Communication Matters

AUGUST 2018 VOLUME 32 NUMBER 2

THE JOURNAL OF COMMUNICATION MATTERS / ISAAC (UK)

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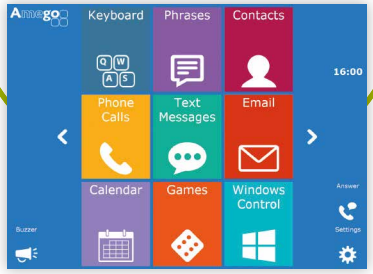

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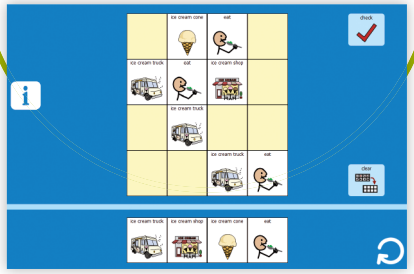

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COMMUNICATION MATTERS JOURNAL
VOLUME 32 NUMBER 2
AUGUST 2018

Contents

Toby Hewson (Co-Chair of Communication Matters) and Harriet Boatwright (representing MEETinLEEDS) at the Conference 2018 Awards collecting our award for Best Partnership or Collaboration.

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Co-chairs' Report

Toby Hewson & Ruth McMorran

Hello everyone! I hope you are all enjoying this lovely weather, at the time of writing we are in the middle of a heat wave, although probably by the time of reading it will be back to our normal summer weather of RAIN!

I want to start this off by saying a big 'WELL DONE' and 'CONGRATULATIONS' to Lee Ridley. I hope you all managed to see and vote for Lee (aka Lost Voice Guy) on 'Britain's Got Talent.' He was his usual brilliant self and thoroughly deserved to be the winner. This was also great for Communication Matters because, for those of you who didn't realize, Lee is a patron of our charity. Again, congratulations Lee and we look forward to seeing you at 'The Royal Variety Performance' in November.

Congratulations also go to Martin Pistorius, he too is a CM Patron. In June, Martin was awarded an honorary doctoral degree by the University of Dundee.

A big 'Thank You' must go to CM Trustee Amy Hanschell from Dundee and some of the team from Smartbox for their brilliant fund raising for Communication Matters. Amy completed the Edinburgh Marathon (on a very hot day!) while the Smartbox team ran the Bristol 10K. Between them they raised over a thousand pounds. We love people fundraising for us – this money will help provided subsidized places for AAC Users to attend conference.

On June 29th I represented Communication Matters and Harriet Boatwright represented MEETinLEEDS from the University of Leeds at the Conference Awards 2018 Lunch. This was held at City Central at the HAC, within the grounds of the Honourable Artillery Company, against the stunning backdrop of the historic Armoury House.

We were one of the finalists in the 'Best Partnership or Collaboration' category and we were up against seven other conferences from all over the world, some were very large corporations with over 4000 delegates at their conferences. We arrived to a drinks and nibbles reception in what can only be described as a football pitch sized marquee. We then enjoyed a beautiful 3 course lunch followed by the Awards ceremony. Our category was called 3rd and guess what, WE WON!!! Harriet and I went up on stage for the presentation and had our photos taken, which can be seen on the conference awards web site. We were then taken away to be interviewed which, I believe, will also be shown on the website for anyone who is interested. We just want to say really well done to everyone at Communication Matters and The MEETinLEEDS team.

Ruth and I are now quickly approaching our last year as Co-Chairs and are on the lookout for someone or ones to take our place. So, if you are interested in becoming a CM Trustee, or even in the future a Chair or Co-Chair now is the time to respond to the 'Call for Trustees' which you'll find in the Friday Announcements and on the CM Website.

The Trustees are looking forward to seeing as many of you as possible at Conference in September!

CM News

AACknowledge Entries

(April 2018)

From Judith Chapman, MMU

Our AACknowledge online evidence base presents information in a variety of accessible formats to help anyone who needs access to up to date information on best practice, services, case stories and research.

Recent Bibliography Entries

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Filling the Gaps

Supporting AAC spoke services through provision of Augmentative & Alternative Communication (AAC) equipment and training

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Introduction

The Kent and Medway Communication and Assistive Technology (KM CAT) Service is an AAC hub. The service is comprised of a dedicated multidisciplinary team who carry out specialist AAC assessments to identify suitable communication aids for adults. We work closely with the local spoke services, as per the Hub and Spoke model of AAC provision. Mostly, we are joint working with speech and language therapists, speech and language therapy practitioners and occupational therapists.

In addition to specialist AAC assessment, we offer a provision-only service which is available to therapists whose clients are registered to a GP in East Kent or Swale. To access this service, the therapists need to have completed an AAC assessment with the client and identified the appropriate communication aid. The KM CAT service is then able to provide the equipment. It is the responsibility of the therapists to provide support, training and ongoing review of their clients. Generally, the provision-only service is suitable for clients who have less physical and sensory disabilities etc., opposed to those who require specialist assessment. KM CAT also offer a consultation service which give therapists AAC guidance and advice to help them proceed with their clients. Therefore, it is mostly during the specialist AAC assessments that the KM CAT team see clients who require AAC, and these clients have the most complex communication needs. Regarding the AAC Hub and Spoke model, NHS England has anticipated that the needs of 10% of the people who require AAC is met through the specialist AAC hubs, and the spoke services should meet the remaining 90%.

Anecdotal evidence showed us that in many cases, the spoke services that we were jointly working with had inadequate AAC equipment, software, and resources, which hindered their initial AAC assessments and intervention. The KM CAT team were also acutely aware that the therapists were disadvantaged regarding development of their AAC skills, due to the lack of access to an array of AAC equipment and resources. The spoke services have a duty to carry out preliminary assessments to establish whether their clients meet the criteria for a specialist AAC assessment. Therefore, they require the tools and skills to do this. To bridge the gap, further support for the spoke services was offered, which was anticipated to be beneficial for clients needing AAC. Since July 2016 the KM CAT service has provided 6 AAC cluster boxes and training to the local spoke services.

AAC Cluster Boxes

Each of the cluster boxes contain a range of routinely used communication aids, the provision of which does not require the input and assessment of a specialist team e.g. low tech AAC; Frenchay Alphabet Boards and E-Tran frames. Battery operated aids e.g. Go Talk 9 and a talking photo albums. Each team also had access to one of each of the following electronic aids; Lightwriter, Allora, iPad, iPod and an android device. The Frenchay Screening Tool for AAC and Test of Aided Communication Symbol Performance (TASP) were included to guide AAC assessments. Therapists were given Matrix Maker software to help them make their own symbol based communication pages/books. A range of photo, symbol and text based apps were provided and a selection of wired and wireless voice amplifiers.

Clients have the opportunity to trial the AAC equipment from the cluster boxes for two weeks or more. This gives the therapists a chance to evaluate whether the AAC system is suitable for their clients and for the clients to make an informed decision about whether they feel it is right for them. Once the therapist has identified which communication aid/app etc., is the best match for their client, the therapist can request provision (long term loan) of the aid/app from KM CAT service (clients in East Kent & Swale). The therapists review whether the communication aid continues to meet the client's needs. Regarding clients in west Kent who do not meet the criteria for our provision–only service, the therapists can still use the cluster box contents to assess their client and apply for funding or seek

help from a charity, armed with good assessment evidence that a suitable communication system has been identified. In other cases, following use of the cluster box equipment, therapists may identify that their client meets the criteria for specialist AAC assessment. The therapist will be able to provide KM CAT service with invaluable referral information, speeding up the process of identifying suitable AAC.

The cluster boxes also contain information on how to manage the equipment, such as, how to book equipment in and out, how to adhere to decontamination processes to keep the AAC equipment clean etc. Each team has their own designated administrator who manages the process and checks that all equipment is logged in and out properly. Therapists are able to go to another cluster box location if they need an item which is not readily available in the cluster box closest to them.

AAC Training

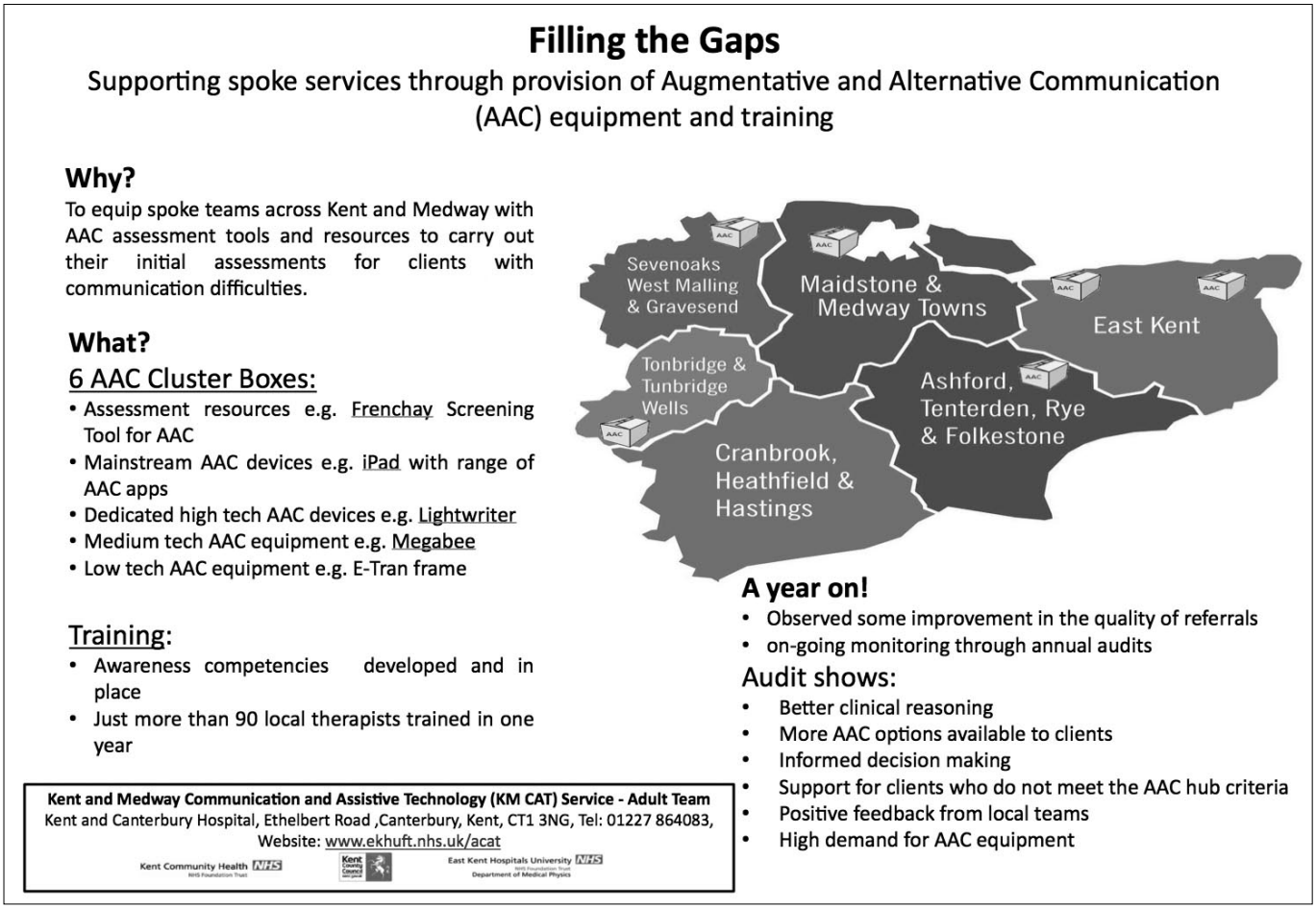
The spoke teams in Kent and Medway have a variety of AAC experience, knowledge and skills. Over the years the KM CAT service has endeavoured to provide as much support as possible to speech and language therapists and occupational therapists who work with clients who need AAC. As an AAC hub, the KM CAT service has the advantage of access to an array of equipment, tools and resources and regular AAC training to keep us abreast of developments in new technology and software. Therefore, it made sense for us to train the therapists on delivery of the cluster box equipment.

