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AGOSCI In Focus is the National Magazine of the AGOSCI Inc. (formerly Australian Group on Severe Communication Impairment). AGOSCI In Focus is a bi-annual magazine and is available to members of AGOSCI. It contains information from and about national seminars, research, new communication technology, resources in the AAC field, news from overseas, and contributions from people who use AAC.

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COVER PHOTO



WA AGOSCI celebrated AAC Awareness Month by ice skating.

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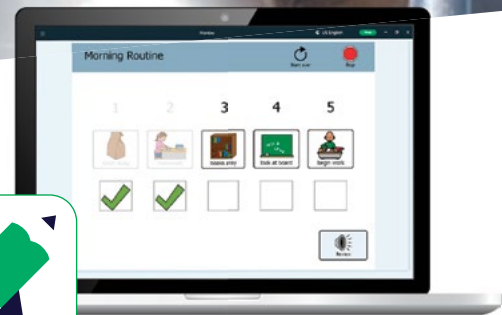
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CHAIRPERSON'S REPORT

HOORAY, it is now less than 12 months until our biennial conference, and fingers crossed we might all get to see each other in person. It will be an exciting conference indeed, hopefully the first of many things to return.

Over the last few months, we have had a great welcome back start to Sheridan Forster as our wonderful AIF editor, and a continuation of our amazing PD program thanks to our coordinator Ria. The executive recently held a one day strategic planning meeting via Zoom, and although not the same without cake 'n' coffee, some good discussions and decisions were made nonetheless.

I hope some of you get to put a 2020 Research grant application in, and some of you start to think about putting in a scholarship application for our 2021 conference.

We continue on our way to becoming Communication Access accredited, thanks to Steph Weir for seeing this through.

We did say a sad farewell to our Listserv which has served us well for many years, and welcome everyone to join our AGOSCI Australia AAC community Facebook group. Although we cannot change this from its original "closed" status, we will still use our FB Page for you to share important information.

And finally, a big hug goes out to all our Victorian members and friends, who have had to endure some difficult times as we try to fend off the COVID-19 pandemic – hopefully we will see you in Hobart too!

:: DARREN TRENTPOHL

EDUCATION REPORT

As this edition of AGOSCI In Focus is being compiled, it is AAC Awareness Month and we're all systems go for events and social media engagement at AGOSCI!

It's always a thrilling time of community engagement and joy! I've had the great pleasure of working alongside a number of inspiring people in our AAC community throughout 2020, and together we have fostered new and enduring partnerships across the AAC landscape.

Our member webinar series is coming to a close as we near the end of the year, and we are most grateful to all our presenters who have contributed this year! Member webinars remain an integral AGOSCI member benefit and we love creating a platform for our community to share their unique experiences, research, and knowledge. I want to extend a big thank you to all our partner organisations, speakers, and volunteers for your ongoing commitment to the AGOSCI community and the sharing of your time to bring great events to our professional development calendar. We're looking forward to extending the professional development calendar in 2021 and exploring new partnerships along the way.

Finally, I'd like to thank our AGOSCI community for your flexibility and patience as we've navigated the online professional development event space through the ups and downs of lock down. Our volunteer AGOSCI executive team inspires me every step of the way and I thank them for their support of me in this role, and of our professional development calendar. Despite the trying times of COVID-19, it has been a pleasure to continue in the role as Professional Development Coordinator for AGOSCI this year, and I'm excited to see what 2021 brings for us all.

As December rolls on, please take stock of the year that was, but most importantly take time to look after yourselves, and as always look after each other. Stay well AGOSCI community, we will see you all in 2021

:: RIA FERRIS

SECRETARY'S REPORT

Hi again to everyone,

We've had a pretty good year so far for memberships with around 386 members, which is higher than this time last year. Special thanks to Ria for all her hard work in organising the many webinars we have learnt from. I look forward to having more face-to-face events in the future. We had our Executive meeting three weekends ago via Zoom. It wasn't quite the same as meeting in person but a lot of discussions around steering AGOSCI for the future were had.

I have been busy typing up minutes and processing memberships and member enquiries.

Many thanks again to all the members who have joined this year. We value your membership and strive to provide an organisation that you wish to belong to. I look forward to seeing you in Hobart next year for the 2021 AGOSCI Conference. A lot of hard work is going on in the background to make this happen. Thanks to the conference committee.

This year we are also saying farewell to the listserv. I have enjoyed the discussions and the information everyone has contributed and shared over the many years. I look forward to the discussions over our FaceBook page instead.

Thanks to everyone who continues to support AGOSCI and keep it going for everyone.

:: MELISSA BAKES

EDITOR'S NOTE

I learnt a lot putting together the last edition: I learnt through mistakes and successes. This edition has a theme of learning through mistakes. Mistakes can be learning points and they can be discoveries of a different way of working. They can drive us to do things better in the future. In Victoria, the Office of the Disability Services Commission have a saying: It's OK to complain! Taking their lead, I think it is OK to make mistakes.

An important area of learning from mistakes is the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. We look to this for national solutions to doing things better for people with disability, including those with complex communication needs.

It is also a pleasure to share all of the wonderful photos and stories celebrating AAC Awareness Month, 2020.

:: SHERIDAN FORSTER

TREASURER'S REPORT

Hi everyone,

Things have been ticking along quietly this year for me in my role as Treasurer. I am continuing to fulfil AGOSCI's financial obligations in submitting our quarterly BAS statements to the tax office. AGOSCI continues to be in a strong financial position but will most likely make a loss again this year following on from our cancelled National Tour and limited opportunities for providing professional learning. It was great to meet with the executive team in September via Zoom to discuss our financial position and look at ways to keep AGOSCI financially stable for many years to come.

I hope you are all doing OK in these challenging times. I hope to see you all in person again at the 2021 conference in my home city of Hobart.

As always, if you have any questions about AGOSCI's finances, please get in touch with me.

:: TRACEY HANIGAN

STATE REPORTS

SOUTH AUSTRALIA

AGOSCI SA celebrated AAC Awareness Month 2020 with a picnic at a local playground. Although the weather was cool and windy, it was great to see everyone gather for this annual celebration. There was so much to chat about since we saw each other last year.



The face painter was an exciting addition to our picnic and Ruthie had her first hand painting ever! It certainly was fun deciding what animal to be painted.

Put Sunday 24th October 2021 in your diary, we look forward to seeing you all then.

:: JODIE WHITFORD



AUSTRALIAN CAPITAL TERRITORY



It's been glorious to get out and about in Canberra lately as it's the greenest it has ever been! Unfortunately, our October AAC Awareness Month picnic was rescheduled to November due to the unusual amount of rain that fell on the capital through October. Stay tuned to see some wonderful photos from our November picnic in the next issue.

Lots of families have contacted me to ask about building opportunities for their people who use AAC to chat with other AAC users. If you're interested in teaming up with other AAC users, send us an email at agosciact@agosci.org.au to register your interest.

Wishing everyone a magical holiday season,

:: JESS DETHICK

STATE REPORTS

TASMANIA

Our community has had to say a sad goodbye to our friend, Rhys Linden, who died in June 2020, aged 16. His high school friends described him like this: He was courageous. He was fun. He was intelligent. He was awesome. He was hilarious. He was brave. He was the best. He is loved. He is so sorely missed.



Rhys and his family made AAC a part of their rich and vibrant lives. Many people in our local community saw AAC because Rhys had it in his life from the age of 2.

In AAC Awareness Month, Rhys' best mate Rhodry ran a marathon to pay tribute to their friendship. The Wynyard community supported his efforts and raised \$18000 for the Cerebral Palsy Education Centre.

We also held an AACessible Yoga event at the beautiful Penguin Surf Club.

:: FELICITY LOVATT



"It was definitely an emotional run. There was so much support through Wynyard and I am a bit emotional about that." Rhodry



Rhys and Rhodry's families celebrate after the run



STATE REPORTS

NEW SOUTH WALES

Hi everyone, unfortunately our Halloween themed AAC Awareness Month event needed to be cancelled due to stormy weather, however we are looking forward to hosting another event later this year. The event will take place at the same venue (Livvi's Place park, Ryde) and we will look for a day with better weather! Of course, we will be referring to the NSW government website for COVID-19 advice relating to restrictions and gatherings.

Here are some snaps of us dressed up in our Halloween costumes! We hope that everyone is staying safe and enjoying the relaxing of restrictions to date!

:: SABRINA FONG & CECILIA ROSSI



WESTERN AUSTRALIA

Some of our AAC community in WA escaped the heat for some ice skating fun!

To celebrate AAC Awareness Month, AGOSCI WA hosted a meet up at an All Abilities Ice Skating Session. There were lots of smiles and giggles as young and older slid around the ice rink, stopping for breaks to chat and share fun moments.

Everyone commented on what a great experience it was, and if you missed it, we can highly recommend getting a group together and heading down to another of Cockburn Ice Arena's All Abilities Sessions. They are held on most Friday afternoons and occasionally on weekends (check out their website for details).

Following many requests here in the West, AGOSCI is also looking forward to partnering with Indigo (formerly ILC) to host an Introductory PODD Workshop early in the new year.

:: YVETTE THEODORSEN



STATE REPORTS

QUEENSLAND



This year has certainly been very difficult for connecting with AGOSCI members in person so it was so exciting to be able to celebrate AAC Awareness Month on Saturday, 31st October, 2020 by having a picnic at a park in Brisbane. Families were able to have their faces painted, read stories and explore several Halloween themed activities. We finished the picnic just in time to beat the Queensland summer storms as well, which was very lucky!

