

Communication Matters



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Choosing Words - EyeCommander - Taking on AAC - Literacy Informed Approach
- Gaming - Evolving Grids - Service Providers Perspectives - Motor Neuron Disease -
Autistic Children - Switch Development - Language and Literacy - Music Making



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Our member Gabriel Davis with his mum (Tamara) and Teacher (Sarah) dressed as 'The 3 Things' at this year's Communication Matters Conference fancy dress night. The theme was 'Back to the Future' and they won a prize for the best group fancy dress - don't they look fantastic!

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Chair's Report

HELEN WHITTLE



Thank you!



A Big Thank You to Annalu Waller for the fundraising she did for Communication Matters as part of her 'Summer of Madness' to celebrate her 60th Birthday. Annalu raised a fantastic £4000, which equates to 20 subsidised places at the CM Conference for AAC users and their support teams.

The Communication Matters Conference took place on 10-12th September at a time of really warm weather. We welcomed 411 delegates including 34 AAC users. Communication Matters were delighted to be able to fund 94 subsidised places for AAC users, their Personal Assistants and family members to attend. The Exhibition had 17 companies exhibiting.

Thank you to our fantastic Keynote and Plenary speakers, Graham Pullin and Abdi Omar, for bookending the conference with such important AAC messages. Thank you to everyone else who presented, the programme was very wide-ranging this year. Thank you, also, to our sponsors for your support. The raffle this year raised just over £1000, which was fantastic.



The fancy dress theme was 'Back to the Future'. Well done to everyone who dressed up, it all added to an amazing night. We enjoyed piano playing during the drinks reception by Bill and then wonderful singing from Corin during the Conference dinner on Monday evening, which was hosted by CM member, Jamie Preece. We then danced the night away to DJ Oli, and he showed some great photos of people who were celebrating birthdays.

The smooth running of the conference was helped by eight volunteer Conference Makers who were all Speech and Language Therapy students from either Leeds Beckett University or City, University of London. Thanks must also go to Kerry Schofield who took the helm at this year's conference, on behalf of the University of Leeds Conference and Events team.

We had some new ideas for this year's conference. We introduced a "newbies session" for those delegates that had not attended a CM conference before. Almost 40% of delegates were first-time attendees this year, so this was really well attended, and we hope it was useful for those who turned up early on the Monday morning for this. We also introduced an Assistive Gaming Zone on the Sunday afternoon, which was supported by Everyone CAN, an Assistive Technology charity. Julian and his team gave delegates the opportunity to try out the latest solutions in assistive gaming technology using adaptive controllers. The other new idea that we had was an Open-Mic night

in the bar on Sunday night. We had seven people put themselves forward for this which ranged from a poet and a dancer to a comedian. It was a great evening and we have had some wonderful feedback. So, get your thinking caps on for what you can do for next year's Open-Mic night – all sorts of entertainment will be welcome.



The CM Trustees have been busy representing you at various meetings and events since September. Helen Hewson has been interviewed for the IABLEd podcast. Helen's episode will be released during AAC Awareness Month, which is October. Have a listen - I think we will all learn something from this in-depth interview. Amy and Michelle had a Communication Matters exhibition stand at the Cerebral Palsy Scotland Conference on 3rd October. The Royal College of Speech and Language Therapists (RCSLT) are continuing their project to re-write the AAC Guidance for SLTs and Communication Matters is represented on this author group.

The Communication Access UK training is spreading more widely across the UK, which is great. The Citizen Advice team in Drumchapel are the first Citizens Advice Bureaux in Scotland to gain the accreditation – congratulations! Find out more at <https://communication-access.co.uk/>.

The Mentoring Project is entering an exciting phase with a new funding application for England being completed, as well as a newly submitted bid application for a 5-year project in Northern Ireland. Following a successful pilot project in Scotland this year, we are in the process of writing a full application to expand the mentoring project in Scotland in the future. Keep your eyes on the Friday Announcements and our social media channels for more information about all these projects and more.

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Jamie: Who Chooses my Words?

JAMIE PREECE

AAC User

ANDREA LEE

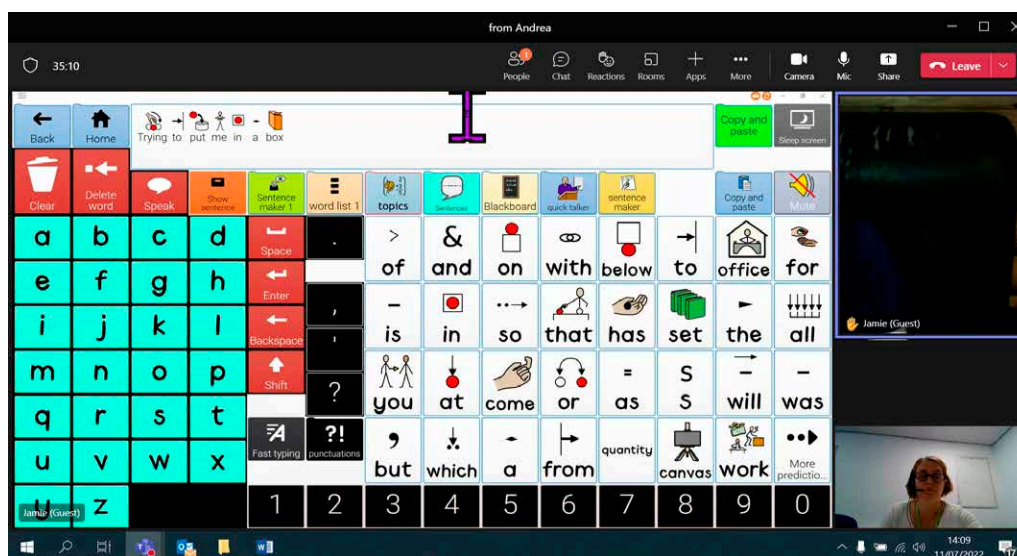
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This paper is produced by Jamie Preece, AAC Service User Representative at the Barnsley Assistive Technology Team. Jamie uses symbols to communicate and, for this paper, he used the symbols to express his thoughts about how he developed his own way of organising the symbolised language he needed and consequently how this highly individualised use of a communication aid has impacted his internal thinking and language.

Jamie used a multimodal approach to write this paper: some thoughts were communicated through screen sharing on video calls as in the photo below, some were sent through social media messages as and when they came to him, and some were co-constructed through three-way discussions between himself, his colleague (the co-author) and his partner, Emma. Jamie's partner is able to re-voice Jamie's natural speech and interpret his personalised gestures in a way that is not describable or teachable to others – their communication synchronicity has developed through 20 years of a close relationship and shared experiences. Ordering Jamie's thoughts and selecting appropriate illustrations was done through a collaborative process with the co-author and his partner. Jamie presented this paper at the Communication Matters Conference 2022.



When I was younger, people told me I wouldn't be able to use AAC because I couldn't read or write. I believed them. They said it would make me lazy with my speech. I believed them. So, for 36 years I relied on people interpreting my speech and gestures. All my life people had been changing my words. I might say, "he's a fucking bastard", but the person might censor my words and say, "he doesn't like him".

What I said



What they said I said



I saw a demonstration at a roadshow of someone using the Grid with symbols. I had a lightbulb moment and thought, I can do that. I realised I didn't want people choosing my words any more; I wanted to speak for myself. I downloaded a demo version of the Grid software on my home PC and borrowed an old communication device from Smartbox.

Once I got my own device it was like an



of words.

I started with a ready-made vocabulary but it just didn't make sense to me.

Tech 😊



Words ☹️



The way it was organised was like a



to me,

I couldn't work with it. I could do the technology but not the words.

I felt like they were...



After two weeks of trying, I knew I needed to take control.

A lovely man from a charity came to my house and spent six hours showing me how to edit. He told me to edit rather than create from scratch, but it didn't work for me, I wanted things where I wanted them. I asked Smartbox for advice about creating my own grids and they said I was crazy, that I was making work for myself.

It was hard for me: all the words were in my head, but they were mixed up and in no order.

There were many words I knew, but had never been able to use as I could not vocalise them.

I needed to put them in an order that made sense to **ME**.

Looking back now, I feel if I hadn't done it my way I might have given up and not become an AAC user.

This thought has blown my brain as writing this presentation was the first time I thought about that. Now I look back it was the start of a new life for me, a new way of existing.

I was given advice from different people wanting to help. Someone said I had to start with needs and wants ...



...but after 36 years I already had ways of communicating those. I knew I wanted to express much, much more than that but didn't know what.

A speech and language therapist once told me to plan what I wanted to say before a situation, for example, to decide in advance what I might want to say the next day in a meeting.

I said "ok, I will do that if you do the same". They thought about it and realised they couldn't. Who knows exactly what they want to talk about tomorrow? I don't, do you? I might say something at home one way, but then want to say it differently in the office, I might not know how I want to say it til I get there. Presentations and interviewing are the only time speaking people do this, and I'm the same.

My communication aid is the same as your speech. If I didn't have the option to improvise, it wouldn't be natural communication for me. My goal has always been to be a natural communicator.

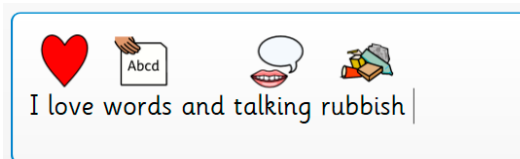
I can express what I feel with my own grids as I know where to find everything. Doing it my way has made me realise I love words and I love talking about whatever I want, whether it's serious or just rubbish.

I collect words and love it when I find a new word. As time goes on my vocabulary keeps growing.

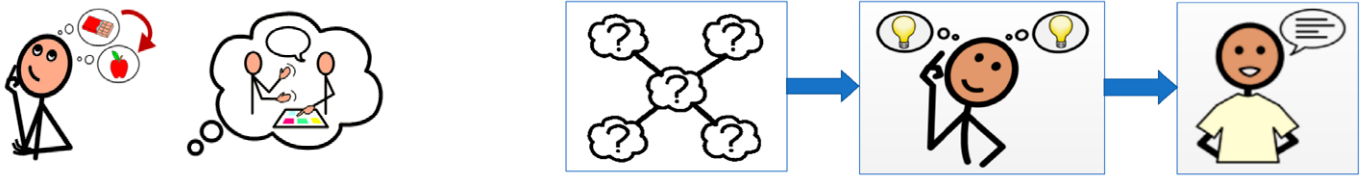
I can get a word from anywhere, even a Facebook post or story.

Sometimes I hear a word and think I don't want that, but other times I think I really need that one, or sometimes I think I've needed that word for ages.

I now think more in words. That may sound strange, but I didn't used to. Words are more than just talking tools: they are thinking tools.



I didn't used to have an inner voice. I had ideas floating around, but without the words attached to them. I now have an inner dialogue and have the words I need to talk through situations in my head as well as out loud. The voice in my head is the same voice as my communication device. Sometimes I put headphones on and talk to myself to test words out. I think of it as like a baby learning to talk.



The more I collected and organised my own words, the more I found I could organise my thoughts.

As I became more aware of how important different words are, my speaking improved and I now use words I would never have tried before.

I say the word I want to say rather than the word I know people will understand. If it isn't understood then my partner can re-voice my speech or I can use my communication device to say it again or give clues.

If you think about it, no two people use the same words. My communication aid came with a describing page but this didn't work for me. I needed different words so I made my own with words like "jerk", "bully", "beard". These are the describing words I use.

We all use different words, communication would be boring if we didn't.

I bet I can name more ciders than you.

I am interested in politics and social justice and often need very specific words to discuss this.

I do stand-up comedy. Do you think it would work if one comedian wrote another one's act?



I don't know what words you use when you want to be intimate with your partner, and you don't know what words I want to use with my partner. Can you imagine if you had to use the words I chose for you?

I find swearing adds emotion or humour to my communication, but some people hate swearing.

I make my own pages of words. I have a whole page for the different ways I might want to ask for a cup of tea. Do you say it exactly the same every time?

I think I store words differently to other people as I didn't start my store properly until I was an adult.

I store words in two ways. I do it by category and by first letter.

I start with blank pages either for a situation or a topic and then I gradually fill them. Objects are mostly grouped by location of where they live or where they are used, for example, in the kitchen, or they are grouped with other items they are used with, for example, assistive technology items.



Once I am confident about the first letter, I move them to my alphabetical store which is like my own personalised dictionary. I have designed my own keyboard where words are stored under their first letter in word lists. This is helpful for me as I can usually learn the first letter of a word.

Action words are stored by their first letter, for example "go" is under G and "went" is under W. I would not put "go" and "went" together as in my mind these are not related.

After a while I might realise I can now spell a word, then I would delete it from my alphabetical store and use my keyboard and prediction.

I use as many short cuts and strategies as I can; I need all the help I can get to say what I want to say.

Chat history and location prediction have been game changers for me.

Yes ☐

Learn predictions

Improve your prediction suggestions by learning which words you use most often.

Yes ☐

Record chat history

Each time you speak, store the message in your chat history so that you can quickly find and speak messages later.

Yes ☐

Use my location

Store your location with chat history messages and use this to make more relevant suggestions.

When I arrive at a bus stop, my location prediction pops up with the last things I said in that location, so my regular destinations and ticket choices come up. It even remembers to ask for a split save ticket, so I don't have to find each word.

When I enter the office, my communication device predicts that I will want to say *"can someone sign me in please?"*. I am the most efficient team member at remembering to sign in.

If I want to tell Andrea the same thing that I told my Emma the day before I use my chat history. No one else would know what I said the day before. I am the only one who knows my words.

I ask people to write their names in my communication device so I can save them, and I use the camera to add photos, the internet to find pictures and I search the symbol libraries.

I have gone on to help others with this, and it has been a gamechanger for them. I have seen many people who cannot say what they want and are restricted by their vocabulary set up.

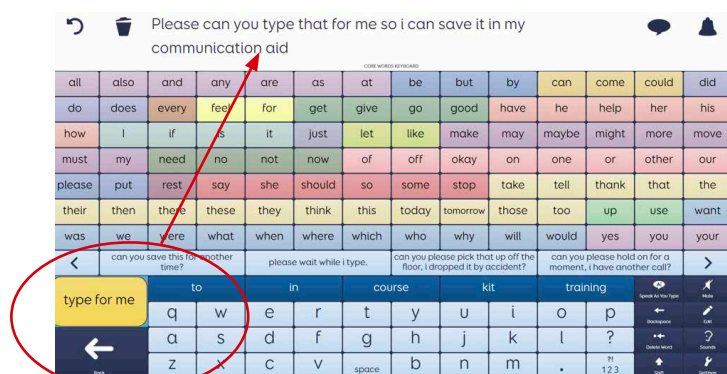
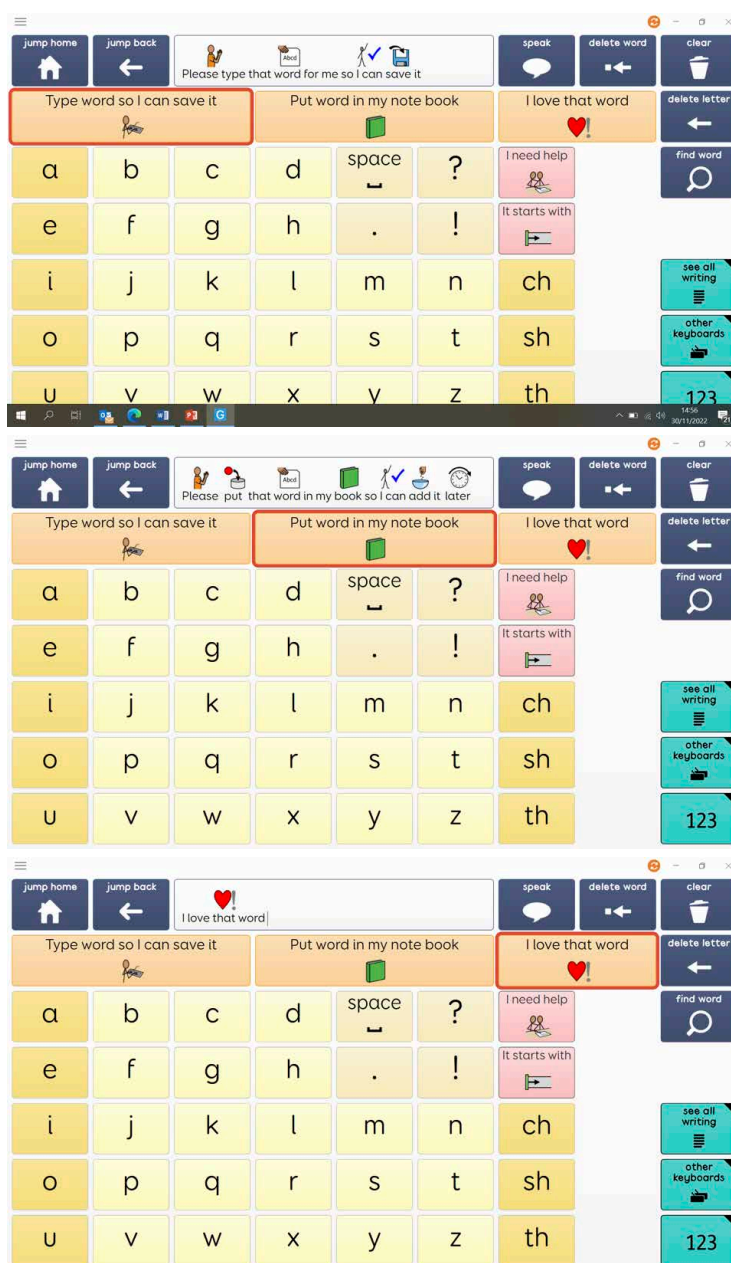
Andrea and the team now encourage self-editing for clients as soon as possible and give symbol or partially literate users tools to ask for help with this. It's important that AAC users learn to love words.