The aim of the training was to help raise awareness of the different types of AAC apps and AAC equipment, for example, many speech and language therapists have experience of using a Lightwriter but some therapists have not used an Allora, these are both text based systems. Training also covered general guidance on where to start with AAC, and key areas e.g., text, symbol and photo based AAC systems. The training compared and contrasted the different AAC systems, including AAC apps. It has been acknowledged by our team that therapists will sometimes need support finding a suitable app for their clients, as matching an app to a client's needs can be a challenging and lengthy process even for an experienced AAC speech and language therapist. Training also paid attention to the key areas to consider; language, literacy, cognition, sensory, physical ability (access) when thinking about AAC selection. As each therapist progressed through the training, he/she signed the specific AAC 'awareness competency' box.

During the training it became evident that some therapists were seeing some of the communication aids and apps for the first time. Therefore, it was an important aspect of the training to advise that therapists try to find time after the training to learn more about the communication aids and assessments, now that they have access to them. We acknowledged that the AAC training was not comprehensive. Therefore, therapists were encouraged to make contact with us if they needed any further help.

Measuring the Process

The KM CAT service conducted an initial audit using cluster box data for the period of July 2016 until February 2017. A second audit has been started and some early findings are included here. The aims were to investigate whether the AAC equipment and resources were being used and to glean feedback from the local



teams on how the process was working. Furthermore, to identify any issues early on and to try and address these. The data from the log sheets were analysed and qualitative information collected, as all the teams had been emailed and were asked specific questions e.g. was the desired equipment available each time? It was also decided to analyse information from 35 provision–only referrals (July 2016 to Jan 2017) to find out whether the use of the cluster boxes was having any impact on clinical reasoning. Thus, how did the therapist come to a decision about the communication aid/app they were asking for? Did the cluster box contents and training appear to help?

Issues were identified early on in the process whereby one team was understaffed and had little opportunity to use the cluster box. Some therapists stated that collecting equipment from the nearest cluster box location was not always easy regarding the distance and their time. One administrator said that keeping an accurate log of equipment coming in and out could be difficult; with therapists coming and going. Other teams were managing.

Overall, feedback from the teams was positive. Some therapists stated that they did not need to wait very long, or at all, for a specific communication aid to be available in the box, whilst others did have to wait. The iPads (with selection of AAC apps) and the voice amplifiers were the most used pieces of equipment, and the Lightwriters also proved to be popular. The frequency of use of these items varied across teams. The AAC assessment/screening tools, battery operated AAC and low tech (e.g Etran frame) were rarely used by any of the teams.

Therapists stated that they were finding the cluster boxes useful. Therapists were using the cluster boxes during their AAC assessments and have provided good and excellent detailed clinical reasoning when requesting a specific communication aid from the service. Referral information showed that therapists were trialling more than one AAC system with their clients and clients were able to make an informed decision. Examples taken from referral information:

The client trialled two text based apps and expressed a preference.

West Kent team: The client has purchased the voice amplifier he trialled.

Use of the Frenchay AAC Screening Tool: went well and helped me in assessment-will now create a communication book for a patient

In some cases there has been some confusion with regards to the therapist's referrals for AAC apps. We believe that this is possibly due to the client not having enough time to trial the app/s (is it suitable for them?) and /or some therapists needing further AAC training. The AAC assessment/screening tools are rarely used. This could be due to therapists using their own formal/informal assessments. Some therapists who had not previously used the Allora device have now had experience in their AAC assessments and therefore they are developing their AAC knowledge. The use and underuse of equipment is affected by many factors, such as, the type of clients on the caseload at the time and also the fact that some therapists may already have access to their team's existing equipment e.g. Etran-frame.

Since the audit, in response to feedback, each cluster box has been given another iPad and more voice amplifiers in order to reduce waiting times.

Although there have been and still are limitations e.g. the cluster boxes are not always easily accessible for busy therapists and there is a limited amount of AAC equipment, it has been an encouraging start. The spoke services have access to much needed AAC equipment and the KM CAT service and spoke teams are working together to make positive changes in AAC intervention.

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Creating a Comprehensive Communication Classroom

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Given the advancements in and increased access to tablet technology, a wide variety of AAC solutions are available. Although hardware and software are ever changing, the need for quality therapeutic support remains constant. It is important to include essential therapeutic supports topromote language acquisition and effective communication with AAC. It is important to include all of a child's learning environments in the plan, including home and school. By using the Language Monitor built into many devices, you are now able to develop a full therapeutic plan for a classroom including the teacher, speech therapist, and classroom assistants, as well as parents and friends at school. It is possible that many of the verbal students in the classroom can benefit from the implementation methods that are put in place and increase their literacy and writing skills.

In thinking about the practice of AAC, it is common to consider hardware, software, and support.

Each area requires special attention in order to foster effective and efficient communication via AAC. Appropriate hardware decisions need to be made to meet the access needs of the client.

Similarly, communication software needs to be equally scrutinized to ensure it will meet the linguistic needs of the individual, not only for today, but for many years to come. It should be grounded in what we know about vocabulary and language development. Last, but certainly not least, the support of the AAC system needs to be planned and executed to help the individual using AAC find success.

AAC support includes training in the operations as well as language structure of the AAC system, clearly defined goals, an intervention plan, therapy and therapeutic supports to fulfill the intervention plan and reach goals, and professional development to advance knowledge related to the practice of AAC and tools to document progress. If you focus on these supports, the success of the student will improve drastically. The case study of a classroom at Sweetwater Elementary School will be discussed. We looked at the supports in both the school and home environment, what techniques were implemented, and how these were determined based on LAM data from all AAC devices. We looked at how these services can be utilised to promote best practice when supporting an AAC system.

Drager, Light, and McNaughton (2010) propose eight areas of considerable developmental risk for those with complex communication needs; (a) functional communication skills, (b) speech development, (c) language development, (d) cognitive/conceptual development, (e) literacy development, (f) social participation, (g) access to education, and (h) overall quality of life. Well informed AAC supports and intervention may promote development in these areas for many individuals.

Additionally, Binger and Walsh, 2011, write, "…recent publications of the writings of people who use AAC clearly indicate that mastery of grammar is possible for some individuals (e.g. Fried-Oken and Bersani, 2000). However, there is no doubt that attaining grammar is a struggle for many individuals who require AAC." Given this, individuals using AAC can benefit from language therapy. With language therapy, individuals can learn new vocabulary, morphology and syntax.

Language learning allows individuals to be more clear, precise, and/or complex when communicating. Providing AAC language intervention requires training in the language organisation of the AAC system, therapeutic techniques and supports, as well as progress monitoring.

Strategies can be provided on how the entire team can work on specific goals based on the developmental stages of language development. Data can be taken directly from students' devices to determine whether or not there was carry through on the skills that were introduced. This information paired with observation, input from communication partners, social/geographical context, and other communication modalities were used to help determine current level of functioning, as well as provide insight into where to go next. A social circle can also be formed with the intent for the student's peers to also play a part in reaching some of the educational and social goals.

When a student is introduced to AAC in the classroom, it is easily possible to incorporate language learning and social communication in the classroom using the existing curriculum. It is important to include all staff in training to ensure the most success.

RELATED RESEARCH

Drager, Light and McNaughton, 2010, purpose 8 areas of considerable developmental risk for those with complex communication needs: A. functional communication skills, B. speech development, C. language development, D. cognitive/conceptual development, E. literacy development, F. social participation, G. access to education, and H. overall quality of life. Well informed AAC supports and intervention may promote development in these areas for many individuals. Additionally, Binger and Walsh, 2011, write, "…recent publications of the writings of people who's AAC clearly indicate that mastery of grammar is possible for some individuals. (e.g. Fried-Oken and Bersani, 2000) However, there is no doubt that attaining grammar is a struggle for many individuals who require AAC."

Developing a novel system to support language acquisition in children with CCN: An ethnographic study

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Background

This article describes an ethnographic study undertaken by the AAC Research Group at the University of Dundee as part of a PhD project. Here we undertake preliminary work to explore a proposed technical innovation in augmentative and alternative communication (AAC) - the broad field of communication systems and techniques that seeks to assist people with little or no functional speech - aiming to address a fundamental barrier to successful outcomes in language acquisition and literacy for emerging communicators.

Communication aids designed for use by young, and therefore pre- or non-literate, children, are typically based on a word phrase retrieval system using a grid-based symbol access paradigm. In such systems, access to vocabulary is commonly presented through discrete symbol labels. Unfortunately, such an approach may not best support the needs of these emerging communicators (Higginbotham et al, 2007; Light & Drager, 2007). Are such systems' user interfaces in fact a barrier to technology uptake during a critical developmental phase for this particular user group? Prior research reveals compelling evidence that early intervention (EI) is key to the attainment of optimally beneficial outcomes for children with complex communication needs (CCN) (Odom et al, 2003), but for some EI may be impacted by access that does not accommodate their particular needs effectively.

To investigate a solution for this problem we proposed applying a strictly user-centred design (UCD) approach to build and test the efficacy of a mobile device with a more user-friendly interface for this group of emergent communicators; one that would enable its users to experiment with utterances and explore - and update their device's vocabulary to reflect - the lexicon of their surroundings autonomously.

The Ethnographic Study

As a first phase of the research the ethnographic study described in this article was carried out over the course of three months in the autumn of 2017. Its aims were to collect and analyse data on the means and efficacy of current practices in a participating special educational needs and disabilities (SEND) school to gain a comprehensive understanding of the domain in order to support subsequent engineering and research phases.

Historically UCD has been seen to be problematic with children with CCN, and perhaps under-utilised with this group as a result. A key strength of this overarching project would be to provide evidence of the feasibility and benefits of working closely with children in a SEND school. Thus, one envisaged output of this work was to generate guidelines for UCD collaborative work with children with complex disabilities; and another was to identify suitable participants for the subsequent user-centred engineering phase. Finally, it was hoped to establish which AAC strategies, technologies and/or techniques are currently being utilised within a representative SEND context.

Data Collection

The methods used for the study were a mix of participant observation, field notes, and audio-recorded semi-structured interviews with staff and parents. The researcher observed the children and staff during their day at school, using ethnographic tools such as still photography to document artefacts (Figure 1), and journal notes to record activities related to vocabulary acquisition and the support of literacy skills, identifying any assistive technologies utilised, and instruments used, especially in support of teaching.

Participants

Participants were a mix of adult stakeholders (special education teachers, communication disorder professionals, learning & care assistants, parents) but clearly also included vulnerable group(s) - pupils attending the school - with a diverse range of ages, and of cognitive, developmental and/or physical disabilities. As such, a number of consent forms were prepared, tailored appropriately to be accessible for their respective recipients, and ethics approval was sought from the University of Dundee, whose code of practice for non-clinical research ethics on human participants was strictly adhered to in order to minimise any risk to those involved.

Analysis

Thirteen interviews with adult participants were held (SLTs (n = 3), teachers (n = 5), LCAs (n = 3), parents (n = 2) with a mean duration of 48 minutes (max

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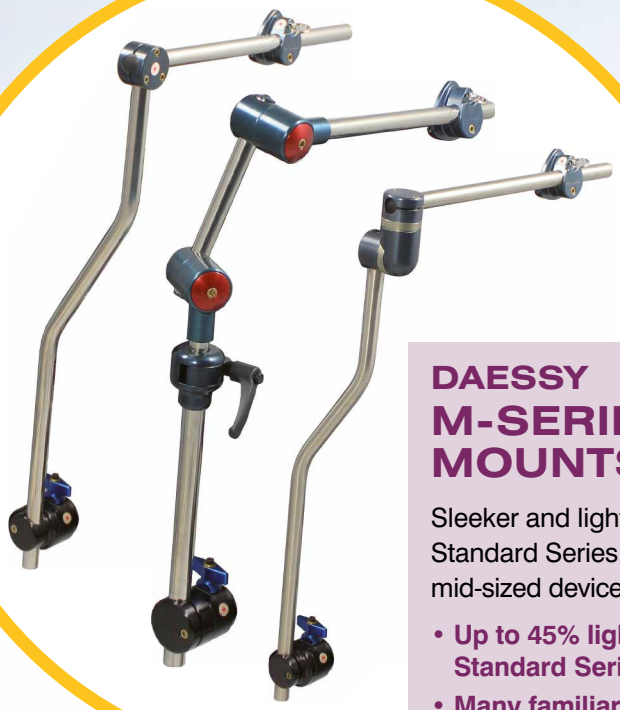

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Figure 1

53 mins, min 31). A thematic analysis - currently ongoing - was to be carried out on transcriptions made from these interviews, and the field notes ensuing from the data collection phase, using the approach recommended by Braun and Clarke (2006).