Also, we're very excited in QLD to be running two, one day PODD Alternative Access Workshops. These workshops will be presented in Brisbane by Janelle Sampson, on Wednesday the 25th and Thursday the 26th of November.

:: EMMA GOLDSTON



VICTORIA



Understandably, it has been a quiet quarter for AGOSCI Vic as we have bunkered down at home over the second half of this year, sheltering in place alongside the rest of the Victorian community. But, while the lockdowns have been a very tough time for so many, we at AGOSCI are in awe of how all Victorians have pulled together in this collective effort to keep each other safe, including, of course, the wonderful AGOSCI Vic community. We look forward to sharing doughnuts with everyone when we can finally all get together again, safely!! In the meantime, stay tuned for some photos of the AGOSCI Vic community celebrating AAC Awareness Month in isolation, and rocking some very stylish masks!

:: STEPHANIE WEIR

THE AGOSCI AUSTRALIA COMMUNITY FORUM

(PRIVATE GROUP ON FACEBOOK)

DO YOU USE FACEBOOK?

HAVE YOU LOCATED OUR AGOSCI PAGES?

On Facebook we have AGOSCI Inc that is our public page for promoting special events and public campaigns.

We also have our AGOSCI Australia Community Forum that is a private group which members and non members can join. AGOSCI aims for this group to provide a safe and inclusive space for all people to have conversations about communication and complex communication needs.

(Please note that our Listserve is no longer being used)

 www.facebook.com/AGOSCI

 www.facebook.com/groups/agosci.forum

WHAT IS IN A VOICE? KATHY HOWERY ASKS US TO REFLECT ON THE MEANING AND POWER OF VOICE

By Ria Ferris

In July, the AGOSCI community was treated to two interactive online workshops with Dr Kathy Howery, following the sad cancellation of her scheduled National Tour earlier in the year. Kathy presented on her doctoral research into the lived experience of those who communicate with or through an aided communication system. She invited workshop participants to reflect on the meaning of “voice” and “time” from the perspective of people who communicate with AAC. Kathy explored concepts including voice as a personal identity, and the complexities of communicating in *text time* alongside others communicating in the flow of natural speech.

Kathy's doctoral research participants explained powerfully, through her interviews, that having a voice, a voice that was theirs and enabled their participation in conversation, was not to be taken for granted. Through these workshops, we were encouraged to deeply reflect on the experiences, words, and knowledge of those who communicate with and through an aided communication system, and to strive towards extending the reach of every individual's voice towards autonomy.

These workshops are not to be missed and are full of practical considerations for daily practice and teaching.

The registration links for Kathy's recordings are accessed here:

[➔ www.agosci.org.au/Workshop-Recordings](http://www.agosci.org.au/Workshop-Recordings)



Gathering Lived Experience Descriptions

20-07-21 Kathy Howery, PhD 28

The slide features a large red outline of a smartphone with a speech bubble icon on the screen. To the right, there is a stylized illustration of a person's head and shoulder. A small video inset in the top right corner shows a person in a grid of video feeds.

SOCIAL CLOSENESS, RELATIONSHIPS, AND COMMUNICATION

The following is an excerpt from page 3-4:
Alant, Erna. (2017). *Augmentative and alternative communication: Engagement and participation.* © Plural Publishing, Inc. Used with permission.

Like many of the most elementary insights into human nature, the premise of this book was in many ways catalyzed by a brief—and unanticipated—interaction.

It was five o'clock on a Thursday afternoon, and I had rushed to the grocery store to buy a packet of white onion soup. A friend of mine was coming over later, and the soup was an integral part of the recipe that I was making for dinner that night. I picked up a shopping basket, as I knew I only needed a few things and would be out of the shop in a few minutes. But when I got to the soup lane, searching for the white onion soup I saw every possible variation and flavor of soup, but not the one I was looking for! In desperation, I swung around to see if I could identify someone who worked at the store and could help me. Instead, however, I became aware of a young boy in a wheelchair who was watching me closely. His mother was also busy searching for a grocery item, but she was facing the opposite shelf.

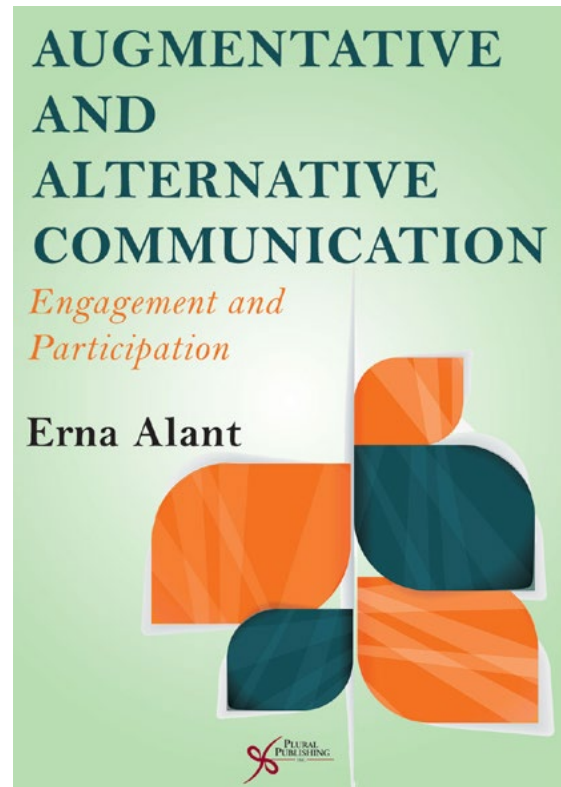
The young boy was watching me intently, and I sighed to show that I was tired of searching through the soups. In response he wiggled, shifting around in his chair, and smiled broadly. I winked at him, selecting a packet of soup that could act as a substitute for white onion soup. Before I left, I turned around and gave him a thumbs up. He made a gesture with his hand and gave me a broad smile. As I got into my car, I realized that my mood had change: I had walked in to the store, a stressed professional who needed to perform a number of duties efficiently—shopping, following a recipe, preparing dinner—but walked out at person who, after the quiet interaction with the young boy, was now on my way home, looking forward to preparing and then sharing a meal with my friend. I already knew I was set for a much better evening.

Somehow a short interaction with a young child in a grocery store had changed my whole approach as well as my expectations of the evening ahead of me. How did this happen? There was neither a verbal exchange involved, nor did we know each other. Reflecting on the interaction, I realized that the child's attention to and his interest in me had encouraged me to stop and pay attention to what really mattered in that moment. The focused attention that the child had given me was

effectively an invitation into his mental space, and I was thankfully able to be receptive to it!

What transpired between the child and me is fundamental to the argument of this book and constitutes, I argue that core of communication—that it, the basic ability to (a) pay attention to the other and (b) be receptive to the other in interaction. It is then somewhat ironic that we tend to get caught up in the technical aspects of communication (e.g., how to speak operate a device, used communication boards, and teach communication strategies), while the deeper aim of communicating—meaning-making between two people and the developing of friendships—extends well beyond our ability to send and receive messages.

In this chapter, I provide and description of communication as a meaning-based process, discussing the related concepts of emotional resonance and social closeness. I also explain the basic components of communication, engagement, and participation and discuss their application within the context of interaction with people having little or no functional speech. Finally, I describe the characteristics of a meaning-based approach and propose one way of identifying different levels on meaning in interaction.



THE ROLE OF AAC IN SUPPORTING INCLUSIVE EDUCATION

By Teresa Iacono, PhD

Most children with disability are educated in mainstream schools – at least, that’s what the data indicate, with special schools making up about 5% of primary and secondary schools (Australian Bureau of Statistics, 2016). More difficult to determine is the number of students who receive their education in mainstream schools, but who are functionally segregated from their peers, such as in special units within mainstream schools, or those denied access to peers (with or without disability) because parents, out of dissatisfaction with both school systems, opt for home schooling (Iacono, Keeffe, Kenny, & McKinstry, 2019; Mann, Cuskelly, & Moni, 2018). It seems that those with the most significant disabilities, including children with complex communication needs, have little choice but to attend special schools because of practices known as micro-exclusion or gatekeeping, such as mainstream principals encouraging families to enrol their child in schools better able to cater to their needs (Iacono et al., 2019). These practices occur despite national legislation, and national and state policies promoting the rights of all children to a mainstream education through the provision of reasonable adjustments to meet their needs (Iacono et al., 2019).

In addition to concerns about human rights violations in denying access to quality education alongside peers with diverse abilities (United Nations, 2006), segregation of students with complex communication needs also segregates practitioners (teachers, teacher assistants, and allied health professionals) skilled in meeting the needs of these students. In a project completed for the Victorian Principals’ Association of Specialist Schools, we found that mainstream school staff felt ill-equipped to meet the diverse needs of students with disabilities, but welcomed peer support and sharing of expertise found in special schools (Iacono, Keeffe, Kenny, & McKinstry, 2017; Iacono, McKinstry, Wilson, Bagley, & Kenny, 2020). We also found that allied health professionals were considered a highly valuable resource, but teachers in both mainstream and special schools found them difficult to access. Allied health professionals who worked in mainstream schools were reportedly occupied with assessments for funding eligibility, while those who worked in special schools were so busy that teachers rarely had the opportunity to work with or learn from them (Iacono et al., 2017).

