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Topics include: Adult Scaffolding - Self-Representation on Social Media - Stephen Hawking -Talking Mats - Communication Access UK - Literature Review on Language Abilities -The Communication Project - Assessment Procedures - Lego-based Therapy - Conference -Social Media for Engagement - Switch Access





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Contents



CM member and AAC user, Sophie, using a MegaBee frame to communicate at the CM2018 Conference

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Communication Matters / ISAAC (UK) 3rd Floor, University House, University of Leeds, Leeds, LS2 9JT Tel: 0113 343 1533 Email: admin@communicationmatters.org.uk Website: www.communicationmatters.org.uk Registered Charity No. 327500 Company Registered in England & Wales No. 01965474

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Emily Campbell Email: admin@communicationmatters.org.uk Design & Production

Kaarin Wall & Emily Campbell Advertising and Overseas Subscriptions

Tel: 0113 343 1533 Email: admin@communicationmatters.org.uk

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- 2 Co-chairs' Report
- 4 Changes in Adult Scaffolding in Conversations with Children Who Use Aided AAC Gat Savaldi-Harrusi and Gloria Soto
- 7 Self-representation on social media for young people who use augmentative and alternative communication (AAC) Amanda Hynan, Juliet Goldbart and Janice Murray
- 9 My Experience of Stephen Hawking's Memorial Service Jemima Hughes
- 10 How can Talking Mats help with determining capacity? Joan Murphy and Nicki Ewing
- 14 Communication Access UK the journey continues... Catherine Harris
- 16 A Literature Review on the Language Abilities of Children and Young Adults who use aided AAC during language development Yvonne Lynch, Juliet Goldbart, Shakila Dada, Liz Moulam, Nicola Randall, Simon Judge, Stuart Meredith and Janice Murray
- 21 The Communication Project Kim Mears
- 25 Investigating the Assessment Procedures for Children with Complex Communication Needs: The Participation Model

Elena Theodorou, Eliada Pampoulou and Nikoleta Sampson

- 28 An Introduction to Lego-based Therapy Dannii Keenan and Lois Thomson
- 31 A review of the talk "Participation For Young AAC Users" Adam Lenartowicz
- 32 Social Media for Engagement: Safe and Enjoyable New Frontiers for People who use AAC Bronwyn Hemsley
- 34 Switch access: the first way forward in AAC assistive technology Esther Dakin

Co-chairs' Report

Toby Hewson & Ruth McMorran

It was great to see so many people at CM2018. A CM conference is always an occasion for everyone from the world of AAC to get together. This year we had more delegates than in the last few years, with 36% of attendees who were either new or people who had not attended over the last three years. We were particularly delighted to see many AAC users who had never attended conference before – several presented posters or platform sessions and many others commented that now they've been a delegate, they want to be back next year with their own presentation – we look forward to receiving their abstracts in the Spring. The remaining delegates included speech and language therapists, occupational therapists, teachers, suppliers of AAC, researchers, parents and family members of AAC users, clinical scientists, students and more!

We were pleased that so many delegates took the time to complete the evaluation form either in paper format or online. It's good to be able to tell you about some of their comments:



Co-chairs' Report

However not all comments come from the evaluation form – here is a taster of some comments on social media:

Thanks to all, it has been another fantastic 2 days

Has been utterly fantastic thank you everyone involved in make it The most awesome conferencel #CMROCKS What an amazing 3 days IThank you to all who organised or presented at it. It was lovely to meet everyone S Monday night was a particular favourite S CM ROCKS II x

> Such a brilliant, informative and well planned event, so pleased I attended. Communication Matters really does rock. Thank you so much X X

We are also thrilled to receive acceptances from the winners of this year's Alan Martin and Jamie Munro Awards:

Alan Martin Creativity Award Winner 2018

Dave Young – Performance Artist and Poet

"I am completely overwhelmed and delighted that not only was I nominated but that I won the award. I feel very privileged to be able to inspire other AAC users with my work and to encourage everyone to have a voice in society. First of all I would like to thank Amanda Hynan for Nominating me, as well as Jo Cope and Janet Mayes for inviting me to facilitate poetry workshops at 1 Voice this year in July. I also want to thank Claire Hodgson, the Joint Artistic Director of Diverse City and Extraordinary Bodies, for enabling me to have a voice in the arts in the first place.



I really hope I inspire more people to use their communication aid in a creative way, even just writing poetry for themselves, because writing poetry is a great way to learn English and encourages self-expression. I have found that creativity is the best form of communication. It has helped me so much, to develop my sense of self, and I am proof that turning a hobby into a career is possible. I would love to read more poetry written by AAC users, and anyone is welcome to share anything they may have written through The Shouting Mute Facebook page.

During that weekend I realised that AAC and communication aid users still feel that they are left out, so I want to make a promise here and now. Over the next 5 years I will create more artistic opportunities for AAC and communication aid users as The Shouting Mute, through working as a spokesperson, and by facilitating more workshops of this kind. In exchange I want to hear from other communication aid users. I want to know who else is using their technology to be creative. Social media is great for bringing us together, and for continuing a conversation, so don't be shy! Be creative, express yourself and most importantly be heard. Without shouting nobody will know we are here.

Thank you all very much."

Jamie Munro Inspiration Award Winner 2018 Janet Scott

"I was extremely honoured to be nominated for the Jamie Munro Inspirational Award ... and even more surprised, touched and humbled to find that I had been voted the lucky recipient (against two other very worthy contenders). Unfortunately, I was not able to be at this year's conference to collect the award myself, however I now have it and it is sitting in pride of place on my mantlepiece. I feel very fortunate to have met so many people who have inspired (and encouraged and motivated) me throughout my career and my work in AAC – too many to name (and too fraught with the possibility of missing an important someone out if I tried to!). So, this award is really an acknowledgement of, and a thank you to, every-

one who I have had the privilege of working with and for over the last 40 years."



Save the Date

The 33rd Annual CM Conference will be held at the University of Leeds 8-10th September 2019.

Changes in Adult Scaffolding in Conversations with Children Who Use Aided AAC

GAT SAVALDI-HARRUSI, PH.D

Department of Communication Disorders, Ariel University **Email:** gatharrusi@gmail.com

GLORIA SOTO, PH.D

Department of Special Education, and Department of Speech, Language and Hearing Sciences, San Francisco State University **Email:** gsoto@sfsu.edu

Social interaction provides a foundation for children's language growth (Clark, 2014; Clarke, Soto, & Nelson, 2017; Soto & Clarke, 2017; Veneziano, 2010). Adults play a crucial role in supporting language acquisition through conversational exchanges. The quantity and quality of adults' scaffolding (feedback) influences acquisition and later development of grammatical forms and lexicon (Clark, 2018). American children in high socioeconomic classes are exposed to 2,153 words per hour, 215,000 per week, 11 million per year, and 44 million in four years (Hart & Risley, 1995). Whereas children with typical development acquire language naturally through exposure and interaction without formal instruction (Ravid & Hora, 2009), children with motor speech disorders who use speechgenerative devices (SGDs) embark on a long journey of explicit instruction within language intervention. Children who use augmentative and alternative communication (AAC) must learn the oral language and the linguistic symbols, and their organization in the device.

Scaffolding: Typically Developing Children

Typically developing children receive extensive feedback on their speech during their first years, allowing them to practice what they hear and repair ungrammatical or unclear messages (Clark, 2014). Adults adjust their speech to the children's level by using short sentences, pauses, and repetition. In successful language learning, the child converses with the adult on a shared topic (joint attention) and assesses whether the adult shares the same attention or needs more information (common ground, Clark, 2014, 2017).

Adults use verbal scaffolding such as models, recasts or prompts to support the interaction (Veneziano, 2010), jointly construct a dialogue within a shared context, and expand and build the child's communicative intent. Verbal models are verbal scaffolding in which the adult models new words or information relevant to the child's previous utterance. Adults often use fixed frames, for instance, introducing new nouns with the frame, "That's _ During shared reading, the child may ask, "What it is?" and the adult may reply, "That's a flower." For new verbs, adults ask a general do question and then introducing the verb: "What's he doing? He's knitting" (Clark, 2018).

Adults use *Recast* or *Reformulation* to check the child's intention when the child makes an error by reformulating the previous utterance without interrupting the conversation flow. Clark (2018) explains reformulation as especially necessary when children use one or two words because omission makes it hard to understand their intention. For instance, the child says, "Milk, milk," and the adult checks the child's intention, saying "You want a milk." When the child uses ungrammatical forms such as incomplete verbs construction—omitting auxiliary verbs, subjects, or modals—the adult's recast or reformulation provides the conventional form in the next turn, allowing the child to correct the error as in the following example (Clark *et al.*, 2017; Veneziano, 2010):

Child: Don't fall me downstairs!

Father: I would not drop you downstairs.

Child: Don't drop me downstairs (Clark, 2018)

Prompts are verbal cues that help the child produce a target utterance or self-repair. They include a scaffolding strategy such as Yes/No and WH (i.e. begin with who, what, where, when, which, why, whose, and how) questions, and have their own acquisition hierarchy. The scaffolding type depends on the child's prior utterance, action, and linguistic level. Adults change the structure and organization of the dialogue according to the child's language level, and the scaffold intensity and quality changes with the child's changing abilities (Peterson & McCabe, 1996). During conversional exchanges with young children, verbal scaffolding is vertically structured (Figure 1)—the adult scaffolds the child's utterances by asking questions, providing corrective feedback, and extending the child's previous utterances with more complex language (Clark, 2014).

Adult	Child
Where did you go with Nana?	
	Park
Oh, you went to the park?	
	Went Park
What park did you go to?	

Figure 1. Example vertical scaffolding during an adult-child interaction.

Scaffolding: Children Who Use AAC

Language interventions are designed to promote the linguistic skills of children who use AAC and develop operational competencies expressing the oral language via the graphic symbols in communication devices.

In the aided communication hierarchy, verbal scaffolding is often considered the least intrusive prompt, while full physical assistance hand-over-hand is the most intrusive prompt. The communication partner is encouraged to use least-tomost prompting to achieve independent communication (Finke et al., 2017). Many children with significant disabilities have poor communicative responsivity and reciprocity, limiting their opportunities to participate in natural, authentic interactions that support language. Within the vertical structure of AAC, the adult may use predominantly Yes/No questions, control the conversation topic, and repair communication breakdowns, whereas the child produces single-word utterances with less repetition.

The last two decades have seen a call to include verbal scaffoldings in language interventions for children with disabilities to parallel typical acquisition. Soto and Clarke (2017) adopted this technique in a study of eight children with motor speech disorders who used SGDs. Following a 10-month language intervention in which clinicians supported essential linguistic structures, such as pronouns, verbs, and bound morphemes, in personally meaningful and scaffolded conversation, study participants improved vocabulary and grammatical skills (i.e. production of independent clauses, bound morphemes, and vocabulary). Although the study reported on the children's outcomes, it did not describe in full the types of scaffolding strategies used by the all adults involved in the study, or how these strategies changed as the children's language improved.

Therefore, the purpose of this paper is to describe the types of scaffolding strategies used by adults in interaction with children who relied mostly on aided AAC to communicate, and whether the strategies used by the adults changed as the linguistic skills of the children changed.

Methods

Research Design

This study involved analysis of a data subset from the Soto and Clarke (2017) study-specifically, transcripts of all generalization sessions for four participants: two girls (Child A and B) and two boys (Child C and D) between the ages of 8 and 13 years. These transcripts reflect conversations between each child and a familiar adult about topics on which both the child and the adult agreed. The adults were not part of the intervention and had received no instructions on how to talk with the child. Each child conversed with the same adult across all generalization sessions. Although the adults were familiar to the child, each varied in their degree of AAC training. For Child A, the adult was her AT/AAC specialist; for Child B, and D, the adult was their instructional assistant and for child C the adult was his adult sister. These conversations occurred once before the intervention, every six intervention sessions, and after the intervention had ended, at two-, four-, and eight-week intervals whenever possible.

To participate in these conversations, the children used high-tech SGDs that included core vocabulary and grammatical markers to allow construction of grammatically correct utterances. The children were competent users of their SGDs (with English output). Before the intervention, the children communicated mostly through single-word utterances in unstructured interactions. During intervention, their expressive vocabulary and production of grammatically correct spontaneous utterances increased significantly (Soto & Clarke, 2017).

Coding Scaffolding Strategies

In the current study, we analyzed and coded the adults' contributions to the conversations into the following scaffolding strategy types:

1. Open-Ended Question

Question cannot be answered with "Yes" or "No"

Adult: What are you going to do for spring break?

