

Communication Matters



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THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

Provision Pathway - Early Core Vocabulary - Young AAC Users - Smartphone Apps - Hand Motion Recognition - Transitions - AAC Strategies - LEGO®-Based Therapy - Students with ASD - Suranuclear Palsy - Personalise EyeControl - Cornwall Team Update - Creating Helps



Tom uses Grid 3 AAC software on a Grid Pad 12, with an Irisbond Duo camera.



Meet Tom, he is 8 years old and just starting out with Super Core



This is Tom, a cheeky boy with a rare condition that affects his ability to communicate verbally. Using his eyes to access his Grid Pad, Tom is now able to speak and interact with his family.

Tom is in the early stages of his communication journey, starting out with the Super Core Learning Grids and creating activities that introduce him to new language.

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“Smartbox has changed everything. They are the most amazing company with the best support system you could ever want. If we have any problems at all someone is always on hand to help us. Tom is never left without his eye gaze.”

Megan Roberts (Tom's carer)

Read more about Megan and Tom's journey with AAC
thinkSmartbox.com/meet-tom



Congratulations to the AT Therapy Mentor Team, winners of the Student Award, at our inaugural AAC Awards ceremony held on 11th October 2019 at the University of Leeds.

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Chair's Report

HELEN WHITTLE

We are just putting the final touches to the first journal of 2020. I was meant to be checking my report for errors, but instead I am re-writing it in light of the Covid-19 pandemic.

My first thoughts are to all of you, to stay safe and at home if possible. This will apply to many of our members. But we also have many members who will be re-deployed from their current role to work on the front line within the NHS. This will be a challenging time for all.

As a result of the Covid-19, we have cancelled all of our Study Days and are hoping to offer them again later in the year, if appropriate. The Glasgow AAC Information Day has been moved to 24th November 2020, again if it is possible to continue on this date.

Yesterday we made the very difficult decision to cancel the Communication Matters International AAC Conference 2020. At this stage no-one knows what will happen in the next few weeks or months, but we felt that it was the most sensible decision to make now, to protect our AAC users and members and those working to support

them. We did explore the option of running the conference later in the year, but due to us needing to have a conference in the university holiday time, this was not possible. So, we are looking forward to welcoming you all to Communication Matters 2021 on 12-14th September. The ISAAC Conference has also been postponed until August 2021.

We are hoping to continue with Friday Announcements as usual, so please email admin@communicationmatters.org.uk with any AAC-related items you would like us to distribute. During these unprecedented times we are keen to share all sorts of resources with our members. This may include innovative ideas for remote working or online resources that AAC users may find particularly useful or amusing.

The Trustees' Board Meeting due to take place in May will undoubtedly be taking place remotely.

Look after yourselves and won't CM2021 be a wonderful opportunity to catch up with people?

If you are shopping from home, please can you use the links below to raise free donations for CM at this uncertain time:

Amazon Smile - <https://t.co/KOATkZlp5e>
Give as you Live - <https://t.co/xrXhU2oWzy>

A Glittering Affair.... The Inaugural AAC Awards

VICKY HEALY – DEPUTY CHAIR OF THE BOARD OF TRUSTEES (COMMUNICATION MATTERS)

On 11th October 2019, Communication Matters and the conference organising team from University of Leeds, welcomed 140 people to Leeds for the first AAC Awards Ceremony being held in the UK to help celebrate International AAC Awareness Month. Many months of planning had finally reached fruition. The audience was made up of a myriad of people – family and friends of those involved with CM, suppliers, therapists, teachers, support workers and so many more involved in the AAC world - but most importantly, there were 28 AAC users in attendance.

The lead up to the evening had been the influx of nominations since we started advertising at our annual conference in September 2018. We were delighted to receive nominations from such a high calibre of individuals and teams from all over the UK and also one from the other side of the world! An experienced and

diverse judging panel, including an AAC user, an ex-CM chair, Specialised Services managers and a Professor of Assistive Technology, had been hard at work for several months shortlisting the nominations, based on a tight set of criteria. Just before our annual conference in September 2019, the panel met in a locked room to decide the winners. This was no easy task due to the high standard of nominations and it is certainly true to say that all those shortlisted could so easily have won their category.

As the evening began with a champagne reception, the buzz in the room and the excitement amongst the growing number of guests was palpable. Everyone had turned out in their finery – suits, dresses, kilts; the array was glorious and glamour was definitely the key.

The team at MEETinLEEDS had done us proud and the room looked stunning. The tables had been dressed with

Trustees' News



just the right amount of sparkle - each place setting had a name card, an Awards programme and a beautiful grey and yellow candle, customised for the event by Wonky Candles (you may remember Patrick who had a stand at our Art Exhibition at Conference in September 2019) and we are very grateful that he had time to make these bespoke gifts.

The tone of the evening was set by Meredith Allan's welcome video (the current ISAAC President from Australia), in which she enthused about the awards and spoke of the importance of raising awareness of AAC and celebrating all its successes. We followed this with the Communication Matters "Roar" video to get everyone in the mood and to showcase the diversity of people using AAC, their families and support teams.

Our main host for the evening was comedian Alistair Barrie who set the pace with some edgy jokes to test the water of the audience's humour (he found out quite quickly that they were up for anything) and tried to keep us all to time. He had been carefully prepped in the running order and mostly, all went to plan!

Each award was presented by a distinguished guest who had a link with the award or the person that had won the category. The audience were kept informed along



Meredith Allan

the way by videos, photos and testimonials, cleverly set to music and graphics compiled by friends of CM, Will Davies and Brett Walsh. Every attendee also had their programme to act as a souvenir and help navigate the proceedings.

Amongst the prestigious guests we had in attendance, who were also invited to present awards, were The Lord Mayor of Leeds, the Vice Lord-Lieutenant of West Yorkshire (in full ceremonial dress to represent the Queen) and the Deputy Vice-Chancellor of Leeds University. Robert McLaren came from Policy Connect (a cross party think tank involved with technology) as well as one of our patrons Martin Pistorius. We thank them all for giving up their time to attend.

Just before supper we were entertained by some amazing signed song performances by Sign Out Loud - the young people, their parents and of course Kate and Sally, blew everyone away with their passion and confidence. A sumptuous three-course dinner with wine (fit for any top awards do) followed by coffee and chocolates was then enjoyed by all.

Alistair started the second half of the awards shortly after and once more the standard of nominations was high. Lee Ridley, Lost Voice Guy and 2018 Winner of Britain's Got



John Larkins & Professor Janice Murray



Ace Centre & The Vice Lord-Lieutenant of West Yorkshire

Trustees' News

The Awards

SETTING OF THE YEAR

Ace Centre

One Voice • SCTCI

THE ALAN MARTIN AWARD

John Larkins

Jodie Turner • Oli Cunningham

THE INNOVATION AWARD

Talking Mats

Debbie Jans (CODES framework)

THE RESEARCH AWARD

Professor Janice Murray

Oliver Wendt • The I-ASC Project
(under the leadership of Professor Janice
Murray)

THE STUDENT AWARD

The AT Therapy Mentor Team

Helen Paterson

OUTSTANDING COMMUNITY

INCLUSION

CALL Scotland and the Scottish Book Partnership

Sign Out Loud

THE JAMIE MUNRO AWARD

Anna Reeves

Marion Stanton

THE RISING STAR AWARD

Laith Ritchie

Jemima Hughes • Amy Hanschell

THE LIFETIME ACHIEVEMENT AWARD

Paul Hawes



Sign Out Loud

Talent and another of Communication Matters' patrons presented the award for Rising Star – particularly fitting given the success Lee has achieved in recent years. We were also treated to one of Lee's hilarious comedy sets. Whether you were seeing him for the first time or an old hand, his humour around disability and communication challenges is cutting edge.

Our aim for the night was to celebrate a wide spectrum of achievements and those who attended would agree that we did just that! No award ceremony would be complete without a Lifetime Achievement Award and this was no exception. The particularly poignant moment when Martin Pistorius thanked the recipient of this award, Paul Hawes, for all he had done to support his communication and technology over the years left the audience in awe. His lasting thoughts made a great impact on the room.... *"Our words, however we communicate them, are amongst our most powerful tools – capable of bringing comfort, sharing love and ideas."*

Everyone shortlisted took away a certificate and the winners received beautiful glass trophies. The full list of winners and highly commended nominees from the night are listed here:

Thank you so much to everyone involved who made the evening such a resounding success.



Lost Voice Guy

Trustees' News



Laith Ritchie



Paul Hawes & Martin Pistorius

It truly was a night to remember and planning has already begun for the next awards. We are already looking for sponsorship and any help that you might be able to offer. Please contact the CM office or speak to one of the CM Trustees. We really can't wait!



We have had so many positive comments about the evening. Here are just a few of them:

We wish to congratulate Communication Matters on such a well organised event which was inspiring and highlighted the wonderful work that you and all the other related charities do to support the amazing people whose life is enhanced with the use of AAC

Katie Dawson - Senior Solicitor, Lupton Fawcett

It was such a celebration of the inclusivity and diversity of AAC - in all its guises - and really was a showcase for all that is great about AAC...."

Janet Scott - former CM chair

Thank you so much for inviting myself and my wife..... please pass on my thanks..... we loved the whole evening. Communication Matters is a truly wonderful organisation and it was a privilege to witness it in action on Friday evening.

Tim Hare - Vice Lord Lieutenant of West Yorkshire

Thanks so much for inviting me, it was a brilliantly executed event.... I've come away inspired by all the winners, and with a renewed sense of the possibilities for the AAC sector - as users, researchers, families and practitioners.

Robert McLaren - Policy Connect

CM2019 Conference – Parents' Meeting Feedback

JENNY HERD & ZOE CLARKE, TRUSTEES OF COMMUNICATION MATTERS

Communication Matters (CM) Trustees were keen to give parent/carers as much opportunity as possible to share experiences and make suggestions for how CM can better support families.

To that end, there was an informal half an hour coffee break gathering on Monday morning, and then a longer session on Tuesday morning, facilitated by CM Trustees Jenny Herd (parent) and Zoë Clarke (sibling).

Due to the number of people attending Conference 2019 and the number of sessions running, it was never going to be possible to avoid some clashes, however, a good few parents were able to attend the coffee break meeting and then 11 parent/carers took part in the longer session on Tuesday. The ages of AAC users represented ranged from young child to 30-something adult and so there was a broad spectrum of experience and knowledge.

The discussions centred mainly around the actual CM Conference itself and how it could be made more "parent friendly". There were also some more general issues around AAC devices, lack of knowledge about AAC among social care professionals, supported living, recruiting Personal Assistants (PAs) and issues around Teaching Assistants (TAs) and support in mainstream schools.

Conference

Some of those present felt that the conference is still widely seen as mainly for Speech and Language Therapists (SLTs) and not parents/families and wondered if the actual name "conference" made it seem more academic than it actually is. However, there was complete agreement in the room that the conference has a lot to offer parents and so ideas were put forward and discussed about how to make it more attractive to parents and families.

- 1 **A buddy system for new delegates** - As there is so much going on it can be overwhelming for new delegates, especially those attending on their own or for the first time. Once a new delegate has signed up, CM would offer a 'buddy', another parent they can meet at the conference and perhaps even contact before conference.
- 2 **A private parent/carer CM Facebook group** - Once parents have paid to attend the conference, they would be given the option to be added to a private parents' group on Facebook for that year's conference.

A parent present at the meeting volunteered to co-ordinate the Buddy Scheme and to moderate the Facebook group, so watch this space!

- 3 **Google Group** - A message board for parents.
- 4 **Flyers** - Some flyers to be produced giving some 'parent experiences' of conference.
- 5 **Themed "lightning sessions"** - Parents plan the topics but with views from all involved (Parent, AAC User, PA, TA, SLT, Teacher, Social Worker, Supplier etc), discussions and Q & A. These would be short, themed sessions at conference and would actually be of interest to a much wider audience than just parents as they would give a unique multi-viewpoint insight into a particular issue.

This will be discussed with the 2020 conference planning group as to how we can facilitate this.

How parents actually hear about CM, and the conference, was also discussed with a number of suggestions for increased reach, such as via local services (with flyers). People at the meeting had found out through a variety of sources but not consistently via a SLT. Zoë has highlighted this with national AAC Advisory Groups with the potential of adding it to guidance for local teams.

AAC Devices and Suppliers

Parents generally wanted more time to talk to individual suppliers about their specific issues and suppliers want to hear this feedback, but both found that the schedule was too busy with not enough time for individual conversations.

There was also more general discussion around issues of device reliability, with a number of those present expressing frustration at similar problems, but sometimes seeming to be told by suppliers that they had not come across the issue before. Those present appreciated that the suppliers work hard to develop new equipment and systems and felt that there could be benefit in more AAC users, families and other professionals being part of early development, testing, early adopter feedback and ongoing development and evaluation work.

Problems caused by software updates, and reduced battery life with heavy internet use were also flagged up.

Summary

The session felt very constructive, with some really interesting new ideas which will hopefully help ensure that going forward, the CM Conference is a welcoming and relevant event for AAC users and their families. Feedback about the meeting was provided to the Trustees and considered when looking at work to be undertaken over the next couple of years.

Trustees' News

CM2019 Conference – AAC Users' Meeting Feedback

AMY HANSHELL, TRUSTEE OF COMMUNICATION MATTERS

The Communication Matters (CM) AAC users meeting 2019 was held on the Monday afternoon of conference. The meeting was chaired by Toby and Helen Hewson. Toby and Helen explained the aim of this meeting was for AAC users to share their views on a range of topics.

Discussion started with how AAC users can get involved at CM. A number of attendees expressed their sadness about Toby leaving his role as Co-Chair of CM. Toby explained that being a Trustee could be hard work and takes up of a lot of time. Some people said that they already had a lot on but would still like to be involved in some way. There was agreement that it would be useful to know more about being a Trustee. An AAC user consultation group that could give feedback to Trustees was also suggested. This could be done via an online group chat.

CM Trustee Martin Fisher shared an idea of an Open Day or Drop-in day for AAC users. AAC users could get together and share ideas. There could also be help with communication aids or a chance to look at new devices. There was a positive response to this idea.

The group discussed communication aid reliability and battery life. Attendees shared information about where they received support and funding for devices. One attendee encouraged others to visit the exhibition stands whilst at conference for support and information. Improving access to art and music software was also raised as a key issue.

The group shared information about mentoring and training projects they had been involved in. The lack of training for teachers in mainstream schools was highlighted as a particular problem. It was suggested it would be a good idea to get into universities and be able to chat to and train student teachers.

The meeting concluded with attendees discussing how conference was going so far and sharing ideas for next year. One attendee asked if there could be a social get together or space for AAC users on the Sunday afternoon of conference. This would allow people to catch up and for new delegates to get to know one another. It was also requested that delegates be allowed to choose what name and title goes onto their conference badge. There were some concerns raised about the temperature in some of the rooms and the timetabling of the AAC user led sessions. There was much agreement to the idea of having two CM conferences a year!

If you have anything else you would like to add, or if you would like a full copy of the meeting minutes please contact us on: admin@communicationmatters.org.uk

CM Trustees are currently exploring ways to encourage more AAC user involvement.

In response to one of the suggestions at the meeting, CM is looking into the possibility of having a social event/space for AAC users on the Sunday afternoon of conference. We would welcome any ideas as we move forward with the planning.

Charity Fundraising Adventure

AMANDA HYNAN, TRUSTEE, 1-VOICE COMMUNICATING TOGETHER

Last September, I raised money for 1-Voice by completing the first women's only motorbike ride from Kathmandu to Everest north basecamp in Tibet, China. The trip was led by a famous female overland motorcyclist called Steph Jeavons and organised by Nomadic Knights.

The weather was very bad in Nepal due to a late and extreme end to the monsoon season that turned the roads into a quagmire of mud. The general chaos caused resulted in stranded trucks, numerous landslides, waterfall crossings and dangerous motorcycle riding conditions. 23 women started but sadly 10 had to withdraw due to minor injuries. The challenge tested everyone to the limit and through their own fear



barriers, however we developed a strong bond through our team spirit, determination and bravery.

Seeing Tibet (China) was truly moving and it was fascinating to learn about the people and their history. Base camp is a precious and fragile place and the challenge is something I will never forget. Thanks to an amazing level of generosity, through online and offline donations I raised £1,673. The trip has received coverage worldwide on motorbike forums, radio stations and magazines. The photograph featured here with the 1-Voice logo even made it into the October 2019 copy of MCN (Motorcycle News, a well-known motorcycling newspaper).

AAC Provision Pathway: Single Item Activation to Linking Ideas and Navigating

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Introduction

Acquired brain injury (ABI) can result in complex neurological presentations impacting sensory (e.g., visual), physical, cognitive, and communication abilities (Ylvisaker 1998; Light & McNaughton 2014, Kielhofner 2008, Wallace 2010). These challenges can result in multiple barriers impacting access to Alternative and Augmentative Communication (AAC). This paper presents a pen portrait of an AAC journey in an inpatient neuro-rehabilitation setting at The Children's Trust and the Surrey Teaching Centre. The authors worked with secondary-school-aged pupils who were unable to functionally use high-tech communication systems, and found that there were limited high-tech resources which bridge the gap between basic cause and effect skills and functional high-tech AAC use. They aimed to create activities which progressed through these skills. Noticeable gains were observed using AAC for meaningful self-efficacy and expression. The authors also reflected that joint working between therapy and education was pivotal, with education taking ownership of the process.