Results

As a contemporaneous project with active analysis ongoing, literature review and early observations revealed:

- A variety of assessment tools in use generally (VB-Mapp, Vineland II, ASRS, PPVT 4, CELF, BPVS etc) – and at the current partner school (Roots for Learning, PVCS, Derbyshire Language Scheme).
- A range of unaided, aided, low and high tech AAC tools and strategies in use (PECS, Makaton, Canaan Barrie (Figure 2), Objects of Reference, E-tran frames, Talking Mats, communication passports; and single switches, eye gaze access, interactive plasma screens (Figure 3), auditory scanning, Proloquo2Go, Tobii Dynavox Communicator & Snap Scene, GoTalk VOCAs).
- A number of intervention strategies used by prior researchers (systematic instruction and contingent reinforcement (Ganz et al, 2014); the provision of certificates of participation as a tangible reward (Menzies, 2013); use of singing, colours, storytelling, tactile play, to enhance engagement and reinforce learning).
- Practical solutions for the curation of artefacts in a relatively chaotic or "hostile" environment (for sensitive electronic recording equipment and paper documents vulnerable to damage) including introducing tech gradually for familiarisation, and delaying physical capture of data and artefacts until participants have vacated the room.

What has also emerged however, through the work-in-progress of the thematic analysis of our collected data, is a whole range of other issues that may be contributing to the lack of progress we perceive in the uptake of technology in this domain, despite the best efforts of educational practitioners and AAC developers in the field.

Conclusion

At the time of writing, we are not in a position to confidently share the multifaceted outputs of our research to date. What the data is saying to us is that there remain barriers that prevent the power of technology from being effectively harnessed in this domain as well as it might be; and in the spirit of conscientious research, having teased out these unexpected themes, the focus of our work may now be changing as we regroup to reflect upon our discoveries - and how we might contribute to improving the situation. We look forward to having more to report on the direction of this research later this year.

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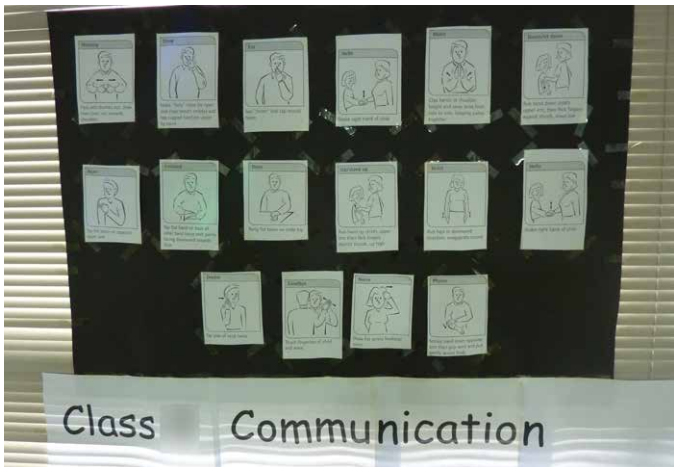

Figure 2

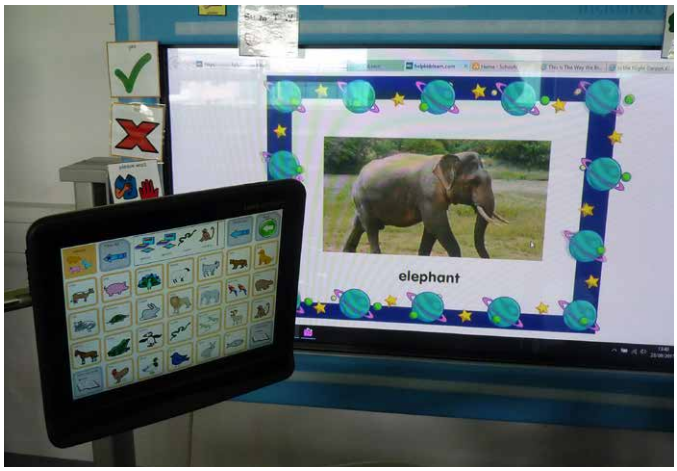

Figure 3

Is AAC really Sugar Free?

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I initially had this idea of writing about this topic as I went for a health appointment, I was quite surprised when the Doctor talked to my Care Enabler as if I am in the third person, and not in the first person; instead of having no pre-conceived ideas about who they are meeting. Therefore, speak to me directly, as their patient. Thus, I came up with the title, and I asked my friend, Simon Stevens, to assist me to write it, to explore the phrase, is AAC sugar free?

Even though I have my Eyegaze, at the first appointment I had with my new chair, when I went to Selly Oak, I was asked if I knew what was going to happen. Then for half of the appointment I was talked to like a 5-year-old boy. The situation really annoyed me, so my sarcastic part of my nature comes out. Immediately, I said some sarcastic answers, they soon changed and started to talk normally. This reaction isn't unusual, but why, seeing as they deal with complex disabilities regularly? We'll try to explore this and suggest some of the ways this may change.

The Core Issue

The title, is a play on, does he take sugar. It's still very much alive and prevalent in every walk of my life. When I go to health appointments, they should have no pre-conceived ideas about who is coming in, instead of seeing me as the third person.

There's no specific thing relating to the third person, in this context, I've come up with the 'Sugar-Free' Syndrome, it's the able-bodied person scared of encountering a severely disabled person, yet alone, an AAC User. The term 'does he take sugar?' has been an urban myth within the disability field, since I can remember and was the title of a BBC Radio 4 programme on disability.

From the able-bodied person's perspective, the presumed fear of meeting a person who's different from the social norms they are used to. They'll subconsciously speak to the Care Enabler, instead of stopping to take stock of the situation. This concept is, we named as, the fear of 'otherness', the subconsciously speaking as the AAC User is not in the room, ie, the 'third person'.

People could say, they don't know how to react to a nonverbal disabled person, I would say that healthcare professionals are the worst group for just assuming there's a practical difficulty when it's only perceived. They may also assume I have a learning disability.

We all have expectations of everybody we meet, being socially uniform, to fit inside our preconceived constructs. as everyone knows, this isn't the case. These pre-conceived constructions are extremely difficult to overcome.

The disabled person often seen as the third person, in the existing carer/cared for a socially constructed relationship, where someone requires an informal carer to represent them. This assumption has taken over from the assumption that a family member, seen in that role as mother/brother, is their representative. The notion that someone with a severe impairment can be their representative themselves, with the support of a personal assistant, is a new one for many professionals.

Within saying the above, obviously the AAC User is in the room so the only coping mechanism that the non-disabled person has, it would seem, is to crouch down and start talking as if we have no comprehension of English and thus patronise, but not deliberately, and this happens whether I find I have my Eyegaze on or not.

By taking the premise of the fear of the unknown forward, may technically explain why people subconsciously adopt the baby talk attitude, to the non verbal, disabled person, whether or not they have an AAC device in front of them. The fear created by the situation gives the AAC user a degree of power in the relationship, which the professionals attempt to regain unconsciously through patronising behaviour,

A classic behaviour that Health Professionals adopt on first meeting with me, is to talk slowly and very loudly, as if I am deaf or to undermine my intelligence, instead of doing the actual reverse. They should have no preconceptions of a person's disability at the start of the appointment and make an assessment, based on the initial meeting. This is often an unconscious response to the new situation, which the Health Professional finds themselves in. I find both is a multigeneration response, however, the younger Health Professionals are better for treating me, as an AAC user, because probably they have had a brief training period.

The fear of the unknown could be the seen as a defence mechanism for the

embarrassment of the Health Professional towards the AAC user. The artificial construct of the AAC user is based on stereotyping and appearance, this is very slowly breaking down, as more people with disabilities and AAC users are becoming more in the public perception, and hopefully, their construct will change.

Going Deeper

If we explore the relationships within this specific interaction further from a psychological and sociological perspective, we can see a number of things happening that are beyond the control of the doctor or myself, therefore reducing any notion of blame. To understand the situation, we need to understand some of how disability is constructed beyond the social model.

If we assume that impairment is the biological differences that have always existed, disability is a number of social constructions of how individuals and society respond to people with impairments. While the main construction we understand is about the construction of the built environment, the one we're most interested in here is how disability is used as a fear to control social behaviour.

People fear becoming impaired or more impaired because having a disability has been constructed as not being fully whole, a lack of complete personhood comparable to death that reduces what society believe they can be expected of achieving. This fear has wide ranging practical usage in the control of people's behaviour at a societal level because our fear of becoming impaired or dying will motivate us to comply with safety laws and guidance like wearing seat belts.

The fear is reinforced by the security brought by the notion of otherness. In order to define any majority or therefore the normal, you must define the abnormal. In order to understand what's good, it can only be defined by understanding what is bad, which is easier to identify. Understanding nobody is without some level of impairment, disability had to be defined as a form of stigma to create 'non-disabled' people, causing otherness.

These concepts explain the context in which the interaction between the doctor and myself exists; it only goes part of the way of explaining it. Improvements in the built environment, attitudes and inclusion in society means, people are more comfortable with people with impairments than they used to. This is however not universal across all the different impairment groups as some people with impairments are regarded as more socially acceptable than others. Significant cerebral palsy or similar impairments, especially when someone has a speech impairment or no speech, is still very uncomfortable for many non-disabled people to interact with for a number of reasons.

One reason is that the spasms and other involuntary movements, additionally any speech difficulties, subvert the normal body language and social cues that people generally use when interacting with each other. This means that while I'm intellectually and practically able to communicate with others in words and language, the differences in my body language is something most people are unfamiliar with to a point where it enters the realms of freakism.

Another reason is my reliance on people to support myself to get to the meeting place and to be present while I am communicating with the doctor. The care enabler's presence in the room confuses the doctor regarding who is the lead communicator and so responsible adult, as the assumption is that my level of impairment means I must be 'looked after' as I am unable to make decisions unaided, which I certainly can!

The second reason is that because my communication methods are unfamiliar to the doctor, and they may fear embarrassment if they try and fail to communicate with me, they're likely to prefer to communicate with my care enabler's because they can relate to them and therefore would find it easier, so appear to ignore me, pushing me to become the third person.

It's clear that my communication method provides me with the upper hand in terms of the power dimensions between myself and the doctor. Besides my emotion based noises that occur outside social norms, one core reason for this is the silence that exists when I'm preparing a sentence to speak out. Because I use an Eyegaze, that is a subtle input device, it's unclear to those new to my communication method as to if I'm reacting to what they are saying at all. These periods of silence are awkward to the normal flow of conversation and therefore puts the doctor in an unusual disempowered position.

In order to reclaim the power balance, the doctor is then likely to unconsciously try to regain control of a situation they're uncomfortable with. This could come in the form of attempting to engage with my care enabler or to make patronising comments. While the doctor may consciously not assume I lack intelligence, their fear of the situation and the context of otherness may result in poorly prepared comments aimed at undermining my intellectual ability and, to their mind, restoring the social order between patient and doctor.

Patronising comments from the doctor to undermine my intelligence will ironically lead me to question their intelligence and treat them with less trust as I feel I have to make extra effort to prove my intelligence from a defensive position, besides achieving the outcomes I require from the conversation. To make matters worse, the more I'm patronised, the more I become annoyed, which becomes involuntarily visible in my body language, which unnerves the doctor, causing them to be more patronising.

Coping strategies

In order to tackle the relationship difficulties that my communication method brings, I've needed to learn a number of coping strategies to improve the situation and ensure those I wish to communicate with are supported to listen to me.

The first issue to overcome is when people assume I lack intelligence. I've naturally learnt that sarcasm is the best way to demonstrate my intelligence. If someone has made their mind up that I've learning difficulties, I state I went to university, it's simply a phrase I have been taught to say, and university should be a polite way of saying day centre I've been taught to boost my ego. Telling a standard joke may seem clever, but again, it can be learnt without understanding.

Sarcasm, the ability to make a successfully humorous insult based on that specific situation and context, requires great intelligence. It also breaks any illusion that I may be in a vulnerable situation and demands equality with the people I'm communicating with. It can be a useful shock to the system for the listener, who won't be expecting to be insulted clearly by someone they had perceived to lack any ability to meaningful communication, therefore jumpstarting the conversation.