2. Yes/No Elicitation

Yes/No question for the purpose of eliciting information to start or continue a conversation topic

Adult: Do you want to talk about spring break?

Child: Yes.

Adult: Are you going to Grandma's house?

Child: Yes.

3. Yes/No Clarification

Yes/No question for the purpose of requesting clarification of the child's previous utterance.

Child: Bonny feed bowl dog same dog Luna.

Adult: So Bonny and Luna are the same kind of dog?

4. Yes/No Operational

Yes/No question about the device operation or child's seating position *Adult*: Do you have the word "Handsome" in your device"? *Child*: No.

5. Recast

Reformulation of the child's utterance *Child*: I want to play at car. *Adult*: I want to play WITH car. *Child*: I want play videogames.

Adult: You want TO play videogames.

Interrater Reliability

Two coders were repeatedly trained until they reached 99% reliability. They independently analyzed 30% of the randomly selected transcripts. Interrater agreement ranged between 93% and 96% for each code, with lower agreement for Yes/No Clarification than for Yes/No Elicitation.

Results

Analysis of all the adult scaffolding strategies in the dataset yielded 688 scaffolding strategies (Table 2). All adults used all five strategies. For three children (A, B, and C), the adults primarily used two categories—*Open-Ended* and *Yes/No Elicitation Questions*—and for Child D, the adult used mostly *Recast* and *Open-Ended Questions*. No pattern was found in the scaffolding for *Yes/No Operational*.

Adult Scaffolding Changes Over Time

Although the adults varied in their preferred strategies, some patterns emerged. Mainly, the type of scaffolding strategy changed for all adults as the children's language skills improved. For Children A, B and D, the adults increased the use of *Recast* over the 10-month period (Figure 1). For Children C and D, the adults decreased the use of *Yes/No Clarification* (Figure 2)

Discussion

This study's preliminary results suggest that the type of scaffolding strategy communication partners use with aided communicators changes as the children's vocabulary and grammatical skills improve. This is consistent with typical development and clinically relevant, whereas typically developing children are "naturally" exposed to extensive feedback, children who use AAC depend on professionals, teachers, and parents to provide opportunities to practice linguistic skills and device usage. Communication partners of children who use aided AAC need

Table 1. Summary of Adult Scaffolding Strategies by Child

			Strat	egy				
Child	Frequency (%)							
	Open-ended question	Yes/no elicitation	Yes/no clarification	Yes/no operational	Recast	Total		
A	212 (30.8)	212 (30.8)	87 (12.6)	95 (13.8)	82 (11.9)	688 (100)		
В	127 (24.0)	188 (36.0)	59 (11.0)	101 (19.0)	54 (10.0)	529 (100)		
С	221 (30.0)	142 (20)	129 (18.0)	116 (16.0)	119 (16.0)	727 (100)		
D	101 (25.0)	79 (20.0)	45 (11.0)	51 (13.0)	127 (31.0)	401 (100)		

Figure 2. Increased Recast use over time (Child A, B, and D).







to be aware of the different scaffolding strategies they tend to use with the children and the ones that support language growth.

In this study, adults used *Open-Ended* and *Yes/No Elicitation* questions most often, increased *Recast*, and decreased *Yes/No Clarification*. This suggests that as adults perceived the children able to self-repair (once they start to combine words), they began to use *Recast* at a higher percentage. *Open-Ended* questions and *Yes/No Clarification* are also facilitative in the sense that they advance conversation and establish a common ground by eliciting more information. Lastly, *Yes/No Operational* questions while used at a lower rate, remain a helpful and unique strategy for children who use SGDs.

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Self-representation on social media for young people who use augmentative and alternative communication (AAC)

AMANDA HYNAN

Senior Lecturer in speech and language therapy, Leeds Beckett University **Email:** a.hynan@leedsbeckett.ac.uk

JULIET GOLDBART

Professor of Developmental Disabilities, Faculty of Health, Psychology & Social Care, Manchester Metropolitan University **Email:** j.goldgart@mmu.ac.uk

JANICE MURRAY

Professor of Communication Disability (AAC), Faculty of Health, Psychology & Social Care, Manchester Metropolitan University **Email:** j.murray@mmu.ac.uk

Background

Many people with physical impairments who rely on AAC have spoken positively about the value of digital technology to support communication. Martin Pistorius (2011), in his book Ghost Boy, spoke about feeling sick when his computer stopped working, saying all he had "to communicate with now [was] a battered old alphabet board that won't reach around the globe". Face-to-face AAC-mediated conversations often present challenges for interactional communication (sharing experiences), creating narratives, and sharing humour due to factors such as: disrupted turn-taking, reduced opportunities to contribute, slowed rates of communication, and (often well-intentioned) dominance by conversation partners. Advances in digital technology have allowed people who rely on AAC to use online communication tools to bypass many of these challenges by creating multi-dimensional ways in which to communicate (Hynan, Goldbart & Murray 2015; Caron & Light, 2016). This in turn strengthens control over self-directed activities and leisure and supports the maintenance of social relationships (Caron & Light, 2016). Being online can also support opportunities to increase numbers of communication partners (Grace et al. 2014). A particular theme which will be explored in this article is the increased support for self-representation through social media tools, such as Facebook™ (Hynan, Murray & Goldbart, 2017).

AAC, the Internet and social media research

A research project (Hynan et al. 2015) explored how AAC-users self-reported their experiences of accessing and using the Internet and social media, and how they perceived this impacted on their ability to determine their own lives, represent themselves, and interact socially online. 25 people aged 14-24 years old (13 males and 12 females) took part, 24 had face-toface interviews and one person provided information in a blog. The research (Hynan et al. 2015) used an approach called constructivist grounded theory which means that interview data is collected and analysed concurrently to generate theory. This current article will present selected data from 9 of the research participants to

Table 1: Participant demographic data

Name Age Orthographically Device control literate AAC Computer Keith 19 Yes Direct access Will Bluetooth 19 Yes Head switch USB cable Nancy 21 Yes Head mouse camera Ben 14 Yes Direct access Moira 22 Yes Direct access Peter 17 Yes Head switches Parental support Caroline 21 Yes Head switches Harriet 22 Yes Direct access Carol 19 No Direct access to symbol-based device Communication supplemented with Makaton™

illustrate how many of their insights into their online self-representation resonated with existing psychological and sociological theories about identity formation. The participants' names have been changed to protect their identity.

Self-representation data

In terms of self-representation, Carol explained through gesture that Facebook[™] was good because it allowed her to share information about herself with friends. Peter said it helped him to illustrate what was important to him, such as things he liked and places he had visited. Ben said he used his profile to show he knew "French, English, and Portuguese". Keith explained his profile picture of Pikachu[™] (a Pokemon[™] character) by saying "I like Facebook[™] because I like seeing me holding Pikachu[™]". Will said that he used his status on Facebook[™] to tell people "what I think". Nancy felt the best thing about Facebook[™] was "it good show pictures" and when Moira was asked what kind of things she put on Facebook[™] she said "anything, well I am mixed person". Another feature of social media use that emerged as important was the ability to limit misunderstandings and to increase perceived equality. Peter said that being online was "a really good way for people to get to know you better and understand you" and Nancy felt that "people understand me better in writing". Caroline wrote in her blog, "I read what everyone is up to, I like or write comments, and look at photos. I like that because I communicate equally with everyone." Moira found that an advantage was "it shows people that how they have to wait to hear what I say". Harriet touched on issues to do with expressing humour and creating narratives by explaining that she liked to put silly stuff on Facebook™, for example she said she had a picture of herself "leaning on a shopping trolley". She also liked the timeline function on Facebook™ because it allowed people to look back at "really old" posts.

Theories of identity formation

In order to understand how theories of identity may be relevant to the information given by the participants, the ideas of psychological and sociological theorists will be briefly outlined. Goffman (1959) suggested in his work, 'Presentation of the self in everyday life', that the social relationships between people, groups and institutions can be interpreted as theatrical performances. Central to this idea is that individuals create and act out roles that they hope will be taken seriously by others. Erikson (1963) proposed an eight-stage theory of psychosocial development based on ego identity from infancy to late adulthood. He suggested that each stage presented a specific challenge or conflict within a natural, cultural, and ecological context. Two stages related to adolescence and young adulthood and were labelled by Erikson as 'identity versus role confusion' (12-18 years), and 'intimacy versus isolation' (19-40 years). Within the 'identity versus role confusion' stage, Erikson proposed that an intense exploration of the self takes place to establish beliefs, values and goals and to create an integrated sense of self with an increased focus on alignment with cultural icons (e.g. fashion, music, etc.). The next chronological stage outlined by

Erikson focused on an individual searching for intimate relationships with others outside of the family circle in order to build long term commitments. It was also theorised that problems resolving these challenges, or conflicts, could lead to problems for the individuals concerned. for example, confusion about their role in life or feeling isolated. Marcia (1980) considered identity formation in adolescence as the self-creation of an internal concept to carry through into adulthood which had been shaped through a re-examination of childhood physical, cognitive and social constructs. He argued that if this is well developed, an individual will have a sense of stability and internal validation. However, if poorly developed, the individual may seek external validation for a sense of self. Smith (2005) considered adolescent development within the context of young people who rely on AAC; she discussed the ways that adolescents attempt to forge their own identity as their bonds with parents weaken and their relationships with peers take on greater significance. She argued the increased linguistic demands required during adolescence can be difficult to navigate within the complex context of using AAC.

Livingstone (2008) researched social media use by young people and adolescents and suggested that the convergence of multimedia sites offered a relatively safe place to carry out complex explorations of self-presentation within a social context. One potential advantage of being online for those with physical impairments is the ability to take control over the negotiation of their identity (Seymour & Lupton, 2004). Zhao, Grasmuck and Martin (2008) carried out an analysis of the content of Facebook[™] data collected from 63 university students and suggested that the construction of identity happens through public announcements being made and interpreted by others. They suggested that there is a continuum of identity strategies: the implicit visual end, where the self is shown as a visual actor ('watch me' e.g. photographs but no narrative), which progresses to an explicit narrative ('first person self' that creates more detailed descriptions to explain the self). There is also a midpoint with an enumerative self ('self as consumer' where a person lists cultural interests, books, music, films, etc.). Zhao, et al. suggested that creating online 'digital selves' had concrete consequences within offline environments. These suggestions about the construction of a Facebook[™] identity through announcements resonate with the ideas expressed by Goffman (1959) about social performances.

To conclude, adolescent and young adult development is characterised by a desire to establish self-identity through role exploration and the presentation of self. This is accompanied by a re-examination of childhood constructs from a new viewpoint and the desire to build intimate and close relationships outside of the family circle. Being online appears to offer novel opportunities to enrich the exploration of self and 'digital selves' have consequences in the offline world. The medium of social media also offers new ways to express and explore disability.

Applying identity theories to the research data

The participant data outlined earlier (Hynan et al. 2015) suggested that young people who rely on AAC attached importance to their profile information. Keith liked seeing himself holding Pikachu™ (an internationally recognised icon), which may be significant for him as he used tonal vocalisations to express emotions and short phrases understood by those who know him well. Ben wanted to show people he had knowledge of other languages, and Peter wanted to illustrate places he had visited and things he liked. It could be argued that online social media is being used by these young AAC-users to fulfil aspects of identity formation in adolescence that have been outlined earlier. Erikson (1963) discussed the importance of role exploration and alignment with cultural signifiers, Marcia (1980) suggested that the formation of internal concepts was crucial, and Livingstone (2008) argued that online spaces are relatively safe environments in which the self can be explored. The data from Moira, Nancy, Caroline and Harriet suggested that they used social media to challenge perceptions; Moira felt she could show people they had to wait to hear her views and she could express her mixed personality, Nancy thought it increased opportunities for her to be understood, Caroline felt she had increased equality, and Harriet enjoyed expressing humour. Goffman's theory (1959) about the presentation of self suggests that individual performances can be used to influence other people's perceptions. The participant data also supports the findings of Zhao, Grasmuck and Martin (2008) that digital selves created on Facebook[™] can have concrete consequences in the offline world. Many aspects of the Facebook™ continuum (Zhao et al. 2008) were carried out by the participants discussed in this article: implicit (showing photographs), enumerative (showing likes and dislikes), and explicit (offering more complex narratives to explain the self). Harriet's photo of herself leaning on a shopping trolley may also be an opportunity to perform an act of resistance, as outlined by Seymour and Lupton (2004). As a wheelchair user, could it be that she is creating an ironic comedy moment or maybe expressing a political statement about shopping trolley design? Will, Peter and Carol illustrated how Facebook™ may support interacting more intimately with others; Will suggested that he can show people what he thinks, Carol felt she could share information about herself, and Peter thought it was a good way to get to know people. Erikson suggested establishing intimacy with others was a major factor in resolving his 'intimacy versus isolation' stage during young adulthood.