Pathway

Although presented here as a chronological narrative, progression is not necessarily linear and skills may be worked on in parallel. Broader cognitive and communication skills can be developed and consolidated whilst targeting a specific skill (Rice & Kemper 1985). This journey worked through the following stages:

- 1 Single item activation:** The first challenge could be scanning the whole screen and activating a single target icon. For example, clients with visual challenges may have a tendency toward items presented in a particular area of the screen, which can lead to perseveration or a perseverative zone on the screen. A component skill in such a case might be to encourage the person to change the perseverative behaviour. Grids were created where single cells containing orientation information moved around the screen (see Figure 1). Additionally, a football game was created where the ball appeared in different parts of the screen (see Figure 2). The size of the targets was reduced to increase the challenge.
- 2 Single item activation with distractors:** The presence of a distractor icon/symbol can be the next challenge. The user will need to select the intended target while ignoring the other options on the screen. The level of distractor can be stepped up and down as needed. For example to start with, the distractor cell could be small. The challenge could be stepped up by increasing the size or number of distractors (see Figure 3).
- 3 Multiple item presentation:** Next might be finding targets from a selection set. The young person could be presented with a page of 8 cells (for example 8 pictures of film genres), some of which are motivating

and some non-motivating. The young person would be expected to select the motivating option. Multiple grids could be created with the motivating options appearing in different positions each time. By changing the locations of the motivating option, we were able to see how consistently the young person scanned the whole grid and selected the intended cell (see Figure 7). For a young person with visual challenges, presenting motivating options outside of the perseverative zone might lead to compensatory strategies (e.g. turning their head more to search). Another example is a high-tech grid acting as a TV remote, to see if the young person correctly scans through TV channels (e.g. if they would use the cells differentially to go back to a channel they wanted but went past, see Figure 5).

- 4 Linking symbols:** We may work on linking symbols to create short phrases, e.g. 'more' + 'dancing'; 'I like' + 'Disney'. High frequency/core/carrier phrase symbols (e.g. more, stop, like, don't like) can be presented alongside motivating and less motivating options to assess whether the young person's comments are appropriate (e.g. whether they are asking for more of something they are known to enjoy, see Figure 7)
- 5 Categorisation and Navigation:** We may work on this skill before, after or at the same time as linking symbols. Both are often eligibility requirements

Table 1

Visual

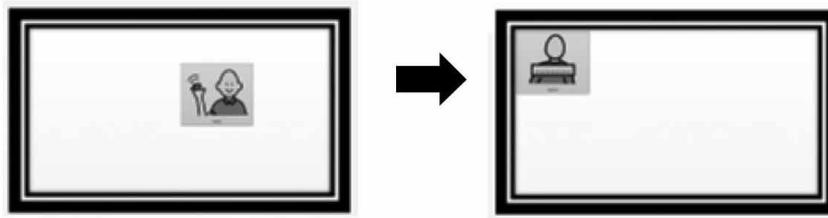


Figure 1: Single item activation

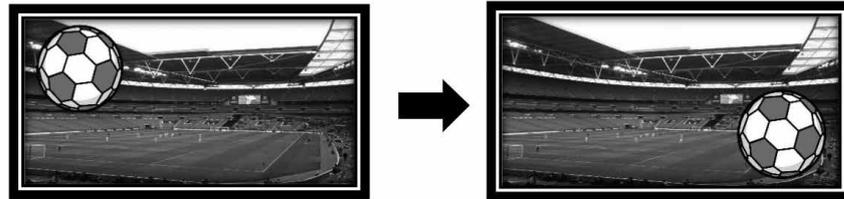


Figure 2: Single item activation

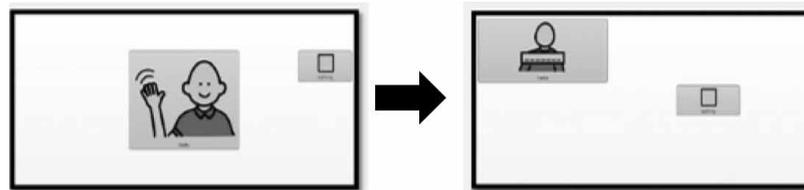


Figure 3: Single item activation with distractor

Motor

Timing, encourage reach via positioning; challenge endurance

Cognitive



Figure 4: Multiple item (shifting distraction)

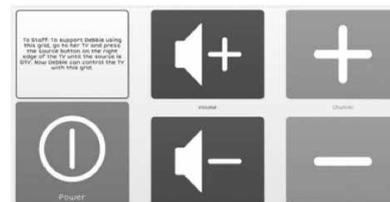


Figure 5: Multiple item (shifting distraction)



Figure 6: Navigation

Language



Figure 7: Linking symbols



Figure 8: Categories (for navigation)

for symbol users to receive equipment issued from high specialist AAC hubs. For young people struggling to navigate using the AAC device, categorisation could begin with sorting low-tech picture cards into broad categories. A high-tech example could be an 8-cell category grid with broad categories. When the category symbol is activated, this could link to the corresponding 8-cell page with vocabulary from that category. We could work on 'finding' words in the grid, e.g. showing a picture of a dog, and encouraging the young person to go into the 'animals' section and find 'dog'. Including a 'back' cell provides opportunity for independent navigation between pages (see Figure 6).

Examples broken down into component skills are included in Table 1 on previous page.

Process

During recent implementation of the above pathway, the authors reflected on Ylvisaker et al.'s (2001) approach to brain injury rehabilitation. This research suggests that rehabilitation is most effective when implemented by everyday people in everyday settings. Since the children live in houses with specialist nursing care in our setting, school is the closest context to everyday settings most likely to resemble their pre-injury and post-discharge experience. Interventions in school also allow for short bursts of skills practice, with frequent repetition opportunities in different contexts of classroom-based learning throughout

the day. A few therapy sessions a week is not enough for a student with complex difficulties to consolidate AAC-use skills. Fatigue is commonly reported following acquired brain injury (Wilkinson et al. 2001); education-led intervention enables the duration and timing of the intervention to be targeted around the young person's fatigue levels.

Another change in the process was that a small number of professionals (typically a teacher, a therapist, and an assistive technologist) met more often to specifically discuss progress on the AAC pathway. Often when the larger team of professionals met, broader needs dominated the discussion, and AAC was not discussed in sufficient detail to adapt the interventions. This allowed more frequent and rapid adaptation of resources, whether upgrading or downgrading or adding variety, which keeps the young person engaged, motivated, and continuously working on a relevant skill.

Summary

Many skills are required for eventual independent functional communication using AAC. A pathway of targeting skills may help bridge the gap from early cause and effect skills to functional AAC use. Progress may be tied to highly individualised interventions, and is often nonlinear. A process of frequent ongoing, multidisciplinary, dynamic assessment by a core nucleus of professionals and frequent, targeted work in everyday settings, delivered by everyday people, appears to be beneficial.

References

- LightJ & McNaughtonD (2014) Communicative Competence for Individuals who require Augmentative and Alternative Communication: A New Definition for a New Era of Communication?, *Augmentative and Alternative Communication*, 30:1, 1-18, DOI: 10.3109/07434618.2014.885080
- KielhofnerG (2008) *Model of human occupation: Theory and application*. Lippincott Williams & Wilkins
- NHS England Specialised Commissioning (2016) Specialised AAC service specification. NHS Commissioning Office Directorate, Publications Gateway Reference 04790
- RiceML & KemperS (1985) Child language and cognition. *Topics in Language Disorders*, 5(4), 80-81
- WallaceSE (2010). AAC use by people with TBI: Affects of cognitive impairments. *Perspectives on Augmentative and Alternative Communication*, 19(3), 79-86.
- WilkinsonJ, MarmolNL, GodfreyC, WillsH, van EijndhovenQ, BotchwayEN, SoodN, AndersonV & CatroppaC (2018) Fatigue following paediatric acquired brain injury and its impact on functional outcomes: a systematic review. *Neuropsychology review*, 1-15.
- YlvisakerME (1998) *Traumatic brain injury rehabilitation: Children and adolescents*. Butterworth-Heinemann
- YlvisakerM, TodisB, GlangA, UrbanczykB, FranklinC, DePompeiR & TylerJS (2001) Educating students with TBI: Themes and recommendations. *The Journal of head trauma rehabilitation*, 16(1), 76-93.

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...and much more!

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Teaching Early Core Vocabulary – Where on Earth do I Start?

EMILY GABRIELLE

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It's a commonly held opinion that when thinking about AAC Vocabulary, core words give us good 'communication' value for money. They can be used across contexts, have multiple meanings and can promote a wide range of language functions beyond simply requesting.

With numerous studies confirming that our highest frequency words used are, on average, around 80% core, we know that it makes sense to be teaching core words, alongside meaningful nouns, early on in an individual's AAC journey. Indeed, in reflection of this, many AAC vocabularies now available are based on this idea and we have a range of core-rich vocabularies at our disposal.

But when starting someone on the long road to ultimate AAC competency, how do we choose which core words to teach in the early days? What influences our decision-making in selecting vocabulary and what should we be considering?

What influences the core words we choose?

The research perspective

The studies into vocabulary frequency all provide word lists indicating what, in fact, were the highest frequency words within each sample. If we look at the word lists, we can begin to identify consistent, frequently-occurring words across samples. One could argue that in using these lists to influence the words we choose, we will be ensuring that we are teaching the most frequently used words early on. However – proceed with caution! As in fact when we look at these

lists, some words which appear include those smaller words such as 'helping' verbs which will not be used in isolation. As we would anticipate someone early on in their AAC journey to be using single words initially, some of these high frequency words suddenly become useless. So, whilst we can certainly use the research into word frequency to inform our decision, it cannot be wholly based upon this information.

The developmental perspective

In early expressive vocabulary development, we develop a robust vocabulary of single words before we begin sentence building. Only once a robust vocabulary is established at a single word level do we begin to combine words into simple sentences. With this in mind, words we choose to teach early on must be able to be used in isolation to convey meaning (and as discussed above, not all the highest frequency core words do this). So, when choosing the early core words we teach, we must remember to ask ourselves – 'Can this word be used in isolation?'

Verbs (action words) and prepositions (location words) can allow for dynamic and engaging language opportunities – so it's important to ensure the early words we choose to teach include these word types.

The historical perspective

We tend to have a bank of core words we go to when starting out teaching a vocabulary. But do we ever wonder why we keep going back to the words we do? Often

these words can be functional, motivating and easy to teach. It's also often the case that a deep-rooted culture of using certain core words within a setting means that staff are more confident in how to model them to others. The important thing is to regularly review our list of 'go-to' first words to make sure they remain functional and relevant.

What considerations should we take when looking at the core words we choose?

Language functions

It's important to consider how we can extend language functions beyond requesting or commenting, even at a single word level. Think about which core words target different language functions. Examples include:

Requesting: want, need, help, again

Directing: put, do, eat, read, go, stop, get, drink, give, make, colour, play

Expressing Feelings: feel, happy, sad, mad, good, bad, hungry

Asking Questions: what, do, where, who

Protesting: no, stop, don't, not

Commenting: like, awesome, cool, funny, slow, fast, big, little

Multi-meaning vocabulary

The most powerful core words can be used in multiple situations and represent multiple meanings. When building up an individual's vocabulary, we need to think about how we can model the multiple meanings of words as soon as possible, to ensure generalisation.

In early vocabulary development, how can we ensure value for money from the words we teach? By focusing on dynamic, engaging words which can be used across a variety of play activities, activities of daily living, and classroom activities.

The personal touch

We are all unique individuals and as such we all like different things! Personal influences on vocabulary may include such things as:

- medical, physical, sensory or dietary needs
- interests and hobbies

We need to make sure that, in addition to the nouns taught, the core words chosen reflect the interests and needs of the individual in order to provide a vocabulary which is functional, multi-meaning and MOTIVATING. If an individual was completely nil by mouth, would we focus on 'eat' and 'drink' in the early days? Possibly not. If someone had

a pony at home, would we be more likely to include 'brush' in the early vocabulary we taught? Absolutely! Don't be afraid to select core words which best represent each individual.

What resources can help us?

Teaching core words across the day

Based on PRC's 'First 50 Core Words', this resource is a bank of activity ideas for each individual core word in the above list, including teaching multiple meanings and language functions. It also contains 20 session plans based on common activities, with ideas on how to teach core vocabulary within this. Freely available, it can be downloaded from: <https://www.liberator.co.uk/media/pdf/TeachingCoreWordsAcrossTheDay-2018.pdf>

Planning tools

To support planning of core vocabulary we have several tools available to download including AAC Participation

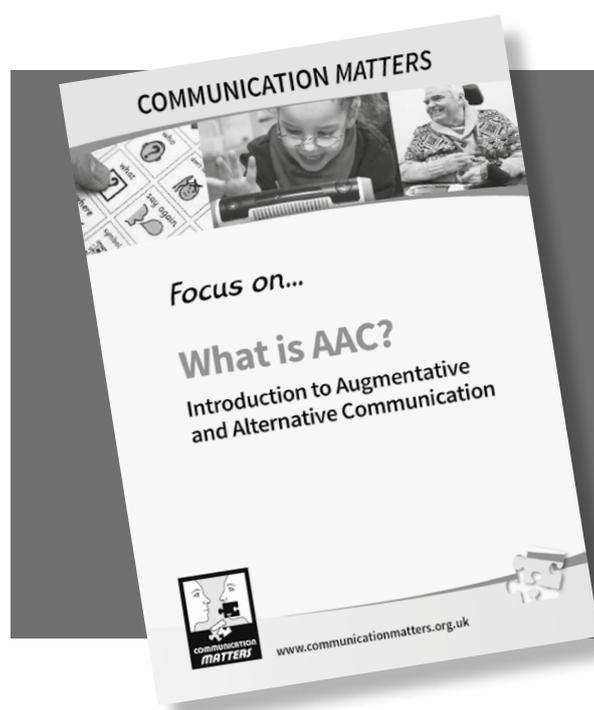
Plans, AAC Activity Planners and Activity First Planners. All these tools can be accessed via: www.liberator.co.uk/resources/handouts-and-presentations

A World (Wide-Web) of support

As always there is a wealth of support through social media and blogs which can provide inspiration, ideas and suggestions for which words to choose and how to model them.

Reflection

When starting out teaching someone core vocabulary, it's important to remember which words can be used for multiple functions, which can be used in isolation, and those which reflect what we know to be high frequency words. However – one size doesn't fit all, and we must always remember that everyone will have differing interests and circumstances which should also influence the core words we choose.



'What is AAC?' Focus On leaflet

Please contact us on
admin@communicationmatters.org.uk
to place an order.

CM is very happy to distribute these leaflets to spread awareness of AAC free of charge, but donations are always welcome!



Participation for Young AAC Users

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People with disabilities have indicated that participation is about: choice and control, access and opportunity, meaningful engagement, social connection and supporting others. Participation levels vary depending on the severity of the individual's condition, age, self-management, and movement and function in society (1). The AAC users within the presentation all had a diagnosis of Cerebral Palsy (CP). The limitations caused by CP influence participation in various contexts and those with greater functional and intellectual impairment are the most restricted (2).

Development occurs through a dynamic interaction between the child and environment. Research states that as children with CP grow up, they are likely to be less socially active and are more isolated than typically developing peers. It is through social participation that children and young people with CP have life satisfaction, develop a sense of competence, form social networks and learn skills which are essential for physical and emotional wellbeing (3).

There are a number of reasons for lower levels of participation for children with CP which are complex and multifactorial. The Participation Model (4) considers participation and communication needs across environments. The model aims to identify the main access and opportunity barriers that exist. Access barriers relate to AAC users' or device limitations that obstruct communication. Opportunity barriers are those which are imposed on the AAC user by outside sources such as

policies and practices, attitudes and lack of communication partner knowledge and skill.

Access Barriers

The slow rate of communication using aids, lack of access to an aid, or lack of access to vocabulary are common difficulties faced by children who use AAC (5). There can sometimes be a delay in the acquisition of AAC and even if the child becomes an AAC user early, their interaction with their peers will depend on adults as interpreters for a while as they need to learn the symbols on their device. They are often expected to extract rules from spoken language and to apply them to alternative, very different systems (6).

Opportunity Barriers

Within early years, children spend a lot of their time talking in the context of play. Children with CP tend to spend more time on daily routines and consequently have less time than their peers for play and social activities. They can have small social networks consisting mainly of family and professionals. When interactions do take place, there is commonly a conversational asymmetry whereby the AAC user often takes on the role of responder instead of initiator due to his or her decreased rate of communication, reduced knowledge of how to begin a conversation and different life experiences. Communication partners can dominate interactions as it can quickly fall into a pattern of yes/no questions and a high anticipation of someone's wants/needs. Children can

therefore appear passive, which can result in lower expectations both socially and academically.

Theory of Mind (ToM) and Emotional Regulation

ToM is the ability to assign mental states to other people and to understand that these mental states influence their behaviour and is the foundation for understanding the social world (7). When considering the early social and communication experiences for some children with CP, it is not surprising that there are reported difficulties understanding their own and others' mental states. Children who understand others' emotions and who can identify their own emotions and regulate them in a way that is socially acceptable are more likely to be able to engage in successful interactions. Children with CP can encounter labile emotions and ineffective emotional regulation strategies which can affect their ability to develop successful peer relationships thus impacting self-esteem (8).

Adolescence

Participation changes as children with disabilities transition to adolescence. Small peer groups usually develop which create opportunities to develop social skills, share problems and support each other thereby allowing autonomy from parents. For adolescents with CP however, participation diversity decreases as activities are more passive, home-based and tend to be done alone or with parents rather than with friends (9).

Adolescents are often concerned about changes in their physical appearance with the development of secondary sex characteristics. As peer contacts become central, there is a lot that is learnt and shared about dating. Young people with CP have extra hurdles to overcome during the teenage years including: developing a positive relationship with their bodies, learning to deal with physical limitations, and possibilities and needs regarding sex (10).

The case studies of four adolescent high-tech AAC users have been shared to highlight some of the difficulties with participation experienced following transition to a new setting with a higher level of academic demand. The information above aims to enhance understanding of why these problems may present. Various interventions were employed to overcome some of the access and opportunity barriers.

Case Study 1

Aaron is 14 in Year 8 at a mainstream school. He is a wheelchair user and uses a device accessed via a switch positioned by his knee. Upon initial assessment, Aaron was experiencing frequent technology failures and his AAC was not mounted, meaning poor AAC availability. He used his system to respond to questions and his spontaneous communication was often sexualised or language was inappropriate. His access method was slow and fatiguing which resulted in him giving up part-way through a message. Aaron accessed social media, however there were difficulties with e-safety as he sent repeated messages to female peers of a sexual nature.

