

And when asked what delegates learnt, some people said:

"Made me more aware of the different aspects of AAC."

"I am relatively new to AAC, so I learned a lot about the user's perspective, and best practice for working with users and families."

"Learnt so much during the conference, I really appreciated when presenters provided signposting to websites that I could use practically day to day."

"Having known next to nothing about AAC, I got a good idea of what technology is currently out there, and some of the key things to bear in mind when choosing and using AAC."

Reflections on 28 Years of Communication Matters Conferences

ALLAN WILSON
Information Officer, CALL Scotland (Communication, Access, Literacy and Learning)
Allan worked at CALL Scotland from 18.10.93 – 31.8.21
Email: call.scotland@ed.ac.uk

Earlier this year I mentioned to Emily that my record run of attending every CM conference since 1993 would be coming to an end as I planned to retire at the end of August. Ever keen to get contributions for the Communication Matters Journal, she asked me to write an article reflecting on past conferences.

I started working as Information Officer for CALL Scotland (then, The CALL Centre) at The University of Edinburgh in October 1993, and within a week I was travelling down to Portland College, Mansfield with Paul Nisbet (now Director of CALL) and Gillian McNeill (then with FACCT in Fife, but now with CALL) for my first Communication Matters National Symposium. Sally Millar from CALL was already there when we arrived as she had been involved in Trustee meetings earlier in the day. For me, it was a case of being thrown in at the deep end, but it provided a perfect opportunity to find out what AAC was all about. I was struck by the friendliness of the delegates, particularly when I caused confusion with a badge that still said "Helen Galloway", whom I had replaced. The general friendliness of the CM conference has lasted well!

The Symposium seemed very busy, with around 140 delegates attending 30 workshop presentations, 3 plenary sessions and an exhibition with 10 suppliers, spread across 12 slots. These numbers have all grown significantly over the years, with nearly 450 delegates attending 80 presentations, 7 timetabled meetings, 2 plenary sessions, 11 poster presentations and an exhibition with 18 suppliers and organisations in 2019.

The Venues

During my time, the conference has changed venue three times, starting with the move from Portland College to the University of Lancaster in 1994, then to the University of Leicester in 2004, before settling in the University of Leeds in 2013.

The conference had definitely outgrown Portland College by the time of the move, and there was also a feeling that we were imposing on the lives of the students, despite it being their half-term break. Most of their possessions had been locked into cupboards in the bedrooms we were using, but there were still students on campus whose lives were disrupted by so many visitors descending on their campus.

Coming from Edinburgh, the move to Lancaster gave us a welcome reduction in the length of the journey, while the opening of the George Fox conference centre in 1995 provided good space for the exhibition and for plenary sessions, but the number of breakout rooms became an issue as the conference expanded. The layout of the campus also created problems, particularly for wheelchair users, as accommodation and dining facilities were at the opposite end of the campus from the conference centre, with delegates facing a long trail from one end to the other.

The University of Leicester was more popular than Lancaster with delegates from the South, and addressed the space issue from Lancaster, but there were other problems. Some of the accommodation was old and not up to current standards, while there wasn't a single space large enough to hold the conference dinner, which had to be split between two buildings. The Supplier Exhibition was held in a marquee erected specially for the conference – it leaked in bad weather. More importantly, two roads with significant traffic cut through the campus, creating a hazard for wheelchair users.

The University of Leeds has proven to be the best venue yet for the CM Conference, with excellent support from Meet in Leeds. It more than meets the basic requirements for the conference, though there can be a bit of a trek between the accommodation and the various rooms used for the presentations and exhibition.

The Conference Programme

Looking back, I am surprised how little change there has been to the basic structure of the conference over the years. In 1993, the Monday Programme, for example, consisted of:

- A plenary lecture (Dr Tom Vincent)
- 3 x workshop sessions (1 hour)
- Lunch/exhibition (1.5 hours)
- 2 x coffee/tea/exhibition (1 hour each)
- Communication Matters AGM (1.5 hours)
- Conference Dinner & Raffle
- Barn Dance

By 2019, the conference had extended into Sunday afternoon with the CM AGM, award ceremonies, a drinks reception, supper and Pub Quiz, but the Monday Programme still consisted of:

- A Plenary Lecture (Karen Erickson)
- 4 x 45-minute workshop sessions
- 1 x 45-minute exhibitor session
- Lunch / Exhibition (1 hour)
- 2 x 30-minute Coffee/Tea/Exhibition sessions
- Conference Dinner & Raffle
- Disco

Throughout this time, there has always been a mixture of stimulating keynote presentations by leading specialists from AAC and related fields, accompanied by a broad range of workshops aimed at people with different knowledge and experience of AAC. Two keynotes at the 1993 conference were particularly memorable for me, providing a debate between advocates for Dynamic Graphic Displays and Semantic Compaction (Minspeak) as different methods for constructing a message using a communication aid. Walt Waltosz from Words+ spoke for Dynamic Displays, which allows an AAC user to navigate a path through different screens of symbols and words to put a message together, while Barry Romiche from Prentke Romich Company supported Minspeak, which allows the user to create a message by pressing a short series of symbols with different meanings depending on context. Dynamic Displays probably won the battle, as this is the system now used on most computer-based communication devices, but Minspeak can still be very effective for some people.

Between 1997 and 2002, CM ran the Distinguished AAC User Award, to give people who use AAC practice in preparing and delivering a presentation, and to encourage them to submit a presentation to the ISAAC international conference. By the time it came to an end, many people who used AAC were able to give excellent presentations, so there was no longer a need to provide a special slot. I think every conference I have attended since 1997 has included a plenary session with a presentation given by a person using AAC. The presentations by Alan Martin and Martin Pistorius were outstanding.

The workshops were always interesting, often giving an indication of future directions of travel in AAC. Eye-gaze, for example, was first mentioned as a method for accessing AAC back in 2005 in a workshop featuring the ACE Centre's work in the COGAIN Project, and has featured in almost every conference since. Since 1995, much of my time at CM has been taken up with looking after the CALL stand in the exhibition, but I have always tried to find time to attend workshops, and even presented a couple on AAC Resources on the Internet in 2001 and 2003. Since then, my presentations have been restricted to supplier sessions, focusing on the work of CALL Scotland.

Figure 1: Allan and Paul from CALL with Sandra Miller from FACCT in the Exhibition marquee in 2007

The Exhibition

I have vague memories of the exhibition at Portland College consisting of tables scattered around a corridor, or hallway, with most having a tablecloth covered with random bits of equipment and a few fliers, and a pop-up banner stand behind the table. Things have moved on since 1993, with most exhibitors now having professional stands. There were ten companies in the exhibition in 1993, most now long gone. Whatever happened to Cambridge Adaptive Communication, who provided a voice for Stephen Hawking and MARDIS? Of the ten, Liberator are still going strong, though I think CM regular, Mark Street, has only been with them since 2002. For some of the other 1993 exhibitors there is a clear link to a present-day supplier, e.g. Paul Hawes' work with the Foundation for Communication for the Disabled leading to the birth of Smartbox and the Lightwriter, originally developed by Toby Churchill Ltd and now distributed by Abilia.

There is a definite sense of community among the exhibitors, with rivalry less intense than in many other fields, and people regularly moving from one company to another. There was a time a few years ago when I would arrive at CM wondering who Neil Hansen, Martin Fisher and Martin Green would be working for this year.

The Social Side

Many people attending the CM Conference only see each other once a year, so it is inevitable that the social side of the conference becomes important as people catch up over a pint, or a glass of wine, particularly on the Sunday evening. There was always a programme of social events, but it was not unusual for a team competing in the Sunday Night Pub Quiz to lose a star performer as a result of a chance encounter with a long-lost friend at the bar. I became quite popular on Quiz night as I developed a reputation for knowing the answer to obscure questions such as the name of the Scottish cricket team that won the National Village Cricket competition (Freuchie) and recognising African and South American states from an outline on a map.

Figure 2: SCTCI at CM Conference 2018

Monday night featured the Conference dinner – for many years delegates would arrive wondering how the chicken would be served this year. (There was also a vegetarian option.) In recent years, 'fancy dress' has been encouraged for the dinner, with some people taking this more seriously than others – SCTCI and the ACE Centre have both put a lot of effort and creativity into their costuming, while Toby Churchill, Smartbox and Tobii Dynavox have all come to the fore from the supplier side.

The Conference dinner would almost always over-run, leaving whoever was providing the music for the dance (disco/barn dance/ceilidh) worried that nobody was going to turn up. They needn't have worried – people at CM usually know how to party! In my early years attending the conference, there would often be a musical interlude of calm as Paul Hawes (FCD/Smartbox) brought out his harp and started to strum.

In the past, particularly when the conference was held in Lancaster, the dance would lead into a night of hard drinking for many, so people attending workshops at 9am on the Tuesday morning could never be sure if the presenter would turn up, or be well enough to finish the session. Levels of sobriety on Tuesday morning have definitely increased since the Lancaster days!

Figure 3. Allan, Gillian and Paul at the 2017 Communication Matters Conference.

Final Thoughts

Many people look back on conferences with memories of the major keynote presentations that have changed their way of thinking, or the launch of a new device that has had a positive impact on the lives of so many people. I certainly have these memories, but I also remember more personal moments, like being approached by an SLT and thanked for the help I provided when she was a student many years earlier that led her to follow a career in AAC.

As I write, colleagues are looking forward to a second Virtual CM Conference, but, equally, hoping that 2022 will see the return of an in-person conference, which has been missed so much during these pandemic days. Who knows, I might even come out of retirement and pop down to Leeds for a visit!

This article can also be watched on video at:
https://youtu.be/pBEvNHk9U4w

Making the Most of our Fully-Funded Learning and Development Opportunities for AAC Users (c/o the National Lottery)

A story from one AAC user

During the global COVID pandemic, from May to October 2020, whilst in the national lockdown, I completed the NCFE Level 2 in Employability Skills. The funding for this course came from the National Lottery, and was given to Communication Matters. Creativity in Practice delivered the Employability Skills training. Communication Matters is a UK-wide organisation that supports people of all ages who use Augmentative and Alternative Communication (AAC). Their mission is to help people who struggle to communicate – through education, events, training and lobbying.

My learning and training were completed on the computer. My tutor, Verity Elliott, sent me worksheets and coursework via email. I would complete this and then return it to my tutor for marking.

> *I think it was fantastic, because* Communication Matters *understand about the needs of AAC users.*

Verity and Communication Matters made it very accessible and inclusive for me. The funding received also allowed for a BSL interpreter to support me. I would not have been able to access the course without an interpreter. Because we could not meet in person, my interpreter met me on Zoom twice a week for a two-hour session. My interpreter was able to sign and interpret the work that my tutor had sent to me. My interpreter would also scribe for me, ensuring that my answers were captured and typed out on the computer, and then sent to my tutor. Meeting on Zoom worked really well. I was able to see my BSL interpreter, and we could share documents on the screen. I use a communication aid (Dynovox) to communicate, as I have no verbal speech. I would type my answers out on my Dynovox, and then play them aloud for my interpreter to listen to and then scribe for me. It was a smooth process, but there was also lots of hard work involved.

I think it was fantastic, because Communication Matters understand about the needs of AAC users. They gave me the time I required to process and digest the information, and didn't rush me to complete the work. Verity also communicated with me and my interpreter regularly via email, which is my preferred method of communication. She provided me with detailed feedback throughout each unit of the course. My tutor, interpreter and I all had to work closely together in order to achieve the results.

For more information, please take a look at the following link:
https://www.communicationmatters.org.uk/what-we-do/projects/mentoring-project/

Communication Matters

CiP

COMMUNITY FUND

"Is he the only one with something like this?"