My current grid set suits me, but it is a work in progress and will never be complete.

Recently I was in a difficult situation. I knew I was right, but I didn't have the words to deal with it.

My communication is constantly developing and will never stay the same; there are always new words to learn.

I love going out on my scooter independently, for example to a bike club or for long drives in the country. It is like going for a walk – it is my thinking time and I feel free. I now have an iPad mounted to my scooter so I can talk then too.



I now dream in my communication aid voice – it is more than just a voice - it is the voice of my thoughts and my identity.

EyeCommander: Developing an Affordable Access Method Through the Power of Machine Learning

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This article will outline how Ace Centre supports our clients by developing new software solutions. It will outline how we identify gaps within the existing commercial solutions, and the process we follow to develop and validate our own solutions to these problems. The article will focus on an example of how we used this process to develop an application that uses machine learning to detect when a client blinks to enable the use of blink as an access method.

Ace Centre provides a range of services to Augmentative and Alternative Communication (AAC) users and people who support AAC users. For example, we provide free e-books and paper based AAC resources, Ace Centre learning courses, a free advice line, and assessment and provision of AAC solutions.

How do we decide what problems to work on?

As we, Ace Centre, provide these services, we see a vast number of AAC users with a spectrum of complete AAC solutions to meet their communication needs. In most cases we give clients a combination of 'off the shelf' products put together in various configurations to meet their language and access needs. However, sometimes we end up in a situation where we can't find a solution to fully meet the needs of the client using these products. We can often find a compromise that mostly meets the needs of those users. Ideally, we wouldn't have to make these compromises at all. When we find these gaps in existing solutions, we add it to our list of problems that we haven't been able to provide an ideal solution for.

Over time, we can identify trends of problems that reoccur and how much they affect our clients. We can then target our effort on the problems that occur most often and have the biggest effect on our clients.

What problem does EyeCommander solve?

An example of a trend that reoccurred regularly is the need for a blink switch.

We know using your eyes is a great access method as it allows users to access AAC. It only requires users to be able to control where their gaze is directed. There are many commercially available systems that allow a user to rely on gaze as their input method. When it can be setup correctly and in the right environment, EyeGaze can provide users with efficient access to AAC and their computer in general.

However, there are various situations where a user might want to access AAC with their eyes, but there are barriers preventing them from doing so. For example, users who wear varifocals might have issues using gaze systems as the camera might have an obscured view of the pupil. Lighting conditions can also cause gaze-based systems to be unreliable, especially if the user wants to regularly go from high to low light situations. Other factors that might affect a user's access to gaze systems is cost and chair positioning.

Some gaze-based systems attempt to solve these issues in various ways. However, we have had experience of users who still cannot use gaze-based systems at all.

Once we have exhausted all gaze solutions for a client, we often want to continue to explore other ways they can access their AAC with their eyes. This is what lead us to the desire to be able to detect when a user blinks and allow them to use that to access their AAC.

Using blinks is not a totally new area of AAC. Over the years, there have been some attempts to develop blink-based systems, all making various compromises.

Some specific gaze-based systems allow for blink detection. However, those share all the same potential issues previously outlined. There are also unique solutions, for example the Nous ^[1] headband is a wearable device that detects when a user makes

a deliberate blink. However, after testing the headband for a range of people, we find that sometimes it works reliably, and other times it does not work at all.

There is also a variety of blink-based systems that use built in webcams that are affordable and are easy to use. Android systems have built in 'Camera Switches' which allows users to control their android system with just blinks. Apple laptops also have 'Alternative Pointer Actions' which allows you to control your laptop with blinks and other facial gestures. These camera-based systems are very effective and cost effective. The main problem is they all only work on a specific operating system, which limits their use.

We often find users who want to use blink technology to access an application that is only available on a Windows device, which currently has no built-in blink detection. For all the reasons above we decided to fill this gap by building our own solution.

What did we build?

To solve the previously mentioned problems, we built EyeCommander^[2], a Windows application that uses a webcam to detect when you blink and uses that as a switch input into your chosen Windows based AAC software.

This means that you can install EyeCommander on any Windows computer with a webcam and use it to access an AAC application. You trigger a switch scanning simply by blinking; the AAC application will treat your blink as a standard switch press.

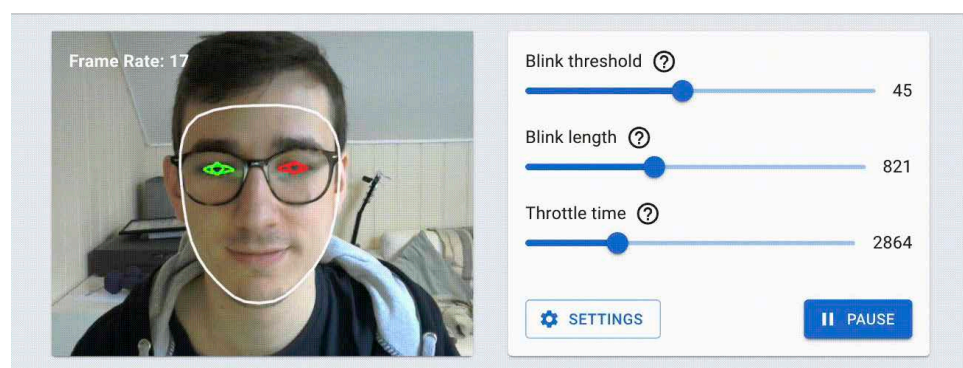


Figure 1: A screenshot of EyeCommander that shows the camera view and the settings

EyeCommander relies on machine learning to detect the position of the user's face. This means that there is no calibration phase to find the user's face in the frame; it can find it instantly. It is designed to be easy to use so that anyone can download EyeCommander and operate it without prior training.

As EyeCommander is camera-based this means that you need no specialised equipment to use it. It works with any built-in webcam to any laptop or a low-cost USB camera. This makes it an affordable solution. It is worth noting that it does require a medium to high end machine to run efficiently, but we are hoping to improve that in the future.

It has been built so that the default settings should allow users to start using EyeCommander as a blink switch straight away. We also tried to balance the ease of use with customisability as we know that to get the most optimal setup, specific tweaks to settings may be necessary. Therefore, we offer as many settings as possible, making no assumption of the 'best' or 'correct' settings.

EyeCommander is available fully Open Source^[3]. Specifically, the application is given the MIT^[4] license which means that the current version of the application is freely available to everyone forever. It also means that anyone is welcome to work on developing EyeCommander, which in turn means that EyeCommander has longevity beyond any one individual or organisation, as others can carry on development regardless of our investment in it. Our motivation for making the application Open Source is that we feel that access to technology is a fundamental right as well as wanting to encourage other people to contribute new features which in turn will benefit our users.

How does it work?

EyeCommander^[2] uses modern machine learning techniques to find a user's facial features in a camera feed. Machine learning consists of a 'model' which has been trained to complete a specific task. It is trained by showing it lots of faces and telling it exactly where the facial features are.

In the case of EyeCommander, we use a freely available model provided by Google called MediaPipe^[5]. The benefit of using a model provided by Google is that they have trained the model using lots of diverse data that we wouldn't otherwise have access to. They trained their model on users in various lighting conditions, different types of eye wear, races, and camera qualities. MediaPipe takes a camera feed and tells us exactly where all the different parts of the face are, including the eyelids and the iris.

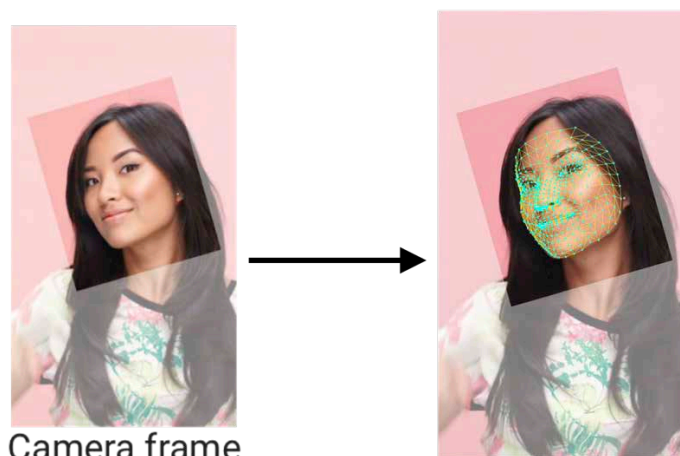


Figure 2: A demonstration of how the MediaPipe model can detect lots of facial landmarks

However, the model does not tell us specifically when the user blinks, but we can use the data it gives us about the eyelids to calculate this. At first thought, it seemed simple to calculate given that we know the position of the upper and lower eyelid. However, on further research it is slightly more complicated than that.

On average, humans blink around 12 times a minute, and they last for roughly 333ms every blink^[6]. This means we cannot simply detect all blinks as we would detect when a user makes an involuntary blink which is not a useful signal. Instead, we need a way to tell the difference between a voluntary and involuntary blink. To achieve this, we opted to rely on the time that the eyes are closed for to determine the difference between a voluntary and involuntary blink. We suggested that users keep their eyes closed for a fraction of a second to indicate that the blink is deliberate and then EyeCommander can ignore all shorter blinks. This setting can be customised to meet the users need but does require some training of the user.

Once the system can detect blinks, it needs to be able to output them so you can control your chosen AAC app. EyeCommander works simply by telling the computer that a keyboard key has been pressed every time the user blinks. This means that if the AAC application can use keyboard input within its switch scanning settings, it can connect with EyeCommander. EyeCommander does have specific settings to connect to common AAC Apps like Grid and NuVoice, but it doesn't exclude any.

How does it work in practice?

We have used EyeCommander^[2] with several of our clients and have also heard from other specialised services who have tried it with their clients. In practice, we have found that it can require fine tuning to make sure that it only registers the blinks that are voluntary but once you tune it. Overall, it has proved to be a successful solution for clients for whom we would have previously struggled to provide solutions.

Dawn was one of the first people to try EyeCommander. She previously relied on partner assisted scanning with her partner and carers. She used her eyes to indicate when she wanted to select a row or go back. She was very efficient using this method, so any new technology had to be just as efficient and not add to much complexity to her setup. She had previously tried to use an EyeGaze solution but due to her alternative strabismus, it didn't work for her. However, she was confident using her eyes to make selections, so we tried her with EyeCommander. We have left it with her to trial for an extended period of time, but we hope it will provide her with another mode of communication alongside her current methods.

What's next?

Since releasing the first version of EyeCommander, we have had lots of feedback from users and have quickly integrated this feedback into a new version. We are regularly fixing small issues with the software to improve it for all users.



Figure 3: Dawn using partner assisted scanning and using EyeCommander with Grid3

We take issues publicly and list them on the project page. Amongst those identified are other eye gestures and ways for the end user to pause gesture detection. For a full list and future updates see that we have planned checkout our project page [7].

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Taking on AAC: What I've Learned as a Parent and (recovering) SLT

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Introduction

Bringing a presentation, something I'd written to share with people in a room, people I could see and interact with and transforming it into written work, has proven incredibly challenging. The very act of presenting has changed and evolved the initial thoughts. Furthermore, in sitting to write this, I have discovered that, for me, there is a feeling of comfort in speaking in a room and that transforming this into written work changes the feel and the purpose. The multimodal nature of a presentation afforded benefits that I'm simply not able to replicate here.

So, if you'll indulge me, I'd like to take a slightly different approach to writing up this presentation in which I will make use of my reflections and the benefit of hindsight. I will readjust some of the things I presented, miss some out entirely, and provide some questions to promote thinking and rethinking.

Part 1: Acknowledging and sitting with difficult feelings

In the presentation, this section was called 'diagnosis'. Initially, I talked about Lucy's diagnosis and how that left us feeling. I talked about acceptance and grief, and my discomfort with how this language feels too polarizing. I cited Griffin (2021) who says 'Overall I think people should be wary of making simple comparisons with grief, using it as shorthand for a very complex and personal experience.' and brought in some of the AAC literature (Moorcroft et al 2019) which discusses parent grief and acceptance as one dimension of a complex picture of why AAC is accepted or rejected.

In all this, my key takeaway from my lived experience of diagnosis was that I needed people around me who would be able to sit with discomfort and not try to save me or cheer me up. I described times when information about services and support were withheld because I was perceived as 'not ready' when, at the same time, I'd been looking for exactly such services for myself. I've thought about this a lot, and I wonder if this is because practitioners are trying to (without knowing) save themselves from the discomfort and challenge of allowing difficult feelings.

Part 2: Honest dialogue about therapy provision

In the presentation, I described our therapy journey. In fact, this began before we saw a Speech and Language Therapist. I gathered information, spoke to friends and found out what current thinking was telling us about how to support Lucy's communication. I spoke about the therapists we've seen. Somehow putting this down on paper makes me feel uncomfortable. I've done this in the past on the blog, you can read that if you wish, but with the benefit of reflection and the distance of time, I take a different approach. I want to write about the complex of contexts which means we didn't get the support we needed at the time we needed them. It's easy to be critical of individual therapists' lack of knowledge, but they operate in a larger context. Some have limited development time and large caseloads, some smaller caseloads but funding or policy constraints. My thoughts about how therapists act in any of these contexts however haven't changed with the benefit of time. I still believe that I want any professionals working with us to be honest about the factors limiting their ability to provide the service I expect and/or need. For me, this brings to mind some of the advice from the I-ASC project (2019): 'Be mindful of policy-compliant decisions that are not in the child's best interest and avoid if possible' and 'Consider whether the available resources are overly influencing the decisions within the recommendation process. If so, consider altering the recommendation process to closer align with child need rather than available resources'. I want to be clear here. I don't want side conversations like 'well you know how it is with funding,' or 'the NHS these days,' or 'if you get this then someone else does not', but an open conversation about what is funded, what the framework and policies are that drive decisions that may not be based on need, along with acknowledgement that this is not easy to hear. Only with this open and honest dialogue can we parents make truly well-informed decisions about how we want to spend our resources in time, energy, or finance.

Part 3: Trust is in the eye of the beholder.

In September, I used our journey with school to illustrate how I came to understand and acknowledge the complexity of the relationship I had with school. Lucy began school in September 2019 and Covid crashed into all our lives soon after. This led to massive changes to daily school life even after 'the return'. I realised that, although I knew that she was well cared for in school, I'd come to be concerned that she was not learning and that fundamentally while I knew Lucy was safe, I felt discomfort with school... then I heard this quote:

"(Trust is) ...choosing to make something you value vulnerable to another person's actions." (Feltman 2021)

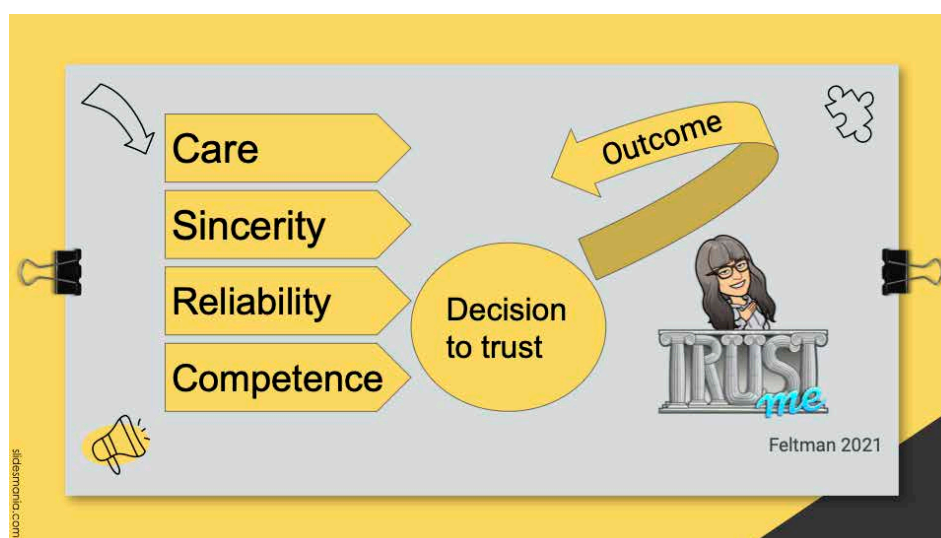
(I heard this quote on 'The Skies We're Under' podcast by 'Born at the right time' links to both of these on the reference site, and I recommend diving in).

I decided to explore Feltman's work more. His book is a very quick read and, in my opinion, worth anyone's time. As shown in the picture of one of the slides I presented in September, he describes four components which contribute to a decision to trust:

- Care- having the other person's interest in mind;
- Sincerity- being honest and actions align with words;
- Reliability- keeping promises;
- Competence- ability to do what you say you're going to do.

I was able to recognise that my trust was being eroded because of inconsistent or absent messaging from school, due to the physical distance that had developed due to Covid policies.

People decide whether or not to trust us. It's not absolute, and there can be aspects where trust is strong but other areas where it is not. In this case I was secure in care, sincerity and competence but not reliability. Interestingly, after the presentation, a participant who tweeted about the session picked up on a point that I'd added to the presentation at the very last moment which was that parents do not always get to choose things like school placement, educational approach, how drop off happens, so they are pushed into a position of not trusting where they have no choices that they are able to make.



Part 4: Personal and Professional Identity

At the online CM conference in 2021, I sat in the presentation by Sarah Hayward (Hayward, 2021). One of the themes emerging from the work was that of identity. I was so excited to hear this as it resonated so much with my experience. I really wanted to expand on this and to achieve this I found I had to contact Sarah and ask if it was possible to get a copy of her presentation. Why? In my excitement on the day of feeling so seen, I had only written the name of the session and then the words 'yes', 'of course' and 'absolutely' over and over. A year on at CM 2022, I talked about why this work had really resonated. Hayward found that all of her participants talked in some way about identity and how that had changed in relation to caring for a disabled child. The themes about 'loss of old self', 'being powerless' and 'my child as my job' really resonated.