In the last 12 months, I've started to have an introduction card to provide professionals I'm communicating with to introduce myself and my communication method. I believe it's better to have this

in written form so people can digest it in their own time and ask questions. Having it as a prepared speech on my communication aid can come across as monotone and too much information for someone to process at some.

A long-term solution would be to provide training for healthcare and other professionals on how to communicate with people using a wide range of methods, which is about techniques like patience and asking closed questions when appropriate.

Summary

In summarising our paper, we've shown how the relationship and interaction between myself and health professionals occur at a psychological and sociological level. I believe it highlights the limitations of current AAC technology in overcoming these informal barriers to socially normal interaction.

While I've acknowledged there the interactional barriers aren't the fault of either party, this ignorance of the situation should not be an excuse for healthcare professionals not to improve the efforts to acknowledge and assume the intelligence of all users, and communicate accordingly. I've a responsibility to ease the situation, which can be achieved by preparing an introduction cards to my communication methods.

In making recommendations, I would argue that healthcare professionals should be trained, about a variety of impairment needs and especially that the non-verbal patients do have a brain. I also further believe this is an area that could warrant observational research and it's interesting to note it has not been a priority previously.

In answering the question to whether AAC is really sugar free, that it provides users opportunities to full and equal socially normal conversation without psychological and sociological barriers, I believe I can conclude there is still a long way to go.

Appendix: Introduction card

My name is Patrick Bates, I am 49 years of age. I have Cerebral Palsy, Quadriplegia. I use a wheelchair, and have no verbal communication. Although I have physical disability, I do not have any learning difficulties, so please talk to me normally. I use an Eyegaze, communication device, which is in front of me. I am quite slow at typing, so please be patient.

Using Data Visualization to Support Bilingual AAC Use

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Abstract

Some AAC devices can collect client-generated language and using such data can help inform decisions about intervention. The authors have developed an online tool that can turn the raw numerical data from some devices and apps into more intuitive graphic representations. The system was initially designed to analyse English but has been extended to work with German, and a Spanish version is in development. In this paper, the authors will briefly present the underpinnings of the online analysis tool and demonstrate how it can be used by parents and professionals to work closely on developing and tracking intervention plans in different languages. Examples from a German/English bilingual speaker will be included.

Automated Data Logging: Values and Limitations

Automated Data Logging (ADL) is a feature of some voice output communication aids. Such data can be useful in providing clinicians with information on how a client is using a device and, more importantly, how well that client is using it to communicate effectively. However, there are limitations to the data, which include;

a. Absence of input from communication partners
b. Absence of any multi-modal elements
c. Absence of social/geographical context
d. The need to mark explicitly if someone else is using the device for modeling/teaching

Given that these limitations are recognised, it is still possible to use the information in a fruitful and constructive way. For example, one simple measure of AAC use is to count words used, which can give an idea of an individual's knowledge of the lexicon available to them in their AAC system. Another is to measure the time period between linguistic events so as to get an idea of communication rate. A third is to look at the type of words being used and determine the spread of different parts of speech.

One challenge with machine-logged data is that in its raw form it can be difficult to interpret. It is possible to use manual and semi-automated systems such as SALT (Miller and Chapman, 1983), AQUA (Lesher, Moulton, Rinkus, and Higginbotham, 2000), PERT (Romich, Hill, Seagull, Ahmad, Strecker, & Gotla, 2003) and QUAD (Cross, 2010) to convert such raw data into more user-friendly formats. Another method is to use specific data visualization software that is designed to convert numeric and textual data into graphic formats.

Cross (2013) demonstrated a beta version of a web-based automated data analysis software that allowed for the uploading of a log file to a secure server, where it could be parsed in several ways so as to present summary data in the form of a visual dashboard. The commercialised version of this is now available as the Realize Language system (Prentke Romich Company, 2015), which is able to analyse data log files created by devices manufactured by the Prentke Romich Company, from the Saltillo Corporation, and the *Words For Life*™ and *TouchChat*™ application programs running on the iPad® tablet.

Graphical Representations and Analytical Widgets

A design goal of the Realize Language system was to take text-based data logs and turn them into more easily comprehendible graphical representations collected as widgets on themed pages. Table 1 lists the different widgets available and the function of each. These representations can then be used as a starting point for more detailed discussions amongst stakeholders. During beta testing of the system, parents who were using the Realize site found that seeing the data graphically, as opposed to a native TXT data log file, made it possible to talk with therapists and teachers about what their child was doing and ask more questions. As mentioned earlier, there are inherent limitations with using ADL such that simply looking at the data on its own can be counterproductive, but the purpose of the Realize Language approach is not to provide stakeholders with all the answers but to help them ask better questions.

For the both English and German languages, the system allows for data to be analysed in terms of;

- Word frequency
- Parts of Speech (POS)
- Performance against a customized target vocabulary
- Daily/Weekly/Monthly device use

Table 1: Pages, Widgets and Functions of the Realize Graphical Interface

Page	Widget	Function
Use	Daily	Bar Chart showing every 15-minute period in which the device was used during a day.
	Weekly	Bar Chart showing every 15-minute period in which the device was during a week.
	Monthly	Bar Chart showing every 15-minute period in which the device was used during a month.
Words	Cloud	Word Cloud showing the most frequently used words.
	Top 10	Bar Chart of the 10 most frequently used words used during any time period.
	A-Z	Alphabetised list of all the different words used.
	List	Frequency-ordered list of words and non-words used.
Log	Week	Calendar showing 15-minute periods where the device is used during any week.
	Month	Calendar showing 15-minute periods where the device is used during any week.
Analysis	Parts of Speech	Horizontal Bar Chart showing Parts of Speech by frequency.
	Word Groups	List of words used by the client from targets in the Manage Goals widget.
	Manage Goals	List of target words created by stakeholders.
Reports		List of all reports and graphics generated using a "Generate Reports" tool.

Let us now look at some specific examples that illustrate the type of graphical representations available.

Example A: Word Cloud Widget

Being able to see the words a client has used during a specific time period as a *Word Cloud* is popular among parents who use the Realize Language system. The cloud shows the most frequently used words, with the font size enlarged to indicate which words are used most often. In Figure 1, the word *ich* appears as the largest with the words *ja*, *nein*, and *essen* coming close behind, demonstrating that the word *ich* is the most frequently used word.

Figure 1: Word Cloud showing German Words by Frequency

Example B: Parts-of-Speech Bar Chart

For clinicians, it can be useful to be able to see how words are being used by POS. In Figure 2, a client's vocabulary is shown as a bar chart with the part-of-speech most frequently used being at the top.

It should be noted that the POS widget requires a specific language database to work fully but all the other widgets do not. This means that data generated in Spanish, for example, can still be analysed using all the other Realize widgets but you won't be able to break the data down in to nouns versus verbs versus adjectives, and so on.

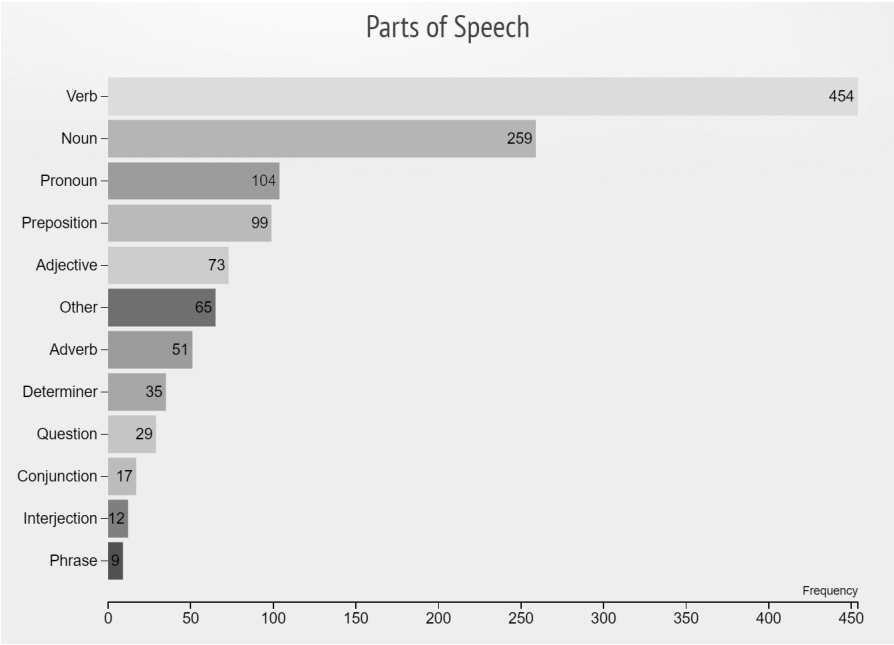

Figure 2: Vocabulary by POS

Example C: List of Spelled Words

The *List* widget provides stakeholders with a way to look in more detail at not only the frequency with which words are used but also whether they have been prestored on buttons or spelled out letter by letter. For tracking clients who are

just beginning to spell, this can be a useful feature. In Figure 3, you can see a list of words and non-words that have been spelled out in German.

Notice that in the first column, the words *ruft*, *du*, *das*, *ist*, *kom*, and *ich* are all spelled out, yet all of these are already available as prestored words in the client's vocabulary program. This suggests that a good teaching target would be to show the client where these are and make it faster to communicate. Furthermore, you can see that the non-word *uj* appears as often as *du* and *das*, so it would be important to find out why this is happening and what the presumed target word is. Perhaps *und* (*and* in English) which is a high frequency word. The important point to note here is that the *List* widget is a useful tool for analysing word use by clients who are literate, non-literate, or in the process of developing literacy.

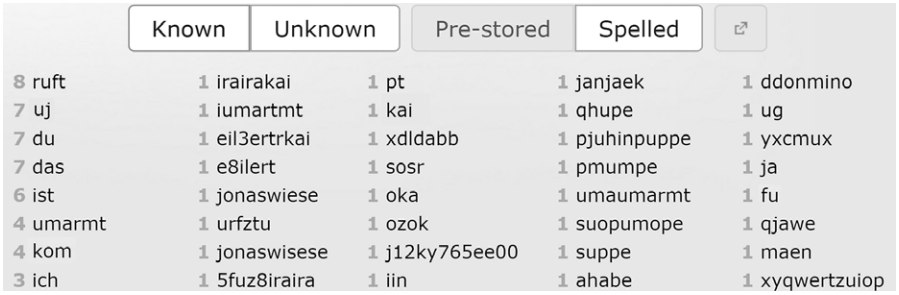

Figure 3: Listing of client's spelled words in German

Example 4: Tracking by Word Groups

The Realize Language system includes the capability to allow the matching of words used by the client against any target word lists. Using the *Manage Goals* widget, a target list can be created and then switching to the *Word Groups* widget shows how many of the target words are being used. In Figure 4, the target list is based on the 40 words included in the Dolch First Words list (Dolch, 1927).

Notice that some words are larger than others, which reflects the relative frequency of use e.g. *how* and *had* are used more often than *walk* and *take*. Words that are not boxed have not been used.

Conclusion

Given that we can identify the limitations of automated data collection, there are still many areas of analysis that can be of use to all stakeholders involved with improving a client's use of an AAC system. The Realize Language system seeks to take raw data and present it in a much more accessible visual format. Using English and German vocabulary databases, two different languages can be tracked by Part-of-Speech, but many others can also be analysed using the other widgets. The intention is to add other databases as they become available.