The research also indicates that most AAC work is occurring in segregated settings. At the last ISAAC

conference, I presented findings of a scoping review of the AAC research literature conducted in school settings (Iacono, 2018). I found that over half the studies published from 2000-2017 were conducted in special schools or other segregated settings. Most of these studies addressed improving use of AAC or communication skills, more broadly, while those conducted in mainstream schools were focused on peer interactions. Since then, I have been working with colleagues Professor Juliet Goldbart, Dr. Sarah Douglas, and Ms. Ana Melga Garcia to extend this review, tightening criteria and search strategies, and extending the timeline to bring it to recent publications. We found 169 studies that met inclusion criteria, with only 17% conducted in truly inclusive settings (i.e., in mainstream school rooms with peers). Further, the focus on peer interactions became even more evident in this more rigorous review, with teaching competency in using AAC taking an even lesser priority.

The lessons from these studies seem to point to a tendency for the good work in supporting students in using AAC to be occurring in settings that are far removed from mainstream schools, and hence, mainstream society. The danger is that mainstream school communities will continue to lack exposure to the many benefits and opportunities that can be offered students with even the most significant disability, as well as their peers and teachers. The gap in the ability of mainstream and special school personnel to adjust their curriculum to address the needs of these students, or to incorporate AAC as part of universal design for learning or the practices of the school community will only widen.

Of course, there is always the potential for research to have missed the mark in terms of what is happening in education and AAC practice. In a previous issue of *InFocus*, Amelia, Michaela, and Harry, from *TwoWay Street*, described strategies to enhance Harry’s experience of inclusive education. It was also notable, and reflective of our systematic review findings, that Amelia had included the teaching of school staff and peers about AAC as a strategy to support Harry’s education. This strategy offers the potential to increase teacher skills in making adjustments to the curriculum to incorporate Harry’s AAC, and for peers to similarly understand and accommodate for differences that occur during social interactions involving AAC.

AAC is the means by which students with complex

communication needs can access the educational curriculum and social milieu of schools and classrooms. It is time to move AAC expertise into these mainstream settings, thereby preparing society to be inclusive of varied ways of communicating and supporting people with disability.

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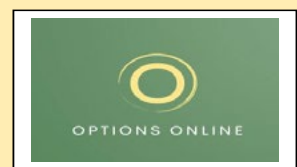
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TEACHING READING: ARE WE ASKING THE RIGHT QUESTIONS?

By Ann Sullivan

New York, New York... some things are so good, it seems, they are worth repeating. This often happens when I am asked the question, "How do you teach a child to read if they cannot speak?" I answer the question and then inevitably hear them repeat it with a slightly different emphasis, "No, but *how*?" Over time, I've come to realise that repetition should probably only be applied to New York or in the context of belting out a song. My eager enquirers are, I feel, really wanting me to answer a different question second time around. They don't need me to tell them 'how' again, they need me to tell them 'what'.

Since the mid-1980s, the volume of academic research into how children learn to read has massively increased and teachers, psychologists, and speech and language therapists (UK terminology) are now in a much better position to say, pretty much unequivocally, what is the best way to go about it.

In 1986, Gough and Tunmer, published their research-led model, *The Simple View of Reading*, which has stood the test of time. Within this model there are two keystones to becoming literate: having good oral language comprehension and being able to decode the words on the page.

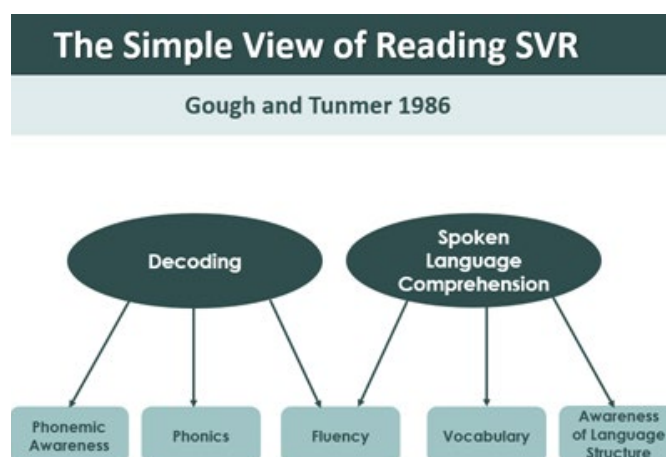
Let us start by thinking about 'decoding'. Written language is viewed as a 'code' where letters (graphemes) visually capture on paper the intangible sounds (phonemes) we hear in spoken words. So, reading can be described as decoding (translating the letters into sounds and making words). Phonics refers

to the study of the graphemes and the phonemes they represent and developing a body of knowledge that maps the relationships between the two. However, decoding words is not just a matter of having this phonic knowledge. A child also needs to have a set of skills in their toolbox so they can access and work with the sounds in words. These are the phonemic skills that begin with developing awareness of rhyme, alliteration, syllables, onset (word beginnings) and rime (word endings), leading to discrimination and isolation of sounds. Later comes the 'advanced' phonemic skills; blending for reading (pushing sounds together to make a word), segmenting for spelling (splitting a spoken word up into its component sounds in sequence) and phoneme manipulation, which is needed for both reading and spelling (sliding sounds in and out of words). Notice that I refer here to both reading and spelling (decoding and its reverse, 'encoding') as these can be considered to be two sides of the same coin within the alphabetic code. Reading and spelling should be taught in tandem within literacy instruction.

Basic phonemic awareness happens without the child being taught the letters, but more recent research indicates that blending, segmenting, and phoneme manipulation are best taught in the context of letters and words, that is, as reading (and spelling) instruction begins (Ehri, Nunes, Willows, Schuster, Yaghoub-Zadeh, & Shanahan, 2001). It is the combination of phonemic and phonic skills that enables a child to decode printed words. As their knowledge and accuracy increase, they become more fluent.

When thinking about the second aspect of the Simple View of Reading, understanding spoken or oral language, the child has to have an awareness of language structure and a good, and continuously expanding, vocabulary. These elements also contribute to the development of reading fluency as the child's understanding of spoken language can be applied to written language, resulting in reading comprehension. With accuracy and reading comprehension improving, the child becomes able to read with increasing pace and prosody (the ability to read with expression, appropriate intonation, rhythm, and emphasis).

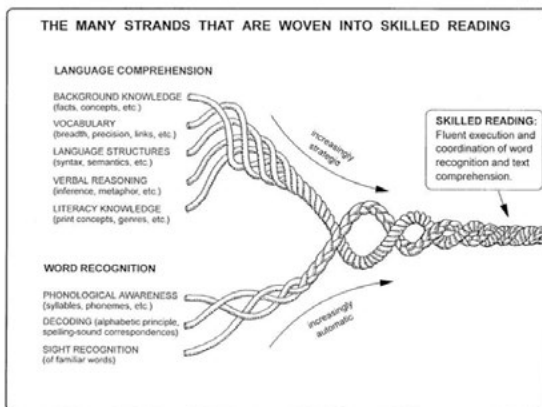
In 2001, Scarborough produced an infographic known as *The Reading Rope* that illustrates the relationship between all of these aspects using the analogy of a



The Simple View of Reading (Gough & Tunmer, 1986)

The Reading Rope

Scarborough 2010



The reading rope (Scarborough, 2010)

rope made up of strands that twist and bind together as a skilled reader develops.

Scarborough also included a strand for 'sight recognition' of words. By the term 'sight words' she refers to that seemingly elusive ability to look at a word and simply know it and say it, achieved by orthographic mapping (a process that occurs within the brain when phonemes and graphemes are overlaid and which secures the word in long term memory for almost instant retrieval when required) (Ehri, 2005). What she does not mean is showing the child whole words and asking them to visually memorise the shape or 'look', a strategy that has some short-term success but is ultimately limited.

So, the task ahead for all our pupils is, armed with phonemic skills, crack the phonic code to be able to read and spell words and ultimately store them in long term memory via the process of orthographic mapping. So, how do we teach them to do this?

The answer is simple – explicit instruction using a systematic, synthetic phonics approach. Systematic refers to cumulative coverage of the whole alphabetic code alongside opportunities to learn and master phonemic skills and phonic knowledge. Synthetic refers to the 'bottom up' approach of 'synthesising' or building words from component letters and sounds rather than the top down 'analytic' approach of learning to recognise a word by its shape and *then* consider the phonics of the letters and sounds. For a pupil

with special educational needs, though, a linguistic approach is particularly beneficial. Linguistic phonics is a sub-set of synthetic phonics that frames the instruction around the way writing naturally evolved over time, from the need to fix speech into print to send messages or set down thoughts for posterity. Linguistic phonics presents instructional information in this natural direction, 'a sound is represented by a letter (or letters)'. This is easy for children to understand and offers up simple, but effective, strategies for reading and spelling words.

As educators of pupils with complex needs, we must be mindful of the impact of the science of reading and the need to take a research-based approach to teaching this group of pupils just as we would for typically developing ones. As such, there are a few things we need to be clear about.

Our pupils have to work with the same alphabetic code as everyone else – there is absolutely no way round that. So, to be able to read and spell they need to learn and understand:

- the same relationships between phonemes and graphemes,
- the same concepts about how the code is put together and how it works, for reading and spelling
- the same phonemic skills, and
- the same body of phonic knowledge.

We know what the best way to teach reading and spelling is, so surely, we should take the *same* optimal approach for pupils with special educational needs, even if their needs are multiple and complex? We owe them this.

For our complex learners then, we should do this by providing explicit instruction that systematically and cumulatively covers the entire English code – just like everyone else. We should also do this in the context of teaching a content rich curriculum that expands and broadens vocabulary, language skills, and background knowledge – just like everyone else.