Conclusion

Social media research with people who rely on AAC is currently under-represented (although research is emerging), so not much is known about the opportunities for self-representation in online environments for AAC-users. The findings of this research suggested that the use of online social media had the potential to support the self-representation of people with physical impairments and complex communication needs. The ability to use social media sites to support narrative generation and explore a sense of self with others may also underpin important psychological and sociological factors related to identity development.

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My Experience of Stephen Hawking's Memorial Service

JEMIMA HUGHES

Email: jemima.hughes@btinternet.com

On 15th June I had a really amazing day at the Stephen Hawking memorial service at Westminster Abbey. I went with Kate Caryer and her PA Nat, Lois Thompson and my mum Janet Mayes. Access was really good, I had BSL interpreters in the service, and they had the mobiloo changing place toilet. I felt sad about Stephen Hawking, but he had a fantastic life and showed what people with disabilities and AAC can do. After the service there was a garden party, I met Brian Cox and talked to him about Dr Who. I also met the astronaut Tim Peake and talked to Lucy



Hawking about how Stephen Hawking was my role model when I was growing up; she was really friendly.

Stephen Hawking showed everyone that someone who is disabled and uses a communication aid can be really intelligent and do important work. He was a great ambassador for AAC users. I loved his Little Britain Comic Relief sketch, it's so true and funny, and so many people patronise AAC users like that. He really inspired people.

How can Talking Mats help with determining capacity?

JOAN MURPHY

Co –Director, Talking Mats Ltd Email: joan@talkingmats.com

NICKI EWING

Talking Mats Associate Email: nicki@talkingmats.com

Background

In 1948 Eleanor Roosevelt, as the chair of the United Nations Human Rights Commission, was the driving force in creating the Universal Declaration of Human Rights Act (1948).



Since 1948 many countries have passed laws stating that people with communication disabilities should have equal rights including in the complex area of mental capacity.

In the United States there is the **Americans** with Disabilities Act of 1990

In England and Wales the key Acts of Parliament are the **Mental Capacity Act (2005) England and Wales** and in Scotland the **Adults with Incapacity Scotland Act (2000)**.

The UK Acts provide the framework for assessing mental capacity in adults aged 16 and over. The Acts state that **every**

adult has the right to make decisions unless proved otherwise.

These acts are designed to both empower and protect people who may be unable to make decisions, for example, because of dementia, brain injury, stroke, learning disabilities or mental health problems. It is important to remember that just because a person has one of these conditions does not necessarily mean they lack capacity to make a specific decision.

There are a number of key expectations behind these Acts which are significant for people with communication difficulties.

- Everyone should be supported to make their own decisions, including those who use Augmentative and Alternative Communication methods
- Adults should be encouraged to make use of their skills and to learn new ones where that would be helpful
- Information to support understanding needs to be given in a way that is appropriate to the person's circumstances. For example using simple language and visual aids
- People are entitled to make their own decision this is not about what others might think is good or bad
- If someone is judged to lack capacity, then decisions must be in their best interest, and any measures taken on

their behalf are to be the least restrictive to the person

Judgements on capacity:

- cannot be based on age, behaviour or disability
- cannot be based on past experience of decisions – they need to be focused on the here and now
- must take into account the adults' socio-cultural circumstances wherever relevant
- must recognize that where a person is able to retain the information relevant to a decision for only a short period, this should not prevent him or her from being regarded as able to make the decision



Determining Capacity

Both the Mental Capacity Act (2005) in England and Wales and the Adults with Incapacity Scotland Act (2000) identify the following components which determine whether or not someone has capacity to make their own decisions. The Acts state that we must assume that someone has Capacity, unless it is established that the person has substantial difficulty in one or more of these components.

How Talking Mats helps

Talking Mats is a research-based (http:// www.talkingmats.com/projects/ research/) interactive resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them.



How Talking Mats supports the four criteria for determining mental capacity



Communicating decisions



Allowing the person to express their own views, irrespective of whether they are right or wrong Giving control to the person being interviewed Providing a visual space on which to build up their composite views Working in conjunction with existing communication systems



This can either be a physical, textured mat, or a digital space, for example a tablet, smart board or computer screen. Once the topic is chosen (e.g. *where you live*), the participant is given the options one at a time and asked to think about what they feel about each one. They can then place the symbol under the appropriate visual scale symbol to indicate what they think.

If there is doubt about the person's ability to make a decision in a particular area of their life, the Talking Mats framework helps assess capacity by allowing people to consider each option around the topic then choose where they place the symbol under the appropriate top scale.

This process helps identify the level of decision making ability the person has. For example, the person may be able to make day-to-day decisions, but struggle to understand the implications of more complex decisions such as moving into a care home.

It is important to remember to assess people when they are in the best state to make the decision. We have found that many people, who would otherwise be judged not to have capacity, can show that they can indeed understand and express their views about aspects of their lives. The process of completing a Talking Mat helps people retain their view. If they have memory problems the picture of the mat is also a good prompt to enable recall.

Using symbols based on the ICF framework, Talking Mats can evidence the thinker's ability to make decisions and facilitates their ability to make more abstract decisions by making them more concrete.

Equally, our work so far indicates that if someone cannot use Talking Mats, this may be an indication that they do not have capacity for that particular decision. An additional benefit is that having a visual record of the mat can help ensure that capacity evidence is up-to-date and re-evaluated over time.

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- World Health Organisation., 2001. WHO-ICF: International Classification of Functioning, Disability and Health. Geneva: World Health Organisation.
- For more information about Talking Mats and blogs on Capacity, visit <u>www.talkingmats.</u> <u>com</u>

Final Thought







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Communication Access UK – the journey continues...

CATHERINE HARRIS

Email: accessproject@communicationmatters.org.uk

The title of the session was 'The Journey Continues...' Although sometimes overused, 'journey' is an appropriate term to describe the experiences through the 2-year pilot project for Communication Access UK. As with so many journeys it is not always as simple and straightforward as it may first appear and takes much longer than estimated on Google maps! There have been ups, downs and holdups and we are still travelling!

The aims of the pilot were:

- To launch a symbol for communication which is recognised throughout the UK
- To develop a communication training package for businesses
- To test out resources with staff at the University of Leeds as a pilot site
- To involve people with communication support needs as mystery customers and presenters to deliver training
- To train at least 3 other businesses before the end of the pilot phase

These aims have all been met, although it is recognised that it was perhaps an ambitious vision. There is still a lot more to do! However, a useful part of the pilot has also been to highlight issues to find what works, what does not work and what factors have had a significant impact on the delivery and potential roll out.

A steering group, running parallel and overlapping with the pilot project, has been focussed on the symbol consultation and development, standards and a longerterm strategic plan. The Steering group has representation from Communication Matters (CM), Royal College of Speech and Language Therapists (RCSLT), Headway, Motor Neurone Disease (MND) Association, Stroke Association and the recent addition of representatives from Disability Rights and the Disability Business Forum. The steering group networks out to over 60 other charities and organisations who have communication support included within their remit. It has felt that it has been essential to work in partnership from the beginning if CAUK is to have maximum impact and sustainability, even if this at times appears to slow down the rate of progress.

The Symbol

Following a very extensive consultation process we do now have a symbol for the UK, which is being further evaluated through the early adopter phase. Although an international symbol for communication access would be the preferred option for some, this has proved to be unachievable at the present time



for many and complex reasons. The twostage UK-wide consultation resulted in over 6000 responses. In the second round with over 3000 responses, 26% were from people with communication support needs which was really encouraging (see fig 1). The views of AAC users have been well represented.

In the first consultation, in addition to choosing a preferred symbol, participants were asked what helped them communicate effectively. From these, operational standards or indicators have been developed and these were confirmed through the second phase of the consultation (see fig 2). Organisational standards are also being developed, which link to previous work on inclusive communication, to ensure a top down and bottom up approach and together these will support a framework to monitor whether standards are being met.

Training

Training packages have been developed and trialled at the pilot site of the University of Leeds. Over 100 staff from a variety of staff groups including hospitality, catering, admin and security teams have attended workshops and have shaped the content and format of the presentations. There was the request for a short acronym or prompt to aid recall following training. The TALK prompt has been tested over a 3- month period with people with communication support needs including AAC users, SLTs and business contacts and has received positive reviews.

- T TIME
- A ASK WHAT HELPS
- L LISTEN
- K KEEP TRYING

This prompt has now been integrated into the training.

Early Adopters

AAC Hubs, Specialist FE colleges and SLT departments are being encouraged to become early adopters of the symbol and to engage with local businesses to promote CAUK. Training workshops are being delivered by the project lead to local businesses in Southbourne-on-Sea, Bournemouth, SuperTram Sheffield and a small pub chain as part of the pilot. Two local authorities have also agreed to be early adopters selecting two departments initially to have training input. The aim is to use a 'Train the Trainer' model for delivering face-to-face workshops to businesses as requests are received. 10 SLT champions have been 'recruited' from around the UK who are willing and able to deliver workshops to business staff.

Figure 1





The plan is to have a 'Train the Trainer' workshop before the end of 2018 to encourage more SLTs to become involved during the roll out phase. In the longer term an e-learning module will need to be developed to enable organisations to include communication access in induction and mandatory training. There have been initial discussions on this with the RCSLT learning team.

Mystery Customers

Mystery Customers can collect baseline data through the use of the mystery customer questionnaire. This is part of the framework which will help with monitoring impact. Six AAC users are active as mystery customers and workshop presenters to date. Another four have done 1-2 mystery customer visits. Central to the vision and success of CAUK is having input and feedback from people with communication support needs including those who use AAC. Through the pilot it has been identified that a rolling programme of engaging mystery customers will be required to ensure sustainability. This has been a challenge but could be achievable with the support of SLT champions in the FE specialist colleges who are able to introduce the mystery customer role to their students. A bonus is that these visits can be planned in the context of community involvement programmes.

Legislation

If CAUK is to be embraced by business then we have to answer the question as to WHY should a business adopt the symbol?

- The laws state that someone with a disability should be able to visit places, buy things, have fun, get help and get information just like anyone else.
- It is against the law to deny someone a service due to their disability.
- It is necessary to make '*Reasonable Adjustments*' to accommodate people with disabilities.
- (Disability Discrimination Act 1995 and 2005 and Equality Act 2010)

It is also hoped that CAUK will help reduce social isolation and improve quality of life for people with communication support needs and increase public awareness of communication support needs. A prospectus for early adopters has been produced and the training workshops give the opportunity for these factors to be discussed in more detail. Evaluation of the impact of CAUK will be a key factor as we move forward.

Where do we go from here...

At the outset it was hoped that this initiative could be self-funding in the longer term. It became apparent fairly quickly that this was not workable for the UK if the intention was wide reach and maximum impact. Any fees for the training workshops (even if a business is willing to pay) would only cover the immediate costs of the trainers and resources and not the infrastructure needed to support the ongoing administration and marketing. This has resulted in the need for a revised financial plan with bid writing and sponsorship which will be essential if CAUK is to be rolled out across the UK.

Beyond the end of the pilot, it has been agreed that CM will:

- Host CAUK information on website
- Support CM representation on the Steering group

The Steering group are working on:

- Brand development and promotion of symbol
- Case for support for financial planning
- Coordinating full launch of symbol
- Potential of an 'Alliance' to take CAUK forward
- Promoting public sector (including government), private sector and wider third sector adoption

As the pilot project lead this has been an exciting rollercoaster ride and it is not over yet! CM has started something which could be very significant in raising awareness of communication support needs and improving the experience of all people including AAC users in the community.

Please contact CM if you would like to join us on the journey:

accessproject@communicationmatters. org.uk

A Literature Review on the Language Abilities of Children and Young Adults who use aided AAC during language development

YVONNE LYNCH¹ (yvonne.lynch@mmu.ac.uk), JULIET GOLDBART¹, SHAKILA DADA², LIZ MOULAM¹, NICOLA RANDALL³, SIMON JUDGE³, STUART MEREDITH¹, AND JANICE MURRAY¹ (j.murray@mmu.ac.uk)

¹Faculty of Health, Psychology and Social Care, Manchester Metropolitan University, United Kingdom ²Centre for Augmentative and Alternative Communication, University of Pretoria, South Africa ³Barnsley Hospital NHS Foundation Trust, Assistive Technology Team, United Kingdom

Introduction

Children who use aided AAC are in a unique language development context. They are communicating with graphic symbols while learning the spoken language in their environment. Hearing speech but 'speaking' through symbols can create challenges to language development. Understanding how communicating with symbols might influence language development could inform AAC system design, selection, and intervention. The Identifying Appropriate Symbol Communication (I-ASC)¹ study was a 3-year funded National Institute for Health Research study exploring how we choose symbol communication aids for children. Specifically, the study involved identifying the child characteristics, communication aid features, and other factors that influenced decision making. The project included three literature reviews to gather and synthesise the existing research evidence about the child, AAC systems and decision making processes. This paper describes the findings related to the language development of children and young adults who use aided AAC.