Reflections on Running an AAC Club Bringing Users and their Families Together

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Introduction

Systematic reviews conducted by Baxter, Enderby, Evans, and Judge (2012) and Moorcroft, Scarinci, and Meyer (2018) emphasise what many of us on the ground know: integrating an AAC system into daily life is challenging. Speech and Language Therapists aim to help educators and families to use AAC in their everyday interactions by using effective implementation strategies such as Aided Language Input (ALI; O'Neill, Light, & Pope, 2018). However, putting these techniques into practice can be difficult, particularly for family members who often don't come across others that use AAC. In order to provide support to the families of Aided AAC users, SLTs from the Brothers of Charity Services Ireland, Southern Region, (BOCSI-SR) set up a monthly Saturday 'AAC club'. The goal was to create an immersive environment where family members could observe ALI being used and engage in opportunities to use their child's AAC system themselves. The club aimed to provide informal training and support through the presence of SLTs, supported by university student volunteers, while providing a space for parents to meet other families.

Club AACtivate SLTs

Club AACtivate was held in a special school and utilised the gym hall, a corridor, the sensory room, the multi-disciplinary team room and an outside space with swings. A tent provided an additional quiet space. There were two sessions: the first for AAC users under ten years of age, and the second for users over ten years old. Each session followed a set schedule that was shared with family members by letter in advance and via Social Stories™ with the AAC learners. Free-flow time to access stations was staggered between two whole-group activities to bring people together. A shop was open for the second half of the session. All participants had a diagnosis of intellectual disability, and most were also autistic. Parents had been introduced to ALI individually with their SLT, and some had attended training held by members of the SLT department over two evenings.

The communication and regulation needs of the participants necessitated that plenty of facilitators be available to allow for individualisation of the timetable where needed. 8 -12 volunteers joined the 6 SLTs in running the club each month. They were made up of 4 SLT students from University College Cork (UCC), 5 recently qualified SLTs who were seeking AAC experience, and 3 members of the general public. The volunteers were provided with tutorials on AAC and ALI.

The roles of all attendees were clearly identified in advance. Family members were asked to accompany their child throughout the session, provide guidance to and build confidence in their child by taking part in activities themselves, and "speak AAC", using their child's AAC system to whatever level they felt comfortable. Volunteers were asked to facilitate activity stations and to "speak

AAC" by adding symbols to their speech using wearable coreboards. SLTs were responsible for corresponding with parents and volunteers, devising the session plans, designing activities and facilitating the session.

Before and after the club took place, researchers from UCC interviewed parents about their knowledge, use and experience of using AAC, their expectations for the club and experiences in taking part. The SLT students who volunteered for the club were also interviewed before and after taking part.

Child and mother

Method

Participants

Following ethical approval, the purpose of the research project was explained to all families, and they were invited to participate. Participants included the parents of ten AAC users with an intellectual disability, nine of whom were also autistic. The AAC users themselves were male and aged between 5 and 17 at the time of interview. Four used symbol-based "no-tech" systems and six used symbol-based "high-tech" systems. The student volunteers that took part in the research were in their third and final years of study on the BSc in Speech and Language Therapy course.

Procedure & Research Design

Semi-structured interviews were conducted by phone with parents, and through focus groups with students, in September 2019 and again in May 2020. Ten parents participated in the pre-club interviews and seven participated in the post-club interviews. Three student SLTs took part in the pre-club focus group, and two in the post-club focus group.

Data Collection and Analysis

Parental interviews and focus group discussions were transcribed and anonymised using pseudonyms. Transcripts were coded by two researchers before being grouped. Transcripts were analysed using thematic analysis (Braun & Clarke, 2006).

Results

Due to COVID-19, only four of the planned eight sessions were conducted between October 2019 and February 2020. Across the 4 Saturdays, the average number of AAC users who attended was eighteen, and the average number of family members was thirty two. Following cessation of the club, a playlist of YouTube videos focused on using ALI in daily life was created, for remote support.

Pre-Club Themes

The pre-club themes centred on current and previous use/attitudes towards AAC systems. Below is a table of the themes and subthemes identified in the pre-club interviews. "Lámh" is the Irish-adapted key-word signing system used with people with an intellectual disability.

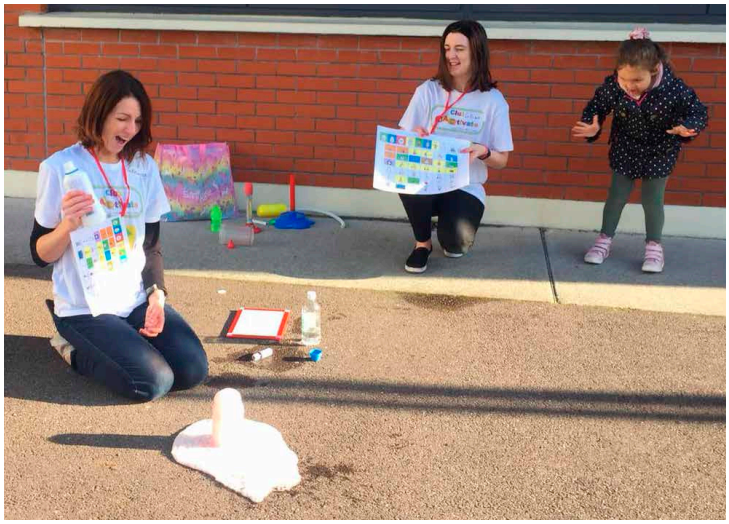
Table 1- Pre-Club Themes

Themes	Subthemes	Examples
Current Circumstances and Aspirations for the Club		• Social opportunities for children • Meeting other parents • Broadening contexts in which AAC system is used
The Perceived Role of AAC		• Positive attitudes towards AAC • Appeals to visual learners • Supports communication and conversation
Impact of AAC on Education		• Academic progress • Increased confidence
Changes in AAC systems	The Limiting Nature of Picture Exchange Communication System (PECS)®	• Increased verbal communication • Becomes obsolete with age/communication progress • Limited communication acts – i.e. requesting only • Limited vocabulary
	The Use of Lámh©	• Lámh© as a secondary AAC system • Difficulties with accurate sign production • Limited communication partners
	Attitudes Toward Communication Boards (low-tech AAC systems)	• Positive attitudes towards personalisation of board • Problems with updating fringes

Before attending the club, parents reported an interest in their child interacting with other children outside of the school setting, meeting other parents, and broadening their own and their child's use of the AAC system.

> ***"I'd like to see....try get him to interact because he doesn't interact a whole lot"***
>
> **Parent 10**

> ***"I suppose just for myself to kind of link in with other families- {who have} a child that uses a device as well"***
>
> **Parent 4**



Club AACtivate SLTs and volunteers

Post-Club Themes

There were three major themes evident in the post-club parental interviews: "Experience of the club", "COVID-19" and "Suggestions for the future". Within these themes various subthemes emerged, as illustrated in *Table 2*.

Table 2 - Post-Club Themes

Themes	Subthemes	Examples
Experience of the club	Activities and Environment	• Satisfaction with station system • Appropriate to have quiet areas
	Relationships with SLTs	• SLT knowledge and helpfulness
	Impact of club on Family Members	• Knowledge gained by other family members
	Parental Confidence	• Increased confidence • Increased knowledge • Increased confidence for other parent
	Interactions with other Families	• Limited opportunities for interactions
	Social Outlet for Children	• Social outlet besides school • Sense of belonging
COVID-19	Families' Use of Videos	• Helpful and worthwhile for parents • Limited interest in children
	Experience of Lockdown	• Coping well during lockdown • Communication and use of AAC system during lockdown
Suggestions for Future	Timing and Duration	• Increased number/duration of sessions
	Allocation of Volunteers	• Matching similar personalities • Consistently matched with same volunteer
	Activities and Environment	• Expand quiet areas • Make use of outdoor areas
	Support for Parents	• Group families with same AAC system • Interest in increased opportunities to interact with other families

There were mostly positive reports from parents when asked about any increase in their confidence with their child's AAC due to the club. Another parent reported no change for themselves but an increase in confidence for their child's other parent. Parents reported that although the club provided a social outlet for their children, the sessions were too busy for them to talk to or interact with other parents.

Parental Confidence

"It [the club] did give us that confidence alright and made us realise that there's no point in having it over on the worktop and we not using it"-

Parent 9

"I found it good to see the SLTs demonstrating and showing you different situations how to use it" -

Parent 5

Social Outlet for Children

"There's not a lot of places you can bring them to where he doesn't stand out … it's great to bring him to a place where he's not different from a*nybody else." –*

Parent 10

Parental Support

"To be honest I wouldn't mind some refresher training … some kind of parent group … sometimes it's nice to meet other parents in the same situation you know but it's very hard when the child is swinging out of you" –

Parent 3

SLT Students

Themes from pre- and post- club student focus groups have been combined as illustrated in the table below. A sample of some comments are included below the table overleaf.

Themes	Pre-/Post-Club	Examples
Bridging the Theory-Practice Gap	Pre-Club	• Hoped to gain practical experience
	Post-Club	• Gained Practical Experience
Impact on Learning and Confidence	Pre-Club	• Lack of confidence working with AAC
	Post-Club	• Increased Confidence working with AAC • Learning with Parents • Lack of Assessment
Support from SLTs	Post-Club	• Comprehensive Training • Parental Expectations
Perceived Experience of Parents	Post-Club	• 'Normalising' AAC • Learning with Parents • Brief Interactions between Parents

Bridging the Theory-Practice Gap

"We have studied AAC in class and in lectures but theirs [the tutorials] was the practical side of SLT about getting it acquiring and AAC device and practically choosing which one is best going about getting it"

Student 3.1

"I think in terms of skills, I hadn't really had a placement or experience working with children who use an AAC device so I kind of felt a big difference myself between the start of the day and the end of the day ... and being able to cue myself with the kids and realising to let them take the lead, usual clinical things that you just need to practice in"

Student 3.1

Discussion

Overall, there appears to be a benefit in continuing to provide the AAC club. The quality of the support provided by SLTs was commended, and the current structure of the sessions was deemed largely appropriate by parents and students.

Based on the analysis of parental and student transcripts, a number of suggestions were identified that may enhance their experience should the club be run again:

1. The addition of an optional coffee break for 30 minutes when the club is finished would allow parents to meet other families.
2. Quieter spaces for members who cannot tolerate the large hall should continue to be provided.
3. Families could be matched with the same tutor over consecutive weeks to allow rapport building.
4. Ensure parents have access to a clear, efficient pathway to request updates to their communication boards' fringe vocabulary.
5. The YouTube videos were well received by parents and may indicate the feasibility for online training in the future.
6. The fact that volunteers are not qualified SLTs should be regularly re-emphasised with parents in order to meet expectations.

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This article can also be watched on video at:
https://youtu.be/VZb67rgxDPU

The Use of Adapted-PECS: Promoting Functional Communication and Speech in Children with Autism Spectrum Disorder (ASD)

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Introduction

The purpose of this article is to report the clinical experience of a Speech and Language Pathologist (SLP) in Brazil. Ten children with Autism Spectrum Disorder (ASD) without functional speech participated in the study. The results of early language therapy using Augmentative and Alternative Communication (AAC), specifically with the use of Adapted-PECS, showed the participants started to request more easily and expand their functional expressive vocabulary.

Figure 1 - Speech and Language Pathologist using Adapted-PECS in Phase 1.

Autism Spectrum Disorder (ASD) is a severe neurodevelopmental condition characterized by impairments in behavior, speech and language, and social communication. It is estimated that between 25% and 61% of people with autism do not develop articulate speech or functional speech to communicate their desires and needs (Weitz et al., 1997). According to Klin (2006), individuals with ASD have, before three years old, significant impairments in communication and socialization skills.

Considering the deficits in the functional communication of children with ASD, they are candidates for Augmentative and Alternative Communication (AAC), which proves to be a very effective strategy in the acquisition of a communicative repertoire and social interaction skills (Mirenda, 2003). Thus, early introduction of an AAC system for people with autism is essential, such as PECS (Bondy & Frost, 2001) and Adapted-PECS (Walter, 2000).

Adapted-PECS - Engaged People Communicating Socially

The Picture Exchange Communication System (PECS), described by Bondy and Frost (2001), combines principles of applied behavior analysis (ABA) with graphic symbols. PECS is one of the most prominent aided AAC interventions to enhance functional communication skills in autism (Ganz et al., 2012).

A version of this system proposed in Brazil, with modifications in its application regarding the phases of the program and the forms of registration, was called Adapted-PECS (People Engaged Communicating Socially - Walter, 2000, 2015).