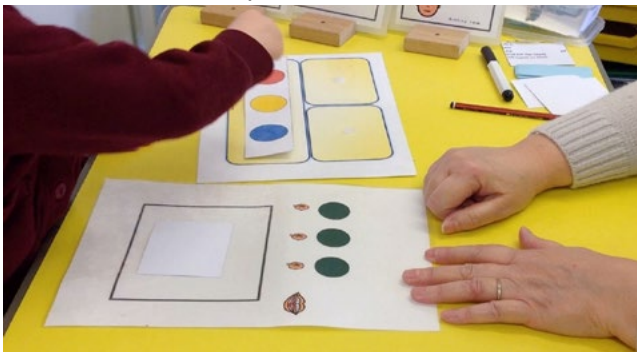
Pupils with complex special educational needs, such as speech, language and communication needs, autism, severe learning difficulties and physical disabilities that impact on fine motor skills are, however, are likely to need teaching materials and their presentation to

TEACHING READING CONTINUED

be adapted to enable access and participation. For some pupils, alternative strategies may also need to be used to enable them to respond and ask questions themselves. Additionally, we need to be aware that the pace at which the pupils work through the content of a programme is likely to be slower.

Adaptation of this type is surprisingly straightforward and easy to do. It relies on a relatively small number of simple low-tech strategies to enable pupils to access the materials and a relatively small number of simple low-tech communication strategies to enable them to respond to the activities and tasks. Using these strategies, I am easily able to provide all the content of my linguistic phonics programme, Phonics for Pupils with Special Educational Needs to my pupils with complex needs.

You can see this in these pictures of a pupil (aged 4 and in a UK reception class) using some of the resources that enable access. On the right of the pupil in the first picture is an 'I have something to say' card with added symbols. By pointing to individual symbols, the pupil is able to ask me to 'say it again', 'do it again' and much more. On the left of the pupil in the second picture is a 'My work' card that enables them to respond to the specific activities and tasks by choosing from a selection of symbol cards or by selecting items anchored to a visual place marker. You can watch me



teaching this pupil using a range of strategies on my Youtube channel Phonics for SEN.

So, thinking back to the questions I am frequently asked, the answer to the 'what' question, is that the content and structure of instruction for these pupils should be the same as for all other pupils. The answer to the 'how' question is that phonics programmes need to be adapted to enable access according to the pupil's individual needs.

To quote a song I know... 'start spreading the news...'

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Ann Sullivan is a specialist teacher, ex SLE (Specialist Leader in Education) for physical disabilities and is based in the UK. She is the author of the programme 'Phonics for Pupils with Special Educational Needs' published in a series of seven books by Speechmark, Routledge 2018.

Phonics for Pupils with SEN is a systematic, synthetic, linguistic phonics programme. A companion eResource booklet is available containing adaptations for all the activities to enable pupils with a range of complex needs to access the programme.

 www.youtube.com/channel/UCza2XtCMj7efoaJtw9cXeWg

 www.phonicsforpupilswithspecialeducationalneeds.com

LEARNING FROM MISTAKES: EXPLORING ACCESS FOR AIDED COMMUNICATION

by Ruyi Tong, Advanced Speech Pathologist,
Therapy Focus

I first became interested in exploring access for individuals with complex communication needs more closely when Alex*, a client that I work with, decided to explore his communication device using his hands in addition to his eyes. Alex is a 15-year-old boy with complex communication needs. He is an extremely capable eye gaze user. Eye gaze is his primary access method, chosen as his ability to control how his arms move is inconsistent. He accesses his eye gaze device that is mounted to his wheelchair or placed on a robust surface whenever he has something to say. In addition to his communication device, Alex uses his Pragmatic Organised Dynamic Display (PODD) book for communication.

Recently, his mother and I noticed Alex's tendency to use his hands to access his device whenever his messages were misunderstood. To physically access symbols on his device accurately, Alex would rest his right hand on the edge of his device and use his index finger or thumb to select a symbol on his device. Interestingly, although the messages constructed were notably shorter (e.g., single symbol messages) compared to those constructed when Alex used his eyes (e.g., three plus symbols), he was able to engage in more frequent communication exchanges using the former method, as he could *get his words out* quicker. Of note, given the shorter messages constructed using physical touch, his communication partner had to scaffold these interactions using cues in the environment and his PODD book. Intrigued, we wondered whether this new way of accessing his device was because his eye gaze was faulty. This was not the case.

This was a fascinating observation that led me to think about access for individuals with complex communication needs more deeply. Following chats with Alex, his mother, carer, and colleagues, it became clear that Alex chose to access the same communication device in different ways (e.g., eye gaze, physical touch) depending on the context in which the communication occurred. Alex highlighted a tendency for others to make decisions on his behalf, as a barrier for him to access his device for authentic communication. He felt this behaviour stemmed from the assumption that he has nothing to say, or required assistance to think about what to say, due

to long periods of silence in between communication exchanges. Communication partners who were less/unfamiliar with how Alex communicates may have found it awkward waiting in silence, as Alex thought about and composed his messages on his talker.

Reflecting, this was an eye-opening experience for us. Together we decided to:

- Normalise Alex's desire to use two physical access methods (fingers and eye gaze) interchangeably as he wished. We acknowledged his access method may change over time based on needs and context.
- Value all types of messages constructed regardless of symbol length.
- Reinforce the importance of ensuring communication partners understand and give individuals with complex communication needs, the time and space to construct their messages.
- Commit to rectifying assumptions and incorrect stereotypes related to how communication partners perceive and support individuals with complex communication needs and complex communication access needs whenever these arise.

I conclude by encouraging further conversations about access, interpreting messages constructed within different contexts, and of the importance of challenging assumptions.

*Alex is a pseudonym. Name and gender were changed as requested by the client and family.

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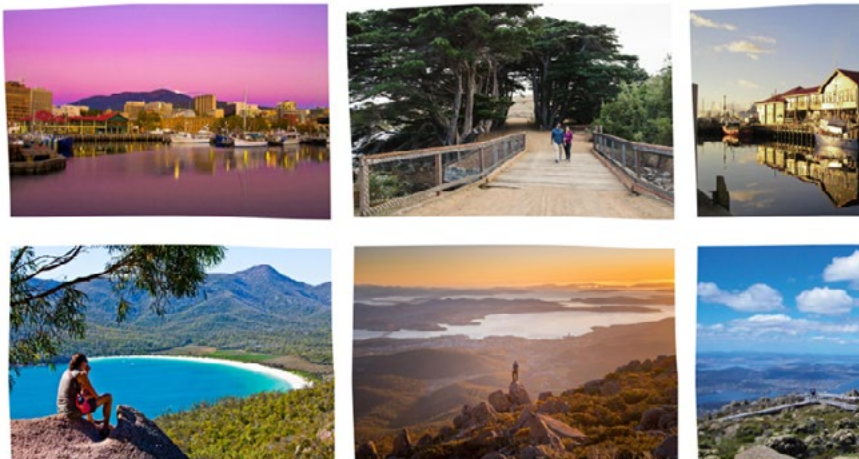
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CONNECTING OUR AAC COMMUNITY AT KIDS PLUS

Jenna O'Brien (Senior Speech Pathologist) and Noah Callan

Kids Plus Foundation is a not for profit organization based in Geelong that specializes in intervention for babies, children and young people with cerebral palsy and similar neurological conditions.

At Kids Plus, we see many young people who require the use of AAC from a very young age. Excitingly, many years on since Kids Plus started, we are now seeing our young people grow into teenagers and young adults who use AAC. This is extremely rewarding, but also allows reflection on missed opportunities along the way.

Early on in my career as a speech pathologist, I wish I had more experiences speaking with and learning from AAC communicators who could reflect on their experiences of starting out with AAC and building relationships as they got older. That kind of knowledge for a speech pathologist is as inestimable as it could be for a family starting out with AAC, a family that is struggling to make progress or integrate AAC into their daily life, or a family that feels isolated from others with similar experiences. Researchers are also now highlighting the importance of building connections within the AAC community. We knew at Kids Plus we had to take action by helping build an AAC community by bringing together, individuals who use AAC, their families, and supports through shared knowledge and

experiences. A big part of our vision and goal was to develop more face to face group training opportunities and involving individuals who use AAC to be a part of this process. After all, individuals who use AAC in their daily life are the experts and have such important stories to tell to help shape and guide experiences for others along their AAC journey.

One of our first steps, was to involve an individual who uses AAC in our newly developed group parent and support worker training program. An individual who uses AAC could not only share their experience but also support development of the training content and, more excitingly, delivery of this content. For a parent or support worker involved in the program, to learn directly from a young adult who uses AAC is extremely powerful for many reasons, including: supporting acceptance of their young person's AAC system, reassurance about challenges or bumps along the way, increasing family motivation, and encouragement to persist with AAC.

At Kids Plus, we engaged Noah Callan in 2019 to help us inform and influence our AAC parent training program. This was after a chance meeting at an 18th birthday party, where Noah's communication device helped us make a connection. Noah developed 3 of our 10 AAC modules delivered weekly to families and support workers. Noah developed PowerPoint and video content on the lived experience of AAC, how to be a good communication partner, and presuming potential and advocacy.

