

AGOSCI

in focus



Painting title:
"it is called The Last Stand, because I don't think I could paint another like it"
By Peter Rowe

This issue ...

Tricky Issues: Positive Solutions

Start planning NOW to join us in 2010!



Hosted by Spectronics, the conference focuses specifically on “inclusive learning technologies” – technologies designed to advance independent achievement for people with disabilities, people with complex communication needs and students experiencing difficulties with literacy and learning.

Meet some of our International Keynote Presenters



Dr Caroline Musselwhite

Dr Caroline Musselwhite PhD, is a Speech Language Pathologist and an Assistive Technology Specialist with more than 25 years experience working with children and adolescents with severe disabilities. She is a founding member of the International Society for Augmentative and Alternative Communication (ISAAC). She is a truly dynamic and inspirational presenter whose enthusiasm for her work is catching! Join us to hear Caroline on her first visit to Australia in over ten years!



Dr Gretchen Hanser

Dr Gretchen Hanser PhD, is an expert in assistive and instructional technologies, especially for students with the most significant disabilities. As a school-based Occupational Therapist and Assistive Technology Specialist in the USA, she developed innovative solutions for the most difficult to support students.



Ian Bean “Mr Priory Woods”

Ian Bean is the Consultancy and Training Manager at Inclusive Technology in the UK where he leads a team of teachers and therapists who provide consultancy and training to schools in the use of assistive technology to support the learning, communication and leisure needs of students with special education needs.

In Australia and New Zealand, Ian is perhaps better known for his work at Priory Woods School and for the popular Priory Woods website which he designed. So popular in fact, that there have now been 3.5 million downloads of the free switch and touchscreen programs which he wrote for the site!

Registrations are now open!

Numbers are limited, so reserve your place by visiting our website

www.spectronicsinoz.com/conference and follow the links to register online.



Find us on
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You can now find the Inclusive Learning Technologies Conference 2010 on Facebook!
<http://tinyurl.com/fb-ilt-conference2010>



Maureen Casey is the latest addition to the Liberator team. With over 25 years experience in the field & a degree in Special Education plus a Masters in AAC, she brings a fresh outlook & insight to Australia. To arrange on-site training or a meeting with her to cover anything from literacy to cognition to device features & suitability, simply call (08) 8362 5655 or email maureen@liberator.net.au



Maureen is an accomplished teacher of Minspeak, but is also conversant with low-tech approaches like the unique **Pixon**

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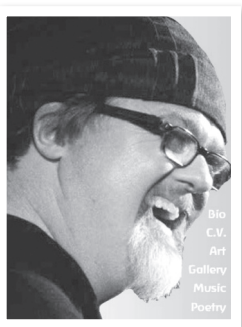
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AGOSCI *In Focus* is the National Magazine of the AGOSCI Inc. (formerly Australian Group on Severe Communication Impairment). AGOSCI *In Focus* is a bi-annual magazine and is available to members of AGOSCI. It contains information from and about national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

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Biography:

Peter Rowe is a multi-talented artist. He is a painter, a writer and a poet. He has been painting seriously for the last eight years. His paintings are abstract and represent his life's journey. He has also written and illustrated three published children's books with another four children's books soon to be published. He lives with his family at Caloundra on Queensland's beautiful Sunshine Coast. He is currently studying for a Bachelor of Arts (Creative Writing) degree at the University of the Sunshine Coast. Peter communicates with gestures, a Dynawrite, a low tech QWERTY board and some speech. He needs the support of Facilitated Communication for typing and has a goal of becoming more independent. You can see more of Peter's paintings, writings, and poetry on his website at www.peter-rowe.info

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editorial

The theme of this edition is Tricky Issues: Positive Solutions and in the vibrancy of AGOSCI, as I write, a great discussion is taking place on the listserve about the pros and cons of AAC users spending time with other people with disabilities. The discussion is rich with life experience and hopes for the future.

Writing about tricky issues is not easy. It calls for the ability to clearly state the issue and explore the solutions – perhaps the theme should have been Tricky Issues: Tricky Solutions. I take my hat off to all those people who have contributed to this edition and managed to express the issues and ideas.

Today I was lucky enough to go to a short seminar on the Victoria Charter of Human Rights and Responsibilities, 2006. Freedom of expression was a key right discussed. In freedom of expression, people have a right to express both popular and unpopular ideas. Perhaps in this edition you may read articles that you don't agree with. I hope the articles will stimulate thought: agreement, disagreement, passion to act, and passion to share your thoughts.

My thanks, once again, go to the editorial committee for bringing this edition together. My thanks, in particular, go to Emily Armstrong, who is stepping down from her role as co-editor. Emily bravely took up the role in 2007, and she has contributed the magazine being both informative and very

attractive. She has also been mentoring our new co-editors, Kirsty Holcombe and Dominic van Brunschot (should I add child and one on the way!) who will be taking over the role of advertising and working with our printers.

So by the next edition Kirsty and Dom will be settled into the co-editor hot seat and will bring you the next editorial. The theme of our next edition, inspired by Melanie Fried-Oken's recent tour, is AAC From HealthCare to the Community. We're looking forward to getting your contributions.

Your contributions are what make AGOSCI In Focus. Steve Lopez, in his book *The Soloist* (recently made into a great movie), said, "The challenge isn't to figure out how to write, I realized, but why. Without a mission and a sense of whom you write for, you aren't worth reading" (p. 66, 2008). So I encourage you all to think about why you may write, your audience (AGOSCI members), and help to continue the vibrancy (and shall I say Power, with fond memories of Canberra) that is AGOSCI!

Sheridan Forster
Editor

What is AGOSCI?

AGOSCI was established in 1981 by a group of professionals who saw the need to promote information exchange about severe communication impairment and related issues.



AGOSCI aims to lobby for the rights of people with complex communication needs, increase public awareness of complex communication needs, and to provide relevant educational and professional development events across Australia.

AGOSCI (formerly Australian Group for Severe Communication Impairment) is a voluntary and non-profit organisation.

What are the key areas of interest for AGOSCI?

AGOSCI's key area of interest is the implementation of augmentative and alternative communication, for example:

- Sign and gesture systems
- Lo- / Light-Tech communication options
- Voice output technology systems including speech generating devices and software
- Switching and mounting options for technology
- Mealtimes issues related to disability
- Saliva control
- Current research

- Consumer advocacy and stories
- Literacy and AAC
- Community and capacity

Who can join AGOSCI?

Anyone interested in complex communication needs can join AGOSCI. Our membership includes individuals experiencing complex communication needs, family and community members, teachers, speech pathologists, occupational therapists, rehabilitation engineers and other professionals.

What does AGOSCI offer?

AGOSCI membership offers:

- Twice-yearly AGOSCI *In Focus* magazine
- Discounted rates for AGOSCI events
- State / Territory study groups and meetings
- Access to the AGOSCI Listserve for on-line discussions
- Biennial National Conference
- AGOSCI website
- Consumer scholarships.

How do I join AGOSCI?

Simply download the membership form from <http://www.agosci.org.au> or contact your State representative (details listed over the page).



CONGRATULATIONS...

To the groundbreaking Australian, New Zealander, and British teens, who have been inspirational educators on the web, teaching people all about AAC – well done Holly, and Emma, Morgan and Beth! Check out their videos at <http://www.youtube.com/watch?v=woCsgnXwOyg> and <http://www.youtube.com/watch?v=JGQ7wCsT3AY>



AGOSCI Conference 2011 Update

Although many of you may still be recovering from the 2009 conference, here in Adelaide, we're already gearing up for 2011. This, and future updates in this magazine will keep you abreast of some of the great things to come at....

AGOSCI 2011 – Taking it to the Streets May 12 -14, 2011 at the Adelaide Convention Centre

So, pencil the date into your calendar for 2011, and keep an eye out for more updates, call for papers, and registration details as they come out.

The conference theme, Taking it to the Streets, is designed to promote awareness both within and outside of the disability sector. We aim to encourage thought, innovation, and action that will enhance the participation of people with CCN through enhanced understanding, skills, and awareness of those in their social networks. This includes family, personal attendants, educators, right through to government and the general public. We encourage contributions to the conference that explore these issues.



Much of our conference planning and preparation is also designed to address the goal of increased awareness. As a first step, our fantastic new logo has been designed by a student at the

local TAFE College who won a design competition. Thanks to Lorna Fenech (a conference committee member) who briefed the students on AGOSCI, AAC, and CCN. The students then set about designing a logo for the conference. Of the many entries the one you see above was designed by Leigh Philip. Congratulations to Leigh and the whole class who creatively embraced the concept and learned a little about AGOSCI along the way.

The enthusiastic committee are now hard at work organising speakers, exhibitors, social events, and many other exciting aspects of the conference. For up to date information about the conference, or to contact a committee member, visit our website www.alloccasionsgroup.com/AGOSCI2011 and complete an expression of interest to receive updates. You can also or e-mail us at agosci2011@aomevents.com

We look forward to seeing you in Adelaide in May 2011.

Janelle Sampson
AGOSCI 2011 Conference Convenor



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Chairperson's Report

Wendy Webster

How do members of AGOSCI highlight to the Australian community the joys and frustrations of being a person who cannot speak but has lots to say? A tricky question. We have tried submissions to 2020 Summit and the National Disability Strategy. After hearing Dr Norman Swan speak several years ago, I have become firmly convinced that positive solutions to highlight issues around the lifestyle of AAC users in the community, involve AGOSCI members finding a way to engage with the mainstream media. There was an attempt to engage with Australian Story. Movies such as Dance Me to My Song and Black Balloon have realistically presented contemporary Australian lifestyle involving communication disability and trying to live a comfortable, contented life. But these expressions are not accessible to us ordinary folk.

I believe there are ways to be part of the positive solution of informing the community and government. The first is You Tube where there are countless representations of persons chatting with AAC. Try <http://www.youtube.com/user/lvoicemovies#p/a/O/IGQ7wCsT3AY> where Emma, Morgan (who are AGOSCI members) and Beth from the UK introduce themselves and describe their communication systems. Thank you for the joy this video has given many.

The second is the ABC program QandA which allows the general public to post written or video questions to a panel of prominent Australians. Both question formats stay online for perusal. AGOSCI attempted to have questions asked to The Honorable Bill Shorten MP, Parliamentary Secretary for Disabilities and Children's Services. Though ours were not asked on air they are there to be viewed. Here they are:

If a person can't talk, do they still communicate?; If a person can't talk, can they still make decisions (menial or life-changing)?; If a person can't talk, do they still have a right to express their opinions?; Do the panel members know how to communicate with someone who doesn't talk? Harmony

Ann McDonald in her acceptance speech for the Personal Achievement Award for the National Disability Awards pleaded "Please listen to me now". Her plea related to access literacy teaching and disability, especially those who cannot speak. What indications are there that Anne is being listened to and that education of those who cannot speak includes expectation of functional literacy teaching? Comment: This is on behalf of AGOSCI (formerly the Australian Group on Severe Communication Impairment) I am the current Chairperson. www.agosci.org.au Wendy Webster.

I am a 17 y.o. female and I use a communication device and a

wheelchair but I'd like a job, a house and a relationship. My question to Mr Shorten and Mr Abbott is, why in 2009 do people with disabilities still not have the same opportunities as other young people for employment and appropriate housing. And to Bettina Arndt, how do I get a boyfriend if I have to live with my parents for the rest of my life? Morgan Webb Liddle.

Social inclusion has become the key words in the government's policy framework for people with disabilities. However for people with disabilities whose needs may be beyond the needs being accepted for financial assistance because they need attendant care for daily living tasks and communication aides for communication, these people are still fighting for assistance to become part of the community. When will these people be recognized as potential community contributors if given appropriate support without having to continually fight for funding to be socially included? Maree Ireland.

But there was a wonderful video question aired from Able Australia relating to disability and employment, especially a person who is deaf blind and has particular communication support needs. You can view this at: http://qanda.abc.net.au/_Question-for-Bill-Shorten-MP/video/825160/30560.html Most, if not all the above questioners are AGOSCI members or have had involvement with AGOSCI. So there are positive solutions to the tricky questions. Please all get on board and post your videos and questions.

What else is happening in AGOSCI world? Janelle has had her little one. Welcome to Sierra Kate. Hope you realize that Mum has a conference to plan! We have had great feedback about the "Feel the Power" Conference regarding both content and finances. We have had a successful tour of Melanie Fried Oken highlighting AAC in medical settings. Thanks heaps Karen Bloomberg and Speech Pathology Australia for the support. Jane Farrall has a Literacy Intensive and tour by Joanne Cafiero for next year. Whether Sierra likes it or not, Janelle is heading up the Conference planning for Adelaide 2011. Sally continues to be wonderful. She and Paul have updated the website, and Sally continues to moderate the listserv. Emily is handing over her part of the Editor role to Kirsty Holcombe and Dominic van Brunschot. A great big thank you to Emily for all your hard work. The state representatives, Melissa, Jenny and Sheri continue to beaver away so that AGOSCI can get the word out there. And all this with volunteers!

See you on You Tube and QandA



Notations ...

 **Secretary's report**
Melissa Bakes

Well Hi again to Everyone,
Another busy year has come to pass for AGOSCI. We've had a good year for memberships this year with around 220 members and some from overseas. This is a little down from last year. It was a very busy middle half of the year with organising all of the receipts for membership. Hopefully this will go a lot smoother for next year with a faster turnaround. Things will slow down now until early next year. I look forward to a rush of memberships ready for the National Tour.

My next big task will be gearing up for next year's AGM. I have a feeling it will be my biggest one yet with maybe a few rule changes.

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 hearing from you all again next year.

Thanks also to everyone who has contributed to the listserv. I have enjoyed the discussions and the information everyone has contributed and shared. Keep up the good work.

Mel

Money Matters

 **Treasurer's report**
by Jenny Arthur

Everything is going well in the financial land of AGOSCI. Our conference this year ended up making a profit, which was very exciting news. This was the first year we had employed conference organizers and this, of course, added a great deal of expense to the conference. Because of this and the fact that the conference was being held outside the bigger cities for the first time, we were unsure if the conference would even break even. Another exciting factor in this conference was that we had the largest number of scholarship holders attend which was covered by a government grant and money from AGOSCI.



JOIN THE AGOSCI LIST!



The AGOSCI list is an email forum for people with complex communication needs, family members, carers, therapists and teachers. Anyone who is interested in AGOSCI can join. Ask questions, share resources and praise. Everyone's opinion is treated with respect. There is so much to learn from each other!

We have members from all over Australia and the world. Go to www.agosci.org.au and click on 'List Serve'. (It's free!!)



State Reports



VICTORIAN BRANCH REPORT

Katie Lyon & Stacy Cohen

We would like to take this opportunity to introduce ourselves to all our Victorian members. We look forward to taking up our new positions as the AGOSCI Victorian State representatives. A big thank you to Helen Tainsh and Melissa Riepsman for all their hard work and dedication in supporting the continued success of AGOSCI in Victoria. We have both taken this role on immediately before the hugely successful AGOSCI Conference in Canberra where it was great to meet up with so many of our Victorian members who were there as both participants and presenters. Congratulations must go to the following very worthy Victorian members:

Gayle Porter for her fabulous keynote address; Jane Farrall for receiving the 2009 AGOSCI Award - Service to AGOSCI - and Melinda Smith for receiving the 2009 AGOSCI Award - Service to AAC.