Table 1- Summary of Differences Between PECS and Adapted-PECS

PECS and Adaptations to the Natural Functional Curriculum → Adapted-PECS

PECS (Bondy & Frost, 1994; 2002)	**Adapted-PECS (Walter, 2000; 2006)**
7 Phases at the beginning, and 6 training Phases later on	Adapted-PECS (People Engaged Communicating Socially) consists of 5 phases
No verbal prompting until phase IV	The whole program uses natural dialogue, verbal prompting and speech modelling
Physical trainer supports learner in Phases I and II	Can be carried out with or without a physical prompter to assist in exchanges
Training done in specific, selected environment	Training done in natural environment of school, home and community
Only authorised trainers can train new professionals to use PECS. Requires official training and accreditation	Replaces carrier-phrase 'I see' with 'I am' and uses emotion symbols in a natural teaching context
Uses the term 'reinforcer' for the desired item in Phase training	Anyone can use Adapted-PECS with learner: teachers, parents, professionals = growth in awareness and use
	Uses the term 'item you want' and support is given depending on level of need

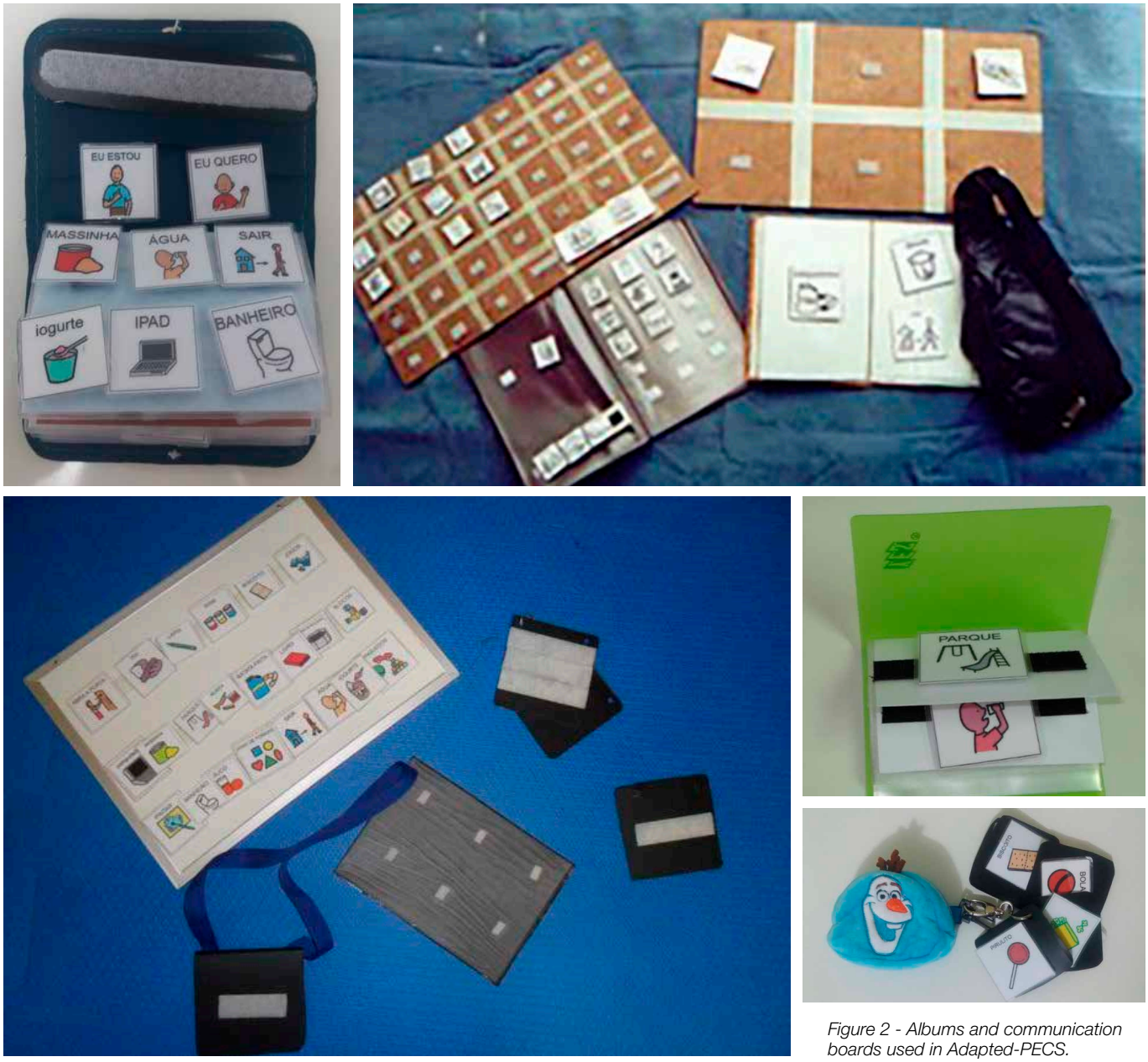

Figure 2 - Albums and communication boards used in Adapted-PECS.

The proposed adaptations were based on the methodology of the Natural Functional Curriculum (Leblanc, 1991) and consist of a program divided into five phases, where the interlocutor interacts, through the exchange of communication cards, with the person with autism (or other severe deficits in oral communication which present with difficulties initiating dialogue spontaneously or with serious social disabilities). For example, Adapted-PECS is indicated for individuals who try to remove objects from people's hands, or who cannot point or even indicate the desired items to others. In these situations, the interlocutor should make sure that they are presenting an irresistible item for a particular child, and the child should then be encouraged to exchange a picture for the item. Thus, the item becomes naturally reinforcing and the child starts to request the item again, delivering the desired picture to the communication partner, in a relaxed way. The symbols used may be from PCS, ARASSAC, Google images, photos, drawings, etc. See Figure 2.

Considering the importance of early initiation of language interventions with children with behavior suggestive of ASD, this presentation aims to describe an account of the professional experience of a clinical Speech-Language Pathologist (SLP) detailing the development of language through the use of Adapted-PECS by children with signs and symptoms suggestive of ASD.

Subjects

Ten children with a diagnosis of ASD who started the therapeutic process between 1-3 years of age and who presented with deficits in communication, especially in the development of language, pragmatic function and speech. It is important to note that the study is longitudinal, and that in the follow-up phase the children were already aged between 3-5 years.

Methods

This was a descriptive clinical experience study. The families sought the Speech-Language Pathology service in several ways: on their own initiative, simply because they noticed a delay in speech acquisition; by referral from doctors (especially neuropediatricians); and by referral from day care centers/schools that perceived difficulties with speech and language and/or social interaction. Participants attended speech therapy sessions individually at the Conecta clinic. The sessions were held twice weekly, lasting one hour each session. The participants were eight boys and two girls. At the beginning of the therapeutic process, they showed behavior typical of the disorder, namely: lack of communicative intention, infrequent and inconsistent eye contact, instrumental action (using the adult as instrument), rarely answering when their name is called, and sensory disturbances. Participants had unusual behaviors, with variations among them, namely: four had restricted interests; five had little social interaction; nine participants were nonverbal – one participant being verbal, but not functional; five of them had little functional use of objects, and one presented with apathy and generalized demotivation.

Analysis

The cases were analyzed by assessing the participants' language and use of AAC, and the communicative behaviors presented before and after the application of the Adapted-PECS program.

Results

All participants were able to reach Phase 1 and Phase 2 of the Adapted-PECS program, being able to request a desired item by delivering a communication card to the Speech-Language Pathologist. There was an increase in the communicative intention of all participants. They advanced their use of AAC and shared action. It was also possible to observe that all the participants showed development of multi-modal communication: use of AAC combined with some spoken words.

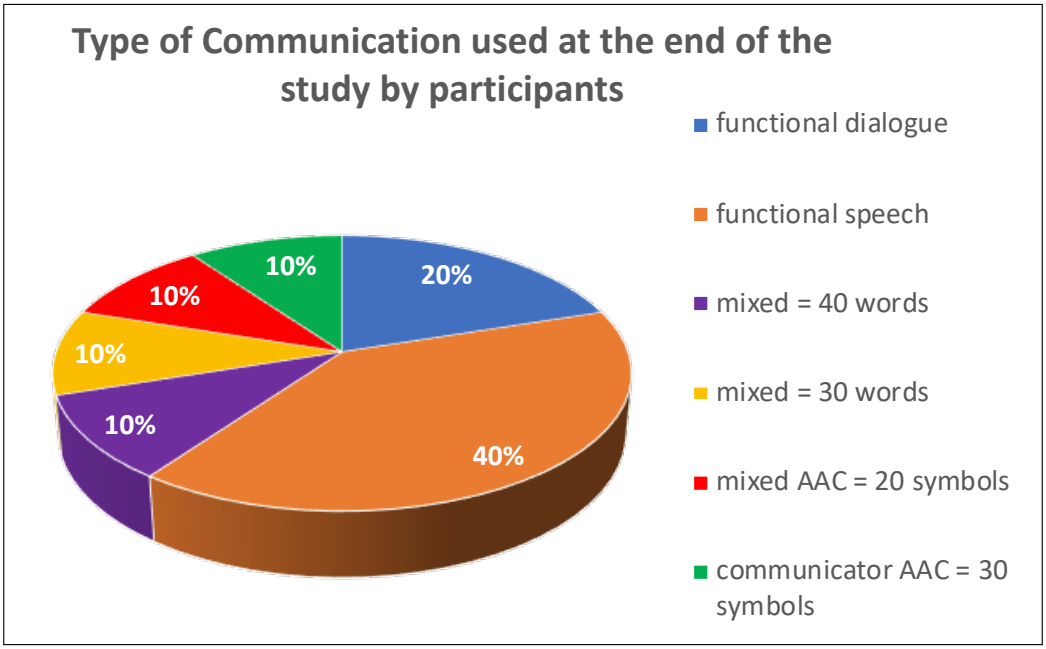

Figure 3 - The different types of AAC and the participants' speech at the end of the study.

Participants developed their ability to discriminate between symbols, and began to use communication cards with the intention of communicating something. In Phase 3 of Adapted-PECS, which aims to provide image discrimination, participants P1, P2, P3, P4, P5, P6, P7 and P9 broadened their communicative ability through AAC. Participants P1, P3, P4, P5 and P6 initiated the use of functional speech and did not need to continue with Adapted-PECS. At the end of Phase 3, participants P1, P3, P5 and P6 were given Speech-Language Pathology, with monitoring, after a period of between sixteen and thirty-six months of therapeutic intervention. In this sample, P2 was the only participant who needed to maintain Adapted-PECS use, and progressed to Phase 4. *See Figure 3.*

A follow-up took place 2 years after the results of the sessions, to find out how the ten participants had progressed. Only two continued in the Speech-Language Pathology service, using AAC, and the others developed functional speech.

Discussion

Considering this present case study, it is very evident how important the SLP's work is in using alternative forms of communication, and especially the use of PECS or Adapted-PECS in promoting an increase in communicative acts and in social interaction with different interlocutors (Mizael & Aiello, 2013; Togashi & Walter, 2016). In this context, PECS and Adapted-PECS look to be very promising, already accumulating several reports of excellent results, as in the cases presented here (Nunes & Walter, 2018; 2013; Walter, 2015).

Conclusion

More important than a communicator, than a system, communication book, pictures, Ipads, photos, etc... is the "person" with whom we are exchanging ideas, feelings, desires...communication is fundamental in life!