Noah reflects on his experience in the program:

Being unable to communicate verbally is really hard and sometimes it can be a challenge to get my message across. One item that has changed this for me is my Grid Pad. It allows me to communicate effectively just with my eyes. To be honest, it has given me the voice that for a very long time I didn't have. When Kids Plus invited me to be a part of their new AAC training program, I said yes without any hesitation. Being involved in the development of the



program was a great feeling, both when asked by Kids Plus and also whilst preparing content and presenting. This meant that I could share my AAC knowledge and pitch some of my ideas to make our sessions more interesting and entertaining while building capacity in AAC. Not to mention the feeling of empowerment and sense of achievement a person feels when being asked to be involved in something so worthwhile. I couldn't miss the opportunity to share my experiences of being an AAC user and my knowledge of technology with families who are new to using Augmentative and Alternative Communication. As a presenter and someone who uses AAC, it's important to clarify that learning how to communicate using AAC is a journey. One that will have its moments of both frustration and joy, and to remember that where the individual who uses AAC starts is not where they will end up, that's for sure. We are trying to show how AAC can unleash a child's voice and their communication skills. It won't happen overnight but we're teaching them how to build the stepping stones to get on the right path to success and to help increase expectations for participation and engagement.

As someone who uses AAC, I am more than happy to share some inside information around what it is like to be non-verbal, navigating through life and using my communication device. It is especially valuable to share my experiences about how people react

around me when I use AAC. It is really refreshing to be asked to be part of the conversation because as a user, my experiences matter and will help others! The feedback from the families attending the course has been positive so far and they seem interested to hear how AAC survives in the real world and also how people react to it. Some of the questions I received from families and support workers were about if I could swear, how it worked with my siblings growing up, how I learned to read and what I wished my parents knew. I think even using my device as part of my presentation at Tech Talkers is really powerful in demonstrating to the audience the impact it can have in connecting and communicating with others, and also shows the practicalities of using AAC when communicating with others. You can never underestimate seeing the power of AAC firsthand.

Whilst we wish this kind of program was implemented a long time ago, the great news is, it is up and running now for the benefit of our current community. AAC content development and delivery should involve individuals who use AAC. They have the power to inform and influence a new generation of families and young people who will require the use of AAC and a sense of community. This ongoing collaboration will help us continually evolve our AAC programs for the better, for parents, support workers, siblings, educators, and professionals and help continue to build a strong and empowered AAC community.



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PLAIN ENGLISH THOUGHTS ON INTERIM REPORT: ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY

by Sheridan Forster

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is important for people with disability in Australia, their supports, and the community. The Interim Report came out on the 30th October 2020.

The report includes the background to the Commission, what the Commission has done, and what they have learnt so far.

The report is more than 500 pages long. There is a summary report. The Easy Read report is written in two sections: An Easy Read guide and What have we learnt so far. There is also an Auslan video summary.

I had a look at the long report. I wanted to know what the report said about people with complex communication needs. I searched the report for the words communication, communicate, speech and augmentative and alternative communication, AAC, complex communication needs. I looked at how the words were used and how many times they were used. I have put what I found out in a table.

Communication was highlighted a number of times in the report. I saw a few different themes about communication. Having a communication impairment

could contribute to the risk of violence, abuse, neglect, and exploitation. There were broad themes of how the Commission communicates and issues of how different groups communicate with each other (e.g., families and medical personnel). There were issues for people with disability not being communicated with in a way that they understood, for example in health care and justice settings. The need for training of teachers and support workers in communication was highlighted. There were a small number of comments regarding people needing means of communication other than speech, such as visual displays and communication devices. Importantly, the denial of a communication device to someone who owned one was noted as a mechanical restraint in the person's life. Terms that we may commonly use such as having complex communication needs and using AAC were rarely used in the interim report.

I only had a very quick look at the Interim report, and need to give it a thorough read. It did strike me that having complex communication needs was not addressed explicitly. Instead, there was an implicit theme that communication breakdowns between people with complex communication needs and all partners posed a risk factor for violence, abuse, neglect, and exploitation.

TABLE 1. NUMBER OF INSTANCES IN WHICH WORDS ARE USED AND EXAMPLES

WORD AND THE WAY IT WAS USED		QUOTE EXAMPLES		
Communication / communicate People with communication disability	25	People with communication disability, culturally and linguistically diverse people with disability and people with intellectual disability are particularly likely to be excluded from statistics about violence and abuse experienced by people with disability. (p 28)	Some organisations who have responded to our Criminal justice system issues paper have told us about concerns regarding police approaching or questioning people with disability and not identifying that the person has disability or making appropriate adjustments to the way in which they interact or communicate. (p 401)	When a person can't communicate, or can't communicate in a traditional way, Maya said: their lives are viewed as having poorer quality and they are viewed as second class citizens ... Many of our issues stemmed from communication breakdown or pre-judgement of a situation and decision-making that is not clinically based. (p 280)

WORD AND THE WAY IT WAS USED		QUOTE EXAMPLES		
Communication / communicate Communication barriers and communication access	10	The Royal Commission has heard about the barriers that people with disability can face when accessing services and supports. These include attitudinal, institutional, environmental and communication barriers. (p 35)	The social model shows how people can be disabled by social barriers, which can include negative or discriminatory attitudes, inaccessible physical environments and inappropriate or inaccessible forms of communication (p 330)	Communication barriers, which can arise when information is not accessible, such as audio or verbal communication being unavailable in written text, Easy Read, Auslan or captioning for people who are deaf, have hearing impairments or have complex communication needs and do not have appropriate technology and support to communicate. (p 364)
Communication / communicate Communication between different or groups like schools and families	12	Poor communication and collaboration between school staff and students with disability and their parents, which may lead to neglect, compared to the role of positive relationships in providing safe, inclusive and quality education. (p 39)	Tessa is also angry about the lack of clarity in communication she continues to experience while dealing with her son's health and wellbeing. (p 190)	Poor communication and collaboration leading to potential neglect. (p 223)
Communication / communicate Giving information in a way that people can understand	15	Importance of communication and information sharing, including health professionals communicating directly with people with cognitive disability and their parents or supporters, as well as between health services and health professionals. (p 43)	Jennifer told us that in her experience medical staff will often dismiss the concerns or questions of patients with disability in the belief that 'they know better'. She said they routinely fail to provide clear information at a patient's communication level. (p 106)	Good communication is also crucial to quality health care. An aspect of good communication is supporting people with cognitive disability to make informed decisions about their care and treatment. (p 260)
Communication / communicate How the Commission communicates including how they communicate with First Nations people	21	Examples of how evidence has been given include: - by video link using communication devices - incorporating videos - using photographs and other images - with Easy Read formatting of statements with support persons. (p 152)	The Royal Commission's power to communicate information. (p 115)	Good communication is also crucial to quality health care. An aspect of good communication is supporting people with cognitive disability to make informed decisions about their care and treatment. (p 260)

WORD AND THE WAY IT WAS USED		QUOTE EXAMPLES		
Communication / communicate books, boards, and devices, Auslan	8	... insufficient training of the education workforce to increase awareness of disability and insufficient use of communication, educational techniques and suitable materials to support students with disability. (p 220)	Mechanical restraint – ‘the use of a device to prevent, restrict or subdue a person’s movement for the primary purpose of influencing a person’s behaviour but does not include the use of devices for therapeutic or non-behavioural purposes’. Examples include tying a person to a chair, disconnecting the power of an electric wheelchair or taking away a person’s communication device. (p 357)	One medical expert expressed the view that it is viable for the health system to implement adjustments that are most frequently needed for people with intellectual disability, such as longer appointment times, appointments being booked at certain times of the day or the use of visual aids to overcome communication difficulties. (p 266)
Nonverbal Complex communication needs Severe communication impairment Augmentative Alternative communication AAC	1	... communication barriers, which can arise when information is not accessible, such as audio or verbal communication being unavailable in written text, Easy Read, Auslan or captioning for people who are deaf, have hearing impairments or have complex communication needs and do not have appropriate technology and support to communicate. (p 364)		
Speech pathology – Speech Pathology Australia and speech pathologist	2	Speech Pathology Australia told us that inaccessible complaint procedures can be harmful for those who are non-verbal or deaf. (p 371)	For example, Speech Pathology Australia described an incident where a Do Not Resuscitate order was placed on a person with disability in intensive care without the doctors consulting the person with disability or their family. (p 386)	
Speech – impairment or “confined to speech”	4	If you are deaf or have a hearing or speech impairment, telephone the National Relay Service on 133 677 and give 02 6146 1468 as the number you want to call.		

PAGE NUMBERS REFER TO THE ACTUAL PAGE ON THE WORD DOCUMENT.

[HTTPS://DISABILITY.ROYALCOMMISSION.GOV.AU/SYSTEM/FILES/2020-10/INTERIM%20REPORT%20-%20SUMMARY.DOCX](https://disability.royalcommission.gov.au/system/files/2020-10/interim%20report%20-%20summary.docx)

THE ART OF MAKING MISTAKES

by Claire Fraser, Registered Arts Therapist

There is a Japanese form of weaving termed Saori weaving, developed in the late 1960's by a woman named Miso Jo. She was practicing traditional Japanese weaving, however as she wove, she made a *mistake*. She decided she quite liked the way it looked and continued creating mistakes, weaving in a free form way that felt natural to her. Saori is an art form, but also a life philosophy – mistakes are assumed within the process of creating a rich and unique piece of weaving.

Art Therapy is a form of therapy where the combination of materials, environment, and therapeutic relationship enables the gentle exploration of risk, mistakes, and uncertainty. A space to experiment, try something, push a boundary, sit in the unknown, take a risk, and see what emerges.

Reflecting back, I can recall many moments in my career as an educator and art therapist, working with children and adults with complex communication differences, often paired with mental health challenges where moments of *making a mistake* have been ones of learning, change, a shift, or a significant moment in the therapeutic work.