Research question: What does the literature tell us about the language abilities of children and young adults who use aided AAC during the language development period?

Method

The review was conducted using a robust strategy to identify relevant research studies. Well-established study-evaluation protocols were used to assess research quality. These protocols were used to determine if each study had been well designed and well conducted so that we can be confident in the study results. Irrespective of age of study, only those meeting the inclusion criteria and passing the quality appraisal were included in the review. See https:// www.crd.york.ac.uk/prospero/display_ record.php?RecordID=36785 for more information.

Results and Discussion

The review included 11 research papers (see Table 1 for details of the studies). Across all papers, there were 143 children and adult participants who used aided AAC. Most participants in the review had severe speech and physical impairments with no learning difficulties. The results, therefore, reflect children and adults with this type of profile, who are only one group of people who use AAC. The studies examined the language abilities of children and adults who were experienced aided communicators, and the review results are set out below under the following headings: language understanding, expressive use of symbols, narrative skills, grammatical morphemes and social competence.

Language understanding

Two studies reported on language understanding (Geytenbeek 2014, Lund and Light 2006). In one study, 68 children were assessed to examine their spoken sentence understanding. The results indicated that while all children followed a typical pattern of development, their spoken sentence understanding was more typical of a child younger than their (chronological) age (Gevtenbeek, 2014). Similarly, in the second study of seven young men, who had been using AAC for 15 years or more, all participants scored below average (i.e., younger than their age) on language understanding (Lund and Light, 2006). Participants did not have identified learning difficulties, so, the results suggested that factors affecting language development included language learning opportunities and the influence of communicating with graphic symbols. Currently, we know too little;

¹ National Institute for Health Research, UK Health Services & Delivery Research Project: 14/70/153 - Identifying appropriate symbol communication aids for children who are non-speaking: enhancing clinical decision making

further research is needed to identify how AAC systems and language learning opportunities can best support children to achieve their potential.

Expressive use of symbols

Three studies considered how participants generated graphic symbol output (Soto & Toro-Zambrana, 1995, Van Balkom & Donker-Gimbere, 1996 and Trudeau et al. 2010). While there was much variation across participants, many were able to use limited vocabularies successfully to communicate a range of messages and language structures. For example, in one study, adolescents used an average of two symbols per message to tell stories. However, it was clear that they used extra skills to communicate with fewer words, e.g., using strategies such as 'it sounds like' or repeating words. Some participants used different word orders to the spoken language in their environment. These word order variations were used to make the intended message clearer, suggesting that the symbols used may influence how children convey meaning with symbols. Word order patterns did not appear to be related to age or motor impairment severity but did correspond to the child's language understanding abilities. In summary, there was a wide variation in the language abilities and graphic symbol use of children using aided AAC, and some children have developed highly creative and innovative skills to overcome the restriction of small vocabularies. More research is needed to understand how children develop these strategies and to support more children to use them.

Narrative skills

Two papers from one research project looked at the story telling abilities of children who use AAC (Soto & Hartmann 2006a and Soto & Hartmann 2006b). Across participants, storytelling abilities varied widely. One of the studies found that some children could give a lot of details in their story, while others found it much more difficult to do so. All participants had some difficulty with independently telling stories and using different story elements. The results indicated that maintaining the topic of the story was an area of strength. Children overly relied on one-word messages and because of the limitations of their communication aids, they often depended on their communication partner and allowed the partner to take control of the story. Specifically, children did not use a lot of action words (e.g., run, jump) or pronouns (e.g. 'he' and 'she') in their stories.

They did not use joining words (e.g. 'and' or 'because') either. As a result, it was harder to follow their storylines. These findings suggested that children may need more opportunities to tell stories and may need AAC vocabularies that support story-telling.

Grammatical morphemes

Grammatical morphemes are small words or word-parts of a language that can be used to change meaning. For example, adding the past tense ending -ed turns 'I look' into 'I looked' to show it happened in the past. Some studies looked at how children who use AAC understand and use grammatical morphemes (Blockberger & Johnston 2003, Redmond & Johnston 2001, and Sutton & Gallagher 1993). The results suggested that children who use AAC found it harder to understand and use grammatical morphemes than children who are speaking. The results also suggested that children may leave out grammatical morphemes because of limited opportunities to use them or because communicating with symbols may make it harder to learn grammatical morphemes. These results indicated that children may need more opportunities to learn grammar morphemes even if they are not expected to use them in everyday communication, e.g. drill and practice activities. Based on the findings, it can be proposed that we need to think more about AAC system design and selection to support children learning how to use grammatical morphemes.

Social competence

Finally, one study looked at the ability of four young adults to adjust their communication abilities based on different social situations using a test of social competence (Colquhoun Sutton, 1989). Participants had the most success with communicating messages that could be fulfilled with one word (e.g., 'yes') and with providing information (e.g., that's my coat). Participants had more difficulty with expressing messages more formally (e.g., Could I look at that?) and with expressing feelings (e.g. I love it!). The participants' performance scores did not reflect their age, number of symbols available on their AAC system, or their language understanding. A further result was that participants who interacted with more people on a weekly basis achieved higher scores on the social competence test. This finding suggested that having more communication opportunities is important in

supporting ongoing communication skill development.

Summary

Across the language areas considered here, there was a wide variation in language abilities in children and adults with severe speech and physical impairment who use aided AAC. In some studies, this variation did not appear related to language understanding, access to symbols or age, but did appear to be linked to opportunities to use symbols in communication contexts, and to the number of regular communication partners. Communicating with symbols did affect how children developed skills; despite restricted vocabularies, in many cases children developed specific strategies to support communication demonstrating creative and innovative ways to express themselves.

Clinical Implications

It may be necessary to have a greater focus on language development alongside communication skills in AAC interventions. For example, the opportunity to learn how to use grammatical markers in structured tasks may be important, even if a child will not be expected to use them communicatively (i.e., for efficiency purposes). The review suggests that access to more communication opportunities with more partners is likely to promote language development. Moreover, giving access to vocabulary to support the use of grammatical morphemes, storytelling and different social functions must be considered.

Research Implications

This review indicates that the evidence base on the language profile of children growing up using aided AAC is emerging, but knowledge gaps remain. For example, no UK study merited inclusion in the review. Most studies considered were North American, and so there may be cultural factors that mean the findings may not fully apply to children growing up in other parts of the world. More UK studies are needed. Furthermore, the studies primarily focused on children and adults with severe speech and physical impairment, thus we need to learn more about children and adults with other abilities and challenges who use AAC. Finally, the review suggests that growing up using aided AAC can influence language learning, language use, and communication, however performance varies widely as well. We need to better understand the influences on language outcomes so that we can support more children to achieve their potential.

Table 1: Data extracted from each of the studies in the review

_	Study	Description of Study participants	AAC system(s) used	Aspect of language development studied	Outcomes
1	Blockberger and Johnston (2003) USA and Canada	20 children aged 5.8 -17.1 years who could speak no more than 10 words and had no known hearing loss or second language issues. Diagnoses: Cerebral palsy, developmental delay, syndromes or no diagnosis. Attained age equivalent scores on the PPVT (receptive vocabulary assessment) of between 4yrs – 8:11yrs. The children were compared to 20 children with typical development and 15 children with language delay.	Each of the children had their own individualised communication system often combining unaided modes and light and high tech. Symbols used ranged from PCS, Minspeak, Dynasims to traditional orthography.	Understanding and expression of 3 grammatical morphemes: Possessive "'s" (e.g. Jack's car) Past tense "ed" (I walked to school) 3rd person regular "s" (She walks)	The children using AAC had greater difficulty learning and using grammatical morphemes (both comprehension and expression) than children of the same age with typical development or younger children with language delays who had the same language learning level.
2	Colquhoun Sutton (1989) Canada	4 adults with severe speech and physical impairment (SSPI). 2 male and 2 female ranging in age from 18-29 years Receptive vocabulary (PPVT) age equivalent abilities 8:4 – 11:10 years	All had used Blissymbols for more than 9 years with displays of 461-900 symbols. 1 produced some intelligible spoken words 3 produced vocalisations Participants were estimated to interact with 15-40 communication partners er week	Social verbal competence	Varying pattern of social verbal competence was observed across participants. Achievement scores did not reflect age, number of years using Blissymbols, number of symbols available or receptive vocabulary. However, number of communication partners per week and scores on the measure of social verbal competence seemed to correspond. Participants had the most success with the informing function (3 out of 4 scoring at a 13-14 year level). Difficulty noted with the authority context (expressing in a formal register). 3 out of 4 had most difficulty with the feelings function and 1 had most difficulty with the ritualising function. Participants had the most success with speech acts that can be fulfilled with one word.
3	Geytenbeek (2014) The Netherlands	68 children out of 87 (19 did not pass screening) Severe cerebral palsy (GMFCS levels 4 and 5). Anarthria (productive spoken vocabulary of fewer than 5 words). Able to match spoken words to objects. Children with severe hearing loss were excluded. Children without Dutch speaking parents excluded. And 806 children with typical development.	Not specified	Language comprehension	The children followed a typical developmental pathway but at a slower rate. The children using AAC were more delayed in learning 'who' questions and complex sentence types (significant difference in all sentence types). Children with dyskinetic cerebral palsy had better outcomes on complex syntactic analysis than children with spastic cerebral palsy.
4	Lund and Light (2006) USA	7 young men with SSPI related to cerebral palsy. They ranged in age from 19-23 years and had a range of cognitive skills	All had used AAC for at least 15 years. Systems used: Communication boards (2) Computers (3) Lightwriter (1) Dynavox (1) 5 used indirect selection and 2 used direct selection.	Language comprehension	All participants scored below average on language comprehension
5	Redmond and Johnston (2001) USA	4 children SSPI related to Cerebral Palsy or other neuromuscular condition. Aged 11-15 years Who had fewer than 5 spoken words and used AAC as their primary communication system. Normal hearing and normal corrected visual acuity. School aged. Monolingual English. No issues with an auditory detection probe. Comparison groups: 11 children aged 4-6 years with typical development. 13 children aged 7-10 years with typical development 21 adults	Indirect access to black and white line drawings (no symbols) (1) Direct access to a Liberator device with minspeak (1) Direct access to a Dynavox device with dynasyms (1) Direct Lightwriter with traditional orthography (1) The length of time the children had been using AAC was not specified	Morphological competence – ability to recognise grammar errors	Despite the wide variation in profile of the children with SSPI, a similar pattern of performance was observed across all four children. The children were able to identify when the past tense ending was missing from irregular verb but they missed more errors than their peers who were typically developing but were matched as having the same vocabulary skills. 3 out of 4 did better identifying where a regular past tense ending was used where an irregular past tense ending should have been than vocabulary-matched peers. The children with SSPI were more likely to accept errors where a regular verb was missing the ending than vocab-matched peers. Bare stem regular verbs were particularly challenging for children with SSPI and past tense irregular verbs were an area of strength

