

AGOSCI

in focus



THIS ISSUE:
AAC Here, There
and Everywhere



Tobii S32

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contents



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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.

AGOSCI *In Focus* is an ISAAC affiliated publication.

ISSN: 1443-9107

Cover Photo - Morgan Liddle Dogsledding at Mt Hotham 2009



Thank-you to the Liddle family for use of their photos. To find out more about Morgan read her interview on page 26.

Editorial	2
Memoriam - Anne McDonald.....	2
National / State Executive Members	3
Chairperson's Report	5
Treasurer's Report	6
Secretary's Report	6
State Reports.....	6
AGOSCI National Conference Update	8
ISAAC Australia Report	9
Membertalk	11
AAC on the Radio.....	12
Telecommunications Website Project.....	13
Vision Impairment and the Visibility of Key Word Signs	15
AAC in Hong Kong	17
The Power of Speech the Power of AAC	19
Photos.....	24
Kingsley's AAC Journey	29
Surviving an AVM.....	34
AAC in North West Melbourne.....	37
Camp Have a Chat (QLD)	39
Big Mouth Camp	40
Book Review	41
DVD Review	41
Research	42
Writing for AGOSCI.....	42

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Editorial

After four years as co-editor of Agosci In Focus (3 with Emily Armstrong and the past year with Kirsty and Dom), I have decided to hang up my editorial pen. Putting aside the pen with this great issue is a pleasure: AAC Here, There, and Everywhere.

I was inspired to the theme after seeing a spelling kickboard at the end of the bath in a colleague's house. People need to be able to communicate everywhere. AAC covers all means of communication that augment or provide an alternative to speech. Such means of communication include both formal (such as boards and devices) and informal means (such as facial expression and body language).

Never more was the breadth of AAC made more real to me than at a play I recently went to. The play, which starred Melinda Smith and other Wheel Women (several performers had CCNs), was about the main characters relationship with her husband, son, and closest friends, and navigating perspectives when one character makes a shocking announcement. In the play love, frustration, pain, and hope were not just expressed in text (spoken both using devices and natural voice), but through dance, movement, gestures, and, at times, through silence.

In this edition of AGOSCI In Focus, I hope you catch a glimpse of the broad range of ways that people with CCN are able to communicate Here, There, and Everywhere. You'll see communication on the radio, telecommunications, in air, and in the snow. You'll read about communication in Cambodia, Vietnam, Hong Kong, and in Australian communities. And you'll read about some important work that has been done to ensure that people can use systems optimally – knowing what vision people need to be able to see signs. Additionally, a number of personal pieces have been included, Marco Borzini's and Meredith Allan's; these two pieces teach us in the unique way that only an individual with CCN can. In addition, we bring to you a number of resource reviews and an overview of AAC research happening in Australia.

I'd like to close my last editorial with thanks to the editorial committee and all of the contributors to AGOSCI In Focus. You all contribute to the magazine being a great read every edition. Keep your ideas flowing, in particular for our next edition which will focus on AGOSCI's 10th biennial conference: AGOSCI Taking it to the Streets, to be held in Adelaide.

Signing off – *Sheridan Forster*

In Memory of Anne McDonald 11 January, 1961 – 22 October, 2010

It is with great sadness that the AAC community learnt of the death of Anne McDonald. Anne was a great contributor to AGOSCI and had presented at a number of AGOSCI conferences. She was also a personal inspiration to a number of AGOSCI members.

Anne had severe athetoid cerebral palsy and as a result was institutionalised in St Nichola's Hospital at the age of 3 where she suffered neglect and abuse. At the age of 16 with the assistance of Rosemary Crossley she developed a communication system that used facilitated communication as an access strategy. In 1979 when Anne was 18 she was forced to go to court in the Supreme Court of Victoria in order for her communication system to be recognised as valid and to enable her to the right to manage her own life.