Laughing alongside a young man whose paint roller slipped off the paper and onto the wall is an example of this. There was a moment of disbelief as we shared extended eye contact paired with a cheeky smile which said, "Me?! Marking the classroom wall?" There is joy and excitement in taking a risk, or when something that isn't meant to happen occurs, or when a *cardinal rule* is broken. Don't make a mess, stay in the lines, stick to the paper. To even have the experience of *making a mistake* is one people with disability so often are not granted.

Again, sitting side by side with a woman, tears streaming down her face, because the wool on her wall hanging she had created wasn't symmetrical on both sides... We sat together in the distress and extreme discomfort she was experiencing facing her *mistake*, how to sit with it, and move through the moment. This became the work over several sessions – grappling in the space of panic and uncertainty, then moving towards tolerance, acceptance, and problem solving around the *mistake*. It is the process that is the therapeutic work, not the finished product.

The final example I wish to share is one of working around a marbling tray with an older woman with

extremely shaky hand movements. She continually touched the paper sitting in marbling dye, while it was meant to be left to sit still and make its imprint. When she lifted the paper, the marbling ink had printed the most beautiful pattern – fainter, more detailed, and a unique mixing of a kaleidoscope of colours. This was not a replica of how other marbling prints looked, instead, she had created her own unique style of marbling. I recall her look of fascination and curiosity at her artwork, amazed at her own skills. In this moment there was a shift from "I'm doing it wrong" to "I'm doing something different and unique."

From the few moments I have shared, you can see that the materials offered within the context of a therapeutic relationship enable safe engagement with *making mistakes*. It opens the door to exploring what happens when you let go of the need to do it *right* or follow the rules; offering an opportunity to reframe, explore, or create something entirely new. These experiences amass to discovery and growth, adding a richness and depth to one's experience of what it is to be human.

When I look at my own Saori weavings – each work is a mish mash of pulled threads, clashing colours, unconventional textures thrown together. These *mistakes* amount to a piece that is uniquely beautiful, because of the mistakes, not in spite of them.



A TEAM EFFORT: AN APPLICATION OF COMMUNICATION PARTNER TRAINING TO SUPPORT A YOUNG WOMAN, K, WITH SIGNIFICANT COMMUNICATION AND INTERACTION NEEDS

By The support worker team (Jodie, Bron, Vicki, Jess), family members, and Jane (SLP)

Summary

This paper summarises an intervention approach for a young adult with significant challenging behaviours and complex communication needs. Interventions were founded on a communication partner training approach and delivered solely by her family and support workers over three years. The process and outcomes highlight how:

1. It is a mistake to consider someone in a too hard basket
2. Communication partner training can be co-designed for sustainable and best outcomes
3. Communication partner training can be delivered remotely and through telepractice.

I, the speech-language pathologist compiling the following information, and the team collectively we all hope it will inspire readers and remind them of the words of AAC expert, David Yoder:

“Nobody is too anything...”

Introduction

In December 2017, an opportunity presented to provide an intervention to a young woman who lived interstate. The young woman, referred to as K, had extreme challenging behaviour and complex communication needs arising from autism and compounded by movement disturbance, anxiety, and sensory-motor difference. K was seen once face to face for assessment purposes. Considerations at the time of assessment included that it was not appropriate or safe to provide a speech pathology intervention face to face and there was a lack of local speech pathology services to provide direct or indirect support. K experienced periods of restrictive practices (seclusion, chemical, environmental, and physical restraint), high levels of frustration and anxiety, and significant complex communication needs. In discussion with her family, it was decided to try an indirect approach with an emphasis on knowledge and skill development for the people who supported her in the family home.

Key assessment points

In her childhood, K had been exposed to classroom use of Key Word Sign and a GoTalk communication device. There was no evidence that Augmentative and Alternative Communication (AAC) had been continued after her years in specialised education support. Aided communication, in particular high tech, was not identified as viable due to the risks involved and K not allowing staff or family to use technologies including their phones and computers. There was also no evidence of previous communication partner training for family or support staff.

K's speech and language featured perseverative words (particularly when anxious), single words with significant articulation errors, but an ability to answer some questions with “OK” for the affirmative. Her mother reflects that:

In 2017 our life was a roller coaster ride. The ride was constant, it never ended, and we had no control over the ride... K did not have the skills to communicate her wants and needs verbally, she was very frustrated and communicated through unwanted behaviours. Nor did K have the ability to cope with the impacts of sensory integration disorder. At times K was very agitated and aggressive... K could escalate very quickly, sometimes attacking intensely with little or no warning. K was at times also extremely controlling. Not only of her physical environment, but also anyone within it e.g. doors and windows were not allowed to be open, no TV was allowed on in the house, family and support workers could not wear jumpers, glasses or shoes. At one stage family members were not allowed out of their rooms, and certain members had to eat outside.



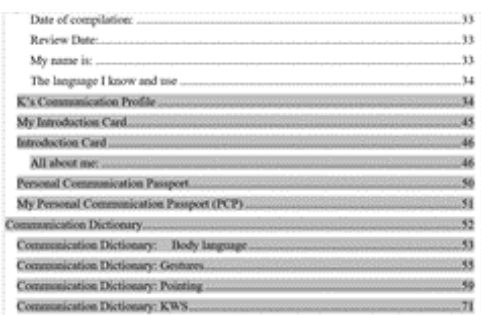
With an interest in communication partner training, I discussed with the family an alternative way of delivering a service to K. I envisaged that primarily a series of one day workshops might assist the team supporting K. I did not ever anticipate the positive outcomes that would occur for us all.

Designing a communication partner training model

Communication partner training has been consistently identified in the literature as beneficial to both users of

AAC and those with whom they interact. In a meta-analysis of the outcomes of communication partner training, Kent-Walsh, Murza, Malani, and Binger (2015) determined that “the central finding of this review is that communication partner instruction has positive effects on communication performance of individuals using AAC” (p.279). Also, in 2015, McNaughton and Light reported that “partner training is now widely recognized as a key component of effective interventions” (p. 266). However, from the perspective of the person

with complex communication needs, communication partners play a pivotal role where “some partners were ‘wonderful’ and others were ‘hell’” (Trembarth et al., 2010, p. 84). Therefore, it was important to deliver training that was meaningful, to listen to the team, to collect written, photograph and audio-visual data, and to design training that met their immediate needs. Table 1 summarises the communication partner training design between 2018 and 2020.

TRAINING	CONTENT	OUTCOMES
2018: 3 one-day (6 hr) face to face workshops. Aim: to develop understanding of difference and what AAC is about. Respond to team’s strengths.	Introduction to AAC and collect data on K and knowledge/skills of team members. Introduction to Key Word Sign. How speech and language happen. Introduce Social Stories™. Review and extend Key Word Sign and Social Stories™. Introduce information on autism, movement, and sensory disturbance.	Team members had some knowledge of Key Word Sign. Develop this knowledge and skill. Introduce Makaton Project data recording sheets. Team able to identify the difference between Social and Information stories and use Key Word Sign at a sentence level. With disability and AAC knowledge the team were better able to respond.
2019: 3 one-day (6 hr) face to face workshops. Respond to K’s interest in speaking and signing. Examine ways aided communication can be introduced safely.	Review Social Stories™ and introduce Zones of Regulation®, and Cued Articulation. Catch up for new team member. Introduction of literacy to support AAC and speech that is now being heard more. Introduction of light aided communication such as wipe boards and visual schedules, light choice displays for sensory-motor activities as well as daily living choices. Making AAC accessible. <div style="display: flex; justify-content: space-around; margin-top: 10px;">   </div>	Social Stories™ used to praise behaviour in functional activities. Team to speak as well as write Social Story style. Zones will not work as K has no colour concept. Cued articulation will be helpful. Workshops continue to be evaluated by team as “highly valuable and effective”. Team carry wipe board and use for choice, sequences, and mind mapping.
All workshops include from trainer: quizzes, activities, role plays, lecture, slides, and videos. All workshops include from team: data collection and homework share, team support.		
2020: Covid 19 and move to telepractice weekly from May and supplemented with self-paced and online courses in becoming a better communication partner.	Training moves to indirect support to family such as writing and reviewing the Social stories written by team members as K’s anxiety escalates. The 2019 work on mindfulness shows new value. Photos used for Chat books and Social stories. The Connect Me Tool Kit is compiled. <div style="margin-top: 10px;">  </div>	Review ways to maintain and keep extending team knowledge and skill. Team is consistent and diligent, supportive, and confident. Team maintaining Key Word Sign at sentence level with naturalistic conversational speech. Team maintaining knowledge and skill with light aided communication in a variety of contexts. K demonstrates communication skills: initiating spoken, signed and aided communication and uses language in conversation; respond, ask questions, show humour, and give feedback. Mean length of utterance 4.5 words.

A TEAM EFFORT CONTINUED

Comments from the team

When we started, we did feel a little overwhelmed, but we took it step-by-step. We started out slow and over time K and her support staff have worked together to use AAC every day. When we introduced Key Word Sign into our everyday interactions with K, we started off with single key words, but now we can all use Key Word Sign in sentences that relate to K and her wants, needs, and interests. We used story books and Key Word Sign songs to practice our skills and we have all encouraged and helped each other. Our success, and K's has stemmed from Key Word Sign, modelling, and being consistent. K now uses sign throughout her day and her sign vocabulary is getting larger. Currently, we use 150 signs in our natural speech with her and we have recorded that K uses 75 signs independently.

