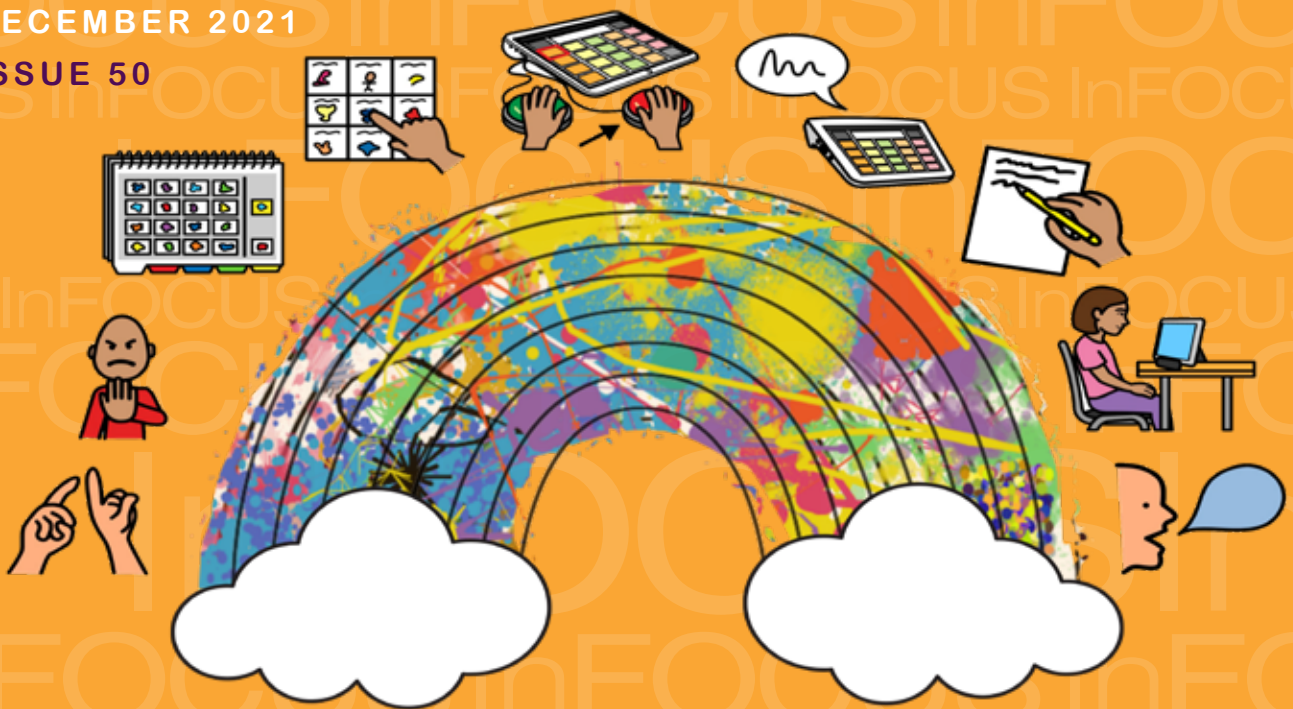


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DECEMBER 2021
ISSUE 50



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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 PICTURE



by Barry and the Bear aka Claire Gutke

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CHAIRPERSON'S REPORT

Hi members and friends, what a roller coaster of a year it has been. Firstly, thanks to everyone for being patient and understanding with regards to the postponement of our biennial conference. It was bitterly disappointing for the organising team and exec, but I am sure the wine of Tasmania will taste sweeter when we reconvene in September 2022.



AGOSCI has still been busy though, with webinars, workshops, Facebook activity, and planning for a National Tour in 2022! Thanks to Ria for her amazing work. The national executive met via Zoom in August and we started to put together our next Strategic Plan – thanks to Rob for his help on that.

AAC awareness month was mostly online due to COVID-19, so we hope you were able to hear some amazing stories. A few face-to-face events got off the ground, so we look forward to some photos of AAC fun!

A big thanks goes to Sheridan Forster for what promises to be another thoroughly interesting edition of In Focus – Communication So Many Ways. The AGOSCI exec is discussing this matter itself, as defining ourselves is a critical foundation for where we go and what we do.

Since the last In Focus, our exec welcomes Rob Wong as Vice Chair, Stephanie Wong as NSW rep, Megan Lay as NT rep, and Stephanie Weir rejoins as Victorian Co-rep after a maternity leave stint, yay! Sadly we still have a vacancy for ACT rep, so please contact me if you are interested.

AGOSCI relies on volunteers to make this organisation great, so if you feel inspired in any way, please let us know.

Enjoy, and pass your magazine onto a friend after you have done.

:: DARREN TRENTEPOHL

EDUCATION & EVENTS

2021 has been a big year for education and events. Despite the many difficulties posed by COVID-19 restrictions, we've still managed to connect with our AGOSCI family far and wide via online events and some well-timed in-person workshops (hello social distancing).



This year we've enjoyed a virtual National Tour, a fabulous collection of free member webinars, a number of live international workshops, an ongoing schedule of in-person PODD workshops, 2 online LAMP trainings, research updates from our research grant recipients, and online learning opportunities delivered exclusively for AGOSCI by our major AAC suppliers.

I'd like to thank all our webinar presenters, our national tour speakers Debbie and Jaquie, our international presenters, our PODD and LAMP trainers, and our workshop partners including Indigo, Rocky Bay, and Scope. I'd also like to thank and acknowledge the generous contributions of our event sponsors including Liberator, LinkAT, Zyteq, AssistiveWare, Indigo, and ECU.

In 2022 we're thrilled to be hosting a face-to-face National Tour with Fiona Beauchamp. It is so exciting to be back on the road after the disruptions caused by the pandemic. Make sure you grab your early bird tickets before the end of December!

Keep an eye out for other education and events offerings in early 2022, and as always if you'd like to present something for us, or you know someone who should be in our event schedule, please contact me at education@agosci.org.au to start the conversation!

Last but not least, to all our wonderful AGOSCI members, you are a delight to work with and for. Bringing events together for our AGOSCI audience is always fulfilling and exciting. Thank you for your patience, encouragement, and support as we've navigated through the ups and downs of COVID-19 in 2021.

Happy holidays to you and your family from our AGOSCI family. We'll see you in 2022.

:: RIA FERRIS

SECRETARY'S REPORT

Hi again to everyone,

We've had a good year so far for memberships with around 577 members which is an increase of 191 members from this time last year. Special thanks to Ria for all her hard work in organising the many webinars and events we have learnt from. We have continued our meetings as the Executive and a Strategic Planning meeting via Zoom. It wasn't quite the same as meeting in person but a lot of discussions around steering AGOSCI for the future.

I have been busy typing up minutes 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. Sadly, we had to postpone our Conference for this year in Hobart, but I look forward to seeing everyone next year. A lot of hard work is still going on in the background to make this happen. Thanks again to the conference committee.

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

Mel

:: MELISSA BAKES

EDITOR'S NOTE

It is with great pleasure that I bring you the December, 2021 edition of AGOSCI In Focus.

The theme of this edition is Communication So Many Ways. It is a celebration of the many ways in which our community of people with complex communication presentations and their respective communities communicate.

Within AGOSCI, people communicate in so many different ways. Some use speech of different forms with different partner supports and supports for being most effective. Some use body language, their face, eyes, and behaviours. Some use signs and gestures. Some use communication devices and books.

I was thrilled as I received each submission. Leanna, Liss, and Siobhan mentioned Minecraft, which happens to be my son's first love. I told him that each paper felt like precious obsidian. He told me that you could not mine obsidian with a normal pickaxe, but need a diamond pickaxe. A normal pickaxe would crush them to pieces.

I hope that with the complement of great papers, editing support from the Editorial Committee, and our broad, inquisitive readers, that I have wielded the diamond pickaxe well and mined each obsidian in way that make shine.

Find out more about our next edition on page 15. It's sure to bring out more precious stones from you!

:: SHERIDAN FORSTER

TREASURER'S REPORT

Hi everyone.

It's been a busy 6 months for AGOSCI, despite the ongoing challenges presented to us by COVID-19. We were very sad to have to postpone our 2021 Conference to be held here in Tassie. Nonetheless, we are thrilled to have been able to provide you with a fantastic range of learning opportunities and local events. Many thanks to our Education and Events coordinator Ria Ferris who has organised these for us and to the state reps who have supported her.

I've been busy behind the scenes processing payments and paying the bills. I'm currently in the process of arranging our annual audit where we will look at AGOSCI's finances for the year. I'll report on this at our next AGM to be held in May next year.

In the meantime, wishing you all a fun and relaxing Christmas period. I hope you get a chance to spend time with family and friends. Hoping to see you all in Tassie in 2022 for our much anticipated conference. It's not one to be missed!

:: TRACEY HANIGAN



STATE REPORTS

TASMANIA & CONFERENCE PROGRAM CHAIR



For this Tasmania state report, we have taken inspiration from the AAC Awareness Month theme. We know you will all join us to bounce back and break through the screens for the Hobart AGOSCI Conference September 3-6, 2022!