Anne completed a Humanities degree at Deakin University in 1993. She was an author and strong advocate for the rights of people with disability, particularly advocating for the rights of people to communication. On her website she wrote: "Communication falls into the same category as food, drink and shelter - it is essential for life, and without it life becomes worthless." Anne was frequently seen presenting at conferences both nationally and internationally and wrote articles and papers related to disability issues. She was a lover of adventure, travel and fun. Her website tells of her love of reverse bungy jumping in New Zealand.

Remarkably Anne touched not only the lives of those who knew her, but also a great many more through her writing and the film of her book. For many young people the first time direct contact they had with the concept of a person having a disability and the power of communication was through reading the book "Annie's Coming Out" which she co-authored with Rosemary Crossley. As AGOSCI member Toni Green described in her posting on the listserv, "...I read Annie's book when I was 17 and was so inspired, couldn't have known then that years later my own child would have athetoid CP and be non-verbal, when she was born guess which book I re read."

With her passing the AAC community and the world, has lost a passionate crusader, a generous communicator and friend to many. The members of AGOSCI express their sympathy to Rosie and Chris, family and friends.





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Chairperson's Report

Sue Owen

I would like to begin by acknowledging the work done by Wendy Webster as chairperson. After putting in a wonderful stint of 6 years, she will be a hard act to follow. When there has been such good momentum and team work it is important not to lose that as we target issues that may need change in order to keep the organization alive, growing and relevant to the needs of all members.

A strong committee working as a team is vital to the health of the group. Traditionally committee members have been nominated and elected at the AGM held biennially at the AGOSCI conference. There may be some merit in reinstating the practice of having "Assistant" positions for committee members allowing for smooth transitions at the end of the term of office. I am only too aware of the dangers of burnout for these voluntary positions and welcome discussion about what measures we could adopt to protect our working committees.

Farewell and thanks to Marion Schultz from the Northern Territory who is resigning as NT rep. We are yet to fill this position, so anyone in the Northern Territory who is looking to contribute a bit more to towards changing things for people who have CCN in the Territory, now is your chance.

We are also losing Sheridan Forster, our co editor for this magazine, who is stepping down after 4 years. Sheridan, we will all miss you and your contribution to making the AGOSCI in focus the excellent resource it has been over the last 4 years.

This year there have been some glitches in recording the details of people who have paid their membership fees. This has been quite hard on Melissa our secretary and meant extra work for her and for Kirsty and Dom who have had to arrange an extra print out of the magazine as people continue to contact us to say they have not received a copy. Copies were sent out to everyone on the list we had and obviously it is very important to have an up to date membership list. Management of membership fees and records is one of our priorities this year and we hope to have a current and reliable system up and running for next year.

It is good to report a most successful Literacy Intensive and three camps for AAC users in Victoria, Queensland, and West Australia. AGOSCI members were well represented at

ISAAC, which was held in Barcelona this year. Many of the AAC users attending the ISAAC conference were people who had previously attended AAC camps in Australia. It is difficult to over emphasize how much families and children gain from such camps, which provide role models to the AAC users, networking opportunities to the families, practical experience to therapists and teachers, and help with individual AAC skills for the students attending. Not only all that, but they have fun too, ask any camper!

Preparations for the AGOSCI conference in Adelaide May 2011 are going ahead and it is shaping up to be an exciting event. Three keynote speakers have been secured for the conference.

Barbara Collier is a real mover and shaker in the AAC world and we have been trying to lure her to Australia for many years now. If you would like to find out more about her work, visit this site

http://www.accpc.ca/ACCPC_executive_director.htm

Darren Sellwood is an AAC user from South Australia with a heap of experience to share and great presenting skills. He was the winner of the Possum Isaac Aspiration Award 2010

Rhonda Galbally, is a third keynote. She is "Social activist, Chair of the Victorian Disability Advisory Council; CEO of "Our Community", and former head of Myer Foundation and of VicHealth."

Your hardworking conference committee in Adelaide is doing a great job. I look forward to seeing you at the conference in May 2011.