Input started with a review of Aaron's AAC. Alternative access methods including joystick and direct access were explored to facilitate ease and speed of communication. A new hardware solution was provided which was more portable and mounted to his wheelchair. Aaron started to use his device with his peers during unstructured times of the day and when transitioning through school. A low-tech back up (eye-link board) was also provided.

Once AAC systems were in place, joint input with the Clinical Psychologist began. Social Stories and appropriate vs. inappropriate games were effective in supporting Aaron to learn socially acceptable behaviour across environments. Aaron's peers were

included within sessions so he could test developing competencies with some scaffolding support from the Speech and Language Therapist. Aaron was often using sexualised language as a way to make others laugh and form friendships. It was through these sessions that other humorous topics were discovered and clear information was given around the implications of using such language within a school setting. Aaron's peers helped with the identification of further social vocabulary. It is important that youth with CP have the vocabulary typically used by children as they negotiate adolescence, regardless of an adult's view of the appropriateness of this vocabulary (11).

E-safety input was provided rather than stopping access to social media. There are a number of advantages to using social media for young AAC users: connecting with other individuals, feeling typical, making communication easier, gaining independence, getting help, and supporting employment (12). A book resource called 'A five is against the law: social boundaries straight up!' (13) was used to provide lots of activities to support Aaron to understand social boundaries and the consequences of his behaviour.

Case Study 2

Mark is 12 and attends a specialist school. Mark regularly encounters difficulties using appropriate humour with peers and will often offend them. He has lots of questions around puberty and will often ask unfamiliar communication partners about this. Mark struggles to regulate his emotions and will become very upset when there is a problem with his AAC or he receives negative feedback on his social skills.

The strategies implemented embedded lots of positive feedback e.g. Social Stories to list things Mark did well as well as whole group reflection on emotions. This helped Mark to accept support and understand that others experience similar emotions and manage them in different ways. The 'Incredible 5 point scale' book (14) was used to support Mark to recognise an emotion and employ a strategy to self-regulate. This involved joint input with his Occupational Therapist to identify sensory techniques.

Mark started to attend a mentor-mentee group whereby he worked with two AAC Mentors (adults who are highly competent AAC users) and another

mentee who was a similar age. Children may lack experiences with individuals who are competent AAC users, and do not have experience in seeing people who might serve as models for participation in social contexts, which is important to development (15). These groups were powerful in showing Mark that others encounter difficulties with their AAC.

The sex education curriculum was revisited as this was delivered at a fast pace with lots of new concepts and vocabulary. Sessions ensured Mark had the correct vocabulary to support discussions around puberty and the 'chat history' feature on his AAC was amended so Mark could turn this on/off if he wanted to have private conversations.

Case Study 3

Isla is 13 in Year 7 at a mainstream school with a resource base. She acquired high-tech AAC in Year 6 and prior to that rejected all forms of low-tech AAC so mainly used her facial expressions to communicate. Her family were able to interpret these 'microexpressions' well however Isla would often become increasingly fatigued and frustrated as she tried to communicate more complex information. When using her AAC, Isla used lots of directive language and had difficulties with topic maintenance. Isla had low self-esteem ("I am not important", "I can't do that I'm disabled", "Will the CP go away?") and found it difficult to understand why she needed certain input/equipment and her peers didn't.

Communication partner training was delivered to support understanding of Isla's interaction style, the need for AAC and how to create more opportunities to use this. Isla had lots of say and was excited to use a system where she could effectively express herself. Before the training, there was a high anticipation of needs or a long episode of charade-like interactions which reduced Isla's ability to cope with emotionally challenging situations.

Direct therapy targeted development of conversational skills. Comic Strip Conversations and use of partner-focused questions were an integral part of intervention. Isla also started to meet up with an AAC Mentor. She had never met another AAC user/someone with a disability and had lots of questions: "Do you have help with eating? When did you get AAC? Do you have a PEG?" These sessions increased Isla's confidence and also

provided a great opportunity to work on social competence targets.

Joint input with Clinical Psychology was instigated to work on development of Isla's self-esteem. The 'Drawing of the Ideal Self' workbook (16) was used and this helped to discuss aspirations and possible future work experience.

Support was provided to the Multi-disciplinary Team (MDT) to ensure input and equipment were explained more explicitly and that Isla's opinions were heard. Talking Mats and Social Stories were used (see examples below).

Case Study 4

Lisa is 13 in Year 8 in a main-stream school. Lisa has a large peer network at school however prior to therapy input, she rarely used her AAC as she was embarrassed of the voice. Lisa is highly motivated by social media however there were instances where friends misinterpreted her online comments, resulting in arguments.

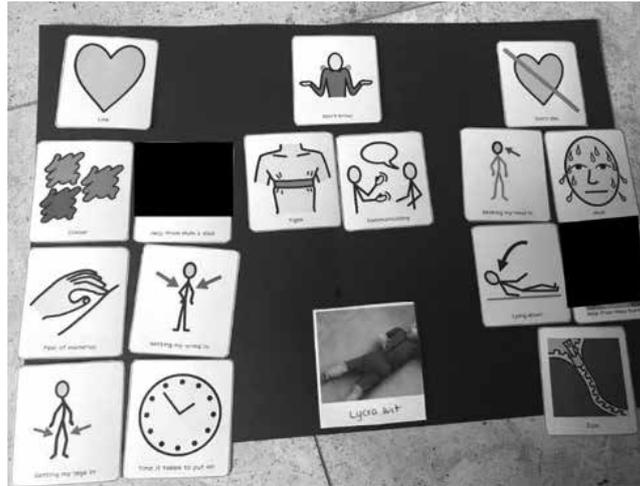
Lisa received input on literacy development to enable her to express herself more clearly and also employ communication breakdown strategies. Through disagreements, Lisa learnt that others had different opinions to hers which is important for ToM development. Her communication partners were reminded not to shield her from such experiences. A 'Britain's Got Talent' style contest was used to select a peer who could voice bank for Lisa so she could have a local accent.

Nothing about me without me

Participation is a goal of intervention and AAC users have a right to be meaningfully involved in every aspect of AAC input if they have capacity. There is a need to understand those early experiences which shape someone's communication and social skill development, and to consider the additional challenges/barriers within the teenage years. Early intervention by the MDT is required to achieve successful communication across different platforms, support the young person to build meaningful relationships and promote positive mental health.

References

Available upon request – fran@attherapy.co.uk



Left: Talking Mat

Below: Social Story

My Wheelchair

On wheelchairs there are lots of different parts to help people stay in a good position.

There are straps that go on people's feet.

There is a harness.

Some people have head rests.

Some people have a tray.

Different people may need different parts:

When people don't wear these parts, they can be in a bad position like this:

In bad positions, muscles and bones don't grow right.

People then get pain and can become uncomfortable.

Health Promotion using Smartphone Apps for People who use Communication Supports

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Introduction

The work discussed here investigates the role of technology in the delivery of health promotion information via smartphone technology for people with intellectual disabilities (ID) or mild cognitive impairments (MCI). It looks at access to technology by people with MCI and ID and currently-available health apps for these client groups. The development and evaluation of two prototype health apps are described, specifically a health and fitness app and a photographic food diary app designed to meet the needs of these client groups.

Participants

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

- Cognitive impairment associated with autistic spectrum disorder and difficulties in processing information
- Intellectual disabilities, with difficulties understanding or expressing themselves
- Developmental disabilities and difficulties with communication
- Literacy difficulties, with possible sensitivity about language simplification

People with acquired conditions (e.g. aphasia and dementia) were not

included in these evaluations as the clinical considerations concerning their support are different to people with life-long conditions.

Health Inequalities

Adults with mild ID and MCI have health inequities compared to the general population. They tend to be exposed to and affected by the most challenging determinants of health, such as poverty, poor diet and poor living conditions (Emerson & Baines, 2016). They are noted to have higher incidence of long term illness and additional conditions (Carey *et al.*, 2016) and their life expectancy is much lower (Emerson & Baines, 2010).

Access to health promotion is adversely affected by communication and literacy difficulties. For people with MCI and ID this may mean they are unable to read instructions on medicine bottles, understand appointment information, and access web-based information or leaflets about the conditions they have or investigations they are about to receive. As a result, they become reliant on others for their own self-management. This in turn assumes that carers, friends or relatives who support them are health-literate also.

Using health apps to improve health and fitness

Higgins (2016) found that app technology was effective in improving patients'

health outcomes. Fitness apps are very popular and accessed regularly by groups in the general population. For example, the use of health and fitness apps on Apple devices increased by 62% in 2014 compared to 33% for apps in general. There is evidence that the use of apps can improve health outcomes. In a trial of an app to increase the activity levels of people aged over 50 years, the group with the app improved by 178 minutes of activity compared to 80 minutes for the control group. Overall there are modest improvements in physical activity for the general population when using fitness apps (Coughlin *et al.*, 2016) and apps designed to improve diet and understanding of healthy foods are successful (Coughlin *et al.*, 2015). However, there is a need for apps to be designed to meet the needs of people who have specific requirements, including those with literacy difficulties and difficulties in understanding.

Currently-available apps are often too complex for a person with MCI or ID to use. Apps can require literacy skills to understand how the app works and to enter data, or can require access to social media to get certain features of the app. The layout and navigation of an app can be complex or the data gathered can be cognitively difficult to understand. Apps often use symbols which are too abstract. Aspects such as these may make an app difficult for a person with MCI or ID to use.

Lussier-Desrochers *et al.* (2017) show there is a digital divide between connected citizens and people with ID. Examples of the use of technology to improve the health outcomes of people with disabilities can however be found: Pérez-Cruzado *et al.* (2013) describe a smartphone reminder app to improve people with ID's adherence to exercise, and Lazar *et al.* (2018) designed an app to assist people with Down's syndrome to manage their nutritional habits and make healthy food choices.

Apps designed for people with ID or MCI should consider factors such as the following. User interfaces should be accessible and engaging. Messages should be made easy to understand, reducing reliance on reading and spelling and simplifying the language and vocabulary used. Navigation should be straightforward, reducing cognitive demands on the user. Apps should be independently usable, reducing the need for carer support. A reward system should acknowledge the user for achievement in a way that they find engaging and motivating. Care should be taken where abstract thinking is required, e.g. during design and evaluation, such that participants feel able to easily contribute their views in the development iterations of the apps being developed. Simplified language should be used throughout testing and evaluation with participants.

Mobile App Development for Special Populations

Two prototype health promotion apps were designed for people with MCI and ID, each with a main theme:

- health and fitness theme
- photographic food diary theme

The first app was designed to provide health-related messages and help users to register activities such as eating healthy foods, undertaking physical activity and drinking fluids in order to help them keep track of health-related activity and provide motivation for adopting healthier behaviour (Lloyd *et al.*, 2017). Symbols were used extensively throughout the interface design. A sample page from this app is shown in Figure 1. It shows the number of user steps counted by the app for the day, with a progress circle showing the achievement level for walking for that day. Rewards (bronze, silver and gold stars and trophies) are awarded for meeting targets, with the trophies being awarded for consistent cumulative performance. There is an option for audio output of results.

A further prototype application (Figure 2) was developed to deliver dietary information and advice (e.g. Brown, 2016; NHS, 2016) to people with intellectual disabilities, facilitating the creation of

a photographic food diary and giving targets for food consumption each day. Targets could be presented in a very visual way using images and symbols. The app could give information about healthier foods and drinks and ones to avoid, while also supporting user interaction with a dietitian. The user can photograph an item, specify whether it is food or drink, associate it with a meal type (breakfast, lunch, dinner or snack) and enter optional comments. The photograph and associated information can then be sent to the dietitian for review. A tutorial was included which could give feedback based on the user's recognition of fruit, vegetables and healthy drinks.

Evaluation

Part of the process of taking part in evaluation requires participants to understand consent forms and information sheets. Such documents are usually text-based and express complex ideas about the processes involved; they were therefore adapted with symbols and simplified language to help make the evaluation process accessible and comprehensible to participants with ID and MCI. Simplifying language and using visual supports (symbols) to make these forms accessible meant that participants were able to understand the information and give consent to aspects of taking part in the evaluation. Symbols used were produced using Boardmaker PCS™ symbols (© [tobiidynavox](http://tobiidynavox.com)).

In pilot evaluations, training was given to participants on using the apps and they were asked to use the apps to record information. They were then asked to complete adapted evaluation forms and give feedback about the apps using their preferred communication means. Carers were also asked for views and evaluations of the apps. Feedback indicated that the prototype apps had good potential for encouraging an improved approach to health-related matters for these populations. The first app (health and fitness theme) was approved by participants. It was said to improve motivation through the reward system, with the users also comparing their scores with each other. One participant would often walk rather than take the bus in order to increase their step count. Another said they were drinking more water as a result of using the app. Feedback indicated that the app had acceptable usability and could have a positive effect on health-related activities of people with MCI, encouraging a healthy

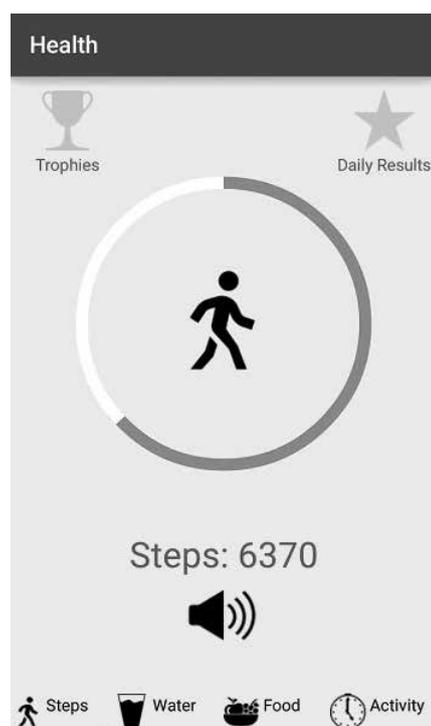


Figure 1: Prototype Health & Fitness app, in step-counting mode

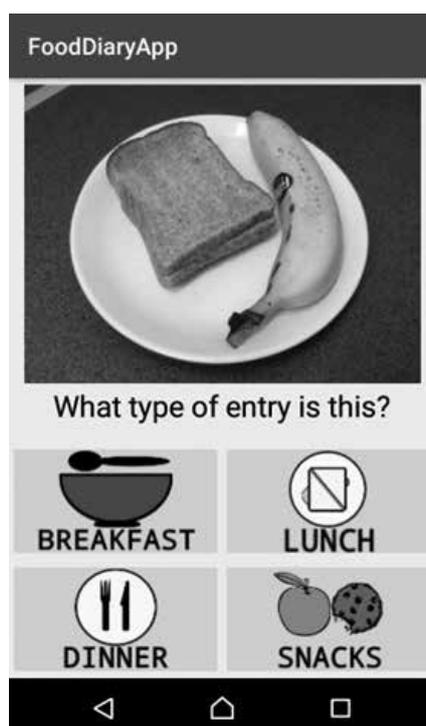


Figure 2: Prototype app to deliver dietary information and advice, with creation of a Photographic Food Diary

lifestyle. The second app (photographic food diary theme) was also liked by participants, who endorsed the number of symbols used in the interface, the large size of the interface buttons and the small amount of text used on it. The app was declared to be graphically well-designed and useful for people with a requirement for symbol access to information.

Conclusions

Prototype health apps have been developed for people with MCI and ID. These include health promotion messages which can be understood and used by people who need symbols to aid understanding. The prototype apps were designed to reduce the complexity of messages and made use of symbols which participants were able to understand. The apps also used simplified navigation processes to reduce cognitive load on the users, and provided them with interfaces which had accessible on-screen keys of appropriate size. Feedback from participants indicated that the apps had good potential for encouraging better engagement with health-related issues for people with MCI and ID. Future developments would aim to refine the user interfaces and include further health promotion messages in the apps. Developing ways of involving participants more extensively in the design process could also be beneficial in making the apps more effective with this client group.

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References

- Carey, I.M, Shah, S.M., Hosking, F.J., DeWilde, S., Harris, T., Beighton, C., & Cook, D.G. (2016). Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice. *British Journal of General Practice*. 66(645), e264-e270.
- Coughlin, S., Whitehead, M., Sheats, J., Mastromonico, J., Hardy, D., & Smith, S.A. (2015). Smartphone Applications for Promoting Healthy Diet and Nutrition: A Literature Review. *Jacobs Journal of Food and Nutrition*. 2:3, 021-, 14pp.
- Coughlin, S., Whitehead, M., Sheats, J., Mastromonico, J., & Smith, S.A. (2016). A Review of Smartphone Applications for Promoting Physical Activity. *Jacobs Journal of Community Medicine*. 2:1, 14pp.
- Brown, A. (2016). Food Fact Sheet: Weight Loss. *British Dietetic Association (BDA)*. Available (April 2018) at: <https://www.bda.uk.com/foodfacts/Want2LoseWeight.pdf>
- Emerson, E. & Baines, S. (2010). Health Inequalities & People with Learning Disabilities in the UK: 2010. IHAL 2010-03. Improving Health and Lives: Learning Disabilities Observatory. (UK Dept. of Health.)
- Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2016). The physical health of British adults with intellectual disability: cross sectional study. *Int. Journal for Equity in Health*, 15:11, 9pp.
- Higgins, J.P. (2016). Smartphone Applications for Patients' Health and Fitness. *The American Journal of Medicine*, 129:1, 11-19.
- Lazar, J., Woglom, C., Chung, J., Schwartz, A., Hsieh, Y.G., Moore, R., Crowley, D., & Skotko, B. (2018). Co-design process of a smart phone app to help people with Down Syndrome manage their nutritional habits. *Journal of Usability Studies*. 13:2, 73-93.
- Lloyd, G., Munro, S.D., & Arnott, J.L. (2017). Mobile delivery of health information for people with Mild Cognitive Impairment. In P. Cudd & L. de Witte, *Harnessing the Power of Technology to Improve Lives* (Vol. 242, pp. 31-37). (Studies in Health Technology and Informatics; Vol. 242). Netherlands: IOS Press.
- Lussier-Desrochers, D., Normand, C.L., Romero-Torres, A., Lachapelle, Y., Godin-Tremblay, V., Dupont, M.-È., Roux, J., Pépin-Beauchesne, L., & Bilodeau, P. (2017). Bridging the digital divide for people with intellectual disability. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*. 11:1, article 1.
- NHS (National Health Service). (2016). The Eatwell Guide. NHS Choices. Available (April 2018) at: <http://www.nhs.uk/Livewell/Goodfood/Pages/the-eatwell-guide.aspx>
- Pérez-Cruzado, D. & Cuesta-Vargas, A. (2013). Improving Adherence Physical Activity with a Smartphone Application Based on Adults with Intellectual Disabilities (APPCOID). *BMC Public Health*. 13:1173, 6pp.