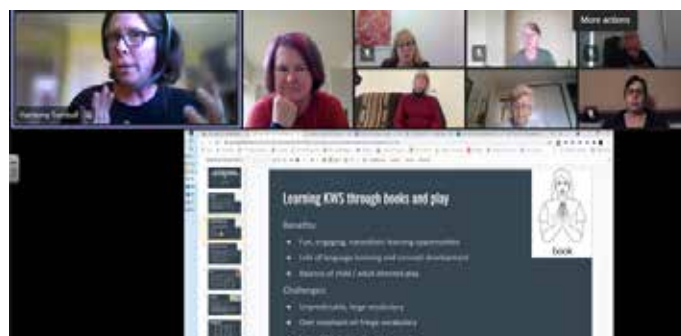


Our AGOSCI Conference Organising Committee member, Janelle McMillan, has expanded her national profile with a feature story on ABC ArtWorks. Check out her vibrant works on her Redbubble shop "Nelly's Wheels": <https://www.redbubble.com/people/nellyswheels/shop>

The Tasmanian Key Word Sign chapter has reconvened with 7 active Presenters. Many of us joined the recent KWS Awareness Day seminar. It was a fabulous celebration within AAC Awareness Month. Harmony Turnbull, who has bolstered the AAC community in Tasmania since her recent relocation from NSW, presented at the seminar. Her interactive session, Read and Play with KWS All Day, was very popular with 50 people attending.

Always happy to hear from AGOSCI members and people with an interest within Tasmania.

:: FELICITY LOVATT



STATE REPORTS

NEW SOUTH WALES

Hi Everyone,

A big thanks to Cecilia Rossi and Sabrina Fong, who have recently stepped down as state co-representatives. Thank you for all the fun picnics and events that you have help coordinate to bring together our wonderful community.

My name is Stephanie Wong and I have recently taken on the role of AGSOCI Representative for NSW. I am a speech pathologist and the Principal director at Olive Tree Therapy, and I have a special interest in supporting diverse communicators to flourish and find or build inclusive communities.

NSW has come out of 107 days of lockdown. It hasn't been easy for many with restrictions, home-schooling and for therapists, the need to pivot to online services. Lockdown has led to some interesting silver linings such as: more time to spend with family, accessible social events on Zoom, individuals and families collaborating with therapists through telehealth, and more time to invest in important relationships.

It's been a pleasure to meet the other state reps at our Annual AGM and I look forward to learning and contributing in this role. I hope to see many of you in person and help host local events. I can be contacted at Stephanie.wong@olivetreetherapy.com.au or agoscnsw@agosci.org.au

:: STEPHANIE WONG



VICTORIA

It has been a tough year in Victoria with all the lockdowns, but we are looking forward to the opening up of the state. The Victorian AGOSCI team is also boosted by the return of Stephanie Weir who comes back from maternity leave.

:: BEN BOND

SOUTH AUSTRALIA

This year the weather was beautiful for the annual AAC Awareness month AGOSCI SA picnic. The group was small, however it was lovely to meet new families and catchup with the regulars. The face painter was kept busy with Halloween designs especially spiders! We look forward to seeing everyone again at the same time next year.

AGOSCI SA is excited to partner with Fiona Beauchamp for our 2022 National Tour. Fiona's workshop will focus on movement, sensory processing, and communication. The AGOSCI National Tour will be held in Adelaide on the 23rd of March in a venue to be advised. Early bird registration is now open until the 31st of December 2021 via the AGOSCI website. See you there!

:: JODIE WHITFORD



Fun at the AAC Awareness Month South Australia picnic

STATE REPORTS

NORTHERN TERRITORY

The main update from here in the NT is that we have a new AGOSCI rep! I picked up the role in July and began by attending the strategic planning meeting (via Zoom). Despite our collective disappointment at not meeting together in Tasmania, it was great to be able spend some time formulating a vision for AGOSCI's future.



There's been a bit of a LAMP movement in the NT of late. For AAC Awareness Month in October we met little Reggie who is doing a wonderful job learning how to communicate using LAMP. We have also had several speech pathologists complete a LAMP professional development workshop online recently, so it has been exciting to add another tool to our AAC toolboxes in Central Australia.

:: MEAGAN LAY

QUEENSLAND

Lockdowns and border closures have been an enduring theme in 2021, so it was wonderful that we were able to have Janelle Sampson be allowed to cross the border into Queensland to present the one-day Alternative Access PODD workshop. In July and October, we had to think a little bit more creatively to run the two-day Introductory PODD workshops, but we were so lucky to still be able to have Gayle Porter presenting the workshop via Zoom and Wendy Webster and Lee Withall presenting in person. Fingers crossed we can all have many more in person events in the very near future!



Kind Regards,

:: EMMA GOLDSTON



WESTERN AUSTRALIA

There's been lots happening lately for our WAAAC users and supporters! In August, AGOSCI partnered with Indigo to host a 2-day Introductory PODD Workshop, with great feedback from those who attended.



Earlier in October we saw many families and passionate AAC supporters come together for the 10th anniversary Variety Motor Mouth Camp, with a team of wonderful volunteers including Kelly Savage - past WA AGOSCI representative for many years, Bec Watson - our WA representative for our AAC Communities team, and AAC mentor Joseph Harrall - keynote speaker for our last AGOSCI Conference. The camp was held over a weekend of engaging activities with everyone benefiting from this supportive community.

To end AAC Awareness Month, AGOSCI WA hosted an event at the Cockburn Ice Arena during their All Abilities Ice Skating session. It was so lovely to gather out on the ice for fun and chats, with some people skating for the first time ever! Thank you to all who came along – if you missed it this time, we can highly recommend getting a group together and heading down to another of the All Abilities sessions held on Friday afternoons and some weekends.

:: YVETTE THEODORSEN



HERE ARE SOME WAYS YOU CAN INTERACT WITH A PERSON WHO IS NONVERBAL

by Conrad Yinfoo

1. Assume we have feelings and thinking when you are speaking to and about us.
2. Smile and say hello before watching us or touching our wheelchairs or bodies.
3. Keep looking at our faces for responses. We might surprise you.
4. It is important you do wait longer for us to try show you our thoughts.
5. Apologize if you make a mistake or you are not understanding our messages. Sometimes it might be you haven't watched us communicate.
6. Please talk about your day and things that are happening. I don't like boring questions about me that I can't answer. I can't tell you things with a lot of words without time and preparation.
7. Provide us with choices about clothes, food, activities, and important decisions.
8. Learn our ways of communicating by asking us or someone who knows us.
9. When we are with other people, help them learn how to speak and interact with us.
10. Humor and kindness helps us relax and get to know each other.



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

KEY WORD SIGN AWARENESS DAY SEMINAR 2021

By Chloe Wine, Libby Brownlie, and Andy Smidt

Key Word Sign (KWS) is something that people love to be involved in. We really love and are committed to KWS, but there is much less literature to support unaided AAC such as KWS than aided AAC. In order to celebrate the value in KWS, on the 10th of October (10/10) in honour of AAC awareness month, we held a Key Word Sign Awareness Day Seminar. We chose the 10th day of the 10th month not only because October is AAC awareness month, but also because we have 10 fingers that we use to sign, and that is all we need!

Our seminar garnered a lot of interest, with over 600 people registered to attend on the day and over a hundred more showing interest in the event and the whole event was very well received. Our event catered to a variety of participants because we know that KWS is important to a range of people. We wanted to cater to everyone and to make sure everyone felt welcome and that they could learn something from this event. We wanted to include teachers, speech pathologists, and other professionals, as well as parents and family members of KWS users, as well as people who teach others to use KWS. To do this, we had multiple sessions running throughout the day.

The keynote of our seminar was presented by Dr. Nicola Grove from the UK. Nicola has been involved in KWS since the early 1990s when she wrote one of the first research papers about Makaton (Grove & Walker, 1990). Having started life as an English teacher, Nicola then qualified as a speech and language therapist, working with children and adults who have severe communication difficulties, using sign language and gesture, voice output communication aids, and then legends and personal storytelling for empowerment and inclusion. Nicola worked with Dr Kaisa Launonen editing a collection of chapters for their book *Manual Sign Acquisition in Children with Developmental Disabilities* (2019). The book is an overview of forty years of research and practice from a developmental perspective. The book includes content about both sign languages and sign systems, linking Deaf studies and Augmentative and Alternative Communication which had historically been seen as separate. This text is the most authoritative single text to date on the topic, and Nicola is recognised as one of the leading experts in this field in the world.

The day also featured a Lived Experience Forum with three parents who talked about their experiences using KWS. This forum was facilitated by Dr Leigha Dark, a speech pathologist and parent of a child who uses KWS. She led Meghan Gold, Liz Dove, and Lynette Bos in a discussion about personal journeys with KWS and discussed the influences on their decision making about using KWS. Each presenter described the joys of seeing their child communicate using signs and the challenges they have faced in creating a signing environment around the child. They described factors that contributed to their success and the barriers they experienced. One of the key themes coming through was about the need to model signs for your child for a long time before they produce their first sign. One of the key phrases used by Meghan Gold in this session was the idea that signs are “caught rather than taught.” We all loved this concept and we think this should be the new catch phrase about KWS. Thanks Meghan!

There were also three concurrent streams running throughout the day. The first stream was a Research stream and included presentations from local and international researchers exploring the use and impact of KWS. This stream was to cater to professionals interested in learning more about the impact of KWS. This stream included presentations from a number of occupational therapy honours students exploring the impact of limb movement on KWS use. International researcher Krista McMorrnan-Maus presented on the history and use of KWS in the United States, and why this is important. Leigha Dark presented on how speech pathologists teach KWS, as well as presenting on her own experiences as a parent of a child who uses KWS and is integrating research. Andy Smidt presented about aided language stimulation.