Social stories have been personally a hard concept to get our heads around, but with practice and guidance we are improving not just writing them but using the language of the stories in our speech with K. Probably like most people, our first social stories were more information stories and were pitched to telling her what was going to happen. We can now see K listening and learning the language in the Social Story framework, waiting more for her turn. We observe that her anxiety is less or lowers in a situation where a social story is used. We have even seen K initiate a conversation from the social story.

K's conversation interactions have also improved with the assistance of Chat books. Not only are Chat Books great to help new people to interact with her but they have helped us to slow down our rate of speech, use less words in sentences, but still get across the same meaning. We are also now more aware of scaffolding the levels of conversation, in particular not going straight from open questions to providing the answer but to use choices more.

AAC is far more than signing or using a communication device. Our training included sampling many different types of AAC with our trainer and working out as a team which one would work for her. All of us were willing to have a go and not let K be in anyone's *too hard basket*. Having lots of strategies to draw from and to support each other with our *never give up* attitude has been great - what may not work one day may work another day. Strategies that have been really important have included modelling, active listening, scaffolding, using unaided language such as gesture and readable signs, slowing down, expanding on a word she may

say or sign, presuming competence (least dangerous assumption). We often say we have planted the seed and let's see how that seed grows.

The face to face workshop has its place, as do video connections for training. In either, we can still listen to each other given positive feedback, lots of encouragement, and a safe place to make our mistakes, learn from each other and support K to be the best she can be.

Comments from K's family

The communication partner training approach has proven to be beneficial and enabled K to trust the team members and for team members to know her better. I did not expect that K would be able to sign – and now I am amazed. This has contributed to a reduction in anxiety, the frequency, duration, and intensity of outbursts; an ability to achieve goals and for K to communicate more clearly. K's spoken language is clearer, her sentence length has increased, she is more fluent, the tone of her voice is more natural (less robotic), and she can also self-regulate better.

An example of this would be when K had recently had a major melt down and was de-escalating on her bed. I asked my son to read her one of the Journey to Calm, Social Stories that had been written for her. He did. K took a deep breath and calmed. We both thought and said, "Well that worked!". I did not think the gains we have made were achievable, so my advice as a parent of a young adult with complex communication needs is...keep an open mind, enjoy the journey, and reap the rewards.

Where we are today?

In parallel to the training there has been an enormous amount of data collection. It has always been a challenge to use time for data collection wisely and to streamline as much as possible how data is collected. It is also important to remember that data on K's communication is only one aspect of the data collection that a support team have to take responsibility for – as an accountability measure and a requirement by funding bodies and individual allied health team members. Therefore, in a team training session we came up with a template similar to a Mind Map (as shown below) and we are trialling this as a data recording method that can be inclusive of the multidisciplinary team and show interactions for the dynamic event that they are.

As 2020 draws to a close this team is more confident to apply AAC and the strategies K needs. Most importantly, they now have the knowledge and skills needed to support new staff to K's team, especially as she begins a transition to an independent style of living in the community.

We all make mistakes, no matter what our role in a support team is. The biggest mistake we can make is underestimating the skills of others and our capacity to assist them.

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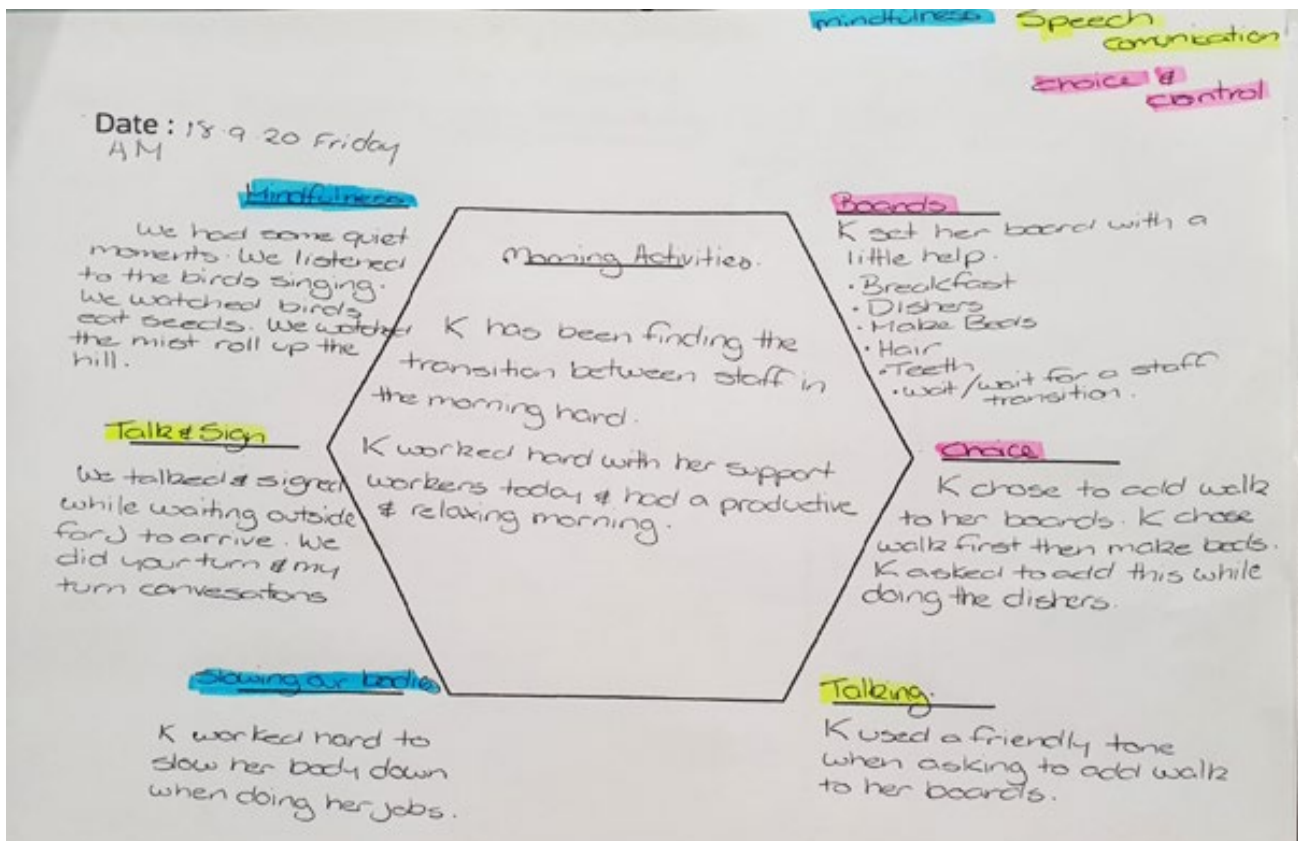
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BOOK REVIEW: EVERYTHING I'VE NEVER SAID

Review author: Leanne Longfellow

Book author: Samantha Wheeler

Publisher: University of Queensland Press

Year: 2018

Themes: Presume competence, Augmentative and Alternative Communication (AAC), disability, siblings, family, and resilience

The key theme of this book is to presume competence in people with disability because everyone has a voice, regardless of whether they can communicate in traditional ways. It is written from the perspective of Ava, an eleven-year-old with Rett syndrome, a disability which means she has little control over the muscles in her body. Ava is unable to communicate through speech or use her hands to point to a communication system. Yet, as she tells the story through this first-person narrative, the reader gains insight into her sassy personality and agency. For example, in chapter two (pages 27 & 28), Ava responds to being stared at by Bella, her sister's friend, by pulling her hair:

Bella's still staring, her lip still curling. I try to look away. I swear I try. But at the last minute, just as Dad's about to turn me, I reach out and grab a handful of white-blond hair. It's soft. I pull. Hard.

'Owww!' Bella howls.

Dad struggles to unlatch my fingers, and Mum rushes over and fumbles to pull me away. But my fingers are gnarled and stiff and stronger than they look.

'Mum! Dad! What the....'

Nic and Mel are running towards us, but Nic stops at the fridge, her face creased with sleep, her eyes wide.

Bella's hair's in my fist. Sophie's mouth's open. Dad's fingers are over mine, trying desperately to tug me away.

'It's alright, Nic,' Mum soothes. 'We just had a little accident.'

'An accident?' Nic yelps. 'Ava, let go. This minute.'

My muscles finally give in and Bella's hair is released.

Bella jumps away like a cat and rubs her head while Sophie, Nic and Mel crowd around her, asking if



she's alright.

'I'm sorry, Bella,' says Mum, her voice tight. 'Ava didn't mean it.'

But she's wrong. I did mean it.

And I'd do it again in a flash.

This excerpt reveals how many of the people around Ava have deficit thinking about her disability. Ava's mother apologises for Ava's behaviour, believing that her hair pulling is unintentional. However, Ava tells the reader that she did mean it "And I'd do it again in a flash." Through this mischievous action, we realise that Ava does have a lot to say. Because she does not have access to a robust form of communication, she is frustrated and often invisible, and her actions are frequently misinterpreted. Ava is viewed by her parents, her teachers, and a speech pathologist, as lacking in competence because she is unable to demonstrate what she knows. Ava's teacher states on page 165 'not everyone has the capacity to

communicate.’ Yet, Ava is determined to prove them wrong.

Communication is viewed by many as a signifier of intelligence; therefore presuming competence is strongly connected to communication. Yet, this book gently guides the reader to realise that our unconscious bias is a barrier to seeing the capabilities of disabled people. The author draws on the social model of disability to convey that the obstacles to Ava’s participation are within the environment, not within Ava. In the story, Ava meets an occupational therapist who is determined to assist her in accessing a system of communication. As well, Ava makes a friend, Aimee, who uses a speech output device, and Ava realises that if she learnt to use a device, she would be able to have a voice. Along the journey to Ava’s increased independence, she encounters family issues, and the theme of resilience is also woven throughout this book.