This led me to reflect on a moment at the hospital with Lucy when she was really little. We were in the large cafeteria at Pinderfields Hospital, and I felt a significant emotional reaction to all the busy professionals coming in for lunch and going about important business. I envied them and deeply missed this part of myself.

So, what did this mean for my motivations as an SLT? I recognized how much the 'busy respected person' role had been important to me and suddenly being placed in a different place in this power dynamic. For a further discussion of this, I would recommend the chapter 'A critical look at the concept of 'service' in speech and language therapy' by Jane Stokes. She invites a number of questions:

"In considering why we want to become speech and language therapists it is useful to consider the following. Does the desire to be a professional person who gains respect because of their knowledge and skills drive prospective speech and language therapists? ... Do we reflect sufficiently on the power imbalance inherent in the therapeutic relationships we engage in? Where does our desire to 'help' come from and can we benefit from more scrutiny of this desire? Do these motivations affect our ability to really collaborate with our service users?"

And then after a thorough examination of some of these themes, she concludes:

"So it is the clinician that needs to continually examine (their) motivations, values and belief systems to ensure that they do something with the clients rather than to the client." (Stokes, 2015)

Closing reflections

In the presentation, I shared pictures and assessments to demonstrate Lucy's progress. I'm not going to do that here as, many months on, there's so much more to say, and on reflection maybe I would not have included that in the presentation after all. I think I included it because I wanted to show off, not just show up. That I wanted to show that I'm STILL a therapist (although I'm technically not), and I can still do the technical stuff. In the end though, I wonder if this detracted from the message that I wanted to make back in September, and it CERTAINLY detracts from my updates reflections since then.

When I consider with the benefit of time what really were the key messages underpinning what I presented, they all link back to very similar themes that I think both parents, families, and practitioners can reflect on:

- Do we get the support we need to be able to sit with complex and difficult emotions both ours and those of others?
- Let's all be really open and honest about our expectations and what we can deliver. Do conflicts arise purely because of a lack of provision or funding or on a lack of honesty about the process?
- Is there merit in exploring the apparently absolute condition of trust and examining how we experience it? Are there ways we can acknowledge why we don't trust and what we can do more to earn trust?
- How do assumptions about our roles and our motivations show up in our interactions? Do we have the chance to examine these?

These are all big questions and take time and effort to explore but in my experience all of these are things that can really help smooth the path of working together. Good quality support for families and supervision for practitioners are strategies that can begin to swing the needle to a better understanding of each other.

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BAC Study Day Booklet

The proceedings from the Communication Matters Becoming an Aided Communicator (BAC) Study Day, which took place in June last year, are available to purchase in a digital booklet.

The booklet is available to anyone with an interest in language development and AAC. The Study Day focused on the language and communication opportunities of children and young people who are learning language using aided communication.

This large summary document (PDF format) includes abstracts, discussion commentary, bibliography, biographies, and a list of existing publications (total 94 pages). It costs £15.00, with all proceeds going to Communication Matters charity. Our sincere thanks to the BAC team for their contribution.

You can buy the booklet online [here](#) and a link will be emailed to you.

Literacy Informed Approach: Supporting Students and Improving Service

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The Kent and Medway Communication and Assistive Technology (KM CAT) Service is a Regional Specialised AAC Assessment Service. We have additional funding from the Local Authority and ICB (Integrated Care Board) to provide ongoing support for schools and the family in the implementation of AAC and AT (Assistive Technology).

We would like to share our findings from the implementation of the literacy programme based on Dr. Karen Erickson Ph.D. Dr. David Koppenhaver Ph.D. 'Comprehensive Literacy for All: Teaching Students with Significant Disabilities to Read and Write'. KM CAT would like to show how feedback from teachers and other professionals supported the development of the literacy programme and workshop for parents.

Additionally, we would like to share how using literacy assessment (as presented in 'Comprehensive Literacy for All') can inform and improve the service delivery, by providing clarification when prioritising cases and allocating resources, and by helping to identify students who are not reaching their potential so that they can receive personalised support.

KM CAT works closely with families, schools, and therapy teams to make sure that everyone has opportunities to develop their communication skills and has appropriate access to the curriculum. Our focus is on the Children and Young People's (CYP's) inclusion, independence, and wellbeing. We are interested in supporting the development of literacy skills, because we believe that it is an important and integral part of everyone's life.

Moreover, when looking at the matter from more practical perspective, it becomes apparent that acquiring literacy skills is a way of overcoming certain limitations posed by AAC systems. The vast majority of CYP are provided with symbol-based systems, so that they can have functional communication. However, using only symbols can limit their communication, as they rely on vocabulary selected by professionals and families working with them. It is vital to teach young people literacy based strategies, so that they can explore and learn new vocabulary, communicate effectively and have access to knowledge.

We stand strongly behind words of Karen A. Erickson and David A. Koppenhaver in their book "Comprehensive Literacy for All. Teaching Students with Significant Disabilities to Read and Write":

"Literacy is a life-long, functional skill. When acquired, literacy helps students not only communicate effectively but also have access to books, learning materials and printed information. It offers the best opportunity to fully access the world around them, to understand their choices and have a power to self-advocate".

It is important to remember that:

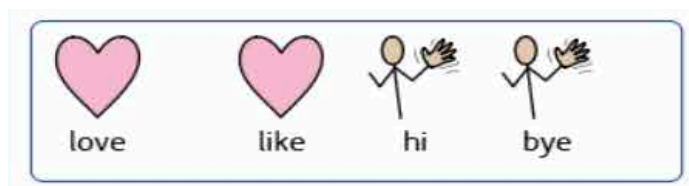
1. No matter how comprehensive, AAC systems will never have ALL the words that a student might need to say.



2. Symbols need to be taught or explained, as their meaning is not always obvious. There is a tendency to create a symbol for every word, even if the picture does not provide clarification or a cue.



3. Symbols are often used inconsistently. Words are used to define the meaning of some symbols that are used generically.



4. With only some knowledge of the alphabet, students can give clues to words. In context, they can combine words and phrases with initial letters to help convey their message. For example:

- **Ordering a drink:** 'I want drink S (Sprite)'
- **Choosing friend to play with:** 'Girl B (Beth) Play B'



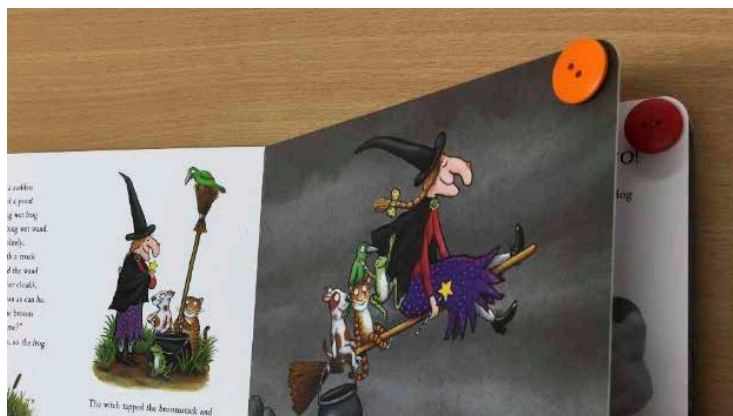
The KM CAT Service has been working with a number of selected students who have been provided with personalised support and with teachers who have decided to improve outcomes of their students by implementing K. Erickson's and D. Koppenhaver's approach in their classes. K. Erickson's and D. Koppenhaver's work provides well-needed clarification, support, and guidelines for supporting literacy development. Our service created a training programme based on approach outlined in 'Comprehensive Literacy for All: Teaching Students with Significant Disabilities to Read and Write' to support teachers and other professionals working with young people and to promote K. Erickson's and D. Koppenhaver's approach within Special Education Needs Schools across Kent and Medway. Additionally, we created a workshop for parents to empower them and give them tools to support literacy learning and home.

When developing the course we collaborated with a number of teachers and other professionals to coproduce our literacy training and make sure that we address any concerns and issues. KM CAT Service comprises Speech and Language Therapists, Teachers, Occupational Therapists (OTs) and Therapy Assistant Practitioners. Multi-disciplinary working allows us to find solutions to challenges and issues that have been highlighted.

The most important issue we have approached was regarding accessible books and resources. Our OTs had a chance to prepare a number of different resources enabling students to access books easier, giving them independence to explore and access reading materials at both home and school. Different students needed or preferred different solutions. Their feedback enabled us to make more 'creative tabs', so that they can turn pages easily (see right).

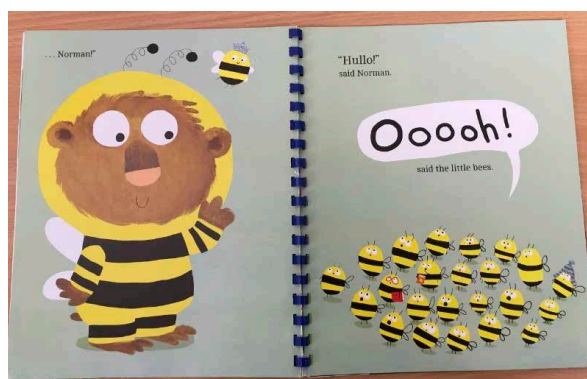
Tabs make the pages easier to turn, but it is important to make sure that the materials used suit students' needs (easy to see, grab and turn).



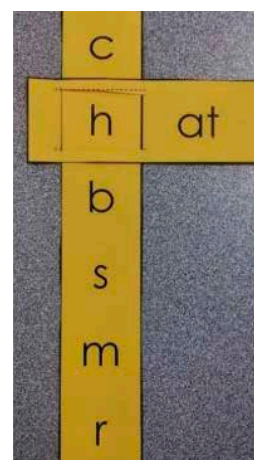
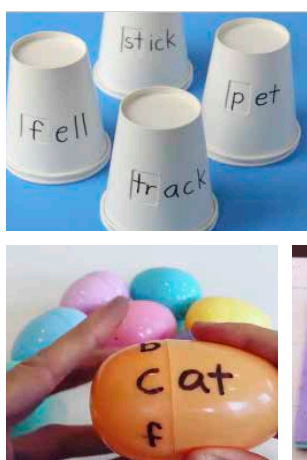


Lollipop sticks can be placed on side or bottom, depending on the CYPs abilities and where it is easier for them to reach it, easy to grab foam stickers can aid students with developing fine-motor skills etc. Separating pages so they are easier to turn helped a number of students to access their favourite books independently. We have used a variety of different materials like buttons and pom-poms (see above).

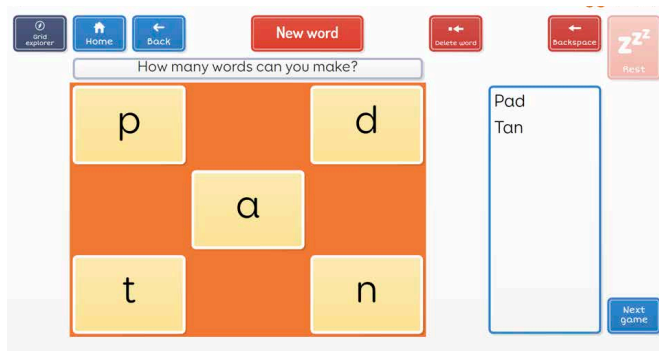
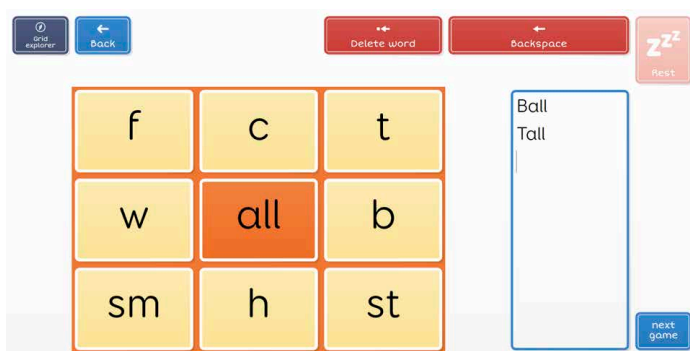
We encouraged teachers to focus on simple solutions, because simple adjustments can lead to big results. For example, re-binding a book and/or printable resources (making a book) will make pages generally easier to turn. The book can lie flat on the surface without closing, and students can write/draw on the pages (see right).

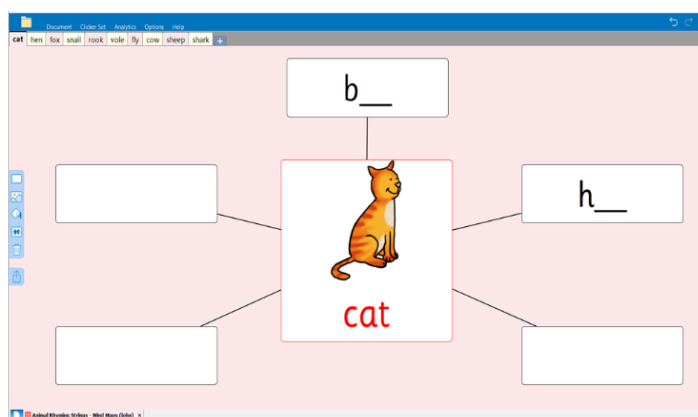
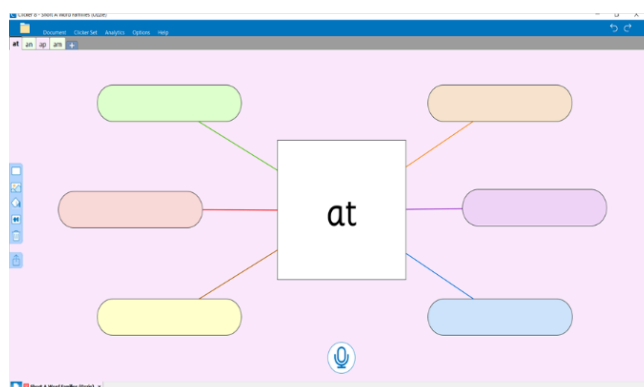


Accessibility has become a very important issue; we have received a lot of feedback regarding easy-to-use resources. While working on making sure that every student can have access to literacy resources, we came up with a whole plethora of fun activities that not only are easy to access but are also fun to use.



Again, we made sure that resources are simple, easy to make by school team or family and accessible to most students. For all those who rely on computers or their AAC devices to access the curriculum, our team created activities that can be used on communication devices and encouraged teacher to explore digital resources like Clicker 8.





While developing a training programme based on “Comprehensive Literacy for All. Teaching Students with Significant Disabilities to Read and Write” by Karen A. Erickson and David A. Koppenhaver, we have realised that there are two different ways we can use it to support CYPs on our caseload and influence the way we work within our service:

Indirect	Direct
<ul style="list-style-type: none"> • Training for teachers and other professionals • Workshop for parents 	<ul style="list-style-type: none"> • Supporting CYPs on our caseload, their families and school teams • Using literacy assessment as a tool to prioritise cases and support service delivery • Using literacy assessment as a way of identifying students who are not meeting their potential

The indirect way of supporting students is the most obvious one but at the same time the least reliable. We can deliver both training for schools and workshops for parents and hope that the approach will be implemented and maintained within a setting. For CYPs on our caseload, we have an opportunity to provide ongoing support and guidance to professionals and parents and to see how students respond to this approach.

The direct way of supporting students on our caseload gives us an opportunity to lead by example, mentor teachers and other professionals, demonstrate different strategies and use personalised resources- giving us a level of control over the implementation of training programme. It will allow us to learn and improve the way we support teams around students on our caseload and see the actual change happening.

In their book, Karen A. Erickson and David A. Koppenhaver are providing us with a simple, four-question assessment:

- Can the student identify most of the letters of the alphabet?
- Is the student interested and engaged during shared reading?
- Does the student have means of communication and interaction?
- Does the student understand that print has meaning?

It allows professionals to ascertain if the young person they are working with requires emergent or conventional literacy instruction. It also can inform our everyday practice:

1. Prioritise cases and support service delivery:

If all students are assessed (using 4-question literacy assessment) and assigned to either emergent or conventional literacy skills pathway, it is easier for professionals to allocate resources and prioritise (‘triage’) cases. CYPs on the caseload can be assigned to three groups - depending on their age:

Under 9yo
Primary Phase
Knowledge focused curriculum

9-11yo
Transition Phase
Knowledge focused curriculum

Over 11yo
Secondary Phase
Life Skills focused curriculum

Primary Phase - students on emergent pathway can be supported in more 'balanced' way; all professionals will have enough time to build the necessary communication skills and train the family and school team. Hopefully, it will allow the student not only to progress beyond the emergent pathway, but also to build some conventional literacy skills before going to Secondary School.

Transition Phase - students on the emergent pathway in this phase are at risk of not developing enough skills to transition to the conventional literacy pathway before leaving Primary School. These students require a more targeted and personalised approach with more support from the class teacher and robust involvement of both the family and school team.

Secondary Phase - students on the emergent pathway in this phase are at risk of never developing enough literacy skills to support their communication effectively (unless the school focuses on literacy as a part of the curriculum). Support from school team and other professionals should address that risk.

2. Using literacy assessment as a way of identifying students who do not meet their potential

Assessing students (as above) gives us a baseline for future support and also provides us with a chance to spot students who are not meeting their full potential. This gives an opportunity to provide them with targeted support.

For example, if the student hasn't moved to the conventional pathway within the expected (and agreed with everyone) timescale, we need to start asking questions focused on finding out what isn't working, where the problem is, and how to support.