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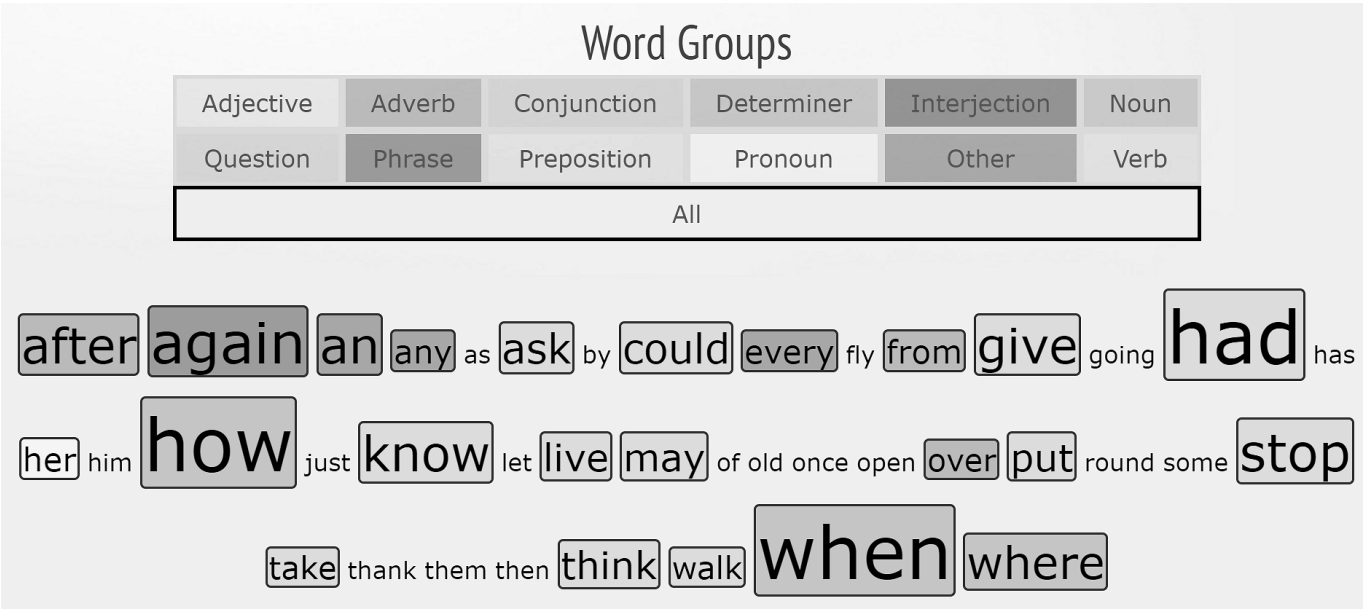

Figure 4: Client's performance measured against the Dolch First Words list

AAC Implementation for Multilingual Persons

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In spite of the prevalence of multilingualism in today's world, studies in language development and communication disorders have focussed mainly on monolingual populations. It is still common to encounter the belief by families and practitioners alike that children with speech and language disorders should not be exposed to multiple languages, as this is seen as an additional risk factor to language development. However, there is no empirical evidence to support this belief (Kohnert & Medina, 2009). At present, supporting all the languages of a person with communication impairment is regarded as best practice (Kohnert & Medina, 2009). How this can be achieved in intervention for persons in need of AAC has not been extensively researched (Soto & Yu, 2014).

In this paper, we will discuss some considerations regarding AAC intervention for persons from multilingual backgrounds. The population that we will consider in this discussion is persons with an understanding of spoken languages rather than those who need an alternative form of communication for comprehension. The ideas are meant to stimulate thoughts and further investigation, rather than present definitive guidelines or prescriptions. The ideas discussed in this paper emanate from previous literature and also from two studies conducted in South Africa regarding stakeholder perspectives about access to multiple languages via AAC. In the first study, focus groups were held with 15 South African AAC service providers, who discussed their practices and perceptions of AAC intervention for multilingual persons (Tönsing, Van Niekerk, Schlünz, & Wilken, 2017). The second study consisted of a survey of 27 multilingual adults who use AAC (Tönsing, Schlünz, Van Niekerk, & Wilken, 2017).

Considering the socio-linguistic context

The larger socio-linguistic context would be important to consider when planning for intervention. In South Africa, for example, most people are multilingual, and speakers (especially those in from urban multilingual contexts) tend to code-switch during everyday conversations.

Other considerations may be the status of different languages, minority versus majority languages, and language policies, for example, those governing the language of instruction at schools. In South Africa, all 11 official languages enjoy equal status 'on paper', as the constitution obliges government to promote and develop all 11 languages equally. However, for historical reasons, English dominates the business and educational sphere although it is the first language of less than 10% of the population (Khokhlova, 2015). Although language in education policies allow schools to use any of the 11 official languages as the language of instruction (as appropriate to the language background of the majority of their students), many schools officially opt to use English only from the fourth year of school onwards.

The language of instruction influenced language choices made by South African service providers who served children in need of AAC. South African adults using AAC reported that their written English proficiency was generally better than their written proficiency in their first language, although they judged their comprehension of spoken English to be poorer than the comprehension of their first language. The language of instruction during their basic education may have had an influence on this, and this situation would then further have consequences on the choice of AAC system(s) that would best match their skills in the various languages they comprehend.

Some questions service providers may consider in relation to the socio-linguistic context would include:

- Which languages are used in the contexts the client is currently exposed to and in those he/she will be exposed to in the future? How are languages used in these contexts?

- What opportunities exist for children in need of AAC to become proficient in different languages (comprehension of spoken language and literacy skills)?
- Which AAC systems, strategies and techniques may be most appropriate in matching both the client's receptive and written language skills in different languages and also the communication demands of the different contexts in which they are expected to participate?

Considering client and family views and preferences

The importance attached to the use one's first language may differ from client to client and family to family. For many people, use of their first language is linked to their identity, heritage, culture, and sense of belonging, and they have a desire to preserve and use their first language. In spite of the prevalence of English, this is also true for many South Africans (Slabbert & Finlayson, 2000) and was also reflected in the views of adults using AAC. At the same time, families and individuals may, at times, make pragmatically-motivated decisions to shift language – for example, deciding to use English only in the home. Historically based inequalities resulting in lack of access to quality education in the first language and perceptions about language status and language utility may underlie such decisions (De Klerk, 2002). For families of persons in need of AAC, other factors, such as the lack of easily available AAC systems in languages other than English, and the view that using and/or learning multiple languages may be difficult for the individual with communication disabilities may be additional factors influencing decisions.

Client- and family-centred service provision is regarded as central to the long-term success of AAC intervention (Soto & Yu, 2014), and conversations about their choices and preferences regarding access to and use of various languages should form a part of such service provision. Some questions that service providers may consider in this regard are:

- What languages are currently used and understood by the client and the family?
- What are the client and family's preferences and expectations regarding the use of and access to different languages, and which language(s) do they feel should be incorporated into AAC intervention?
- What are the beliefs the family holds about multilingualism?

Choosing and designing appropriate AAC systems

The possibilities and limitations of various AAC systems and strategies in representing one or more spoken language(s) are another important consideration. Systems and strategies that do not attempt to represent grammar may be used more easily across different languages. Key word signing, for example, may be used by persons in need of AAC to communicate with partners who speak various languages, provided that the partners understand the unaided symbols (e.g., manual signs from a sign language). One manual sign could be used to represent key concepts in different languages, provided such concepts exist in both languages.

Regarding aided systems, the type of symbols used, as well as the need for and availability of text-to-speech (TTS) synthesis in different languages should be taken into consideration. For clients who are literate in multiple languages, access to text-generation via computers, pen and paper, mobile technology, or paper-based alphabet boards (displaying the orthographic characters relevant to the respective languages) could provide them with an opportunity to express themselves in multiple languages and also to switch between languages. However, unless text-to-speech (TTS) synthesis is linked to this text generation, partners need to be literate and able to see the selections and/or text generated.

TTS synthesis has been developed in various languages spoken around the world. In South Africa, TTS synthesis running on Windows platforms for some of the 11 official languages has recently become commercially available, making it possible to integrate these synthetic voices with Windows-based AAC software programmes (Schlünz et al., 2017). In the absence of TTS synthesis in one or more of the desired languages, recorded digitised speech can be used to provide voice output. However, the person using such a system is then limited to words and phrases that have been prestored and cannot generate their own words. Also, the person whose voice is used for the recordings should preferably be available whenever new messages are prestored, in order to keep consistency across recordings.

Selecting, organising, and prestoring vocabulary in different languages is typically necessary not only when recorded digitised speech is used, but also for a graphic symbol-based system (using symbols from a commercially or freely available symbol library) that are often employed for persons who are not (yet) literate. The symbols themselves should be scrutinised in terms of their cultural and contextual relevance. Symbols representing nouns are often especially contextually bound, yet a taxi in South Africa, for example, looks quite different to the London variety or the New York cab. Country-specific addenda to symbol libraries have started addressing these issues. Examples of the South African addendum for Picture Communication Symbols are provided in Figure 1.

Symbol libraries may also not always be designed to reflect grammatical aspects such as function words and morphemes in different languages. New or additional symbols may be needed to represent the grammar (even if only a rudimentary form) of different languages.

Regarding vocabulary selection, vocabulary lists or prestored vocabulary sets may not be available in all languages. Translation may be an option if the vocabulary content is appropriate and if the grammatical structures of the languages are similar. An example of a graphic symbol-based communication board with gloss in two languages is provided in Figure 2.

However, word-by-word translation is often limited, since words in different languages often do not neatly map onto exactly the same meaning. Especially when prestored vocabulary consists of single words rather than phrases and is intended to allow the person using it to generate sentences, in these cases language-specific pages and overlays may be needed. Various Spanish-English resources and systems illustrate lay-out and organization options of bilingual

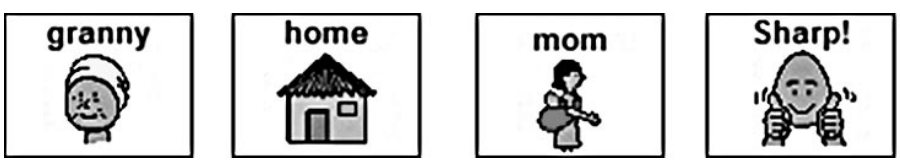

Figure 1. Symbols from the South African BoardmakerTM addendum.

systems (see, for example, the resources by Assistiveware®[1] and the Saltillo Corporation[2]). When considering AAC system selection and design for multilingual clients, service providers may consider these questions:

- To what extent is the system able to and expected to mirror the grammar of the spoken languages?
- Is TTS synthesis required/available in the different languages?
- What vocabulary selection resources are available to guide this process in different languages?

Bridging the language and culture gap

Service providers may not always be proficient in all the languages that their client in need of AAC requires access to. Apart from a lack of linguistic proficiency, they may also have limited insight into the culturally acceptable and expected use of language, including terms of address, register and conversational topics (Baker & Chang, 2006). Working with a language and cultural 'broker' may be one way to overcome this gap. Some South African service providers reported working with formal interpreters, while others indicated that family members fulfilled this role. Service delivery models that do not allow frequent and extensive collaboration with families or other prominent communication partners of the person in need of AAC can significantly limit successful multilingual AAC implementation.

Conclusion

In this paper, we discussed some of the considerations for implementing AAC for persons from multilingual backgrounds. We hope that these preliminary thoughts give impetus to further discussions and ideas about research and practice in this area.

Acknowledgements

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Figure 2. An activity-based communication board for book reading in Afrikaans and English

Footnotes:

[1] Assistiveware ®, Amsterdam, The Netherlands. www.asxsistiveware.com

[2] Saltillo Corporation, Millersburg, OH, USA. www.saltillo.com

[3] Boardmaker is a product of Mayer-Johnson Company (part of the Tobii-Dynavox family), Pittsburgh, PA., USA. www.tobiidynavox.com

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Pathways to Progress: Systematically Grow AAC Skills

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Have you ever climbed a hill only to find another steeper one behind it? That is frequently the experience of augmented communicators and their teams. The first hill is identifying and acquiring the device, but the bigger hill is implementing successful use of it in daily situations while encouraging ongoing growth. It is on this hill that we often see people stall or give up.

This was the challenge facing the staff at Sandfield Park School, the students who use AAC, and their families. Though the staff addressed the challenge head on by creating their own resources with information available on the web and from other professionals, they found that this was time consuming and that it stole focus from teaching students and training staff. Perhaps you have experienced this as well.

As the coordinator of the program, Carly Hynes had 15 students using a variety of AAC solutions with diverse needs and a range of skills which she was to manage in her 6 hours per week planning, preparation, and assessment (PPA) time. Two full-time Communication Assistants delivered AAC interventions three times a week to each student at Sandfield Park, as well as writing post-intervention reports, customising and backing up devices, arranging loans, completing referral forms, etc. In addition, the school identified a Communication Liaison in each class to support AAC users. These members of staff were given activities to do with the students during class time each week which were created and compiled by Ms. Hynes. As in most schools, the team was very rarely in the same place at the same time making communication and coordination challenging.