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This article can also be watched on video at:
https://youtu.be/Z09PrWVgmpU

The Bridge School Breaks New Ground – Yet Again

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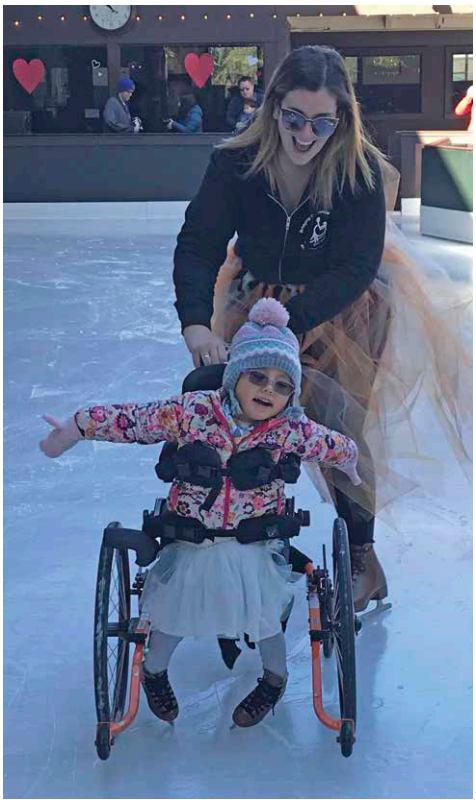
When singer-songwriter Neil Young and his wife Pegi went looking for a suitable school placement for their non-speaking, wheelchair-using young son, Ben, they hit a wall. There was no school that really met Ben's puzzling variety of needs.

When the last real possibility evaporated, Pegi was in tears. "So, looks like you'll just have to start your own school," chimed in their friend (and Neil's agent) Elliot Roberts, in an effort to cheer her up.

So, she did. And now, more than thirty years later, The Bridge School (TBS) still stands as a beacon of hope for young children who have severe physical disabilities, cannot use their natural speech, and often face a variety of other challenges.

In those thirty plus years, The Bridge School in Hillsboro, California, has fulfilled, in a variety of ways, Pegi Young's vision of a small model school pioneering new and better approaches to respond to the needs of kids like Ben. Adaptations of the latest and greatest augmentative communication strategies, materials and devices; and the creation of an international Teacher-in-Residence program that has enabled scores of Speech and Language Therapists, special educators, et al., to come to The Bridge School, live the life of a Bridge staffer, and then bring back to their developing nation the advances pioneered at Bridge.

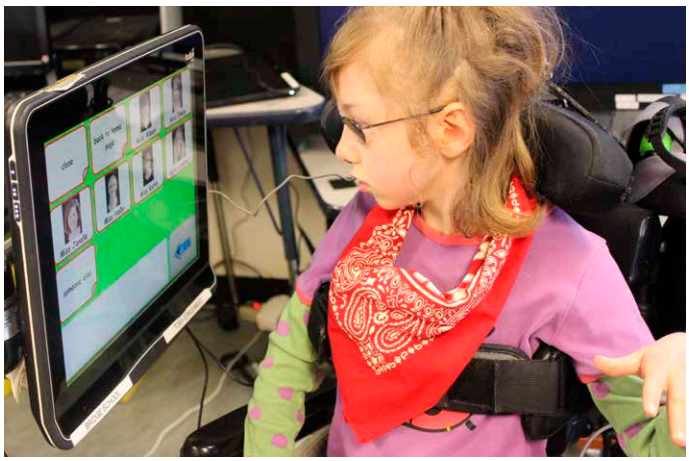
For example: an amazing hands-free upright mobility program that enables children who typically sit in wheelchairs all day and have no ability to move on their own, **to get up on their own two feet, start moving** and head to a learning station of their choice, or go out on the soccer field, or even – unlikely though it may seem – hit the ice-skating rink. And the list goes on – an early literacy program that gets remarkable results; a self-determination program that empowers powerless kids and teaches them to reach for more control over their own lives; a self-operated program that enables the alumni who are now adults, several of them college graduates, to plan and execute their own activities. That's just the tip of the proverbial iceberg, and this one is not melting anytime soon.



And now, in 2021, comes another valuable innovation that would warm the heart of the recently departed Pegi Young: a pilot research project that is demonstrating creative new ways to dig deep into the needs of the growing number of children born with Cortical Visual Impairment, or CVI.

It turns out that, over the decades, more than half of the students who attended the Bridge School experienced undetected and untreated CVI, as do most children in the world who have CVI today. Some ophthalmologists have never heard of CVI. Most children with CVI have never been properly diagnosed, or have been improperly diagnosed.

When ocular visual impairments were ruled out, recommendations to family members, clinicians and teachers on how to "treat" these children too often reflected a "best guess" approach that did not address the condition, or consider that treatment over time could and would result in improved visual function. Then, in 2012, in a dramatic turn of events, TBS found and put to work the world's leading CVI expert, Dr. Christine Roman Lantzy. With Christine's help, the ways in which the school assessed the students' vision changed, and they adapted their learning environments to meet individual students' visual needs. They figured out how to actually improve each child's use of functional vision over time, and



instituted ways to adapt their curriculum and pedagogy to meet the changing needs of these children. The impact of these changes reflected, not only improved communication outcomes for the students with CVI, but also the progress they were able to make across other developmental areas.

And then, to conduct the research needed to verify and certify the positive impacts of the CVI interventions, and then to help realize Pegi Young's dream of spreading The Bridge School's learnings far and wide, along came Sarah Blackstone. Blackstone is a pioneer in the development of Augmentative and Alternative Communication (AAC), a long-time Bridge School board member, the architect of TBS Teacher-in-Residence program as President of the International Society for Augmentative and Alternative Communication (ISAAC), and the "broker" who engineered the introduction of Christine Roman to The Bridge School staff. Blackstone has launched a multi-year project with The Bridge School staff, designed to make what The Bridge School staff and family members have learned about CVI accessible to the thousands of kids with CVI around the world.

How will this happen? With support from the school's executive director, Dr. Vicki Casella, and armed with the results of a careful and comprehensive, longitudinal research study embarked on in 2019, the research team plans to:

1 Develop a video-based curriculum about CVI for professors/instructors around the world who teach the teachers of the visually impaired, or who teach AAC without mentioning CVI (despite the demonstrable high-incidence among AAC users).

2 Collaborate with a funded California project designed to upgrade the knowledge and usage of AAC in six Northern California "Regional Centers" (for people with disabilities).

3 Present at conferences, publish in journals, develop YouTube videos and utilize other available media to provide details, specifics, strategies and insights to parents of, and professionals who serve, children with detected CVI, undetected CVI, poorly diagnosed CVI, poorly treated CVI, mistreated CVI, etc.

4 Promulgate the findings of the careful research that is documenting and describing the results of CVI interventions since 2012 at The Bridge School.

5 Develop a series of webinars and "just-in-time" instructional materials that focus on evidence-based tools, materials, and strategies to support children with CVI who also have severe speech and physical impairments.

Through these and other inventive and innovative means of dissemination, Blackstone, Casella, Roman, and their colleagues at The Bridge School and at the Bridge "satellite" CATIC program in Mexico City (founded by a previous Bridge School Teacher-in-Residence), hope to bring new hope to children and their families who for far too long have been kept in the dark about a growing health crisis in the United States, and other industrially developed countries, that has to this point been sadly under-recognized, inadequately treated when recognized, and usually ignored by policy makers.

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Development and Evaluation of a Mobile App to Assist People with Autism and Intellectual Disability to Engage in Social Conversation

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Introduction

The social relationships and interactions of people who have autism spectrum disorder (ASD) and intellectual disability (ID) are negatively affected by their communication and cognitive difficulties. Difficulty in developing relationships can increase social isolation and affect mental health. This paper describes the development of a prototype mobile smartphone app designed to provide access to a range of conversational communicative acts for adults with ASD and ID. The app was designed to promote a 'no-failure' approach to participation in a simple conversation. It was evaluated with a group of people with ASD and ID.

Intended population

People taking part in these investigations included those who used communication supports such as symbol-based boards and planners. They had associated conditions including:

- cognitive impairment associated with ASD and difficulties in processing information;
- intellectual disabilities, with difficulties in understanding others or in expressing themselves;
- literacy difficulties which might include some sensitivity about the use of language simplification.

Those with acquired conditions, such as aphasia and dementia, were not included in these investigations.

People with ASD have difficulty with social communication (Ganz, 2015) and demonstrate a restricted range of communication acts in conversation. The ability to make use of a range of communication acts is important in developing communication and having successful interactions. It is thus important to enable people with ASD to learn to use a wide range of communication acts in conversational situations (Logan *et al*., 2017).

Of various types of intervention used with people with ASD and ID, research has indicated more support for aided AAC (Augmentative & Alternative Communication) than unaided AAC or manual signing. In comparison to people with ASD alone, those with ASD and ID benefitted from using speech-generating devices (SGDs) and Picture Exchange Communication (PECS), and benefitted particularly from using SGDs (Ganz, 2015).

Mobile smartphone technology and AAC

Many approaches have been explored in the development of aided AAC (Beukelman & Light, 2020; Newell *et al*., 1995; Waller, 2018) and mobile smartphone technology offers certain advantages as a platform for AAC (McNaughton & Light, 2013). The devices are smaller and of lower cost than dedicated AAC systems; they give access to a range of applications, functionality and connectivity; they are socially accepted, and are relatively easy to use.

Mobile AAC technology and people with ASD and ID

While most emphasis in this area has been on developing early skills to request or protest (non-interactive), less attention has been given to developing skills of socially-motivated communication, such as story-telling and building social relationships (interactive). Of eight studies investigating the use of iPods® and iPads® with people with ASD and ID and complex communication needs, seven looked at requests and one at picture-naming (Kagohara *et al*., 2013). There is scope for applying mobile technologies for a broader range of communication purposes, such as social closeness and information exchange (McNaughton & Light, 2013).

Design requirements

A prototype AAC app for people with ASD and ID was proposed, using smartphone technology as an AAC platform to address social communication and encourage the user to develop and use a range of conversational communicative acts. The app would involve the communication partner (Tsai, 2017), be easy to use and appropriate for naturalistic settings, matching skills of the user and addressing challenges they face. The app was intended to foster a 'no-failure' approach to participation in a simple conversation, in that wherever the user tapped on the AAC interface the conversation would progress, with the user guided ultimately towards a satisfactory conclusion to the interaction.

Design and development

Design followed WCAG 2.0 guidelines and evidence-based good practice in design for the target user group (W3C, 2008). Single-button operation was used in the user interface, in order to limit the number of stimuli and options on the screen at any one time: too many options on the screen can be confusing for people with ASD (Elwin *et al*., 2013). Symbols, images and words could all be used as communication elements.

Personas were used to assist the designers in understanding and communicating the needs of the target user group, with user journeys created to help visualise a particular path that the user might take when using the application. Ideas and questions arising as the user journeys were developed could be captured to assist the creative process. Initial visual representations of the user interface were produced using wireframes, assisting the design of interface features (e.g., layout, button size) in relation to user personas.

Content and stages

The content of the app was organised as stages in a conversation. The sequence of stages adopted for a basic interaction is shown in Figure 1, stemming from research on conversation modelling for AAC (Alm *et al*., 1987; Murray *et al*., 1991). The content was hence arranged into groupings for greetings, smalltalk, main section with stories, wrap-up remarks and farewells. 'Wait' pages were included between stages to create pauses to encourage the user to turn-take during conversation. Example smartphone pages with pictograms for these stages are shown in Figures 2-to-7.

Figure 1: Sequence of stages for a basic interaction (after Alm et al.*, 1987).*

Functionality

The app opens on its home page (Figure 2), which shows a greetings button occupying the whole width and most of the length of the screen, supporting the 'no-failure' goal of the conversation app with simplified touch interaction. The user and conversation partner can tap the screen on each page (stage); the conversation will step through its stages from greetings, to smalltalk, to the story options page (main section). Tapping once or making a long tap will act as input and trigger a change of screen. At each stage, an appropriate pre-recorded speech message will play to accord with the text on the on-screen pictogram, depending on selected settings.

Three stories were programmed into the app to form the default content of the main section. Each story consisted of a sequence of pages (images) for the user to step through by tapping the screen. The first default story was about going to a café with friends, the second was about a charity campaign in the city and the third was about a new museum in the same city. These three stories were selected to be topically relevant for local users. A user could choose which story to use from a three-item menu which appears when the main section is reached (Figure 4).

New stories with images can be programmed into the app via the Settings button should the user/carer wish to expand or personalise the available repertoire of stories. The Settings button is located at the foot of the home page and is clearly labelled so that it can be easily located for adjustment of optional settings. By navigating through settings pages, the user or carer has the facility to personalise audio, labels and images to adapt individual stories. Optional text labels can be set to appear on each of the conversation pages, above or below the image. New speech messages can be recorded to match individual pages.