We believe that a Literacy Informed Approach can help us to effectively target support to improve outcomes for the CYPs who need it. We hope that both the training programme and parents' workshop will empower professionals and families to focus on literacy, so that AAC users can have full access to the curriculum and the wider world of literacy. We will be reviewing this work, and our learning will inform future practice.

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Communication in Gaming

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The topic of **Communication in Gaming** was presented at the 2022 CM Conference workshop titled '**Gaming – How To Enable Access For Fun, Friendship And Communication**'. Jordan Brearley, Field Service Technician, the primary presenter at CM and primary author of this paper, with assistance from Marcus Friday, Environmental Control (EC) Service Lead and Joshua Mars, Speech and Language Therapist from the Barnsley Assistive Technology Team.

Gaming Access Is Relevant To Specialised AAC And EC Services

Gaming provides access to entertainment, friendship, inclusion with peers, and communication opportunities. In the AAC and EC field, are we sufficiently aware of how to enable gaming access, and why is this relevant?

Gamers communicate with each other by voice, text, emotes, memes, and coded language which emerges from within the community and may be represented by letters, symbols or images. Friendship groups formed in the physical world can continue online through gaming and chat, or individuals can enter games and find friendship via a shared interest.

Adaptations exist to make gaming accessible and inclusive for many people. This can or should open up exciting communication channels for AAC users. Gaming chat can be inherently accessible in that the items required are usually located within the game and text is often a minimal part of these conversations. The symbolic language used by players can be created rather than learnt and develops through experience and exposure, meaning nonliterate users can be immersed in this and communicate in the same manner as their peers.

Gaming access is supported across the UK and further afield by organisations such as Special Effect, and OneSwitch. There are some specialised AAC/EC services assessing, providing for and supporting service users whose main goal is gaming access.

Gaming is widespread in society, providing access to entertainment and opportunities for inclusion and communication, but for some there remains a stigma attached to this activity.

Removing The Stigma Attached To Gaming

Since the early 1970's, with the advent of the arcade video game, gaming has tended to be viewed as an outsider activity. With the likes of Tron and its later spiritual successors where an ordinary person must learn how to navigate the alien world of the "gamer", it has always been portrayed as just out of reach for the regular person.

Even in 2022, those unfamiliar with gaming would struggle to pick up a controller and not equate it to the controls of a jet fighter, and most media portrayals of those who can handle the multi-layered inputs of a controller are of a clique of hyper intelligent computer specialists and programmers.

So, how is it that gaming remains such a staple of the modern world? The answer is simple: gaming is inherently a social activity. People are what makes gaming fun though this needs some context as to what games are and what they bring to people.

Gaming can simply be a chance to relax and engage in escapism, or distraction therapy. When immersing yourself in the gaming world, you are not necessarily you. You can be a set character, an avatar of your own design, or not even a character at all.

Like a book, games can focus on a message to its players, discussing many themes that with the aid of visual design, sounds, music and interactivity. It grants players the opportunity to explore these themes in greater depth. From tales of life in a digital age, the meaning of life and death, the importance of helping others, working through mental health (not always overcoming it, but learning to live with it), all the while never being yourself, but immersing yourself in the shoes of your protagonists.

These experiences don't always have to be solo endeavours either, as many games cater to our always online world by allowing us to play with people far and wide across the globe, be it in the spirit of mutual cooperation. Be it working to overcome a foe within the game in groups as small as two or as large as a thousand to achieve a shared task, players can often work together to achieve what they might not be able to alone. Similarly, be it on the battlefield or football field, players may also work competitively against one another. A win is a win, no matter the game.

That is not to say that games always need to be high octane adventures where an adversary must be overcome. Minecraft, the best selling game of all time, thrives on its ability to craft, create, and invent, where you need never fight anything. Games can be creative outlets, a storytelling experience, a brain teaser, or a way to test and improve your hand/eye coordination, your reaction time, your short and long term memory, your mental health, and importantly, your social skills.

It does not matter if you play alone or play together with other people, whether it's Joel's decision in the Last of Us, the best romance in Mass Effect, who beat who in Call of Duty, the level reached in Candy Crush, or which player is signing up with which team in the League of Legends Worlds tournament. There will always be common ground between players, be it in a small gathering at the lunch table, online in a "party" or on Discord, at a gaming convention, a gaming festival, or even at an eSports tournament, gaming is a reason to come together.

However, gaming still comes with a lingering social stigma. Many view gaming as a pointless, childish activity, one that is *nerdy*, inherently violent, toxic, with an expensive barrier to entry. It is inherently difficult to change this perception. It is said that the average gamer is reportedly in their mid-thirties and has been gaming for over a decade, but due to the belief that gaming is childish and nerdy, most people wouldn't class themselves as a gamer, despite the fact that the most popular games are household names like Candy Crush, FIFA, and Call of Duty.

The mobile gaming market held 52% of all gaming purchases in 2021 (Wijman, 2021), outperforming both PC and consoles combined. Despite the claim that gaming is too expensive and exclusionary, most game purchases are made on something that most people carry around with them every day.

Further, there is the belief that gaming is linked to and causes violence, as the news often suggests, yet gamers have been categorically proven to be less violent in study after study. In fact, studies have proven the opposite, in that gamers have a much more manageable outlet for their frustrations and are less likely to be violent (Hern, 2020, Przybylski, 2019). Still, there is the belief that because of this outlet, that gaming is toxic.

With the anonymity of the internet providing a platform for the worst in society, toxicity can discourage people from playing, so developers have an incentive to root out and address negative behaviours to encourage people to keep playing and buying their games. Gaming remains the only medium that actively incentivises and rewards the act of reporting and self-policing of their shared spaces to root out hate speech and inflammatory behaviour.

Communicating in Gamer

So, you have the hardware, you have the games, but how do you communicate with your fellow gamers? For most people, gaming can be just playing a game of FIFA or two a night with their friends with a headset allowing you to talk in real time. But how else can you communicate, especially if communication isn't as easy as simply putting a headset on?

The means of how you communicate is entirely dependent on the scope of how and who you want to communicate with. For interpersonal communication, most consoles come with their own version of a private call system where you can form a 'party' and communicate with those in the party. Using systems like quick-chat, ping wheels, and in-game prompts, a player can communicate with their fellow players extremely quickly with surprising speed and context sensitive information.

If playing different games, people often employ third-party tools such as Discord to organise their parties and to stay in touch, even when not actively playing. Just because the controller has been put down for the night, it does not mean you have to stop discussing the games that you wish to play. Many people still communicate outside of the game using different avenues. While there are too many to go too in depth about, the likes of Twitch, Reddit, Twitter, YouTube, Tumblr, game specific forums, game specific websites and many other avenues are often employed for a range of interpersonal and public communication for keeping in touch with fellow players. **Though there is a lot of work to be done on the integration of Twitch, Reddit, and Discord with most AAC equipment and apps.**

Gaming is also not limited to just having a back and forth with players that you actively game with. Many players enjoy watching others play and enjoy their experiences parasocially. Some enjoy watching a smaller streamer who they can actively discuss with. Some enjoy watching someone go through a journey in a game they may have already completed or want to enjoy it alongside them. Some streamers aren't even good at games, they simply have an entertaining personality, where their failures are part of the fun. Some streamers don't even have a visible face and often use the likes of an avatar to represent themselves. Some streamers are so massively popular that it is near impossible to have a sense of kinship with the streamer, and instead the community becomes the focal point. Memes become a universal form of language that are shared between communities, that, once the language has been deciphered, you can express a feeling in a singular image that everyone understands at a glance. Cathartic tragedy can be expressed by a crying little green frog holding his hands up much quicker than a paragraph that may only stay on screen for half a second in a busy chat scroll.

Regarding those who've never picked up a controller and may never for the rest of their life, it is hard to ignore the impact of gaming in popular culture. The Olympics in Japan had their late former Prime Minister dressed as Mario, ESPN and other sports channels host gaming tournaments, with pro-gamers receiving athlete visas. Video game TV and film adaptations are regularly made with Emmy winning quality and big name actors. Supermarkets are littered with gaming merchandise from cutlery to clothing. It is growing ever harder to hide from the influence of gaming on the modern world.

The Future

I have met hundreds if not thousands of players over my life from all walks of life, of all nationalities, ethnicities, backgrounds and religions. I have travelled the world to meet people that I had spent countless hours online with. I have laughed, I have cried, I have fallen in love, and I have lost people that I cared about. And I am blessed to have met every single one of them through the power of video games.

The truth is, there are a thousand reasons someone might want to game, and there are a thousand more as to how someone might want to communicate about their game, but until these two concepts are linked, we remain at an impasse. Game developers are constantly innovating to try and broaden their market appeal to get more people to buy and play their games, but it appears to be a heavily one-sided push from the developer to the gamer.

Until there is a larger push from the AAC, EC field and wider AT community to improve accessibility for people, to improve the means to socially access the avenues of communication and to remove the social stigma that comes with gaming, we are continuing to do those that we support a disservice.

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My Grids and How I Evolved Them to Fit My Life

PATRICK BATES

Email: pbeyepaint@gmail.com

Introduction

My name is Patrick Bates, and I am 54 years of age. I have severe Cerebral Palsy. I live in Coventry with 24hr care support which I employ myself. I use an Eyegaze, on both my desktop computer and my Gridpad, to communicate.

Before, I had the Tobii Communicator, therefore I will be referencing a few things with this. I have been using the Grid for 5 years now and am mostly self-taught, because I can be shown once, and I can remember how to do it. I am authoring this paper from a personal perspective. While my personal Grid layouts may not be right, I have a good sense of logic, and if this helps just one of my fellow AAC Users, I will be very happy.

Smartbox's Grid 3

When I first started to use the Grid, I could not understand why there were so many individual grids that made up a grid set being used in the way Tobii's Communicator works. However, as soon as the people at Smartbox showed me the potential of creating and adapting existing grids and grid sets, I soon changed my mind.

Because each of the grids are separate, I call it modular, and I can put any number of grids together within a grid set. I can insert a rogue element into it, at any point of time, and if you add the correct jumps, you can put any kind of grids in a grid set. Another important thing about this is the ease of mixing full-screen grids and Computer Control grid sets.

Do People Think an AAC User Should Be Satisfied with Just Being Able to Communicate Their Needs?

We all know that the fundamental principle of any AAC program is to enable the nonverbal user to communicate effectively whatever the AAC user's communication needs are, from basic needs, right up to complex communication thoughts that the AAC user can have.

As an AAC and an Eyegaze user, personally, it is all about making my communication life easier, so instead of constantly going in and out of grid sets to access my chat grid set, on the numerous occasions I want to check something with my P.A, I have integrated a chat grid into most of my grid sets, including the Social Media grid set, my email, and my calendar grid set.

To Have a Mouse Button on Every Grid

Would you agree that people use the mouse on a computer regularly without thinking about it?

When I first saw Smartbox's Computer Control grid set with just left-click, right-click, double-click, and drag and drop, on one of the grids, it made no sense whatsoever to go back and forth between the mouse grid set.

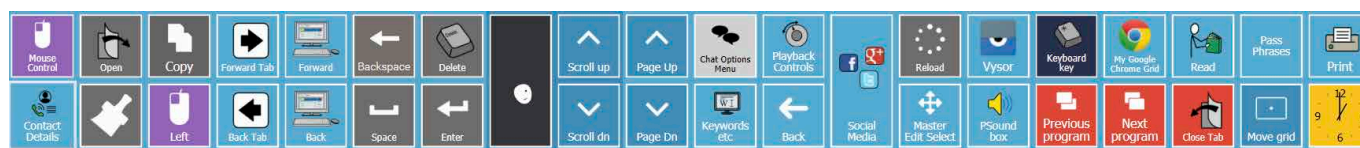
On all my Computer Control grid sets and all the grids within them, I have put, at least, a left-click cell on them. On my word edit grids, I have put drag and drop cells on them, together with the cut, copy and paste cells.

Three of My Computer-controlled Grids

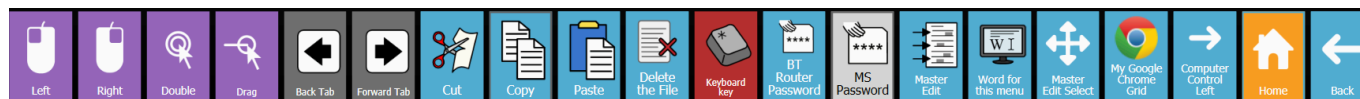
Home grid:



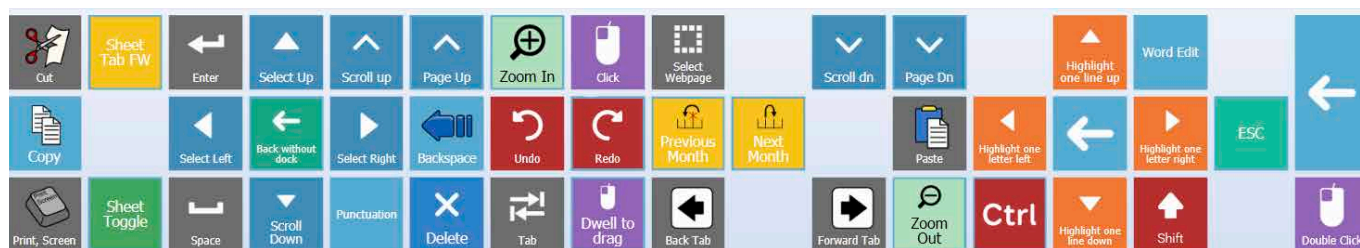
My main edit grid for My Web Browser:



One of my full mouse control grids:



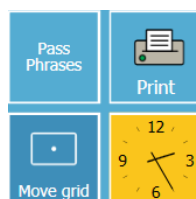
My arrow keys, together with various other editing functions:



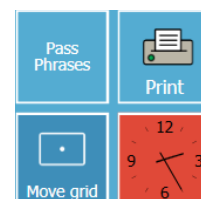
Double-use Cells

I will now give you 2 examples of what I mean by double-use cells. I cannot really wear a watch for obvious reasons, so I like the time on various grids. However, it means using a cell for this which was a 'dead' cell, so I have made it into the Rest cell too!

A selection of edit menu to show the clock which has the rest cell added:



This shows the rest cell working:



Do You Ever Use the Online Grid Sets, if So, Do You Edit Them to Suit the AAC User's Lifestyle?

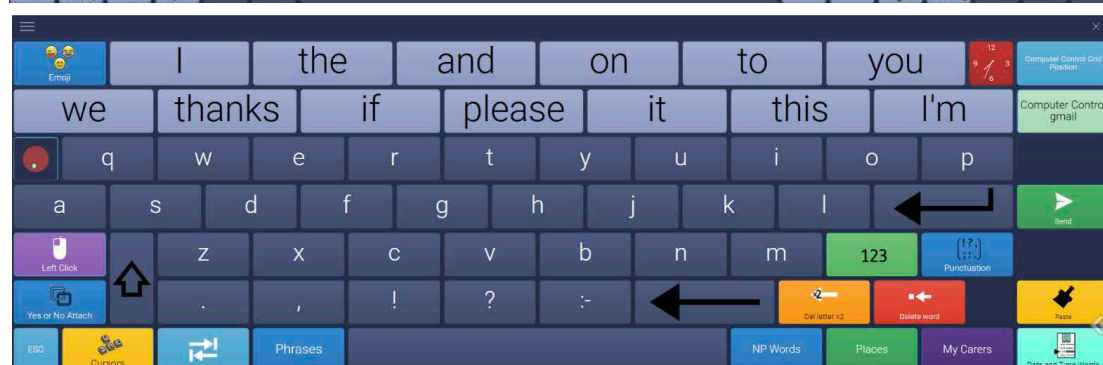
I make skilful use of the online grid sets library that Smartbox has. To have access to this, people need to become a member of the Smartbox's community. Sometimes, I just have a browse through the grid sets library. Other times I want a specific grid set for my Computer Controls grids to download and then edit them to how I feel the grid should be to make it easier for me.

I will now show you and talk through 3 online grid sets. Firstly I will show you how the original grids of the Computer Control keyboard grid set, and a certain email's and calendar's online grid sets. Then I will show you how much I have edited. Obviously, I cannot upload my edited versions of original grid sets, although to my mind, I have made the grids better.

The original word keyboard grid:



My word keyboard grid



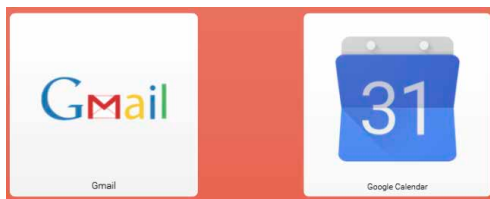
I will explain how I created my keyboard a little later in my presentation
My upright keyboard:

With the grid, I can create any number of keyboard layouts. The reason I have created an upright keyboard is that some websites work better with an upright keyboard, which I use on both my desktop computer and on my Gridpad.