We held our first Victorian AGOSCI meeting on the 28th July. We were lucky to have three Victorian members as our guest speakers presenting summaries of their papers from the AGOSCI conference; (i) Meredith Allan: AAC – A culture revisited; (ii) Jane Farrall: Visual Scene Displays – Pretty Playthings or Powerful Pictures? and (iii) Helen Tainsh: Maximising speech without compromising communication. Thanks to all those members who attended the night, we received good feedback and look forward to the next state meeting which will be a resource sharing session and a chance to catch up before Xmas! The details for the next meeting are: Wednesday, 18th November 2009 from 5.30pm until 8pm at Scope Victoria Boardroom, 830 Whitehorse Road, Box Hill, VIC 3128. RSVP: katie@spectronicsinoz.com

We also are also very excited to welcome Melanie Fried-Oken to Victoria in October who will be running seminars focusing on AAC in healthcare settings. Melanie Fried-Oken is a Speech Pathologist and a leading international clinician and researcher in the field of Augmentative and Alternative Communication (AAC). The seminars will discuss the multi-modal communication process and identify strategies, as well as low-tech and high-tech solutions for medical and community settings. Principles of assessment and intervention that have been determined through expert practice will be presented through case studies using videos and clinical reports. Participants will have hands-on training with the latest speech generating devices and learn to identify device features that meet users' needs. AAC within the social setting will be stressed, including the role of the speech pathologist as an advocate for partner training, policy changes and funding. Registration entitles you to FREE AGOSCI membership for 2010. Your FREE AGOSCI membership forms will be available on registration at the seminar venue. Date: 15th

and 16th October, 2009, Venue: Darebin Arts Centre, Melbourne. For further information please see the following link http://www.scopevic.org.au/therapy_crc_events.html We look forward to seeing you at these forthcoming events!



NEW SOUTH WALES BRANCH REPORT

Harriet Korner and Nicole Thompson

In July, AGOSCI NSW hosted a 'Feel the Power in NSW' feedback event from the 2009 AGOSCI conference held earlier this year in Canberra. We had six presentations and 53 attendees at the event from around NSW. As well as the extremely informative content, attendees enjoyed mingling with one another over afternoon tea. We would like to thank the presenters, Dr Andy Smidt, Teena Caithness, Leigha Dark, Michael Brunac, Martine Fourie, Donna White, Harriet Korner, Eunice Law, Cecilia Rossi, Candy Leung and Laura Ascaino for assisting us in sharing some of the wonderful information that was presented at the conference. Their mini presentations gave a wonderful example of the information that is presented at AGOSCI conferences and evoked questions from curious attendees about the next AGOSCI conference.

Dr Melanie Fried-Oken will be presenting on AAC in Health Care Settings. The workshop is to be held in Sydney on Thursday the 22nd October and Friday the 23rd October at Northcott Disability Services in Parramatta. The workshop will provide innovative learning on the assessment and implementation of AAC in intensive care unit, inpatient, rehabilitation, home, and community settings. The workshop will also provide information on the process for applying to Enable, NSW Health, for funding of AAC equipment and services to assist AAC equipment prescription in NSW. We look forward to participating in and learning more about this exciting area of AAC. Makaton NSW continues to provide Basic Makaton Workshops. So far this year, 853 people have been trained (DADHC – 372, TSC – 83, other – 398 people). There has been wide interest across NSW in Makaton Presenter Training. The next Makaton Presenter Training event is scheduled for Sydney in June 2010. Expressions of interest forms will be sent out next year, so watch out for these.

The speech pathologists within the TASC (Technology Solutions for Computer Access, Seating and Communications) team at The Spastic Centre have recently facilitated 'Chatter Days'. These days provide an opportunity for parents and children who use communication devices to practice and fine tune their skills in a group environment. Chatter Days have been a successful and enjoyable way for children and parents to learn and will continue to be run throughout NSW. Northcott Disability Services will be celebrating their 80th Birthday. Events are planned for October and November to celebrate Northcott's 80 years of disability services, including the services of the CATS (Computer Assistive Technology Services) team who provide information, advice and support for AAC users and potential users. Vanessa Smith, speech pathologist, Early Childhood Support Service, organised



State Reports (cont)

Minspeak training in September, presented by Maureen Casey from Liberator Australia. Vanessa is currently organising two Hanen training days for teachers. Gail Van Tatenhove will be presenting on helping students to use AAC devices in the classroom. The presentation will be titled 'Start Talking in Class' and will be hosted at The Spastic Centre, McLeod House on Thursday the 10th December. Families have been expressing the desire to create networks for young AAC users. Email, Facebook or Ning (a social network vehicle) have been suggested. Livewire is another possible way that people could network. We would be very happy to assist in organising a meeting for families if people would like to get together. This could happen in Sydney or in other regional areas if there are people interested. Please contact us if you would like to discuss this issue. We would love to hear from NSW members with feedback from 2009 or ideas for events in 2010. Our contact details are; Harriett - email harriet.korner@northcott.com.au or phone 02 9890 0157 and Nicole - email nthompson@tscnsw.org.au or phone 02 9586 1077.



AUSTRALIAN CAPITAL TERRITORY BRANCH REPORT

Kate Jarvis

Ok, so this is my first time of writing a state/territory report, hopefully I'll get better at doing this by the next issue!

Obviously, Canberra has seen a fair bit of AGOSCI action this year with the highly successful conference that was held here in May, another big round of applause for the committee! Well, the AGOSCI presence continues here in October with a series of Intensive Interaction workshops run by two of our committee members, Jenny Arthur and Lyn Floyd. If the RSVP list is anything to go by, I think we're going to have a really successful couple of workshops and I look forward to letting you all know how it went.

Much like the other states and territories, the ACT is planning on getting some more professional development going in our area in 2010. We're hoping to lure Gayle Porter back to Canberra for the full 2 day Pragmatic Organisation Dynamic Display (PODD) workshop. Given the overwhelming attendance at her workshops at the conference, I doubt we'd have any trouble filling the spots if she was to return!

Finally, on behalf of the committee I would just like to thank Tara Wright for her work as the ACT AGOSCI rep in 2008/09. Tara is currently on maternity leave caring for her little man and we look forward to having her back on the AGOSCI team when she returns.



QUEENSLAND BRANCH REPORT

Paula Hartwig & Melanie Waalder

Queensland AGOSCI has been gearing up for a busy end to 2009. Paula has hit the ground running, as we have invited Gayle Porter and Helen Tainsh to present the Pragmatic Organisation Dynamic Display (PODD) Introductory workshop in Brisbane on 26th - 27th October. Interest in the workshop has been fantastic, with the workshop places filling up well before the closing date. Sorry to those of you who may have missed out, but we look forward to inviting Gayle to present again next year.

As October is ISAAC's AAC Awareness month, AGOSCI QLD has decided to host an AAC Awareness breakfast on October 27th in conjunction with the PODD workshop. The theme of the 2009 International AAC Awareness Month is "AAC and Communication - Many Methods, One Goal: To Communicate". This will be a great opportunity to network with other AGOSCI members, whilst promoting the important role of AAC. 2010 also looks to be another busy year for AGOSCI. Like all of the state representatives, we are well underway in planning for the National Tour, with Dr. Joanne Cafiero to present around Australia. Dr Cafiero's work is based on her strong belief in the benefit of meaningful, contextually based instruction for individuals with autism spectrum disorder (ASD).

We are again looking to webcast the National Tour, with plans for a far North Queensland site - stay tuned if you live outside of South East Queensland. We also hope to invite Gayle to present the PODD Introductory Workshop in Townsville and Cairns. If you have any questions about AGOSCI QLD events or if you would like to suggest a topic or presenter for a local QLD event, please do not hesitate to contact us (contact details can be found at www.agosci.org.au).



SOUTH AUSTRALIAN BRANCH REPORT

No report submitted.

Amy Furze (nee Martin)

The past six months have been a busy time for AGOSCI in South Australia. Janelle Sampson has taken a step back from her role as AGOSCI SA state co-representative, leaving Amy Furze as the main contact for AGOSCI locally. Janelle has taken on the role of the 2011 AGOSCI National Conference Convenor and is also on maternity leave. Thank you to Janelle for all your great work as the driving force of AGOSCI in SA and best wishes for your two new roles!

There is great excitement that Adelaide will be hosting the 2011 AGOSCI National Conference, May 11-14. Preparations are now well underway with meetings of the committees and subcommittees regularly occurring. There is great energy in this group and the 2011 AGOSCI conference promises to be an event that is not to be missed. I encourage AGOSCI members, particularly those from SA, to let their families,



State Reports (cont)

friends, therapists and colleagues know that Adelaide will be hosting this event so they can put it in their calendars now!

Adelaide will also be hosting Dr Joanne Cafiero for a leg of the 2010 National Tour. We are hoping to make this more easily available to people from regional South Australia via webinar. For more information and updates please see the AGOSCI website (www.agosci.org.au) and stay tuned to the AGOSCI listserv.

If you have any ideas or questions about the Conference, National Tour, membership or other AGOSCI events please feel free to contact me on amy.furze@novita.org.au, or 8349 2014.



NORTHERN TERRITORY BRANCH REPORT

Marion Schultz

A continued effort to recruit new members to join AGOSCI has occurred over the past few months. The Northern Territory (NT) chapter hope that with the upcoming AGOSCI events in 2010 with possible web link ups for the tour and/or workshop(s) will help increase member numbers. The last Special Interest Group meeting is to take place in November. Some discussion has taken place around running a Key Word Signing interest group over the school holidays to help Speech Pathologists, school and disability support staff to 'refresh' their skills and encourage continued use of signing in various settings.

AGOSCI NT were pleased to see that a teacher from a Darwin school, Drew Serisier, had a submission published in the May In Focus issue for the Arts and Sports section; well done Drew! Gillian Fowler, Occupational Therapist, presented the first Mealtimes Matter session to a group of parents in Darwin in July. Mealtimes Matter is an evidence based program with a Family Partnership model for children with feeding difficulties. Gillian provided a further session to therapists; Speech Pathologists, Occupational Therapists and Dieticians, and as a result this program has been continued on a 6 weekly basis and has become a collaborative effort between agencies.

Dr. Jacqueline Roberts visited Darwin in August to provide a 2 day workshop, "Autism Spectrum Disorder: Understanding, Treating and Managing Autism" as the Speaker for the Speech Pathology Australia (SPA) National Tour. This workshop was well attended by school staff, Speech Pathologists and Occupational Therapists. A phone link up with Central Australia Speech Pathologists will take place in November to provide therapists with updated information on AGOSCI news and events. It is

hoped that along with encouraging new members, it will raise discussions and provide networks around working with people with complex communication needs.



WESTERN AUSTRALIAN BRANCH REPORT

Sally Hunter

Movement is afoot in WA for the setting up of an AAC camp. The last camp in WA was held in 2005 and since then funding and time issues have prevented it moving ahead. Variety WA has expressed an interest in supporting the camp and a multi agency meeting has been held to map out the process and the timeline. The biggest challenge is to locate a suitable venue. There have been no formal AGOSCI events held here recently however membership remains steady in WA and we are looking forward to the National Tour next year.

The list serv is buzzing with family and consumer input which is fantastic. I hope everyone is enjoying the fresh look of the website. Thanks for all the lovely photos and keep them coming. I am always happy for contributions and feed back.



TASMANIAN BRANCH REPORT

Diane Symons

Tim Thurlow, a Launceston man with complex communication needs, and I were interviewed on the ABC TV's Stateline program about the State Parliamentary review into the provision of equipment for people with disabilities. The interview was a very interesting process and I think the end result was really positive. For those who would like to know more, there is a transcript of the interview on program's website. <http://www.abc.net.au/stateline/tas/content/2006/s2609673.htm>

There finally seems to be some action on this report with meetings taking place with a project group from the Department of Health and Human Services. With a State election coming up early next year I hope that there will finally be some momentum to this report. If you are interested in reading the government's response to the report, there is a copy at the following website: <http://www.docstoc.com/docs/8192628/Government-Response-to-the-Joint-Standing-Committee-on-Community>. Following our television appearance, Tim and I also did a newspaper interview during speech pathology week with an article and photo in the Examiner newspaper in Launceston. But enough about my moments in the spotlight. It was also very exciting to see four Tasmanians at the Advanced Pragmatic Organisation Dynamic Display (PODD) workshop at CPEC in Melbourne. There is a lot of interest in PODD around the state and together we hope to be able to support and maintain that enthusiasm and provide better programs for Tasmanians with complex communication needs.



CONFERENCE REVIEW: 7TH DEAFBLIND INTERNATIONAL EUROPEAN CONFERENCE, 2009, SENIGALLIA, ITALY

Meredith Prain, Able Deafblind Services
meredith.prain@ableaustralia.org.au

I attended the DBI European Conference including the two-day pre conference workshop on communication from the 21st to 26th September 2009.

Deafblind International is an organisation that aims to share information and resources about deafblindness and improve understanding of deafblindness and services for people who are deafblind.

The pre conference workshop highlighted the work of the DBI Communication Networks and four booklets and DVDs they have produced which look at key elements of establishing social contact, meaning making, and cultural aspects of the language of a person who is deafblind. The booklets are available through Viataal - www.viataal.nl and are a really great resource – the DVDs in particular, highlight aspects of the theoretical framework discussed in the booklets and are very helpful for staff training and development.

The conference went for four days with two plenary sessions each morning and then a choice of three concurrent sessions each day from a total of ten to choose from at any given time. Topics included cochlear implants in children with no formal language, swallowing issues related to CHARGE syndrome, identity, employment, communication assessment, staff development, challenging behaviour, and siblings.

450 people attended the conference from around the world and it was really great to learn of all the excellent work that is going on in the field of deafblindness.

The big reminder and take home message for me was that from my experience, adults with deafblindness are often placed in generic disability services and their unique and special needs are often overlooked and not adequately addressed. There is a wealth of resources and good practice models available for this group and it is important that we, who are interested in improving the situation for people with complex communication needs, are vigilant in raising awareness of the special needs of this isolated and vulnerable group of people.

I am more than happy to be contacted if anyone is interested in obtaining a copy of the conference program, contact details of speakers, or just to discuss strategies and approaches for working with people with deafblindness. Information about the conference can be found at www.dbiconference2009.it

PLEASE NOTE: Deafblindness refers to people who have both vision and hearing impairments to the degree that one sense cannot adequately compensate for the loss of the other sense, and services for people with single sensory impairments do not adequately meet their needs.

Want to know what's happening in your state?

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www.agosci.org.au



AUGMENTATIVE & ALTERNATIVE COMMUNICATION IN HEALTH CARE SETTINGS: SUPPORTING PATIENTS FROM INTENSIVE CARE UNITS (ICU) INTO THE COMMUNITY:

MELANIE FRIED-OKEN, PH.D., CCC-SLP

Review by Karen Bloomberg, Communication Resource Centre
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Augmentative and Alternative Communication (AAC) has become an integral part of medical speech-language pathology, yet many clinicians are not familiar with AAC assessment and intervention principles. Services differ depending on whether patients present with communication needs in the ICU, inpatient hospital ward, outpatient rehabilitation clinic, or home and community settings. (Melanie Fried-Oken, 2009)

October saw a national tour by Dr. Melanie Fried-Oken. Dr Fried-Oken presented three 2-day seminars in Melbourne, Brisbane, and Sydney. She was auspiced by AGOSCI and hosted by the Communication Resource Centre in Victoria, and Speech Pathology Australia in Queensland and New South Wales. The aim of the tour was to highlight the use of AAC beyond the disability sector. Much work has focussed on using AAC with people who have developmental disabilities such as autism and cerebral palsy. AAC techniques are also useful for people with acquired and progressive disorders, however fewer speech pathologists have expertise in this area.

Dr. Fried Oken is a speech pathologist and an Associate Professor of Neurology, Biomedical Engineering and Otolaryngology, and Director of the Assistive Technology Program. Her expertise is in the area of assistive technology for persons with acquired disabilities who cannot use speech or writing for expression. Dr. Fried-Oken has a number of federal grants to research communication technology for persons with Alzheimer's disease, ALS, and other neurodegenerative diseases, and the normally aging population.

The seminars in Australia attracted primarily speech pathologists from the community health and hospital sector. Often these speech pathologists have a roles in the acute care setting, rehabilitation services, and palliative care. There was also a cross-section of therapists working in rural and metropolitan services, and from the states and territories that Dr. Fried-Oken was unable to visit (e.g. ACT and Western Australia).