_	Study	Description of Study participants	AAC system(s) used	Aspect of language development studied	Outcomes
6 & 7	Soto and Hartmann (2006) Two papers – results presented together USA	 4 children aged 5 – 11 years with SSPI with average cognitive abilities and no hearing or vision difficulties. 3 girls and 1 boy Medical diagnoses: Arthrogryposis and cleft palate (repaired) (1) Cerebral palsy (2) Muscular Atrophy (1) 	 Dynavox 3100, direct access intellikeys keyboard, vocalising, yes/no response, pointing and eye pointing. 100+ customised Spanish and English pages. combining 3-4 symbols. 7 years AAC experience. Dynamyte direct access 30 locations accessed with accuracy. Can comment, request and greet. Working on more complex sentence formulation. 5 years AAC experience Dynavox 3100 with Picture word power. Teacher reported an active vocabulary of: 257 adjectives, 605 verbs, 23 prepositions and thousands of nouns. Typically produced 1-2 word utterances but could produce up to 8 word utterances. 3 years AAC experience Techtalk, dynavox, Step by Step, icon board, printed alphabet board and uses a computer with adapted keyboard and joystick. 9 years AAC experience 	Narrative skills through 5 elicitation tasks	Across the 4 children narrative contribution ranged from very limited detail to appropriate levels of detail. Topic maintenance was a clear strength. Heavy reliance on co-construction with communication partner but could direct the conversation back to a previous point. However, lack of use of conversational control strategies, overuse of 1 word utterance and the limitations of the AAC device often results in all children having to yield conversational control. Appropriate event sequencing was observed in book-based activities but not in other activities. For the two youngest children, language production lacked structure and inclusion of basic story grammar elements There was a lack of action verbs and concrete supporting details within the narratives. Referencing was absent except for eye gaze use (could be considered 'proto-referencing') and occasional use of pronouns for some children Conjunctive cohesion – use of one word utterances and short phrases meant there were limited opportunities for use of linking devices (such as 'and' or 'because'). Pragmatic use of conjunctions was not evident and there was a lack of narrative coherence and fluency in narrative telling
8	Soto and Toro- Zambrana (1995) USA	3 adults with SSPI related to Cerebral Palsy aged 25 – 32 years 2 male, 1 female	Blissymbol communication boards ranging from 120-500 symbols	Morpho-syntactic complexity of language output	The participants were able to convey a wide range of meanings with different language structures using their restricted vocabularies. They demonstrated use of a range of compensatory strategies to aid communication in the absence of the desired vocabulary being available.
9	Sutton and Gallagher (1993) Canada	2 adults with SSPI related to Cerebral Palsy. 1 male aged 25 years 1 female aged 26 years	Communication displays with 450 Blissymbols and alphabet access via numerical codes and yes/no responses	Ability to learn how to use encoding to mark regular and irregular past tense endings	Suggests that individuals using AAC may have a reduced repertoire of language skills that may be related to modality restrictions (i.e. communicating through symbols impacts on language learning).
10	Trudeau, Sutton and Morford (2010) Canada	27 children with severe speech impairment Aged 7:5 – 17:5 years for whom French was their first language Using AAC system for at least 3 months with at least 30 symbols Excluded if using an alphabet system, semantic compaction or if speech problem occurred after primary language development (2 years)	 15 had VOCAS with graphic symbols (range over 30 – 1000 with no. of symbols unknown for 4 participants) 7 had symbol boards (with 60 – 700 symbols). 16 used direct selection 2 used mixed methods 2 used scanning AAC experience ranged from 6 months to 41 years (unknown for 6 participants) 	Ability to construct and interpret symbol sequences	Majority of participants showed consistent patterns in how they interpreted and constructed graphic symbol sequences with a small number showing differences across interpretation and construction of sequences. As most were consistent, this suggests learning to understand and to use graphic symbol sequences develops at the same time (rather than comprehension preceding expression). The majority used the spoken word order in the construction task unless they needed to change it to avoid ambiguity in the meaning. Performance was not related to age or severity of the motor impairment or receptive vocabulary however performance was related to syntactic skills and cognitive abilities.
11	Van Balkom and Donker- Gimbere (1996) The Netherlands	4 adolescents with Cerebral Palsy	All 4 participants used multimodal communication with communication boards. Described as experienced graphic symbol users. The participants communication boards had between 215-400 symbols 1 participant used Single words 1 used Single words and PCS 2 used Rebus and single words	Ability to describe pictures in children's books	Word order deviations from spoken language were observed. Participants used an average of 2 graphic signs per message. The majority of the graphic symbol messages were a succession of nouns with the use of nouns or noun combinations observed in the place of action verbs in some cases. The participants demonstrated overt meta-linguistic skills such as the use of self-corrections, repetitions and other strategies to overcome the restrictions of limited vocabularies to convey meanings.

Legend:

PPVT = The Peabody Picture Vocabulary Test

SSPI = severe speech and physical impairment

GMFCS = Gross Motor Function Classification System

VOCA = voice output communication aid

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The Communication Project

KIM MEARS

Independent Specialist Speech and Language Therapist, TherapyThread **Email:** Kim@TherapyThread.co.uk

In September 2016, a new Speech and Language Service was commissioned at St Ann's Special School in Ealing, West London. St Ann's School is a Secondary Special School for 90 students with severe and profound and multiple learning difficulties. A full-time therapist was employed to provide regular input and I was employed one day a week to work on the Communication Project.

The Communication Project was an initiative to increase staff confidence and student participation in school. The staff at St Ann's are highly skilled, however, they did not always recognise their abilities and they had previously had a limited service from speech and language therapy to support them. It was felt that staff would benefit most from regular, direct support to enhance their current skills.

After reviewing previous research the following aims of the project were agreed by the governors and senior management:

Staff

- staff will have increased knowledge of how to implement individualised communication strategies into class and throughout the school day
- staff will have increased confidence in delivering communication strategies to students that they work with

Students:

• students participating in the project will have identified strategies and methods to communicate with others and they will actively use them for at least 75% of their school day with varying levels of adult support depending on the student's need.

 students participating in the project will use the communication strategies/methods to have a measurable increase in their participation in activities in school. The increase in the level of participation would be specific to each child and based on the findings from the baseline assessment.

Four classes were identified as the classes to be involved in the project and each class had intensive input from myself with support from the full-time speech and language therapist as needed. The classes involved ranged from students who were wheelchair users and had significant access difficulties in using AAC, to students with autism and high levels of behaviours that challenge.

The following strategies were used (see table overleaf) and they were chosen based on their clinical evidence and how practically they could be implemented in school.

What worked in promoting staff confidence?

- Direct weekly input from me to the students, over the term, enabled staff to become increasingly confident and use the techniques in other lessons.
- Individualised support for staff was most effective when compared to inset and class training.

- Having a synergy with staff with everyone contributing their knowledge.
- Encouraging staff to recognise the knowledge they have.
- Being available on the ground to regularly 'tweak' strategies.
- Having a fulltime person to answer questions as they came up.
- Not rushing to train up staff and enabling confidence to grow gradually.
- Communication profiles which gave staff a quick way to know how best to support a student's communication.
- Having a focus to the weekly therapy session, such as sensory story, as everyone was clear in their role and how to work together to support the students.
- Involving senior management and Governors as they were able to support staff to access training and the project became part of the school and not an outside intervention.

A word about student participation:

The project was found to be successful mainly in the area of staff confidence and there were some signs of increased student participation. However, this appeared to be due to staff feeling more confident to implement strategies. It is felt that staff confidence was the most important starting point for the project and that much more time was needed to see measurable increases in student participation. It was also found to be challenging to quantify and measure participation as a whole. If I was to do the project again, I would focus on staff confidence with a small number of case studies to indicate direct impact on student's participation. This would have enabled me to look at individuals specifically and gain information about their progress rather than the class as a whole. It would also have been useful to have decided on a tool to assess participation levels as a number of different screens are currently used.

What I learnt?

- To allow for lots of time. I knew it would take time and even so I still underestimated how much time it would take to implement new strategies even with the focus on only 4 classes.
- Regular consistent input is needed to effect change and support staff.
- Speech and language therapy needs to be explained to staff and then demonstrated regularly. Therapy needs to be direct and the therapist needs to be available as much as possible. The previous model of consultation did not have a lasting effect on staff and their ability to implement communication strategies in the same way as the direct model did.

What next?

Since September 2017 the strategies that were found to be effective, such as the communication profiles, were rolled out across the whole school. Speech and language therapy in school has continued to support staff to increase their confidence and feel supported and programmes have been written to specifically target increasing student participation. In addition to the strategies used as part of the project new initiatives are being trialled. Initiatives include supporting students, who have had access difficulties, where the multidisciplinary team jointly assess the student to optimise their access to voice output devices and to PODD. Parents coffee mornings have continued to be successful and the school is looking to put small training videos on their website as reminders for parents on how to use talking tiles etc. Following from an article in this journal (Choose your words) the 'word of the fortnight' was started which gives staff a word to focus on which they have found useful. It has also been made available for parents to use at home.

Strategy	How it was implemented	Outcomes		
Implementing Pragmatic Organisation of Dynamic Display (PODD)	All staff in the classes were trained to use the books to model to students and some students had personalised books.	This worked well and was rolled out the following academic year to the whole school. Many parents also found PODD to be useful and practical at home.		
Supporting Makaton signing	Makaton was already used successfully throughout the school and as such needed minimal support to be supported.	This continued to be effective.		
Sensory Stories by Joanna Grace	Joanna Grace's sensory stories (sensory project) were used in class and staff practised the stories at other times. Activity boards were created to be used alongside the PODD books.	This was very effective. All the staff enjoyed the stories and many students participated in the story using symbols and PODD. More stories were purchased and activity boards designed as a result. Staff then started running stories without SLT input.		
Staff training (inset, class and individual)	Research suggests that training can be most effective when it is delivered in the setting with specific situations. Training was delivered in many different formats across the school.	The most effective training was the combination of time with staff without students explaining the plan for each student followed by demonstration in class with the staff member and the students.		
Interviews and questionnaire	Initially staff members were interviewed about their confidence with students and in their knowledge of communication strategies. This became increasingly difficult to complete due to time constraints and so not all staff were interviewed. All staff in the school were given a questionnaire at the end of the school year.	The results of the questionnaire indicated that the staff who had been part of the project felt considerably more confident in working with the students. All staff said they would like more help and support.		
Parent coffee mornings	Parents were invited to attend a themed coffee morning once a term. The theme was either PODD or using voice output devices. It ran for 2 hours with some presentation from the therapists and practical exercises.	Initially these were poorly attended, however, as time went on more parents attended and there were regularly 15-20 parents. Parents found it very helpful and commented that they could learn from other parents.		
Voice output devices	Big Macks and Talking Tiles were used to enable students to participate more. Staff were shown how to utilise them in sessions and through the day.	Students were given devices to take between home and school with recorded messages on, such as, what they did at home. This was then played in circle time. This had the most significant impact on participation and parents and students both appeared to enjoy using them.		
Communication profiles See example profile (Figure 1).	Communication passports had been found to be too wordy for supply staff and often were not regularly updated. Communication profiles were trialled in half the classes to see if they helped staff to be more familiar with student's needs. They were displayed prominently in class and updated as needed.	This was by far the most effective method used during the project. There was a noticeable difference between the classes that had them and those that didn't, in terms of staff feeling confident to know what student's communication needs were and their targets. Since September 2017 all classes have profiles on display and they are sent home to parents once a term.		

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In December 2017, St Ann's was given an outstanding rating by OFSTED and the inspector commented that "the [communication] profiles mean that all adults who work with pupils know how best to communicate with pupils... As a result pupils make substantial progress in meeting their communication targets." As a team and as a school we were proud that the hard work by staff had been reflected in the positive outcomes for the students and acknowledged as a contributory factor in the success of the school gaining the outstanding rating. Work is ongoing in maintaining and extending the speech and language therapy service at St Ann's and I look forward to seeing how it progresses over the next few years.

I'd like to express my thanks to Sara Marlow (the full-time speech and language therapist at St Ann's) for her help with the project and to all the students, staff, parents and governors at St Ann's for their help and support in implementing the project. I would also like to thank Victoria Joffe for her advice on collecting data and Joanna Grace for her support in optimising the use of her sensory stories.

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Figure 1: Communication profile for Philippa

How I communicate:

I use some signs, a PODD book and voice output devices (talking tiles)

What I like to communicate about:

music, food and my family

When you communicate with me please remember:

to have my PODD book with me and when I sign car it means I want to go home.

I am working on:

Being able to use my PODD book and signs to communicate with less familiar people in school.





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Investigating the Assessment Procedures for Children with Complex Communication Needs: The Participation Model

ELENA THEODOROU, ELIADA PAMPOULOU AND NIKOLETA SAMPSON

Department of Rehabilitation Sciences, Cyprus University of Technology **Email:** eleni.theodorou@cut.ac.cy

Abstract

Research has shown the positive effects of using different communication methods for enhancing communication of individuals with Complex Communication Needs (CCN). In the field of Augmentative and Alternative Communication (AAC), the relationship between assessment and intervention has been investigated and it is widely accepted that comprehensive AAC assessment is of great importance for successful AAC services and hence, this initial step of the clinical procedure cannot be underestimated. A comprehensive AAC assessment covers elements such as language and communication, symbolic understanding, and the appropriate assistive technology. Previous research by the authors has shown that the AAC assessment process by Cypriot speech and language therapists is neither comprehensive nor systematic (Pampoulou, Theodorou and Petinou, 2018). In order to explore this issue in more depth, a questionnaire with open-ended questions was developed. The questions were based on the Participation Model (Beukelman and Mirenda, 2005), with the focus being on the participation patterns, the barriers to participation in communication situations, and the effectiveness of existing strategies that aim to enhance participation. The findings confirm that speech and language therapists do not follow a systematic way for assessing the needs of children with CCN. The assessment procedure is driven mainly by their own clinical judgment and their clinical

decisions do not follow evidence-based practice. It includes a number of areas such as language, communication and social skills, whereas the assessment of assistive technology is conducted by colleagues specialising in the specific field. In addition to the evaluation of the individual's needs and skills, they also assess his/her preferences, usually through observations of his/her behaviour. The participants expressed their understanding that for a successful AAC intervention, family and community support is of paramount importance.