The second stream was Practical Teaching and Implementation, and included talks about how to support KWS use, how to teach KWS, and more. This stream was to cater to KWS presenters, and people interested in implementing sign use in different ways. One of the presentations in this stream was a panel with staff from different schools for specific purposes discussing how they use and implement KWS within the classrooms. Presenters such as Cathy Basterfield, Ashley Harling, Cathy Prior, and Kerry Revell presented on how to conduct and adapt KWS workshops. Ruth Rogers and Tracey Richards discussed the benefits of signing choirs. Finally, Harmony Turnbull presented on

Special **40%** discount code for AGOSCI members for Nicola's book
(hardcopy, softcopy, or e-book). Promotion code: **leaflets40**

<https://novapublishers.com/shop/manual-sign-acquisition-in-children-with-developmental-disabilities/>

how to use KWS in everyday activities such as book reading.

The final stream was KWS Practical Sessions, and it covered practical ways to implement and use KWS, such as in singing and book reading. This session was aimed at people who do or want to use KWS regularly, such as parents and teachers. Stephanie Weir and Emily Fernandez presented on how to use KWS in book reading as they worked through "Where's Spot" and "Going on a Bear Hunt" respectively. Tracey Richards presented a workshop on signing while singing and taught the signs for "I Still Call Australia Home." And finally, Janine Hall, Cathy Prior, Jayde Mott, and Libby Brownlie discussed the use of Auslan signs with KWS.

Following the overwhelming interest in this event, we hope to run this seminar again next year. While we were delighted at the level of interest, there were

unexpected costs involved in running such a large event. Next year, we might charge a small fee to keep this event running. For more information about KWS in general and the seminar, please see the KWSA website. We will be posting recordings from the presentation on the Key Word Sign Australia YouTube page and eventually on the KWSA website.

References

Grove, N., & Launonen, K. (Eds.). (2019). Manual sign acquisition in children with developmental disabilities. Nova Science.

Grove, N., & Walker, M. (1990). The Makaton Vocabulary: Using manual signs and graphic symbols to develop interpersonal communication. *Augmentative and Alternative Communication*, 6(1), 15-28. <https://doi.org/10.1080/07434619012331275284>



INCLUDE ALL ABILITIES IN ENGLISH LESSONS, ENGLISH IS OUR LANGUAGE.

TURN STRUGGLES INTO TRIUMPHS, BE INNOVATIVE!

by Janelle McMillan

The following is a presentation prepared for the Tasmanian Association of Teachers of English conference.

Firstly, I would like to thank Daniel for inviting me to talk to you all today. I hope that you take something away with you from my presentation.

Daniel and I attended Cosgrove High School together in the 90's. I was a year above him.

My memories of Daniel are how he became friends with another student who was in a wheelchair and who was totally non-verbal. This student would blow a kiss for yes and stick out his tongue for no.

I remember that Daniel along with two other able-bodied students had this extraordinary friendship with this student with a disability. You could see the love and the respect that these three students had for the student with a disability.

I have no doubt that Daniel's friendship with this student with a disability is the reason why I am here today.

I have asked Daniel to read my speech. I chose not to use a communication device because I want to talk to people with my voice.

People can communicate in so many ways these days, such as email, Facebook, on computer or through an iPad. I do most of my communicating with the outside world using email or Facebook. It is like I am not non-verbal when I talk to people on Facebook. Facebook is not all bad.

As you know my name is Janelle McMillan OAM (Order of Australia). I am an artist and an author.

I am living with a physical disability called Cerebral Palsy (CP). My type of CP is where my body movements are jerky and uncontrolled. Basically, my body is out of control all the time. I am non-verbal, but I communicate with people through a number of different ways. I use a wheelchair because I can't walk on my own.

I have a great sense of humour and love a laugh. Friends think that I am hilarious because I tell things just how they are. I don't take life too seriously. I need

assistance with all daily tasks that an able-bodied person can do for themselves.

I can operate a computer through using a joystick instead of a mouse. I use a head switch to click for the mouse button. I type through the on-screen keyboard in Windows.

I used to be able to draw artwork by hand, but it takes me hours. I love doing art on the computer. I have done hundreds over the past 22 years.

Now, I am going to tell you all a bit about me growing up and what sort of things that I have done throughout my life.

I went to D'alton School for students with disabilities, Bowen Road Primary School, Cosgrove High School and Claremont College for my education.

My favourite subjects were maths and art at high school. English class was my least favourite subject because I was not taught how to spell and read properly in primary school. It was no point sitting in English class if I didn't have the basis skills for reading or writing.

Who needs English? I couldn't read and spell to save myself as a teenager. I feel the teachers didn't see how important it was for me to be able to read and spell due to me being non-verbal.

But I needed to be able to spell out words to communicate with people and no one seemed to consider that fact.

After leaving college, I worked my butt off at home on my English skills. I started reading lots of biographies and stories about people's lives. I fell in love with reading.

I learnt to spell words better backwards and write sentences backwards by being innovative. I had to sit on the floor to write because I couldn't hand write at the table.

I would hold the paper under my knees. I used my knees to steady my hand with the pencil in it, to be able to write or draw.

I hand write backwards because I find it much easier

to start on the right side of the page and go to the left side. I spell the words backwards. I start at the last letter of the sentence and work my way to the front.

I turned my struggle into a triumph by becoming a children's author. I love to prove people wrong.

My children's book is called Rafting, A Wheelchair Won't Stop Us! It is about a group of friends taking their friend with Cerebral Palsy on a rafting adventure, like I did with the Ranger Guides.

The most fun I had at high school was on sport days because my friends used to help me to participate in races and other sporting events.

The high jump was so much fun because two of my friends would pick me up by my arms and legs. They would swing me over the high jump pole and I would land on the high jump air bag. You couldn't do this these days, lol.

It was my Support Aide and I who thought to have a disability awareness week called Wheelie Aware Week at high school to give teachers and students an understanding of what it was like living with a disability.

I went to my grade 10 year leaver's dinner, all dressed up.

I was a member of the SRC Committee at Claremont College.

I have been snow skiing twice in Victoria. I used a sit ski to ski; it is a seat on a ski.

I went horse riding for the disabled when I was younger.

I had lots of fun participating in wheelchair basketball and swimming.

I was a Brownie, Girl Guide and Ranger Guide. I was involved in lots of different activities like cooking, crafts, kayaking, water rafting, beach activities, leadership weekends, water regattas, and going away on camps both in Tasmania and interstate.

I went to Adelaide and Western Australia on Ranger Guide camps. I had so much fun doing things, like going down water slides and cable skiing with someone helping me.

One of my friends and I participated in some fun runs in our teenage years. She used to push me in my wheelchair in the fun runs. Now, she was a real friend!

I enjoyed riding on a ski biscuit behind a jet boat and going 4 wheel-driving.

I love watching the football and the cricket, especially the 20/20 matches live.

I am a big Richmond fan because my father played for Richmond.

I love watching the live footy matches.

I have worked with the Glenorchy Access Committee to help make Glenorchy and the surrounding suburbs wheelchair accessible.

I have done lots of fundraising over the years and many of my artworks have been used by different charities such as breast and brain cancer groups. Some of the charities are: Love Your Sister, Just Like Jack, Drought Angels and Down Syndrome Queensland.

I fundraise by putting my artwork onto mugs, phone cases, tote bags and T-shirts and sell them through a website called Redbubble. Here's the link to my Redbubble page: <https://www.redbubble.com/people/nellyswheels?asc=u>.

I have shaven off my hair a number of times for the World's Greatest Shave to raise money for the Leukaemia Foundation.

I try to have a positive attitude always by reminding myself that there are lots of people who are worse off than me for a number of reasons. Being an able-bodied person doesn't necessarily mean that they are happy in life.

It is very frustrating to have people treat me like I am a kid. A large number of people will talk down to me when I go out in the community. Another thing is that some people will talk to the person who is with me, about me, like I am not there. I have been patted on my head by people in the community like I am a puppy dog.

My advice to you - don't judge non-verbal people from the outside because they have feelings and thoughts just like you. It might be scary for you not knowing how to react to non-verbal people, but just be yourself.

Are there any questions you would like to ask me about anything?

I have asked Daniel to read my book called Rafting, A Wheelchair Won't Stop Us! to you.

Yes! I did type every word of this!

THE GOOD SPEAKER: WHAT IS IT AND WHO CAN BE ONE?

By Lesley Champion

Speak up!

Find your voice!

Be heard!

It is no mistake that all these expressions employ the idea of the voice. We often hear that the ability to speak is at the heart of our status as human beings, and it may be this basic premise that keeps it so intimately bound up with the self and the public presentation of that self.

Speech has long been tied to the idea of the good citizen. Dating back to ancient Greek and Roman traditions, public speech has enjoyed a privileged position as the vehicle for civil practice and democracy. In these traditions, the good speaker was one who demonstrated competence in their ability to harness an argument. This competence, over time, became dependent on intellectual capacity, and the ability to harness that capacity into an argument, an argument which adhered to given contextual rules.

Think of all the things a voice can do; all the things that we are told that our voices should be able to do. Our voices are expected to perform so many different roles. Far from merely communicating our needs to each other, our voices are responsible for entertaining, educating, sharing our opinions, beliefs, and selves. To have a voice in our society is to be listened to, to be heard and respected. It is our way of advocating for ourselves and our rights, exercising our agency, and being recognised for our capacity to act independently. In fact, being a good speaker, in many ways, has come to signify our very status as human beings and our ability to make our own choices.