It was to meet these very challenges that Tobii Dynavox created Pathways for Core First™ which is a free app (IOS and Windows) offering evidence-based resources to support successful use of AAC and ongoing growth in skills of AAC users and their communication partners. Pathways for Core First includes a goal setting tool, lesson plans, video demonstrations of top partner strategies, and more which are based on the principles of adult learning (Binger et al, 2010). Upon learning of Pathways for Core First, staff at Sandfield Park School agreed to collaborate with Tobii Dynavox and explore the impact it might have on the efficiency and effectiveness of their services by gathering quantitative and qualitative data from the program coordinator, school staff, students, and parents.

Goal setting, creating lessons, finding resources, training staff, creating and sharing homework, etc. took approximately 18 hours per week which was 12 hours above and beyond her allotted PPA time. As most dedicated teachers will admit, doing work at home is part of the job but, being a full-time teacher as well, Ms. Hynes had the whole weeks' worth of planning for her AAC students to do as well as planning for her own class. Using the lesson plans with pre-made activities in Pathways for Core First, that time was reduced by 17 hours per week thus reclaiming PPA time and allowing Ms. Hynes to focus on student instruction and training staff.

Below, we share additional impact of the resources in Pathways for Core First on AAC implementation at Sandfield Park School.

Systematic and Evidence-Based Assessment and Intervention

The Goals Grid in Pathways for Core First is an interactive version of the Dynamic AAC Goals Grid-2 (DAGG-2, available free from Tobii Dynavox). Like the DAGG-2, the Goals Grid in Pathways offered Ms. Hynes progressive goals focusing on linguistic, operational, social, and strategic competence (Light, 1989). Initial completion of the Goals Grid offered a picture of the student's current skills which could be shared. Furthermore, it offers at least one lesson plan to address every goal as well as progress tracking.

Both staff and parents found it useful to see where the student's skills currently lie so that they could plan and provide more intervention. The examples in the Goals Grid assisted staff and parents to understand more readily the skills being targeted and the lessons allowed them to address the target successfully.

Focus on Growth

Often, we find augmented communicators plateauing because it is unclear to partners what skills should be addressed next. The progressive goals in the Goals

Grid offer a path for growth which can be easily followed and implemented by staff and parents. Ms. Hynes found that this encouraged independent movement from skill-to-skill by staff and parents rather than remaining in a holding pattern waiting for direction.

As we know, progress within special education and for students who use AAC in particular is not always linear. The Goals Grid offered an alternative when children plateaued in one area (e.g. linguistic) but were making rapid progress in other areas (e.g. strategic and operational). It assisted staff to move on to a new skill rather than remaining stuck. This allowed students to demonstrate that they were capable of progress and encouraged partners to expect competence and growth:

Goals and lessons in Pathways range from those for emergent communicators such as attention to high-level language skills including adverbs. The sheer number of goals and lessons offers opportunities for students to continue growing throughout their time in school and beyond. Ms Hynes commented, "It is probable that we'd struggle to deliver every lesson and activity in Pathways for Core First to every AAC user within their lifetime at the school; that's how much is on there!"

Consistent Quality of intervention with Variety

Each lesson in Pathways for Core First contains five days of activities and materials (books, cards, examples, etc.) addressing a particular goal/skill. The lesson plans were a major contributor to the time savings Ms. Hynes experienced as well as improving the consistent quality and variety of intervention. In fact, 100% of staff polled reported these lessons to be easy-to-use and helpful while 100% of students reported enjoying the activities.

Typically, Ms. Hynes would meet with each individual member of staff to explain what their student was working on and share an activity which they could do in class to address it. With Pathways for Core First, she could direct a member of staff to deliver a specific lesson which they could locate on their iPad or Windows computer and start teaching within seconds. This drastically reduced the need for hand holding and raised staff confidence in AAC intervention deliver.

It also increased the variety of interventions. While Ms. Hynes's previously created lesson and resources could be used repeatedly. This resulted in a "Groundhog Day" experience when, for example, the same activities and books were used each time a specific core word was targeted. The lesson plans in Pathways for Core First offer multiple activities to work on skills as well as the opportunity to create variety within those activities.

Engagement and Empowerment of Parents

Parents of students at Sandfield Park often asked for homework and, while they were happy to work on academic skills, they wanted to address communication skills. Previously, Ms. Hynes created a unique set of activities for them. With Pathways for Core First, she was able to send a letter and homework (both found in the lesson plans) that directly impacted interaction on the part of the student. 100% of parents indicated that the lessons were easy to follow and useful at home. They liked the fact that they didn't need extra equipment (i.e. books or cards came with the lesson) or, if they did need something (e.g. bubbles), it was clearly stated. Further, parents and staff both noted that the companion app sat perfectly alongside the Snap + Core First (communication software from Tobii Dynavox) but that it could be used to grow skills with any AAC system.

Improved Communication Partner Skills

Modelling, creating a positive communication environment, and looking for success were foundational strategies at Sandfield Park. The training resources on these topics in the Top Tips section of Pathways for Core First (including video examples) reinforced the training Ms. Hynes provided her staff and parents allowing them to independently refresh and refine their knowledge without the need for organising additional training.

Student Progress

Pathways for Core First clearly offers benefits to those coordinating and providing AAC services but the greatest benefit of all is on the augmented communicator him/herself. As you read previously, students not only reported enjoying the activities but demonstrated less regression after school breaks and more consistent progress. Isn't that what it is all about?

Pathways for Core First is a free resource for Windows and IOS. While it was designed with Tobii Dynavox's Snap + Core First in mind, the lessons and strategies are evidence-based and applicable to AAC globally as demonstrated at Sandfield Park School.

Use Pathways for Core First to help you scale the hill of successful implementation of AAC in daily situations while encouraging ongoing growth.

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Mentoring at ATtherapy

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ATtherapy is an independent speech and language therapy company who employ Speech and Language Therapists and assistants, Assistive Technologists and AAC Mentors. ATtherapy are based in Manchester, however they cover a wide geographical area to assess, diagnose and provide therapy for individuals with speech, language and communication and/or swallowing problems to help the individuals to communicate to the best of their ability. The multidisciplinary team (MDT) specialise in assistive technology and a large proportion of the caseload use augmentative and alternative communication (AAC). Learning to use a new system of communication is challenging and this can occasionally result in lack of motivation and confidence to use the system, limited use in different social contexts and in some cases communication aid abandonment. Most adolescents and young adults who use AAC do not have regular access to adults with similar experiences who can serve as appropriate role models and mentors (Light et al. 2007).

In September 2016, ATtherapy set up a new Mentoring service to develop the support around individuals to enable them to use their AAC more effectively. This role also has the added advantage of giving meaningful, paid employment to people who use AAC. ATtherapy initially appointed two individuals who use high technology AAC and are highly proficient at using their systems. Due to the success of the service, the team has expanded and currently the team consists of four AAC Mentors.

"I believe the quickest and easiest way to learn what can be done for and by everyone with communication disabilities, is to meet a fluent AAC communicator, someone who has overcome the very difficulties that some people believe are a marker of no hope" (Michael Reed, AAC user)

Mentoring is a way of giving time and support to another person to help them make changes in their lives. Mentors will have had relevant life experience and an understanding of what another young person is going through or what their concerns are. Adults who use AAC, who have successfully overcome barriers and achieved their educational, vocational, social, and personal goals, offer a rich, potential source of effective problem-solving strategies and encouragement for others with similar disabilities who confront comparable challenges (Light et al. 2007).

The benefits of mentoring for AAC users alongside the need to develop employment opportunities for people who use AAC is increasingly documented within AAC research. A pilot research project was conducted by Cohen and Light (2000) that paired four adolescents and young adults who used AAC with mentors who also used AAC and followed their interactions over a 4 – 6 month period. The mentors used e-mail to develop supportive relationships with mentees and to discuss a wide range of topics, including education, employment, independent living, personal care attendants, assistive technology, family issues and communication difficulties. The mentees in the pilot study were positive about their experiences with their mentors however the mentors did not receive specific training prior to commencing their role which they felt would have been beneficial. This was then addressed within a subsequent study, The Mentor Project, by Light et al. (2007) which was designed to develop, implement, and systematically evaluate the effectiveness of a web-based leadership training program intended to teach effective mentoring skills to adults who use AAC. The study taught the mentors different skills such as sociorelational skills and problem-solving strategies to support them in their mentoring roles. The participants reported that they were better prepared to effectively mentor and empower others with disabilities.

In today's society, employment is strongly tied to issues of financial independence and self-esteem. People who use AAC however have the lowest employment rates of all disability groups which is thought to be due to a number of barriers including; communication and assistive technology barriers, few opportunities to find jobs, poor educational preparation, lack of appropriate supports and negative societal attitudes (Muller, 2014).

Employment for individuals with severe physical disabilities who use AAC is often limited to those with strong literacy skills. For individuals who use AAC who have mild/moderate physical disabilities, employment outcomes are more varied including roles such as parking lot attendants and restaurant staff (McNaughton & Bryen, 2007; McNaughton et al. 2002). Successful employment outcomes are not only built on a range of internal

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Nadia and Jess

Face masks

Football trip

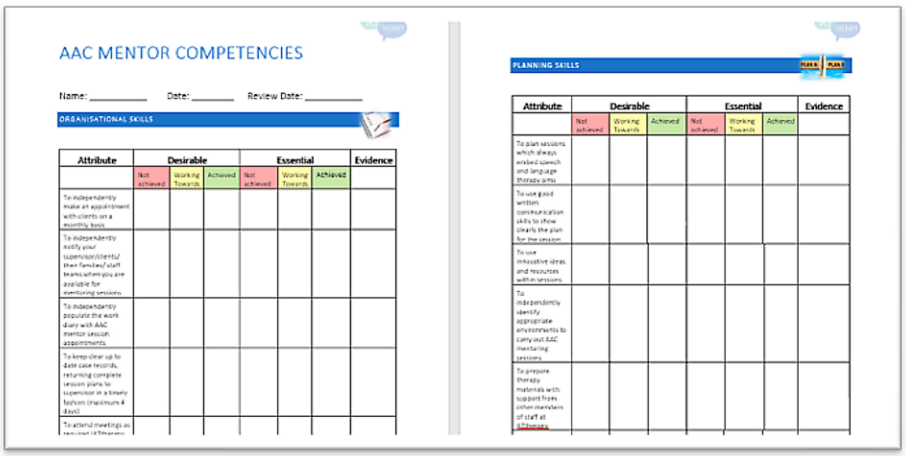

Figure 1: AAC Mentor Competencies

supports including personal characteristics like self-determination, the 'process by which someone takes control of their life' (Wehmeyer & Palmer, 2003) and good interpersonal skills but also external supports such as strong educational experiences where expectations of teaching staff are high (Blackorby & Wagner, 1996), large employment-related social networks (Hansen, 2000), employer and co-worker attitudes (Ochocka, Roth & Lord, 1994), barrier free environments (Roessler & Sumner, 1997) and a high level of family support (Heal & Rusch, 1995).

The Mentors at ATtherapy have received high levels of support to develop their skills as an AAC Mentor. A competency framework was devised (see figure 1) dividing skills up into six key areas; organisational, planning, communication, presentation, professional development and professional skills. This framework is used within monthly supervisions and workshops have been run on certain skills including a planning workshop and developing independence and assertiveness workshop. Additionally, the mentors have been supported to attend some external training and participate in shadowing experiences. ATtherapy have been able to support with assistive technology including making paperwork accessible on mentor's AAC systems and improving access to emailing.

A number of the Mentors from ATtherapy have also attended a Level 2 Mentoring course which helps the individual to; understand the role of being a mentor, to

Adam and Aidan

Mentor session at Alton Towers

be clear about mentor/mentee relationships, develop good practice, recognise specific skills for mentoring, engage in reflective practice and understand legal and ethical requirements. Following this course, AAC Mentors have stated it has helped them particularly to understand role boundaries, the importance of maintaining confidentiality and safeguarding.

The outcomes of the Mentoring service have been measured by gathering feedback from mentees and their support networks. One of the mentors at ATtherapy, Nadia Clarke, has presented case studies to demonstrate the outcomes of this service. Nadia received her first AAC system aged 5 and in her teenage years she has evidenced great self-determination from; independently travelling the world, talking in parliament, giving speeches at university to students, carrying out voluntary work, undertaking a college course, winning best individual employer of the year and finding paid employment.