Figure 2: Home page, with Greetings stage & Settings button.

Figure 3: Smalltalk stage, to follow the Greetings stage.

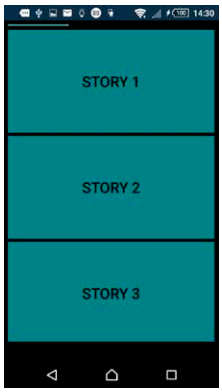

Figure 4: Main stage, with menu offering a choice of three stories.

Figure 5: Main stage, with first page of Story 1: A visit to a café in the city.

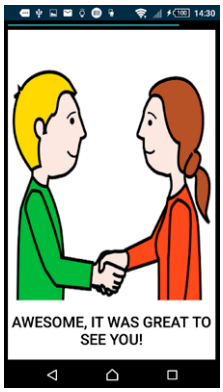

Figure 6: Wrap-up remark stage, with Handshake pictogram.

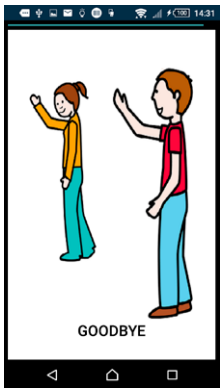

Figure 7: Farewell stage, with Goodbye pictogram.

Evaluation

Researcher Preparation

The researcher received specialist training and support, including work observation with Speech & Language Therapists (SLTs) and an SLT Health Care Support Worker (HCSW), to become more familiar with the needs of people with ASD and ID. There was role-play with the HCSW showing how to interact with a person with ASD and ID, including strategies to manage any difficulties which might arise. Inclusive Communication training was also provided. A demonstration of the Talking Mat® method (Murphy & Cameron, 2008) was given, with practice and guidance on how to carry out an evaluation using it.

Participants

An evaluation was conducted with five adult participants (P1-P5) with ASD and ID, from a daycentre for people with ID. Symbolized information, consent and release forms were created for them. One carer from the same daycentre participated (P6) as the conversation partner throughout the evaluation. The study took place at the daycentre. Participants P1-P5 each had a practice conversation with the conversation partner P6 in order to familiarise themselves with the app. P1-P5 then each held a second conversation with P6, which was video-recorded for subsequent review.

Feedback and Talking Mats®

A feedback exercise was conducted using a Talking Mats® approach (Murphy & Cameron, 2008) to gather opinions regarding the app and its design. Participants P1-P5 were given the choice of using the Mat or a feedback form to express their views on the app; four participants (P1-P4) chose to use the Mat while one (P5) chose to use the feedback form.

Use of Talking Mats® was recorded and photographed. The Talking Mats® completed by participants P1-P4 gave generally positive feedback. Most of their symbols were clustered on the left-hand ('happy') side of their Mats, with some in the central ('unsure') area and a small number on the right-hand ('unhappy') side, meaning that the participants were largely happy about aspects of using the app. Some concerns emerged about its appearance, the size of the screen and knowing what to do. Larger display screens, as on tablets, and further familiarisation with use of the app might help to resolve such concerns. A completed Talking Mat® is shown in Figure 8.

Figure 8: A Talking Mat® from the feedback exercise.

Participant P5 described the app positively on their feedback form: "It's good because it can help problems". The conversation partner P6 (carer) was also asked for their view of the app; this they gave on a feedback form, indicating that the app was very easy to use, could be very beneficial for those unable to communicate verbally and beneficial also for those with reduced social skills as it would give them a choice of conversations (stories) to use. P6 concluded: "Overall … a fantastic app to have".

Video Analysis

Several aspects were observed on the video-recordings, such as conversation breakdowns (e.g., going off-topic, not understanding the conversation partner), the timings of interactions and the eye-contact occurring between each participant (P1-P5) and the conversation partner (P6).

Conversation breakdowns: prompts to participants P1-P5 from conversation partner P6 were required on a total of 12 occasions, to overcome pauses in proceedings. One participant required the majority of these prompts (8 of them) while other participants accounted for the remaining four. ***Eye contact:*** two participants tended not to give eye-contact as they were concentrating on the screen before them, two gave eye-contact when prompted by P6's response, while one gave eye-contact after each page and increasingly at the wrap-up stage when asking questions. ***Timings:*** the time for most participants to respond and tap the screen varied from 0 to 3 seconds, although one took up to 30 seconds when selecting a story, even with prompting from P6.

Evaluation Summary

Overall, there was relatively little communication breakdown for all but one of the participants with ASD and ID and they were able to accomplish successful exchanges. Eye-contact could be affected by participants concentrating on the screen rather than on their conversation partner. Timings varied, but usually not to a problematic extent. The mobile smartphone offered a suitable platform for this type of application, although larger displays, as found on tablets, might be preferred for some users, particularly those with sight limitations.

Discussion and Conclusion

A prototype AAC smartphone app was developed to promote engagement in simple conversation by people with ASD and ID. In evaluation, participants experienced successful interactions with a conversation partner (a carer) who also found the app useful and enjoyable. Conversation structuring in the app reduced challenges faced by participants, all of whom were able to complete interactions with the co-operation and encouragement of the conversation partner. The 'no-failure' theme meant that all participants with ASD and ID were guided by the app towards appropriate completion of their interactions. Some prompting by the conversation partner was required in places, although this was not a big factor for most of the participants, and further practice

in use might reduce this further. Inter-personal eye-contact was limited due to participants concentrating on the display. While smartphones were a good platform for the application, larger displays (e.g., tablet screens) might be better for some users. This investigation was considered successful and gave positive indications for further exploration and development in this area.

Acknowledgements

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

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Other icons and images © The Authors.

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Taking Symbols to the Mainstream

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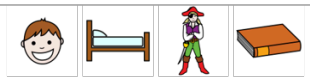
January 2021, winter, we're all in lockdown, schools are mostly closed, teaching is online, teachers are stressed, children don't know what's going on…what better time to drum-up interest for our project to support communication symbol use in mainstream classes?

Well, communication difficulties haven't gone away, and with routines all over the place, there is an even stronger argument for the systematic use of symbols.

Any Speech and Language Therapist who has tried to promote the use of symbols in school will know that there are a number of barriers to get through: awareness and acceptance of the power of symbols, the availability of software that makes it easy to add symbols into regular documents, knowledge of how to use symbols effectively. Symbols software that works with Office documents now exists (Commtap, 2021), but what about actually using symbols in lessons?

Apart from some very symbols-enthusiastic teachers, symbol use in mainstream schools often doesn't extend beyond laminated cards stuck on drawers and doors, perhaps a few visual timetables. Integrating symbols into the body of a lesson is unusual.

We are piloting a project to explore symbols use in lessons which isn't a burden to teachers and is useful for children. We work with teachers in a school, and together discuss how symbols could work in classes and lessons. We talk about key principles for using symbols, illustrating how they can help access to text (by using them to support information given in an unfamiliar language), how they can be used to draw out key information, and how they can be used with children at different levels – not just with those who are struggling with communication or reading. Teachers send us lesson materials and we add symbols to those materials, with suggestions as to how they be used. See example, right:



It was a warm, quiet night and Robin was wrapped up in bed with his favourite pirate book.

ಇದು ಬೆಚ್ಚಗಿನ, ಶಾಂತವಾದ ರಾತ್ರಿ ಮತ್ತು ಮುಂಗೊವನ್ನು ತನ್ನ ನೆಚ್ಚಿನ ಕಡಲುಗಳ್ಳರ ಪುಸ್ತಕದೊಂದಿಗೆ ಹಾಸಿಗೆಯಲ್ಲಿ ಸುತ್ತಿಡಲಾಗಿತ್ತು.

Bringing out key information from a story using symbols – if the symbols help you to access the text on the right, then you know they are likely to be of some use to people who have difficulties accessing text in any language.

Feedback we have had from teachers so far:

> ***[discussing the symbols used in the story] deepened [the children's] understanding of the recount.***
> ***For the children working just below and (unconfidently) at the expected level [the symbols] gave them a confidence boost.***
> ***The symbols made the learning and comprehension lessons fun and enjoyable, as well as extremely clear and "safe".***

We hope to extend this project through publishing a guide to using symbols, creating a bank of example symbolised lesson materials, and putting together a training package for delivery by SENCos, with support from a Speech and Language Therapist.

Whether this project goes ahead will depend on funding. However, if you are interested in knowing more or getting involved – including extending the ideas to communication support for adults – please contact neil.thompson@commtap.org

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Arasaac Symbols (used in article) *author: Sergio Palao* ARASAAC (http://www.arasaac.org) *License: CC (BY-NC-SA) Owner: Government of Aragon (Spain).*

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Developing the EyeTalk

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Introduction

In 2020, the Kent and Medway Communication Assistive Technology (KM CAT) Adult Team developed a new paper-based communication aid called the EyeTalk. This alphabet-based aid enables people to select letters with their eyes and is inspired by elements of the Frenchay Eye-Transfer (E-Tran) Frame and the Speakbook.

Existing Options

As a Specialist Augmentative and Alternative Communication (AAC) Service commissioned by NHS England, we have many service users who are literate but have significant motor impairments. This may mean they cannot write or directly access a communication aid via touch or pointing.

Many of these people will try a voice output communication aid, but non-electronic options are always considered too as they can be used very successfully. Frequently recommended AAC options include: the E-Tran frame, Megabee, EyeLink, Speakbook, or an alphabet chart with partner-assisted scanning (PAS). All AAC recommendations depend on an individual's language, cognitive, physical and sensory skills.

The E-Tran frame is a transparent frame with the alphabet arranged in blocks around the board. It is typically used with eye-pointing and makes use of colour-coding. It requires the user to direct their eyes to the block where their letter is and then to the corresponding colour circle. The conversation partner then interprets the selections to de-code the letter and word.

The Megabee is a battery-powered version of an E-Tran frame, and works in a similar way: the user eye-points to a block and then the letter. When using a Megabee, the conversation partner can select the user's choices using buttons on the device. The choices are then highlighted with a light and the letters appear on a small screen. This can provide some visual feedback and prompting for the user. It is also possible to save abbreviations for words on the device.

The EyeLink is a transparent board with the alphabet printed onto it arranged in a grid. The board is held between the user and their communication partner. The user must focus their eye on their letter of choice. The conversation partner will look at the person's eyes and move the board around until they 'link' or look directly at the user's eyes. They will then both be looking at the chosen letter.

The Speakbook (2011) is a phrase-based system developed by Patrick Joyce, based on his own experience living with Motor Neurone Disease. It is a free printable template for a communication book which can be used with eye-pointing. Multiple versions have been developed, including in different languages and a version for colour blind users.

Unlike the other options, PAS is an indirect access method and involves multiple steps. The benefit of PAS is that it can use any reliable movement or gesture, for example moving a hand, blinking or looking up. The user can choose an alphabet chart that best suits them, including QWERTY, ABC or frequency, or even a phrase list. To use PAS the conversation partner systematically points to the row (visual scanning) or letter and/or reads it aloud (auditory scanning). The user then indicates their selection using a movement. Research by Swift (2012) comparing PAS, E-Tran and EyeLink found that PAS was the slowest method for people with Amyotrophic Lateral Sclerosis.

The Challenge

Whilst these tried-and-tested AAC options work well for many users, they can be challenging for people with cognitive difficulties, particularly the E-Tran, Megabee and Speakbook. These require a two-step process to spell each letter of a target word. Additionally, the E-Tran and Megabee rely on colour to code the letter, which means it is not suitable if the user cannot distinguish the colours (e.g., yellow against a white background) due to visual difficulties.

The Idea

It was a visit to a service user that sparked the idea for the EyeTalk.

Mrs C had Multiple Systems Atrophy (MSA) and had been known to the KM CAT service for a few years. Mrs C had tried a range of communication aids, including a Lightwriter, alphabet charts with PAS, phrase charts, an E-Tran, and a Megabee. Unfortunately, as her MSA progressed, a combination of cognitive and physical changes meant Mrs C had difficulty using all of these options.