Day one covered models of assessment and goal setting. Melanie addressed the needs of patients in Intensive Care Units (ICU) and in Acute Care settings. She also discussed how to support patients following surgery for head and neck cancer and voice disorders. In Victoria, the first day ended with a presentation of funding options available for both electronic (i.e. Aids and Equipment Program) and non-

electronic (i.e. Non-electronic Communication Aid Scheme (NECAS) communication aids.

Queensland and New South Wales also discussed the funding options unique to their respective states. Participants then had the opportunity to try a range of communication aids with support from the technology suppliers who were present during the seminars.

On day two AAC services in rehabilitation and community health settings were addressed. Melanie specifically discussed issues for patients with:

- ✓ motor impairment eg. Motor neurone disease, Parkinson's disease, Multiple sclerosis, and spinal cord injury, and
- ✓ language and cognitive impairments eg. aphasia, primary progressive aphasia and dementia.

She also covered the use of AAC in residential care, with consideration of services to nursing homes, for palliative care, and for people with developmental disabilities.

Melanie provided a wealth of printed material with many useful web addresses. She promoted the book, Beukelman, D., Garrett, K. L., & Yorkston, K. M. (Eds.). (2007). *Augmentative communication strategies for adults with acute or chronic medical conditions*. Baltimore: Paul H. Brookes, and used some of the practical handouts from the book within her presentations. Examples that were contained in the handout package included:

- AAC Screening in the ICU – a simple checklist assessment
 - Examples of items that may be incorporated into an ICU cart – based on research by Happ, M.B. & Garrett, K. *SPEACS: Study of Patient-Nurse Effectiveness with Assisted Communication*
 - Asking yes-no questions for reliable consistent responses
 - Eye transfer communication – how to construct and use an ETRAN Board
 - Wall chart system – for quick communication
- Melanie talked about voice banking pre-operatively, and how access to a digitized device can reduce the impact of communication difficulties post-operatively.



Photo – Melanie Fried-Oken and Chris Richards – Victorian winner of the book prize *Augmentative communication strategies for adults with acute or chronic medical conditions*.



AUGMENTATIVE & ALTERNATIVE COMMUNICATION IN HEALTH CARE SETTINGS (cont)

Principles learned from patients with Guillaume-Barre Syndrome and Locked-in Syndrome who received AAC say:

- Keep learning to a minimum
- All AAC is unnatural to a sick person
- Provide handouts about successful interventions for the family, caregivers, and patient
- With decreasing length of stay in hospital, provide information and referral services
- Know your equipment before you arrive
- Electronic options are last
- Staff training is essential
- Identify an AAC advocate to serve as an information carrier across sites
- Have separate strategies for basic and emergency needs
- Consider the patient's personality
- Alphabet board use is not as simple as it seems - develop a training program
- Don't forget vocabulary for finances, will, family concerns, unfinished business, and negative emotions

The second day of the seminar focussed primarily on patients with motor and cognitive impairments. Melanie addressed issues in outpatient rehabilitation, community inclusion, and residential care. She stated that 87% of adult conversation is for chatting or social communication and we need to find ways to support this. She discussed patient's clinical pathways for communication changes with Amyotrophic Lateral Sclerosis (ALS). A 5-stage approach was outlined: stage 1 = normal speech processes; stage 2 = detectable speech disturbances; stage 3 = reduction in speech intelligibility; stage 4 = used of AAC; and stage 5 = no functional speech. The handout package contained a communication needs profile, strategies of what to do when someone does not understand you, simple low tech devices to use with voice banking and use of encoding for alphabet boards. Participants were also directed towards the AAC-RERC website, where a range of resources and video clips are available.

Primary progressive aphasia was identified as a syndrome often followed by cognitive decline. It was described as a language disorder that does not easily fit into the classical types of aphasia. Melanie provided handouts that gave an overview of Primary progressive aphasia and what can be done to help with communication. She also shared strategies for developing vocabulary lists, including conversational control phrases and an aphasia needs assessment.

Melanie stressed the importance of utilising high and low tech strategies. Throughout her presentations, she used the technologies made available on the day. Victoria participants were lucky enough to have trade displays provide by the companies Zytec, Spectronics, and Technical Solutions. A special thank you to these companies for their support. The

other states also had displays provided by their local technology services. In NSW we greatly appreciated the assistance in provision of technology for the workshop by Technability, TASC, and CATS and for information about funding applications provided by Enable.

Testimonials from the Days

"Although the basic principles of AAC were not new. The forum provided me with many new ideas for practice and confirmed some of what I am already doing. I think the biggest gain was the massive amount of resources & website links that were provided which I will definitely feed back to my department." – Hospital based speech pathologist
"I am inspired to set up better AAC for my PPA and AD patients with PPA (Primary Progressive Aphasia) and Motor Neuron Disease"

"AAC already plays a role in my service but seminars such as these of high quality get the brain working and thinking about my current practice and how I can make it even better." – Hospital based speech pathologists

Useful Websites and You Tube clips

www.aactechconnect.com/aacinfo.cfm - Speech generating device feature matching analysis - The website matches the individual's physical, cognitive, sensory and social skills to a range of electronic communication aids including: ease of programming, symbol set used, size and portability, symbol display, output e.g. synthesised, digitized, vocabulary, access options, and any other unique features.

www.aac-lerc.com - The AAC-RERC (Rehabilitation Engineering Research Consortium) conducts a comprehensive program of research, development, training, and dissemination activities that addresses the National Institute on Disability and Rehabilitation Research priorities and seek to improve technologies for individuals who rely on AAC technologies. The mission of the AAC-RERC is to assist people who rely on AAC to achieve their goals by advancing and promoting AAC technologies and supporting the individuals who use, manufacture and recommend them. (See webcasts for Colin's Portnuffs video clip)

www.brain.northwestern.edu/PPA - Provides access to information about Primary progressive aphasia. There is an online newsletter, data base, and family support. The site is maintained by The Cognitive Neurology & Alzheimer's Disease Center at Northwestern University.

www.cini.org - Founded by speech pathologists, people with ALS and family members, Communication Independence for the Neurologically Impaired (CINI) is the only not-for-profit organization solely devoted to improving the quality of life of people with ALS/MND (Lou Gehrig's Disease), by disseminating infor-



AUGMENTATIVE & ALTERNATIVE COMMUNICATION IN HEALTH CARE SETTINGS (cont)

mation about the communication technology that can help them.

<http://video.aol.com/video-detail/supported-typing-for-people-with-als/1903252760> - YouTube video of a person with ALS using supported typing on a Lightwriter.

<http://www.youtube.com/watch?v=Y2UiPIDAej4&feature=related> - YouTube clip of partner assisted scanning
<http://video.google.com/videosearch?q=talking%20photo%20album&rls=com.microsoft:en-us&oe=UTF-8&startIndex=&startPage=1&um=1&ie=UTF-8&sa=N7hl=en&tab=ww#> - Talking photo album

http://www.youtube.com/watch?v=VKsIoZ9oa_Y&NR=1 - Use of a head mouse

<http://www.youtube.com/watch?v=Oev92bys2qI&feature=related> - Eye gaze with Tobii

<http://video.google.com/videosearch?q=proloquo2&rls=com>.

microsoft:en-us&oe=UTF-8&startIndex=&startPage=1&um=1&ie=UTF-8&sa+N&hl=en&tab=ww#q=proloquo&hl=en&emb=0 - Use of Proloquo

Useful Books and References Beukelman, D., Garrett, K. L., & Yorkston, K. M. (Eds.). (2007). *Augmentative communication strategies for adults with acute or chronic medical conditions*. Baltimore: Paul H. (See chapter Garrett, K.L., Happ, M.B., Costello, J. & Fried-Oken, M. (2007) AAC in intensive care units) National Joint Committee for the Communicative Needs of Persons with Severe Disabilities (1992). Guidelines for meeting the communication needs of persons with severe disabilities. ASHA, 34 (Supplement 7), 2-3. Yorkston, K., Strand, E. Miller, R. Hillel, A., & Smith, K. (1993). Speech deterioration in amyotrophic lateral sclerosis: Implications for the timing of intervention. *Journal of Medical Speech-Language Pathology*. 1, 35-46.

MEMBER TALK SALLY HUNTER

Member talk is a new initiative of AGOSCI In Focus. The purpose is to tell people about members of AGOSCI who come from a diverse backgrounds and have different interests. We could be contacting you next!

How long have you been a member of AGOSCI?
 I don't know really. I think I have been a member for about 6 years. I became involved working with Sharon Osborne, the speech pathologist who worked here at the ILC many moons ago who set up the first AGOSCI website.

How are you involved with people with complex communication needs?

I have been an OT for 20 years and have worked in settings providing services to people with developmental and acquired disabilities, and in that time I have met many people with complex communication needs. Significantly, in my past I met a man who was using an Apple II E with Bliss Apple software (probably about 1988). It was my job to help him learn to use a switch, but in reality he taught me about AAC. He was 40 and lived in a nursing home. On his first time using it well, he told me he wanted a holiday and he liked the receptionist a lot. I took him to the movies for the first time. This experience, for me, was very memorable and important. In the last 10 years I have worked at the Independent Living Centre working closely with some fantastic speech pathologists to support people to explore communication options.

Why do you like about being a member of AGOSCI?

I think it is one of the best facilitators of training in our sector! Through AGOSCI professional development I have learned so much. It is always of a high standard and practical. I also enjoy the list serve. It is the most useful one around (but I may be biased).

What do you think have been the best things in AAC in the past 10 years?

I think the best things have been the profile of AAC being raised dramatically and the developments in technology to enable people to seamlessly interact with their environment/information technology and communicate more effectively.

What do you think we need to learn more about in the next 10 years in AAC?

Speaking as a fairly lonely OT in this organisation, I believe we need to continue to market AAC to other health professionals and service providers (accommodation, employment and alternative to employment, respite and respite services), so it is seen as a priority and valued in the sector.



A POSITIVE SOLUTION FOR LIVING LIFE AFTER SURVIVING STROKE

*Barbara Solarsh (PhD), Regional Communication Service, Bendigo Health BSolarsh@bendigohealth.org.au
Glenda Norton and John Norton, Central Victorian Stroke Support Group*

For stroke survivors and their families, medical staff and therapists provide the first buffer between the immediate sequelae of the stroke and the long term life that must then be lived. They work hard to help the survivor gain as many skills as possible for the long journey ahead. But this buffer progressively decreases with time, until it disappears altogether. Then there is just the life to be lived, with all the challenges of coping with change, sustaining hope, keeping connected to friends, and continuing to be part of the society around.

The involvement of the Central Victorian Stroke Support Group (CVSSG) enables stroke survivors and their families in central Victoria to face all this within a circle of support, empathy, compassion, humour, and hope. Through their own lived experiences, members of the CVSSG can play a critical role in helping survivors onto a path which sees opportunities rather than only the barriers and limitations.

The stroke support group began its life in 1997 when three stroke survivors living in Bendigo got together at a local coffee shop to socialise and have a chat about how they were coping with life following their strokes. They found that they were all struggling to manage the many changes that had occurred. They decided to meet regularly to discuss the challenges that they were facing because neither health professionals nor their partners had the answers to these post stroke "life" challenges. They found that by talking about issues, sharing feelings, and discussing possible solutions, they were greatly encouraged and ceased to feel so isolated. Most important of all, they found that sharing their experiences and solutions helped to lift their morale.

Gradually more survivors joined the group, as did their partners. This was the start of The Central Victorian Stroke Support Group (CVSSG). One of the distinguishing characteristics from the outset was that all these founding members had a strong belief that to be successful in the recovery journey each needed to be responsible for their own recovery and to be proactive in doing something about it.

As the group matured, the desire to help each other expanded to a strong desire to help new survivors coming through the hospital system. This required the development of a collaborative relationship with the local hospital, Bendigo Health. It was becoming evident to the group that peer support had a vital

role to play in assisting survivors and families after stroke. In 1998, members of CVSSG were invited to participate in a medical ward in-service day where they provided some feedback from a survivor perspective. The members shared the issues that they thought nursing staff needed to be more aware of when nursing and communicating with stroke patients.

In 2005, the CVSSG Visits Program began with 2 of the members carrying out regular weekly visits to patients in the stroke rehabilitation ward at Bendigo Health. The program had three main objectives that were specifically directed at meeting the ongoing needs of survivors and carers, particularly on their return to the community when they are confronted with the challenges of post stroke life.

1. **Advice on existence of the support group, its role, and activities.** They would explain the benefits of sharing and talking to other survivors and being able to acknowledge that stroke survivors feel isolated after stroke. They could also convey, at the monthly lunches and other social activities of the group, that life after stroke can continue to be enjoyable and filled with laughter.
2. **Role modelling, moral support, and encouragement.** By visiting a new stroke survivor, they could provide tangible evidence that there is life after stroke. Further, that recovery does take place, albeit over a long time period and with a lot of hard work, self belief, a positive approach, and with support and assistance from a range of people.
3. **Provision of information on stroke and stroke recovery for survivors and their families.** A key role and focus of the Visits Program was to provide relevant, clear, and simple information about stroke and its various impacts in "layman" terms. They provided information about the Stroke Recovery Kit that was put out by the Stroke Recovery Association of NSW, and provided the CVSSG brochure.

Members of the CVSSG Visits Group began to realise that not only were they providing a service to others, but they themselves were experiencing some benefits. Their comments included:

- You gain enormous satisfaction from the knowledge that you are making a difference in someone else's life, no matter how small.
- You are sharing your experiences with others, both survivors and carers
- You can feel you are part of a team involved in a survivor's recovery
- You are helping the staff at the hospital, just like they helped you when you had your stroke.

The CVSSG Visits Group has evolved, withstanding the many practical difficulties of becoming an integrated part of a large



A Positive Solution for Living Life after Surviving Stroke (cont)

busy organization. Through their persistence and passion for what they were doing, they are now becoming part of the Bendigo Health Volunteer Program, and are working closely with staff on the Stroke Unit to make their Visits Program as successful as possible. While never losing sight of the human purpose of their group, they have formalised the Visits Program through systems of record keeping, strategies for visits, and systems for being informed about new patients. The group now consists of 12 people, 7 survivors and 5 partners who are rostered to do the weekly visits.

With the development of the group they realised that although none of them was left with an ongoing significant communication difficulty, there were members of their group who were. They acknowledged that they needed information and skills, not only to interact with these members but also for interacting with survivors in the hospital who had some degree of aphasia.



A new collaboration was developed with the Bendigo Health Regional Communication Service. Four workshop sessions were held to answer questions such as:

- How do you communicate with someone who doesn't appear to understand you or be responsive to you?
- How do you offer support and share your story when you are not sure if you are understood?
- How can you help a person to ask the questions he/she cannot articulate?
- What can you do to help the survivor and partner to benefit maximally from your visit when they are shocked and bewildered by an unknown future looming before them?

Through the workshops, the group acquired an understanding of what aphasia is, the many ways to communicate, and need to use all ways of communication. They were made familiar with Stroke CommuniKit, introduced by speech pathologists at Bendigo Health. The kit is a set of resources that explain, in an accessible format, stroke, the pathway through the hospital, and the role of all the hospital staff. It also provides some basic communication aids and writing materials. This kit sits above each bed in the stroke unit. The group were informed about Supported Conversations (The Aphasia Centre North York Toronto) and encouraged to use the strategies. Finally each

person, survivor and partner, undertook to write a personal account of their stroke. These are being developed into a personal resource for each them. This will give each of them a visual means of communication, using photos where possible, to share their experiences, even with people unable to communicate at that time.

This group of dynamic people are now creating a resource guide of local services for stroke survivors in the region. They are developing a Hospital Visits Guide for other people who may want to start such an initiative. They are planning to create a publication of their life experiences as stroke survivors and partners, to share with and inspire others.