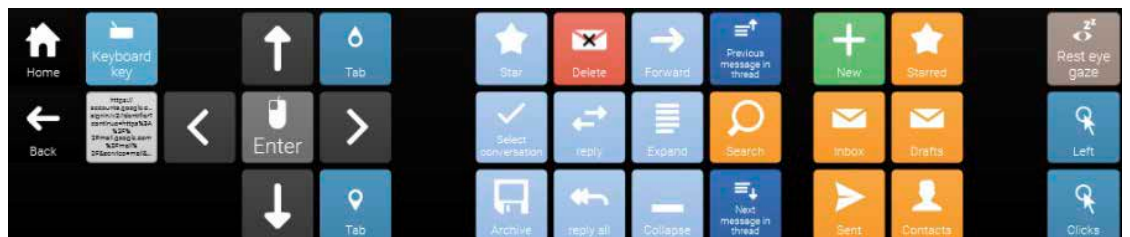


The Original Gmail and the Google Calendar

These grids in one grid set:



The Gmail grid:



The calendar grid:

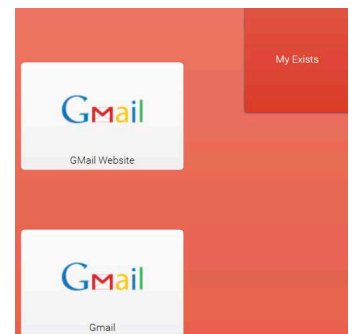


What I did to the Grid Set

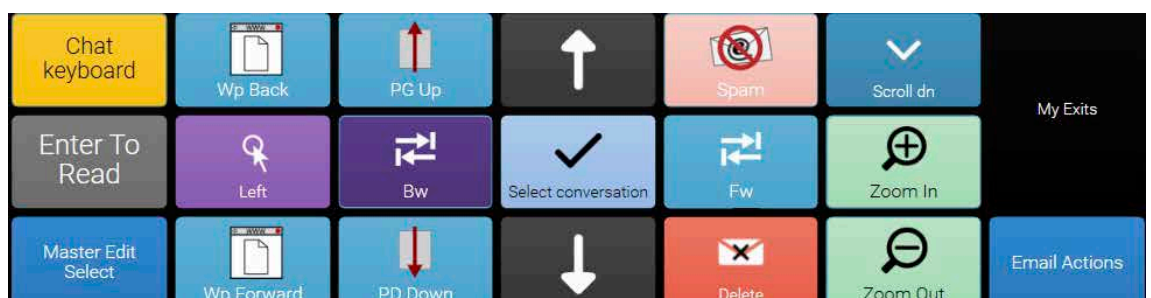
To my way of thinking, there should be 2, stand-alone grid sets here, so I created 2. First, I will show you my version of the Gmail grid set.

Gmail

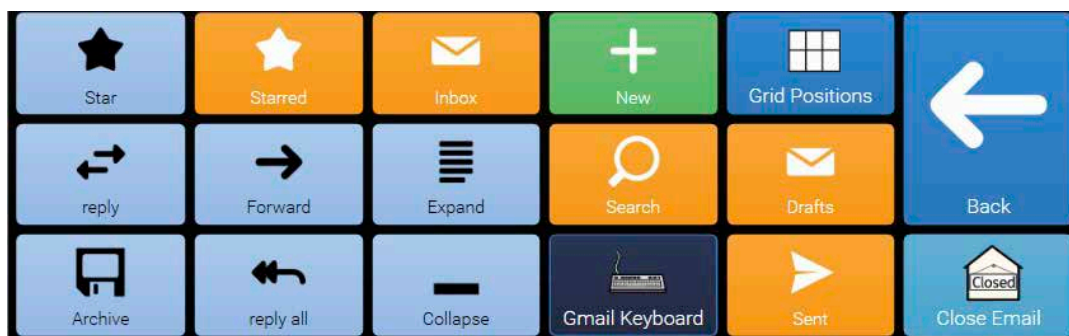
The top Gmail square opens the Gmail website and then goes to the first Gmail grid. The bottom square just goes to the Gmail grid (right):



I have spilt the Gmail functions up over two grids so the above grid actions (below):



This grid (right) is email composing:



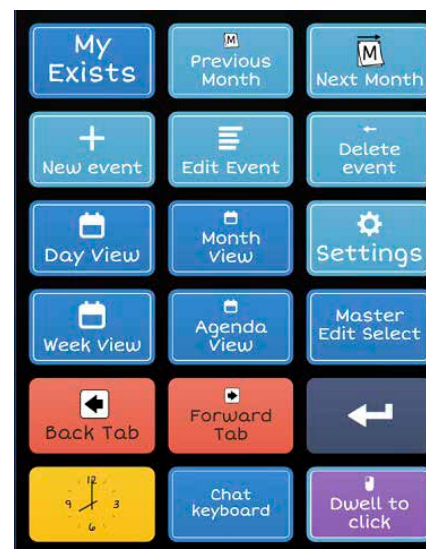
Google Calendar

I chose to create a vertical calendar grid simply because Google Calendar displays better (right).

Notice the Chat cell. I can incorporate the chat grids in any grid sets. I can copy the grids from any other grid sets, so I can quickly create my style of grids on any online grids I choose to.

My Exits

As I use most of these grids with my Computer Control on my desktop computer and my Fast Talker, on this Gridpad I thought I would show you a self-explanatory grid.



Cloud Storage Facility

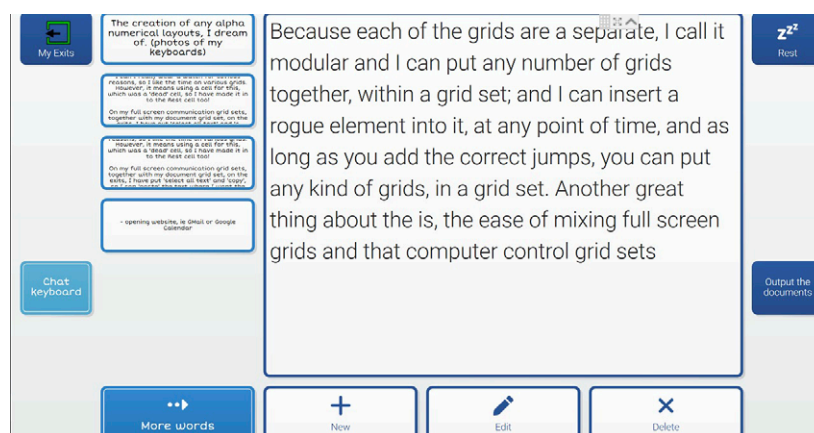
Making use of notes and documentation that can be accessed from both my desktop computer and my Gridpad, just as an able-bodied person does. As I have previously said, an AAC device is used for communicating on many levels of complexity, but for other AAC Users like me to be able to create documents seamlessly on my desktop computer and my Gridpad is an important ability to have.

To have the ability to achieve this, I make effective use of the facility of Dropbox, one of the arrays of Cloud storage systems that is available to everyone. Another great benefit of using Dropbox to save my grid sets on is when I want to make changes to my grid sets on my Gridpad. I can do this on my Desktop computer, and within 5 minutes it will be uploaded on my Dropbox, and then I can use it on my Gridpad.

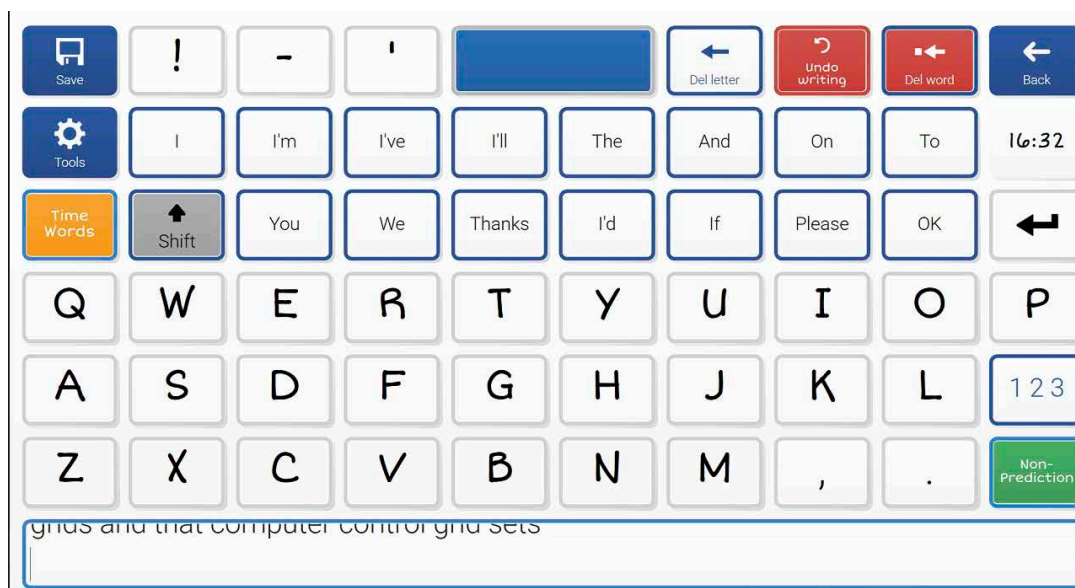
I have authored this paper on my 2 devices using the word processing Grids. First, I took them from Fast Talker and made them into a standalone grid set, so I can use it on both my desktop computer and my Gridpad. I have requested that the Smartbox's developers change the saving facility from the local source, i.e. either on my desktop computer or my Gridpad, to a cloud storage system to do this seamless transition between the two of them.

Then I changed the layout as the pictures show.

The front grid of the word processor with my chat grid and my exits (right and below):

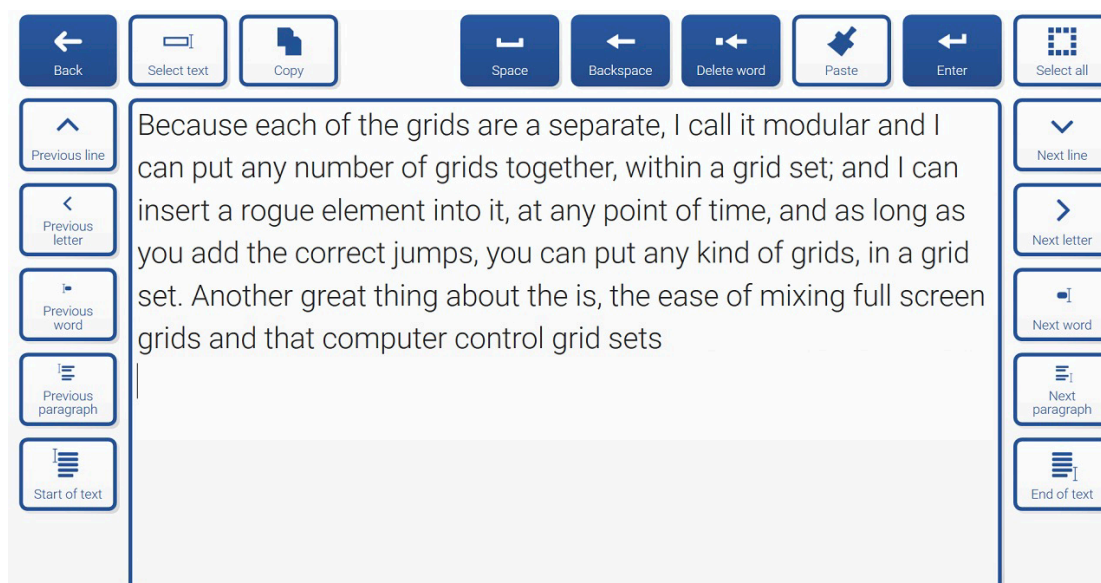


I have put an output grid, which loads either the web version of MS Word or Google Keeps (for notes), together with cursor controls and the paste function, together with my Computer Control or my Fast Talker grid sets.



I chose this keyboard layout, because I just feel that it is easier with my Eyegaze input method - that is all!

On the back cell, I have put the 'copy all text' comment. Also, on the save cell, as a temporary measure, I have the 'Add Word' function on it, until, as I said before, the saving directories are changed to allow for the seamless working between my desktop computer and my Gridpad.



To compensate for the small text display on the keyboard, I have reflected this by having a large text area in the editing tools grid.

Add and Remove Words

I know I was slow to learn about the power of the 'Add Words' function in the grid sets. Until last year, I thought that the add and the remove function was to do with the prediction of words as Tobii's Communicator had been. You will think: why didn't I ask Smartbox when I first started to use the grid?

That is a good question. I thought I could work the functions out by myself. However, it was not until last year when I saw a friend's grids. They showed me the proper use of the 'Add Words' and the 'Remove Words', and since then I have been adding new 'Add Word' grids into my grid sets, such as date and time words, places, my P.A. names, and non-prediction words, both in my full screen and my computer control grid sets. The possibilities are endless.

The next couple of pictures show you various 'Add Words' grids and how I have integrated them into my Chat and my Word Keyboard.

My carers:

Adrian,	Ana,	Claire,	Dave,	Fazila
Jacqui	Kerry	Margaret	Saba	Zoe,
+	zzz	-		←
Add phrase	Rest	Remove phrase		Back

Date and time words:

Computer Control Grid Position	st of	nd of	rd of	th of	am	pm	hrs	Write date	←
minutes	hour	morning	p/h	afternoon	evenings	daily	weekly	fortnight	monthly
yearly	yesterday	today	tomorrow	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday
Saturday	January	February	Valentines Day	Spring	March	Good Friday	Easter	April	May
Summer	June	July	August	Autumn	September	October	November	Winter	December
Christmas							+	zzz	×
							Add word	Rest	Remove word

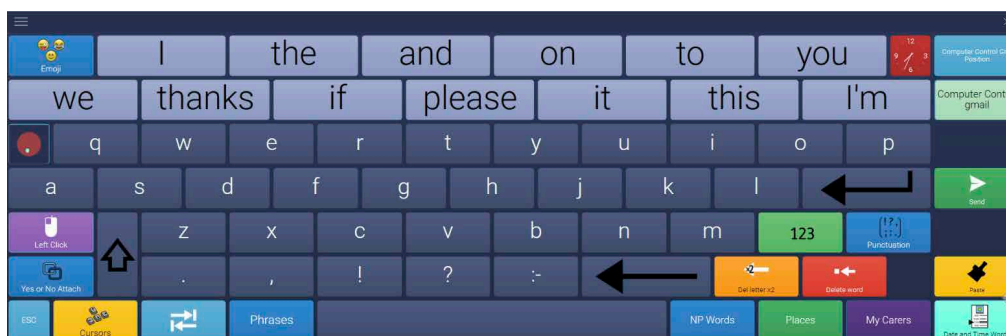
Non-prediction words:

AAC	Amoxicillin	Cerebral Palsy	Covid	Dropbox	Eyegaze	
GMail	Gridpad	grid set	Ipad	Iplayer	legbag	←
LFT	Motability	Naldex Exhibition	non-prediction	Omicrom	Paysheet	zzz
Power Bank	Satnav	screenshot	Smartbox	Tobii	webcam	+
						zzz
						×
					More words	Remove Personal Information

Places in Britain:

Coventry	Birmingham	Manchester	Liverpool	←
Sheffield	Dover	Ramsgate	Leatherhead	London
Stratford	Eastbourne	Gatwick	Nottingham	Oxford
Malvern	Bristol	Essex	Dunmow	Llanmaes
Wales				
		+	zzz	-
		Add phrase	Rest	Remove phrase

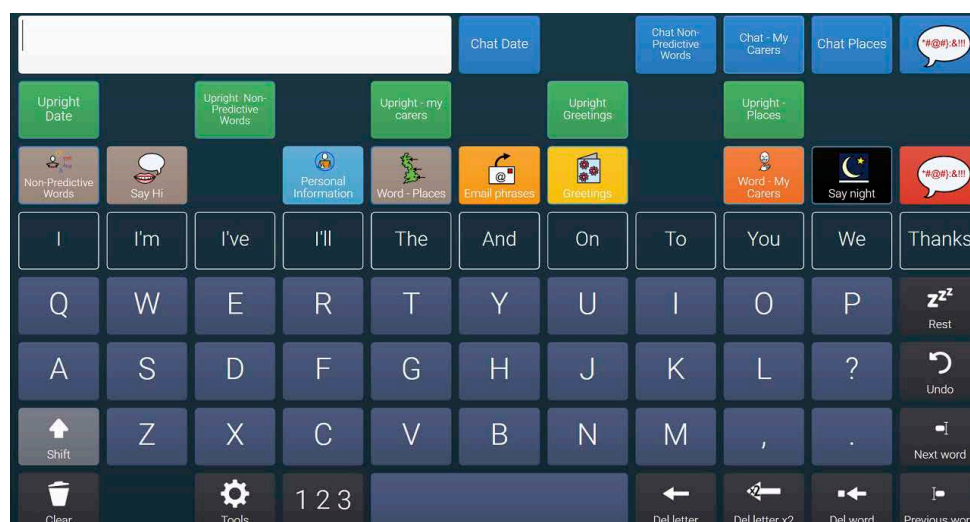
My word
keyboard:



As promised, I am now going to talk a bit more about how I changed the basic Word Keyboard.

The first thing I did was increase the predicting cells, because to me it is just logical, as I do with every word prediction grid. As the previous slide shows 'My Carers', 'Date and Time Words', 'Non-Prediction Words' and 'Places', the following pictures will show the 'Phrases', and I have created a dedicated 'Add Words' grid.

My opening chat phrases for my friends on Facebook. At the bottom of the grid are some phrase subjects on separate grids:



I probably overthought this, but I have created a dedicated 'Add Words' and phrase grid, and once I have created them, I have put just all of the word out and phrases grids. The top row is for my Chat, the middle row is for my Upright Keyboard, and the bottom row is for my Word Keyboard. This grid works well for me!!

Conclusion

I have been extremely impressed with the Smartbox's Grid 3 since I have been using it. As I have demonstrated, I have been tailoring the creation and I have adapted the existing online grids to suit my evolving lifestyle. I will constantly be learning from other people to make my grid sets the best to fit my life.

If you want any more information, you can email me.