Nadia is very passionate about inspiring others to see what can be achieved by using communication aids. She works with the lead speech and language therapist to embed aims within her sessions and is now independently organising and planning motivating and engaging sessions for her caseload. Nadia will initially meet the person with a therapist and find out what they like, their hopes/aspirations and what they are having difficulty with. She provides input to three mentees seeing them once per month in lots of different environments including home, school and out in the community. Within the sessions, Nadia always has a personal assistant who is trained in British Sign Language (BSL) due to her hearing impairment and sometimes will also be accompanied by the lead speech and language therapist.

Case Studies

G is a young lady who is 18 years old who loves eating out and shopping. She uses an Accent 1000 uploaded with Unity software and accesses this using a head mouse. When G first met Nadia, she did not initiate conversation using her device and did not use her communication aid outside of the college environment due to feeling underconfident. Nadia arranged sessions with G at home (pamper night/takeaway) and in the community (restaurants) supporting G to develop her confidence. She also worked with the lead speech and language therapist to carry out activities to support G to develop her initiation skills. G is now using her device more across contexts and starting conversations with a range of communication partners. A family member provided the following feedback;

"The mentoring service provided has helped to boost our daughter's confidence to use her communication aid more.

Nadia with her experience and ability is a great example for others as to what can be achieved as a communication aid user out in the public domain.

The mentoring service is structured and purposeful, offering encouragement and interaction with our daughter which is great to see"

J is younger female mentee, aged 10, who loves Frozen and One Direction. J is homeschooled and consequently has limited social contact with any other individuals with similar disabilities. She communicates using a Grid Pad 13 device uploaded with the Grid 3 software accessed via eye gaze. She is learning a new, more complex vocabulary package. When Nadia first met J, lots of games and music were played to build a positive rapport however J rarely responded to questions from Nadia and was often looking away from her eye gaze towards Nadia. Nadia worked with the lead therapist to support J to learn to develop her attention and listening and to navigate to new vocabulary on her system to respond and ask questions. She also worked with the family to support J to access increased community activities (bowling, museums). Nadia's impact on the wider family is really evident in this case with J's mother and siblings often asking Nadia questions on a range of topics, for example during a meal out, "how did you learn to drink with a straw?"

Nadia's final mentee, L, is 12 years old and loves dogs and spending time with her twin sister. She also has a hearing impairment and is learning to use different AAC systems as she encounters significant difficulties with access. Sessions have focused on supporting L to use her AAC more in the community however this has brought challenges due to both the mentor and mentee having hearing impairments. L's staff team have reported

the positives of having a BSL trained personal assistant and have developed their signing vocabulary. Her lead speech and language therapist has also observed increased determination and motivation in AAC mentoring sessions.

Nadia has found her role at ATtherapy very rewarding as she has developed her own self-esteem, her skills and confidence in her role as an AAC mentor through engaging in lots of new experiences to add to her CV. She also now has increased financial independence. Nadia has found some aspects of the role challenging including; completing paperwork, her mentees seeing her as a friend, the speed of workplace communication and work-related vocabulary and managing her role at ATtherapy with her other voluntary commitments.

ATtherapy have witnessed improved parent/carer/AAC user engagement since commencing the AAC Mentor service. Speaking with the AAC mentors regularly has enabled the lead therapist to problem-solve and have an AAC user's perspective. When delivering training to staff-teams or families/ professionals around the mentee, having an AAC mentor deliver this has made training more powerful. As a team, we have been very committed to this role however it has brought some challenges. Apart from joint visits, workshops and supervisions, communication has been via email/phone which has been difficult, "even for individuals who are highly competent in the use of AAC... communication in the work-place remains a challenge" (McNaughton & Byren, 2007). The time and flexibility needed to provide the necessary support has been significant and lots of modifications have had to be made via learning from different experiences, for example, some sessions had to be shortened due to AAC Mentor fatigue.

The level of support needed for the AAC mentors is high however the positive outcomes for both the AAC user, their support networks and the employee are very rewarding for ATtherapy. The AAC mentor role is a highly valued role and at ATtherapy there are future ideas to enhance the service further, providing more skill development workshops/ peer support meetings so the mentors can share ideas as well as creating more social and professional development opportunities. The role has been particularly beneficial for those AAC users who have new devices, are undergoing a transition, are underconfident/have low self-esteem, have an MDT which require some additional training and have limited contact with other AAC users.

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Local AAC Services – Tying it all together with LAACES

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From April 2013 NHS England has been responsible for commissioning specialised AAC services for people with the most complex communication needs. This has led to a National Service Specification for AAC and 14 specialised AAC services across England being formed. These services form part of a 'hub and spoke' model of provision. The 'hub' *or* specialised services are commissioned by NHS England, whilst evolving 'spoke' *or* local AAC services are commissioned by Clinical Commissioning Groups (CCGs), education and social care commissioners. Commissioning and provision of services is dependent on local priorities, service history and local AAC knowledge; therefore, it differs across areas. This results in inequitable access to support and provision of AAC. Ace Centre is working to support the development of local AAC services in order to address this imbalance and enhance standards of AAC services and provision.

AAC Services – Local and Specialised

'Specialised services support people with a range of rare and complex conditions.' (https://www.england.nhs.uk/commissioning/spec-services/). For a specialised AAC service this is frequently defined as the 10% of people who require AAC with the most complex need. By nature of this definition the remaining 90% of people who require AAC should have their needs met locally. This includes people of all ages with a wide range of AAC needs, including those using low tech and high tech AAC solutions, and those who are acquiring skills to use AAC and to access technology. It is important to note however, that whilst the specialised AAC service will provide the assessment and equipment for the 10% with most complex needs, the day to day support will still be overseen by professionals who need support from or are members of a local AAC service; thus, a local AAC service would monitor all individuals in their local area who require AAC.

Remit of a local AAC service

Providing support for such a wide range of AAC users requires a skilled multidisciplinary workforce. Support might include identifying specific AAC needs, assessment for AAC, implementation of AAC, review and management of the technology. Support might be required within education or employment sectors, for children, young people and adults, or at points of transition. The potential role is very broad.

Guidance

In 2012 Communication Matters published the Augmentative and Alternative Communication (AAC) Services Standards and AAC Quality Standard for Commissioners. (http://www.communicationmatters.org.uk/page/national-standards-aac-services). These state, 'The aim is to deliver improvements in the health, education and wellbeing of the AAC speaker.' This Quality Standard sets out what AAC users, their families and support workers should expect from local services and in turn what standards local services are expected to deliver. Additionally, 'Guidance for commissioning AAC services and equipment' (https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/guid-comms-aac.pdf) outlines the remit of a local AAC service and the need for a local AAC budget, jointly commissioned between health, education and social care, in order to deliver it.

Commissioning aims to provide the best possible health outcomes for the local population. Services are commissioned according to local need, however accurate information about the local need for AAC is often poorly defined. This is where LAACES begins to tie it together…

Tying the knot between specialised and local services

Ace Centre is working with pilot areas across the North West and Thames Valley and Wessex NHSE Specialised AAC Service regions to establish jointly commissioned **L**ocal **AAC** servic**ES** (LAACES). LAACES aims to bring together education, health and social care funding for multidisciplinary services that support children and adults with AAC needs. The pilot areas have been identified where the need for a local AAC service has already been recognised and there is an enthusiasm and commitment to work together with Ace Centre.

LAACES in different shapes and sizes

It is not anticipated that all LAACES teams or local AAC services will look the same; this cannot be possible when local commissioning arrangements differ, the age

range of those who the service is for, geography, local expertise available and history of provision will all lead to different services. There is an opportunity however, to learn from and share different models.

Currently, one pilot area is already jointly commissioned by their CCG and children's services to deliver a paediatric local AAC service. Ongoing work aims to ensure that this is continued, and the service is developed further, potentially offering an all age service in the future. Other pilots vary in size, make up of professionals involved, age range of individuals their service aims to support and level of knowledge and skills in AAC. Ace Centre hopes to showcase the diverse approaches and models of local AAC provision and how these have been achieved and their services are delivered.

Multidisciplinary LAACES

Ace Centre is working with local professionals, commissioners and other local and specialised AAC services to facilitate shared learning through the development of two toolkits in order to support the establishment of commissioned local AAC services and provision. A Commissioning Toolkit will include resources that can be used to demonstrate the type and level of AAC need and model of provision within a defined area, such as exemplar data gathering tools, business cases and care pathways. The toolkit aims to enable local teams to demonstrate the need for a local AAC service, what resources it would require, how much this would cost and what difference it would make to a defined population. Information that is gathered about local outcomes will also help to inform National data for benchmarking.

In addition to the Commissioning Toolkit will be a Local AAC Service Toolkit to support professionals to deliver a local AAC service. This will include (but is not limited to) existing and new resources, such as good practice guidelines, an AAC Screen, exemplar eligibility criteria for a local AAC service, train-the-trainer materials for new and interested staff and AAC awareness raising resources.

A further key element of the LAACES project is to utilise IPAACKS - Informing and Profiling AAC Knowledge and Skills, (http://www.nes.scot.nhs.uk/media/2507407/nesd0214aacframework-re.pdf) to audit training needs and further inform the development of new training materials. IPAACKS was developed by NHS Education for Scotland, building on the AAC Competencies Project undertaken by Communication Matters and the AAC Competencies Framework (Bousaki and Latham, 2011, unpublished). It provides a framework for workers to develop their knowledge and skills in order to support people who use AAC, and is suitable for health, education and social care practitioners. It is therefore, an ideal framework for a local AAC service.

The LAACES pilot areas will reflect on their knowledge and skills individually and collectively as a team. This information will be used to inform further training opportunities to ensure that the team has a range of skills and all areas of IPAACKS strands are met.

LAACES now and in the future

The LAACES pilot areas have been identified and a rolling programme is planned. Initial work has begun, but already it is evident that the key to success will be the drive from local champions who see the need for this type of service; they know their local area and are committed to raising awareness, working with local commissioners, other local AAC services and with the specialised AAC services. In some areas this work is being led by education champions; in others by health, but all aim to achieve a shared goal.

Outcomes from LAACES will include two toolkits. Where these will be hosted is currently under discussion with Communication Matters. The hope is for this to become a national project and as such a National Working Party involving members of the National Specialised AAC Services has been established to collaborate, share resources and a vision for equitable AAC services and provision in the future.

Rethinking technology design for and with children who have severe speech and physical disabilities

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ABSTRACT

Communication in its broadest sense enables people and things to 'connect'. High tech augmentative and alternative communication (AAC) technologies provide one perspective for supporting communication. Unfortunately, these technologies are largely under-utilised by children, suggesting a need to understand how they are used and not used in interpersonal communication. This paper reports on work that is part of a doctoral project that is investigating how digital technologies for communication might be designed in new ways. This paper reports on work that is examining how communication happens in a primary special school environment, involving children, adults and AAC. We consider design implications based on the findings of our qualitative video study.

INTRODUCTION

The international AAC community is an interdisciplinary one that has investigated many aspects of AAC and communication including social interaction, role of conversation partners, language representation, electronic voice issues and many other areas. Theoretical and empirical insights from this body of work have informed the field of AAC greatly, yet separately, this literature has not 'talked back' to interaction designers working on designing AAC. In the field of human computer interaction (HCI), work on AAC has predominantly focused on how to involve AAC users in the technology design process. There is therefore a need for understanding the relationship between children's everyday communication and AAC design, so that future technology design can account for and support everyday interactions.

In this paper, we describe one part of a broader doctoral project. We start by examining previous work from the AAC and HCI communities and then use insights from previous AAC literature to investigate how communication 'happens' in the context of children's everyday lives. We present findings from a qualitative video study involving children, adults and AAC and consider possible new ways of designing for communication.

BACKGROUND

AAC research

AAC research has investigated communication in the context of people's everyday lives. This has taken a situated view for communication. Thirty years ago, Arlene Kraat highlighted that interactions are made up of people, the communication setting, rules for language use and other factors (Kraat, 1987). The idea that communication is distributed across many separate yet interlinked factors and situated within its environment and context has continued to inform AAC literature. This represents an alternative perspective to the notion of a 'sender-receiver' model of communication, that focuses solely on the transmission of information. For example, investigating the multimodal ways that communication was achieved in naturally occurring conversations, Higginbotham alluded to a wide range of temporal and contextual factors that people attended to in the moment as they worked to achieve common ground (Higginbotham, 2009).