I usually do not recommend books about disability unless disabled people write them. This reasoning is because non-disabled people usually portray disability from their non-disabled perspective, adding to the disempowerment and persistent inequity that disabled people experience in our society. But this is not the case in *Everything I Never Said*. The author, Samantha Wheeler, draws on her experience of parenting her daughter, who has Rett Syndrome, to carefully and sensitively imagine how Ava, the main character, experiences the world. This book is a celebration of Ava’s emerging autonomy and capacity for independent decision-making. It is suitable for students from primary upwards and should be on every student’s reading list.

Teacher’s notes are available at this link:

 <https://www.uqp.com.au/books/everything-ive-never-said>

If you would like to explore your own beliefs about the presumption of competence in disabled people, below is a checklist I have developed. This checklist is a way of developing a critical consciousness of the notion of *presumption of competence*. Please read each statement and tick the box that represents your level of agreement. When completed, total each section. If your score falls mainly within the “agree” or “strongly agree” section, you have a strong understanding of the presumption of competence. If your score falls within the other areas, it would be helpful to reflect on your values and beliefs regarding the education of students living with disability.

STATEMENT	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE
You recognise that people with disability may understand far more than they can demonstrate.					
You speak to people with disability in an age-appropriate manner, although you may adjust this for each person’s preference to incorporate fewer words or softer speech.					
You find ways to support the communication of people with disability through words, picture symbols, sign language, speech-generating devices, vocalisations, eye gaze, and gesture.					
You treat each person with disability with the presumption that they have a rich set of thoughts, feelings, opinions, and ideas they may be unable to express.					
You avoid speaking about people with disability in their presence as if they are not there. Instead, you talk to a student directly and offer them the same amount of respect you would offer anyone else, even if they cannot respond.					
You hold up your side of the conversation even if a person with disability is unable to hold up theirs.					
You provide choice to people with disability and to support decision-making.					

CLICK TIPS FROM... DEBBIE AND CALLEE PETROPOULOS

Our guest Click Tippers this month are Debbie and Callee Petropoulos. They share online links that may provide you with inspiration, motivation, and opportunities to learn more about AAC, assistive technology, communication and more. Happy clicking!

Callee has Aicardi syndrome, a rare genetic disorder characterised by partial or complete absence of the connection between the two hemispheres of the brain, the corpus callosum.

➔ www.aicardisyndrome.foundation.org/aicardi-syndrome

Please note :: AGOSCI is not paid or affiliated with any companies mentioned below.



Jane Farrall Consulting: Let's Chat with Personalized Alphabet Cards

After reading a post on Jane Farrall Consulting website titled *Lets Chat with Personalized Alphabet Cards*, I was eager to make a set with Callee. Together we went through each letter of the alphabet with Callee using her AAC device (Proloquo2Go) to select what/who she wanted on each card. We then went through her camera roll to select the image.

These alphabet cards have been such a positive communication tool.

They have been able to provide meaningful opportunities for communication between Callee and her new support workers and therapists who have come on board. New team members can ask questions about each card and Callee is keen to give information back using her various forms of communication.

➔ www.janefarrall.com/lets-chat-with-personalised-alphabet-cards/



iESLp App

This app, for us, has been a fantastic add to our communication toolbox.

iESLp app allows you to create interactive activities and visual supports for use on the iPad, such as sorting, matching, counting, and sequencing. It also allows you to create these as printable activities.

The app has many features, but one that Callee and I really like is the built-in 24,000 SymbolStiz symbols. These are the same symbol set used in Proloquo2go. The app allows the user to import photos from the camera roll, attach a voice recording, and print.

We have been able to create lots of activities that have helped Callee to develop language and helped her develop skills in navigating through her AAC.

There are various YouTube tutorials and a website with lots of ideas.

➔ www.ieslp.wordpress.com



Bjorem Speech Publications

The Bjorem Speech Sound Cues are picture cards that match each phoneme in the English language with an environmental sound children can relate to!

We have been using these sound cues with Callee and her Prompt® Therapist from GRP Speech Therapy. These sound cue cards give Callee such a great visual cue as they have the cutest illustrations. They are helping Callee with speech sound acquisition and phonological awareness and they are teaching the *sounds* and not the *letters*.

➔ <https://bjoremspeech.blog/2020/10/06/top-15-ways-to-use-the-bjorem-speech-sound-cues/>

➔ <https://www.silvereye.com.au> (Australian distributor)



AssistiveWare Facebook Lives with Miss Amanda

Callee really enjoys watching the Facebook Lives with senior speech pathologist, Amanda Hartmann.




Each fortnight Miss Amanda goes live on the AssistiveWare Facebook page using her AAC. She encourages users and carers to bring their AAC for a fully interactive session of various activities, which can include shared reading, writing activities, games, cooking, and a lot of fun. At the end of the session there is time for a Q&A.

These sessions are recorded and can be viewed at a later time that suits your worldwide timeline.

Callee catches up with the LIVES at a more suitable time for her, as she is usually still sleeping when they air here in Australia.

AssitiveWare have also recently added On Demand training videos that are available for rent and watch at a time that suits your schedule.

These have been valuable for us as we have had new support workers watch the training videos alongside Callee.

-  <https://www.youtube.com/watch?v=OMaM9fZVdHA> (FB LIVE)
-  <https://www.youtube.com/watch?v=jBbl5hi13D8> (AAC Activities)
-  https://vimeo.com/assistiveware/vod_pages?utm_source=website&utm_medium=CTA%20block (ON DEMAND VIDEOS)



Pictello

Another must app for us and one we have used for many years is Pictello.

With Pictello you can create social stories, an event log, and memory books.

Simply add photos or a short video from your camera roll, add some basic text, record your own voice or download many of the high-quality voices. The app has a Wizard feature that guides you through the set up. Another option is a Sharing Account that allows you to share your story with other Pictello users. A more recent feature was added allowing you to import Tar Heel Readers into your library.

We have recently started using Pictello as a recipe book. We do this by adding step by step photos with basic instructions that the app reads out word by word for Callee. Callee can then turn each page manually once she has completed that step. There is also the option to run the story/book as a slideshow, which is awesome.

We have started to print the recipes out and plan on combining them as a hard copy cookbook... It's also just so easy for Callee to have one iPad with Pictello open and her 2nd iPad is open to Proloquo2go where she loves to say "I stir, mix, pour or spread". The two apps work so well together.

-  <https://apps.apple.com/au/app/pictello/id397858008> Pictello App



AGOSCI WEBINAR SERIES

The AGOSCI webinar series is designed to promote skills and knowledge about AAC across all sectors of the Australian community. All webinars are free to attend for AGOSCI members only.

 www.agosci.org.au

To attend a future webinar, please log-in to your AGOSCI account and proceed to the members only page to register.

To view past webinars, please log-in to your AGOSCI account and proceed to the members only section to view recordings. Past webinars are online within 48 hours of the view date. Our past webinars include:

What is AAC, and what does it look like? Presented by Janelle Sampson

Towards cohesive language development in AAC Presented by Cathy Binger

Being part of the AAction Presented by Fiona Given

How I became an AAC communicator Presented by Nick Bradbury

Championing communication access for all Presented by Barbara Solarsh and Georgia Burn (from Scope)

AAC and the NDIS - Surfing the waves of change Presented by Gail Bennell

Achieving functional communication through Minspeak Presented by Siobhan Daley

Assessment and AAC - Where do we start? What am I looking for? Presented by Janelle Sampson

Communication assistants: What strategies do they use in conversation with people who have Down syndrome, Rett syndrome or Cerebral Palsy? Presented by Dr Jane Remington-Gurney

What's in a voice? An overview of message banking and voice banking Presented by Peta Booth, Speech Pathologist from LifeTec Australia

Understanding parent rejection and abandonment of AAC systems Presented by Alison Moorcroft

Using AAC to give evidence in court and tribunal hearings Presented by Fiona Given

Implementing music therapy and AAC in a lower resourced set Presented by Kylie Hinde and Farhin Chowdhury

Championing Communication Access for All Presented by Barbara Solarsh and Georgia Burn (from Scope)

Online therapy: Making the most of technology to support AAC users and people with complex communication needs. Presented by Edward Johnson

Finding your way with AAC AT provision in the NDIS: A joint collaboration between AGOSCI and Speech Pathology Australia Presented by Cathy Olsson and Jessica Moll

AAC and literacy Presented by Ash Harling

"How do I need to be in order to be with you?": Supporting adults with profound intellectual and multiple disabilities Presented by Sheridan Forster

Encouraging the promotion of long-term AAC use: Learning from social identity theory Presented by Ruyi Tong

I have a dream for communication - AGOSCI Conference Keynote Presentation 2019 Presented by Joey Harrall

SPA x AGOSCI: Considerations for AAC assessment in the world of NDIS Presented by Cathy Olsson and Jessica Moll

Moving beyond object requesting for AAC users with ASD: What does the research say? Presented by Kristy Logan

SPA x AGOSCI: Considerations for AAC assessment in the world of NDIS (Webinar #3) Presented by Cathy Olsson and Jessica Moll

International perspectives on Easy English and Easy Read: What do we need to know? Presented by Cathy Basterfield

Exploring the spoken language development of school-aged children on the autism spectrum with minimal verbal language Presented by Lauren Davis

Connection, Isolation, and Online Life in Lockdown Presented by Siobhan Daley

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