Footnotes

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HandShake – Using Hand Motion Recognition to Enable Communication

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Introduction

HandShake is designed to enable people who cannot use physical controllers such as buttons or joysticks, but who can make an intentional hand or arm movement, to be able to interact with switchable Augmentative and Alternative Communication (AAC) software. Videos and links to the project software and documentation can be found on the project website [Oppenheim].

Beaumont College in Lancaster educates around 100 students with a spectrum of disability, mostly resulting from cerebral palsy. Many of these students require AAC. The Technologists at Beaumont College identified a group of students requiring AAC who can perform intentional hand movements but who are unable to interact with the physical controllers required to operate AAC. This group find operating physical controls difficult due to having a limited range of hand motion or being unable to accurately control their movements. Some members of this group have hand motions that are too violent and uncontrolled to safely use physical controls without a risk of hurting themselves. HandShake is designed to enable this group to interact with switchable AAC. The acceleration that the student's hand is moving with is constantly monitored using a small circuit board worn on the wrist. When the acceleration exceeds a preset limit, a key press command is sent to the student's AAC software. The threshold of acceleration at which the system triggers can be changed without having to touch the device on the wrist. This allows the system to be adjusted

to cater for both gentle and energetic motion characteristics.

HandShake uses the BBC micro:bit [BBC] educational circuit board as the accelerometer sensor platform. As this board is deemed safe to give to 11-12 year-olds in British schools, there are no safety concerns about using the device with the students at Beaumont. This allows the project to be safely replicated using cheap and easily-available hardware.

Significant prior work exists for unique hand gesture recognition for people with no impairment to their hand motion [Rautaray & Agrawal, 2015]. No prior research on using hand gestures for participants with impaired mobility as assistive technology was found.

Early attempts

We initially looked for a solution that did not require the student to wear a device, to increase the comfort of using the system. Several camera-based technologies were tested.

The Microsoft Kinect [Microsoft] game controller was tested with the target user group. This is a camera-based system that builds up a 3D depth image. The Microsoft Kinect creates a 'skeleton model' of a person, and the software design kit made available by Microsoft allows the position of each joint to be tracked. We found in testing that the software would not accurately track the motion characteristics of the target user group. The Microsoft Kinect has since been discontinued by Microsoft.

The Leap Motion [Leap Motion] is a small

camera-based hand-tracking device, capable of imaging finger motion as well as hand motion. The Leap Motion was tested with students selected by Technologists and Occupational Therapists at Beaumont College. Leap Motion were kind enough to donate a unit to the project. Some people with cerebral palsy have tight musculature, which leads to a clenched hand position and small, erratic hand movements. This led to the Leap Motion not consistently recognizing the students' hands and being unable to track them. The algorithms used by the Leap Motion do not appear to cater for the hand motion characteristics of the target user group.

After failing with vision-based systems, we moved on to testing wearable technology, such as smart watches. Smart watches often contain an accelerometer and wireless communication technology such as Bluetooth. This allows the smart watch to detect a shake motion with the accelerometer and to communicate this to AAC hardware. Several smart watch platforms were tested, including the Pebble Smartwatch and the TI EZ430 Chronos. The production and support for the Pebble Smartwatch was discontinued in 2016. Battery life is a limiting factor for the TI EZ430. This smart watch uses internal lithium cells which would need replacing several times a day.

Several prototype wearable devices incorporating an accelerometer and a wireless transmitter/receiver were developed at InfoLab21, Lancaster University. These were tested with the student population at Beaumont College. Results indicated

that a wearable, accelerometer-based system was a workable solution. However, using custom-made hardware presents a barrier for implementing the idea in the 'real world'. Fortunately the BBC micro:bit became available in 2016, which contains the necessary technology to implement the code and ideas learned from testing with the prototypes.

BBC micro:bit based system

Over 1.5 million BBC micro:bits have been deployed in the UK and Worldwide. The board has an accelerometer, a robust board-to-board radio, an array of LEDs and two push button controllers. The power source is two AAA batteries. The HandShake system consists of two BBC micro:bit boards, one Freetronics Leostick [Freetronics] USB dongle and software written in Python installed on the AAC device. One BBC micro:bit is configured as a transmitter, which is worn on

the wrist – see Illustration 1. The second is the receiver, which is attached to the communication device running the AAC software using a micro USB cable. The Freetronics Leostick is also connected to the AAC device using a second USB socket. All the files and software necessary to recreate the system can be freely downloaded from the project GitHub site [GitHub] along with setup instructions. A complete HandShake system can be implemented for under £50. The battery life was tested and found to exceed 24 hours of continual use (simulating one shake detection per second).

The transmitter board detects that the student has made an intentional hand shake and transmits this information to the receiver board using the BBC micro:bit's built-in radio. The transmitter board also indicates the instantaneous amount of acceleration being detected and the threshold acceleration needed

to trigger a shake on its LED array. The receiver board then transmits a trigger signal to the AAC device from the USB port that it is connected to. Software on the AAC device then sends that trigger to a Freetronics Leostick connected to a separate USB port. The Freetronics Leostick emulates a keyboard and sends a simulated keyboard key press back to the AAC device.

Ideally, the software running on the AAC device would generate a simulated keystroke and there would be no need for the Freetronics Leostick USB dongle. Unfortunately, Smartbox's Grid 2 software blocks keystrokes generated through software. Some example code was sent by Smartbox to enable software control of their Grid 2 software but we could not get this to work. The Freetronics Leostick is able to overcome this block as it appears to be a physical keyboard to the AAC device.

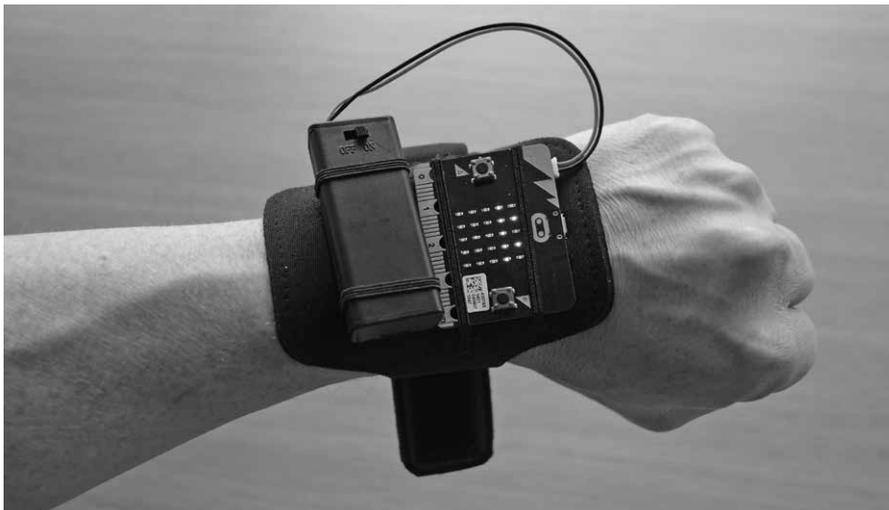
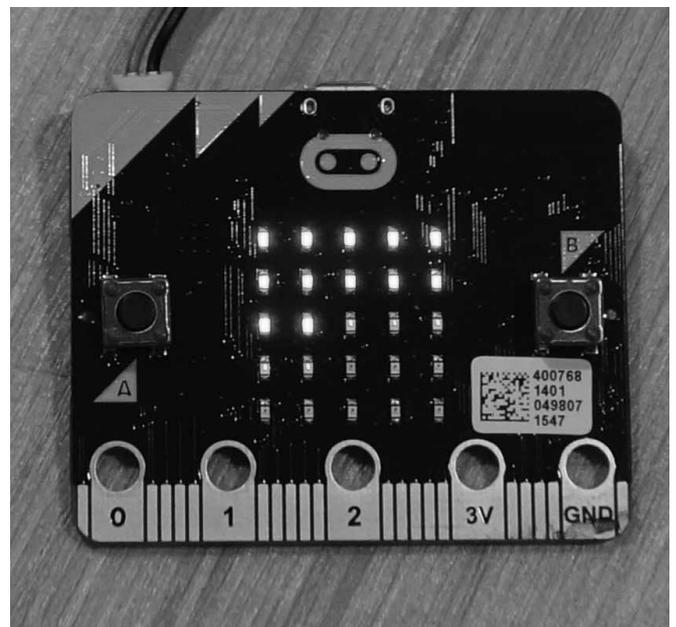
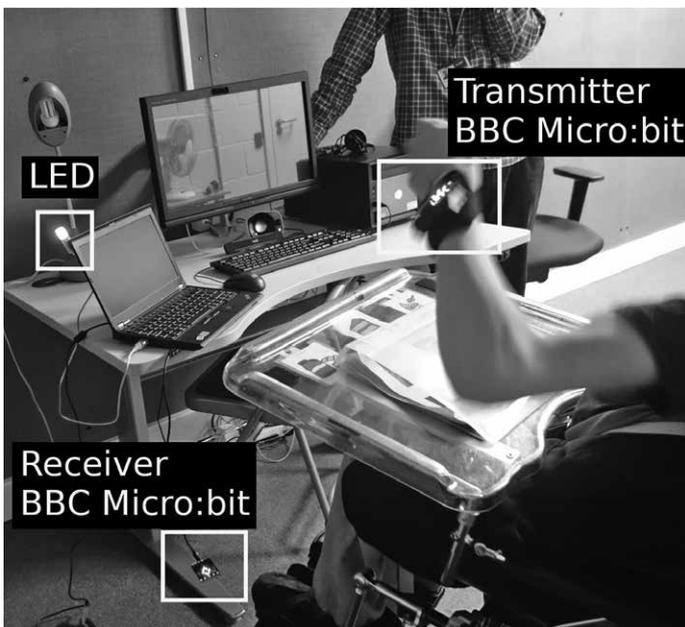


Illustration 1: BBC micro:bit and battery pack on a home-made wrist holder.

Illustration 2: Testing the BBC micro:bit. The Transmitter micro:bit on the student's wrist detects an intentional shake, which signals the Receiver BBC micro:bit to trigger the LED to flash.

Illustration 3: Transmitter in normal operation. The bright LEDs are the amount of shake detected, the faint ones show the detection threshold.



Preliminary testing using Smartbox's Grid 3 software on Windows 10 suggests that software triggers are sufficient to control Grid 3. This means that the Leostick is not required when using Grid 3. The code and user manual on the project GitHub site will be updated to reflect this simpler system.

For the initial usability testing, the communication software that would normally be running on the tablet or PC was replaced with a Python script that made a bright LED flash when a shake was detected.

A simple orientation invariant acceleration threshold recognition algorithm was implemented in Micropython on the BBC micro:bit. The threshold of the acceleration that triggers a detection can be adjusted using the buttons on either the receiver or transmitter BBC micro:bit. As the algorithm is orientation invariant, the system is not restricted in use to when the student is sitting e.g. the system can be used when laying down in bed, perhaps to turn on a light or to signal for attention.

As the trigger level can be adjusted using the buttons on the receiver board attached to the AAC device, the shake detection threshold can be adjusted without having to touch the participant. Both the receiver and transmitter boards display the same patterns on their LEDs when sensitivity is being adjusted up or down or when a shake event is detected. The BBC micro:bit was attached to the student's arm using a converted smart phone holder arm band. A commercially available wrist holder can be obtained for the BBC micro:bit from Pimoroni for £7.

Initial testing of the BBC micro:bit hardware took place under the supervision of the Lead Assistive Technologist at the College used for testing. The testing used two candidates from the student population who the Head Technologist selected as being the most suitable to trial the technology. Several trials of accelerometer-based prototypes took place with

other volunteers prior to testing with the BBC micro:bit. It is not practical to ask the students to fill out the standard questionnaires that are commonly used in user studies for human computer interaction testing due to the nature of their disabilities. Instead, feedback is gained from the supervising Technologist or Occupational Therapist.

A photograph from a testing session is shown in Illustration 3. The BBC micro:bit configured to detect the intentional shake motion is worn on the student's wrist. An LED mounted on the laptop is lit as a shake has been detected. The receiver BBC micro:bit can be seen hanging below the laptop.

As the transmitter board moves, the instantaneous acceleration is represented by the number of bright LEDs lit on the board. The trigger threshold is represented by faint LEDs on the transmitter board. Once the number of bright LEDs exceeds the number of faint LEDs, a shake is detected and a trigger sent from the transmitter to the receiver board. Illustration 3 shows a transmitter BBC micro:bit board.

The BBC micro:bit based system is now a part of the tool box at Beaumont College, to be used with students who are able to intentionally make arm movements, but who are unable to use physical switches such as button switches or joysticks.

Having a system that gives a visible signal in response to an intentional arm movement is of use in itself. The system can be used to help assess if students are aware that their arm causes an external change.

The first stage of training, prior to using an AAC system such as Grid 3, would be an exercise similar to the one conducted during this user study: training the student to recognize that their hand movement caused an external event. The next stage would be to work towards integrating the device with the student's preferred communication method.

Future work

There are as many arrangements of assistive technology as there are people using it. The algorithm used for shake detection may well need to be adjusted for different individuals. The author of this paper is happy to help with the implementation of this project elsewhere. As the programming environment for the BBC micro:bit and the project code are freely available, the software and code for the BBC micro:bits can be adjusted by any developer.

Please go to <https://www.seismicmatt.com/handshake/> to find links to the project code and manual as well as videos and further information on the project.

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References

- BBC (2018). BBC microbit. Retrieved 2018 March 5, 2018, from <https://www.microbit.co.uk/home>.
- Freertronics. (2017). LeoStick (Arduino Compatible) | Freertronics. Retrieved 2017, November 21, 2017, from <https://www.freertronics.com.au/products/leostick#.WoroRa5l99N>.
- GitHub website: <https://github.com/hardwaremonkey/microbit>
- Leap Motion (2016). Leap Motion. Retrieved 2016, October 19, from <https://www.leapmotion.com/>
- Microsoft. (2018a). Kinect - Windows app development. Retrieved 2018, February 19, 2018, from <https://developer.microsoft.com/en-us/windows/kinect>
- Oppenheim website: <https://www.seismicmatt.com/handshake/>
- Rautaray, S. S., & Agrawal, A. (2015). Vision based hand gesture recognition for human computer interaction: a survey. *Artificial Intelligence Review*, 43(1), 1-54. doi: 10.1007/s10462-012-9356-9

Transition in AAC: A Proposed Framework for Decision-Making

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In some contexts, the word *transition* conjures lovely visions such as winter turning into spring and caterpillars becoming butterflies. Transition in the world of AAC is not always so delightful. In fact, it may bring to mind images of frustrated AAC users and strife between team members. But why would this be? After all, most of us utilize a client-centred and team approach. Aren't these elements enough for a positive transition (i.e., between devices, strategies, vocabularies, access methods, features, etc.)? It seems not. One element appears to be missing in many transitions – a systematic decision-making process.

The AAC Transition Tool was developed to address this need across environments, ages, diagnoses, and type of transition. An evidence-based framework, it is largely based on clinical expertise/expert opinion (including published references below) and client/patient/caregiver perspective. External scientific evidence was used as a source for best practices related to AAC. However, such evidence could not be located specifically related to the transition process.

Version 1 of the AAC Transition Tool was presented at the Communication Matters conference (September 2019) where participants with varying backgrounds were encouraged to offer feedback. Version 2 integrated this feedback as well as further development by this author. It was sent out to interested participants for additional review. The current version is available for download from this site for your use to guide and document the transition process. Link to tool <https://>

pathwayslms.blob.core.windows.net/pathwaysforfl/AAC%20Transition%20Tool%20v3.pdf.

Any transition journey must start by asking if transition is necessary and/or appropriate and this is where the AAC Transition Tool begins. This question encourages us to avoid transition just for the sake of using something new without considering the impact on the user and the environment. Factors which may support transition include changes in the individual's needs, skills, and environment, aging technology, and/or reflection on the level and quality of support for the current system.

Once the decision is made to transition, the tool leads us to review the user's investment in their current AAC by posing questions related to effectiveness and team support. This information points us toward an approach and timing for transition – moving directly to a new system or combining systems, using both simultaneously or gradually moving from one to the other – based on an AAC evaluation. Finally, the AAC Transition Tool encourages use of best practices in carrying out any transition including evidence-based strategies such as modeling and providing opportunities for communication. Such support encourages successful transition.

We must remember that transition is not a one-time event in the lives of most augmented communicators as their skills and needs change. It can be an emotional process for the user as well as their partners. A clear and intentional process for carrying out transition offers the user

much needed support and partners the assurance of having offered thoughtful intervention.