As the new Chairperson, I will be working to keep communication channels open for all AGOSCI members. Networking is so important for all AGOSCI members to use in promoting change for people of all ages with CCN and their communication partners around Australia. We have some awesome networkers amongst us. Let us try to reach as many people as we can.

Sue Owen

thanks

to Sheridan Forster, who for the last 4 years has worked hard as co-editor for AGOSCI in Focus. The job of an editor is a year round commitment and Sheridan's diligence, enthusiasm and commitment has helped create the quality magazine you have been reading.

Thanks also to Marion Schulz, who is retiring as NT Rep. You will both be missed.



Money Matters Treasurer's report

Jane Farrall

Before I get into my report, I would like to start with a BIG thank you to Jenny Arthur for her four years as treasurer. Having been in the role for a couple of months now I have realised what a big task it is – and how confusing all the financial jargon is to someone from a non-financial background – so I now have a much deeper understanding and appreciation of what Jenny did. Thank you!!!

My actual treasurer's report will be quite brief. At the time I am writing this, we are still collating all the information from the 2010 National Tour with Joanne Cafiero, the Literacy Intensive with Karen Erickson and David Koppenhaver, and the various state events that have been run. It looks like we have made a loss again this year – but all of that will be confirmed in the annual financial statement.

I am learning lots doing this new role within AGOSCI – and look forward to having a full year in the role next year.



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 320 members and some from overseas. This is up by around 100 members from last year, so it's great to see the AGOSCI word spreading. Just on the membership front - I would urge all members who use EFT as their payment to also send or post a copy of your membership form to me. Especially if your organisation is paying- I would just remind them to also post/fax the membership form, as this will make it easier to process your membership. It gets a little tricky sometimes trying to match a name with no other identifying information. Things will slow down now until early next year. I look forward to a rush of memberships ready for the conference.

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 and hopefully seeing you at the conference.

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

State Reports



TASMANIA

Diane Symons

As I am a little "light on" for things to report about this edition, perhaps the readers will allow me to use this space for a little self indulgence...but with an AAC twist of course! I have just returned from a holiday to Cambodia and Vietnam. When travelling in countries where you don't speak the native language it reminds me of the challenges of verbal communication.



Where I travelled the local people generally had excellent English but there were still the inevitable subtleties that got "lost in translation". Just try explaining Australian sarcasm to someone from a different language and cultural background!

As well as changing my language to use short, simple sentences, and carefully selecting my vocabulary, I also found myself accepting things that perhaps weren't exactly what I wanted, but it was just too difficult to explain! I was reminded of how naturally we all augment our verbal communication: lots of pointing (sign and gesture), really appreciating menus with photographs of the dishes (picture symbols), carrying maps and hotel business cards to show to taxi drivers (remnants/object symbols).

I returned home with a heavier suitcase, many photos, and new friends, but also a renewed sense of the importance of communication and appreciation of my communication skills.





State Reports (cont)



WESTERN AUSTRALIA BRANCH REPORT

Sally Hunter

Plans are well and truly underway for the Variety Motor Mouth AAC camp to be held in May in 2011. There have been many expressions of interest and the organising group has booked the venue: the Point Walter camp site. There has even been interest from participants outside of WA. Kelly Moore recently attended Big Mouth Camp in Victoria for a second time. This time her brief was to note the incredible logistics to make the WA camp a success as well as have a blast and support the campers.

The next AAC device interest group will be held at The Centre for Cerebral Palsy on the 21st of October at 3.30 where Kelly Moore will give feedback from her attendance at the ISAAC and Spectronics conferences. Contact Sue Ash at TCCP for further details.

Makaton WA (soon to be Key Word Sign WA) recently held a 3½ day presenter training workshop. Heather Cullen presented the training, and the new key word sign vocabulary was a focus for the training. The training was rounded up by the fabulous Makaton Musos who travelled all the way from Albany to entertain and enthuse all (see them on Youtube <http://www.youtube.com/watch?v=WZxpqjCzp8g>).