But who counts as a good speaker? And what does this mean for someone like myself, whose voice is often experienced as different, unreliable, or difficult to understand? Does it affect the ways we can exist as human beings? Past research would suggest so, suggesting that impaired speech can have an impact not only on peoples' ability to tell their story, but also on the ways their voices can be recognised. In my research I have become increasingly interested in the latter, exploring impaired speech not in terms of physical impairment, but rather as it is constructed through our ideas about it. This involves questioning how and why (a certain type of) speech is connected to the idealised human being, how this connection may

impact peoples' ability to tell their story, and whether this story is accepted. We need to start asking whether voices are heard, and listened to, in ways which not only validate the voice, but also the story and the person.

One of the biggest issues here is the connection between the good speaker and the idealised, normative, human being. In our ableist culture, we are all measured against norms which tell us who we should be, what our bodies should look like, and what they should be able to do. Disabled bodies fail to fit into these idealised representations of what the human body should be, and are therefore thought of as inferior to their able-bodied counterparts. It is these ways of thinking and talking which turn bodily variation into abnormality, and label disabled bodies as abnormal. These bodies then become defined by abnormality and subject to never-ending efforts to 'fix' what is considered broken. But do we need to be fixed, an effort which inevitably denies diversity and humanity? Or should we instead reconsider our relationship to normality?

As a society, we are becoming increasingly aware of the damaging effects of ableist norms, and within disability studies there is a large amount of work aimed at identifying and combatting norms which privilege the able body. However, when I started to explore the literature which spoke specifically about speech, I found that there is much more work to be done around speech and different ways of speaking, and, indeed, different ways of listening.

The ties between speech and competence decide which individuals and groups can speak and which speech is listened to and considered effective. Ideals of competence, mastery and coherence decide who is considered to be a good speaker. The stories of disabled people and especially those with impaired speech, often fail to conform, or are seen to fail to conform, to these ideals or follow accepted rules. They are categorised as abnormal, their stories broken, their voices often ignored, and their personhood called into question.

It is not difficult to imagine how voices might be silenced by these beliefs and excluded from the ranks of good speakers. If a person is not expected to be able to speak well, they are less likely to be listened to and less likely to be recognised as a person with the freedom to make their own choices. However, can we

find alternative ways of thinking about speech and voice that allows for greater recognition of voices which may be diverse in nature? To do so we must first develop a greater understanding of how different voices exist in the world. So far we have been talking about the idea of the normal human being as if it is an external force which shapes only the ways that disabled people are seen and recognised by other people. I think an equally important question when we are talking about ableist norms is how disabled people see and recognise themselves.

In a world where human speech is defined by norms of mastery and coherence which work to define who can and who cannot speak, how do people who speak differently think about their speech and their ability to be heard? To ask such a question does two things. Firstly, it allows us to examine the effect of existing ideals around the normal human speaker. It is important to investigate how these ideals shape the way that disabled speakers think about themselves. This better allows us to combat potentially damaging ways of thinking about our voices as well as the voices around us.

Secondly, and perhaps more excitingly, it provides a space for different ways of thinking about speech, what it means to speak, and what it means to be heard when we speak. Reading this magazine, it is clear that there are many different ways of speaking, each of which carries the potential for new ways of speaking about speech, and the possibility of diverse ways of being recognised as good speakers.

I am currently conducting research examining the experiences of Australian adults living with a disability which impacts their speech. This PhD project has been approved by the Human Research Ethics Committee at the University of Melbourne, and the first phase of this research will consist of an online survey. We wish to know what you think is important when you speak and how you feel about your voice. If you are interested in contributing to this research, and making your voice heard, we would like to hear from you.

To participate, or for more information, please contact Lesley Champion

e :: l.champion@student.unimelb.edu.au

AGOSCI IN FOCUS

DO YOU WANT TO SHARE A STORY WITH THE AGOSCI COMMUNITY?

AGOSCI In Focus is AGOSCI's magazine that comes out two times a year.

We publish papers by people with complex communication needs, family members, therapists, and other interested people.

Our next edition will be coming out in June 2022.

We will publish many highlights from our conference in Hobart.

We are also looking for papers about the theme **"Are we on the same page?"**.

You might want to ideas on literacy, information modification for more people to understand. You could write on how someone you knows needs partners to modify their communication to meet understanding. Or even how you create a shared meaning with someone.

Contact agosciinfocus@agosci.org.au to discuss your idea

 www.agosci.org.au/In-Focus-Magazine

Claire is a 10-year-old Queensland girl who loves water, chocolate and Taylor Swift. She loves school, and is currently a student in Year 5 at her local, inclusive primary school. Claire is learning to communicate with AAC, primarily her PODD book and her Tobii Dynavox I-13 eye gaze device with PODD pagesets in TD Snap.



Claire Gutke

Learning



tonkatruckss Claire and I went to Fraser Island, here we come. First support working gig... not a bad location! #fraserisland #aacrockie #meetingofthree #autismsyndrome



tonkatruckss Support worker training today for the whole team with Claire Anderson, speech pathologist. #communicationpartnering #aac



tonkatruckss Linear colour selections @claire_matilda #aac #podd #aidedlanguagestimulation #disabilitychat



tonkatruckss Reading all about camp in Claire's ABC of Camp book. #letterC #alphabetknowledge #letteroftheday #personalizedbooks



claire_matilda CPL AAC Camp in Boonah. I have something to say... I like this - happy, lucky, fun! #cpl #aidedlanguagestimulation



tonkatruckss Claire's best hugs from the cutest little Tinkerbell in on her way to her school Christmas concert. #multimodalcommunication #besthugs



tonkatruckss Ice skating was new for me! Claire may have been asking me to go faster. #aidedlanguagestimulation #swimteamaac #dangeroousthree



tonkatruckss Exploring Caves Beach after a fabulous weekend at Point Wolstoncroft for the Cri Du Chat Family Weekend #cri #autismsyndrome #fraserisland #aac



claire_matilda Talking with friends at my 9th birthday party. #about #aac #aidedlanguagestimulation #friends #fraserisland #aidedlanguagestimulation



claire_matilda Our first PODD Squad event was FUN! Unicorn sundaes and a school disco. #aac #podd squad



tonkatruckss PODD training with Janette Sampson and Wendy Webster... OMG #effectivecommunicationpartner #podd



claire_matilda Learning at home. Watching and writing about Taylor Swift's Lover film clip today. #podd19 #independentwriting #writingathome



claire_matilda Online story time with @tvs. Amelia loved my invitation but there are too many closed borders right now. #throwstweetonline #aac #shadreading



tonkatruckss My favourite birthday card by far. Thanks @claire_matilda. #aac #independentwriting #lockdownbirthday



tonkatruckss Today's letter of the day was "F". I brought Finn to work to play with Furley. FANTASTIC! What FUN! #explicitalphabetinstruction #lockdown



Together



Annabell Tonkin

Annabell is a 20-something-year-old Queenslander who also loves water, chocolate and Taylor Swift. She loves school too, so much in fact, that she is studying to be a primary teacher and is currently in her final year of the BEd program at USQ. She is also learning to use AAC to communicate, primarily with Claire.



claire_matilda
Loving reading my book from Annabell. Thanks @tonkatruckss! Merry Christmas 🎄🎅🎁 #lovexmas #sharereading #comprehensiveteracy



tonkatruckss
It's carnival time again. #tooombacarnivaloflowers #toof #springassprung #sharebankpark



claire_matilda
Annabell's back from Christmas break! 🎉🎉 That calls for milkshakes to celebrate. #tobi #PODD #greatbigsmiles ... more



claire_matilda
Tonky helped me write a birthday card for Mum... Mum loved it of course 🥰 #independentwriting #alternativespencil #loveum ... more



claire_matilda
COVID lockdown! can't stop our fun. PODD Squad has gone online! #booklockdown #poddsquad #havesomethingtosayspeechpathology



claire_matilda
You know you've found a winner when she makes her own PODD Squad work uniform 🥰🥰 #aac #podd #poddsquad #dreamsupportteam ... more



claire_matilda
That moment when you realise the birthday celebrations aren't for you. Yeah... happy birthday Annabell. #tookscouldkill #aac ... more



tonkatruckss
I told Claire it's time for homework.... I don't think she's keen. #communicationautonomy #tobit3 #tobidynavox #napcorefirst ... more



claire_matilda
PODD Squad today... I think it's YUMMY 🥰🥰🥰 #aac #pcw #predictablewriting #sharewriting #literacyforall #poddsquad #yumy



tonkatruckss
No amount of Tay Tay is too much... right @claire_matilda_? #ipromisethatyouneverfindanotherlikeme #taylorswift #toptansworldwide ... more



tonkatruckss
"I want a hug hug hug" The girl gets what she wants. #aac #PODD #hughugs #workpeep ... more



claire_matilda
Buy writing a birthday card for a special friend who likes yellow. 🥰🥰🥰 #independentwriting #pod #alternativespencil #literacyforall

This collection reflects some of the ways Claire and I have engaged with each other to build the foundations of our relationship as an emergent communicator and a communication partner, both learning to use AAC. To build this foundation it was important for Claire and I to discover our shared interests and hobbies. This allowed us to engage in mutually enjoyable activities and embed AAC into daily life. Together, Claire and I have engaged her peers and others in these experiences to build wider networks of communication partners. We have continued to develop Claire's literacy skills to support her ultimate goal of communication autonomy. With the support of Claire and her mum Hannah, I have regularly participated in professional development including PODD training, webinars and Claire's therapy, which has increased my knowledge, skills and confidence. Learning to use AAC and building my relationship with Claire whilst simultaneously studying to become a primary teacher, has provided me with unique insights and experiences beneficial to my roles as a support worker and beginning educator. The ideas and experiences shared in this poster have contributed to her family's vision to promote an inclusive and wonderful life for Claire where she is valued and adds value.