References

- Frost, L., & McGowan, J. S. (2011). Strategies for transitioning from PECS to SGD. part 1: Overview and device selection. *Perspectives on Augmentative and Alternative Communication*, 20(4), 114-118.
- Frost, L., & McGowan, J. S. (2012). Strategies for transitioning from PECS to SGD. part 2: Maintaining communicative competency. *Perspectives on Augmentative and Alternative Communication*, 21(1), 3-10.
- Hartmann, A. (n.d.) Transitioning from symbols to text-based AAC. Retrieved from <https://www.assistiveware.com/blog/transitioning-from-symbols-to-text-based-aac>.
- Perkins, Margaret (2014, May 6). Transitioning for AAC. Retrieved from <https://aaclanguagelab.com/blog/transitioning-for-aac>.

AAC Strategies and Tools for Persons with Aphasia: From the Start

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Treatment of persons with aphasia (PWA) typically focuses on restoration of speech. Addressing compensation using augmentative-alternative communication (AAC) often becomes part of the equation only when speech does not improve as much as hoped. This approach neglects two important things we know about AAC; AAC is normal and AAC offers more than replacement of speech to PWA.

AAC is Normal

Every day, each of us use AAC. We show pictures when we are asked about our children or latest trip. We draw maps to provide directions. We gesture to help people understand what we are saying. When we cannot speak because of illness or environmental factors, our use of AAC increases. AAC is normal!

AAC Offers More than Replacement of Speech

Acknowledgement of the normalcy of AAC might still leave us, PWA, and their partners with certain false beliefs which we need to address. The first is that AAC will keep an individual from regaining speech. Overwhelming evidence (research, expert opinion/experience, user/partner feedback) exists supporting that this is not the case. If possible, PWA will use their speech because it is how they have always communicated and want to continue to do so. The second false belief is that AAC functions only as a replacement for speech. Kraat (1990) reminds us that AAC offers much more than just replacement of speech to PWA (Kraat, 1990). It can:

- Facilitate reacquisition of speech.

- Cue or supplement speech.
- Serve as an alternative to speech.

AAC is an important part of our treatment strategy for PWA and, more so, may be the key to facilitating participation in life for PWA.

AAC from the Start

If we approach treatment with this in mind, we will begin using AAC tools and strategies as soon as therapy begins (Weissling & Prentice, 2010). Our sessions will include use of meaningful gestures, rating scales, written choice communication techniques (Lasker et al, 1997), drawing (Sacchett, 2002), scripts (Goldberg et al, 2012), low and high tech AAC, etc. from the start for all the purposes Kraat described. We will use:

- Rating scales to ask how challenging an activity was.
- Written choice communication techniques to talk about sport or weather.
- Drawing to discover what they did over the weekend.
- Scripts to practice speech, cue it, and substitute for it when needed.
- Low or high tech AAC as stimuli for a naming activity. When the PWA is struggling, we use the same tool as a cue for their speech. And, if they still cannot produce the word, we have them use their low or high tech AAC as a substitute for speech.

Use of these techniques from the beginning of therapy session #1 shows PWA and their partners that the PWA can communicate for themselves. As we model use of strategies and tools to connect with

PWA (not just for treatment), it encourages partners to do the same and it offers hope to all for a return to participation in life. Weissling & Prentice encourage us with this.

An eager and confident attitude toward such an approach [addressing restoration and compensation from the start] is necessary to foster enthusiasm in people with neurological impairments, and maybe to an even greater extent, their family members and caregivers. Education on the benefit of all forms of compensation, which assist in bridging the gap between function and desired outcome, is vital to AAC acceptance and program success.

References

- Goldberg, S., Haley, K., & Jacks, A. (2012). Script training and generalization for people with aphasia. *American Journal of Speech-Language Pathology*, 21, 222-238.
- Kraat, A. (1990). Augmentative and alternative communication: Does it have a future in aphasia rehabilitation?. *Aphasiology*, 4 (4), 321-338.
- Lasker, J., Hux, K., Garrett, K, Moncrief, E., & Eischeid, T. (1997). Variations on the written choice communication strategy for individuals with severe aphasia. *Augmentative and Alternative Communication*, 13, 108-116.
- Sacchett, C. (2002) Drawing in aphasia: moving toward the interactive. *International Journal of Human-Computer Studies*, 57, 263-277.
- Weissling, K. and Prentice, C. (2010). The timing of remediation and compensation rehabilitation programs for individuals with acquired brain injury: Opening the conversation. *Perspectives on Augmentative and Alternative Communication*, 19, 87-96.

Considerations for Adapting LEGO®-based Therapy to Develop Communicative Competency

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LEGO®-based therapy is a collaborative play therapy designed by Daniel LeGoff in 2004. This intervention targets a child's natural play and exploration, to enhance the development of social communication and interaction skills (LeGoff and Sherman, 2006). In this paper we explore what LEGO®-based therapy is, and how it can be adapted for AAC users to develop communicative competence. We offer three case examples of developing single and multiple communicative competencies using adapted LEGO®-based therapy and offer considerations for implementation.

Why LEGO®?

A prominent issue with the use of many social communication interventions in speech and language therapy is a lack of motivation for children and young people to participate. Programmes such as Yellow Brick Road Social Skills and the Social Use of Language Programme (SULP) aim to integrate motivators into the therapy including characters from the Wizard of Oz and monsters, however these therapies then rely on the children participating liking those specific topics

Using LEGO® as the intrinsic motivator, LEGO®-based therapy provides each child with a role to fulfil, as they communicate and work together following the social rules of communication to collaboratively build LEGO® sets. Social skills targeted include joint attention and listening, problem-solving, communication (both verbal and non-verbal) and to an extent, a level of creativity (Owens et al., 2008). There are four key roles within LEGO®-based

therapy: the Engineer, Supplier, Builder and Inspector (LeGoff, 2004). Each role has an individual responsibility within the task. For example, the Engineer directs the rest of the group on what pieces are needed and where to put them; the Supplier controls the release of the bricks as and when required at the direction of the Engineer and provides these to the Builder. The Builder is required to put the pieces together, by following instructions from the Engineer. The Inspector is a supplementary role, focusing on the identification of problems within the group or the 'build' and is required to adopt a problem-solving approach. Also, the adults provide a facilitatory approach (not instructive) to develop co-operative learning between the learner, their facilitator and their environment (Palincsar, 1998). The facilitator enables learners to demonstrate their capabilities and draw their conclusions during LEGO®-based therapy intervention.

LEGO®-based therapy is a naturalistic social communication intervention that has succeeded in participants generalising their learned skills to other environments (LeGoff, 2004). There is growing evidence to support the efficacy and effectiveness of LEGO®-based therapy in supporting the development of social communication and interaction in children and young people with Autism Spectrum Disorder (ASD) (LeGoff et al., 2014; Lindsay, 2017).

While many other traditional social communication interventions focus on reducing negative social behaviours such as interrupting or topic-looping in

conversations, LEGO®-based therapy targets the development of social strengths and interests (Owens et al., 2008). A recent study by Andrews et al. (2012) highlighted other potential benefits, including improvements in verbal communication skills such as vocabulary development, understanding and consolidation of use.

Communicative Competence

Communicative competence (CC) is defined as successful communication achieved by integrating the functionality and adequacy of communication, with knowledge, judgment and skill (Light and McNaughton, 2014). Calculator (2009) proposes that the achievement of CC is essential to a positive quality of life and in meeting a range of goals including personal, educational, vocational and social goals that can often be challenging for users of AAC. Light (1989) also highlights the dynamic nature of CC, suggesting that overall competence may differ between individuals depending on context, environment or communicative partner. Light (1989) originally highlighted four areas of competency within communication: linguistic, operational, social and strategic competency. Light and McNaughton (2014) later added two additional factors that influence the development of CC: environmental supports and psychosocial factors.

Many therapies used by Speech and Language Therapists with children who use AAC specifically target one area of competency development (although they may subtly target other competencies

Psychosocial Factors:

Motivation to communicate
 Attitude toward AAC
 Communication confidence
 Resilience

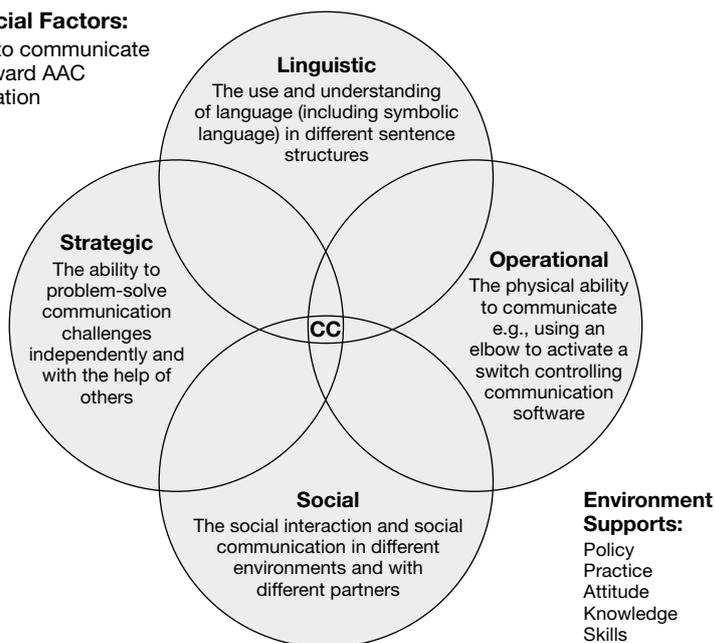


Figure 1: Communicative competency (contents based on Light and McNaughton (2014))

which may or may not be recorded within evaluative methods). There are no specifically recommended programmes for children who use AAC that explicitly target multiple areas of competency development. Profiling tools such as ‘The Augmentative and Alternative

Communication Profile’ (Kovach, 2009) assess and document single and multiple areas of competency development. There is however, no research evidence to suggest that assessment frameworks such as this are consistently used within the field of AAC.

Adapting LEGO®-based therapy for users Of AAC

A series of case studies were conducted within a specialist educational provision in the North-West of England to pilot an adapted form of LEGO®-based therapy for pupils who use AAC as their main form of communication. The aim was to explore the development of CC and whether by adapting LeGoff original LEGO®-based therapy design it would be suitable for use with AAC users. Adaptions made to LeGoff’s (2004) original therapy design included personalisation of resources, preparatory sessions, the use of adult facilitators and timings of sessions.

Additional time considerations are required to develop and personalise vocabulary sets and symbols for some AAC users prior to adapted LEGO®-based therapy sessions. Preparatory sessions of one-to-one intervention may be required before clients access an adapted LEGO®-based therapy session (LeGoff, 2004). The purpose is to facilitate the development of pre-requisite skills (LeGoff et al., 2014), including folder navigation, understanding and use of vocabulary such as colour, shape, size, or social phrases such as “I don’t understand”. This ensures that users have access to the appropriate,

Table 1: Ways in which adapted LEGO®-based therapy can help to facilitate and develop CC (adapted from LeGoff, 2004; and Light and McNaughton, 2014)

Linguistic	Operational	Social	Strategic	Psychosocial factors	Environmental Supports
Provide opportunities for children to use a range of sentence structures including verbs, adjectives and prepositions e.g., “stack the red brick under”	Practice operating new/familiar aided communication systems including new/advanced folders and vocabulary	Take turns in line with their LEGO® job role	Provide clues for other group members where the required vocabulary may be lacking e.g., “ice cream” instead of the target word ‘cone’	Motivation: For LEGO® lovers this is a fun opportunity to interact and practice communication	Policy: Group rules established to ensure inclusion
Understand and use symbols/spoken language they may not have heard/used before, or familiar words in a different context	Learn to navigate new pathways between folders in aided communication systems	Practice using communication for different purposes e.g., to instruct, to question and to comment	Use fun and humour to establish and maintain a positive relationship with other group members	Attitude toward AAC: Participation can establish positive AAC use in this context	Practice: Groups facilitated by a trained professional
Safe and supportive setting in which to practice code- switching (changing between different forms of communication e.g., signing and symbol use)	Provide fun opportunities for children to capture photos to support their communication in other contexts	Develop positive relationships with other group members based on joint interests and successes	Allow a partner to help in navigating folders/vocabulary pathways to lessen demands and speed up communication	Communication confidence: Creating or enhancing the belief that successful communication is achievable in this context	Attitude: Opportunities for meaningful interactions
	Practice unaided communication such as acting out what needs to happen next in the build	Be an active participant in interactions	Ask for help in predicting the ends of words when spelling for ease	Resilience: Practice recovery from communication challenges or failures	Knowledge: Communicative partners who are knowledgeable in supporting communication
		Choose the most effective means of communication to interact with other children and staff within the group			Skills: Communicative partners who use supportive strategies e.g., recognising attempts, confirming understanding

physical resources to enable them to fulfil their communicative potential. When planning and costing intervention, this must be taken into consideration and may be an important factor in the clinical commissioning or funding of this form of AAC intervention.

In adapted LEGO®-based therapy, adult facilitators may also be required to act as communicative partners when including AAC users. Sessions were typically shorter than the recommended times within the manual due to the fatigue encountered by many of the users, especially those using eye gaze access methods of access. Sessions generally lasted between 15 minutes and 45 minutes.

Table 1 illustrates how adapted LEGO®-based therapy has the potential to facilitate and develop CC.

Single competency development example

An 8-year-old, non-verbal child with ASD was trialled with LEGO®-based therapy to target the challenge of social interaction, which had been raised repeatedly by members of the child's teaching staff. Staff reported that when using his iPad Mini as an access method to a symbol-based voice output app, the child would often 'talk over' their classmates, especially other AAC users who took longer to navigate their devices and formulate sentences. Staff also reported that the child lacked eye contact towards their communicative partner and would instead switch his attention between the given activity, their environment, and their device.

After twelve 30-minute sessions (once per week) the class team reported an increase in social competency, with a significant anecdotal increase in the time the child would wait for their communicative partner to respond/formulate their sentence before beginning their own. After a further six sessions, they also reported that they began to show an interest in their communicative partner's form of communication, engaging by eye contact and leaning over to look at their device if responding using a form of AAC.

Multiple competency development example

A 9-year-old child with Cerebral Palsy was trialled with LEGO®-based therapy to develop their overall CC. The child used an iPad as an access method to a symbol-based voice output app to support their speech, as they were largely

unintelligible. The child often found it difficult to interact successfully in sustained interactions with their peers due to the need for a skilled communicative partner to facilitate/interpret their communication. Their class team reported difficulties integrating the development of their touchscreen skills and sentence structuring into their curriculum lessons.

The child was supported by several therapists (Speech and Language Therapists and Occupational Therapists) with different areas of specialism, who were targeting different competencies within their therapy sessions. This included the child's linguistic and strategic competencies (the use of Makaton signing to support their verbal communication and speech sound development). Communication targets were integrated with an operational, Occupational Therapy target for touchscreen access to increase the child's accuracy when targeting symbols on the screen. A competency target prompt sheet was created for the adult facilitator during the child's adapted LEGO®-based therapy sessions, to ensure that every opportunity was taken to work on their challenges in each area of competency.

After twelve 30-minute sessions (once per week), developments in the client's social, linguistic and operational competencies were noted by the therapist and the child's teacher and teaching assistants. During sessions the child was keen to use their communication aid (which was often not the case within their classroom environment). The child's folder navigation skills within their communication software were faster within targeted folders such as 'describe' and 'chat' and they appeared more confident in creating longer utterances to instruct their peers.

Considerations for implementation

The use of the intervention with children using AAC systems has proven successful and may be used as a positive indication of the generalisation of this adapted intervention with other client groups developing overall CC. Findings of these case studies were consistent with Lindsey et al's review (2017), that an adapted form of LEGO®-based therapy has the potential to be used to develop multiple competencies within CC, including social and linguistic, and with client groups other than children and young people with ASD.

When planning and costing LEGO®-based

therapy, the time required for preparatory sessions and personalisation of resources must be taken into consideration and may be an important factor in the clinical commissioning or funding of this form of AAC intervention.

References

- Calculator, S. N. (2009). 'Augmentative and alternative communication (AAC) and inclusive education for students with the most severe disabilities.' *International Journal of Inclusive Education*, 13 pp. 93-113.
- Enderby, P., Judge, S., Creer, S., and John, A. (2013). 'Beyond the Anecdote: Examining the Need for, and Provision of, AAC in the United Kingdom.' Research Report, Communication Matters. [Online] [Accessed on 2nd December 2018] http://eprints.whiterose.ac.uk/76406/1/2013_AAC_Evidence_Base_Beyond_the_Anecdote.pdf
- LeGoff, D. B. (2004). 'Use of Lego® as a Therapeutic Medium for Improving Social Competence.' *Journal of Autism and Developmental Disorders*, 34(5) pp. 557-571.
- LeGoff, D. B. and Sherman, M. (2006). 'Long-term outcome of social skills intervention based on interactive LEGO® play.' *Autism*, 10(4) pp. 317-329.
- LeGoff, D. B., Gómez de la Cuesta, Krauss, G. W., Baron-Cohen, S. (2014). *LEGO®-Based Therapy*. London: Jessica Kingsley Publishers.
- Light, J. (1989) 'Toward a Definition of Communicative Competence for Individuals using Augmentative and Alternative Communication Systems.' *Augmentative and Alternative Communication*, 5(2) pp. 137-144.
- Light, J. C. and McNaughton, D. (2014). 'Communicative Competence for Individuals who require Augmentative and Alternative Communication: A New Definition for a New Era of Communication?' *Augmentative and Alternative Communication*, 30(1) pp. 1-18.
- Lindsay, S., Hounsell, K. G., Cassiani, C. (2017). 'A scoping review of the role of LEGO® therapy for improving inclusion and social skills among children and youth with autism.' *Disability and Health Journal*, 10, pp. 173-182.
- Owens, G., Granader, Y., Humphrey, A and Baron-Cohen, S. (2008). 'LEGO® Therapy and the Social Use of Language Programme: An Evaluation of Two Social Skills Interventions for Children with High Functioning Autism and Asperger Syndrome.' *Journal of Autism and Developmental Disorders*, 38, pp1944-1957.
- Palincsar, A. S. (1998). 'Social constructivist perspectives on teaching and learning', *Annual Review of Psychology*, 49(1), pp. 345-375.

What do we do with the Students with ASD?