Perspectives of AAC Service Providers in Canada on Factors influencing Effective Use of AAC technology

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Approximately 1.5% of the Canadian population five years and older have difficulty speaking or being understood, however it is not known how many people use augmentative and alternative communication (AAC) (Statistics Canada, 2007). Research evidence supports the use of AAC to improve communication and social participation for people with communication disabilities. Despite the benefits of AAC systems (i.e., tools, communication aids, and strategies), according to a national survey in Canada, 51.5% of children and 72% adults with a communication disability did not have their needs met by specialized equipment or aids (Statistics Canada, 2008). This suggests barriers to accessing AAC systems, however, little is known about AAC services across Canada. We sought to explore the perspectives of service providers on current practices and services and identify barriers and facilitators to the provision and use of AAC in Canada.

To explore AAC services in Canada, the cultural, political, and geographical context must be considered. Canada is geographically the second largest country in the world, yet it has a relatively small population of approximately 37 million residents (Statistics Canada, 2023). Canadians are spread across the vast landmass divided into ten provinces and three territories. Canada is home to a culturally diverse population and has two official languages – English and French. Education and most health care services are administered by the provinces or territories, which are responsible for managing funding and delivery of services, including provision of assistive devices (Intergovernmental Affairs, 2022). These factors have implications for service delivery and the practices of service providers in Canada.

This article discusses implications of findings of the research study, *Factors influencing access to and effective use of augmentative and alternative communication (AAC): Perspectives of AAC services providers in Canada* (Lackey et al., 2023). We conducted online focus groups with 23 AAC service providers across nine Canadian provinces, who worked with people who use AAC and were involved with the assessment, recommendation, and/or implementation of AAC. Participants comprised 14 speech language pathologists (SLP), six occupational therapists (OT), two communicative disorders assistants (CDA), and one teacher. Our research team identified common themes that reflected current practices and service-related barriers and facilitators to AAC use. These are described below.

Need for Accessible and Equitable Services

Variability in service provision was revealed in discussions about current practices and structure of services. As expected, variability in practice was reflective of differences among service provider roles, work settings, and the specific population being served (e.g., children or adults, direct or indirect access methods). As stated by an SLP, "my role varies a little bit depending on the age, the diagnosis, the medical environment of the user." Differences in services were also related to geographical location, funding models, eligibility for services, and access to resources including devices and personnel. Inconsistency in personnel is illustrated in the contrast between these two statements. One participant explained that as an SLP in a rural area, "we [SLPs] serve everybody

doesn't matter [the severity]...there are no extra people". This was not the case for another participant, an SLP from another province, who stated "we always have an OT on the team, and sometimes even a physical therapist available." In Canada, provincial funding may largely contribute to differences in services across the country. Service providers reported different experiences with funding depending on their province. One SLP explained, "we have a lot of funding...which is a real luxury, I think, compared to the rest of Canada." In contrast, an SLP from a different province described lack of funding as "one of the biggest barriers" to accessing AAC.

Some participants spoke of supportive resources such as trial devices, funding, and access to other professionals. Others described the lack of such resources as a challenge to their practice. Our findings raise questions about the equity of services across Canada, particularly if there is a scarcity of AAC resources in rural and remote areas. Our study suggests the need for further exploration of how services are organized in Canada and a need to develop minimum standards of service delivery to support equitable and accessible service.

Assessment and Recommendation of AAC Systems

As discussed by service providers, the assessment process involved consideration of a combination of factors related to the individual who uses AAC and AAC systems. Participants described holistic approaches to assessment which, for some participants, involved guidance from assessment tools and an interdisciplinary team. Participants named several details that informed decision making around recommending the 'right' device including client factors such as goals, physical ability and preferences, and factors related to the AAC system such as features, compatibility with other technology, and size. For example, an SLP stated, "we will often also take into account the size of the device, or the means of communication chosen, depending on whether the [individual] is in a wheelchair...in a walker, whether there are difficulties of balance." A participating CDA mentioned multilingualism as another factor to consider, noting that there can be "a second language that maybe the family, especially grandparents, [speaks]...the child needs to communicate with all the family". The ultimate goal of assessment is to facilitate the connection between the individual who uses AAC and an AAC system that meets their personal needs and preferences. Participants expressed interest in more guidance, such as guidelines or tools, and cited the need for more empirical evidence to support decision-making in the provision of AAC systems. There is a need to develop comprehensive tools and processes that can support service providers and increase consistency in service delivery across provinces.

Effective Implementation of AAC System

Participants indicated that their roles, with respect to the implementation of AAC systems, differed. Some provided training or support following the recommendation of AAC systems whereas, others provided consultative service and therefore focused only on assessment and prescription of AAC systems with government funding. When speaking to what is important to AAC use, an AAC teacher emphasized, "ongoing training and support...they need to actually implement a device in different contexts". Participants acknowledged that intervention in the natural environment of the person who uses AAC is beneficial; however, they admitted this is not always possible due to time, resources, and their role. A participating SLP explained, "there's a time factor because there's very few of me and teams to... support [implementation]." This raises questions as to how different service delivery models impact effective use of AAC systems in real world contexts. Establishing minimum standards of practice may help to ensure the thoroughness of support with consideration for available funding and personnel resources needed to meet such standards.

When asked how outcomes of AAC intervention are measured, participants described multiple indicators of success such as achievement of client goals, positive feedback, independent use of AAC system, participation in social activities, and support from communication partners, such as family. Service providers reported several different measures of success which were often informal, suggesting a need to adopt standard tools to measure use of AAC and the effectiveness of AAC services. Such metrics could provide evidence of the important work of AAC services providers and inform areas for improvement.

Collaborative Practices

Participating service providers acknowledged that effective use of AAC requires support of professionals, family members and peers. The most immediate support, primarily family, was described as influential to the selection of AAC systems and key to implementation. Many participants discussed how working together is key to success. One OT participant expressed that "implementation happens as a very collaborative approach" involving the client and often members of their family. Another OT participant spoke positively about collaboration, stating, "you can have four different professionals in one client appointment...I definitely enjoy that collaborative piece of it." Conversely, service providers discussed the challenges to collaboration such as lack of time, communication breakdown, and conflicting expectations; for example, between family, practitioners, and/or school staff.

The importance of team approach and collaboration was underscored by the concerns expressed by participants about impact of the general lack of knowledge about AAC. Participants explained that misconceptions held by key communication partners, such as staff in schools and long-term care settings, created barriers to AAC use. For example, an OT explained that the attitude of communication partners, such as discomfort with technology or fear of breaking an AAC system, can limit AAC use. Another barrier encountered in schools, as described by some participants, was the notion that access to AAC could be limited to scheduled times, denying the right to communication. AAC service providers are well positioned to reduce such barriers through collaborative practices, sharing information and building capacity while working alongside families, schools, and other professionals.

Implications for Research & Future Directions

Our research revealed that provision of AAC services is variable across Canada, largely based on location. Evidence from previous research suggests that service delivery models and processes influence AAC recommendations (Batorowicz and Shepherd, 2011;

Lindsay, 2010; Lynch et al., 2019). However, more research is needed to better understand the impact on access to and use of AAC systems for people across Canada. AAC assessment is complex and multifaceted, and service providers need support to reduce the gap between research and practice (Lynch et al., 2019; Murray et al., 2019). Research to identify service-related factors supportive of AAC will help to shape priorities for AAC services and can help to develop practice guidelines needed to support the decision making of AAC service providers and foster equitable services in Canada. This is in line with previous research from the United Kingdom that highlighted the need for service delivery models and decision-making processes that are client-centered, collaborative, and supported by evidence (Lynch et al., 2019; Murray et al., 2019; Webb et al., 2019). Our team has been also seeking input from people who use AAC, their family and caregivers regarding priorities of AAC services. A Delphi study is currently underway, which aims to identify joint priorities (i.e., consensus among different stakeholders) with respect to AAC in Canada.

Conclusion

This research helped to identify service-related factors that influence the access to and use of AAC from the perspectives of AAC service providers across Canada. The findings shed light on the realities of AAC services as well as opportunities for improvement. AAC services in Canada may benefit from development of practice guidelines to support decision making, implementation of collaborative practices, and improved access to resources to provide quality and equitable service nationally.

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How to Facilitate Acceptance of AAC for People with Motor Neuron Diseases?

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18 years ago, I started working as an SLP in Belgium. I soon developed a special interest in Motor Neuron Diseases (MND) and worked closely together with patients and families who lived with the challenging conditions that come with an MND diagnosis.

I specialized in the treatment of speech and swallowing disorders and focused on maintaining motor capabilities for as long as possible and the transition to alternatives when natural speech and swallowing were no longer sufficient.

It made me understand that different people call for different approaches, and I know the journey of MND may vary a lot on your environment, your support system, your mindset. But sadly, it can also depend on whether you have the right aids or not.

The world is turned upside down overnight when you get an MND diagnosis. It is a harsh message. You have an incurable disease. You will lose the ability to walk, talk, use your hands...and you will die from it in the foreseeable future...

Many emotions will present themselves after hearing this message and appear in different order each time: grief, anger, disbelief, resignation. This storm of emotions helps patients to process the message and its meaning.

Grief is a prominent factor in the MND journey. It is an intense form of sadness because people are forced to say goodbye in various areas in their lives. There is grief because you have to accept the disease and the fact that you are dying from it. There's grief for the loss of abilities and because you get dependent on others. Grief because of the limited physical activities that you have left and future plans that you have to give up on. Grief because you realize you will not see your children or grandchildren grow up.

Apart from grief, I have also seen a lot of hope, and scientific research shows that hope is very important for people with life-threatening conditions. Hope turns out to be a source of strength, it enables people to better cope with their disease, and it reduces psychological suffering. Hope can reduce anxiety, depression and feelings of helplessness.

But where can people find hope in a situation like this?

There is no cure, you know you have a limited life span left, and you know that you will have to live with progressive physical limitations. Yet people almost always find hope in their situation.

Maintaining hope does not mean ignoring the realities of the disease or suppressing emotions. It is a delicate balance between acknowledging the difficulties while also nurturing a positive outlook. I think that AAC professionals can play an important role in this.

They may not be able to offer a cure, nor stop the process of speech and swallowing deterioration, but we can play a significant role in improving their quality of life and emotional wellbeing.

I learned that high-tech AAC can be an important instrument in this challenge. The fact that these communication devices and software exist and are available to them can be a tremendous relief and reason to keep going for MND patients.

Let me introduce you to two people I treated as an SLP: Etienne and Dave. They both were diagnosed with ALS and sadly passed away, but the way they spent their last months are very different.

Etienne was 65 years old, loved classical music, arts and woodworking. He had just retired when he got his diagnosis. He didn't get an AAC device. Where he was positive and courageous when I met him shortly after his diagnosis, he got more and more depressed and distant when he lost his voice and hand function. He began to feel like a burden to those around him and lost his sense of identity and purpose. He had no more will to live. He chose to have euthanasia way before his family was ready to let him go, but they couldn't convince him not to go through with it.

Dave was 42 when he got diagnosed. He was a sound engineer, father of 3, loved music and surfing and cared a lot for the climate. I started working with him as his speech and swallowing started to deteriorate. He got an I-series with Communicator software. He

used it to type letters to his wife and children, so he could share how he was feeling, what dreams he held for their future. He made a playlist with his favorite music on Spotify that I and his friends still listen to. He kept in touch with friends and started a project on Facebook to raise money to plant a forest. He succeeded.

When his time had come to pass away, he left a lot behind: his letters to friends and family, his music and his forest. He felt prepared and at peace. The communication device had a huge impact on the quality of life of Dave and his family. Dave's family and friends were left with cherished memories, a forest to honour his passion for the environment and a profound sense of peace knowing that he had embraced his fate with grace and courage. His story emphasizes the significance of empowering patients to stay connected and engaged, not only with their immediate surroundings but also with the broader world, fostering a sense of purpose and fulfillment during their final months.

It is important to acknowledge that not everyone is ready to embrace assistive communication technologies like eye gaze, even when they could greatly benefit from them. People often feel great resistance to accept this solution for their loss of speech and hand function. Heart and mind are not aligned when it comes to accepting aids. You know that it is necessary and inevitable, but you are not ready to accept a wheelchair, a communication device, a feeding tube...this is a normal feeling that I have seen many times and the process takes time.

Acceptance of aids cannot be forced, but it can be facilitated. AAC professionals have an important task in helping people overcome barriers for acceptance. A first barrier professionals come across quite often, is the financial worry. To overcome this barrier, we must look into funding.

Are there age requirements in your region? Is there a possibility to rent a device? To purchase one through funding? Are there any charity organizations looking after this?

If we can answer those questions, we can overcome this first barrier.

The second barrier is the fear of technology. In this case, it is important to search for technology that they already know and use.

We should start from what they know and feel comfortable with and build from there. I find that browsing with eye gaze is the perfect solution to introduce eye gaze. If they are already familiar with browsing, it is a small step to add eye gaze. It is a safe environment to try things, it isn't emotionally loaded like communication can be; you can't really make mistakes.

As I said before, different people call for a different approach. Use their prior knowledge and take time to make them feel at ease with the technology.

It happens quite often that a potential user is in denial of his speech deterioration. In a case like this, one could explain how a communication device can be used augmentatively, not as a complete alternative for the way they communicate. You could ask if the person ever feels too tired to speak, maybe in the afternoon or evening, or if their voice sometimes lacks power to be understood. Most people will recognize these examples. It is really important for an ALS patient not to tire the muscles. If you keep talking when you are tired, you might lose even more power, because you might not recover from this exhaustion.

People often believe that communication is not that important to them. They were not very talkative anyways. But a communication device is more than the ability to chat. It is a way to stay connected, entertained, to keep up your role in your family and in society. It is a way to share thoughts, feelings and needs.

So to those people, I would ask: what IS important to you?

Maybe it is music, movies, keeping in touch with children, grandchildren?

Do they want to maintain independence, be able to contribute?

Do they want to be able to get information and communicate around end-of-life decisions? Because to a lot of MND patients, this is a very important topic.

To conquer the last barrier, we need to address the medical professionals, because some of them see the loss of speech and hand function as something inevitable and something to just accept. We should make them see that a communication device improves the quality of life for these people. It offers them a way to stay connected. They can ask for personal or medical care. It reduces feelings of depression and isolation. It improves access to information and entertainment. It gives them a sense of autonomy, self-esteem and dignity.

To ensure a better quality of life for our patients, we should think about what matters most to them, what makes their lives worth living, even with pain and discomfort. Handling grief and accepting the disease and its results is easier when a patient can take control over his life and illness. When they think about their lives, about what is important to them, where they want to live, how they want to be remembered and what they want to do with the limited time they have left and take action on this, it has a positive effect on their mental health.

The main purpose of AAC for MND patients has always been to meet the communicational needs that occur when speech intelligibility reduces or speaking gets too tiring. AAC offers them a way to communicate, stay connected with the people around them, to be able to ask questions to medical professionals, to be able to share information on their clinical situation, to be heard as a person.

But communication isn't the only need that can be met with this technology. The need for computer access for e-mailing, browsing the internet, writing and editing documents, online banking to name a few tasks that require a computer. This is important to this user group, who has always been informed, independent and in charge, before they got diagnosed. Access to information helps a patient to make informed decisions about their health and care. Because of these aids that provide them computer access, it

might be possible for a patient to continue working, and there for maintaining financial independence. It offers them a meaningful daytime activity and the feeling of contributing.

An AAC device can also be an important tool for environmental control. Opening doors, closing sunscreens, adapting the inside temperature, turning on the lights, even adjusting the position of the bed. How wonderful that a patient with limited motor control, can still maintain independence and autonomy.

AAC devices are also an important source of entertainment. When your physical mobility makes it difficult to engage in physical activity, it is easy to get bored and depressed. Being able to select and watch a movie independently, read an e-book, get engaged on social media, play games. It becomes a crucial source of enjoyment and relaxation. These activities can offer a way to escape from the challenges posed by their condition. Engaging in games and reading, can help maintain cognitive function and offer a sense of mental accomplishment.

Overall, an AAC device gives people great independence. Not needing caregivers for entertainment, environmental control and computer access gives a sense of dignity, self-worth and empowerment. AAC professionals play a crucial role in supporting their patients towards achieving a sense of preparedness and inner peace as they approach the end of their lives. This compassionate guidance and assistance can be one of the most profound gifts we can give in life.

Rethinking a child centred approach to introducing AAC to young autistic children – why we should put parents first

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I help parents who have a child who is nonspeaking or who has minimal speech for communication learn new words and communication through introducing high tech AAC apps. My approach 'Communicate with Joy' offers an individualised 1:1 parent coaching programme over 3 months. Most of the children are between 2 and 8 years of age and families join me from across the UK.

Firstly, what rights do children and families have? 'The Right to Speak' legislation came into effect in March 2018 in Scotland. This legislation places a duty on health boards to provide or secure the provision of communication equipment, and the support in using that equipment, to any person who has lost their voice or has difficulty speaking (<https://www.gov.scot/policies/social-care/assisted-communications>)

Secondly, can we agree on long term outcomes for Autistic Children? Kieran Rose, an Autistic Advocate says that Acceptance, Agency, Autonomy and Authenticity should be our goals. We now know providing a robust language system (often through high tech AAC) can be a critical part of achieving these outcomes for individuals and that AAC should be a first line in intervention, not a last resort.

Are our services delivering support that aligns with this vision AND legislation? Child centred approaches evolved out of a necessary shift from therapist led approaches, but now we need to look at this again and see if our current approaches are enabling us to deliver these outcomes for young children who are Autistic, or would a focus on parents and FAMILIES be more helpful and effective.

So, how are we doing right now?

These are quotes from different families, from across the UK.

"We've had no help with AAC"

"We've been fobbed off"

"We've been waiting years"

"We can't get a referral for AAC"

"We begged for AAC"

"We were only offered PECS then discharged"

"We were told our child was too complex"

"We were met with reluctance when we suggested AAC"

"We were told "No" when we asked about AAC"

This is what families have been telling me about accessing AAC and support to introduce it successfully.