Annabell

claire_matilda · socky album terrific Annabell will superhero I think you go see



follow me @claire_matilda_



COMMUNICATION SO MANY WAYS... SOME THOUGHTS

By Anonymous

When Sheridan messaged me to ask if we could write a piece for AGOSCI In Focus around the topic of 'Communication So Many Ways' I was excited. As a family we embrace and celebrate Multi Modal Communication. We honour it because it is communication, because effort and intention have gone in to communicating, because I know that by the time, we have got to the stage that a tight nod, a slight smile, a crinkled eye is used to communicate "yes", everything else has already been tried. Tried until my family member is beyond exhausted and frustrated, and is ready to shut down.

My family member lives with a very complex body. It changes constantly. To this date, no switch site has ever been able to be sustained, eye gaze requires the ability to scan and then dwell or control a blink which is not always possible; light tech requires skilled communication partners that can adjust their scan speed to suit the moment, and an understanding that timing a nod is not always possible, so they need to watch for anticipatory body language and eye movements. This is a highly skilled interaction that requires knowing my family member very well.

We have always honoured all communication. Many years ago in conversation someone said to me "even amoeba communicate" That person was in no means being demeaning or ableist, more commenting on the fact that communication is more than words. It is body language, movement, intention.

I get it, I know the purists among the SLP's don't like it when a person isn't just using their voice output device or their light tech. I know that there are people who use AAC who have shed blood, sweat and tears to get to the point where their voices are heard clearly and I celebrate that their communication is for the most part fluent, recognised and heard.

But what of those who are still struggling?

What happens when on top of the constantly moving body, the cognitive load of holding your message in your head while trying to control your eyes, your head and your body, while searching your low or high tech for the words you need to get your message out, managing distractions, pain, and the anxiety that builds as you sense expectation and sometimes impatience in the person/s you are communicating with, and when your CVI kicks in and you can't find the word or the sentence.... What happens then? For us that is

the time we most honour multi modal communication. Perhaps we say "Let's take a minute to breathe, your communication is important, your feelings are valid. Let's take a breath and try again". And we return to communicating because to have your voice ignored because your message is not presented in the way the person you are talking to expects is horrific.

Imagine you meet me for the first time, and you assume I speak English. I live in Australia and appear to most likely have English as my first language based on my appearance. But instead, I respond to you in Taushiro (a very nearly extinct language from the Peruvian Amazon). Are you going to keep talking to me in English, demanding I respond to you in English? Or are you going to find out what my language is, get a translation app and learn to speak my language. Are you going to honour my communication even though it is not what you expected or prefer?

This is the thing I find most challenging, that sometimes in the desire for what others view as optimal communication, multi modal communication is undervalued or ignored. That gesture – it meant something. Go back and ask for clarification. That eye point and head turn towards the bedroom, it means go to the bedroom, I'm telling you about something in there I need. That slightly pointed finger is a warning that you are in big trouble. That total body response is communicating a rise in emotion and needs to be honoured. Yes and No have absconded in the extreme fatigue that has taken over the body. Holding concentration to listen to you, the communication partner, is a strain but the eyes still are communicating. Watch them. That facial expression? It wasn't random, it wasn't a muscle spasm – this person is communicating something in response to your words – think over what you just said for context, now ask a question to clarify.

I don't have a degree in speech therapy or occupational therapy but even from the early days when I knew nothing about disability, I recognised that everyone communicates in their own way. We just need to find it, honour it, and give dignity to all communication.

FROM PAPER TO THE NEURO NODE: NATALIE'S HIGH-TECH UPGRADE

By Rebecca Staple, Better Rehab

Natalie has difficulty being understood by others due to her cerebral palsy. She's previously used paper-based communication aids, however they were no longer fulfilling her communication needs and she needed a high-tech upgrade. When I came on board to work with Nat she knew exactly which communication device she wanted due to a previous assessment - the NeuroNode Trilogy.

The NeuroNode Trilogy is an advanced device that is very expensive and required a lot of convincing to be approved. I worked alongside Nat's support team and device supplier Control Bionics to make this happen. I guided Natalie through a device trial via Telehealth due to the lockdown and worked with her on further trials of the NeuroNode, as well as trials of multiple other switches and access methods to demonstrate why this device was the best one for Natalie. After 18 months, the long wait is finally over - the device was approved and a week later was delivered and set up.

Immediately after setting up the device, Natalie was able to answer Yes/No questions. After a bit of exploring through the different apps on the system she was also able to request something to eat and drink. I asked Nat if she liked her new device, and Nat used the NeuroNode to reply "Yes!".

In the few weeks since receiving her device, Nat and her supports have dived headfirst into building her communication skills with the NeuroNode. She is currently working on using the NeuroNode EMG switch combined with eye-gaze access to answer Yes/No questions and make everyday requests.

Natalie is an active member in her community. In the future she would like to work in a volunteer role at an op-shop. Not only will this device allow her to express her wants, needs, and opinions, but it will also enable her to develop her customer service skills. Nat has been working hard and practicing with her device every single day, so there's no doubt she'll be achieving these goals in no time.

About the author

Rebecca is a speech pathologist at Better Rehab. Better Rehab is an NDIS registered allied health provider servicing throughout Australia. Our multidisciplinary team delivers innovative and effective interventions for people with chronic medical conditions and disabilities in their homes, our clinics or remotely via Telehealth.



www.betterrehab.com.au



TONY HAD A STROKE: HE RAISES AWARENESS OF HOW HARD IT CAN BE TO COMMUNICATE WITH CARERS

By Dolly Bhargava and Tony Jones

I am a Person Of Disability in my late sixties. A year ago, in August 2020, I had a major stroke that put me in hospital for several weeks. The stroke left me with a left hemiplegia, paralysed completely down the left-hand side of my body, and with very weak core muscle strength. It also meant that I was doubly incontinent and was fitted with a catheter. Full-time catheterisation meant that I was prone to bladder infections (which are not pleasant). The stroke also badly affected my speech and talking became something of an effort. Indeed, if I am emotional, or in pain, or my throat is dry, or I am not feeling well, or for reasons unknown, I cannot speak at all and have to resort to using other forms of communication: Makaton sign language (UK) or my Voice pen (Pen that speaks when positioned over a symbol it recognises) and symbol board. As if not all that was enough, I found myself having to cope with lengthy periods of pain and poor post-hospital provision.

An IRON POD

I am not just a POD (Person of Disability), I am a specific category of POD; an IRON POD (Individual Reliant on Others for all Needs). Without the assistance of others, I can do very little for myself. I would not be able to get out of bed without help. Only having one arm and hand (and those not working at 100% efficiency) is somewhat handicapping. I struggle to do the things to which I didn't give a moment's thought prior to the stroke. Try going through a single day without using your left arm or hand for any purpose at all. Let your left arm hang uselessly by your side throughout the day. If you move it at all, you've failed the situation. You will soon begin to understand what a blessing two functioning hands are to you.

As an IRON POD, life can be fairly (unfairly?) frustrating, and it is easy to find yourself getting angry at inanimate objects simply because they are not behaving as you would like! If the television remote falls to the ground from my one working hand because my fingers are not fully functional, I cannot bend and just pick it up. I have to call for assistance, somebody has to come and help me, or else I will not be able to turn up the volume on the program that I have been wanting to watch. It is easy to get annoyed and such an experience can alter my mood for quite some time afterwards. In itself, it would not be enough to cause a Behaviour Of Concern (BOC) but these setting events coupled with a triggering event might be sufficient to

bring about some untypical behaviour on my part.

Communicating with Carers

I pay for care provision three times a day. A two-person team arrives to assist me with whatever I require doing at the time that they arrive (breakfast, lunch, and an evening call). Given my speech difficulties I usually resort to Makaton sign language. Makaton signing requires the use of two hands and, so, I have had to be creative and adapt it for use with a single hand. Both the nurses (whilst I was in hospital) and my care teams (my care is not provided by one pair of people, almost anyone can turn up - I see many faces during an average week) did not have any knowledge of sign language and would stare at this crazy man, moving his right hand around, befuddled! They might ask me a question and, before I had the chance to respond, have asked a whole string of following questions while I was still trying to answer the first! They would then assume that my hand's movement was the response to the last question asked and ascribe a meaning to it based on the (wrong) question and some subjective contextual aspects. It was obvious that they would be wrong, and I would become even more frustrated! I'm trying my best to communicate an answer ('I don't know') to their initial question and, because the sign for 'I' involves me pointing to my chest, the carers think that I am telling them about a pain, start to ask me a whole new series of questions about heart attacks! All because I was signing and pointing to myself in response to a question asked of me many previous questions before. I might have been angry had I not found the whole situation to be quite humorous. The use of humour can be an effective method of diffusing a potential BOC situation providing the individual concerned is capable of understanding the joke.