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Kent and Medway Communication and Assistive Technology Service (KM CAT)

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KM CAT (Kent and Medway Communication and Assistive Technology) Service is a Specialised AAC Service, commissioned by NHS England to provide assessment, review, equipment and training for those with the most complex communication needs. As a specialised service, we also have a responsibility to support local services and schools to support students who do not meet the assessment criteria, but who nevertheless need AAC (Augmentative and Alternative Communication) to support their communication.

At KM CAT, we receive additional funding from our local authority, Kent County Council, to work with schools and local services to provide additional follow-up support to children and young people who meet the national criteria for a communication device.

At the beginning of 2018, KM CAT identified that we did not have a clear pathway for our students with Autism Spectrum Disorder (ASD). We recognised that this is a very diverse population, some of whom meet the national criteria and some of whom don't. We wanted to ensure that we are providing an equitable service, and that there is support in place for those who do not meet the criteria.

We had a lot of questions:

1. Which ASD students meet our criteria? Can we refine the questions we ask at referral in order to assign them to the right pathway?
2. What can we offer for these students if they do not meet the referral criteria for full assessment?

3. Which factors predict success with high-tech AAC? (Communication environment, partners, vocabulary package, peer group, individual personality/traits.)
4. How can we support local services and schools to get a student to the stage where they are ready for KM CAT assessment?
5. For those students who do not meet our criteria, how can we support local services to move them on from simple requesting?

I will attempt to address these questions in the course of this article. There were several aspects to our service development in relation to ASD students. These will be outlined when I attempt to answer the questions above.

1. Which ASD students meet our criteria? Can we refine the questions we ask at referral in order to assign them to the right pathway?

Below are the NHS England referral criteria for a specialised AAC service.

An individual accessing a specialised AAC service would have the following:

- a severe or complex communication difficulty associated with a range of physical, cognitive, learning or sensory deficits
- a clear discrepancy between their level of understanding and ability to speak

In addition, an individual must:

- be able to understand the purpose of a communication aid
- have developed beyond cause and effect understanding

and may:

- have experience of using low-tech AAC which is insufficient to enable them to realise their communicative potential

Further reading into the service specification tells us "the person should be able to consistently make purposeful choices. Evidence of this will be required". The "referring therapist should evidence that the person is moving beyond basic choice-making and would now benefit from the use of technology in order to communicate a larger variety of choices for increased communicative functions e.g. to make requests, question, comment, interact etc." In addition, "the person should demonstrate ability to link ideas/semantic categories and syntactic functions beyond basic requests". Importantly, "communicative intent would need to be demonstrated, as this funding stream is not intended to cover devices provided for the purposes of language modelling, behaviour management and the development of social interaction skills." (1).

A first step was to update our referral form so that evidence of communicative functions is more prominent. We added a table (Fig 1) which takes up a whole page of the referral form.

This page highlights to referrers the importance of gaining clear evidence of communicative functions. It also gives us insight into communicative intent, and language level. It can provide insight into the communication environment and opportunities for communication. Since introducing this page, we have found it much easier to assess a referral against the criteria.

Functions of Language	
Please give specific examples of what the CYP has communicated, for all functions of language that apply, including using verbal or non-verbal means.	
Functions of Language	Examples, include frequency (never, always, sometimes...)
Makes a request for something, somewhere, action, more or help	
Greets	
Gives information	
Describes something or someone	
Directs a person or activity	
Asks questions	
Comments	
Repairs misunderstandings	
Reasons or negotiates	
Expresses feelings	

Above: Fig 1: Communicative Functions page on the referral form

Right: Case studies

Case Study 1: Noah

- Noah has a diagnosis of ASD. He is 14 years old.
- Prior to referral, Noah communicated non-verbally by body language, some signs and gestures, some symbols in the classroom and PECS.
- Limited evidence of a range of communicative functions. He was mostly making requests.
- A consultation meeting was offered by KM CAT. At this meeting, KM CAT recommended trialling a loan iPad with a standard vocabulary package.
- Following this trial, there was evidence of greater range of communication functions, including commenting and describing, and answering questions.
- What were the factors for success? – all of those we are about to discuss, but especially good communication partners in all environments.
- Because there was now evidence of a range of communicative functions, KM CAT could recommend a full assessment. This was carried out and Noah now has a long-term loan of an iPad with Symbol Talker C.

Case Study 2: Ruben

- Ruben has a diagnosis of ASD. He is 9 years old.
- Prior to referral, Ruben communicated non-verbally by body language, loud vocalisation, and with some signs and gestures. He used some symbols in the classroom and used PECS. There was limited evidence of range of communicative functions. Like Noah, he was mainly making requests.
- A consultation meeting was offered by KM CAT. At this meeting, KM CAT recommended trialling a loan iPad with a standard vocabulary package.
- Following an extended trial, there was no evidence of greater range of communication functions. Ruben was still making requests only, and these were heavily prompted by adults.
- There were limited factors for success, not least of all student factors. Ruben was possibly not developmentally ready for more than requesting
- No assessment was recommended by KM CAT. Instead there was a recommendation for the family to pursue charity funding for an iPad and standard communication app to use for requesting, with adult support.

2. What can we offer for these students if they do not meet the referral criteria for full assessment?

If a student does not meet the full criteria for assessment, we are able to offer a one-off consultation. This 90-minute consultation is attended by a KM CAT Speech and Language Therapist, Occupational Therapist and Teacher, along with the student’s parent/carer, teacher and local therapists. If appropriate, the student attends. Video of the student using their current communication aids is brought to the consultation, and this guides discussion. An action plan is drawn up in the consultation, with clear objectives, roles and responsibilities for moving the student forward in their communication. This might include the use of paper-based AAC systems, access to AAC, use of apps on a tablet or computer, and opportunities to develop more functional communication in a range of environments.

We identified through consultations that there was a need for a loan bank of tablets or iPads so that a student could try out a communication app. Anecdotally, the ASD population are said to favour

technology over paper-based resources, but families and schools did not always have ready access to such devices. We therefore began to give short-term loans of 6-8 weeks, with clear objectives set in the consultation. It was possible that during this trial the student would either demonstrate they met the referral criteria for assessment, or that they were not suitable for assessment, but might benefit from an ‘off the shelf’ AAC solution. In the latter case, KM CAT could then give recommendations and signpost the family to sources of funding for mainstream devices and apps.

To demonstrate this, here are two case studies, Noah and Ruben.

3. Which factors predict success with high-tech AAC? (Communication environment, partners, vocabulary package, peer group, individual personality/traits.)

During the course of this work, we felt it would be useful if we could identify ‘factors for success’. Identifying which students are likely to succeed with high-tech AAC might be helpful when considering

referrals, and might also help us to direct our support more effectively.

Because KM CAT are commissioned by the Local Authority to support children and set and review objectives towards their EHCP (Education and Health Care Plan), we had a wealth of quantitative and qualitative data to draw from. We looked at individual objectives and the records of visits and discussions around why each young person did or didn’t meet their targets. We had data from TOMS (Therapy Outcome Measures) which told us about the support around the young person. We were able to divide the ‘factors for success’ into five areas. Examples of factors are shown below.

- Communication environment. The Voice Output Communication Aid (VOCA) is out and working; it travels with the students; there are opportunities for structured and spontaneous interactions
- Communication partners. They assume competence and assign meaning to interactions; they are familiar with the VOCA and vocabulary package; they

model words and phrases throughout the day.

- Communication package. Core vocabulary is accessible; layout is consistent; there is an onscreen keyboard for spelling words not included in the symbol vocabulary.
- Peer group. There are peers who use a VOCA; peers are interested in the VOCA; there are opportunities for supported peer interaction.
- Individual. The student is motivated to use the VOCA; they have a hunger to communicate; they are persistent; they take care of their VOCA.

We went on to develop a questionnaire which would give us a rating for each of the students currently on our active caseload.

In the period we looked at, we had 16 students with ASD on the 'support and review' pathway. Students who are on the 'Support and Review' pathway have objectives set, and support is put in place to enable the student to achieve their objectives. This might include training or mentoring, class or home support visits, parent/carer groups, teen group in the summer holidays, community events or support, and literacy support.

The KM CAT team completed a questionnaire for each of the 16 students. This was a snapshot of the situation right now.

The key findings were:

- The lowest score was 14, whilst the highest was the ceiling of 33.
- No students had low scores for 'communication package'.
- 10 had low scores for 'CYP'.
- 7 had low scores for 'peer group'.
- The two students with the lowest overall scores (14) were the only ones with low scores for 'communication environment' and 'communication partners'.
- The three highest-scoring students (with scores over 32) had high scores across the 5 domains.

We concluded that we can't change the student or their peer group, but we can change the environment, the partners and the package. This is where we can support change.

The questionnaire is a useful tool for teams to analyse the factors for success, and where intervention needs to be targeted. KM CAT team members were often

Students with ASD who use a VOCA:	
FACTORS FOR SUCCESS QUESTIONNAIRE	
Student's Name:	
Please tick all that apply. If it is not applicable, then leave the tick-box blank. If there are any factors that you feel are important, please write these at the end.	
The Communication Environment	
The VOCA is out in class all the time.	
The VOCA travels with the student around the school and on school visits.	
The VOCA is consistently charged overnight.	
The VOCA is correctly set up with all accessories.	
The VOCA is used in structured learning routines, e.g. registration, snack-time.	
There are opportunities for free-flowing conversation.	
The learning environment is set up to consider the student's sensory needs.	
Communication Partners at school	
At least one communication partner in school knows the basic functions of the VOCA (on/off, volume).	
At least one communication partner in school knows basic navigation (home, back, groups).	
At least one communication partner in school models language using the VOCA.	
At least one communication partner in school shows persistence if they can't find a word.	
At least one communication partner in school models or encourages communication using the VOCA.	
At least one communication partner in school models or encourages communication beyond simple requests.	
At least one communication partner in school tries to use a range of pages on the VOCA.	
At least one communication partner in school asks open questions or prompts the student to say more.	
Communication Partners at home	
The VOCA is used at home.	
The VOCA is used on family outings or at clubs/activities.	
At least one communication partner at home knows basic functions of VOCA (on/off, volume).	
At least one communication partner at home knows basic navigation (home, back, groups).	
At least one communication partner at home models or encourages communication beyond simple requests.	
At least one communication partner at home tries to use a range of pages on the VOCA.	
At least one communication partner at home asks open questions or prompts the student to say more.	
The Communication Package	
There is enough vocabulary for the student's current needs.	
There is potential for vocabulary growth (new words can be added).	
The vocabulary includes the CYP's special interests.	
There is a mix of core and fringe vocabulary.	
There is consistency in the layout of the vocabulary (core words in familiar places, new words added at end).	
There is an onscreen keyboard within the package.	
Peer Group	
There are other students using a VOCA.	
Non-VOCA using peers are interested in the VOCA.	
The CYP uses their VOCA in activities with their peers (this may be supported by an adult).	
The CYP	
They are motivated to use the VOCA (this might include use of visual supports and incentives).	
They are motivated to use the VOCA without needing an extrinsic reward.	
They have a hunger for communication.	
They have shown persistence in using the VOCA to get a message across.	
They have shown that they want to take care of their VOCA.	
They use the VOCA without prompting.	
They use the onscreen keyboard at times.	
TOTAL SCORE	

'Factors for Success' Questionnaire

identifying these factors intuitively and this was guiding their objective-setting. Using the questionnaire made this decision-making more transparent. It is also a useful tool for joint reflection with parents/carers, teachers and local services.

4. How can we support local services and schools to get a student to the stage where they are ready for a KM CAT assessment?

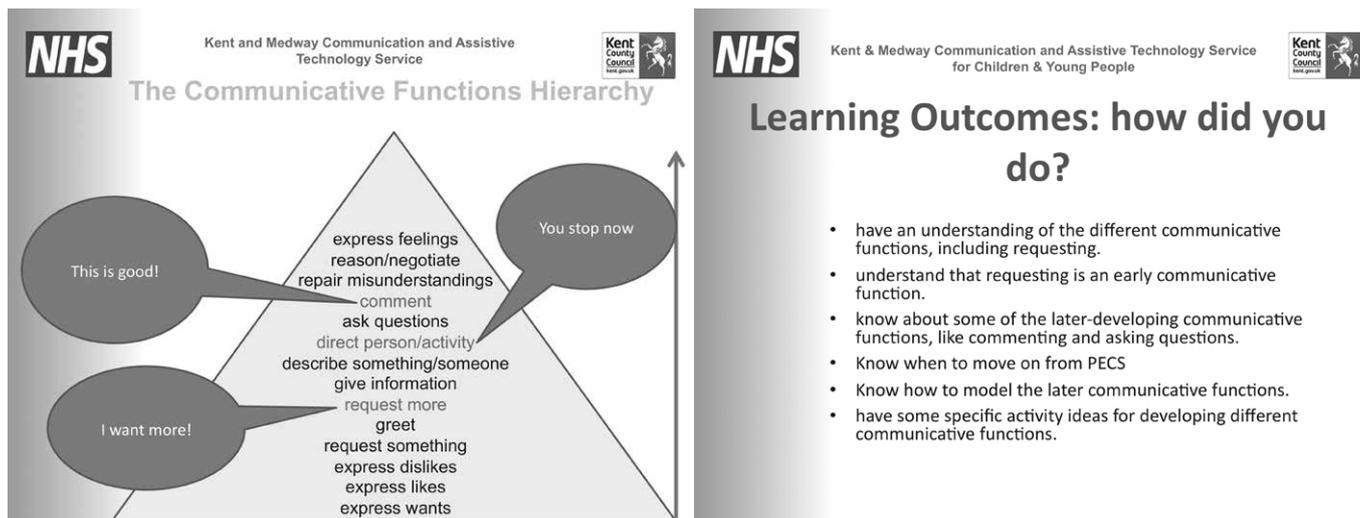
5. For those students who do not meet our criteria, how can we support local services to move them on from simple requesting?

In this period, KM CAT was developing our eLearning training offer. This was in response to falling numbers of school staff and therapists attending our face-to-face training. Even though this training is offered free of charge, schools and local

services reported to us that they cannot release staff for training because they cannot provide staff cover.

We already had an eLearning module called 'AAC: Little and Often' which is an introduction to AAC and how to embed AAC communication into daily routines.

We identified that there was a need for an eLearning module which would give ideas for how to extend the communicative functions used by a child or young person. We had noted in our referrals that there was a bias towards 'requesting', but not other functions. It was possible that children and young people were not being given the opportunity to extend their communication to commenting, asking or answering questions, giving their opinion, and so on. We therefore developed an eLearning module to explain what the



A screenshot from 'Beyond Requesting' eLearning module

different communicative functions are, the typical order of acquisition, and how to provide opportunities and modelling to enable a young person to extend their communicative functions.

Our current eLearning offer includes the following modules:

Augmentative and Alternative Communication (AAC): Little and Often

This interactive module gives an introduction to AAC and language development. It offers ideas for providing opportunities for communication throughout the day, in daily routines and in play.

ASD and VOCAs. What are the factors for success? This is a presentation, rather than an interactive learning tool. It is designed to guide referrers so that they can reflect on the factors that might need to be addressed in order for a referral or trial of AAC to be successful.

Beyond Requesting: Extending the Communication of Children with ASD

This is an interactive module, which explains the various communicative functions and why they are important. Ideas are given for modelling and supporting the development of a wider range of functions.

So far, our eLearning modules are being accessed by a wide range of professionals, and we are gaining positive feedback. We are also encouraging parents to access the training so that they can support their child at home. We are noticing that users tend to access several modules.

It is felt that eLearning modules are an important tool to sit alongside face-to-face training and mentoring.

We feel that the 'Beyond Requesting' eLearning module is of particular use for the ASD population. We frequently signpost teaching staff and local therapists to this module in order to start preparing a student for referral to KM CAT. It is also useful for queries about students who are unlikely to meet our referral criteria, but nevertheless need support in moving on from simple requesting.

Our service objectives for 2019/2020 focus on transition to adulthood, and these eLearning modules are starting to be used with our local Adult Social Care and Adult Learning Disabilities partners.

In the course of this work, carried out over a whole year, KM CAT feel that we have clarified the questions posed at the start of the year. This of course is an evolving

process, and we continue to learn from feedback from our service users, schools and local services.

KM CAT would welcome your questions or suggestions. We can be contacted at kcht.cat-admin@nhs.net.

References

Carolyn Young 'AAC Service Specification' December 2018, Communication Matters website
<https://communicationmatters.org.uk/wp-content/uploads/2018/11/aac-serv-spec-jan-2016.pdf>

Websites

<https://www.kelsi.org.uk/support-for-children-and-young-people/support-for-schools/kent-and-medway-communication-and-assistive-technology-service>

KM CAT's eLearning modules can be found at:

<https://cpdonline.theeducationpeople.org>

The eLearning modules are best accessed using Chrome. You will need to create a login with an email address.

Augmentative and Alternative Communication for Patients with Progressive Supranuclear Palsy: Introduction

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Abstract

Progressive Supranuclear Palsy (PSP) results in a harsh and strained voice quality, slow, monotonal and slurred speech with articulatory errors, stuttering and repeated words. By the later stages of the condition, speech can be largely unintelligible.

Patients with PSP, once they have a severe/complex communication difficulty associated with a range of physical, cognitive, learning, or sensory deficits and a clear discrepancy between their level of understanding and ability to speak, are eligible to be seen by a specialist NHS England funded AAC service.

Typical ways of accessing a communication aid are: directly, using hands with adapted styli and /or keyguards, using switches activated by different body parts (e.g. hands, head, knees, feet), using a head mouse and using eye gaze. The way that PSP affects a person physically means that each of these access methods becomes difficult. In addition, cognitive and behavioural changes can affect whether a person is able to learn to use a new way to communicate, and problems with vision can affect placement of a communication device so that its use can be functional. We have reviewed our caseload of approximately 20 cases with PSP to draw some indications about which approaches best match the difficulties caused by PSP, and where a communication device does not meet the needs of the patient, what caused the difficulty.