"We feel isolated"

"It's overwhelming"

"We feel alone"

"I feel like I'm drowning"

"I feel helpless"

"It's been harrowing"

"We're failing"

Many families can't even get off the starting blocks with AAC. Parents 'know' that their child can communicate more than they're able to right now. Parents aren't failing; they're being failed.

My approach aligns with our understanding of Autism and what we now know about starting early with AAC. Making sure the parents are truly heard helps us to create and implement an approach together that is effective and sustainable. We know we need to meet the child where they are but first we need to meet the parents where they are.

The key lies in 'Connection'.

What happens when you put parents first in the earliest stages of their AAC journey and work directly with the parents, rather than with the child?

- 1 The 'intervention' is immediately more meaningful for the child who gets a chance to build communication moments with their favourite people
- 2 It makes the AAC intervention more effective and efficient, because it builds on existing connection between the parent and child - I do not need to work on this first.

This is one parent's response to hearing the Jane Korsten 84 years quote about the huge amount of modelling that needs to be done for AAC intervention to be successful.

"It was like a punch in the gut. I lost my breath, I slumped forward, tears sprang to my eyes. Panic rose quickly. I felt the weight of not doing enough, of failing her"

Dana Neider, Uncommon Sense Blog

I don't share the Jane Korsten quote with parents at this stage. Think about when you learn new things best, when you're feeling overwhelming pressure and sadness, or when you're excited and hopeful?

Therefore, I try to lead with compassion and so THIS is how I want parents to feel:

"On our hardest weeks, we still communicated, we still connected and we still took action and moved forwards for our child. We achieved something new and we saw new communication moments emerge. There is never a perfect time. But look at what can be achieved at our toughest times"

The secret to achieving this for parents is to listen, recognise and reflect back the significance of the small steps.

"Sometimes the solution is not as complex as the problem appears to be"

Hannah Joy Communication

Making sure families are heard, meeting them where they are, presuming competence for parents, high quality coaching that's family centred. Keeping momentum. Using dynamic assessment - give the child a robust AAC app and let them show us where we need to go next. Parents need to love the AAC app. Collaboration with education services. Advocacy. Walking with families and shining a light on the next step. In my experience, these are all essential factors for successful and joyful implementation of AAC within a family.

"We achieved more in our 10 weeks than we have in our 4 and a half years since our son was diagnosed with ASD"

"We are in awe of how far we have come"

"We did not expect visible results so quickly"

This is what parents say. But what is really great are the outcomes achieved by the child - sometimes within minutes they are using AAC communicatively, sometimes in weeks. But real, measurable progress. A mother I support sent me a video last night of her 5 year old nonspeaking son spontaneously saying 'I love you' with Proloquo. Just a few months ago, she had been told "No" when she asked to try high tech AAC.

Parents have a right to an approach that truly celebrates first words and milestones with AAC. Central to my approach is the expectation that we will *"give your child enough words that the possibility is there that they will surprise you - that they'll say the unexpected, at a time you didn't expect, to a person you didn't expect, in a way you didn't expect"*

And then we celebrate every new milestone achieved by the parents and by the child.

Parents have a right to an approach that is right for Autism AND AAC AND their family.

Family centred, neurodiversity affirming support.

When will we stand up and say that a robust AAC system is 1 better than PECS and 2 is essential alongside Hanen, PACT and Intensive Interaction? It's not one or the other.

I'm going to 'follow the lead' of families who successfully introduce AAC to their child in spite of the barriers they face.

I'm going to step into a future of hope, action, excitement, inspiration, possibility and surprises.

But we won't reach OUR potential until we join up collectively with parents on a much bigger scale, until WE become less directive, more tuned in and follow parents lead.

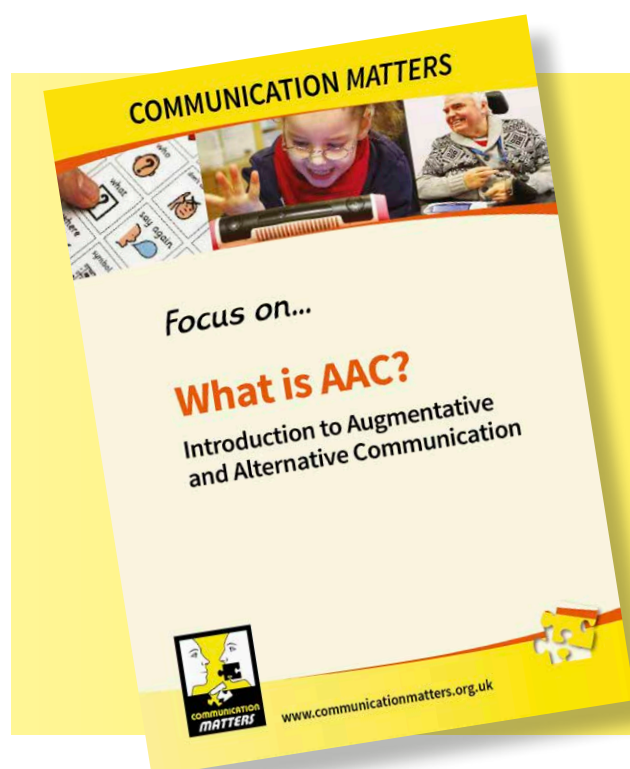
It's time we make parents and families the centre of our practice, our policies, our research and our vision. If they can do it for their child, then we can do it for them. Let's change things.

Biography:

Hannah Joy Communication offers specialised support to families with children who are Autistic and have no speech or minimal speech for communication. The service, available online across the UK, focuses on helping children communicate effectively using innovative Augmentative and Alternative Communication (AAC) technologies.

The "Communicate with Joy" individualised parent programme helps a child learn new words and communication skills within a dedicated 3-month time frame. Hannah Joy Communication provides expert coaching aimed at transforming the lives of families dealing with communication barriers, using AAC solutions as a first line of intervention rather than a last resort.

Hannah has helped children and families with complex communication needs for 18 years within the NHS and now independently within her business Hannah Joy Communication to help parents transform communication for their child.



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The Seven Stages of Switch Development

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Abstract

For children with complex neurodisabilities, for whom communication and movement are very challenging, switch technology is an enabler in developing skills for accessing the environment and giving the child a voice. The Seven Stages of Switch Development is a framework developed to support switch users and those working with switch users to understand the steps towards switch skill progression. The framework is written for switch users and features child-friendly stories that aid learning. Surveys and focus groups were conducted to gather opinions of switch users, carers and professionals regarding the framework and preliminary ideas. Suitable adaptations to the framework were then carried out to develop the Seven Stages of Switch Development Framework.

Introduction

For children with complex neurodisabilities, for whom communication and movement are very challenging, switch technology is an enabler in developing skills for accessing the environment and giving the child a voice (Østensjø, Carlberg et al. 2005). Switch-enabled communication can positively impact a child's social communication skills, access to education, play, and ability to explore and control their environment (Cosbey and Johnston 2006). As technology has become more advanced, so have switches' variety and functional capability (Schaefer and Andzik 2016). However, without sufficient awareness, knowledge and experience in understanding switch progression, it can be challenging for health and education practitioners to navigate (Griffiths and Price 2011).

There are a variety of switch progression frameworks that offer health and education practitioners guidance for types of switches to use and switch skill progression. These include, but are not limited to, the Switch Progression Road Map by Ian Bean (2011) and Steppingstones to Switch Access by Linda Burkhart (2016). These frameworks are designed to be used by practitioners, but with the increasing emphasis on person-centred practice, the child or young person who is the switch user must have the opportunity and resources available to be included in the decisions made.

Despite the availability of switch progression frameworks, in our experience of working in schools and alongside teachers, unless specific training has been received or experience gained, knowing how to progress a child or young person with using switches is challenging. Furthermore, we have found that incorporating and embedding frameworks into routine practice can be challenging. We have identified the need for a framework that includes switch user preferences, is helpful to practitioners and is easy to use for all involved. To address this need, we propose a clear framework of switch progression that accommodates each switch user's unique needs and preferences.

We have proposed the 'Seven Stages of Switch Development,' which provides a framework for understanding the gradual progression of skills necessary for successful switch use. The stages are designed to support switch users, their families, caregivers, and those who assist them in using switches, offering a clear scheme for measuring and tracking progress. The framework features child-friendly characters and stories that aid learning and engagement, a unique feature compared with other switch progression frameworks. It is intended that while the stages are not rigid or fully comprehensive, each stage emphasises the switch user in the learning process and offers a way for prioritising their needs and perspectives.

The Seven Stages of Switch Development is hoped to provide a fun, engaging framework for switch learning and progression that will support children with complex needs to enhance their communication and physical access skills.

Switch users will be motivated by tracking their progress and understanding what they need to achieve to attain the next level of switch proficiency.

Target Audience and Relevance

This manuscript and the Seven Stages of Switch Development is intended for switch users, those who work with or care for switch users, and professionals in the field of AAC (Augmentative and Alternative Communication) and AT (Assistive Technology).

Method

Phase 1

The first phase of the research was exploratory to understand current evidence, knowledge and experiences of switch users, parents of switch users, and practitioners using switch development frameworks. This phase was made up of two components:

1. Carry out a literature search to establish current research concerning switch progression frameworks.

A literature search was completed using Google Scholar, AMED, CINAHL, and Medline. The search terms used were switch skills, AAC, switch progression, switch development, paediatrics with Boolean operators AND, OR.

Although many studies report the efficacy of switch use, very few studies reported on specific switch development frameworks. As a result, the original intention of writing a literature or scoping review was replaced with an opinion-based article.

2. Obtain feedback from switch users, parents of switch users, and practitioners concerning their experiences of switch development frameworks.

A survey exploring switch development framework knowledge and experience was sent to service users, parents/ carers of service users and practitioners. The survey received 91 responses. Key points generated from the survey are outlined in the results section below.

Phase 2

The second phase involved gaining feedback about the stages' content, characters representing each stage, terminology, and additional resources. This phase consisted of sending out a survey and conducting a focus group.

1. Introduce the Seven Stages of Switch Development and gain feedback.

A survey was sent to service users, parents/ carers of service users and practitioners outlining the Seven Stages of Switch Development framework and generated qualitative feedback. The survey received 15 responses. Key points generated from the survey are outlined below in the results section.

One focus group took place with four practitioners who worked in clinics, schools, and one nursery. Questions were based on the survey questions and enabled further exploration through discussion.

Results

Phase 1

- 29% of respondents reported that it was not easy to remember which switch progression frameworks were available and how to measure progression or next steps.
- 40% of respondents reported no consistency of use with switch progression frameworks in their workplace.
- 66% of respondents either agreed or strongly agreed that there were no standard procedures for recording switch development or progression.
- Simple, easy to remember, and user-centred aspects of a switch development framework were considered the most essential aspects.
- There were mixed responses regarding how much the switch user needed to be involved in understanding switch progression.
- Providing support for parents was highlighted as an essential factor.
- A simple and fluid framework rather than rigid and linear was highlighted as key. The respondents emphasised the importance of recognising the uniqueness of each service user and that a 'one size fits all' approach that is typically aligned with a developmental pathway is not appropriate.

The feedback gained from this survey was incorporated into informed phase 2 of the Seven Stages of Switch Development framework.

Phase 2

Seven Stages of Switch Development characters:

- Respondents felt the terminology may not reflect the uniqueness of each child or young person. For example, a child or young person who remained a novice or beginner could dishearten parents.
- Respondents liked the idea of normalising switch use through stories with characters that offer a way of helping the child or young person learn in a way that is accessible for them.
- Most respondents liked the idea of a superhero theme for the characters but felt that the characters looked like a typical non-disabled person sitting in a wheelchair instead of the presentation of a typical switch user.

Seven Stages of Switch Development Assessment Framework:

- Respondents felt that each stage could be standalone, without the child or young person feeling they have 'failed' if they did not move beyond a stage.

- Respondents liked the visual representation as this would assist with visibility for tracking achievement.
- Respondents felt that this could fill a gap in schools as there were no known frameworks that specifically included the child's or young person's voice.
- Respondents felt potential cost implications may be a barrier to schools' use.
- Respondents reported that it was important for the framework to:
 - Be available electronically.
 - Have accompanying resources, e.g., activities relating to each stage.
 - Incorporate the view of the switch user.
 - Provide information about switch access points.
 - Provide information about switch types and mounting.

Focus group feedback:

- The character ideas were considered more appropriate and accessible for a younger cohort, which risks excluding older switch users.
- Participants reported that activities for switch-use progression are usually up to the therapist and are based on their knowledge and experience. Having a bank of activities for each stage was considered positive and time-efficient and was particularly important for the child or young person who may not progress to another stage and remains within one stage. It was also crucial for parents and carers to know about the different activities to prevent carer fatigue.
- The differentiation between physical skill and cognition was expressed as needing to be more explicit.
- Participants felt that the character names needed to be more diverse and that the competency-based labels may be counterproductive.
- Participants discussed the need for the framework to demonstrate more than linear progression. They felt each stage should also work as a standalone concept that a child or young person could progress within without the unrealistic demand that they would move beyond a specific stage.

Outcomes and Benefits

As a result of the feedback from the surveys and focus groups, the following adaptations were made to the framework.

- The progression-based names, such as novice and competent, changed to positive and standalone names, such as exploring and journeying.
- We have diversified the names.
- An alternative pathway was developed to assess children and young people who may remain within one level.
- The feedback informed and supported the story type about animal characters with disabilities coming to help switch users.
- Feedback was provided to the illustrator that the disabled characters should be more relatable to people with disabilities.
- Stories were adjusted to talk directly to the reader and address relatability.
- Terminology within each stage was changed from early, consolidating and competent to emerging, consolidating and proficient.
- A cognition and physical scale were introduced to differentiate between these two fundamental areas of strength and challenge.

The Seven Stages of Switch Development will benefit switch users, their families and those who work with switch users. It will provide a model for switch skill progression and can guide the types of switch activities used and the goals to be set for switch users.

Stage 1:

Exploring Egbert

Learning by experience
(circle/red)



Stage 2:

Journeying Jiao

Intentionally make happen
(square/orange)



Stage 3:

Growing Gareth

Playing with two switches –
making two things happen
(triangle/yellow)



Stage 4:

Budding Brayton the Bear

Using two switches for one
activity
(rectangle/green)



Stage 5:

Flourishing Fatima

Playing with Switch scanning
– error-friendly learning
(kite/blue)



Stage 6:

Succeeding Saffi

Using Switch scanning –
finding the right one
(oval/pink)



Stage 7:

Celebrating Syed

Independent in
functional use
(star/purple)



Discussion and Conclusion

Feedback from the surveys and a focus group were incorporated into the switch progression framework to design a client-centred, user-friendly and valuable framework for the intended user. Further development of the Seven Stages of Switch Development will take place to increase the number of accompanying resources and create a training package that can be delivered to schools to support the use of the framework as a school-wide system. See our current model framework (above).

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Supporting Language and Literacy: Common Threads, Common Practices

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M. Ed., Educator

BETHANY DIENER

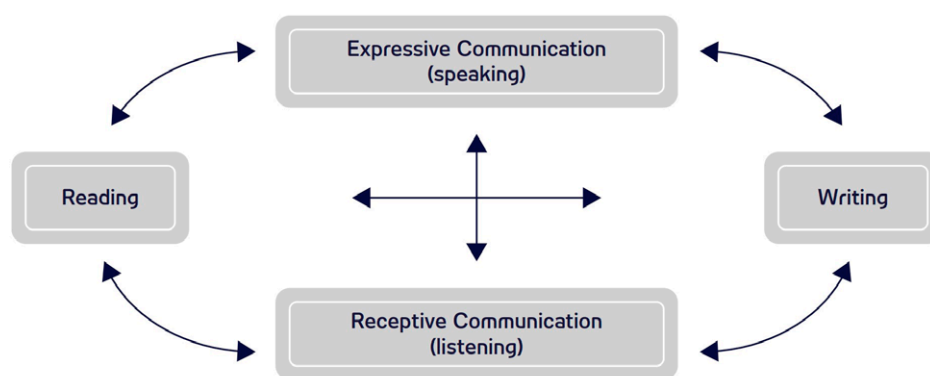
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At the start of our careers, Maureen, an early childhood educator, and Bethany, a speech-language therapist developed the misconception that our purviews were separate: Maureen's job was to address literacy, while Bethany's was to oversee communication. Additionally, it was (and in some places still is) widely held that communication ability is a prerequisite to literacy development. This is why interventions for either literacy or communication tended to fall in one or the other camp. Today, evidence points to a different approach that seamlessly integrates and cultivates both simultaneously, saving teachers time and helping AAC users grow. Maureen and Bethany designed this talk (and this article) to share our passion and knowledge for how to support both.

Thirty years later, we embrace communication and literacy development as branches emerging from the same tree, developing from a common source. Like a tree, growth is constant, even when it can be difficult to perceive. The conceptual framework shown below by Kalman, Koppenhaver, et al. provides a visual representation of this thinking. This framework suggests that all aspects of listening, speaking, reading, and writing nourish and support each other. Time in any domain will produce gains in others. This conceptual framework encourages us to take advantage of the common threads and practices that simultaneously support and enhance communication and literacy. It also suggests that outcomes tend to be enhanced when professionals across disciplines (parents, teachers, SLTs) work together toward these ends (Erickson, 2017).