Communication breakdown is a possible trigger for BOC. The breakdown can be because others don't comprehend my communication efforts or because I have not understood what is being asked of me. While, in my case, the latter is unlikely, there is a distinct possibility that, what is being asked, is beyond my present capabilities with more than half of my body not functional. Normally, I would explain what they were asking/expecting was beyond my capabilities, but communication from me is likely to be unsuccessful and the situation can quickly go from bad to worse.

With or Without Control

I have a hospital style over bed table without which I couldn't manage. It has to be precisely positioned because everything I need has to be within the radial movement of my right hand and arm. I have very weak core muscle strength. As such, I find it very difficult to reach across my body to retrieve something that has been placed on my left. Carers assume, because an object is placed near to me, that I can twist my trunk round to the left and, using my good right hand, take the object when I require its use. They could do it easily while sitting in bed so the same must apply to me, mustn't it? They are wrong to think in this way. It is not only my arm and leg that the stroke took from me, many other functions were affected also. Necessary items have to be placed in what I call my 'proximal zone of accessibility'. If items are only two centimetres outside this zone they might as well be on Neptune because they would be agonisingly just out of reach. I would then require the assistance of an Other.

My mantra became the 'goal is control'. Not Others controlling me, but me in control of others, my environment and my life. I found that Others much prefer to be in control of me and will perform acts without informing or involving me without seeking my express permission. Early in my first period in hospital following the stroke, I had to call a nurse to look at my catheter bag, which was full. The nurse said,

"Oh Christ!"

and hurried to get a disposable bottle in which to empty it. I then asked the nurse for the bed control. She gave me a quizzical look and asked,

"What do you want that for?"

I explained that I wanted to raise the top of the bed. She asked,

"Do you want to sit up?"

and using the bed control herself proceeded to raise the top of the bed saying,

"Tell me when."

I protested,

"No, give the control to me."

My speech was very poor, and the nurse just carried on in control saying,

"Too high?"

and began lowering the top of the bed! I repeated, as clearly as I was able,

"No, give it to me".

This time the nurse appeared to understand me and passed me the control stating,

"Fine, do it yourself."

She was not pleased as she walked away. Carers like to be in control. It is not the Carer that needs to be in control, it is the POD. An example will illustrate this concept further. I had been saving some dental chewing gum on a little piece of tin foil on my bed table. I had a piece of gum every day and I had saved it over a week. It may not have been too hygienic, but it was my choice. One morning, a Carer spotted the gum on my table and, without asking me, picked it up and threw it in the rubbish bag! I was angry that she had taken away my control. Another time, while in hospital, I was in a bed with a faulty bed control. It was night and the lights were out. I was very uncomfortable but could do nothing to help myself except to try to use the bed control to reposition my body a little. In the poor light, I hit the 'raise bed' function thinking that I was raising the top of the bed just to sit up. When I realised that I had raised the whole bed by mistake. I tried to lower it but that particular function was faulty and not working on my control, so the bed remained raised in its highest position. A while later, a night duty nurse, on seeing my elevated position, came up to me and started to scold me like a little child. I tried to explain but my speech was bad following the stroke and I struggled to speak. The nurse made no effort to listen and comprehend my poor communication and continued to berate me. He used the separate bed control at the foot of the bed to lower the bed. He told me that I should go to sleep and stop messing with the bed control as it was not safe to be 'way up in the air'.

He then took my bed control and positioned it behind me such that I could not reach it and had to spend the remaining part of the night without any control over my position whatsoever. He said that he would be in trouble if I were to fall out of bed so high up (where was the concern for me?). Fall out? I could not even roll over on my own let alone fall out of bed. The side railings were in use and in the up position! How could I possibly fall out of bed even if the bed was atop a mountain? That particular nurse showed no understanding of my condition or my predicament. I

TONY HAD A STROKE CONTINUED

was just a 'naughty child' messing with the bed control in his mind. I was angry that he had taken away my control. The goal is control. An important part of control is having choice. While the goal is control, choice is a voice.

Control & Choice over:

- my health
- the way in which my Carers interact with me
- my environment
- my own being.

Conclusion

In conclusion, my dreams and aspirations include experiencing individual choice and control over my life, to be supported with expressing my preferences using my preferred style of communication, and to keep well and healthy. Control with Choice is empowering. No control or choice is both demeaning and dehumanising. A paucity of control and choice can lead an otherwise placid person into exhibiting BOC. Sheer frustration from a curtailment of control and cancelled choice without an effective means of communication, is a recipe for outbursts of anger (even from me).

About the authors

Dolly Bhargava, is a Speech Pathologist with a Masters in Special Education. She works as a Behaviour Support Practitioner and Speech Pathologist with children, adolescents, and adults with complex social, emotional and behavioural difficulties. Dolly is the founder of Behaviour Help



www.behaviourhelp.com

Tony Jones is a teacher with a Masters in Special Education with over forty years experience. He has worked across the world and gained national recognition including the National Training Agency's Innovation award for the UK and the first Makaton Centre Of Excellence Award for a UK college Although currently retired, he still maintains his website talksense.weebly.com a guide to Special Education with a particular focus on communication and Profound Learning Difficulties. In 2020, Tony had a stroke which put him in hospital for several weeks resulting in severe disability. Being a Person Of Disability with impaired speech now has given Tony an unique and fresh perspective with an insider's insight into communication and disability.



Fiona Beauchamp

agosci inc.

AGOSCI NATIONAL TOUR SPEAKER 2022

The banner features four photographs: top left shows a woman and a child at a table; bottom left shows a woman in a red jacket standing; bottom center shows a woman and a man at a table; bottom right shows a woman sitting. The agosci inc. logo is in the top right.



agosci inc. National Tour

EARLY BIRD TICKETS

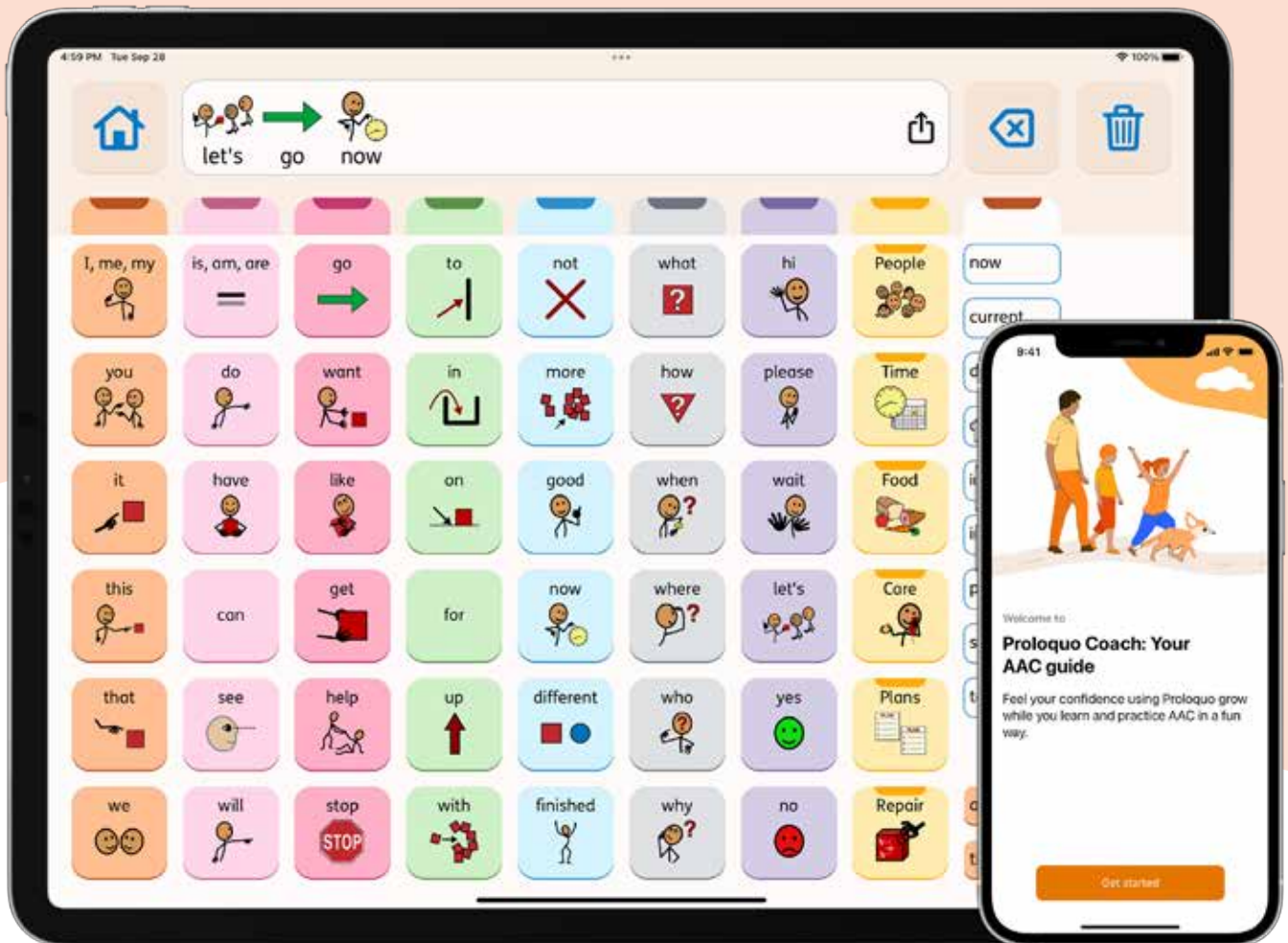
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The poster features a stylized black bird icon.