Literature Review

AAC is becoming a well-known field and it is part of clinical practice of speech and language therapists. This field focuses on individuals with CCN and whose speech cannot serve their daily communication needs. People who experience CCN comprise a heterogenous group in terms of their skills and abilities, experiencing a variety of difficulties: motor difficulties, difficulties with language use, cognitive problems, symbolic problems etc. (Agius and Vance 2016; Erickson and Geist, 2016; Geytenbeek, et al., 2010; Pampoulou, 2015).

Research has shown the positive effects of using AAC interventions for enhancing language learning (both receptive and expressing), the communication of individuals with CCN and for enabling social and academic skills (Millar et al., 2006). Its positive benefits have been documented extensively for both developmental and acquired disorders for people of all ages (Beukelman and Mirenda, 2013). It is also widely accepted that for successful intervention, a comprehensive AAC assessment is of paramount importance, and hence it is a prerequisite for successful AAC services (Binger et al., 2012). The AAC assessment covers elements such as language and communication, symbolic understanding, and the appropriate assistive technology. It is also agreed that it should be focused on individuals who need AAC; focus on strengths and weaknesses of the individual being assessed; take into account factors beyond the individuals' capabilities and needs; and take place in a natural environment. Additionally, a comprehensive AAC assessment requires assessing the person in the different environments that he/she communicates in, while also selecting information from his/her communication partners. Due to the complexities of the difficulties that people with little or no verbal speech might experience, a multidisciplinary approach is essential. Members of the team could be the speech and language therapist, physiotherapist, occupational therapist, classroom teacher, parents and definitely the person who needs support (Glennen and DeCoste, 1997).

Despite the fact that a comprehensive AAC assessment is vital for the subsequent success of the intervention and hence the quality of services provision, currently there are few standardised assessment tools and protocols. Moreover, very few

have been translated and standardised in the Greek language (Pampoulou, Theodorou and Petinou, 2018). Further, the procedures that speech and language therapists follow in order to reach their diagnostic conclusions and recommendations have not yet been studied (Lund et al., 2017).

The Participation Model is one of the frameworks often used during the AAC assessment and it focuses on the choice of methods that enables individuals with CCN to participate in different environments as their peers do. According to this model, communication is evaluated within the context of the individual's life and takes into consideration not only the ability of an individual to convey their thoughts to others, but also the ability of the communication partner to receive the information successfully. Based on this model, amongst others, the assessment procedure includes the opportunities that an individual with CCN is provided to communicate, whilst the identification of any barriers that might prohibit successful communication are also investigated. An important strength of this model is that it focuses not only on assessing the communication participation of the person with CCN, but also the ways in which his/her peers communicate in the environment in which he/she is placed. This enables the assessors to understand the communication nature that occurs in a given environment better and hence, helps them, first, to identify the barriers that might exist and second, to choose goals that are appropriate for the person with CCN (Baukelman and Mirenda, 2013). An illustration of the model is provided in Figure 1.

Regarding the case of Cyprus, a recent study revealed that AAC practices are still in their infant stage (Pampoulou, Theodorou and Petinou, 2018). In order to clarify the current situation in the country, and also contribute to the existing literature on an international level in terms of the diagnostic procedures followed for AAC potential users, the research aims were to:

- explore the assessment procedure followed by speech and language therapists in Cyprus
- identify the areas that are evaluated during the assessment procedure
- explore whether participants collaborate with other professionals during the assessment process.

Methodology

The method used was a questionnaire that included questions based mainly on the Participation Model (Beukelman and Mirenda, 2005) and the existing literature about AAC assessment. The first draft of the questionnaire was presented at the **Communication Matters Conference** (September 2017) and comprised 52 open-ended and multiple-choice questions. Despite the efforts of the research team through purposive sampling identifying participants to complete the questionnaire, out of the six participants chosen, only two managed to complete it. The participants were speech and language therapists, who at the time of data collection were providing AAC services in two different settings (privately and in a special school). Nevertheless, the outcomes of the pilot study were valuable as they helped the research team to simplify the questionnaire in terms of developing a second draft, which mainly contained multiple-choice answers. In this paper, the focus is on the findings from the pilot study, whilst at the end information about the main study is also provided. The first section of the questionnaire focused on demographic information and the second, on the services provided to people with CCN (e.g. population, and available services that provide AAC in Cyprus). The third section was on AAC assessment and asked the participant to think of a person with little or no functional speech



Figure 1: The Participation Model (Beukelman and Mirenda, 2013, p. 109)

with whom they worked in the last academic year and to answer the questions in that context. The questions, based on the Participation Model, focused on the procedures followed for AAC assessment in terms of opportunities, and barriers, including the individual's constraints (see Examples 1- 4). In the fourth and last section, the participants had the opportunity to make suggestions regarding the current AAC provision as well as about their needs in relation to their education.

Examples

- Did you record the individual's desires during the assessment procedure?
- What kind of sensory stimulus did you use for the assessment?
- Did you try any environmental modifications to assess the AAC effectiveness?
- Which abilities of the individual did you assess?

Results and Conclusions

The findings show that despite the fact that the participants were identified through purposive sampling (i.e. the research team knew that they support people with CCN), their overall failure to complete the questionnaire could be due the limited knowledge that the focal clinicians have in the field of AAC assessment and/or because of the non-systematic procedures they follow, thus making the description of them is difficult. The results suggest that the participants do not follow a systematic and comprehensive way for assessing the needs of children with CCN. In particular, the AAC assessment is not driven by any formal or informal protocol or framework, but rather, is based, mainly, on their clinical judgment. Further, evidence from prior research is not integrated into assessment procedures such that the decisions are guided by evidence-based practice, as has been recommended (Sackett, 1996). When developing the profile of the individual, the participants reported how they assessed a number of areas, such as language, communication and social skills, whereas they stated that the assessment of assistive technology is conducted by colleagues specialising in the specific field. Yet, for the assessment of the individuals' needs they did not utilise the available diagnostic tools, either formal or informal, but instead restricted their assessment process to clinical observations of behaviour. Additionally, while the importance of the

environment (including the family) for a successful implementation of AAC methods has been acknowledged, evaluation of the opportunities for communication that the individual has and the barriers that the environment might put up is not conducted. In contrast, the participants shared that their assessment focuses on an individual level, away from environmental stimuli that involve the settings and the people. Lastly, they responded that they collaborate with other professionals for assessment purposes. However, given the fact that the participants did not elaborate further, their role in the team was not identified.

In line with Beukelman and colleagues (2008), it would appear that whilst SLTs provide assessment services for individuals with CCN they are not trained in this. However, this cannot be said with certainty due to the fact that this was simply a pilot study, albeit this outcome aligns with the findings from a previous study (Pampoulou, Theodorou and Petinou, 2018). The intention here is not to blame SLTs, but rather, to highlight the need for further education in the field of AAC. It is important that these professionals possess the appropriate knowledge and skills relating to the AAC assessment process (Binger et al., 2012). Given the wide field of speech and language therapy, individuals with CCN should seek the services by SLTs specialising in the AAC field.

To conclude, the findings from the pilot study presented here raise a number of issues. First, it has become clear that the assessment services that are provided for people with CCN need to be investigated further in order for the researchers in the AAC field and stakeholders to understand better the procedures followed by SLTs for the particular service. Second, the type of the questions that are included in the questionnaire seemed to be difficult for the clinicians and hence, there is a need for it to take a different form. A second draft of the questionnaire was developed that mainly consisted of multiple choice questions with the aim of collecting more information that will allow the research team to understand the assessment process better. The development of this version relied heavily on the feedback from the pilot study presented above. The questionnaire was distributed to all speech and language therapists working in public schools in Cyprus and a 60% response rate was received. It is our goal to share the findings of this study in the near future.

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An Introduction to Lego-based Therapy

DANNII KEENAN AND LOIS THOMSON

Specialist Speech and Language Therapists, National Star College **Email:** dkeenan@nationalstar.org

Lego-based therapy is a social communication intervention which uses Lego as a motivating therapeutic tool to indirectly target areas of difficulty. The approach follows a consistent and highly structured routine, incorporating specific roles and rules to scaffold social interaction skills including joint attention, turn taking, shared goals and team working.

The intervention was originally developed by Dr Dan LeGoff, a Clinical Neuropsychologist based in Philadelphia, evolving from his naturalistic observations that children with high functioning autism would spontaneously engage in Lego play with others whilst in his clinic waiting room. This client group typically attended mainstream school, and experienced difficulties with higher level social communication skills including problem solving; negotiation of social scenarios; and maintaining the pace of interactions involving multiple communication partners and conversational topics.

Lego-based Therapy is a relatively new intervention and as such, the current evidence base is limited both in terms of quantity and research subjects; however there is a small but positive evidence base to demonstrate its effectiveness as a social skill development intervention for children with high functioning autism. Anecdotal findings and clinical outcomes based on our learners at National Star have indicated to us that Lego-based Therapy also has successful applications with young adults with more severe autism, learning disabilities, language delay, and those who use Alternative and Augmentative Communication (AAC) systems to support their verbal communication.

The intervention is based upon a collaborative play model, in which the group members work together to achieve a shared outcome, and involves a set of rigid roles and associated rules.

Engineer: leads the project, chooses the build, identifies what resources are needed and how they are constructed, directs instructions to the Supplier and Builder. Specific social behaviours: looking at communication partner (i.e. Supplier/ Builder), initiating interactions, directing comments/instructions to appropriate peer.

- Supplier: waits for Engineer's instructions about what pieces to find, listens to instructions, looks for what is needed, passes the pieces to Builder. Specific social behaviours: waiting for turn/instruction, listening to communication partner (i.e. Engineer), responding to instruction – looking for target pieces, sharing target pieces with appropriate peer (i.e. Builder).
- **Builder:** waits for Engineer's instructions and Supplier's resource sharing (i.e. has to wait for 2 turns), looks to Supplier to receive pieces, listens to Engineer's instructions about how to construct the build, interacts with Engineer and Supplier to check construction is correct. Specific social behaviours: waiting for turn/instruction, receiving target pieces from appropriate peer (i.e. Supplier), listening to communication partner (i.e. Engineer), responding to instruction – constructing pieces correctly.



In addition to these specific roles and responsibilities, the structured group context also promotes a range of more general social interaction skills including offering and asking for help, sharing resources, working together, problem solving and tidying resources away. Finally, the intervention provides a safe, structured and familiar environment in which group members are able to practice the social behaviours which they find challenging; with lots of praise and positive feedback provided by the group facilitator, in order to reinforce the skills being developed.

The inherent requirements of a Legobased Therapy task lend themselves well to the development of functional social interaction skills, including turn taking, sharing, joint attention and working towards a mutual goal. The practical nature of the activity is also beneficial for developing these important social communication skills in a manner which is less intimidating for group members than a direct conversational group; for example, it may be more achievable for some individuals to direct a comment which relates to clear and motivating instructions, rather than a question or response about an abstract social topic such as sharing weekend news. This relates to a key theory within the Autism Spectrum Disorder (ASD) literature, that of "Reading the Mind in the Eyes" (Baron-Cohen et al, 2001).

Another theory from which Legobased Therapy has developed is the "Empathising/Systemising Theory of ASD" (Baron-Cohen, 2002); in line with these principles, structure, routine and time keeping are crucial elements within the motivating group task so that all participants have adequate time to complete their role; enjoy the building activity; and explore the completed construction which they have created together. This is essential for encouraging feelings of positive self-esteem for all group members; and feelings of pride in their achievements, both individually and as part of a group.

What we particularly like about the approach is its focus on positive peer relationships and self-esteem. The use of Lego as a motivating therapeutic tool offers a natural peer group for session participants, as it provides at least one common interest with others. This is particularly significant for children and young adults who are aware of their social



communication difficulties, and can offer the potential for meaningful relationships to form outside of the structured group context. Similarly, the use of Lego enables a 'Can do' approach to learning and skill development, as group members are familiar and confident in the use of this resource as a leisure activity.