During re-assessment in early 2020, Mrs C could eye-point to a block of letters when using an E-Tran or Megabee, but she struggled to manage the next step required. Despite her best efforts, she could not eye-point to the corresponding colour of her chosen letter.

Mrs C's main form of communication was eye-pointing to 'yes' and 'no' cards to answer closed questions. Although this method was effective, it was very restrictive and did not allow her to communicate novel messages.

Mrs C's husband, Mr C, had an idea for an electronic device mirroring an E-Tran/Megabee design, where each block of letters would open up to a separate screen when selected. This would narrow down the choices quickly with a focus on choosing the target letter in that block rather than having to follow a separate process to select a colour. The team agreed with Mr C that this was a good idea, and it led to many discussions around whether we could create something like this in paper form.

Sadly, Mrs C passed away before she was able to try the EyeTalk.

Development of the EyeTalk

After discussion with my colleagues, I began to create the EyeTalk.

We outlined the specification for the communication aid as:

- Alphabet-based, to be used to spell messages
- To be used with eye-pointing
- Did not require coding, i.e., choosing block then colour, so that the cognitive load is reduced
- Suitable for people who are colour blind or require high colour contrast
- Option for a numbers page
- Easy to use by communication partner
- Printable so it could be shared freely and be inexpensive to produce

The EyeTalk

I was inspired by eye-pointing AAC along with the design of the E-Tran and Megabee, with the alphabet arranged around the edge of the frame, and the Speakbook with multiple pages in a book with tabs.

There are two versions of EyeTalk: 'EyeTalk' and 'EyeTalk with Numbers'. The printable document creates an 8-page book with a window in the middle. On the 'Start' page (Figure 1), there is a full alphabet distributed around the frame. On the following pages there are 6 larger letters or numbers per page (Figure 2).

The letters and numbers are all black text on a white background to provide high visual contrast.

There are instructions and some hints and tips for the communication partner on the front of the book.

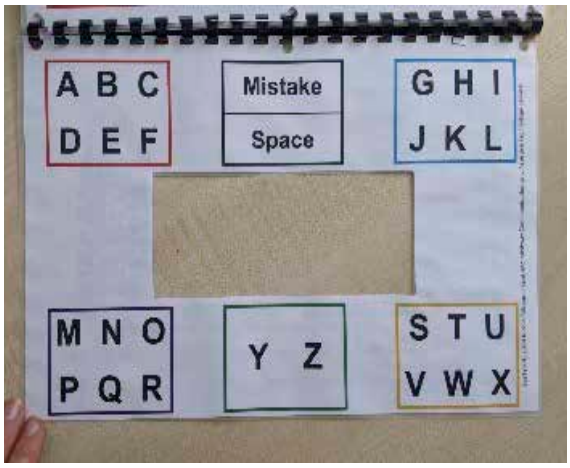

Figure 1: User side of EyeTalk Start Page

Figure 2: User side of EyeTalk M-R page

How to use the EyeTalk

The conversation partner holds the book with the 'Start' page open. They hold it up so they can see the user through the window.

The user will eye-point to the block with their chosen letter (Figure 3). The conversation partner will be able to see a mirror alphabet on their side of the book.

The conversation partner can then turn to the corresponding page; these are matched by both colour and labels on the tabs.

Once on this page (Figure 4), the user just needs to eye-point to their chosen letter.

There is a 'mistake' and 'space' cell on the home page of the EyeTalk, so the user can alert their conversation partner to mistakes, or start a new word.

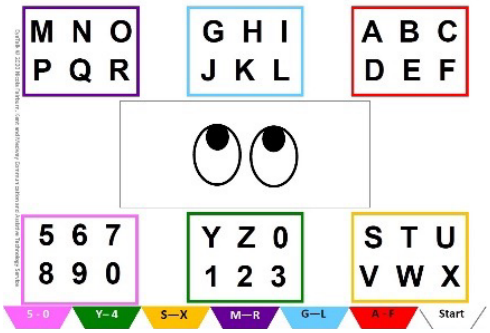

Figure 3: Diagram of start page, partner side of EyeTalk with Numbers

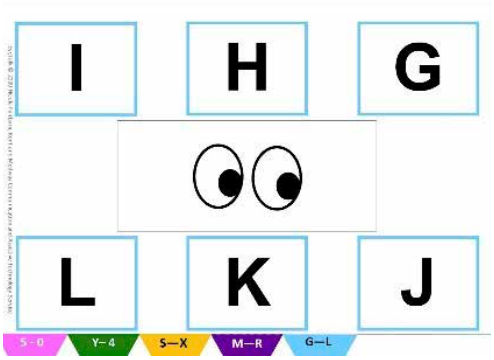

Figure 4: Diagram of G-L page, partner side of EyeTalk with Numbers

Tony

Figure 5: Tony and Richard using the EyeTalk prototype

KM CAT has successfully implemented the aid with one of our service users. Tony (Figure 5) was keen to share his experience using the aid so that others who might benefit from it could use it too. His story was taken up by the local press, and he was delighted to be featured on the regional news.

Tony has Multiple Sclerosis (MS) and has been known to KM CAT since 2019. Tony mainly communicates verbally and through facial expression. However, in recent years, his speech had become became more unintelligible and effortful, especially when Tony fatigued later in the day, therefore he required something to supplement his communication when his speech was unclear.

When we met Tony, he wanted to focus on non-electronic AAC options. As Tony has weakness in his upper and lower limbs, he cannot directly access a communication aid via touch, therefore Tony had previously used PAS with an alphabet chart to spell words. Although Tony had a clear 'yes' and 'no' (nodding and shaking his head or verbalising), he found PAS slow and effortful. There were frequent communication breakdowns, and at times Tony struggled to express his needs and wishes to others.

During assessment with KM CAT, Tony trialled an E-Tran frame. Similar to Mrs C, Tony sometimes had difficulty completing the second stage of using an E-Tran frame (he could select the block of letters but not the colour). We suspected this was due to attention and working memory difficulties, combined with visual impairment. Tony has optic nerve damage linked to his MS which made it difficult for him to distinguish colours on the E-Tran.

Although Tony and his carer, Richard, practiced using the E-Tran, it was challenging for Tony, and they found the alphabet chart with PAS was more successful.

Once the EyeTalk prototype was completed in May 2020, we thought Tony would be an ideal candidate to try it. We posted Tony a copy and agreed to train and support him and Richard to use it via video appointment. Unfortunately, we were unable to connect the video. However, when we spoke to them on the phone, we were delighted to hear Richard say they had already started using the EyeTalk - Richard reported Tony had asked to watch the horse racing on TV!

Since May, Tony has been using his EyeTalk and EyeTalk with Numbers as a tool when his speech is unintelligible. He has been using the EyeTalk to communicate increasingly complex sentences; using it to request and answer questions but also to express his emotions, comment and tell stories. For example, Tony will update Richard on what his cat has been doing in the garden, or what shows he has watched on the television.

Tony and Richard also like the portability of the aid, as it is small and lightweight.

When interviewed by the local press, Richard said, "it means he is less isolated, he can really communicate and make his views known. He was able to ask to sit outside when we went for dinner recently."

The resource has also helped when communicating with medical professionals, and there is now an EyeTalk in Tony's pack for the emergency services. Tony has demonstrated he can use the EyeTalk even when he is stressed or unwell.

Richard has been vital in the success of the EyeTalk for Tony. Richard will remind Tony what letters he has already chosen and write these down to keep Tony on track. They have known each other for many years, so Richard can often predict and guess what Tony is trying to say once he knows the first few letters.

Tony also hopes to be able to use the EyeTalk to share his story of living with MS.

What next?

The KM CAT team plan on continuing to consider the EyeTalk as an aided AAC option in future assessments, alongside the existing options.

We would like to make some minor changes to the EyeTalk, based on feedback and observation of Tony and Richard. We plan to add labels to show which side is for the user and which is for the partner, so that the book is always held the same way around and the alphabetical side is facing the user. Also, we are developing an A5 version which will be even more portable.

We have shared the PDF for the EyeTalk and EyeTalk with Numbers on the KM CAT website for free. We are hoping it will be useful for other AAC users, and any feedback on the EyeTalk will be welcomed. Please get in touch if you have any thoughts or feedback.

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Links

The EyeTalk and EyeTalk with Numbers can be downloaded here:
https://www.ekhuft.nhs.uk/patients-and-visitors/services/radiological-sciences/medical-physics/kmcat/professionals/resources/

A video of Tony using the EyeTalk can be found here:
https://www.youtube.com/watch?v=l-R5s5YvmDQ

My Lockdown Experience

SARAH-JANE SHEARER

In 2020, it was a strange year for everyone. What do you think of lockdown? I know it was a shock, but now I think it is the new normal. Everyone is now wearing masks. Shops are closed. Disabled people are at high risk. So, here is my lockdown story.

2020 was already a stressful year for me as the social work cut my hours for my carers. I was getting fourteen hours when they decided to cut my hours to seven last year. After they promised me that they weren't going to cut my hours, they did as I got a new social worker. This already made me depressed and then lockdown made me feel more depressed as I didn't get to go out.

Lockdown has also affected me as I haven't gone to my appointments. I am overdue an operation which lockdown has held back. It has made me sore which made me depressed. I was also meant to get physiotherapy, but it got cancelled then they said that I wasn't allowed any.

Lockdown has affected me as I was doing sports three times a week. I was doing race running twice a week and dancing. What is race running? Race running is a sport for disabled people. Athletes use a running bike which has three wheeled frames like a walker with a saddle and body support. In doing my sports, I was doing my physio so I couldn't do it because of lockdown.

Lockdown has also affected me as I haven't been able to see my family and friends. This has impacted me the most as I am missing them. Social media is great, but it isn't the same as meeting them. I am missing going out with my best friends.

Lockdown has some positive sides to it, like some people might try something new. For me, I got involved with AT Mentor and now I am working for them. I took a level one mentoring course and now I am doing the second level. I have met new people through it, and they are nice.

Communication Matters

CiP

COMMUNITY FUND

This is our third year of funding from the National Lottery Community Fund for our mentoring project and we have a wonderful range of qualifications for AAC users in England including personal and social development, mentoring and employability.

All sessions are free and delivered via Zoom or Teams and learners can complete workbooks and activities from their own home. We are working with Creativity in Practice Ltd who will provide 1-1 support and guidance. They can also help with setting up a local peer mentoring project in school or college, or through another service.

We are currently exploring options to host similar projects in Scotland, Wales and Northern Ireland.

For more information about any of these free opportunities, please visit our website - https://www.communicationmatters.org.uk/what-we-do/projects/mentoring-project/

Where Next for People with Cognitive Disabilities and Electronic Assistive Technology?

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Barnsley Assistive Technology Team
AMY WRIGHT
Children's Trust
JOANNE SURRIDGE, ALYSIA MARTINDALE
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On 29th November 2019, Communication Matters held a Study Day in conjunction with The Children's Trust in London on the topic of, 'Where next for people with Cognitive Disabilities and Electronic Assistive Technology?'. The venue and food for the day were supported by Irwin Mitchell.

For many years, Zoë has been thinking and talking about the use of Electronic Assistive Technology (EAT) by people with more significant cognitive disabilities. This could be people with congenital learning disabilities or people with more significant acquired cognitive disabilities. In 2018, she had been in contact with a number of different people around this and, at a similar time, Amy had put a question on the Access Group Forum (access-group@googlegroups.com) around this topic. Zoë and Amy chatted, and from this, and after speaking to some other key people, a small team was formed and the idea of a study day created.

The premise for the study day was that it is easy to underestimate the importance of controlling a single function, or a small number of functions, but this can enable a person to experience increased independence, which they may not have in any other area of their life. The importance of developing the use of Electronic Assistive Technology with this group of people was highlighted in the Mansell report 2010 (Mansell, 2010)[1]. The idea of the day was to consider 'Independent Control' (rather than pure AAC or Environmental Controls) as an area which requires exploration and, ultimately, national guidance.