Between 2006 and 2009, 248 stroke survivors were offered visits by the group. More than 140 survivors were visited, with 53% being residents of Bendigo. Other people were from Maryborough, Echuca, Swan Hill, Heathcote, and Charlton

The Central Victorian Stroke Support Group and Visits Program

has been conceptualized, developed, and implemented primarily through the initiative of this group of committed people. That is its strength. It has found a way to offer a positive solution to survivors and partners who survived stroke and must now live life.

Note: The information for this article has been drawn from CVSSG policy documents and briefing documents compiled by John and Glenda Norton.

For further information about the Central Victorian Stroke Support Group please contact:
John and Glenda Norton on jandgnorton@bigpond.com

References

The Aphasia Centre, North York, Toronto (distributors) Supported Conversation for Aphasic Adults, "I know you know" Stroke Recovery Association of NSW http://www.strokensw.org.au/after_stroke

IMAGE The Central Victorian Stroke Support Group at a workshop with Barbara Solarsh (Regional Communication Service, Bendigo Health)



conference



**AGOSCI 10th
Biennial National Conference
Adelaide Convention Centre
Adelaide
12 - 14 May 2011**

The Conference

The AGOSCI Biennial Conference will be held at the magnificent *Adelaide Convention Centre* in 2011.

The program will include keynote addresses and presentations from Australian and international speakers, preconference workshops, and a stimulating social program, including a welcoming cocktail party, *celebration of AGOSCI's 30th birthday* and a formal dinner.

The conference theme – *Taking it to the Streets* - is designed to encourage thought, innovation and action that will increase understanding and awareness both within and outside of the disability sector.

This conference will be of interest to individuals experiencing complex communication needs (CCN), family and community members, teachers, speech pathologists, occupational therapists and other professionals.

What is AGOSCI?

AGOSCI is a group representing people with CCN as well as those who live, know or work with people with CCN.

AGOSCI aims to lobby for the rights of people with CCN, increase public awareness of CCN, and to provide relevant educational and professional development events across Australia.



For further information or to express interest in attending please contact:

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E: agosci2011@aomevents.com | W: www.alloccasionsgroup.com/agosci2011



A RESPONSE TO TRICKY ISSUES IN DYSPHAGIA SERVICES FOR ADULTS WITH DISABILITY: DISABILITY DYSPHAGIA NETWORK

Rosie Miller – Speech Pathologist
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The Disability Dysphagia Network is an informal network of speech pathologists and other professionals interested in addressing the gaps in dysphagia services for adults with disability and dysphagia in Victoria.

The Disability Dysphagia Network came about after discussions between Bronwen Jones, Rosie Miller, and Cath Wilmott, about how we provide dysphagia services for people with disability in Victoria. Training for disability workers, access to services, and quality processes in dysphagia service provision were identified as particular concerns.

An initial forum was organised in April 2008 to bring together speech pathologists and others working in the area to discuss issues. The discussion focused on identifying current strengths and weaknesses and formulating an action plan. Not surprisingly, many problems that were being experienced were common across the sector, but some issues were specific to particular service providers.

A Number of Structural Issues Were Identified

The need for dysphagia policies and practice guidelines, benchmarks, and improved quality improvement processes at an organisational level, were common themes. The importance of speech pathology leadership and representation (e.g. senior clinicians and practice advisors) within organisations was also noted.

Training for Support Workers was Identified as a Key Issue

Apart from Scope, most disability service providers in Victoria do not offer mandatory mealtime assistance training for permanent and casual staff. This creates difficulties in developing skills and building the capacity of direct support staff in the workplace. Without an understanding of dysphagia and its potential health impacts and an ability to recognise its symptoms and know when to refer to speech pathology, there is a risk that people's needs may be left unmet and their health may be compromised.

Some Gaps in Services Were Also Identified

Annual nutrition and swallowing risk screening has been implemented in Department of Human Services disability accommodation services in Victoria but not in non-government agencies.

There has been a reduction in the number of outpatient video-fluoroscopy services in some areas of Melbourne with some clients having to travel long distances to access these services.

Clinicians were also finding it difficult to achieve a multi disciplinary approach to dysphagia assessment and intervention

with limited access to specialists such as dieticians, occupational therapists, and physiotherapists.

Some of the everyday challenges faced by speech pathologists in their practice include: high turn-over of disability support staff, limited awareness of the role of the speech pathologist in dysphagia, poor compliance with mealtime guidelines, poor awareness of the symptoms and health implications of dysphagia, and the challenges of supporting people with dysphagia across diverse environments (e.g. home, day service and community).

So What Do We Do About These Challenges?

The Disability Dysphagia Network has identified benchmarking, mealtime assistance training, and health promotion as initial priorities for action.

A project proposal to develop benchmarks of best practice for dysphagia services in the disability sector is currently being developed. Consultation with people with dysphagia about what service components are important to them is a key feature of the proposal.

The network stays connected through a My Connected Community (mc2) online forum. Along with occasional meetings, this has enabled the group to keep the conversation about quality in dysphagia service provision going, and it has also been a great way to share information and resources.

If you would like further information about the network, please contact the convenor Rosie Miller on 0438 560 954 or rmiller@scopevic.org.au

Do you have an AAC user's story for the AGOSCI website?

**Contact Sally Hunter:
sally@ilc.com.au**

Positive Solutions to Tricky Issues in Dysphagia Management.

Janet Wilson – Speech Pathologist
janet.wilson@yooralta.com.au

In an ideal world, every tricky issue would have a positive solution. The application of the solution would solve the problem forevermore and we could all live happily ever after. Speech pathologists working in the field of adult disability have long ago lost their illusions. Instead they have had to be creative. They have had to develop strategies that support those with disabilities and their care workers to achieve best practice and health outcomes. Along the way there are many obstacles, limited resources, and moments of self doubt. The parallels with fairy tales continue, but this is a serious issue so here are some of the real life issues.

In working alongside people with disabilities, it soon becomes clear how many restrictions are just taken for granted, and if the person requests some variation, how tricky it can get. Dignity of risk versus best practice was demonstrated in a recent request for assessment of the eating and drinking needs of a woman with a disability. The woman in question acquired permanent profound physical disabilities at the age of 13, but is not cognitively impaired. Now in her 30's and living in shared supported accommodation, she manages her dysphagia by having a minced and mashed diet with thickened liquids. As if this isn't enough of a restriction, when last hospitalised the speech pathologist recommended crushing medications, which can disperse the awful taste. This was extremely unpleasant for the woman and she requested staff to give them to her whole. Staff refused: they had a duty of care to follow discharge directives. She asked for a reassessment and although she did not want a videofluoroscopy, she negotiated to sign documentation that she was aware of the risks. This took enormous courage on her part and intensive lobbying for what she wanted. Three months on, she is happier and more relaxed at mealtimes with no adverse outcomes.

How do we demonstrate that the choices people are making are informed? This was a tricky situation facing another speech pathologist in this service. She created a document written in easy English with picture symbols to represent the choices and the consequences around dysphagia issues. This empowered the person to better understand the issues and gave them responsibility for making choices. The outcomes were spectacularly successful, as there had previously been furtive eating of "forbidden" foods, now the person felt they were in control.

Mealtime placemats have also been found to be a simple solution to tricky situations. Mealtime placemats are documents in the form of table placements that are co-developed with the clients to include what they like and dislike and how they want their mealtime assistance and medication administration to be done. The physical presence of these mats on the table, the sense of pride and ownership by the clients, and the immediate access to important information, result in better health and social well-being outcomes. Again, the person with swallowing

problems has more control over their meals because they could immediately communicate their needs and things that they did not want. An example of this was the young man with cerebral palsy who had such severe swallowing problem that he gets his primary nutrition via a gastrostomy tube. Despite this, well-meaning carers felt he shouldn't miss out on treats like chips, chocolates, and lollies. Somehow that didn't count as food!

The last straw was a choking episode with a Malteser (hard, round chocolate covered ball that should never be swallowed whole). Apparently prior to the terrible incident the mealtime profile wasn't read and verbal directives were forgotten. But more recently a mealtime placement has been, permanently attached to his wheelchair tray and his mother says it has been a great success and has inspired her to make similar posters for all his care needs in the bedroom and the bathroom.

Sometimes it seems that the root cause of all these tricky problems is lack of awareness. One solution is getting the message out to house supervisors and area managers, as they are the gateway to referral. If they don't know there is a problem that needs speech pathology referral, the person misses out. Once these key people are aware of what issues the person with communication and swallowing difficulties face, they often come on board with full gusto.

This can in turn lead to another tricky situation; that of wanting to thicken and vitamise everything! Before long, the person who is supposed to be on nectar-thick liquids (a consistency similar to fruit nectar) is having almost solid juice from a spoon and is also facing hydration issues. Hands-on mixing sessions and try-outs by the staff usually work much more effectively than all the posters, photos, and careful descriptions of the measures and consistency required.

Speech pathologists are stretched by huge caseloads and waitlists. This is compounded by the isolation of being in sole positions. Expertise is often developed on the job through working with people who have already developed solutions to their own specific issues. Networking in the industry has been a lifeline. A Disability Dysphagia Network and an on-line network was set up last year that has enabled a wealth of information sharing to help overcome many of the issues addressed above. Of all the solutions this has been the most rewarding one so far.

Supporting the client and the worker to achieve the best outcomes is not about a speech pathologist coming in as a higher authority. If that is how it is perceived, it not only disempowers the person with a disability and their assistant, it leads to the notion that swallowing problems and their solutions are set and immutable. It can even put the speech pathologist in an adversarial role. This prevents day-by-day, situational problem-solving and the sense of satisfaction that accompanies cooperative learning.



ORAL HYGIENE: BRUSHING UP ON THE FACTS

Breanne Hetherington - Speech Pathologist

Breanne has a background in Health and Disability

Good oral hygiene is important for anyone for a number of reasons, which include improved overall health as well as self esteem and quality of life. Poor oral hygiene has been linked to dental caries, oral thrush, ulceration, dry lips, dry mouth (xerostomia), and bad breath. When some of these pathologies are present, eating and drinking can become unpleasant, which can lead to unintentional weight loss and dehydration. Furthermore, bad breath can impact on a person's self esteem. Another significant health concern, especially if someone experiences swallowing difficulties (dysphagia), is aspiration pneumonia. When poor oral hygiene is present, there is an elevated presence of bacteria in the mouth and saliva. If a person with dysphagia aspirates this saliva, an aspiration pneumonia may develop depending on (a) the type, volume and amount of bacteria in their saliva, and (b) their response to it via protective actions and immune responses (Yoon & Steele, 2007). Therefore, given the consequences of poor oral hygiene, it is important to consider this when supporting people with disabilities.

Saliva

Part of having good oral hygiene is having adequate saliva in the mouth. The movement of saliva through the mouth is important to prevent dental caries from developing. Scott and Johnson (2004) report that the other important functions of saliva are:

- moistening lips and tongue during speech
- lubricating the food in our mouth when we are chewing and making it easier to swallow
- regulating the acidity in the oesophagus
- destroying microorganisms and clearing toxic substances
- helping with taste
- starting carbohydrate digestion

We produce approximately 600mls of saliva per day (Scott & Johnson, 2004). However, there are a number of factors such as age, gender, and medication that can impact on production rates. It is important to remember that when people have difficulty controlling their saliva, it is rarely a result of too much saliva production, but rather other factors such as poor lip closure and reduced frequency of saliva swallows.

Risk factors

There are a number of risk factors that can contribute to poor oral hygiene, other than irregular or ineffective oral care. These risk factors may include:

- dry mouth due to dehydration, mouth breathing, regular oral suctioning, or the side effects of medication
- antibiotics which can change the natural flora in the mouth and allow other bacteria such as oral thrush to grow
- certain autoimmune diseases (e.g., scleroderma which have a direct effect on the salivary glands)
- reflux, which can lead to the erosion of teeth when the acidic contents enter the mouth
- diabetes, which can contribute to reduced blood flow to the tissues of the mouth
- tooth grinding
- dependence on others for oral hygiene
- aging, which leads to a progressive loss of soft tissue that may result in root exposure and loose teeth.

Some adults with intellectual disabilities may have a number of these risk factors present and may also have a history of poor oral care. Their current oral care routine may also be compromised for reasons such as physical and sensory issues, and a reliance on other people for dental care. Of the risk factors, medications are one key important consideration. There are a large number of medications that can cause a dry mouth as a side effect. Some of the categories of drugs that can cause a dry mouth include anticonvulsants, antidepressants, antihistamines, analgesics, and anticholinergics. A person with complex health needs may be on any number of these medications at any one time, so when considering someone's oral health, it is always beneficial to review the medication that they are on.

Oral Health Screening Assessments

Conducting an oral assessment is a useful way to gain baseline information about someone's oral health, especially if they experience complex communication needs (CCN) and are unable to verbally report symptoms. Screening tools can be used to monitor oral health to allow for early identification of issues and determine the effectiveness of any intervention that is implemented (Chalmers & Pearson, 2005). Most oral

ORAL HYGIENE: BRUSHING UP ON THE FACTS (cont)

health tools assess the various structures in the mouth and have prompts to assist the assessor to determine if they are healthy or unhealthy. These tools can easily be used by carers and support workers, but it is important to remember that they do not replace regular visits to the dentist.

Toothbrushing

Toothbrushing is one of the most commonly recommended methods to mechanically remove plaque from teeth (Asadoorian, 2008). There is conflicting evidence regarding the most effective type of toothbrush to use. A Cochran review in 2005 found that only powered toothbrushes with rotation oscillation were more effective than manual toothbrushes in removing plaque and that using an electric toothbrush is no more damaging to the gums than a manual one. As well as the tool, other areas that should be considered when providing oral care include the toothbrushing technique, the person's swallowing and its impact on safety during oral care, and any sensory and/or motor issues that may impact on toothbrushing. A team approach including the dentist, speech pathologist, occupational therapist, physiotherapist, and psychologist may be useful to address any issues when toothbrushing. There may be times when toothbrushing is not recommended because the person may have a sore, irritated mouth or reduced levels of alertness. During these times, foam swabs may be more appropriate, but it is important to remember that they aren't as effective at removing plaque as a toothbrush (Pearson & Hutton, 2002). The foam swabs can be purchased plain or treated with various solutions and can be fitted to suction machines. Lemon glycerine swabs were once commonly recommended, but the foam swabs are now preferred over these. This is because the cotton swabs offer no mechanical debridement of debris and leave fibres in the mouth. Furthermore, long term use of the lemon can be acidic to teeth, and, as glycerine is an alcohol derivative, it can be drying and irritating to the oral mucosa (Scott & Johnson, 2004).

Mouthwashes

When selecting a mouthwash, it is important to consider the alcohol content, as many solutions available at the supermarket have a high alcohol content that can be drying and irritating. Sodium bicarbonate mouthwash solutions are a cheap, readily available and safe option that can be used with most people

including those with head and neck cancer. The solution can be purchased from chemists or can be made from ingredients readily available in most kitchens. When making your own, it is important not to make the solution too concentrated as this can lead to irritation of the oral mucosa. Dodd, Miaskowski, Greenspan, Shih, and Facione (2003) state that the sodium bicarbonate combination is useful because:

- saline promotes healing
- sodium bicarbonate dissolves mucous and loosens debris
- when combined, they raise the pH in the oral cavity that in turn can prevent bacteria from growing.

Chlorhexidine mouthwashes are also commonly recommended due to their antibacterial properties. These mouthwashes have been associated with some side effects such as an unpleasant taste and tooth and tongue discolouration. These mouthwashes can be irritating to the oral mucosa if used long term, so this should be monitored. It is important to note that fluoride and chlorhexidine can not be used at the same time, therefore, it is recommended that the mouthwash is not used directly after brushing (Scott and Johnson, 2004).