The current evidence base for Legobased therapy relates to children aged between six and sixteen years old, with high functioning autism. Whilst there are some limitations in methodology, findings to date indicate a range of positive social communication outcomes including increased initiation and duration of conversations (Le Goff, 2004; MacCormack et al, 2015); increased adaptability within social situations (Le Goff & Sherman, 2006); and reduced frequency of challenging behaviours and autism-specific behaviours (Owens et al, 2008). Promisingly, the literature indicates that any social skill intervention is better than no intervention for children with ASD; however more significant positive outcomes are evident in children accessing a Lego-based Therapy group, in comparison to a conversation or other social use of language group (Le Goff & Sherman, 2006; Owens et al, 2008). Furthermore, improvements in social skills are seen both immediately following Lego-based Therapy intervention and maintained after the intervention has finished (Andras, 2012), thus demonstrating functional skill development and generalisation to real life settings.

In order for our learners at National Star to access Lego-based Therapy, we have made a number of adaptations to the original approach. At a practical level, we use Duplo rather than Lego sets, which include larger bricks and less complex constructions; this ensures that individuals with fine motor limitations and processing difficulties have adequate time to respond to instructions, contribute to the group task, and complete the construction in the time available. We also use a wide range of visual prompts to support learners' understanding of task demands and expression of instructions, including group rules presented in written, signed and verbal formats; a symbolic session timetable which specifies all tasks within the group activity; and stepby-step picture prompts to simplify the original Duplo instruction manuals.

In addition to the fundamental social skills which the group context facilitates, we are also able to promote language development for learners with complex communication difficulties: this incorporates understanding and use of functional concepts such as colour, size, shape and position; vocabulary development; and increased length of verbal utterances, from single word to simple sentence level. Finally, we have observed positive outcomes in terms of functional AAC skills for learners who use low- and hi-tech AAC strategies to support their communication; these include improved skills in navigating their personalised AAC system; increased initiation of communication; choice making; use of comments and questions; and sentence building skills.

Case studies

Names changed to maintain client confidentiality

PAUL

Clinical Profile

- ASD, severe sensory processing difficulties, learning disability
- Verbal does not initiate communication, typically responds to questions/ requests using single words



• Benefits from the use of visual prompts including objects, photographs, symbols and Makaton signing to support choice making and participation

Communication Systems/Strategies

- Developing use of a low-tech A5 topicbased communication book within structured activities, to support initiation of meaningful requests.
- Uses a visual timetable system to support comprehension of daily routine, activity transitions and management of change within structured College routine:
 - Reduce environmental distractions when supporting transitions, to reduce processing demands.
- Verbal instructions presented once, followed by adequate processing/ response time:
 - Non-verbal prompts (e.g. object/ photograph/symbol/pointing) used to support comprehension of task requirements during waiting phase.
 - Choices/instructions presented by only one communication partner, to support comprehension of task demands and reduce processing needs - complete current activity or event BEFORE changing staff support.
 - Model target actions/responses to support understanding of unfamiliar task demands, and encourage participation within activities offer physical prompting/support as required.

• Weekly Lego-based Therapy group participation with familiar peers since September 2016.

Outcomes and Skill Generalisation Following Ongoing Lego-Based Therapy:

- Increased initiation of communication using verbal and/or non-verbal strategies to direct task instructions (e.g. offers appropriate comment re: colour of target piece and/or corresponding picture prompt):
 - Skill generalisation noted through initiation of high frequency requests using communication book within structured education sessions (e.g. navigates to and requests snack preferences when presented with book, increasingly using simple sentences – "I want biscuit").
- Spontaneous identification that use of non-verbal strategies are helpful to support communication, both in terms of expression and confidence (e.g. will initially offer instructions using appropriate picture prompts when interacting with unfamiliar staff, then begins to use his voice as he becomes more familiar with the person):
 - Skill generalisation noted through appropriate use of communication book resource to make requests when presented in a different format (e.g. A4 size), on occasions when his book has been unavailable.
- Increased initiation of session timetable set up (e.g. spontaneously began to remove appropriate symbol

from timetable when an activity had "finished", and now regularly takes responsibility for this system within the group context):

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Lego Club

 Skill generalisation noted through independent set up of his own now/next timetable system, when presented with timetable and all symbols for a given timeframe (e.g. all morning sessions).

Case studies

Names changed to maintain client confidentiality

BRIAN

Clinical Profile

- ASD, cerebral palsy, learning disability
- Communication uses facial expression, gesture, body language, symbolic choice making using photographs, and speech including learnt phrases. Unable to verbally turn take in conversation and wait for peer responses. Limited attention skills and has difficulty engaging in group activities.
- Engagement has difficulty transitioning from one session to another, turn taking, attending to activities for prolonged periods of time.
- Benefits from the use of visual prompts including objects, photographs, symbols and Makaton signing to support choice making and participation

Communication Systems/Strategies

• Uses a now/next visual timetable system to support comprehension of daily routine, activity transitions and

management of change within structured College routine:

- Reduce environmental distractions when supporting transitions, to reduce processing demands.
- Repeat timetable verbally whilst transitioning to relieve anxieties.
- Verbal and Makaton prompting to support understanding.
- Avoidance of trigger words to support processing and challenging behaviour.
- Weekly Lego-based Therapy group participation with familiar peers since September 2017.

Outcomes and Skill Generalisation Following Ongoing Lego-Based Therapy:

- Increased initiation of verbal communication with peers (e.g. will ask a question or give an instruction to peer).
 - Skill generalisation noted through increase in initiation of requests to peers.
- Increased ability in turn taking and waiting for peers (e.g. will identify whose turn is next and will now talk to

support during wait time rather than shout loudly).

- Skill generalisation noted through increase in wait time between each turn and acceptance of peers within the group.
- Increased use of eye contact when sharing bricks with peers (e.g. will look to the peer when passing the brick to the builder).
 - Skill generalisation noted through appropriate use of eye contact within turn taking activity.
- Increased initiation of session timetable (e.g. will now spontaneously verbally tell the group the routine and rules at the start of the session).
 - Skill generalisation noted through increase in responsibility for group timetable system within the group context on a weekly basis.

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Review of paper presented at CM2018 Conference

A review of the talk "Participation For Young AAC Users"

ADAM LENARTOWICZ

Email: adrobherlen@gmail.com

As an audience member who uses AAC, I personally found this talk fascinating and extremely thought-provoking because I, still to this day, really struggle to regulate my emotional response to things. It is often that the emotional well-being of an AAC user, particularly with Athetoid CP, is overlooked or, more commonly, not talked about in as much detail/care as it really needs to be.

I remember my AAC teacher/co-ordinator at high school getting an educational psychologist for me to talk about my teenage hormone "mood swings", but she dived straight into something that was very inappropriate – a resilience test! From listening to the talk, it was quite clear to me that the SALT, who was presenting, had closely worked with the psychologist to help him/her to fully understand how CP heightens one's emotional response(s). I believe that the psychologist at my high school didn't have as much guidance on understanding communication disabilities as the one who worked with this presenter.

Although I really enjoyed the content, I would have liked more graphs and videos on the sideshow to assist me in absorbing such a powerful and sensitive topic. I also really think that some kind of a survey would be a very strong instrument for illustrating some of the issues/concepts.

Overall, I give this talk 8/10 because although I noticed a few mistakes due to being nervous (absolutely normal!), the topic was extremely engaging and very well thought through!

Before I go, I really want to leave you with these ideas – let's speak up about stuff! Like the mental health of university students, the emotional well-being of young AAC users needs to be discussed openly and maturely, and without judgement.

Social Media for Engagement: Safe and Enjoyable New Frontiers for People who use AAC

BRONWYN HEMSLEY, PH.D

Professor of Speech Pathology, University of Technology Sydney, 67 Thomas Street, Ultimo, NSW, 2007, Australia Email: Bronwyn.Hemsley@uts.edu.au Twitter: @BronwynHemsley

This paper is based on the author's keynote presentation at the Communication Matters Conference 2017

AAC, Communication Rights, and Social Media

The year 2018 is particularly important in the field of Augmentative and Alternative Communication (AAC) as it is the 70th Anniversary of the Universal Declaration of Human Rights (United Nations, 1948) which highlights the human right of communication (McLeod, 2018). My presentation at Communication Matters 2017 provides an ideal opportunity to (a) highlight two Articles of the Universal Declaration of Human Rights and of the UN Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) that are relevant to the use of social media for communication, which promotes access to the human rights of communication, and education through the use of technology.

Social media provides an important form of online communication that increases users' visibility, influence, and reach online (Hemsley, Balandin, Palmer & Dann, 2017; Hemsley, Balandin, Palmer & Dann, 2018). Using social media affords users a means of expression with friends and others in the community. Article 19

of the Universal Declaration of Human Rights (United Nations, 1948) states that "Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers." In addition, Article 27 of the Declaration states that "everyone has the right to freely participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits." Similarly, the UNCRPD (United Nations, 2006) emphasises communication rights, in that people have the right to use a range of communication modes and to learn to use new technologies at an affordable cost to increase their participation and access to information. Thus, supporting people who use AAC in the use of social media could facilitate access to their human right of communication and their right to sharing in the cultural life of the community (Hemsley, Balandin, Palmer & Dann, 2018).

Managing risks in using social media: cyberbullying and mental health

Social media users do not tend to rely on a single social media platform for their day-to-day communication needs. Rather, they use a whole range of social media platforms, and may be introduced to new ones quite frequently as these are launched and taken up by peers and the general public. As such, the use of social media is an important element of inclusion for people who use AAC. While the use of social media has many potential benefits, it also poses potential harms to all who use it. The benefits and risks associated with using social media need to be taken into account in any framework designed to support the safe and enjoyable use of social media by people who use AAC who might be more vulnerable to cyberbullying as a result of their communication difficulties. A recent report into social media and children's mental health (Frith, 2017) provides an important context for thinking about how young people who use AAC might experience and use social media. In the UK, the majority of young people use the internet for more than 2 hours per day outside of school. Almost half of the 15-year-olds in the UK are 'extreme' internet users (more than 6 hours per day), with almost all of them using Facebook (Frith, 2017). 'Extreme' users of social media reported lower life satisfaction than moderate users; they also reported more cyberbullying. However, restricting a person's use of the internet in an attempt to increase their safety on social media might not be effective in reducing their risk of harm. According to Frith, restricting use of the internet could "inhibit the development of the skills needed to handle online risk" (p. 7). Rather than seeking to restrict access to social media, it might be more useful and helpful to ensure that young people "are taught and supported to learn digital skills as they start to navigate social media" (Frith, 2017, p.7). Thus, young people who use AAC must be included in educational programs targeting digital skills, as they have the same rights to use social media as their peers without disability, and to do so safely.

Some groups and individuals are more at risk of abuse in social media than others, with important implications for the field of AAC. Henry et al. (2017) reported that as many as 50% of Australians with a disability and 50% of Indigenous Australians have been victims of imagebased abuse online. Younger people aged 16-29, along with lesbian, gay, or bisexual Australians, are also at higher risk of abuse online. In terms of relationship and safety in social media, image-based abuse is on the rise (e.g., pornography, public shaming, impersonation, or fraud) and there is an increased recognition of the blurred boundaries of 'sexting', or sending sexually explicit images through SMS, snapchat, email, or other social media platforms (Henry et al., 2017). Frith (2017) reported that in responding to cyberbullying, young people "use a range of coping mechanisms to deal with online risk, such as blocking other internet users, changing privacy settings or taking a break from the internet" (p.25). However, many young people who have been victimized on social media do not talk to their parents or a teacher about their experiences. Conversations around the safe use of social media need to include ways that people who use AAC can draw upon their own networks of support, both in- and out of the social media platforms.

Social media and 'fake news': judging the quality of information

An important purpose for using social media is the exchange of information within and across communities. Social media platforms enable 'knowledge creation' in that users are encouraged to create original content or materials for sharing in their growing networks. However, while many people might now obtain their news through social media, there is also an increase in the appearance and distribution of 'fake news' (Rainie, Anderson & Albright, 2017). The type and quality of the information obtained through social media varies enormously

depending on the source of the information and the way that the information is shared, interpreted, modified, and exchanged. In identifying ways to support people who use AAC to access social media, it is important to consider both (a) the quality of the information, in terms of its credibility and reliability, and (b) how people who use AAC and their supporters will judge the credibility and 'truthiness' of information. Supporting people who use AAC to critically appraise the source of information they find online, and to identify and judge the type of information as being correct information, or being 'misinformation' (wrong information) or 'disinformation' (deliberately incorrect information designed to deceive) is vital if they are to benefit from having greater access to information via social media.