The day was aimed at anyone with an interest in this area – parents, professionals, suppliers and charities, and the content considered all ages (so not just adults or children). In setting up the day, the team were keen to present the current situation and best practice, but also to have opportunity for discussion about what the challenges are for EAT with this group of people. To achieve this, the morning comprised a series of presentations, followed by discussions in the afternoon. The day attracted over sixty people, illustrating the interest in this area.

Zoë Clarke opened the morning, setting the scene for the day, explaining her role as Environmental Control (EC) Lead in Barnsley, her personal background, having a sister with profound and multiple learning disabilities and her career path into EC, emphasising how this work has always highlighted to her the value of independent control and agency. Zoë also explained how she does not believe that technology can solve everything or that technology is always the right solution for someone, but that not having the opportunity to be able to explore the potential for a variety of reasons is frustrating. Zoë described how it feels potentially 'cognitive-ist' to only consider that people who are going to operate a number of functions should have the opportunity to try. Zoë also highlighted how for this group of people it can be difficult for them to express the importance of independent control, but that understanding its importance for us all suggests that it does have value.

Dr Ben Simmons from Bath Spa University (https://www.bathspa.ac.uk/our-people/ben-simmons/) presented his research on social inclusion for children with PMLD. He cited the typical communication research in the field of PMLD as being (i) interventionist (ii) adult-led (iii) within segregated or artificial contexts, and (iv) scientific/experimental in nature. In contrast, Ben described his research as using a naturalistic framework, looking at how different environments and communication partners created alternative social interaction opportunities for children with PMLD, and an increased sense of agency. This naturalistic research allowed a fluid

and situational exploration of communication and interaction, and raised the question: If communication patterns shift according to context, then how does this inform our use of AAC?

Amy Wright, an Advanced Practitioner in Assistive Technology from the Children's Trust (https://www.thechildrenstrust.org.uk/), explained how they promote the use of single switch access for the young people in their settings to enhance independence and participation. She laid out a clear and detailed pathway of assessment, looking at the current functioning of the individual, including consideration of environmental and personal factors. Amy explained how individual, achievable goal-setting centred around participation, and that these goals were then integrated into the young person's curriculum targets for the classroom, working towards the ultimate outcome of assistive technology access. Amy shared a range of participatory activities that are used within the daily routines of the children and young people she works with, where single switch access to technology, for a small number of functions, increased participation and independence.

Sally Darley, a Speech and Language Therapist working within the Barnsley Assistive Technology Team (https://www.barnsleyhospital.nhs.uk/assistive-technology/), presented a single case study. The case study summarised an episode of care for a young person with complex health needs and physical and cognitive disabilities, who had not been provided with opportunities for independent control before. It illustrated the pathway of access assessment carried out by the Specialist Service, and intervention carried out by the local team, that led to successful single switch access. Sally shared the journey from the point of starting an access assessment for this young man, through to the identification of opportunities so that he could then *try out single switch access to control a variety of simple environmental controls. This process appeared to create a catalyst for onward independent control and "agency". Outcome measures illustrated the significant improvements made in terms of activity, participation and well being, both for the young person himself and his carers.*

Alysia Martindale, who works for Norwood (https://www.norwood.org.uk/) as an Assistive Technology Specialist for Communication, presented a series of case studies about adults with cognitive disabilities within their service, who use electronic assistive technology. These individuals used assistive technology to communicate and enhance their participation in a variety of activities, e.g., art as well as their access to EAT, increasing their computer access and social networks. A variety of access methods were discussed, including switch access, direct access and eye-gaze. Norwood have now secured funding for Alysia to complete a Masters by Research – "To validate and determine how an online training course impacts on the knowledge, values and confidence of people learning to support people who use AAC."

Samantha Hunnisett's (nee Goodwin) presentation shared her experience of EAT for people with cognitive disabilities throughout her career as an Occupational Therapist in a variety of roles. She shared her experience in Scotland with a specialist AAC service, and her observations of the differences for adults and children with cognitive disabilities, in terms of Assistive Technology.

Samantha described her work in ensuring AAC was covered as part of the Undergraduate Occupational Therapy Course at Queen Margaret University, and how a previously unmotivated AAC user had been able to co-present with her as a visiting lecturer. Her presentation also covered a switch skills clinic that she had set up in England at a paediatric therapy centre, outlining the benefits and limitations she experienced. Samantha's presentation ended with a case study about a woman she had worked with. She described how the initial work had started with some single switch functions (both for control of things in her environment and for some simple messages) and how this had developed, highlighting the value of access to this technology, not only for the young lady, but for the family also.

We were really lucky that **Dr Thomas Doukas**, an Independent Consultant who works with PMLD LINK (https://www.pmldlink.org.uk/), was able to join us to give a short presentation on the guidance developed by PMLD LINK: 'Supporting People with Profound and Multiple Learning Disabilities, Core and Essential Service Standards' (PMLD LINK, 2017)[2]. Thomas briefly explained the standards and how the opportunity to explore Electronic Assistive Technology fits with them.

Although tight for time, the morning had definitely set the scene for the afternoon session. People were split into five groups, and were posed four questions. People were asked to discuss the questions on their tables and use a flip chart to record thoughts. These flip charts were collected in, and whilst the next question was being tackled, a quick summary of the previous question was added to PowerPoint to enable us to summarise at the end.

The four questions posed were:

- Are local services able to meet the needs of people with cognitive disabilities in terms of EAT?
- What do we know about best practice in terms of people with cognitive disabilities and their potential use of EAT?
- How do we develop services and pathways for assessment/provision/implementation based on current good practice?
- What should our next steps be to enable development of guidance relating to assessment of clients with significant cognitive impairment, and their potential use of Electronic Assistive Technology?

Following the study day, the flip charts were examined and the information from the day summarised in terms of common themes. The full summaries of these can be found here: https://www.communicationmatters.org.uk/what-we-do/study-days/

Conclusions and next steps

The day had a buzz about it, with feedback suggesting it had been valuable to discuss this area, and that there was an appetite for and enthusiasm to make progress. A number of potential next steps were identified:

- Form Google group or similar for interested people from study day and promote (this will aid peer support)
- Have further discussions with the All Party Parliamentary Group for Assistive Technology (APPGAT).

- Create website for existing guidance - form working group to gather/organise/moderate existing guidance and identify missing guidance
- Plan how to develop new guidance
- Establish social media groups e.g., Twitter chat
- Develop competencies for people working with EAT and people with cognitive disabilities, based on current best practice
- Potential Learning Disabilities stream of presentations/workshops at Communication Matters
- Identify potential training days required e.g., how to introduce EAT; how to develop use of EAT (Communication Matters are already considering the potential of something like an 'Introduction to access methods' training day to run regionally, so this could fit with this area)
- Scoping project e.g., what is currently going on around the UK? And identify potential funding sources for undertaking such a project
- Consider organising meetings similar to the Study Day to gain more information from different perspectives e.g., parents/carers/care staff
- Potentially approach suppliers to hold a meeting where we can discuss current product range and what could be needed/sourced
- Build on existing link with NHS-England
- Identify research questions and explore how we take these forward e.g. PMLD conversation tool (investigate potential links and therefore funding)
- Raising awareness by encouraging more "soft" literature, identification of role models, presentation at conferences
- Identify what information hubs can provide to local services to inform and support, when people are not meeting criteria
- Consider how to use the experience of developing the specialised services to help develop a pathway for this group

Since the study day, links have been maintained, however the effect of COVID has limited the focus that people have been able to have on taking this forward. Zoë has been in touch with NHS England, and there is a proposal to have further discussions in 2021 when hopefully things are more settled. If you would like to get involved or have further questions, please contact Zoë Clarke: z.clarke@nhs.net.

References

1 Mansell, J, (2010), Raising our sights: services for adults with profound intellectual and multiple disabilities, https://www.mencap.org.uk/sites/default/files/2016-06/Raising_our_Sights_report.pdf)

2 http://www.pmldlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf.

AAC and Literacy Project, and the Next Steps

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Literacy learning is important for all, but for young people who use AAC it is a critical skill that can support communication and independence.

In June 2019, four young people supported by ATtherapy (an independent Speech and Language Therapy service) participated in a preliminary literacy study for individuals who use AAC, at Manchester Metropolitan University. The project aim was to explore how literacy and phonological awareness[1] skills can be assessed in young people with severe physical and speech impairments, and to track the literacy learning experiences of young people with reported literacy achievement, and those with reported literacy learning challenges. Current evidence overwhelmingly indicates that children and young people with severe speech and physical impairment have the learning capabilities for early reading and writing skill acquisition (Erikson and Koppenhaver, 2007), however many fail to develop the level of literacy commensurate with their cognitive abilities and potential (Smith, Dahlgren-Sandberg, Larsson, 2009).

The objectives of the study were to: (i) determine individual patterns of literacy and phonological awareness abilities and note specific challenges; (ii) develop recommendations to support future literacy learning opportunities, and (iii) explore the perspectives of the young people and their families on the nature and quantity of language and literacy learning experiences.

The participants were aged from 11-16 years old and engaged in full-time education in a variety of settings including mainstream, specialist school and resource-base provision. Baseline language assessment measures were completed prior to the study to profile the participants' current comprehension levels. This included the Test of Reception of Grammar (TROG), a standardised assessment of ability to understand sentences and grammar, and the British Picture Vocabulary Scale (BPVS), a standardised assessment of vocabulary knowledge.

All the young people had developed some literacy skills, however there were clear differences in expressive ability, vocabulary knowledge, comprehension of grammar and level of literacy attainment, creating two pairs of participants.

Pair 1: Two AAC users who predominantly used symbol-based vocabularies and were beginning to read and spell, however they were struggling to progress with their current literacy intervention. They are referred to as participants A and B.

Pair 2: Two AAC users who used text-based vocabulary packages, were conventional spellers and could read connected text but were keen to develop their literacy skills further. They are referred to as participants C and D.

Over three days in June 2019, literacy skills were assessed using a range of sub-tests from The Assessment of Literacy and Phonological Awareness (APAR). The materials for the APAR were prepared to enable all participants to eye-point to multiple choice answers on an e-tran frame. Given the information we had regarding each young person, the most relevant sub-tests were selected (see table 1). In addition to the e-tran frame, the participants also used their electronic AAC to confirm their response, or sometimes to ask for clarification. To increase motivation to complete the sub-tests, a competitive element was added whereby tokens were gained to win a prize at the end of the study.

Table 1 – List of subtests from the APAR assessment which were completed within the study

Subtest areas	Test and explanations
Listening Comprehension	**Sentence Plausibility** Tests the ability to understand spoken sentences and decide whether they make sense or are nonsense sentences. **Grammaticality Judgements** Tests the ability to identify if a sentence is grammatically correct or not (sentence is read aloud by an examiner and the participant asked to indicate if it is plausible or not).
Reading	**Reading Non-words** The examiner reads aloud a nonsense word, and the participant indicates which written word it corresponds to from a choice of two. **Reading Real Words** The examiner reads aloud a word, and the participant indicates which written word it corresponds to from a choice of two. **Comprehension of Written Words** The participant is asked to read a written word and then indicate which of three pictures matches the word. **Comprehension of Written Sentences** The participant is asked to read each sentence and indicate if they think the sentence is sensible or not (e.g., 'The puppy held the vet'). **Comprehension of Written Texts** The participant is asked to read a text and then asked to answer five comprehension questions using a yes/no response.
Phonological awareness	**Blending Real Words** A word is sounded out by the examiner and the participant is asked to indicate which written word corresponds to it from a choice of three. **Blending Non-words** A nonsense word is sounded out by the examiner and then two words named. The participant is asked which word the examiner had sounded out. **Phoneme Counting** A word is spoken aloud, and the participant asked to indicate how many sounds are in the word. **Phoneme Analysis** In this sub-test, two words were spoken aloud and then a single sound. The participant was asked to indicate which word contained the sound.

To complete the interviews and gain views on what was helpful for literacy development, we used a questionnaire with the young people and their families that employed a traffic light system; this rated the activities as 'easy', 'not so bad' or 'difficult', and those elements were expanded upon using Talking Mat activities (see Figure 1).