On the website front .thanks to all who supplied permission for new photos to be uploaded. I am very keen to keep state events up on the website (very empty at the moment). Remember non AGOSCI events can be advertised here also. Please feel free to send things to me sally@ilc.com.au along with any documents or websites to link to. Please remember to share your ideas and feedback on the listserv and leave training (other than AGOSCI) off the list serv. Thanks to everyone who participate so well.



NEW SOUTH WALES

Sheila Salunke and Johanna Korkalainen

This half of the year, we've had some recent change with our NSW Co-Representative positions. Following Harriet Korner and Nicole Thompson stepping down from this role, both Sheila Salunke and Johanna Korkalainen have now stepped up to the challenge. We would both like to thank both Harriet and Nicole for their amazing contribution and time in building up AGOSCI New South Wales - we certainly have big shoes to fill!

On the 15th July was the first AAC User Group Meeting, held at the Computer Assistive Technology Room at Northcott Disability Services. Following the enthusiasm of a small group of adult AAC users who wanted to establish a forum where all users can get together, socialise and talk about their experiences with AAC, a series of meetings are being planned with the hope

of encouraging more people to attend. We are planning our next meeting towards the end of September. For more information and future meeting dates, please contact Sheila Salunke (sheila.salunke@northcott.com.au) or 02 4640 8720.

Sponsored and supported by ILC NSW, Northcott, and AGOSCI, we are very pleased and excited to announced that Gayle Porter will be coming to Sydney to present a Pragmatic Organisation Dynamic Display (PODD) workshop on the 14-15th November 2010 at Northcott Disability Services Conference Centre, 1 Fennell Street, Parramatta. This is a wonderful opportunity for everyone who is interested in understanding the ins and outs of PODD. For more information and details, please contact Sheila Salunke (sheila.salunke@northcott.com.au); (02) 4640 8720 or Harriet Korner (harriet@ilcnsw.asn.au);(02) 9890 0942.

AGOSCI NSW will be organising a networking afternoon tea for all members and prospective members. It's a great opportunity for everyone to meet, network, and listen to a couple of guest speakers, whilst munching on some afternoon tea. It will be held on the 14th October, 1:00 -2:30pm at The Conference, The Spastic Centre of NSW, 224-244 Restwell Rd, Prairiewood. For more information and to RSVP, please contact Johanna Korkalainen (JKorkalainen@tscnsw.org.au) or, 8777 1777.



AUSTRALIAN CAPITAL TERRITORY BRANCH REPORT

Cathy Hurman

My name is Cathy Hurman and I have recently taken on the role of AGOSCI Representative for the ACT. I am a speech pathologist and have worked at Therapy ACT since 2001. Currently I am working as the speech pathologist in the Therapy ACT Equipment Service. Some of you may remember me, as I was the ACT Representative many years ago. I stepped when I had my first daughter almost 5 years ago but I am looking forward to getting back into AGOSCI. At the moment, I'm focusing on getting myself organised and settling into the role. I will be attending the State Representatives meeting in Adelaide in early October and hope to organise an ACT meeting shortly after my return. I hope to see many of you there so that we can discuss the direction for AGOSCI in the ACT and start some planning for local events. I can be contacted at cathyhurman@hotmail.com.



VICTORIAN BRANCH REPORT

Katie Lyon and Stacy Cohen

Wow! I am still buzzing from my unforgettable experience at the 14th Biennial ISAAC Conference held in the wonderful vibrant city of Barcelona. There were about 30 or so Australians who attended the conference and around 10 of these were Victorian members; such a great effort for us seeing as it is so far away! Many of the Victorian members presented papers at the Conference too and included Naomi Rezzani, Melinda Smith, Karen Bloomberg, Hilary Johnson, Gayle Porter, Barbara



State Reports (cont)

Solarsh, and David Trembath.

A big CONGRATULATIONS goes to Hilary Johnson who was awarded the ISAAC Distinguished Services Award for recognition of her outstanding contribution to the field of AAC through clinical work, information/knowledge, distribution, and research. Certainly a well-deserved winner I'm sure you will agree!