AAC and future social media research

It is not yet known how far reports on the use of internet and social media by young people (Frith, 2017) apply to the lived experiences and views of people who use AAC and social media. To date, only a relatively small number of people who use AAC have been included in social media research. Most attention has been paid to their use of Facebook and Twitter, and almost no research is devoted to their use of image-based or multimedia forms of communication (e.g. Instagram or YouTube). There are some studies showing that young people with disability want to use the internet and need support to use social media in safe and enjoyable ways (Raghavendra, Hutchinson, Grace, Wood, & Newman, 2018). However, there is little information on the safety of young people with communication disability on social media platforms, even though they may be at an increased risk of cyberbullying, and rely more on third party supporters to access the internet, and also be at an increased risk of over-protection, restrictive 'gatekeeping', or exploitation. Therefore, it is important to discover what strategies are needed to support more people with communication disability to use social media safely, and enable them to respond to and recover from problematic situations online. Future AAC research could expand to include a wider variety of social media platforms, research methods, and research questions that look beyond experiences and training to measuring the impact of using social media on everyday life (Hemsley et al., 2017). It would also be important to determine the feasibility of implementing policies and practices suggested to improve social media safety (e.g., Australian Government, 2018) in services supporting AAC users.

Conclusion

Social-media scans and interviews show that people who use AAC use social media for a wide range of purposes, including publishing and marketing themselves or their products, services, company, business, or talent. People working in the field of AAC also use social media for raising public awareness of the many issues confronting people who use AAC and their families. Therefore, it is important for researchers, clinicians, and people who use AAC to talk more about the finer points of using social media strategically.

It is also important to know more about how people who use AAC and their family members and service providers navigate risk-based decision-making when using social media, and use social media for selfexpression and self-promotion. Knowing how people who use AAC view and respond to the dangers of social media, and what they do to avoid any pitfalls and recover from any safety incidents they experienced, could help prepare others for using social media. More AAC research is needed on how people are using social media platforms that promote visual and multimedia communication (e.g. Instagram, YouTube), online gaming, and virtual reality technologies.

With access to the right technologies, funding, supports, and safeguards, people who use AAC could become more visible online through the use of social media, even if they are isolated in real life. They and their families could grow the audience that they want to reach and know how to search for and find connections that work for them. It is important to know more about the roles of family members and direct support workers in supporting people who use AAC to access social media to determine whether the supports provided are (a) overly restrictive, or (b) uphold the person's own wishes, preferences, and their rights according to Article 19 of the Universal Declaration of Human Rights (United Nations, 1948).

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Switch access: the first way forward in AAC assistive technology

ESTHER DAKIN

Head of Education & Development, Smile Smart Technology **Email:** education@smilesmart-tech.com

Switch access today is the most common entry point to AAC devices and autonomous control in a wide range of current assistive technology products. The argument is made that methodological approaches proposed in the past by researchers promoting joystick use in powerchairs over switch access should be rejected as an outmoded concept for those with complex needs due to the multidisciplinary demands and integrated nature of contemporary assistive technology.

Introduction

It is strongly believed that we are currently reaching an important turningpoint in the both AAC and wider Assistive Technology practice (Peters, 2017) (Sik-Lányi Et Al., 2015; Kirkpatrick, 2016) and that we must grasp the opportunity to work more closely with all stakeholders and respect all our colleagues equally regardless of whether they hold a syringe, pencil, switch or spanner as we move forward into the age of the Fourth Industrial Revolution (4IR).

Two of the most basic principles of every creature on this planet are to be able to communicate and move. So technologically speaking the world of disability has evidently made enormous progress in many different ways to enable humans to communicate using contemporary engineering and electronics. The world of movement has also been refined and enhanced through the same electronic advancement process and through use of superior materials, but only up to a point. Many of the advances in movement have been in controls programming, however the method of inputting those controls has hardly varied over the last 10-15 years. For those able to operate a joystick successfully there are various sizes available with varying degrees of sensitivity and at the point of assessment your competency outcomes are binary: you succeed or fail when you are tested.

If you fail that competency test for safety reasons, you become a special case. At this juncture the process has historically been at best confusing and at worst arbitrary. If switches are the chosen option, key consultations with the case physiotherapist or occupational therapist are fundamental to ensuring that the seating is optimized to enable switch operation to be consistent and accurate. The established route is to consider switching as a secondary alternative to joystick use and dependent specifications are prescribed from scale, positioning and ease of operation. This process can take weeks or even months in the UK, dependent upon whom is carrying out the assessment, what resources are available to fabricate suitable switch mounts and the frequency of clinic dates for reviews and alterations to equipment or repositioning. It is felt that greater interdisciplinary assessment consistency and speed must be brought to current systems.

How is communication switching allied to movement?

Whilst there are various aspects of control switching set-ups that are common to both the operations of a communication device and a mobility device, the risks involved in switching for 'driving' is fundamentally different. If a switch is used on a communication device the degree of accuracy in operation is less problematic than for driving. Whilst a random misguided operation of a switch on a device may cause anger and/or frustration for the user, when this occurs during driving, pain or damage can occur very swiftly to the individual or any people and surrounding objects. Whilst both disciplines use fundamentally the same input hardware, their potential operation and outcome can be far apart. If switching is optimized, the fatigue and frustration normally experienced by the users can be much reduced - and through using safe motivational teaching tools and empathetic methods, accuracy of all switch use can be greatly improved.

At Smile we use certain essential principles in our methodology that we formally call 'the Dakin method' which we really call 'sneaky therapy'. This is a gentle progressive teaching method that moves away from the inflexibilities of historical practice. Our areas of consideration are: Ability, Access, Advancement, Age, Angle, Autonomy.

Ability - is a mixture of understanding an individual's potential capacity and our belief in them. Our hardest task is to assess a child or adult with little feedback upon first meeting. We firstly read their eyes and their body language especially where they are non-vocal. We are trying to unravel a detective story and look for clues. Parents, teachers and carers are all vital in helping to provide clues to understanding personal motivations and fears and must be listened to.

Access – Which input device to use? Joysticks are not suitable for everyone, and multiple switching is equally problematic given the layout and space required. A combination of two switches provide many options from scanning to direct steering – you cannot pull a switch sideways as happens with joysticks. Technicians and support staff are important to communicate with to better understand common risk factors in transport, private space and regular technical damage before this decision is made. Many are able to use joysticks

with ease. For those who are borderline we would now strongly encourage focus upon switch access teaching. Frequent use of switching improves switch accuracy rates. Sneaky therapy begins with single switch and timed access, we can stage progress through to a press and hold activation, and for some on to free driving using our in-house tools, starting with the Drivedeck at assessment level. Turning sensitivity settings down incrementally until proficiency enables the user to maintain a constant 'move-to-press' pressure - which is so helpful in the later progression of scanning. Incentivization given by the physical sensation of autonomous movement - the visceral cognizance, the perception of the user's body moving safely through a space controlled with their own repeated action is an extremely powerful motivating force. It is predominantly through the use of switches rather than joysticks that many AAC users will be most immediately integrated into the use of web-based technologies that exist today, therefore we argue for stronger emphasis upon switch access, particularly where safe autonomous driving is not a realistic development option. In view of innovation through 4IR, where mechanical, electronic and biomechanical engineering merge progressively closer together, we are witnessing a greater integration of technologies and skills. We must take care not to needlessly specify overly complex technologies that exhaust the energy of users at the expense of learning essential skills such as switch training.

One example of transitioning to new forms of autonomous situations using simple switch access and in this instance Smile tools is a young man called George. George has Downs Syndrome, he suffered a stroke and became blind. Previously he had independently enjoyed the sensory room as a space to explore switches and play games on the computer. After his stroke, visits to the main sensory space reduced to once a week and often sat in dire boredom in the TV room as he had become unable to move himself around the building or access the computer. To help overcome his new world without his sight, switches and Smile line following tools were provided to him and the computer was moved into his own room. This enabled him to move autonomously when he wanted to visit his friends in the TV room and then safely return to his own room to game or rest, even without his sight or the ability to walk. George's enjoyment of personal independence both physically and mentally was returned to him. The understanding of switches allowed him to adapt to his new sensory world.

Age - We would like to enable all children to start their access to autonomous independence, both physical and communicatory at the earliest possible age. Indeed, we believe that this should be happening at the same age that fully able-bodied children would be beginning their crawling and walking development - to allow them to progress as naturally as possible with the assistance of their relevant assistive technology. To leave a child until they are 8 or older we believe is to waste vital years of integrated development with the right technology. This is a contentious point, but we frequently witness the clear benefit of early intervention and would encourage further research in this area.

Many problems we face concerning age is growth related, particularly in teenage boys for whom delays can mean products quickly become unfit for purpose due to body size and strength. The problem of not looking forward is illustrated by the case of Hercules. His fast growth and increased strength in teenage years should have been given consideration by therapists at assessment and would have benefitted from greater dialogue with other team members. Due to a combination of the traditionally slow prescribing processes mentioned above and his dramatic increase in size through puberty onset, which increased his strength and tonal fluctuations, by the product delivery date the prescribed AT and teaching methods had become obsolete. Nearly two years of productive development was lost.

Advancement - How to optimize potential by looking forward to where technology will be allowing an individual to be in the future. We are currently at a new frontier of electronic assistive technology access. We wish to see individuals optimize the full potential access that their brains are capable of - not limited by physical conditions or historic technology. Advances in technology provide us with access to previously unthinkable abilities such as 3D printing and gaming. One example of a mother's vision involved her eight-year-old girl called Tilly. Tilly's mother had been told by a therapist that her daughter would only ever be able to use eyegaze at the very most and never

be capable of anything more physically or intellectually complex. Tilly's mother challenged this and made the point that her daughter had only recently learnt the use of eyegaze and communicated in three languages. At her first attempt on the Drivedeck, despite never having any previous switch experience Tilly instantly understood the correlation of switch and movement and now enjoys a strong level of physical and communicatory autonomy at home and school. Her mother had a strong perception of her abilities and looked ahead for her daughter who will now have far greater access to education and autonomy in the future.

Angle - Comfort and empathy are key to successful access. We must provide switch users the most immediate and comfortable angle of positioning in switching to enable immediate success. Once new users have realized what they are able to accomplish with the switch, one can then instigate the key physical element of sneaky therapy. Switches can be stealthily moved over time to achieve the therapist's long-term goal for position and activation, as muscle and memory gently allow. Maintaining the momentum and progress gained at any level of success must be kept at all cost, and great care must be taken to consider comfort, as unless the repeat process is painless, success will be slow, limited or absent.

AUTONOMY! - The end goal... the motivation behind the entire process. Giving any individual the ability to move without the pressure of navigating is a tremendous bonus. There is no pressure. It is pure pleasure. Autonomy through switching,

where joystick use is too challenging, is what we see as the key motivation needed to move on to switching in AAC access and the foundation of our teaching. Using these keystones, we build our approach to facilitate the optimum progress of those we work with. This methodology integrates the consideration for the work of our colleagues even if we are unable to speak to them directly. We encourage greater direct communication between all advisors and stakeholders in support teams, with the focal point being upon the holistic provision of streamlined services to speed up all provision of assistive technology devices and integration of therapies. We strongly welcome joint assessment meetings with all stakeholders, as on the rare occasions that this occurs outcomes are greater and faster than the norm.

The historical divide between health and education is we believe outdated {Dakin, 2017, The drive for a holistic approach to mounting communication equipment.} (Dakin, 2017)2017. Technology accessible on the outside of less able individuals is fast catching up with what is on the *inside* of the able bodied. The demand for better, smaller, less intrusive design and innovation is blurring the functions of specialists and placing ever increasing demands upon therapists and care teams. In order for practitioners to work more effectively for those we advise, we each must understand and respect the impact of each other's work more and acknowledge that due to the new interconnected nature of technology, education, communication, driving and health support, we must work more closely together at every stage.

We believe that in AAC and the allied professions of this field our access point to technology must also evolve. Eyegaze and similar ocular dependent access is an important and exciting entry point that we look forward to researching further. Given the cross-over between driving, scanning, gaming and general computer and tablet access, which are all accessible through switches, we feel very strongly that double switch teaching must be encouraged wherever possible. Our approach exists to enable users to make maximum use of switches, whether connected to a communication or mobility device, this encourages users to be proactive not reactive. If one switch can be operated you can communicate and move, if you can operate two switches you can gain access to today's online world and increase opportunities in achieving future education, employment and social goals.

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