Introduction

Progressive Supranuclear Palsy (PSP) is a neurodegenerative disorder that affects balance and mobility, muscle stiffness, speech, swallowing, vision, mood and behaviour, and thinking. It is thought to affect about six in every 100,000 people, affecting about 4000 people in the UK at any one time, is more common in men and usually occurs after the age of 60. Mean survival from symptom onset is 9 years. There are no treatments for PSP although some symptoms can be managed. PSP can be mistaken, especially early in the course of the condition, as Parkinson's disease as the symptoms are similar. Diagnosis of PSP is difficult as the gold standard for diagnosis is neuropathological examination (Litvan et al., 1996).

An early symptom of PSP is commonly loss of balance when walking, resulting in falls and a stiffness of gait pattern. Stiffness of the facial muscles can cause reduced facial expression, and stiffness of neck muscles can result in a backward tilt of the head, further reducing where the patient can see. PSP also causes generalised motor slowing, dystonia and occasionally a resting tremor (Santacruz et al., 1998).

Eye symptoms can include: blurring of vision, slowness of eye movements, difficulties moving their eyes in the vertical plane (with looking downwards being more affected) and difficulties controlling their eye lids, causing them to close with the person being unable to open

them again as well as infrequent blinking. Patients also have difficulties with focusing their eyes on objects that are near to them which can cause double vision for activities such as reading (Armstrong, 2011).

Cognitive and behavioural difficulties result from frontal lobe dysfunction and include impaired executive function that requires shifting between mental tasks, and spontaneous motor behaviour, such as motor perseveration. PSP also causes depression and apathy, changes in judgment, insight, and problem solving, difficulty finding words, memory and slowness of thought. People can also experience increased irritability (Rittman et al., 2019).

Speech becomes slow, quiet and slurred. PSP causes dysarthria which tends to be more spastic and hypokinetic, causing a slow rate of speech with a strained and strangled quality rather than ataxic and hyperkinetic (Frattali & Duffy, 2007). Swallowing is also affected. (Litvan et al., 1997).

As PSP can cause a person to have a severe/complex communication difficulty with an associated physical deficit, such that they cannot select items on a touch screen or keyboard with at least one hand with sufficient speed and endurance to meet their reasonable communication needs, these patients are being referred to the NHS England funded AAC hubs for a Specialised Assessment. As PSP can adversely affect body movements, eye

movements, cognition and behaviour, finding a solution to enable these patients to communicate can be challenging.

Having now seen more than 20 patients with PSP, we decided to review our cases to date and try to draw together some themes relating to what challenges these patients posed and how and whether we found a successful high-tech communication aid for them.

Objectives

To review cases with PSP referred to our AAC specialised hub between February 2015 and August 2019 to determine the range of difficulties experienced by these patients, whether high-tech AAC was recommended and if so what, and also the success and difficulties experienced by patients referred high-tech AAC.

Methods

Case notes were reviewed, and the following information extracted:

- 1 Date of birth
- 2 Date of diagnosis
- 3 Gender
- 4 Date of assessment
- 5 Where patient was living i.e. at home or in residential care/nursing care
- 6 Physical, cognitive and behavioural difficulties and severity at referral
- 7 Assessment findings
- 8 Recommendation for equipment
- 9 Success/difficulties experienced by the patient when using the equipment

(See table 1)

Results

Provision after assessment

- 3 patients were not provided with high-tech as it was not suitable
- 2 with cognitive difficulties, 1 with

- 7 people needed a stylus
 - 4 had keyguards (2 small keyboard cells, 1 large keyboard cells, 1 symbol-based)
 - 3 with no keyguard (2 small keyboard cells, 1 large keyboard cells)
- 13 people did not need a keyguard
 - 2 people used a mouse with Dwell (both small keyboard cells, 1 needed high vis)
 - 11 used direct access
 - 6 had keyguards (2 small keyboard cells, 2 large keyboard cells (1 needed high vis), 2 symbol-based)
 - 5 without keyguards (3 small keyboard cells, 1 large keyboard cells (needed high vis), 1 symbol-based)

Of the 21 people who were provided with equipment, 5 people had their devices withdrawn after a trial as they were unable to use them. One patient wanted to use text to speech rather than symbols (he was functionally illiterate) and was unable to spell so that others could understand what he had written. The four other patients had low motivation and initiation and did not want to use their devices. Of the five patients whose devices were withdrawn, four were in a residential/nursing home, maybe demonstrating that they had a more severe presentation or that opportunities and support to communicate were more limited.

Two patients needed maximal support with prompting each time to use their device rather than speaking, but with this support were able to use their devices to communicate functionally. Both of these patients were living at home.

High-tech AAC worked well for 12 patients following their initial assessment:

- All of these patients were using text to speech (9 small keyboard cells (2 needed high vis), 3 large keyboard cells (2 needed high vis))
- 5 had styluses
- 4 had keyguards
- No one used large keyboard cells, high visibility, keyguard and stylus.

All patients were reviewed periodically but the whole cohort of 24 patients was reviewed in September 2019.

- At this time 11 patients were still alive
- 3 patients had had their equipment withdrawn after the initial trial
- 3 patients had needed a re-assessment:
 - 2 patients progressed from direct access to a switch.
 - 1 patient has possibly too many physical/cognitive difficulties to use AAC now, as switch use is too difficult. Patient is waiting for Botox and it is hoped that she can then use her switch again.
 - 1 patient trialling a switch now
 - 1 patient needs a high wedge due to gaze palsy and retrocollis, but is still managing with a stylus
- 1 patient is not using her device and is choosing to continue to speak. She has now developed double vision so this may be affecting her decision to use her device
- 3 patients report that their device is meeting needs and no changes are needed
- 1 patient is just starting to trial equipment

Discussion

Our cohort of patients with PSP highlights the following points:

Referral of patients from the teams that we work with was not even. This may represent natural variation in the incidence of PSP across our region. The team that referred a quarter of our patients has a specialist nurse for rare neurological conditions, so diagnosis of PSP by this team might be better.

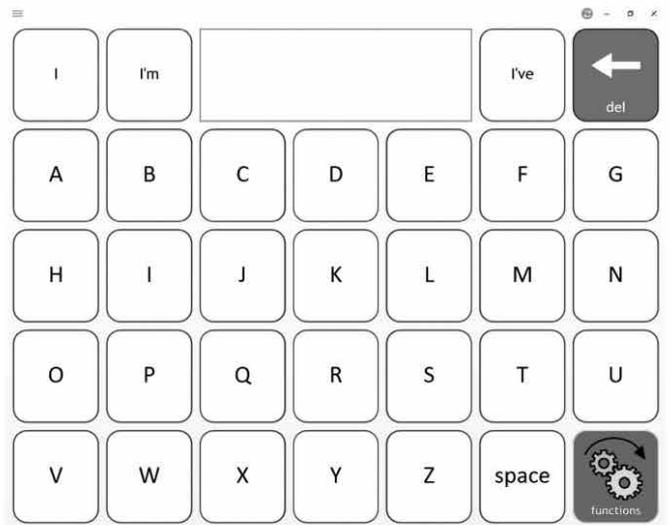
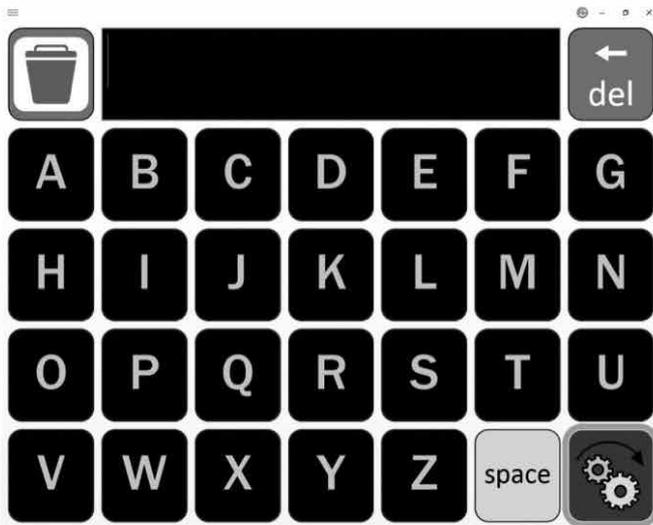
In agreement with the literature, we found that our cohort had slightly more males than females. Also, age of onset, where this was recorded, was over 60 years for all but one patient and their age of onset was over 40.

Disease duration, where this was recorded, was 2.4 years to assessment.

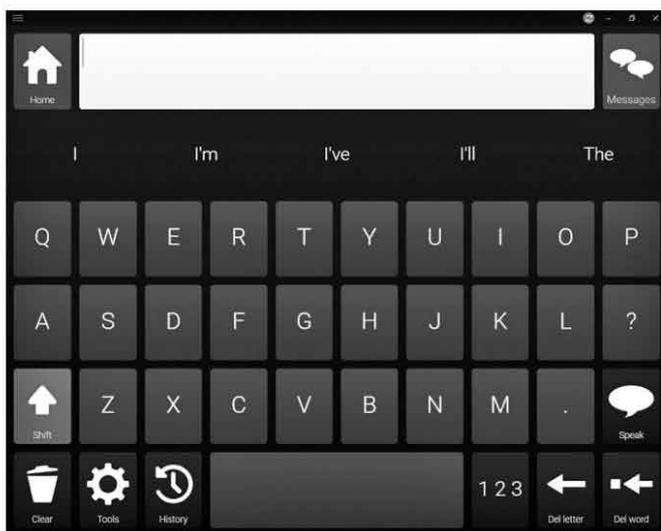
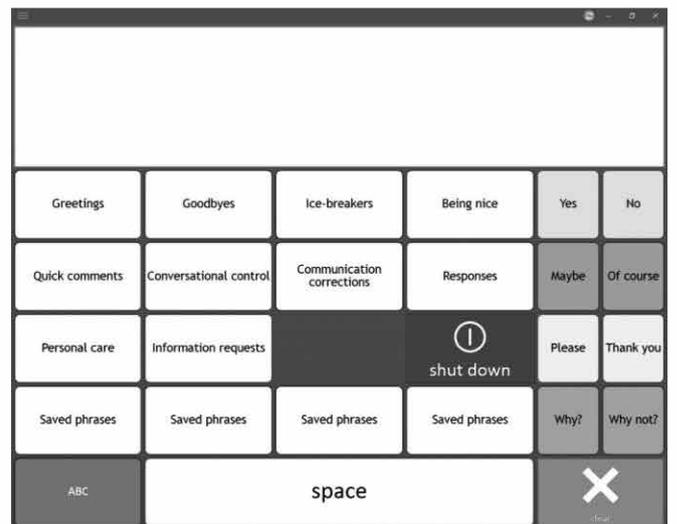
Table 1

Average age at assessment (n=24)	73.5 years	(range 59.2-83.8)
Age of onset = (n=17)	72.3 years (onset date missing for 7 and 5 only gave a year – assumed to be 1/1)	(range 58.7-81.3)
Disease duration (n=17)	2.4 years	(range 0.4-6.4)
Age at death (n=12)	72.6 years	(range 60.4-81.4)
Disease duration at death (n=5)	4.2 years	(range 1.7-6.8)
Residence	Home = 13 Nursing/Residential care = 11	

Examples of big cells A-Z keyboard layouts



Examples of small cell A-Z keyboard layouts



However, the range was wide, possibly reflecting the fact that diagnosis of PSP is often made late. Of more interest would have been the age of onset of symptoms, to gain a clearer picture of when during the PSP disease progression AAC is needed. Similarly, the range of disease duration until death was wide, probably for similar reasons.

The symptoms experienced by patients with PSP mean that many options for accessing and using AAC are difficult. Problems with vertical gaze palsy, and later horizontal gaze palsy, in addition to problems with convergence, means that eye-gaze as an access method is not a practical option. Similarly, motor slowing, resting tremor, motor perseveration and slowness of thought can mean that switch scanning, either with two switches to progress the scan and then select the item wanted, or one switch for automatic scanning, is also difficult. Problems with direct access such as accuracy and activating the screen effectively can be impacted by double vision, blepharospasm, resting tremor and motor perseveration. In addition, axial rigidity and retrocollis can make positioning the screen where it can be seen, and also activated with fingers or a stylus, not possible. Axial rigidity, akinesia and retrocollis also make using a head mouse difficult. Cognitive and behavioural symptoms can mean that support is needed from others, and depending on where the person is resident and who is available to support them, can also result in AAC provision not being successful.

Despite all of these difficulties we found that the following worked for some people :

- a larger keyboard layout with less “clutter”, with or without a keyguard and high visibility layout, as this appeared to be managed by people with double vision better.
- A keyguard and larger keyboard also benefitted people who had problems with accuracy.
- Modifications could be made to the software for people who experienced a resting tremor so that not all keyboard presses were recognised.
- Where patients had a tendency to drag their hand across the screen resulting in mis-hits, a keyguard or stylus was found to be beneficial.
- Support for cognitive and behavioural difficulties was less easy to ensure. Training was given to family members and care staff on how best to support the person.

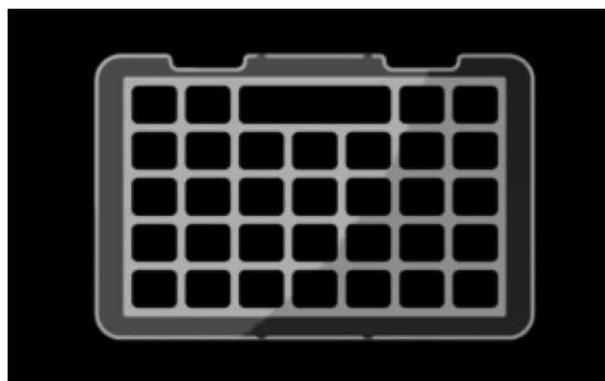
Of the five people who had equipment withdrawn after a trial, four were resident in a residential or nursing home. This may reflect the more severe nature of their symptoms, which in itself would make accessing and using AAC difficult, although two of these patients were still alive when followed up in September 2019. However, it might also be that opportunities to communicate, time available to staff to support the patient and staff continuity within a residential or nursing home were limited. Those patients who were successful at using their device and who needed maximal support were both living at home.

The progressive nature of PSP means the initial provision of AAC needs to be constantly reviewed. As symptoms progress, it can be difficult to find a solution that works, either because of cognitive, behavioural, motor or visual symptoms. It is for this reason that the importance of having a low-tech back-up is stressed to local teams and to patients at assessment.

References

- Armstrong, R.A. (2011). Visual signs and symptoms of progressive supranuclear palsy. *Clinical and Experimental Optometry*, 95, 150- 160.
- Frattali, C. & Duffy, J. (2007). Characterizing and Assessing Speech and Language Disturbances. In: Litvan I. (eds) *Atypical Parkinsonian Disorders*. Current Clinical Neurology. Humana Press
- Litvan, I., Sastry, N., Sonies, B.C. (1997). Characterizing swallowing abnormalities in progressive supranuclear palsy. *Neurology*, 48 (6), 1654-1662
- Litvan, I., Agid, Y., Calne, D., Campbell, G., Dubois, B., Duvoisin, R.C., Goetz, C.G., Golbe, L.I., Grafman, J., Growdon, J.H., Hallett, M., Jankovic, J., Quinn, N.P., Tolosa, E., Zee, D.S. (1996). Clinical research criteria for the diagnosis of progressive supranuclear palsy (Steele-Richardson-Olszewski syndrome): report of the NINDS-SPSP international workshop. *Neurology*, 47(1), 1-9.
- Rittman, T., Coyle-Gilchrist, I.T., Rowe, J.B. (2016) Managing cognition in progressive supranuclear palsy. *Neurodegenerative Disease Management*, 6(6), 499-508.
- Santacruz, P., Uttil, B., Litvan, I., Grafman, J. (1998) Progressive supranuclear palsy: a survey of the disease course. *Neurology*, 50(6), 1637-1647.

Examples of keyguard and styli



Personalization of the EyeControl Product to Improve User Experience

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‘Even more important than the freedom of speech is the freedom TO SPEAK.’

Stephen Hawking

Or Retzkin, CEO and Co-founder of EyeControl, lost his grandmother, Julie, to MND. The sadness and frustration experienced from a loved one losing their ability to communicate gave him a deep understanding of an existing problem and a clear vision for an innovative solution. EyeControl was established in 2016 by co-founders with personal connections to Locked-in individuals. Or joined together with Itai Kornberg, CTO and Co-founder, and Shay Rishoni (1966-2018), MND patient and CEO of the local MND NGO, on a mission to give the Locked-in community the ability to communicate.

Worldwide, millions of individuals are Locked-in as a result of MND, MS, stroke, traumatic brain injury, and Cerebral Palsy. They possess cognitive abilities, but are

unable to move or speak; they therefore rely on eye movements to communicate and control their environment. Existing screen-based communication solutions require calibration, which limits functionality for the user.

The EyeControl is the first wearable, screenless, assistive communication device. AI-powered eye-tracking technology enables Locked-in individuals to communicate using only eye movements. Simple to use, the EyeControl improves quality of life for patients with MND, MS, Stroke and others, allowing them to communicate directly with medical staff and family.

With a growing base of global customers, the EyeControl is CE marked, FDA listed, ISO certified and, is included in the Israeli

“Health Basket” and the UK NHS Supply Chain. In 2019, first sales commenced in Israel and the UK, followed by the opening of a UK subsidiary and the onboarding of a local representative. The company soon plans to penetrate the US market, where the EyeControl device has already been granted Medicare/Medicaid reimbursement codes.

For individuals that possess cognition but lack the physical ability to articulate themselves verbally or otherwise, the EyeControl device has life-altering impact. From the most basic function of triggering the alert signal, to reopening paths of meaningful communication with loved ones and medical practitioners, the EyeControl is revolutionizing the assistive technology market.

Wearable: As a wearable, stand-alone device, the EyeControl provides a 24/7 communication solution, available immediately upon waking, while in the bathroom, in a car and/or outside. While the device can connect to third-party platforms via Bluetooth, there is no screen dependency nor any intrinsic need for calibration.