Morgan Liddle was also one of the stars of the AAC band – who opened the conference with their fabulous musical talents.

In order to share this experience and new found knowledge with our AGOSCI members, the Victorian branch is hosting an ISAAC feedback session on the 6th October. This was such a fantastic opportunity to be part of the international AAC community, to meet so many new faces from all over the world, and to get up to speed with some of the exciting research happening! I would really encourage all of you to attend the next ISAAC conference, which will be held in Pittsburgh in 2012.

As always, we are really open to any ideas you have for education opportunities or just informal catch ups. Please let us know by emailing katie@spectronicsinoz.com



QUEENSLAND

Paula Hartwig & Melanie Waalder

The Queensland Branch report for this edition is short and sweet.

Following Dr. Cafiero's very successful tour in Brisbane and Townsville in March 2010, AGOSCI Queensland had the delight of hosting Gayle Porter and Melissa Riepsamen for another successful Pragmatic Organization Dynamic Display (PODD) workshop in April 2010. The April PODD workshop again held 50 participants from a range of professionals (eachers, teacher aides, speech –language pathologists, and occupational therapists) as well as a few parents. Participants came from all over the state as well as one participant from Tasmania. All participants were full of inspiration following the end of the workshop and were keen to incorporate the skills they had learnt into their profession or home life. AGOSCI Queensland plans to run a number of events in the near future both in Brisbane and other parts of Queensland (e.g., Townsville, Rockhampton). Please contact Melanie or Paula 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.

The Queensland Branch is gearing up for the AGOSCI Conference 2011 in Adelaide – 'Taking it to the Streets' and look forward to Queensland AGOSCI members joining us on the trip down to Adelaide.

ISAAC Membership

What is ISAAC?

ISAAC stands for International Society for Augmentative and Alternative Communication.

- ISAAC is an international organisation that focuses on Augmentative and Alternative Communication

What is Augmentative and Alternative Communication?

AAC is any communication system that supports people who have a severe communication impairment.

ISAAC'S Vision

AAC will be recognised, valued and used throughout the world.

ISAAC'S Mission

To promote the best possible communication for people with complex communication needs.

MEMBERSHIP IS OPEN TO EVERYONE INTERESTED IN AAC.

If you want to become a member, you can join online via our secure website at www.isaac-online.org

or contact: the ISAAC Secretariat, 49 The Donway West, Suite 308, Toronto M3C 3M9, Canada

Phone: 1-416-385-0351; Fax 1-416 385-0352; Email: mona.zaccak@isaac-online.org

ISAAC AFFILIATED PUBLICATIONS

AGOSCI In Focus

Affiliated Publication (formerly AGOSCI News) Published in English twice yearly in Australia – May & November Special ISAAC rate: \$37. CDN

Communication Matters

Affiliated Publication: Communication Matters Published in English in the UK three times per year - April, August and November. Special ISAAC rate: \$57. CDN

ISAAC Israel Journal

Affiliated Publication: ISAAC Israel Journal. Published, annually in the spring, in Hebrew with English abstracts. Special ISAAC rate: AIR MAIL delivery \$33. CDN

Unterstützte Kommunikation

Affiliated Publication: Unterstützte Kommunikation. Published in German by ISAAC-GSC four times per year, March, June



Augmentative and Alternative Communication

(AAC) is the official journal of the International Society for Augmentative and Alternative Communication (ISAAC), published quarterly by Inform healthcare, United Kingdom. AAC publishes original articles with direct application to the communication needs of persons with severe speech and/or communication impairments for whom augmentative and alternative communication techniques and systems may be of assistance.

Special rate for Corporate & Institutional Member \$293. CDN

Special rate for all ISAAC members \$98. CDN

Special rate for PWU AAC/Student/Retired \$59. CDN



AGOSCI Conference 2011 Update

By Janelle Sampson



As I write this update, it's only 7 months to go until the conference, by the time you read it there will be even less. So there's lots to report, and things are hotting up!! Please make sure you **join our Facebook page** (just type AGOSCI in the search window to find us) and/or register at our website <http://www.alloccasionsgroup.com/AGOSCI2011> to receive updates.