HCI and AAC

In contrast, HCI has predominantly contributed to AAC research with a focus on interaction design. This has focused on ways of involving AAC users in the design process. HCI studies have also tended to start with a given 'frame' on technology. For example, de Faria Borges et al, (2012) took a pre-defined learning and therapeutic perspective in order to create a customised communication device for a child with cerebral palsy. Separately, Sobel et al, (2017) focused on conveying non-verbal aspects of communication into AAC displays, for example by focusing on ways of conveying mood and affect. The pre-defined frame that these and other HCI studies have taken has been

useful for extending the range of features that can be built into AAC devices by scaffolding AAC users to access a broader range of tools for communication that are typically available in naturally speaking conversations. However, we took an alternative perspective that was separate from scaffolding traditional ways that communication is typically achieved. Drawing on theoretical insights from the AAC community, yet taking a design orientation, we were interested in examining the link between the complexities of everyday communication and interaction design that is relevant to the concerns of AAC users. In doing so, our aim was to identify design opportunities in the use of AAC based on situated communication.

METHODOLOGY

Context

Our study took place in a primary special educational needs school in the UK over a 14-week period (Nov 2016 – Feb 2017) with 23 visits in total. The first author was familiar with the setting from prior work so held some knowledge about the children, the staff and the school.

Participants

As there are no 'representative' or 'average' profiles for children with severe speech and physical impairments (SSPIs), we worked with children who had a range of profiles of abilities and needs. Following ethical approval via a university ethics board, we recruited five children who offered themselves as 'information-rich' participants who would provide a variety of insights. The sampling criteria were primary-school-aged children identified as having SSPIs, using some form of high tech AAC and who had class-based teaching staff who communicated with them.

Data Collection and Analytic approach

We took a child-centred approach focusing on the interests and communication goals that children expressed through their interactions with peers and adults. We focused on videoing interactions that involved hi-tech AAC technologies. The observation method was chosen to record the multimodal, moment-to-moment ways in which children communicated in everyday contexts. We used conversation analysis transcription conventions to capture the full repertoire of children's communication behaviours, e.g. eye pointing, body movement etc., and used social semiotics as a method for analysing the video recordings (Kress, 2010). We also extracted still images from the videos (converted to line drawing to protect privacy) to capture the spatial arrangements and environmental factors.

RESULTS

The findings were organised into three themes:

- Competence and agency in adult-child interactions describes how adults made assumptions about children's capabilities to communicate via AAC, consequently impacting on child agency.
- AAC as a material object describes the shift from the child's communication via technology to the AAC acting as an external object that obscured or fostered meaning.
- Misalignments and breakdowns capture how AAC and their design faculties led to child-to-child and child-to-adult breakdowns in communication.

For the remainder of the findings, we focus on one of these themes: competence and agency in adult-child interactions. The majority of interactions involving technology consisted of adults initiating communication then scaffolding the child's language by using the AAC technology. During these interactions, the adult had apparent 'control' over the conversation and provided a structured way of addressing child competence by teaching children how to use their devices operationally, and also by modelling language use in specific ways. Whilst supporting learning goals, the ways in which this was done also on occasion inadvertently limited children's agency to use AAC for expressing themselves differently, e.g. to respond in more open and detailed ways, or to initiate communication for themselves. A fuller description of these findings with examples from the data can be found in our other work (Ibrahim et al, 2018).

Despite showing communicative agency through their use of technology, children more commonly chose to use other modes of communication to interact. All five children involved in the study regularly turned to their communication books instead of AAC technologies when responding to adult questions, despite AAC technologies often being readily available to them. This suggested that in naturally occurring communication, the participants used other modes to communicate in ways that were more appropriate to them in the moment. By rejecting technology in this way, children accomplished agency over how they communicated in ways of their own choosing.

DISCUSSION

The goal of this empirical study was to identify design opportunities in the use of AAC based on situated communication. We now discuss design related insights based on competence and agency in adult-child interactions.

Communication is embodied

The children of our study used technology much less frequently than their other modes of communication. This was despite all five children having access to their technologies and being encouraged to use them by their teachers. This reinforces one of the most robust findings in AAC research, i.e. that children rely on multiple modes to communicate and these choices are closely related to context, partners, task and intent (Baxter, et al, 2012). It also shows the prevalence of embodied communication over spoken language use. Therefore, an opportunity exists for further design research that seeks to design for communication through the whole body, and not solely focused on speech.

Respecting child competence and agency

Our study underscores the importance for AAC technologies to develop and 'grow' in pace with a child's competence, while placing child agency in communication at the forefront of design. It also recognises that children might have an uneven profile of competences that relate to their social, strategic, operational and linguistic skills (Light, 1989; Light & McNaughton, 2014) suggesting the need for a nuanced approach to how AAC is personalised.

Supporting child-initiated communication

Our study showed that the communicative functions for which AAC devices were used were limited. This meant children had few opportunities to learn how to participate in more diverse communication situations with adults and other children who use AAC. This consequently added to unbalanced conversation dynamics that are typically structured by naturally speaking conversation partners. Alongside its role in confirming

past findings, our findings suggest that one possible new design agenda might include a focus on ways of establishing common ground with peers who also use AAC. Further, AAC could offer children new ways to explicitly signal that a problem in understanding is occurring, allowing for self-clarifying following misalignments in understanding.

CONCLUSION

Our research aim was to examine how communication occurs in conversations involving children, adults and AAC, and the mediating role of AAC design. Our findings present design opportunities for incorporating an embodied view of communication, and designing to emphasise children's competence and agency. One limitation we faced was capturing repeated incidents of communication involving children and AAC in naturally occurring interactions. Additional research is needed from more diverse contexts. Our study should not be interpreted as providing clear solutions to this complex problem space, but rather identifying new avenues for a future design agenda.

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Teach Us Too

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Eleven-year-old Jonathan Bryan is many things: son, older brother, Christian, baker, lover of Lego and aeroplanes, funny, cheeky, author, poet, mathematician. Above all these though, Jonathan is often defined by his physical disabilities; as Jonathan also has Cerebral Palsy. Alongside this, Jonathans list of labels continues: Chronic lung disease, scoliosis of the spine, transplanted kidney, auditory neuropathy, squint, short stature, deranged liver. Most notably though for Jonathan, upon entering the Special Education System aged 4 he was assigned the label PMLD (Profound and Multiple Learning Difficulties) and it was this label alone that defined Jonathan's education from that point on.

As a child in a Special School labelled as having PMLD, Jonathan was exposed to a largely sensory curriculum. One that saw him sung to (nursery rhymes), read to (toddler style picture books), take part in swimming, physiotherapy, light therapy, music therapy and sensory stories. However, Jonathan's academic potential was not understood; and without any attempt made to teach him the reading and writing skills that his able-bodied peers at his local mainstream primary school were afforded, Jonathan's frustrations grew.

From the early signs that Jonathan's eyes were his access to communicating and learning, it became obvious to Jonathan's family and friends that his cognitive ability surpassed the expectations of his Special School; and with a reluctance from them to embrace his new-found skills, Jonathan was removed for a couple of hours a day for his mother to teach him to read at home! Following a phonics based

program and some guidance from Speech and Language Therapists and specialist educator Marion Stanton, Jonathan's mother guided him through the early stages of reading and writing. Contrary to instinct, when Jonathan appeared to become disengaged in the early weeks, his mother was advised to up the challenge and make it harder. Jonathan was bored! Sure enough, with the challenge increased and the pace and fun of lessons enhanced, Jonathan made incredible progress.

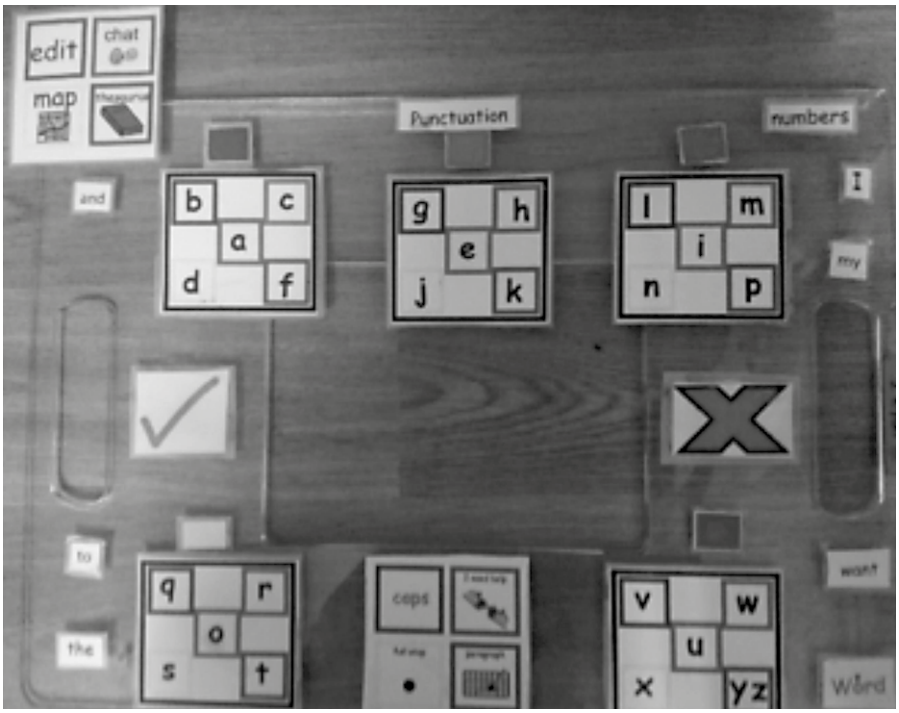
Three years after that first tentative home school session, Jonathan had academically caught up with his able-bodied peers at mainstream primary school, and was invited to attend every afternoon while continuing English and Maths lessons at home in a more suitable environment (following the mainstream curriculum and with support and guidance from his mainstream school teachers).

In contrast to his mainstream school integration, Jonathan is still labelled as having PMLD: Profound and Multiple Learning Difficulties. Jonathan, however, has no learning difficulty at all. In fact, he loves to learn and is currently finishing the writing of his first book to be published in July 2018! There are things that are 'difficult', yes! Jonathan is quadriplegic and non-verbal which inevitably makes communication a challenge. A surmountable challenge in Jonathan's case, as no sooner had his access been found, Jonathan's communication skills developed quickly. Jonathan uses his eyes to communicate: indicating letter, word and number choice from a selection presented to him on a Perspex board.

It is fair to say that none of this was or is easy. It requires communication partners and scribes, time, perseverance and understanding. But, above all, it requires belief! Belief that children with PMLD can learn, make progress and are worth academically teaching. Of course, not every child with PMLD will progress as Jonathan has – sitting Year 6 SATs (and getting an average of 92% across the board), enrolling in mainstream primary or secondary school or indeed writing a book! However, as a voice for the voiceless, Jonathan's message is clear. PMLD is not a diagnosis, it is a label and no label should ever define what is possible. All children should be given the opportunity to learn and be academically fulfilled at a level and pace suitable to them. Communication access is paramount in enabling this journey. Once a child's access to communication has been established this can then be developed beyond the very basics and used to educate them.

Establishing communication access and appropriate tools for each individual child is complex and will inevitably require Speech and Language therapists to work in partnership with teachers, each sharing their expertise – one in communication and the other in education. These two concepts are inextricably linked for without one, the other is impossible! Giving a child a way to communicate, whether that be high or low tech, is not the same as teaching that child to read and write. Making choices on an eyegaze machine, for example, is not the same as learning to read. Once a child is able to access a method of communicating, teachers must then begin the task of teaching that child the literacy skills they would be afforded in any other type of educational establishment.

This campaign is big and unwieldy and requires a fundamental shift in long established perceptions and misconceptions. But at Teach Us Too, we hope that by changing the perception of one person at a time we can make a difference to those children out there who are just waiting for an opportunity to be taught to read and write. Like Jonathan, we can't possibly be the judge of their potential based on their disabilities. We must always seek to teach to their abilities!



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