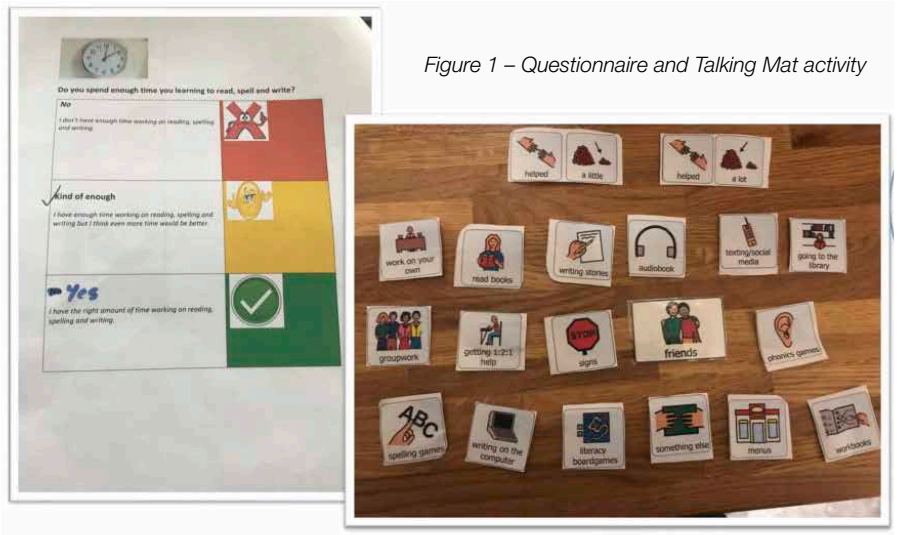


Figure 1 – Questionnaire and Talking Mat activity

One key outcome from the results was the preparation of a literacy report for each young person. The report commented on APAR test performance, documented any error patterns and provided interview reflections. At the end of the report there were summaries of strengths, developing areas, difficulties, and recommended actions.

Summarising the APAR findings, Pair 1's profiles can be seen in Figure 2. This shows results from phoneme analysis and blending of non-words (phonological awareness skills), and reading non-words and comprehension of written words (reading skills). Profiles followed a similar pattern for these skills, with greater variety in the skills of participant B. However, both individuals had strengths in phoneme analysis and

difficulties with reading and comprehending written text. They both had a desire to learn to read and write and acknowledged that spelling is particularly challenging. Similarly, both parents placed a high importance on reading, writing and spelling, with one parent commenting that it was the most important thing for their child. They both felt their children were still acquiring reading, writing and spelling skills and that more time and resources were needed. Most importantly, they felt that topic and content that was motivational for the young person should be at the heart of literacy instruction.

The recommendation section of the reports stated that both participants benefited from competitive endeavours and that tasks should be bespoke and motivating to support participation. To reinforce phonological awareness and reading development, it was recommended that participant A has further spelling practice, opportunities to read and write connected text, and access to books in various forms e.g., audiobooks. Recommendations for participant 2 included more experience of functional literacy activities (e.g., looking at menus), and activities which tap into humour including raps and silly poems. Additionally, ideas were shared to develop single-word reading and spelling, phoneme analysis in consonant clusters, listening games, and activities to develop vocabulary and knowledge of narrative elements.

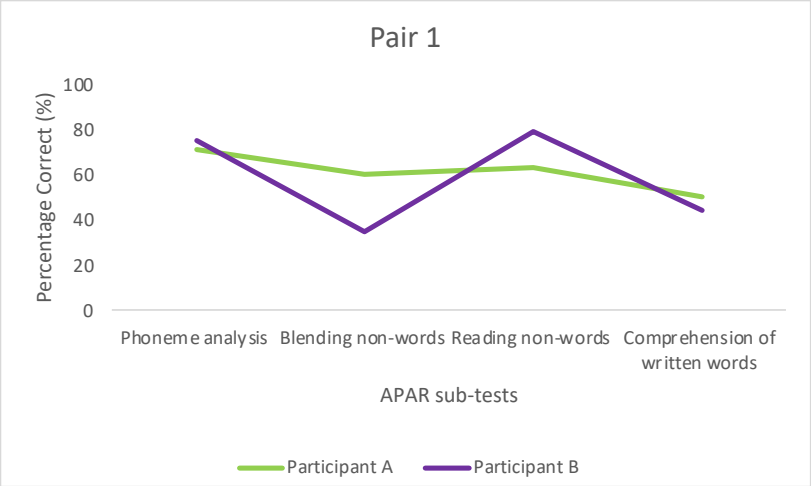


Figure 2 – Pair 1, comparison of results

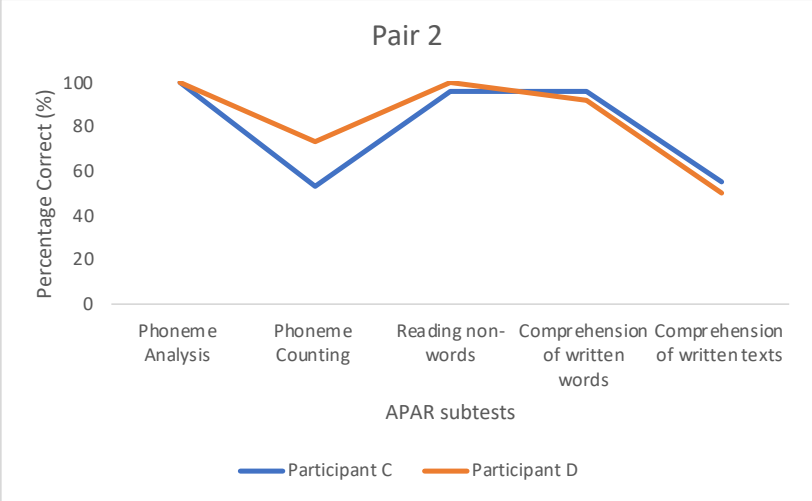


Figure 3 – Pair 2, comparison of results

Pair 2 had very similar profiles, with strengths in phoneme analysis, reading non-words and comprehension of written words. They had difficulties with phoneme counting and comprehension of written texts (see Figure 3). Both participants felt they were still developing as readers, writers and spellers, however differed in their views about the amount of time they felt they needed to spend on literacy instruction. Both parents and the young people highlighted that a lot of their current literacy instruction comes from participating in functional activities such as online shopping, composing emails and accessing social media with use of predictive text. One of the parents from this pair referenced low academic expectations and lack of literacy intervention throughout the school years, stating that a significant amount of their young persons' literacy achievement had been self-taught.

Report recommendations aimed to develop enjoyment in reading and writing as a way of sustaining ongoing development of literacy skills. Possible ideas linked to individuals' interests included: writing a blog, commenting on a Youtuber's post, or engaging in a project such as the mystery shopping questionnaire (Communication Access UK). It was recommended that spelling and writing activities not involving predictive text were carried out, and that both participants had more exposure to connected text and paragraphs with (reading or auditory) comprehension questions.

Following the preliminary literacy study, ATtherapy implemented the recommendations over the course of the next 12 months. The instruction was person-centred and motivating which proved to be pivotal in helping the young people to develop self-determination, participate in tasks, and make progress with literacy and phonological skills.

Pair 1 were given an activity pack with guidance for teachers, teaching assistants, and parents/carers, with classroom and home environments modified to support successful literacy learning. Both participants engaged in daily spelling practice with a word of the week and completed reading and writing tasks across different learning environments using a combination of paper-based resources, iPad apps, websites and bespoke pages on their electronic AAC systems. Competitive games were played regularly to develop spelling skills, including scrabble dash, countdown, bingo and spelling boardgames (see Figure 4). Each young person's symbol-based vocabulary system was edited and symbols were gradually removed to support reading.

Participants in Pair 1 received individual Speech and Language Therapy instruction twice weekly, which continued to target literacy skill development. There was a focus on developing spelling skills as this was an area that both recognised as challenging. This is also an important skill in repairing communication breakdowns. Pair 1 made significant progress in their ability to spell the word of the week independently, and consequently started to access their keyboard page more often and spell words

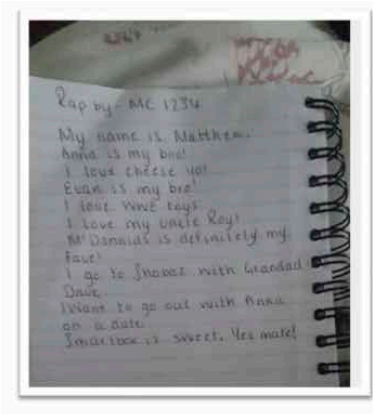
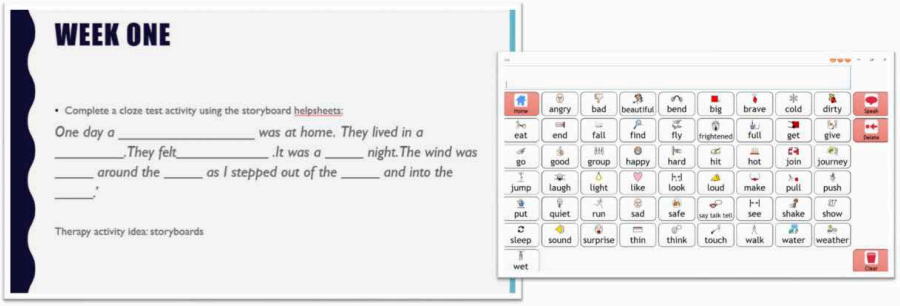


Figure 4 – Example of Pair 1 literacy tasks



independently. Self-selected reading took place regularly, indicating that their motivation to read improved. The volume of written work generated increased, with fewer grammatical errors and, if errors were present, the participants were able to self-correct without support. This was witnessed on various platforms including WhatsApp, emails, and blogs.

Participants in Pair 2 did not receive regular in-person Speech and Language Therapy intervention, however advice and recommendations were often provided remotely through video calls and email support, where specific activities were set, or resources recommended. This model of indirect therapy intervention was in place prior to the literacy study, advising on elements such as access to more books at the correct reading level with age-appropriate content. These were sometimes uploaded onto their communication aid or read on Kindle/as an audiobook. Spelling activities without prediction were set and motivating written work tasks were completed, with feedback. Pair 2 made progress in their ability to spell more complex vocabulary, read connected text and paragraphs, and answer comprehension questions accurately, evidenced by completion of activities. They also commented on how they found literacy learning more enjoyable and sought out more reading material independently. Their confidence in their literacy improved, and this was evidenced by one participant expressing they felt less nervous about upcoming English examinations and another reading books as part of mentoring input with another AAC user.

Over the course of the project and the following intervention, the four young people built a rapport, and some met up again, even sharing literacy resources and ideas. The participants provided regular feedback on the tasks which they enjoyed and didn't enjoy. This supported the development of new, innovative resources to facilitate engagement throughout the 12 months. A broader outcome from the study included building a bank of literacy resources and ensuring that literacy targets and instruction increased for the wider caseload at ATtherapy.

The preliminary literacy study involved considerable time commitment, coordination and negotiation with the young people, their families, and educational staff. Additionally, it was impossible in the 3 days available to complete all the elements of the APAR as well as the interviews. In total, the professionals involved committed approximately 4 days of their time to supporting collection of all assessment data. The follow-on intervention component wasn't without its challenges either, namely time pressures making it difficult to liaise with teaching staff to share resources and ideas, technical issues with AAC systems, and other focuses of Speech and Language Therapy intervention including work on social skills and emotions which were identified as key intervention objectives for those in their teenage years.

The next steps of the study are to repeat the baseline assessment measures to quantify any improvement in language, literacy and phonological awareness skills. Additionally, interviews will be conducted with the young people, parents/carers and teachers to ascertain which elements of the project have been useful and enjoyable. We also aim to repeat the study with another cohort and offer literacy study days, in addition to an annual literacy camp. Children and young people with significant speech and physical impairments have everything to gain from increased efforts to teach them to read and write in meaningful ways. Literacy enables people who use AAC to say exactly what is on their minds, to raise expectations and practice within academic settings, to increase employment options, to engage with social media, and to have greater choices over important life decisions.

APAR available at https://www.elr.com.au/apar/

1 Phonological awareness refers to the ability to identify and manipulate sounds in spoken language, and is fundamental to literacy learning.

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