We now have our 3 keynote speakers confirmed: Barbara Collier, Darryl Sellwood, and Rhonda Galbally. All three are wonderful speakers and will provide the following interesting and thought provoking presentations.

- **Dr Rhonda Galbally AO** - Into the Streets: People with Disabilities Fully Participating in Australian Society
- **Barbara Collier** - Creating Accessible Community Services for People who use Augmentative Communication
- **Darryl Sellwood** - Take This: it's More Than Participation, it's Enabling Satisfying Lives

More details on the speakers and the topics of their presentations are available on the website. <http://www.alloccasionsgroup.com/AGOSCI2011>

Other program highlights include:

- An exciting **pre-conference program** featuring:
 - a practical workshop on telecommunications for people with CCN presented by Darryl Sellwood titled *Finding Telecommunications Solutions for People who Rely on Augmentative and Alternative Communication (AAC) Technologies*
 - a full day session presented by Dr Robyn Young and Dr Julie McMillan titled *Communication and Behaviour of Children with Autism: Recognition and Intervention in Education*
 - and 2 half day workshops presented by

Barbara Collier titled *Directing Personal Assistant Services at Home* and *Directing Communication Assistants in the Community*

- **Breakfast panel discussion** that was originally prompted by a discussion on the AGOSCI listserve about issues people have in convincing others to support use of AAC. The breakfast session is titled *"Making an Influence Outside the Square: Encouraging Others to Get on Board and Support the Use of AAC"*. There is also a scrumptious breakfast to get you started for the day.
- **Key Word Signing breakfast** – State of the Nation - an update, meeting, and cooked breakfast for KWS presenters.
- **Welcome reception** at the South Australian museum featuring an AAC/AGOSCI museum that will also be on display to the general public for a month. This event will also be the official AGOSCI 30th birthday celebration.
- The famous **conference dinner**, drinks, and dancing at the National Wine Centre.
- And of course, an **inspiring program of presentations, poster sessions, and exhibits.**

Registration brochures will be available by the end of November 2010, and Early Bird Registration closes on Friday 25 February, 2011. Also for those eligible, don't forget the scholarships for conference attendance. Information on these scholarships is available at the AGOSCI website www.agosci.org.au

We look forward to seeing you all there.

Janelle Sampson

AGOSCI 2011 – Conference Convenor (on behalf of the full conference committee).



ISAAC AUSTRALIA - Your link to the International World of AAC



By Barbara Solarsh

bsolarsh.crc@scopevic.org.au

The AAC community in Australia is indeed fortunate, with a vital and committed national organization in AGOSCI, boasting a membership of approximately 350, and a smaller, but no less vital and committed international organization in the Australian chapter of ISAAC, with a membership of 51. The fact that most ISAAC members are also AGOSCI members ensures that the two organizations work collaboratively in facilitating our mutual aim of promoting AAC across the country, as well as promoting Australia as a significant player on the international stage.

The members of the 2010-2012 executive committee of ISAAC Australia stretch far across Australia, from Victoria to Queensland and to South Australia.

Barbara Solarsh

Barbara Solarsh is the new president of ISAAC Australia. She works in Victoria at both at the Communication Resource Centre, Scope, and in the Regional Communication Service, Bendigo Health as part of the Communication Access Network. Her interests are in the development



of sustainable service delivery models for adults with complex communication needs (CCN), particularly in regional and rural areas, and in developing the concept of communication accessible communities. Her hopes for her term as president are that in partnership with AGOSCI, AAC will achieve growing prominence and recognition, that AAC users will increasingly take leadership roles in ISAAC Australia, that members across Australia will become active during ISAAC AAC Awareness Month and that the membership of ISAAC Australia continues to grow. Having arrived in Australia (from South Africa) with her family almost 7 years ago, she now feels very much part of Australia.