INTRODUCING

Proloquo and Proloquo Coach



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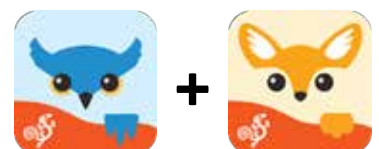
The next step in AAC communication is here

AssistiveWare Proloquo® and Proloquo Coach™ are a set of apps that are designed to work together.

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SOCIAL MEDIA DEVICES



By Leanna Fox (Twitter: @fox_leanna, @LiberatorAus) and Melissa 'Liss' Brunner (Twitter: @LissBEE_CPSP, @ABICommLab) with Siobhan Daley.

Social media can be used on your computer or mobile devices. Social media apps let you post messages and search for information. You can post pictures or videos or links to other things, like news. You can connect with lots of people and talk about many different things. You can also comment on or 'like' other people's posts. Which social media should you use? It depends on what you're into!



So why would you use social media?

Which different social media platforms work, can also influence how you use them. You may want to find information – it could be on things or people you're interested in, or it could be to see what's happening in the world. You may want to watch what other people are doing, or just have fun watching videos on Facebook or YouTube. You might want to share what's happening in your life or talk about your interests, or just share photos from your life without having to talk about it too much. You might want to use social media to connect with people you know, with new people who like similar things to you, or with organisations that could help you or to find support from people who are similar to you. You may want to speak about things you're passionate about, for example politics, music, or climate change.



(Image: a person holding a tablet with social media icons displayed on it, along with the word 'connect', photo by NordWood Themes on Unsplash)

Engaging in social media

You can use social media in many different ways. One way is by interacting with other people. You can watch and read what other people are posting. You can also comment on or react to other people's posts. In Facebook you can show different reactions, you can like or love a post, or show that you're laughing, crying, surprised, or angry or upset. In Twitter and Instagram you can click a heart reaction, in YouTube you can choose a thumbs up or thumbs down reaction. You can also connect with lots of people and talk about many different things just by writing a comment or a reply to someone's post.

Some platforms are built for social networking, where you can interact with others and catch up on news and events (e.g., Facebook, Twitter, and Linked In)



Blog platforms let you discuss topics in more detail (e.g., Tumblr and Reddit icons).



Some platforms are made to share photos (e.g., Instagram and Pinterest),



and some are built to share videos (e.g., YouTube and Vimeo).



Other platforms let you play around with the photos and videos you post a little bit more (e.g., Snapchat and TikTok),



or interact with other people in game worlds (e.g., World of Warcraft, Minecraft, Fortnite, and the list goes on!).



You can access social media via technology such as your phone, tablet, computer or AAC device. Most of the expensive dynamic display AAC devices have social media integration.



(Image below: Screenshot of a social media post by Siobhan Daley that says: "I can easily use social media through my communication device. I have it set up so I can connect to both an external computer and iPhone and access all sorts of social media, like Facebook, and control everything through my device. I also have some programming which allows me to use Messenger from the internal computer on my device".)



Siobhan Daley

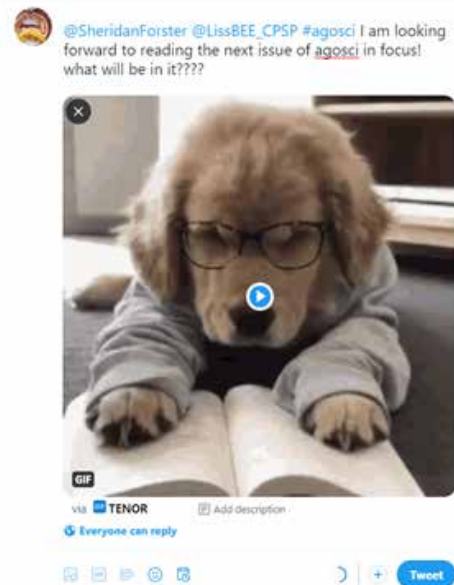
Friends ▼

I can easily use social media through my communication device. I have it set up so I can connect to both an external computer and iPhone and access all sorts of social media, like Facebook, and control everything through my device. I also have some programming which allows me to use Messenger from the internal computer on my device.

Twitter is a kind of 'social messaging' application. Users send and read short messages called 'tweets'. You can post and read tweets and follow friends, or people you're interested in, like celebrities or politicians. You can also upload photos and share links.

We both use it to follow researchers that we like and tweet interesting things we learn at conferences. There are also gamers who use AAC who review games and give feedback for online gaming with a physical disability.

#agosci2022 #seeyouinhobart #AAC #braininjury #puppies #ilovepuppies



(Image: Screenshot of a tweet from Leanna; A puppy is dressed in a shirt and tie reading a book.)

SOCIAL MEDIA DEVICES CONTINUED



Facebook is probably the best-known social media or networking website. You can create a profile, upload photos and videos, and send messages to friends and family. You can connect with others by sending a friend request and once you've connected, your information is shared with those friends you have accepted.

An example is the LAMP WFL users group. This group is moderated by John and Cindy Halloran, the authors of the LAMP therapy approach. Lots of families, therapists, teachers, and others access this group to ask questions and share achievements and resources. The LAMP WFL VI (vision impaired) group also has monthly case studies presented via zoom that anyone can join.



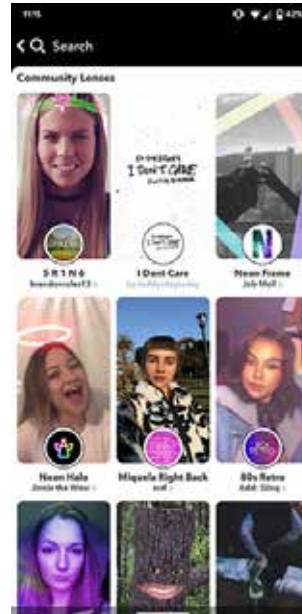
(Image: Screenshot of the Facebook LAMP WFL users group)



Instagram is all about sharing photos and videos. Everyone has a Profile and a News feed, which is updated information and pictures from people you follow. A lot of comments happen on Instagram under the images. You can also create stories which disappear after 24 hours. You can see Instagram images on any computer, but you can only upload and share posts or stories from a mobile device.

Liss uses Insta to share photos every now and then of things that she finds interesting in life - but mostly she enjoys looking at other people's posts about cooking and upcycled craft.

(Image: example Instagram post by @liss_bee which shows a hand with a green heart ring on one finger and a squishy plastic octopus toy sitting on top of the hand)

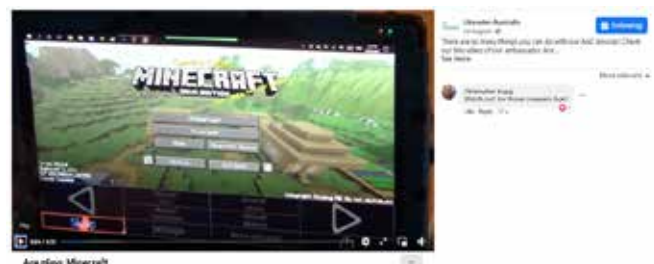


Snapchat is another app used to share photos, videos, text, and drawings. You can add text or drawings to your snaps, use filters, and create stories. Delete is SnapChat's default setting, so snaps disappear after they've been opened by everyone it's sent to. You can also share videos on your 'My Story' page and this lasts for 24 hours and can be seen more than once.

(Image: Snapchat filter examples from alpha)

TikTok is another social network for sharing videos that you've made. You can create and share your videos where you lip-synch, sing, dance, or just talk. You can also look at other people's videos and comment on them. TikToks can be up to 15 seconds long, but you can also connect multiple clips together for up to 60 seconds or you can upload longer videos you record outside the app.

Online gaming is really popular, with many different games available to choose from based on your interests. Online gaming is any video game that offers online interactions with other players, and depending on the game this can be done through video, audio, or instant message chat functions. If you like building things, then Minecraft or Stardew Valley could be for you. If strategy or politics are more your style, then World of Warcraft or Among Us might be a better fit. There are large communities playing these games online and sharing their experiences and tips across different social media platforms.



(Image: Minecraft game title page with eyegaze icon dwelling over sleep cell. Post from Liberator Australia Facebook)

What are hashtags?

Hashtags are used just about everywhere in social media – and they’re used a lot in platforms like Twitter, Instagram, and Facebook. Hashtags on Twitter help us find conversations about stuff that we’re interested in, so we can listen in to what other people are saying and join the conversation. Anyone posting about a topic can add a hashtag to their post. And anyone can search using hashtags to find other posts about that topic. By adding relevant hashtags to your posts, it means that you are sharing your post with as many people as possible. Hashtags on Instagram are used a little differently. Instagram is all about pictures, and people tend to use a lot of hashtags in their Instagram posts to describe the picture. You can still use hashtags to post and search in the same way you can on Twitter. In Facebook, hashtags work in a different way than they do on Instagram and Twitter. Most people don’t really use or search with hashtags on Facebook, but lots of organisations now use them to connect their posts together to make them easier for people to find. So hashtags are just a way of connecting social media posts – it’s all about helping people to easily find posts and conversations they’re interested in.