Methods to Increase Saliva Production or Combat A Dry Mouth or Breakdown Thick Saliva

One of the easiest methods to combat a dry mouth is to drink water regularly to keep hydrated and moisten the mouth. For people with swallowing difficulties who are unable to drink thin fluids, a pump pack of water to deliver a fine mist into the mouth could be another alternative, but it is best to consult with a speech pathologist before using this. There are also a number of commercially available products from pharmacies to combat a dry mouth such as saliva gels, toothpastes, and mouthwashes.

As previously mentioned, having adequate saliva is important for good oral hygiene. Chewing will mechanically stimulate saliva production and this can be achieved through chewing sugarless gum or sucking sugarless lozenges. Selecting lozenges with certain flavours, for example, sour flavour, may assist with increasing saliva production in the short term. If considering this option, it is important to determine if the person can safely manage these and to acknowledge that some lozenges can be high in sugar, which may contribute to dental caries.



ORAL HYGIENE: BRUSHING UP ON THE FACTS (cont)

There are other natural alternatives to combat a dry mouth including a solution of grapeseed oil with peppermint essence (which is used to make the solution more palatable) or sipping some flavoured drinks (e.g., those with a sour flavour, as it can increase the amount of saliva produced). There is little evidence to support if these are effective strategies or not, but it may be worth trialling as some people do report success when using them.

At times, people may develop very thick, tenacious, sticky saliva that can be difficult to manage. Foam swabs can be useful to remove this saliva. Again, there are natural alternatives to combat this but there is little evidence to support their use. Scott and Johnson (2004) state that some of these include taking:

- horseradish and garlic tablets (orally or crushed onto food)
- papian enzyme (an extract from papaya) which can be purchased from health food stores
- some fruit juices (e.g., dark grape juice)

With the juices, these could be drunk or frozen into ice cubes to suck if the person can safely manage these. Again, a pump pack of these juices could be an alternative if someone is unable to safely tolerate thin fluids but this should be discussed with a speech pathologist.

Summary

In summary, it is important to consider oral health when working with adults with intellectual and physical disabilities as it can have significant impact on health and self esteem. Effective toothbrushing and ensuring that there is adequate saliva are important components of oral care. When trying to increase saliva or manage thick tenacious saliva, there is not always a lot of strong evidence to support some of the strategies. Despite this, it is still beneficial to trial as many strategies as are appropriate for the person to then individualise their oral care based on their needs and preferences.

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ISSUE OF INFORMED CHOICE

Anonymous

The following letter was on the PMLD Network listserve in the UK. Since it was posted, I have shared it with many people, and with the permission of the author, I am now sharing it with AGOSCI members. On the listserve there had been discussion about informing people with profound intellectual disability about various health issues, for example self examination of testicles. Some people have suggested resources written in Easy English. This powerful response was given anomalously by a parent; they encapsulate the complexity of the issues of being informed and responding if someone can not be informed. The messages begins with a response relating to the benefit of Easy English resources. Please note that this is an listserve in the UK, hence the term learning disability is used instead of intellectual disability and the term PMLD stands for profound and multiple learning disability.

From: A Parent

And that's great for the majority of people, that's excellent practice for the vast majority of adults (and children) with learning disabilities/difficulties who may well be able to make an informed choice once the choice is presented to them in a simplified manner and with the support of those who know them.

I'm getting a little frustrated though when this is applied to adults and children who are functioning at what for lack of a better term I will call the lower end of the PMLD spectrum. My middle child can indicate yes and no, and when she's not having seizures she can make choices about her life. That's choices such as does she want to wear this nice soft smooth velour top or would she rather the snuggly woolly one or perhaps the crisp cotton shirt. She tends to be responsive for maybe 10-15 minutes at a time, at unpredictable moments of the day. And she chooses to spend that time choosing to do things she enjoys - choosing clothes, listening to music, going outside to feel the wind and rain on her face. Perhaps measured by other people's live it's a terribly confined and cramped existence, but actually she seems to enjoy it and those around her enjoy making it meaningful at her level.

It is meaningless to talk about capacity to make decisions over complex medical treatment. She knows she has seizures, she knows she has a cocktail of drugs to try to control the seizures. She's unresponsive most of the time when I'm giving her her meds via her gastrostomy tube; I'm certainly not going to wait for one of her moments of clarity before asking permission to give them.

We talk about her various doctors. But her understanding tends to be limited to knowing which Dr we are about to see. And which bit of her body or brain they might be looking at. . But she does not have any understanding at the level of "we could try this medication but it might make you sleepy or we could increase the pills you are already on but you might get more twitchy, what do you think?" because that's way above her level of thinking. And as far as understanding enough to make a decision about surgery - she lives in the now and the immediate future. Now, and the next few hours. She has no understanding, no capacity to understand, that a long and potentially fatal operation may help keep her breathing a few years down the line. Once the surgery is happening it's possible to break it down - "You will go to sleep. When you wake up you will be sore. I will be there. You will be sore for a bit but then your hips (touching hips) will be stronger". On a good day she'll maybe understand half of that - I hope she understands the "I will be there" bit because that's what's most important to her.

And I'm aware that amongst her peers (and by peers in this instance I mean the group of children within her school who have also been categorised as having PMLD) she is one of the more cognitively able children. When you have a teenagers who is able, after considerable stimulation, to smile when music is played, cry when they are moved, bite their hand when they drop a toy and go to sleep whenever they enter the light room, how do you even begin to have a meaningful decision about, for example, self examination of the testicles or the benefits of spinal rodding? Under these circumstances surely it makes sense for a loving familiar caregiver to be the one appointed to make those decisions on the individual's behalf? It isn't that the person themselves is an individual without any kind of meaning; I know that we can bring meaning and richness into their lives - we aim to broaden the musical experience, find other things which make the young person smile, try to find ways of warning them before they are moved (as well as using our knowledge of that person and wondering whether perhaps there is pain - getting another medical opinion based on our observations of the individual in question. But it's insulting to that person to suggest that they are able to take responsibility for their medical treatment. That person becomes an adult, and the new carers have a policy which insists the individual is told before they are given their medication, medication which has for years been hidden in a yoghurt as it will be then taken without any problems. So the individual spits the pills because they don't like lumps - or spits the liquid because it doesn't taste right without the yoghurt - and yet that individual has no understanding that these pills are necessary to prevent seizures, control heartrate,



ISSUE OF INFORMED CHOICE (cont)

stop enormous bowel blockages, whatever else it might happen to be.

We have to take those decisions on behalf of others; I believe it's an abuse of the individual NOT to take those decisions for them if they cannot make them for themselves. Which of us would consent to painful surgery for ourselves without an understanding of the necessity? To take each 'specific question' and to have to sit through a multi-professionals meeting or pursue a decision through the courts each and every time is to place an intolerable stress on the person most qualified to make that decision on behalf of the individual in question - the parent or main carer. It delays essential treatment - which of us would wait until a meeting had been scheduled before changing anticonvulsant medication for example? And yet, I've been in a position (where I have not had the right to consent) when that has had to happen. It deskills the parent and leaves the individual vulnerable to those in the medical profession who do not appreciate a quality of life which is undeniably different but no less important for all that.

Of course there need to be checks and balances, and of course there needs to be something in place for those individuals who do not have anyone who is able to become their decision maker. But for the majority of our children, the only thing which changes in them on their 16th or 18th birthday is the number of candles on the cake (which someone else will blow out for them) and the numbers written on their cards (which the cannier friends and relatives will have made out of pipecleaners or wikki stix or something else feelable, and tried to spare parents' feelings by not finding the "key to the door" independence type cards. And yet what happens is "congratulations, parent, you've kept your child alive against medical odds for the past 18 years. We'll take over now because you probably don't have his best interests at heart".

TALK TO THE HAND

*Toni Green jtebgreen@bigpond.com
Mother of 14 year old Emma*

It's a normal Saturday morning and a group of teenagers are hanging out in a coffee shop, laughing and joking amongst themselves. An older lady walks up to one of the teenagers and says in a sing-song voice "aren't you a lovely girl, you have such beautiful blue eyes, are you having a nice cup of coffee with your friends today?" The teenagers all look at each other embarrassed and the teen addressed by the older lady looks at her friends as if to say "do you guys know her? I don't." Horrified, the teenagers gather up their belongings and prepare to leave the coffee shop, wondering to themselves why they are always getting picked on by little old ladies who ask them inane and inappropriate questions, and why the heck they always get addressed in a sing-song voice. Does this scenario sound familiar to you? I find this happening with alarming frequency to my teenage daughter - people address her as if she was 2 years old, in a sing-song voice or with down-right baby talk, often with the assumption that she is 'not all there' to coin an outdated, inappropriate and politically incorrect phrase. I have found myself wondering whether there is a way to educate the community that they don't address teens they don't know and you never, ever talk to a teen with

the assumption that their IQ is diddly-squat just because they are in a wheelchair or because they are non-verbal. We have trained both our children to be polite to be people, so my daughter's response is usually to give the person a dazzling smile and then return to whatever she is doing. I could get her to be aggressive and say (using her AAC) "back off you silly twit", but I don't think that will achieve anything other than to get the little old lady off side and have her assume that my daughter is ill mannered. We have recently trialed a sticker on our daughter's tray. It was designed by Sue Owen and it says "Talk to the hand, because if you talk to me like a little kid, I won't be listening." This was met with a fantastic response from family, friends and by Emma's school friends and staff. I think that more of these out in the community would be a start for changing the way that people are engaged with. I am sure that one of the clever communication specialists out there can come up with a pithy slogan to get the message across, perhaps similar to the popular Not being able to talk doesn't mean you have nothing to say. We have some fantastic adult role models here in Australia and I have to acknowledge their work on behalf of the younger generation of AAC users. Thankfully, things are changing and our society is no longer as ignorant as it once was, but I think that while teenagers continue to be addressed as 2 year olds, we still have a long way to go.

WRITING ON THE WALL – USING GRAFFITI TO SUPPORT COMMUNICATION INTERACTIONS

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All of us use visual cues to help with our communication. If my diary goes missing I am in big trouble. I enjoy looking at people's holiday photos; it really helps me to appreciate the stories about the holiday. In a big shopping centre I go to the map and look for the post office symbol when I need to post a letter.

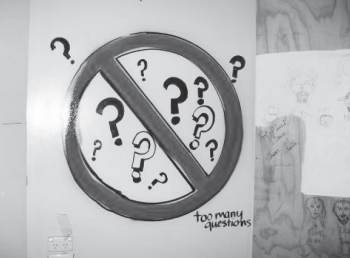




For people with complex communication needs visual cues can provide much needed support for successful communication interaction. Photos and symbols are often used and really do help make things easier for both communication partners. Using a visual cue leads to greater communication success, reduces challenging behaviours and stress, leading to a better quality of life for the user. Typically aided visual cues are displayed in the form of books, boards, or communication devices.

Jerry* is a young man with complex communication needs who has a range of communication strategies: (i) he can use the small QWERTY display for short periods when facilitated; (ii) he can use some gesture such as thumbs up for "Yes" or flapping his hand for "Go away"; (iii) he can point to photos and to words sometimes; and (iv) he can use loud vocalization to get attention. His communication partners do a lot of the work in the communication interactions; asking questions, interpreting body movements and providing facilitation for pointing.

Despite being literate and able to spell when facilitated, his disability is so profound that he can become unable to cope with having people near him or even to listen to speech. In this state he cannot tolerate facilitation and in his distress can become violent. Anything not bolted down is destroyed making it difficult for his support staff to provide visual cues for communication.

At a team meeting it was decided to try painting key messages directly onto the walls of his house. Jerry is an adult so the symbols needed to be adult not childlike. Also Jerry cannot easily tolerate people in his home and is only ever out of the house for short periods so the artists needed to be able to work quickly and finish before Jerry returned from his outing.

An email sent was sent round Lifeline soliciting contacts with graffiti artists who could donate a couple of hours of their time on a Saturday, which is when Jerry is out of the house for 2 hours. Several generous offers were received and in the end two people put their hands up to meet at the house on Saturday ready to do the job. The following key messages were targeted:

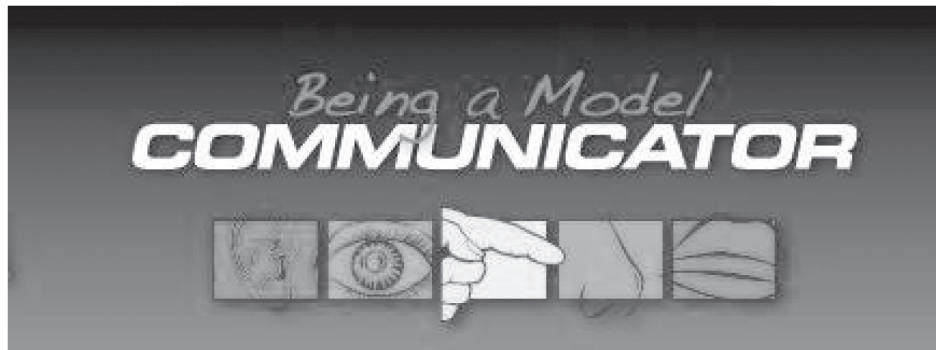
	<p>"Too many questions" Typically Jerry gets bombarded with Yes/No questions, particularly from new staff, and since too many questions puts him into overload he needs a way of indicating when he wants a break from questions.</p>
	<p>"I want to go in there" There is a dark room in the house that can be used as a retreat from sensory overload. It is locked but Jerry often asks to go in.</p> <p>"Leave me alone" When locked out of the dark room Jerry likes to sit in front of the door and is happy to be there for long periods of time.</p>
	<p>"I can't stand the noise" Sometimes the next door tenant becomes very noisy which is distressing for Jerry. This message is for staff to acknowledge his distress and commiserate.</p>
	<p>"This is hurting me" Jerry finds it difficult to communicate about pain or ill health. This picture allows staff to model a message to use when in pain.</p>
	<p>"Stop" A multipurpose message in the day room which allows both staff and Jerry to quickly signal the need to halt an activity.</p>

Staff have been trained to model using the messages whilst supporting Jerry. The hope is that eventually Jerry will be able to use them to avert communication breakdown. No formal feedback from Jerry has yet been received but during the second week staff reported that Jerry spent a lot of time in front of the "This is hurting" message and subsequently had a bad seizure.

The graffiti messages have now been up for 2 weeks and will be evaluated and expanded if found to solve some of the communication breakdowns for Jerry and his staff. *Jerry is not the real name of this Lifeline Disability Services client.



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REFLECTIONS OF BEST PRACTICE FOR TRIALING SPEECH GENERATING DEVICES

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On the 8th September 2009, Natalee and Debbie were invited by Queensland Health's Medical Aids Subsidy Scheme (MASS) to present on their personal applications and use of the MASS trial proformas for prescription of Speech Generating Devices (SGDs). Case studies for the early intervention and school aged population were presented, along with an overview of current trends relating to device prescription and abandonment. The importance of collaboration between all team members, goal driven trials, and measurement of outcomes for accountability were highlighted for successful prescription of SGDs. These issues will be summarised and presented in the article below.

Background

Functional goal directed trials that are documented and evaluated support the appropriate prescription of SGDs, which reduce the risk of device abandonment. Johnson, Inglebret, Jones, and Ray (2006) explored the perspectives of speech language pathologists (SLPs) regarding the success versus abandonment of AAC. They reinforce the important role that clinicians have in evaluating functional outcomes for the overall effectiveness and usefulness of Alternative & Augmentative Communication (AAC). The researchers cite the importance of the team collaboratively making decisions relating to the support, attitude, and system characteristics to find the best fit device for long-term success of AAC and prevention of abandonment. Hodge (2007) further advocates for the need for attention toward development of coordinated systems of support within the policy domains of education, health, and community services, with the provision of supports for technical assistance in the setup and maintenance of AAC.