Bronwyn Hemsley

Bronwyn Hemsley is the Australian representative to the ISAAC Board of Directors. She works in a post-doctoral program at the University of Queensland on research into communication in hospitals. Bronwyn has a special interest in engaging people with CCN, their families, clinicians, industry partners, and researchers in dialogue about developing research that has real outcomes in practice and policy for improving the lives of people with CCN. Bronwyn's role is to be another bridging link between ISAAC and ISAAC AUSTRALIA. Bronwyn is also the contact point for AAC Awareness activities in Australia during October 2010.



Meredith Allen

Meredith Allan has been the treasurer since ISAAC Australia started almost 10 years ago. Meredith is one of the few AAC users in Australia working in the full time open employment. She was a member of the Ethics Committee of Speech Pathology Australia 2002-2008. She is the author of numerous articles about the experience and issues related to AAC, and makes regular presentations at conferences both nationally and internationally.



Deb Schwier



Deb Schwier has been the secretary of ISAAC Australia for the past three years. She has worked as a speech pathologist for Novita Children's Service for 17 years, providing services for children. Her main area of focus is in supporting children with CCN to be active and valued

participants within their community and supporting children with swallowing impairment.



ISAAC AUSTRALIA (cont)...

Currently ISAAC International, with its head office in Canada, has 3,634 members from 62 countries. The biennial ISAAC conference is the life force of ISAAC, and this year's conference in Barcelona was no exception. Australia was very well represented with approximately 30 people at the chapter meeting held during the conference. There was a record number of eight AAC users from Australia, three of whom received a grant from ISAAC Australia to support their attendance.

At each conference the chapter presidents and representatives from all affiliated countries have a day long council meeting. While the Council meeting highlights the diversity of ISAAC, it also brings the differing needs of countries into focus, so that all members are aware of issues internationally. The conference serves not only as an important meeting place for the international AAC community, but also provides the opportunity for members internationally to engage with the three central projects which ISAAC promotes: LEAD, READ, and BUILD.

The LEAD project emphasizes the importance of people who use AAC developing and taking on leadership roles within ISAAC and the broader community. In Australia, Melinda Smith and Karen Bloomberg have made significant contributions to the LEAD project and will continue to work with the new chairperson, Faye Warren from USA. At the ISAAC AUSTRALIA chapter meeting Gayle Porter also volunteered to be involved in this project.

The second ISAAC project group is the READ project. The aim of this project is to inform ISAAC members about AAC and its developments through the website, the Information Exchange, and E-news which is sent to members. It also aims to promote research and development in all aspects of AAC. David Trembath, LaTrobe University, has volunteered to be the Australian link person to the ISAAC READ project.

The third ISAAC project is BUILD. This project aims to promote the use of AAC in emerging countries, as well as countries with no or very limited infrastructure for AAC. Barbara Solarsh has volunteered to be the Australian contact for the BUILD project.

ISAAC recognizes outstanding individuals on the AAC stage through awards at each conference. There are awards for individuals who use AAC and for people who contribute to services or the development of the field. Over the years a number of Australians have received the awards. In 2010, Darryl Sellwood from South Australia won the prestigious ISAAC Possum Award. The award is given to a person who uses AAC to expand their future opportunities. Darryl plans to use the money to further his doctoral studies. Hilary Johnson from the Communication Resource Centre, Scope, was given the ISAAC Distinguished Service Award. The award recognised her outstanding contribution to the field and highlighted the work she has done with the ISAAC Board.

In the next few months we, as ISAAC and/or AGOSCI members have two opportunities to make a contribution to promoting AAC.

October is the official ISAAC Communication Awareness Month. We can make a difference to the Australian AAC community by promoting communication awareness and celebrate what AAC offers. The event can take place at any time in 2010- it is not restricted just to October We will publicly acknowledge your efforts in the next ISAAC Newsletter, so send information and photos to Bronwyn Hemsley. All events are also passed on to ISAAC to go onto the ISAAC website - so let's really put Australia on the map! There are a number of activities planned in Victoria, and we would love to hear that something is happening in each state and territory. You can go to the ISAAC website for ideas of what to do, or contact Barbara Solarsh to hear about what is happening in Victoria.