Online drama and cyberbullying

Most social media platforms make it easy for you to react to someone’s posts, reply to them, and post things yourself. But it can be really easy to react to something and then regret it later. What we say and do on social media can be seen by lots of people. What you post on social media could change how people react to you right now, and it could even affect your life later (for example when you’re looking for a job). Online drama is when someone mentions you or responds to you in a negative way. One of the downsides of social media are the trolls and haters that are online. A social media troll is someone who deliberately says things to start fights or upset people - they often say something controversial just to get a rise out of other users. Other people tend to join in quickly once they see a comment, adding more hate and sometimes threats. Lies and rumours can spread like wildfire online, and it’s not always easy to know the best way to respond. Whether you’re directly involved or not, it’s always best to try and stay calm and help diffuse the situation if you can.

You can take some simple steps to calm online drama down and stay safe:



Be aware scams exist. Always consider something might be a scam. Don’t click links, give out personal information or send money to people you don’t know.

Check your privacy and security settings on social media. If you use social networking sites, such as Facebook, be careful who you connect with and learn how to use your privacy and security settings to ensure you stay safe.

Think before you post, like or follow something. Make sure that the pages, groups, photos, tweets, or videos you like, follow, subscribe to or comment on, are actually things you want to be associated with.

Don’t engage with trolls and haters who post negative and nasty comments. Instead, try saying something positive or changing the subject. You can also block trolls and report them to the platform administrator and encourage other people to do the same.

Check out the eSafety Guide to find out more about the privacy settings for different social media platforms and how to change them.

Check out Scamwatch’s top tips for staying safe online.

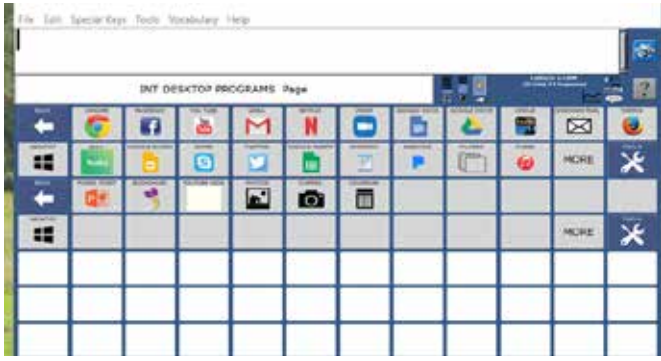
How can you access social media with AAC?

Accent devices have integrated computer commands for different types of computer programs. You can use your Accent device to game or use social media on your device using the internal computer - it is a Windows

SOCIAL MEDIA DEVICES CONTINUED



tablet so it can do whatever a Windows laptop can.



(Image: page from unity 84 sequenced that has a range of computer and social media icons)

What about people who use alternate access to communicate? On the Accent devices there are some pre-made command keys that can be used when browsing the web or playing games. Lots of these are programmed in for everyday apps e.g., Facebook and Twitter.



(Image: AGOSCI Facebook post with icon bar of commands below)

If a game or app you want to use has some sort of keyboard commands, we can program it into a cell. If you are not sure how to do this and want to try please contact your local device representative and they will try to help you.

Bring on the gaming and safe social media use! Find us at @fox_leanna, @LissBEE_CPSP,



INTRODUCING NEW

LIBERATOR CONSULTANTS

The Liberator consultant team expands! Peta Booth will be supporting Queensland, Emily Swanson in South Australia & Tasmania and Delara Kapadia in Western Australia.



Liberator provides FREE 3-week device trials, FREE postage & FREE support.
 (08) 8211 7766 | liberator.net.au

COMMUNICATION SO MANY WAYS: DO PIRANHAS LIKE TO EAT BANANAS?

By Brigette O’Leary and Alice Clapperton, Speech Pathologists, Southern Autistic School (Victoria)

Do piranhas like to eat bananas? We found out the answer during our AAC story time at Southern Autistic School in October.

We ran an online interactive story time to celebrate AAC Awareness month with our students. Due to the Melbourne lockdown, our AAC story time was delivered via a Google Meet with students tuning in from home and a small number onsite at school.

Students of all ages tuned in to read “Piranhas Don’t Eat Bananas” written by Aaron Blabey. The story followed Brian the Piranha and his quest to have his friends try some yummy fruit.

We used a large LAMP core board to model core words such as “like”, “eat”, “you”, “we”, “stop”, and “give”. We used Key Word Sign to support words such as “eat”, “like” and “stop”, and gesture for our body parts.

After finishing the story, many of our students were able to tell us their favourite fruit.

It was great to see so many students take part in our shared reading experience online for AAC Awareness Month.



Fiona Beauchamp

AGOSCI NATIONAL TOUR 2022



March 2022

UNDERSTANDING MOVEMENTS FOR ACCESSING TECHNOLOGY AND COMMUNICATION



1-Day Workshop

- Melbourne
- Adelaide
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- Sydney

Plus: An online workshop for those unable to travel

Learning Outcomes

All communication requires movement.

This workshop will support participants to be able to understand movement challenges, how to observe the movements (including neurodiverse individuals) and learn some strategies to support access to technology and communication, which they can use straight away in practice.

Tickets on sale now!

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www.agosci.org.au/NationalTour2022



National Tour

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CLICK TIPS FROM... FIONA BEAUCHAMP

In this edition, Fiona Beauchamp brings us Click Tips.

Fiona will be presenting the AGOSCI National Tour in 2022. She will be presenting Understanding Movements for Communication and Technology.

Here she presents some of her favourite resources. And I must say I absolutely love these too (Ed. Sheri)!

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



**Cerebral Palsy Education Centre
(CPEC) Learning Place**

CPEC has a few online modules that provide a wealth of information: Understanding the learner, Strategies for Success and Sensory processing.

➔ <https://cpeclearningplace.org.au/moodle/login/index.php>



Snap Type Pro

Many students with physical disabilities or dyspraxia may be unable to use a pencil/pen for writing. SnapType Pro converts a paper worksheet to an electronic worksheet, enabling the user to type, use dictation, or write directly onto the screen.

Remember to take the photo using the camera on iPad and then when creating a new document, get the photos from your camera library – this way you can choose the right orientation!

Apple only.

➔ <https://www.snaptapeapp.com/>



Video Touch

This collection of apps include farm animals, sea animals, vehicles, music, wild animal, bugs and insects, wild birds etc. They are great apps for developing targeting skills with hand/index finger. They are targeted to younger children.

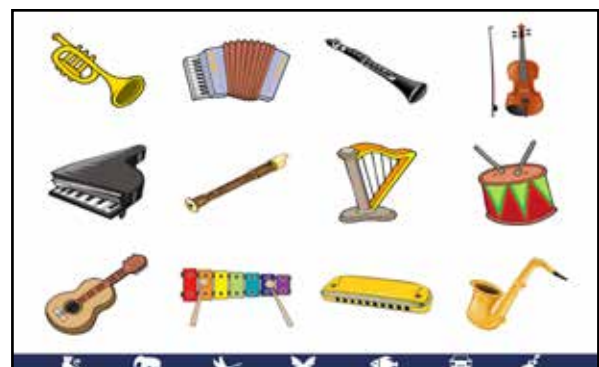
The videos are also short and return back to the main home screen of 12 icons. This gives the child practice so that when they then trial a 15 per page communication device page set, they may have more motor automaticity with their access.

When you shake the iPad, the objects move which helps therapists to see if the child is physically able to get to all areas of the screen, or if they keep selecting a particular objects repeatedly because it is their favourite animal, or they enjoy the video.

f www.facebook.com/SoundTouchInteractive

➔ <https://apps.apple.com/au/app-bundle/videotouch-bundle-250-videos-of-animals-vehicles>

for all 5 apps, or even try all 7 apps!



AGOSCI MEMBER PAST WEBINARS

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 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? *By Janelle Sampson*

Towards cohesive language development in AAC *By Cathy Binger*

Being part of the AAction *By Fiona Given*

How I became an AAC communicator *By Nick Bradbury*

Championing communication access for all *By Barbara Solarsh and Georgia Burn (from Scope)*

AAC and the NDIS - Surfing the waves of change *By Gail Bennell*

Achieving functional communication through Minspeak *By Siobhan Daley*

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

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

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

Understanding parent rejection and abandonment of AAC systems *By Alison Moorcroft*

Using AAC to give evidence in court and tribunal hearings *By Fiona Given*

Implementing music therapy and AAC in a lower resourced set *By Kylie Hinde and Farhin Chowdhury*

Championing Communication Access for All *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. *By Edward Johnson*

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

AAC and literacy *By Ash Harling*

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

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

I have a dream for communication - AGOSCI Conference Keynote Presentation 2019 *By Joey Harrall*

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

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

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

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

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

Connection, Isolation, and Online Life in Lockdown *By Siobhan Daley*

Family, Friendships and Autonomy for the Future *By Hannah Gutke*

Improving communication access in mental health support - How can we help? *By Eleanor Watson*

Autonomy in Decision Making (AiDEM): A summary of the key learning and resources from the project *By Ashley Harling*

"The best PD we've ever had" - What we learned from creating, refining, and delivering an AAC workshop series for parents and carers *By Megan Walsh and Caitie Mitchell*

AAC competencies from coursework into practice *By Ruyi Tong and Abigail Lewis*

Building an AACConnect Community - *By Jenna O'Brien*

The view of an AAC user - *By Noah Callan*



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