To support efficient and effective SGD assessment and prescription, including functional goal setting, evaluation, and collaborative decision making, speech pathologists at the Cerebral Palsy League have been using a trial proforma, developed by the MASS Communication Aids Clinical Advisory Committee (2008), the ICF, and Light's Communicative Competence framework and outcome measurement. The following concepts were applied to device trials and evaluation:

- Use of the World Health Organisation International Classification of Functioning, Disability, and Health (ICF) as a framework to describe the approach to clinical reasoning in the treatment/interventions of children with support needs. This model helped to identify activity limitations and

participation restrictions impacting upon communication where AAC and applications of SGDs might be useful. The model also reflects the impact of contextual factors such as family supports and attitudes toward AAC.

- Use of formalised outcome measures such as the Goal Attainment Scale (GAS) to evaluate how the outcomes achieved met the identified goal, and to provide objective information to support collaborative decision making
- Knowledge of Light's model of Communicative Competence (Light:1989, 1997) to reflect the importance of setting functional goals relating to linguistic, operational, social, and strategic competence.

The following case studies explore the application of these concepts, which assisted to objectively measure outcomes from device trials, and provide the specific information required for filling out MASS forms and applications to request funding toward prescribed devices.

Early Intervention Case Study

F was a 6 year old boy at the time of device trials and was attending an early childhood education program (ECDP) most days. F's participation in social interactions at home and ECDP were restricted by difficulties communicating a wide range of communicative functions with both familiar and unfamiliar people at home and at ECDP. The difficulties were due to impairments at the body functions and structures level of the ICF (gross, fine, and oral motor difficulties related to cerebral palsy and vision impairment). He had a number of abilities that supported his potential to develop greater communicative competency including: cognitive skills (although not formally assessed, he demonstrated a cheeky sense of humour and motivation to interact and get his message across to communication partners); the ability to follow some simple instructions; the use of some single word approximations; developing consistency with use of the yes/no response; and the impending supply of a low-tech AAC system (a 16 cell per page communication book). F also had supportive parents and siblings who, although keen to support F's use of low and high tech AAC systems at home, had minimal knowledge or experience with AAC.

Prior to SGD trials, F was familiar with PCS (Picture Communication Symbols) symbols, which were used in low-tech communication resources in his ECDP environment, and in his communication book. The Unity language system with Minspeak symbols was also discussed with his family as an option for SGDs. Exploring both language systems in SGD trials was felt



REFLECTIONS OF BEST PRACTICE FOR TRIALING SPEECH GENERATING DEVICES (cont)

to be important, given F's young age and the impact that a decision about language systems this early on would have on his use of future SGDs. Additionally, the involvement of the team occupational therapist was also felt to be important, given F's difficulty accessing both means of communication.

The Springboard (from Prentke Romich) and Dynavox M3 were both identified as appropriate SGDs to trial. The timing and objectives of trials were planned with F's family and ECDP team, with a 2 week trial of the Springboard and a 3 week trial of the M3 organised. F's use of both devices were observed at the start of each trial to establish his baseline skill level (GAS score: -2) and the expected outcomes (GAS score: 0) at the end of each device trial was then discussed with the team, reflective of the following GAS scale:

Score
Attainment Level / Outcome

Baseline
(skill level at start of trial)
-2 When the target 'toys' page is set up for him, F produces a 2-symbol sequence ('I want to' + '(activity)') on the Springboard on imitation to tell his Mum/Dad an activity he wants to do at home.

Less than expected outcome
-1 When the target 'toys' page is set up for him, F produces a 2-symbol sequence ('I want to' + '(activity)') on the Springboard with verbal prompts to tell his Mum/Dad an activity he wants to do at home.

Expected outcome
0 When the target 'toys' page is set up for him, F produces a 2-symbol sequence ('I want to' + '(activity)') on the Springboard independently to tell his Mum/Dad an activity he wants to do at home.

Greater than expected outcome
+1 F independently navigates through pages to produce a 2-symbol sequence ('I want to' + '(activity)') on the Springboard independently to tell his Mum/Dad an activity he wants to do at home.

Much greater than expected outcome
+2 F independently navigates through pages to produce a 2-symbol sequence ('I want to' + '(activity)') on the Springboard independently to tell his Mum/Dad an activity he wants to do at home, and produce other vocabulary related to the activity.

At the end of the trials, F achieved a greater than expected outcome (GAS score: +1) on the Springboard trial, however, his GAS goal was unable to be scored for the M3 as the ECDP team were unavailable at the trial's completion due to the commencement of school holidays. F did, however, achieve the informal goal set for home (independent choice making of activities). The MASS 91 Trial Proforma document features a Perceptions Regarding Use of the Device section for the applicant to rate themselves, the team to rate the applicant, and the team to rate themselves in terms of understanding of operational use of the device, functional use of the device, independent use of the device, and enjoyment using the device. This was felt to be a useful measure of the team's overall attitude towards device trials.

Following discussion with F's team at home and school, and the holistic consideration of outcomes and perception ratings on the proforma, the M3 was prescribed. The team felt that F, his family and ECDP's were more familiar with PCS symbols and that the M3 was easier to use and program than the Springboard. Anecdotally, F was also reported to be more motivated to use the M3 SGD during interactions. The use of the MASS 91 Trial Proforma document provided the structure to support collaborative, well organised SGD trials and the comparison of devices across trials in order to make a justified prescription.

School Aged Case Study

The school aged case presented was an 11 year old girl, K, attending a mainstream school. She had previously been prescribed a Dynamo but it had been abandoned due to it not meeting her language needs. Through use of the ICF framework, it was evident that there was reduced knowledge in all environments about functional applications of how the device could be used to increase participation in speech based communication opportunities with a variety of partners across settings. Trial of the Dynavox V was planned with her family and school with the following objectives:

- For K to use the Dynavox V to construct simple sentences to make requests, ask questions, and describe/comment
- For K to be exposed to on-screen keyboards on the Dynavox V to participate in literacy activities
- To ascertain from K's supporting team, views and outcomes from the trial.

Information was gathered at the start of the trial relating to K's baseline skills in the four areas of competence specific to the use of the device. Four separate GAS scales were established for each area of competence with the desired level of



REFLECTIONS OF BEST PRACTICE FOR TRIALING SPEECH GENERATING DEVICES (cont)

achievement during the trial period (reflecting a GAS score of 0) as follows:

1. Linguistic competence: K independently constructs a 3 word phrase using "I want ..." to request needs /wants.
2. Operational competence: K independently turns the device on/off and selects the 'Gateway' folder to access vocabulary.
3. Social competence: K responds to a question and takes her turn using her Dynavox V on 25% - 50% of occasions.
4. Strategic competence: K independently recognises when a mistake has been selected and asks for assistance to repair the expressive message.

At the end of the trial, GAS scores revealed achievement of expected level or above. School and home were provided with a small table reflective of the MASS to report on usage and success. Gathering of anecdotal and formal outcome information made the completion of the MASS SGD application form easier, and clearly justified the prescription of the device.

Concluding Therapists Perspectives

The case studies presented demonstrate the flexibility of using formalised measures such as the GAS across different populations to make the trial of SGD's more objective and accountable. Knowledge and applications of the ICF and Light's model of communicative competence, helped to establish the setting of functional goals for the period of device trials. As clinicians choosing to apply these principles, we found that it encouraged collaboration between all people surrounding the child, and helped to determine the best fit device for the applicant and their family, thus assisting with the justification of prescribed devices when applying for funding through formalised processes such as MASS.

For more information on the Medical Aids Subsidy Scheme (MASS) go to www.health.qld.gov.au/mass

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CONNECTING YOUNG AAC USERS

Toni

To all the young AAC users and their parents, We would like to organise a network of young AAC users.

If you would like to be a part of this group, please email Toni Green on jtebgreen@bigpond.com

If you are under 18 you will need parental permission to have your details added to this list.

We will attempt to get a list of contact email addresses, phone numbers and addresses together to allow the young AAC users to connect.

We also hope to have a get together prior to the next AGOSCI conference in Adelaide in 2011 (so start planning now to be there!).

We will appoint one contact person in each state to allow local groups of AAC users to connect at a local level as well as at a national level.



TECHNOLOGY REVIEW - SPEAKOUT

Angela Guidera
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For those looking for a flexible text-to-speech device the SpeakOut (from Permobil) is one worth considering. It is a sleek device that at first glance could pass for a mainstream piece of technology. The SpeakOut has a QWERTY keyboard and is tilted on a slight angle. The letters are clear and the keys are well-spaced and soft to touch.

Dual Screens

One of the great features of the SpeakOut is that it has two screens - one for the user and one for the communication partner. Not only does it have two screens, but the user's screen is large enough to display seven lines of text with 40 characters on each line. This means you can view more text than on other text-to-speech devices, providing useful visual feedback and making it easier to edit messages that you create. The communication partner's screen is smaller, displaying two lines of text.

Font size can be set to large or small. When set to large three lines of text are displayed on the user's screen. The large font size is likely to be useful for users who have visual difficulties.

Voices

The position of the speaker allows the voice to be projected loudly and clearly. The SpeakOut comes with Acapela synthesised speech. It is available with either UK or US accent voices. Unfortunately no Australian accent voices are available at this stage. To swap from male to female (or vice versa) you need to do a software upgrade. This is easily done via the USB flash drive supplied.

Rate Enhancement

The SpeakOut has an internal word prediction dictionary of around 10,000 words. Word prediction is frequency-based and learns as the user types. The device can be set to predict after one, two or three letters, enabling you to avoid the distraction of words popping up every time a letter is selected.

Communication rate can be enhanced by the use of pre-programmed sentences. Messages can be stored under key sequences of Function + another key. Sentences can be viewed in a list displayed on the main screen, so you don't have to remember all of the shortcuts. Longer documents or speeches can also be stored. Multiple documents can be stored under the combination of Function + each letter key. The SpeakOut also has quick hit "yes" and "no" keys and abbreviation expansion capability.

Reminders

Verbal reminders can be stored for users with memory difficulties or those who tend to have "senior moments". For

example, you could set the device to say "remember to take your medicine" at 12.30 pm. Reminders are displayed with the date, time and a written message. One-off or daily reminders can be stored.

Menus

Something that struck me about the SpeakOut was how easy it was to adjust device settings. The menus are quite intuitive - there is no need to labour over the manual for hours working out how to adjust settings. You press one key to enter the menu system, then navigate the menus using arrow keys and yes/no keys or number keys. You can view a number of menu items at the same time thanks to the large screen.

Scanning

As an alternative to the standard model (which is accessed via direct touch) a scanning model is available. You can use one or two switch scanning. The scanning lights on the scanning model clearly illuminate the keys on the static keyboard. Scanning speed can be adjusted and auditory prompts can be used in addition to visual scanning. The scanning model does not have the option of using direct access.

Connecting to Computer

The SpeakOut can be connected to a computer using the supplied cable. You can open a word processing program on the computer, then type text to send directly to the computer. Saved documents from the SpeakOut can also be transferred to the computer.

Other Features

- Alarm key for gaining attention
- 'Autotext' feature - can set to automatically use an upper case letter

after a fullstop or other punctuation marks

- Calculator
- Time and date
- Phone book
- Standby function - can be set to 1, 5, 10, 15 or 30 minutes
- Ability to print directly to some printers
- Settings can be backed up to the USB memory stick supplied

Accessories

Accessories available include a carry case, a 'raincoat' (moisture guard), a keyboard protector, two keyguards (3 mm and 5 mm) and a mounting plate.

Limitations

Some possible downsides to the SpeakOut are that there is no ABCD layout option, Australian accent voices are unavailable, environmental control capability is currently unavailable and the space bar is towards the right side of the keyboard rather than in the usual location.

Specifications

- Size: 24.5 x 19.5 x 5.2 cm
- Weight: 1 kg
- Run time: approx 8 hours
- Charge time: approx 5 hours



NATIONAL RELAY SERVICE

A PHONE SOLUTION FOR PEOPLE WITH A HEARING OR SPEECH IMPAIRMENT

Alicia Afuang & Libby Price
National Relay Service
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While many Australians are enjoying more choices than ever when it comes to communicating by phone, some still struggle to use a phone at all. People with complex communications needs (CCN) often have to overcome many obstacles to undertake a task that many take for granted. For example, most people don't think twice about just picking up a phone to make a call, but for up to 20,000 Australians, this simple act can be an enormous mental, physical, and technological challenge. Some people with CCN may never have been able to make a phone call in their entire lives. The National Relay Service (NRS) aims, wherever possible, to change that.

The NRS is an Australian government initiative funded by a special levy paid by eligible telecommunication carriers. Using specially trained relay officers who act as a link between callers, the NRS offers a variety of call options for people with a hearing and/or speech impairment, including those using voice output devices and other assistive technology. Relay officers can help by introducing the call, explaining how the person communicates, and interpreting if the person does not understand the caller with CCN. This can help individuals to make calls privately, without having to ask friends, family or carers to help.

Use of the NRS for people with hearing impairments has increased over the years, however awareness and use of the service by people with CCN has been low. At the AGOSCI 9th Biennial National Conference, NRS launched a campaign to increase the number of people with CCN using NRS. The aim of the campaign is to reach people with CCN through those who care for and support them. Education officers from NRS will contact organisations that support people with CCN offering information and training sessions about how individuals with CCN can use the service. Speech pathologist, Libby Price, is also helping in campaign by providing training to NRS staff, and contributing to the development of training and support resources.

NRS wants people to know that it is possible for people with CCN to use the service. A great example of this is twenty-three year old Sam Ren, who attended the AGOSCI conference as part of the NRS team. Sam talked to many professionals and individuals with CCN about how he uses the service and

demonstrated a live call. Sam says that since learning to use the NRS, he has a whole new lease on life. He is not able to walk or use his hands, but he can use a switch-adapted phone dial the NRS and answer calls. Another strategy he uses is dialling numbers on a big button phone using his nose. Once Sam is connected to the NRS, an experienced relay officer then connects his call and stays on the line to re-speak Sam's words if the person on the other end of the line has difficulty understanding him.

"It's great!" he says. "It lets me make phone calls by myself. Before I used the National Relay Service I had to rely on my mum or on support workers to make calls for me. This is much quicker and maximises my independence."

Sam's case is just one example of how people with CCN, even those with physical disabilities, can keep in touch using the NRS. People might need help in choosing the right phone equipment and learning how to make a successful call, but the NRS wants AGOSCI members to take up our call to action: it is possible for many people with complex communication needs to use the telephone.

If you know someone who would like to use the NRS, but is not sure how to get started, or if your organisation would like to an information session, please call the National Relay Service, ring the Helpdesk on 1800 555 660 Monday to Friday 9am-5pm (Sydney time). Alternatively, visit the NRS website on www.relayservice.com.au. All calls via the NRS are confidential and cost about the same as a local call. Training for new users is free. The Helpdesk can also send you the "Staying in Touch" poster with information, which features Sam Ren using a switch adapted phone.



Sam Ren uses a large button phone with a switch to dial the National Relay Service to ring anyone, anytime.

MY LIFE – A STORY AND THOUGHTS ON COMMUNICATION

Peter Rowe

www.peter-rowe.info

My name is Peter Rowe and I am an artist, an author, a poet, and importantly a person with Down syndrome. I say importantly, because I am proud of who I am. This was not always the case for me. When I was younger, I had a different perspective on life. It's funny how our experiences shape us isn't it? When I was young I found it hard to accept that people saw me as different. I'll let you in on a secret – even though I just was little, and even though I had people trying to protect me, I still knew I was not quite the same.

First off, can I challenge you to think outside the square? Think of being in a body that makes people sometimes think you're dumb, a body that doesn't let you speak, and a body that gives people certain opinions about the personality you should have. Do these things add up to indicating happiness? If it wasn't for a couple of things, my life would not be what it is today. What are those things, I almost hear you all thinking at once.

The initial thing is family. It is what keeps me secure, comfortable and confident in who I am - a loving son, brother, and uncle. It is family who have been there for me in the worries, the struggles, the celebrations, and the joys of life. The early years have not only memories of difference, but also memories of laughter and being included. If it was not for family, then there would not have been the laughter.