Oral and Written Language Development

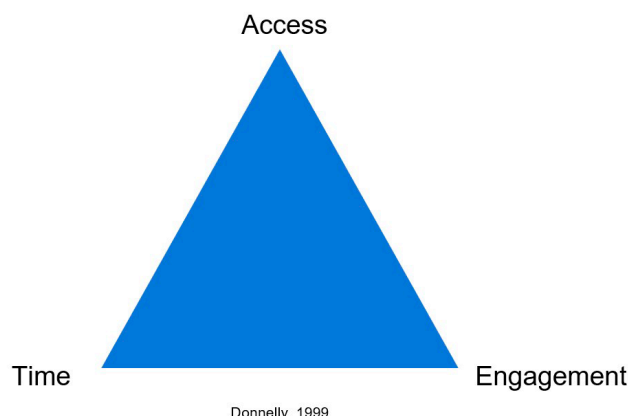
(Koppenhaver, Coleman, Kalman & Yoder, 1991
Adapted from Teale & Sulzby, 1989)

Across the field of special education, different people, in different contexts, mean different things when they refer to literacy and communication. Erickson (2017) defines literacy as “the ability to read silently with comprehension and compose meaningful texts independently.” Diener (2023) defines communication as “the ability to share and receive information for various purposes with ever-increasing spontaneity, creativity, complexity, and independence.” Note that these definitions focus on receptive and expressive skills with purpose and independence rather than any prescribed skill demonstration. Likewise, communication and literacy are developmental by nature, meaning that growth does not follow a predictable, steady cadence. The path to independence begins at birth, if not before, and continues over a lifetime (Sulzby, 1991). Both require thousands of hours of play, exploration, and support from knowledgeable others.

As an early childhood educator, Maureen struggled to feel confident that she was providing all children equal access to learning experiences and the curriculum. To organize her thinking and her instruction, she placed emphasis on the following three areas:

- Access – to tools and learning materials (like books, pencils, AAC supports)
- Time – to learn and explore, independently and in supported contexts, and
- Engagement – which includes connecting learners' experiences and interests in the learning environment

Three Key Tenants



The first area of emphasis is self-evident. For all people, including those using AAC, watching or observing is an insufficient conduit for learning new skills. In nearly all realms, learning requires doing. The goal of communication and literacy instruction is to support learners in developing an independent means to share what they think, know, or feel at any given moment. For non-speaking individuals, this requires access to the tools that support reading and writing. Examples include low or high-tech alternative pencils, accessible books, and augmentative-alternative communication (AAC) comprised of core vocabulary, fringe vocabulary, and pre-stored messages. Some users benefit from customized supports that include (but are not limited to) things like keyguards, eye trackers, or partner-assisted scanning.

Once access, in all its manifestations, is established, learners (particularly those at the early stages of development) require time to learn. Whether calculated via the hours amassed (from Maureen's perspective) or from a lifestyle standpoint (from Bethany's), learners need it in frequency (regularly and often) and duration. If typically developing children benefit from a minimum of 1,000 hours of literacy-related experience before entering school if they are to read on grade level by year 4 (Heath, 1983), children who use AAC require at least this amount of time and likely more. From the perspective of a parent, teacher, or SLT, we must dedicate ourselves to providing it.

Engagement, the third area of emphasis, is layered. One important aspect of engagement is about learning relationships. Young or old, with or without disabilities, we all require relational safety to take the risks that lead to growth. We build that relational foundation when we treat all learners as people with something to contribute or share and assign meaning or intention to their literacy and communication attempts (even before they can read, write, or communicate conventionally).

The second layer of engagement is interest. Younger children often organize around a particular topic, like a character from a TV show or a form of transportation. The passion they have (and the knowledge they possess) is a powerful driver by which to begin instruction. Start with books about the topic (in print or digitally on platforms like Tarheel Reader). Provide learners with a form of a pencil (that includes access to all 26 letters of the alphabet) and a purpose for writing about the topic, even before they can write conventionally because random letter selection and scribbling are essential stages in writing development (Hanser, Erickson, 2009).

The last layer of engagement is about the process. We can facilitate engagement and growth by giving learners cognitive clarity about what we are doing, why it matters, and how it will help them learn and grow (Downing, 1979). Many of the older individuals who use AAC come into our classrooms or our lives with accumulated experiences around literacy and language instruction that have left them feeling defeated. We cannot overlook or ignore this history. As parents, teachers, and SLTs, our double mandate is to provide AAC users with the materials, support, and instruction while also helping them build the disposition toward language and literacy as tools for life.

The next question is: what does this look like on Monday morning? Shared reading is a fun and impactful place to begin for learners at the early stages of their language and literacy journey. The Commission on Reading called it the most essential activity for developing the knowledge required for literacy independence (Anderson, 1985). Reading aloud and inviting input on every page (while modeling AAC use) offers ample opportunities for learners to develop knowledge of print and the alphabet, connect spoken and written language, and introduce new vocabulary and concepts about how the world works (Kaderavek & Justice, 1991)—likewise, shared reading benefits communication by giving learners page-by-page opportunities to share their thoughts and occasionally (but not at first!) their knowledge of the text and their connections to it. We must remember that AAC externalizes

language and typically represents language visually. Visual representation using symbols intrinsically limits the language of AAC users as they must rely on others to provide vocabulary.

Predictable chart writing is another engaging, easy, and fun activity integrating communication and literacy learning. This activity is a method of shared writing that introduces repeated sentence frames as prompts for the learner to complete. We invite learners to share their thoughts as we scribe one by one, providing a real-time connection between writing and thinking. It also cultivates the important double mandate outlined earlier in this article by encouraging all to see themselves as writers. In predictable chart writing, we start with a stem sentence (made up primarily of core/high-frequency words) and invite everyone to complete one sentence. Across the next 4-5 days, we return to the chart. First, we collectively analyze it ("Let's look for all the letter M's."). Then, we create individual sentences and support learners in helping us cut the sentence into words (helping them develop the concept of a word). Next, we invite learners to arrange and rearrange the words to recreate the sentences (enhancing knowledge of syntax). Finally, we create a (what is often a class or group favorite) book where all contributors can create a page with their sentences.

Throughout these two simple yet profound routines, parents and teachers have embedded and naturalistic opportunities to deploy best practices in communication and literacy. As we model the use of AAC, we also demonstrate how we use text to gather information. As we model finding letters and how to use word prediction, we are encouraging interaction without requiring it. As we scribe students' ideas to complete each sentence, we demonstrate the connection between speaking and writing. These routines are easy to execute; they provide a window into how and what learners think and support the integration of communication and literacy. At the session's close, Bethany equated the relationship between communication and literacy development to one between best friends. For all people, literacy and language are things we cannot master– there is always an opportunity for growth! With intention and practice, literacy and language grow together throughout our lives to benefit both.

For specific information and resources about supporting language and literacy for people who use AAC, please consult the following resources:

<http://www.project-core.com/> : free, tactical learning modules about getting started with core vocabulary and integrating literacy instruction

<https://tarheelreader.org/> : free crowd-sourced, accessible reading and writing platform

<https://products.brookespublishing.com/Comprehensive-Literacy-for-All-P1165.aspx> : methods textbook about supporting literacy and language development for students who face complex learning challenges

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Using AAC for Active Participation in Music Making

SARAH DUNN

Email: accessible.inclusive.music@gmail.com

Background

Sarah is a qualified secondary music teacher and parent of two children who love music. Her son (8) is disabled with a diagnosis of dystonic Cerebral Palsy and is non-verbal and non-mobile (GMFCS level 5). He uses a Smartbox eye gaze device and switches for communication and music making. Sarah's passion for making music more accessible and inclusive has led her set up a charity, Accessible Inclusive Music (AIM) (registered charity 1203866), which provides musical opportunities to children and young people up to the age of 25 across the UK, specifically those who are disabled and/or have additional needs and their siblings. Sarah has a personal interest in how Augmentative and Alternative Communication (AAC) can be used for active participation in music making and how breaking down the barriers to meaningful music making can positively impact wellbeing. She is currently studying an MA in Music and Wellbeing at The University of Leeds.

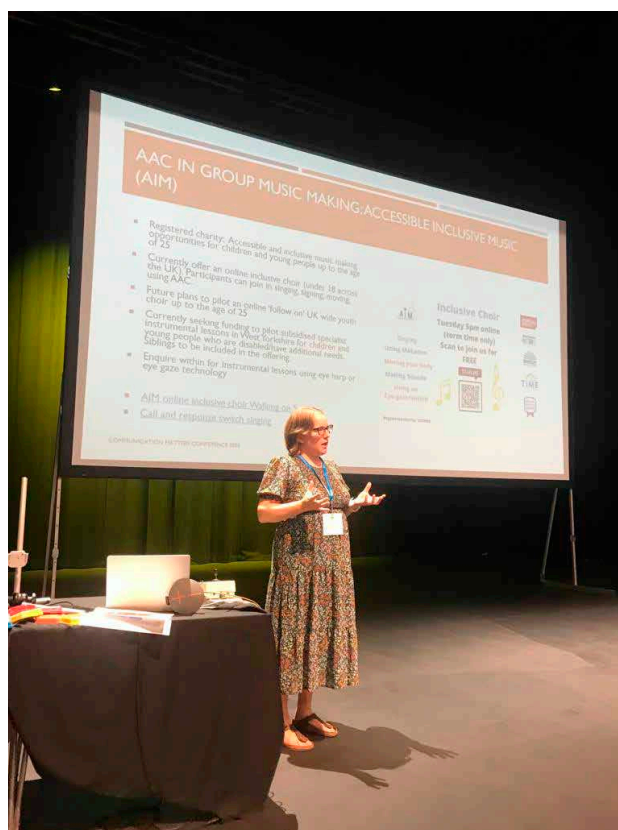
This article is a discussion of ideas that Sarah shared via a Personal Stories and Preferences workshop at the 2023 Communication Matters Conference, summarising different ways her son has used switches and eye gaze on his Smartbox Gridpad to perform musically and access group music making. This workshop focussed specifically on active participation in meaningful music making opposed to musical themed cause and effect games on eye gaze devices*.

Eye Gaze 'Singing' using Text Talker

'Text Talker' accessed via Grid 3 on my son's Smartbox Gridpad has unlocked a whole new world of opportunities for him as an aspiring musician. By his communication partner typing in song lyrics and him activating them using eye gaze, he has thoroughly enjoyed the freedom to perform at concerts in school and in the local community. However, there are some drawbacks to this option. Fundamentally, by inputting text in this way, the user is speaking rather than singing, and the communication only really becomes a musical performance with the addition of accompanying musicians. Voice intonation can be personalised slightly through 'settings-voice settings', for example adjusting tempo, volume, and pitch of speech. However, future development of transforming written text into singing for eye gaze users would be an exciting innovation from my perspective as a musician and parent/carer of an eye gaze user who loves performing musically.



Accessible and inclusive musical opportunities for children and young people in West Yorkshire and beyond.



Eye Gaze 'Singing': Message Banking

Message banking provides a more musical solution to singing for eye gaze users. This can be accessed through text talker. Within the 'message banking' option, select the 'speech' sign in the top left-hand corner, followed by 'record new message'. Type the phrase you want to record and record the audio you want to associate with the written text. Although this provides an alternative solution to singing for non-verbal eye gaze users, recordings are limited by length, and as a parent carer of a non-verbal child it raises questions about identity, the musical voice here being that of a communication partner rather than that of the user.

Eye Harp Software

As a musician and music educator, I feel the Eye Harp is one of the best musical instruments I have come across for eye gaze users and those who cannot access other adapted instruments due to their physical limitations. The circular design of the instrument interface is accessible and intuitive, and there are many ways in which default settings can be adapted and personalised depending on the user and context of the instrument's intended use. Within the software, there are a range of pre-programmed scales, chord palettes, musical instruments and backing tracks. This means the circle interface can act as notes on a pitched instrument, different parts of a drum kit or chord choices on a guitar. Additionally, the number of available notes and size of the circle interface can be adapted, alongside the starting note within a given scale, key, or octave. Accessibility is also supported by colour coding on the circle interface and labelling of these coloured blocks using note names or solfège (do, re, mi etc...).

There is a license cost associated with Eye Harp software, although this is in line with the expected financial commitment that comes with instrumental hire or purchase of a musical instrument. I would recommend downloading the trial version for one month to check it works on specific eye gaze devices (my understanding is that a Tobii eye tracker is required for eye gaze use) and whether it is a suitable option for the specific user.

More information can be found on the Eye Harp website www.eyeharp.org or if you are in West Yorkshire, please contact accessible.inclusive.music@gmail.com for further information about instrumental lessons on the Eye Harp. Subject to funding, license costs can be subsidised for those 25 and under in West Yorkshire through the Accessible Inclusive Music (AIM) instrumental lesson programme. As a musician and music educator, I can also provide advice on how the Eye Harp can be used effectively for group music making within musical ensembles or a classroom setting.



Photo shows an eye gaze communication device with 4 chord options on the screen; C major, A minor, F major, G major. Each chord option has pictures of how the chord is played on a keyboard/piano and/or how the notes of the chord look on a staff.



Photo shows an eye gaze device on the left of the image with an eye gaze musical instrument on the screen (eye harp). There is a multicoloured circle on the eye gaze device screen and different symbols signifying volume, a grand piano image to signify instrument choice and an equaliser symbol. There is a red and yellow switch button underneath the eye gaze device and a laptop screen to the right with the title page of the workshop on the screen 'Active Participation in Music Making Using AAC'.

Eye Gaze Composing

To encourage my son to develop independence in his music making, I have experimented with editing the grid on his eye gaze device. We have populated it with chord choices, instrument choice, tempo (fast and slow) and dynamics (loud and quiet), enabling him to compose his own chord sequence, communicating the musical ideas he can't physically execute himself to his communication partner.

Recordable Switches

Recordable switches are a fantastic way to encourage active participation in music making for those who are non-verbal or have physical limitations. With a touch of creative thinking, the possibilities are endless. They can be used effectively to record short vocal phrases, encouraging interaction in call and response songs (songs where a leader sings a phrase and an individual or group sing this phrase or a similar phrase back). Recording length is limited, but they can be purchased in multipacks so different phrases could be recorded on different switches. 'Talking Tiles' can be purchased from Amazon or TTS group <https://www.tts-group.co.uk/big-point-recordable-button/1003985.html>. Recordable switches can also be loaned from Accessible Inclusive Music (AIM) for those participating in the AIM online inclusive choir or other specific projects offered by AIM.

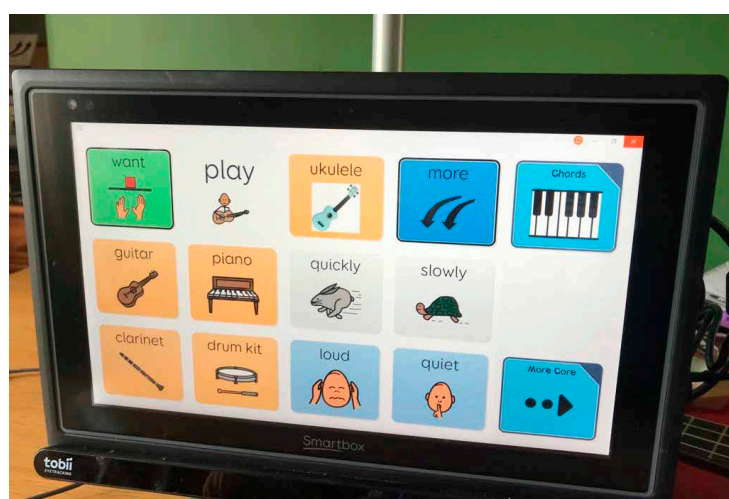


Image shows a communication grid on an eye gaze device that includes pictures and words to enable the user to select; want, play, ukulele, more, chords, guitar, piano, quickly, slowly, clarinet, drum kit, loud, quiet.



Picture shows a young boy enjoying music whilst two people play ukuleles.

Organisations that Provide Musical Opportunities that Encourage Active Participation in Music Making using AAC

There are musical ensembles and organisations across the UK that encourage active participation from AAC users. This includes, although not limited to:

- Accessible Inclusive Music (AIM): www.accessibleinclusivemusic.org.uk
- Made With Music: <https://www.madewithmusic.co.uk/>
- Open Up Music: <https://www.openupmusic.org/> (they have a bespoke musical instrument within their programmes that can be played using eye gaze called the Clarion. There is also a 'lite' version of this that can be accessed from Google).

Endless Possibilities

The possibility of using AAC for active participation in music making is endless. The sharing of ideas and good practice within this workshop at the 2023 Communication Matters Conference was incredibly insightful. It was particularly fulfilling to meet AAC users attending the conference who shared how they had created their own music using AAC, and it would be wonderful to continue collaboration and innovation in this field.

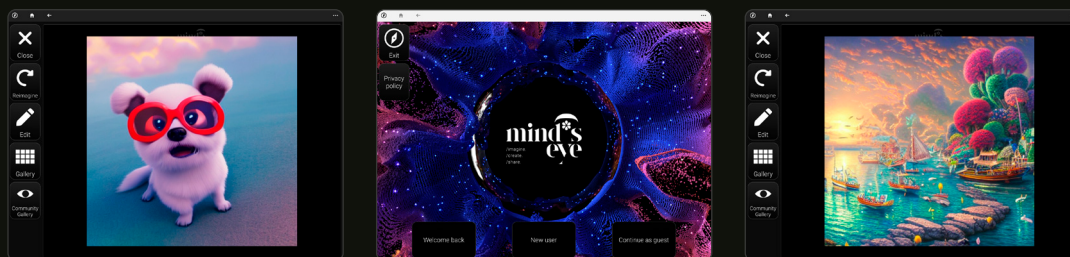
**All recommendations of organisations and products signposted in this article are based on Sarah's personal experience as a musician, music educator and parent/carer. Her role as Chair of Trustees for Accessible Inclusive Music (AIM) is voluntary with no commercial gain. All guidance and advice provided by Sarah through Accessible Inclusive Music (AIM) is offered free of charge at this time.*

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