Personalized: The EyeControl is the first assistive communication device that enables personalization based on the user’s range of eye motion, even at advanced stages of movement deterioration. Cloud services facilitate remote access, including content editing and user preferences. Additionally, an individual can hear their own language and transmit in another language, allowing communication with international caregivers.



EyeControl co-founders: Or Retzkin, Itai Kornberg, & Shay Rishoni (1966-2018)



The EyeControl is a wearable, intuitive communication device that enables Locked-in individuals to express themselves.

Technology: EyeControl's technology is based on unique machine learning algorithms developed via extensive data collection of various eye sizes, shapes, and colors. This allows the device to work without calibration, as well as in a variety of indoor and outdoor settings. Additionally, because every user has varying limitations in their eye movements, EyeControl's technology was adapted for a range of up to five gestures (up, down, left, right, blink), or as few as one. This update is particularly relevant for individuals, who previously couldn't use screen-gazing devices for their communication needs. Finally, the unique interaction between eye movements and audio cues via bone conduction adds functionality.

User Experience: The EyeControl has an average training time of less than twenty minutes; the camera is positioned at nose level, allowing eye contact during communication. The device also grants users privacy, as the bone conduction unit transmits to the patient only before broadcasting the selected communication.

The EyeControl is an innovative communication solution for Locked-in patients suffering from MND, stroke, spinal injuries, or other neurological diseases; it becomes a natural extension of the user's body and relies solely on audio feedback.

The EyeControl is constantly undergoing evolution based on individual customer needs; product personalization plays a unique role in improving overall user experience. With the goal of making the device universally accessible, the company uses knowledge gained through working with patients as a catalyst for product updates and modifications. A

challenge for one individual ultimately manifests in increased EyeControl usability for the masses, empowering patients and restoring self-expression.

Improvements in device hardware are a basic example of product evolution deriving from a user's special needs. The EyeControl was originally developed with a left eye-tracking camera; subsequent to meeting individuals with limited left eye movement, who maintain right eye control, a mirrored model was created. Availability of both hardware options is also beneficial to users with unilateral hearing impairments.

Customization options offered via each user's personal web portal also evolved from customer needs. The EyeControl team recognized at an early stage that caregivers and loved ones need a mechanism for personalizing the device in order to encourage and enable user independence. Words and phrases specific to individual needs, speaker and headset volume, and device language can all be modified in a matter of clicks. Eye gestures, scanning speed and response times are also configured via the web portal.

Although the EyeControl is a stand-alone device, it became evident based on user feedback that it would be advantageous to pair the device with pre-existing third-party software platforms, which provide a visual basis for communication. In such cases, the EyeControl's eye-tracking technology functions as an access switch, not conditional upon screen positioning or calibration.

EyeControl continues to seek product feedback across the board from users, caregivers, families, and assistive

technology professionals. The company's first Continuing Professional Development (CPD) workshop was a huge success: nearly 30 Speech Language Pathologists, Occupational Therapists, Assistive Technology Experts, and Special Education Teachers had the opportunity to trial the device. As field professionals working with a variety of Locked-in patients, their advice and engagement plays an important role in improving user experience.

The EyeControl improves quality of life and restores the voice of a community that cannot speak for itself. The company is democratizing access to assistive technologies, making them easier to use, and providing extensive benefits to the Locked-in community.

*"Magnificent! The **EyeControl** gives hope! Often during transitional times, I get frustrated, because the existing media actually forces me to stay in bed. Even when I'm at home, I cannot move around freely without cutting off communication."*

*"It's incredible! So much independence! You can't even imagine how many possibilities the **EyeControl** has opened for me!"*

*"The **EyeControl** is a lifesaver, especially when I have urgent needs and am not in front of the computer."*

*"The **EyeControl** gives people like me, with MND, more independence."*



Scan to learn more about the EyeControl

Invite the EyeControl team for a product demonstration, patient assessment, or CPD workshop: hello@eyecontrol.co.il



Ryan Goodwin, EyeControl's UK Marketing Product Specialist

Cornwall AAC Assessment Team – Where Are We Now?

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Since the 'Hub and Spoke' model was introduced in 2014 as a framework for AAC services, Cornwall AAC Assessment Team (CAACAT) for paediatrics has developed considerably.

Who we are

The CAACAT now consists of: a 0.4FTE Specialist AAC Speech and Language Therapist funded by Cornwall Partnership NHS Foundation Trust, and 1FTE (job share) AAC Technical Officers funded by Cornwall Council.

There are also two developing Specialist Speech and Language Therapists (Cornwall Partnership NHS Foundation Trust).

The team have developed a good working relationship with many national AAC suppliers, through attending national training events and hosting supplier visits in Cornwall. Dame Hannah Rogers Trust, the local hub for complex assessments through BCAS (Bristol Communication Aid Service), also invite the team to training sessions, and link up for assessments, sharing knowledge and experience both informally and through the South West AAC Clinical Excellence Network.

Historical perspective

In 2009, an AAC assessment service was jointly commissioned for children up to the age of 18 by Cornwall Council and Cornwall Partnership NHS Foundation Trust. Since then, the AAC Assessment Team has gone through a series of changes

and developments. Through self-review with partners, assessment pathways have been reviewed and redesigned, staff have been upskilled and processes have been refined. As a result, the two year waiting list held in 2016 is now non-existent.

Many barriers mentioned in Alison Webb's article (published August 2012 in Communication Matters Journal) have now been rectified, supported and developed further.

Lack of time was highlighted; the service has since increased the amount of staffing time for the assessment process to 0.4 Specialist Speech and Language Therapist (previously 0.2), giving adequate time for the initial assessment period. Additionally, we have two Speech and Language Therapists with an interest in high-tech AAC in a developing AAC Specialist Speech and Language Therapist role. Although a voluntary role, it allows the Therapists to gain more knowledge and skills by working alongside the team and to gain access to training and skill development opportunities for one day a month. This is essential for future-proofing the local service.

In addition to this staffing, a 0.6FTE AAC Adviser post funded by Education has been created to support those young people using high-tech AAC to reach their educational potential within mainstream education. This countywide role provides Local Authority schools across Cornwall with tailored support for an individual's AAC educational needs after

the assessment period has completed and a device is on long-term loan to a young person, due to the situational changes that will impact the assessment trial.

The criteria for the referral process has been refined, in order to ensure referrals in to the assessment team are accurate, comprehensive and appropriate at that time. The assessment process will not take place during a period of significant transition for a young person.

Referral pathways have been developed and improved over time to ensure that each pupil is receiving the same service no matter when they were referred in (with the exception of those diagnosed with a degenerative condition). Pathways help utilise the time from the assessment team, as well as identify the best bespoke high-tech AAC package more quickly for the young person.

Previously, it had been difficult to work effectively within a multi-agency approach. Barriers identified in 2011 included difficulty sending emails and sharing files; however, systems now work very effectively, as files can be shared encrypted, everything is stored electronically and meetings are held at locations suitable for the young person and their team (usually the school setting). Cornwall's One Vision Partnership Plan (<https://www.cornwall.gov.uk/health-and-social-care/childrens-services/cornwall-childrens-trust/working-together/one-vision/>) is working with partners to increase the effectiveness of multi-agency working.

It was previously highlighted in the 2011 article that a lack of resources was a barrier to run the assessment team effectively. Now, Speech and Language Therapists have access to high-tech devices to trial basic AAC software, and there is administrator support for therapists to make low-tech AAC resources. This is aiding appropriate, timely referrals, as the pupil will have been exposed to low-tech AAC already before a high-tech referral. Health have funded the purchasing of some light-tech toys and resources that Speech and Language Therapists could loan and use with pupils. Education funds the high-tech AAC devices (for the 90% of young people who are not covered by NHS England). A bank of devices is available from a range of companies to trial with pupils and to use as emergency loan devices, so pupils will not be without a device if their needs repairing or replacing, ensuring a young person always has access to their voice.

Care pathways and processes

Since the initial CAACAT care pathways were established, we have revised our pathways to reflect the ever-changing nature of our service. We now have 5 main pathways (Local Community & Special School, Local Communication Support Service, NHS England, Degenerative Conditions and Out of County AAC Assessment pathways), to clarify processes and timescales according to the nature of the referral and who is involved in supporting the assessment alongside CAACAT.

We have worked hard to streamline the processes within our AAC assessments and involve young people as much as possible, obtaining their voice as part of their assessment. Initial referrals must be made by a Speech and Language Therapist (either NHS or Private), as they are involved alongside CAACAT throughout the assessment process. We now hold all initial casework meetings within the young person's educational setting. This is to ensure that the young person and the key people who will be supporting the trial are able to attend. We have developed a shared understanding of the expectations and responsibilities throughout the assessment process for all parties involved, which include the young person, their parents/carers, the Speech and Language Therapist, the educational setting, and any other professionals involved. A continuity in supporting the AAC user through transitions is highlighted during the casework meeting and throughout the trial.

Re-referral system

A pathway for re-referrals was developed to ensure any changes in a young person's communication development continued to be supported. Professionals involved are able to make a re-referral to the CAACAT team for a review of the high-tech AAC device. Some young people who were re-referred were found to need different software due to literacy development: the young person moved on from a symbol-based software package to a text-to-speech package. Other young people were re-referred and assessed as needing a change in device as improvements and developments in technology established more refined and appropriate devices for them.

Awareness of the pathways has enabled Speech and Language Therapists to identify which pathway is being used, whilst offering more transparency in what the criteria are for referrals, allowing more appropriate referrals and a higher success rate in their acceptance. The IPAACKS framework (Informing and Profiling Augmentative and Alternative Communication (AAC) Knowledge and Skills, NES Education For Scotland), is being used to support the developing AAC Specialist Speech and Language Therapists, as well as identifying areas in the team that may need to be developed in the future.

Training

There is an increasingly higher level of awareness and skills required by those supporting young people with communication needs. As a result, we have developed our training opportunities internally and externally, continually listening and evolving in response to feedback received, as well as linking with national research and resources. We promote the importance of empowering parents and schools of high-tech AAC users to support their children through training.

All members of the NHS Paediatric Speech and Language Therapy team have a local AAC induction when joining the service, covering CAACAT criteria & processes as well as locally supporting all areas of AAC development. Second opinions can be requested and the CAACAT are expected to attend annual AAC continued professional development updates, responding to service need and continually self-evaluating our own practice.

To support parents/carers, educational staff and other professionals, they are encouraged to access:

'AAC Steps' training - Aimed at parents and educational staff who are supporting a young person through their high-tech AAC assessment in Cornwall. We recently opened our East course to professionals in Devon as a traded service.

- 'AAC in Mainstream' course - Run annually for teaching staff who have AAC users in their mainstream school settings. The course covers target-setting, Phonics and Literacy development, assessing educational progress and adapting the curriculum. Immediate impact has been identified after participants have attended the course.
- 'AAC & Best Practice' - Requested by the Special School Academy Trust in Cornwall to meet their differing needs. This was a part-traded service.
- 'Cornwall AAC Roadshow'- Run annually for the past two years with the Adult Learning Disability Speech and Language Therapy team and national AAC suppliers to increase access to AAC across Cornwall for both adults and children and those supporting them.
- Cornwall Council AAC webpages - Information around the service provided as part of the Local Offer. Resources are available to download and use. We have had positive feedback from a range of people outside of Cornwall accessing this resource. www.cornwall.gov.uk/AAC

We also ensure that CAACAT members continue to develop their knowledge of developments and best practice surrounding all areas of AAC:

- At least one team member attends the Communication Matters (CM) Annual Conference and South West AAC Clinical Excellence Network.
- We arrange AAC supplier training locally.
- We continue to liaise and network with BCAS and Dame Hannah Rogers Trust.

Equipment management

Over the last two years, equipment management has developed and become more cost and time effective. Bulk ordering of some equipment, such as tablets, reduces costs and increases the stock available immediately, cutting the waiting time for

a device. The trial can usually begin 1-2 weeks after the casework meeting, a vast improvement from the previous 6-week wait.

Once a device is on loan, the Technical Officers are able to offer bespoke training for staff and families supporting the young person. This ensures they are confident and competent at editing, programming and backing-up the device.

The Technical Officers have a shared email, enabling any urgent issues to be dealt with efficiently, alongside IT technical support from an IT colleague within Cornwall Council for one day a week who is able to solve more complex IT problems. The Technical Officers are constantly developing their skills and learning new ways to fix common problems and identifying ways to prevent issues that arise. This may include sending out information around next steps to all users of a specific device when operating systems have updated and changed.

Secrets of success

Over the last few years we have informally identified that the most successful trials of high-tech equipment have been coupled with a high parental involvement. When a referral is made it is the responsibility of the referring Speech and Language Therapist to ensure parents are fully engaged with the process. Parents/carers are expected to attend all meetings and an agreement is signed between the team and the parents/carers at the first meeting where we discuss expectations

from both sides at each stage of the assessment process.

We strongly recommend parents/carers and educational staff attend our free two-day AAC Steps training, which originally evolved from the You Matter training (ACE Centre). This aims to up-skill parents/carers and educational staff on techniques to ensure high-tech AAC is successful. Parents/carers and staff have told us that the course has been invaluable to them, and they feel better able to support the young person.

We are committed to ensuring the child is at the centre of our involvement as the assessment team. The young person is involved in the assessment trial and their views are noted and acted on where possible, as referenced in the SEND Code of Practice (2015, page 20).

As CAACAT are a small team that covers a unique area of the UK, it is imperative to open communication across other services locally and nationally. We do this by being part of wider projects such as the AAC Exams Access Working Group (<https://sites.google.com/view/aacexamsaccess/home>), liaising with other local services at the CM Conference as well as working with those close to Cornwall.

Future service developments

Although the team and processes have evolved over the last few years, identified key development areas are:

- Provision for assessment of high-tech AAC needs beyond 18 years old

- An estimated increased future need for high-tech AAC devices. Equipment and device management is a time-consuming part of the Technical Officer's role and we need to research more effective ways of managing a large amount of equipment.
- Upskilling of the workforce surrounding high-tech AAC
- Exams access needs

References

- AAC Exams Access Working Group, <https://sites.google.com/view/aacexamsaccess/home>
- Department for Education, (2015). Special Educational Needs and Disability Code of Practice: 0 to 25 Years, Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf (Accessed: 01/02/2019)
- Webb, A., (2012). Starting From Scratch: Setting Up An AAC Assessment Service For Children In Cornwall, *Communication Matters Journal*, 26 (2), 43-45.
- You Matter, Ace Centre, www.acecentre.org.uk
- Cornwall AAC Team www.cornwall.gov.uk/AAC
- IPAACKS framework (Informing and Profiling Augmentative and Alternative Communication (AAC) Knowledge and Skills), NES Education for Scotland, [http://www.nes.scot.nhs.uk/education-and-training/by-discipline/allied-health-professions/augmentative-and-alternative-communication-\(aac\).aspx](http://www.nes.scot.nhs.uk/education-and-training/by-discipline/allied-health-professions/augmentative-and-alternative-communication-(aac).aspx)

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Creating Helps with Life

DAVE YOUNG, THE SHOUTING MUTE

Email: dave@theshoutingmute.com



The person who says, “you have dribble on your chin”.

The stares from passersby that make you feel like you’re an alien.

The kid asking perfectly fine questions, who gets quickly pulled away.

The embarrassing drunk person lap-dancing on you, a bit hard to say go away but you really want to.

The three steps up into the pub.

The computer freezing when you have a very important point to make.

These are the things that disabled people go through regularly; these are the things that have an effect. They play on our minds. These are the things that affect our ability to be ourselves in the moment. Sometimes they come when we are experiencing a high moment. These things pull us back down to earth and remind us of our difference.

At least 30% of physically disabled people experience a mental health problem. This is no shock to me. Disabled adults are also the least likely to be regularly involved in arts and creativity.

I believe that art and creativity can support people to explore inner feelings. The arts allow us to go beyond words and to explore the issues in our lives. In that space we are allowed to create and express our own selves and our feelings. The arts help us to build views and opinions and give us the confidence to ‘speak’ up.

As you get older you naturally have more worries. Your dreams and anxieties grow as you begin to look for more out of life.

When disabled people grow up we have additional things to think about: money, work, our personal care and support, and living arrangements, to name just a few. As we grow up, we become more aware of our systematic exclusion, and our social isolation grows when we leave education.

Creativity can support relaxation and allows us to dream and create the world we want to live in. Through the arts we can manifest a fantastic life for ourselves now and in the future.

Live art events bring us into the community, even for a short while, and help us to feel included as we occupy space with others.

Arts can settle the crying and shout about the dreams.

We need creativity to imagine our dreams and communicate them. Creativity goes way beyond words. It helps us work with the feelings that we don’t recognise.

Creativity should become an essential in our lives. It needs to be given the same status as physiotherapy and wheelchair maintenance. The creative arts are maintenance for our minds and our souls.

When I am depressed I write for hours. When that depression goes then I can take some of the writing and use it in my work, in a poem or a play. Writing helps me to make sense of the things that are happening to me. Writing and creativity provides me with a space that is just mine. It’s a quiet space in my head where I can work through the very real things that are happening in my life.

For example, I have a series of writings about relationships, partners, and marriage, and some of that has been turned into a play. My chocolate poem is about my joy of eating. It was a response to discussions with doctors, about the possible need for a PEG in the future. Creativity won’t necessarily change the course of the future although, for me, it has become a career. I feel like I am able to express and work through my feelings through my creativity.

Turn your life around.

Turn your life on its head.

Express your feelings and create dreams out of them.

Create, Dream, Shout.

Dave Young is known in the theatre and creative world as The Shouting Mute. He is a writer, theatre-maker, performance artist, workshop facilitator and board member for Diverse City, as well as winner of the Alan Martin Award for his Contribution to Creative Arts, leading writing workshops at the 1Voice annual conferences for communication aid users. Visit him online for more info about his past, present and future projects.

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