The other important thing in life for me came years later. Possibly it was lucky. I met the right person who seemed good enough to not listen to popular thinking and gave me a way of being able to communicate. Communication is the thing that is supposed to be a basic thing we all have a right to. It is the thing that helps define who you are.

In the moments following my connection with a way of communicating, I saw that this great right also had some challenges. My family were a bit surprised, to say the least. The person they thought I was, was being challenged. Was I different? No and yes! I was the same person but the impact of me communicating certainly changed me and my relationship with others. The people outside of my family were often challenged by me communicating.

These people didn't know me. They did, however, think they knew what I should not be able to do because of the way I look. Unfortunately, people believe in the things that make them feel comfortable.

What makes some people feel uncomfortable? Having a person with Down syndrome challenged them to consider the possibility, they have assumed, that people can't think based on

how they look. I'm being honest, sorry if this offends. Offending is not the purpose of this paper. Getting you to reflect is. Getting you to see past a diagnosis is. Is there a theme coming through yet?

Point number three: Being involved brought me happiness too. Growing up always meant doing the same as others. This was important. I am happy with who I am, as I have always been seen as one of the family. Really it has been only since being able to let others know my thoughts through typing that I have felt honestly connected with my community. It has been this connection with the arts community that has helped me throughout some difficult times. I have grown comfortable with myself through being able to share experiences both typed and in different visual medium with family and friends. Do you learn about yourself through chatting about things with other people? If you answered "yes", then we are not different in that way.

So now I have to end this paper in some witty and memorable way? I guess the messages I would encourage you to hold onto are simple. Just accept differences. Accept and welcome things that will cause you to both be Challenged and reflective. The big one is let your eyes tell you only part of the story. The chapters in the book will be revealed when you use all senses and match it up against your heart.

In case there are any people still wondering, I am happy. I am happy that I was lucky to have the support around me to follow a path to happiness. My heart goes out to those that may not have the family, community, or have not been offered the right communication opportunity for them.

That is why I dedicate my books and this paper to: The people who know, but can't tell. Who hear, but can't speak. Who receive the information from the world around them, but can't sort it. And the people who were blessed with the gifts of the body in full working order.

Peter's artwork has been chosen for this issue of AGOSCI in Focus. To learn more about Peter check out his biography on the contents page.

THE BRIDGING PROJECT

Viviana Ortolan

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I vividly recall the first time the Bridging Project was mentioned to me. I was in the middle of training at Scope's Glenroy office. Rhonda Joseph and Jo Watson outlined the hopes and direction of this new initiative.

Mental health has never been something that I identified with, although, discussions with a psychologist have been helpful at times. However, there seemed something quite unique about this project. It was entirely focused on people with Complex Communication Needs, like me. What really impressed me was that the project recognised that people have specific challenges that put them at risk of compromised mental health. The main goal, is to make it easier for people who experience difficulty accessing mainstream mental health services to have access to professionals with specific knowledge.

Personally, communication and making myself understood to others has always been a struggle. Although I have never given up I believe that many of my frustrations have stemmed from not being understood, being misinterpreted or simply ignored.

A short time after speaking with Rhonda and Jo, I received an email about the launch of the Bridging Project, and an invitation to participate in this formal event. A joint presentation of some sort, I thought!

This initiative sparked my interest because there had always been times in my life that I have needed someone to talk to about my problems, someone who could listen without saying – "Stop feeling so sorry for yourself". So, I began to write about memories that I have collected over the years. I recalled times when my disability caused me to feel as though nobody understood. I wrote about how I dealt with these times. Although it was confronting it was extremely powerful for me to spend time reflecting on my life and my emotional well being. As my paper slowly took shape, I became extremely enthusiastic and saw it as an opportunity to not only tell my own story but also make people realise how Complex Communication Needs can affect a person's life. Furthermore, I wanted to show the progress of technology and how it has helped unlock doors.

With time drawing close to the launch, my contact with Jo increased. We decided to put my words and a few photos on PowerPoint so I could present it all entirely myself. I was thrilled but knew this presentation was quite personal and people would hear about some of my difficult times. Somehow though, the Bridging Project seemed worthy of this. The paper depicted various incidents throughout my life.

It focused on times where my Complex Communication Needs have been a hindrance and made me feel isolated. I recalled a time as a child. There were very few times that I played with the kids in my street. I always seemed to be watching from a window or from my front yard, it never occurred to me that I could join in – well, not really. I sometimes ventured outside with a neighbour, who spent some time with me but it was seen as a game of doctors and nurses – guess who the patient was on all of those occasions?



My presentation also posed questions that I will always wonder about. For example, when I started looking back on my schooldays, I realised that what I learnt at school barely skimmed the surface. I sometimes wonder if it was because of my Complex Communication Needs. Did I miss out because I could not quickly answer questions in class? Was I overlooked because my words took ages to get out?





THE BRIDGING PROJECT (cont)

Communication is the key to a fuller, more meaningful life, I'm sure of this. Technology has made a world of difference; my Canon Communicator gave me so much confidence. For the first time, I could type what I wanted to say anywhere and at anytime, to almost anybody. People started to listen and realise that they didn't need to be a rocket scientist to communicate with me. I am pleased to say that I participated in a woman's writing group and successfully completed two writing courses using my Canon Communicator. This is a picture of me with my friends in the writing group. There have been times that I have kept my thoughts and words to myself just because it's easier. How many people, who have Complex Communication Needs do this, I wonder?

Late in 2002, I became quite depressed due to some unexpected changes at home. All of a sudden, I depended on care attendants to come morning and night, which was great until they showed up late, which caused chaos. Around that time, I was introduced to a psychologist from Scope, who had the time and patience to guide me through a tough transition of change and loss. Of course, as with everything, time and funding constraints were of the essence but it really helped to have someone who I could tell my problems to without feeling guilty. I used my Lightwriter a lot but I also would show him some of my writing and poetry to explain

myself further. Unfortunately, psychologists with his expertise are few and far between. This is why the Bridging Project is so important, it is unique and assists people who may not be able to express their thoughts and feelings as well as others. It does this by developing tools and resources for psychologists to use when supporting people with Complex Communication Needs. My involvement didn't end with the launch, to my surprise; I was offered a part-time job assisting the team with various projects. Hopefully, as a person who has Complex Communication Needs, I can make a contribution based on life.

At Last!

Triple C – Checklist of Communication Competencies (Revised Edition 2009) by Karen Bloomberg, Denise West, Hilary Johnson and Teresa Iacono

The Communication Resource Centre – a service of Scope, is proud to announce the new and improved version of the Triple C – Checklist of Communication Competencies. Ten years ago we developed an assessment that was designed for use by support workers. The assessment used a checklist format to determine the communication skills and abilities of adults with severe and multiple disabilities. Now after research and redevelopment we have an even better product. The new and improved Triple C is now available. A "no fail" assessment that is:

- ✓ Easy to learn,
- ✓ Easy to use and
- ✓ Easy to interpret.

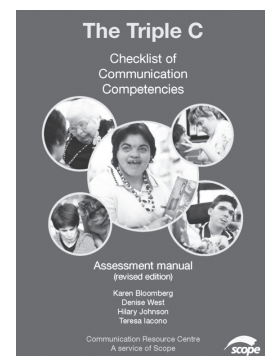
Designed for use with adolescents or adults with little or no speech.

The Triple C is a valid and reliable tool that makes it possible to:

- Assess skills that are observable
- Focus on functional skills
- Assess communication skills at an unintentional level
- Assess skills at an early intentional level of communication

Available for use by communication partners without formal qualifications however, it is recommended, that a communication specialist is involved in confirming the final results.

Get you copy now: contact the Communication Resource Centre (Scope) www.scopevic.org.au



AND YOU THOUGHT YOU HAVE PROBLEMS: A STORY ABOUT WHAT IT IS LIKE TO BE A TEENAGER WITH CEREBRAL PALSY (CP)

By Laurence Byrne
lol.boy3@hotmail.com

What is it like being a teenager with a disability? Well it is different because it isn't like you can go on dates without carers. But this is story how two disabled teenagers did go on a date.

Chapter One

It is my last year of school. My non-disabled school mates are talking about the dance; who they are going with and what they are going to wear and you get the picture. All students but me. Now it is the first day of the school year. I am the only disability student in the school. I am the only disabled person in my town. My homegroup teacher Mrs. Binder walks in the classroom and says to the class, "We have new student. Please make her feel welcome." I thought to myself, great, just another new... What!!!

Chapter Two

It's a girl in a wheelchair and she looks fantastic.
"This is Bea. Can she sit down next to you Laurence?"
I said yes with excitement. "Hello, I am Lol."
"Bea."
I said, "Are you new in town?"
"Yes I moved here just yesterday."
"What have you got?"
"Excuse me?"
"What is your disability called?"
"Cp."
"Me too! Finally someone understands me," I said.
The teacher said, "Quiet please."

Chapter Three

"I am in love."
"You are what?!" asked my parents.
They look like they just saw Japan after the bombings in WW2.
"Are you well?" asks Mum.
Dad looks like he is going to call up the funny hospital.
The next day is my swimming day. Not training for the Olympics but because our muscles are so tight. A carer picks me up in his van. His name is Bob. "We have new passenger,"

said Bob.

Who do you think it was? Yep, it was Bea. To make things better she had a bikini. Bob drove us to the pool where two women helped us get un-dressed and put us in the pool. After our swim I asked, "How was your swim?"
"Good," she said. "And yours?"
"Not bad," I said. "Not bad."
Not bad at all.

Chapter Four

Bea has a body like a supermodel in a power chair who can't walk. She has long brown hair, blue eyes, if she wasn't in a power chair you could see her long legs. Some girls at my school are good-looking but have little or no brains. Not Bea; she has big brains and good-looking body. It is the week before the school's dance. I ask Bea and she says yes. Mum drove me to the dance in my van. Bea was waiting for me.

Chapter Five

We drove around in our power chairs, we danced in our power chairs and then Bea gave me a kiss on the lips and she said, "Let's dance", so we did. Only in my dreams could I have a girl friend. The night was magical for everyone, more so for me and Bea because we imagined that at our school dance we would be sitting in a dark corner being unnoticed. Six months later Bea and I are going to TAFE and studying literature and are getting married. Other TAFE students are happy for us I guess. We are going swimming still.

The End



BIG MOUTH CAMP 2009 WHITE CHRISTMAS

Jane Farrall, Big Mouth Camp Co-Ordinator

Back in June, nearly 100 people gathered in the mountains in Gippsland, Victoria to celebrate Christmas in June. The weather was suitably cold, the decorations were undeniably festive, and Big Mouth Camp was on again for 2009!

This year, 15 students using speech generating devices, their families, and support teams gathered for a fabulous camp in June. The Christmas theme offered the opportunity for festive activities, such as making crackers (with suitably bad jokes), a scavenger hunt, producing highly coloured Christmas wreaths and, of course, the Boxing Day cricket match. Anyone driving past the sports field at Rawson Village on "Boxing Day" must have been surprised to see our highly coloured cricketers (many of them still wearing their sleighs from the sleigh races) – as well as being astounded that anyone would play cricket in the snowy Victorian Alps in late June!

Each morning the campers divided into three groups. Brothers and sisters attended the sibling recreation program. Many families tell us that the brothers and sisters are really keen to attend each year because they have such a fabulous time in sibling rec due to the wonderful work of Lauren and her team. Group two contained the parents – who attended talks from our role model or from therapists attending camp - or who have speech generating device programming training from suppliers.

The third group is the children using speech generating devices. In the mornings they get into small groups and work on their individual goals which are all aimed at improving their communicative competence. In the afternoon each day, they get a chance to put the skills learned each morning into practice, as we all gather together in house groups to practice for the concert and also to do some whole group activities. These may sometimes get a bit chaotic – but they are always fun.

We were also extremely lucky to have Meredith Allan attend this year as our role model. Meredith did a talk to the parents, which the majority of families listed on their feedback form as their biggest highlight. Meredith also MCDed the perennial camp concert – and must have enjoyed herself as she has agreed to return next year.

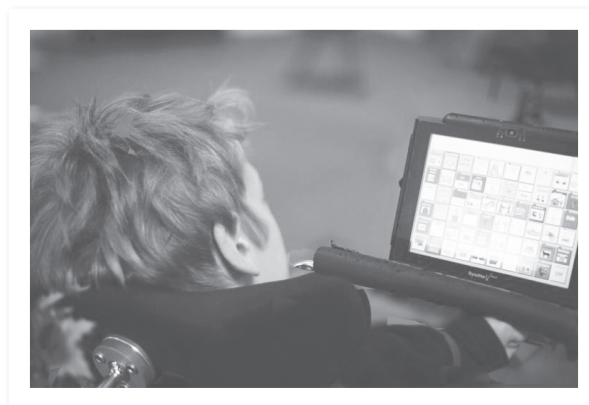
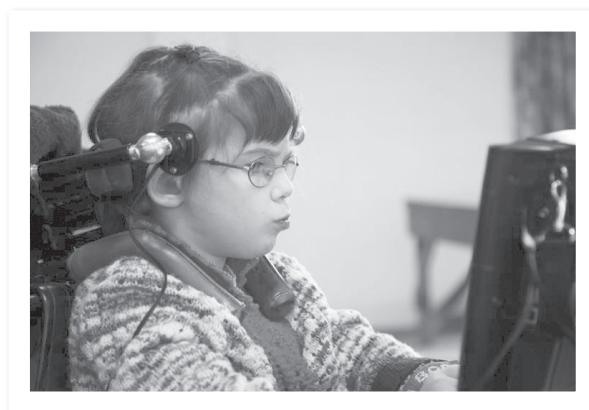
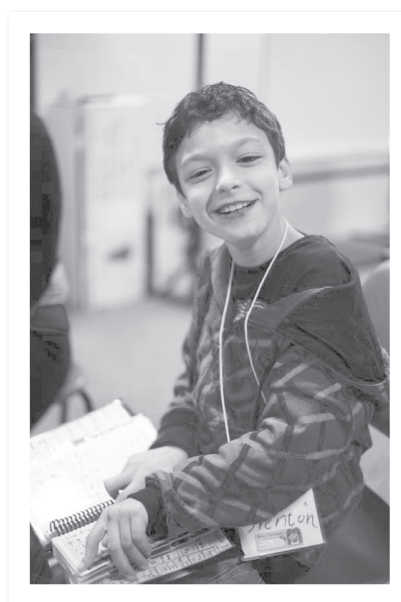
Feedback from camp this year was extremely positive again. The feedback forms included comments like "I gained so much from the camp – even beyond my expectations" and "I had one of the most amazing, life changing experiences of my life."

Applications for Big Mouth Camp 2010 have already opened. If you are interested in attending – or know someone else who



may be – you can find application forms at www.bigmouth-camp.org.au. Or you can call (03) 9848 4812 and speak with us about camp in more detail.

And if you are coming next year – our theme is Hollywood. So get out your tux or ball gown and come along to the movies!





CAMP HAVE A CHAT 2009

Meg Hinselwood
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The Cerebral Palsy League's Camp Have a Chat was held in the second week of the Queensland September/October school holiday. 16 students who use AAC, their family members, and various support people come together for four days and three nights of mayhem. Talented community artists Scotia Monkivitch, from Helicon cpr, and Tamara Kirby, from Struth Arts, who have been part of Camp for many years, are highly skilled in developing and providing a programme that encourages and supports participation from all students. This year's camp, themed The Giant Book of Surprises, was held in Joyner outside of Strathpine. There were participants from Brisbane, the Gold and Sunshine Coasts, Warwick, Townsville, Mackay, and Rockhampton.

At Camp, participants receive a camp communication book, with vocabulary that was planned during the year, to support participation in the activities. Books are designed and constructed by CPL's Communication Board Service, who do a magnificent job! Students exchanged personalised stickers in their Camp Chat Books as they introduced themselves to one another.

Campers, ably supported by therapists and University of Queensland speech pathology students, took part in drama and art activities centred around the theme of storytelling. Students collaborated to write an imaginative story, incorporating many of their favourite characters, then created giant pop up pages to illustrate each part of the story. On the final day, the students showcased their knowledge of the story telling process to family and friends using a question and answer format.

One of the highlights of Camp was toasting marshmallows while telling stories around an improvised campfire (during a total fire ban) followed by a moonlight walk, during which several scary story characters were encountered. As is traditional, Wednesday night saw a fantastic disco taking place in the PCYC hall, complete with games of basketball and limbo competitions! Camp represents a tremendous opportunity for children to use their AAC systems in a fun and meaningful context, to express themselves in unique and creative ways. For some students it is the first time they have seen other children successfully using AAC. Friendships are formed and renewed between families, and the energy and enthusiasm for communication is palpable. CPL and Camp Have a Chat participants are grateful for funding received from Non Schools Organisation and IBM. If you would like further information about CPL's Camp Have a Chat, please contact Meg Hinselwood on 07 3347 7200 or e-mail mhinselwood@cplqld.org.au





AAC RESEARCH IN AUSTRALIA

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A regular feature of AGOSCI In Focus is a report on the current research activity in Australia related to AAC. It was exciting to receive these snapshots of research. Australia AAC research is certainly very active. If you want to find out more about any of the research below, I encourage you to contact the researchers.

Researchers:	Project name:	Main aims:
Sabrina Lee, Bronwyn Hemsley, b.hemsley@uq.edu.au Bronwyn Davidson, The University of Queensland, Communication Disability Centre	AAC Professionals' views on communication needs of children with Cerebral Palsy (CP) and Complex Communication Needs (CCN) in hospital (Honours Project Sabrina Lee)	This is a focus group study involving AAC professionals. The aim of the study is to explore the views of AAC professionals working with children with cerebral palsy and their families on (a) the communication needs of children with cerebral palsy (CP) and complex communication needs during hospitalisation, and (b) strategies and barriers to effective communication for these children in hospital.
Teresa Iacono (teresa.iacono@med.monash.edu.au), Nick Hagiliassis, Jo Watson, Mark Di Marco, Hrepsime Gulbenkoglou Monash University and Scope Victoria	Accessible Depression Tool – Bridging Project (www.bridgingproject.org.au)	This project is part of the Bridging Project, a collaboration between Monash University and Scope in Victoria. The Bridging Project has as its mission to progress the knowledge and resource base to ensure that individuals with complex communication and mental health needs have access to quality services. Presently, we are developing and trialing a new tool for the assessment of depression and related mood disorders. The tool is designed to be accessible to people with complex communication needs.
Bronwyn Hemsley, b.hemsley@uq.edu.au The University of Queensland, Communication Disability Centre	Children in Hospital: Augmentative and Alternative Communication Needs and Experiences	This is a study funded by the University of Queensland New Staff Grant to Bronwyn Hemsley. This is a focus group study involving children with cerebral palsy aged 12-18 who use AAC. The aim of the study is to explore the views of children with cerebral palsy who use AAC on (a) their communication needs and experiences in hospital and (b) strategies and barriers to effective communication for these children in hospital.



Marie Huska, Nick Hagiliassis, Sheridan	Communicating Pain	This project aims to trial an existing tool, namely the DisDAT, in an effort to ascertain how better to support people with complex communication needs to have their pain identified, responded to, and resolved. A literature review has been completed. Analysis of the Literature Review has guided the next phase of the project.
Forster, Jo Watson (jwatson@scopevic.org.au) Scope Victoria		
Bronwyn Hemsley, (b.hemsley@uq.edu.au) Linda Worrall, The University of Queensland, Communication Disability Centre/ & Susan Balandin, University College Molde, Norway	Communication during Hospitalisation: The path to better health care.	This research is funded by the NHMRC Postdoctoral Fellowship to Bronwyn Hemsley. The aims of this research are to (a) remove barriers to successful communication in hospital; (b) facilitate patient participation in health care decisions, (c) reduce adverse experiences of patients with no speech arising through unsuccessful communication with hospital staff, (d) change policy and practice to improve the health care of patients in hospital, (e) improve the health of Australians, and (f) bring economic improvements through better care. This project has two phases: Phase One, 2009, involves interviews with 45 paid carers, adults with developmental disability, and hospital nurses about communication in hospital. Phase Two involves observations of adults with developmental disability and complex communication needs in hospital and will take place over 2010-2011.
Hilary Johnson (H.Johnson@latrobe.edu.au) La Trobe University	Communication in the Social Networks of Adults with a Severe Intellectual Disabilities	The aim is to examine the process of communication between adults who are non-linguistic communicators and members of their social network. Data collection is underway and is being collected through participant observation and interviews. Data is being analysed using a grounded theory approach and a model of the communication process will be developed.



<p>Kate Anderson (kate.anderson@usyd.edu.au), Susan Balandin, Sally Clendon, & Bronwyn Hemsley The University of Sydney</p>	<p>Friendship Experiences of Children Who Use Natural Speech with Peers Who Use AAC</p>	<p>In this small interview study we are investigating the friendships that develop between children who use natural speech and their peers who use AAC. Exploring both the barriers and benefits to these friendships may help to inform social inclusion programs for children with complex communication needs within the community.</p>
<p>Susheel Joginder Singh (skjog1@student.monash.edu), Teresa Iacono & Kylie Gray Centre for Developmental Disability Health, Monash University</p>	<p>Interaction Between Children with Developmental Disabilities and Their Mothers and Siblings</p>	<p>This study aims to describe the communicative behaviours exhibited by children with Down syndrome and cerebral palsy when interacting with mother as compared to siblings, and in dyadic as compared to triadic interactions. The different types of responses given by mothers and sibling to the children's communicative attempts will also be described.</p>
<p>Meredith Prain Meredith.prain@ableaustalia.org.au, RMIT University</p>	<p>Interactions Between Adults with Congenital Deafblindness and the Staff Who Support Them</p>	<p>Most of the research investigating communication for people with congenital deafblindness focuses on children and their interactions with their parents or educators. This project is examining what is currently occurring during interactions between the adults with congenital deafblindness and the staff who mediate their support and also looks at the perspectives and attitudes of the staff involved in the interactions.</p>
<p>Sheridan Forster (sheridan.forster@med.monash.edu.au),& Teresa Iacono Centre for Developmental Disability Health Victoria, Monash University</p>	<p>Interactions Between Disability Support Workers and Adults with Profound Intellectual and Multiple Disabilities</p>	<p>Adults with profound intellectual and multiple disabilities who live in residential services, primary interaction partners are disability support workers. Despite the recognition that the interaction influences quality of life, little is known about what happens when these two people sit down together. The aim of this study is to investigate what happens in everyday interactions within this dyad, and, in particular, how workers use affect attunement in their interactions</p>



<p>Pammi Raghavendra (parimala.raghavendra@novita.org.au), Denise Wood (Uni SA), Lareen Newman (Flinders University), Jan Lawry & Darryl Sellwood Novita Children's Services & University of South Australia</p>	<p>Internet use by Children and Adolescents with Physical Disabilities: Implications for Social Networking</p>	<p>The aim of the project is to investigate the patterns of Internet use, facilitators and barriers to use by children and adolescents with physical disabilities with and without CCN; to explore solutions to enhance the use and study the impact of online social networking on their social participation</p>
<p>Pammi Raghavendra (parimala.raghavendra@novita.org.au), Sonya Murchland, David</p>	<p>Making Music Through Movement: The Efficacy of the Virtual Music Instrument</p>	<p>The Virtual Music Instrument (VMI) is an innovative musical software program developed at Bloorview Kids Rehab in Toronto, Canada. The VMI system creates an augmented environment that allows the simplest movements to be translated into music.</p>
<p>Hobbs, Breeanna Worthington-Eyre, & Prue Shiosaki Novita Children's Services</p>	<p>(VMI) for Developing Early Communicative and Play Behaviours in Children with Severe and Multiple Disabilities</p>	<p>The aim of this project is to study whether the consistent use of the VMI with children with severe and multiple disabilities has an impact on two key developmental areas – their play and communication. Play and communication behaviour data has been collected for 19 children. Preliminary analysis shows increased levels of engagement with VMI.</p>
<p>Teresa Iacono (teresa.iacono@med.monash.edu.au), Denise West, Katie Lyon Communication Resource Centre, Scope</p>	<p>Outcomes of the Non-Electronic Communication Aids Scheme (NECAS) for Adults with Complex communication Needs</p>	<p>Adults with complex communication needs rely on communication aids to participate in everyday communication. This study will determine how different aids provided by the State Govt. funded Non-Electronic Communication Aids Scheme (NECAS) best meet their needs. The outcomes of NECAS aids for individuals in their daily communication will be explored and include documenting their stories. The study will also address strategies to enhance support for people requiring communication aids.</p>
<p>Melissa Kuek, Bronwyn Hemsley, b.hemsley@uq.edu.au Nerina Scarinci, The University of Queensland, Communication Disability Centre</p>	<p>Parents' views on communication needs of children with Cerebral Palsy (CP) and Complex Communication Needs (CCN) in hospital (Honours Project Melissa Kuek)</p>	<p>This is a focus group study involving parents of children with cerebral palsy and complex communication needs. The aim of the study is to explore the views of the parents of children with cerebral palsy on (a) the communication needs of children with cerebral palsy and complex communication needs during hospitalisation, and (b) strategies and barriers to effective communication for these children in hospital.</p>



<p>Pammi Raghavendra (parimala.raghavendra@novita.org.au), Alison Lane, Cathy Olsson, Tim Connell, & Rachael Virgo Novita Children's Services</p>	<p>Participation Profile of Children With Physical Disabilities With and Without Complex Communication Needs: Association Between Social Networks, Communication, Activity Engagement and Time Use</p>	<p>The aim of this project is to develop detailed profiles of participation in daily activities and communication interaction of children with physical disabilities with and without complex communication needs and children without disabilities. The outcomes of the project will provide us with a better understanding of children's participation and the factors that influence participation of children with physical disabilities, especially children with CCN. The data collection has been completed, analysis is underway with the aim to complete the project by April 2010</p>
<p>Abi Thirumanickam, Pammi Raghavendra (parimala.raghavendra@novita.org.au), & Cathy Olsson Flinders University & Novita Children's Services</p>	<p>Participation Profiles of Primary School Children With and Without Physical Disabilities and Complex Communication Needs: The Relationships Between Communication Abilities, Social Networks and Involvement in Activities</p>	<p>The purpose of this honours project was to construct a comprehensive description of the participation and social network profiles of 6 – 9 year old children with physical disability and complex communication needs (Grp.I) and compare it with their typically developing peers (Grp.II). Group I had overall lower diversity, intensity and social context in activity participation, but enjoyed the activities more than Grp.II. Grp.II had 2-3 times more number of friends and acquaintances than Grp.I showing reduced social networks for Grp.I. The interaction between communication, social networks and participation was highlighted with implications for service delivery.</p>
<p>Phil Foreman, Michael Arthur-Kelly (Michael.Arthur-Kelly@newcastle.edu.au), & Deone Bennett The University of Newcastle</p>	<p>Partner Training and Communication Outcomes for Students with Multiple and Severe Disabilities</p>	<p>We are investigating the impact of a program of mentor-modelled professional development on the observed behaviour states of students with multiple and severe disability and the reported and observed changes, if any, in teachers and aides who interact with these students. Using a multiple baseline design we plan to implement the program first in special schools then replicate it in inclusive situations.</p>



<p>Julie McMillan (julie.mcmillan@flinders.edu.au), Pammi Raghavendra, Cathy Olsson, & Margaret Lynch Flinders University, Novita Children's Services & Department of Education and Children's Services</p>	<p>Professional Learning for School Personnel: Impact on Communication of Students with Severe Disabilities Using Speech Generating AAC Devices</p>	<p>This project aims to provide professional development in the use of SGDs for teachers and professional support staff in schools through the use of a collaborative team approach. Student communication skills are measured across phases, including generalisation in the home or community. In addition, support team self-assessment and the teaming approach to supporting students with CCN are investigated. The data has been collected and we are in the process of analysis.</p>
<p>Liora Ballin (lbal6064@mail.usyd.edu.au), Susan Balandin, Leanne Togher, & Roger Stancliffe The University of Sydney</p>	<p>Speech Generating Device (SGD) Mentoring with Adults Experienced in Using SGDs As Mentors To New Learners</p>	<p>Learning to use a speech generating device (SGD) can be a challenge for the new learner. Challenges may include difficulties in obtaining therapy, barriers to SGD-based communication in the community, and communication partners who lack skills in supporting successful communication. A mentoring program to improve SGD use, involving adults who use an SGD as mentors, may help address the challenges that those new to a device encounter. Indeed, people experienced in using an SGD may be well placed to mentor others who are learning, due to already having undergone the process of learning these technologies. The aims of this research are to develop, implement, and evaluate an SGD mentoring program with adults experienced in using SGDs as mentors to new learners.</p>
<p>Jo Watson (jwatson@scopevic.org.au), Erin Wilson, Nick Hagiliassis, Deakin University</p>	<p>Supported Decision Making – Listening to Those Rarely Heard</p>	<p>This project aims to a) further develop, evaluate, and implement a model of supported decision-making with people who communicate informally and their circles of support, and b) define the relationship between enhanced self-determination and behaviours of concern for people who communicate informally and are subjected to restrictive interventions.</p>



<p>Leigha Dark (leigha_dark@hotmail.com), Susan Balandin, Lindy Clemson, & Leanne Togher The University of Sydney</p>	<p>The Experiences of Grief and Loss of Older Adults with Cerebral Palsy and Complex Communication Needs</p>	<p>Older age is often a time of loss and grief, particularly in terms of bereavement, changes in physical, cognitive and communicative abilities, and changes to accommodation arrangements, social networks and sources of support. At present there is little information on the types of loss experienced by older people with cerebral palsy and complex communication needs or the experiences of managing loss and working through grief. This qualitative study aims to explore experiences of grief and loss through in depth interviews and describe arising themes.</p>
<p>David Trembath (D.Trembath@usyd.edu.au), Susan Balandin, Leanne Togher, & Roger Stancliffe The University of Sydney</p>	<p>The Experiences of Volunteers Who Use Augmentative and Alternative Communication</p>	<p>Our aim is to explore the experiences of people who use AAC who act as volunteers in order to identify (a) their motivations for volunteering, (b) the benefits they receive through volunteering, (c) the barriers they face, and (d) strategies that individuals and organisations can use to promote and support volunteering amongst people who use AAC who want to volunteer.</p>
<p>Gwynnyth Llewellyn, Susan Balandin, & Angela Dew (a.dew@usyd.edu.au) The University of Sydney</p>	<p>The Transition of Care from Ageing Parents: Achieving Flexible Relationships Between Adults with Cerebral Palsy, Their Siblings and Service Providers</p>	<p>To explore the relationships between people with severe CP aged 40 years and over and their nondisabled siblings in order to identify the support services required to facilitate the transition from parental to other care. To develop a model for achieving optimal relationships between the adults with severe CP, their siblings and service providers.</p>
<p>Natalie Berg (nber5765@mail.usyd.edu.au), Susan Balandin, Leanne Togher, & Roger Stancliffe The University of Sydney</p>	<p>What's it Like to Live in a Nursing Home (NH)? Exploring the Experiences and Residential Preferences of People Under 65, Their Families and Nursing Home Staff</p>	<p>The 'push' to move younger people with severe disabilities including those with complex communication needs, out of NH care continues to gain momentum. The experiences of three participant groups were explored (i.e., younger people living in NHs, family members and NH staff). Analysis of the data indicates that there is unified hesitancy to 'rock the boat' and move younger people with disabilities out of NH care. Recommendations will be made to assist policy makers and service providers in their attempts to plan for the future residential care of younger people with severe disabilities currently in, or at risk of entering NH care.</p>



aac research