The other opportunity is to make a contribution internationally to some outstanding work being done by Augmentative Communication Community Partnerships Canada (ACCPC). Barbara Collier, director of the organization is a strong advocate for the emerging concept of Communication Access. Communication access is defined as when a person has "the means, skills and supports required to communicate authentically, effectively, meaningfully and equally to others when accessing goods and services" (Blackstone and Collier, 2008, ISAAC conference presentation, 2010). ACCPC has produced a booklet in which Communication Access is described and defined. It is a free download from their website www.accpc.ca. In order to explore the barriers and issues related to effective communication access for people in their communities, two surveys have been posted on the ACCPC website. One survey is for AAC users to complete, and explores their experiences of communication access and what they think should be done to improve the situation. The second survey is for people who are involved in any way with someone who uses AAC. Barbara is appealing for international response to these surveys. She aims to collect a wide spectrum of information that may be internationally applicable. She would like to take this issue forward at both a policy and social level. We, as Australians, could make a valuable contribution!

Finally, mark your calendar for the next ISAAC Conference: ISAAC 2012 www.isaac2012.org in Pittsburgh, USA, July 28-August 4 (for pre-conference workshops, AAC Camp, Executive and Council Meetings, the main conference, and research symposium).

The next ISAAC Australia AGM for members will take place at the AGOSCI conference in 2011 and a warm invitation is extended to anyone interested in the Australian chapter of ISAAC.



Member Talk

SUE OWEN

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!

I use Talking Mats to help clients discuss and record issues that are important to them. I help to create DVDs for people that showcase their life stories and their interests, to share with support staff and friends.

We all know how vulnerable and how little respected people with CCN are in the community, there is never enough time to do all that could be done. I am lucky to have a sympathetic and informed management who will advocate for the person with CCN if an impasse is reached.

Why do you like about being a member of AGOSCI?

AGOSCI is a most important part of my working life. At the times I have worked as a sole therapist it has given me a network of colleagues and friends that I can relate to and ask for advice. I love the listserve and the comments people add to topics being discussed. I love that it brings speakers to Australia that we would not otherwise be able to access and that it promotes Australians who are doing great work in the community. I love to see the progress of people from first tentative comments to articles, presentations, and then to serious research. I love that it includes people with AAC as an essential part of the organization and actively works to bring such people to public forums. To quote my predecessor, Wendy Webster, I am always incredibly proud that AGOSCI flourishes on the efforts of volunteers, and, finally, I really love that it is equally accessible to therapists, educators, families, and people with CCN.

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

These things are not arranged in any order of precedence or importance, they are things that have impressed me over the last 10 years,

- Improvements in AAC technology, including the first moves toward generic technology
- New approaches to working with people with severe intellectual disabilities that show respect and acceptance
- Access to literacy for children who are AAC users

How long have you been a member of AGOSCI?

I can't remember exactly when I first become a member of AGOSCI, but I do remember very clearly the first visit from Hilary Johnson and Karen Bloomberg, who came to Adelaide in the eighties and presented their work and ideas around AAC and Complex Communication Needs (CCN). It provide the spark that ignited the fire and lit up the whole AAC scene in South Australia at that time. We brought speakers in from overseas such as Margaret Walker, Pat Mirenda, and Carol Goossens, Ph.D., CCC-SLP. New communication technology became available and we discovered we could give children access to functional communication despite their having profound disabilities. It was a most exciting time to be working in the field of CCN.

AGOSCI has been part of my working life in South Australia, Victoria, NSW, and Queensland.

How are you involved with people with complex communication needs?

Currently I am working for Lifeline Disability Service based in Brisbane. I provide assessment and support for adults with intellectual disabilities who live in housing arrangements supported by Lifeline. I do staff training to try to maintain a stable communication environment for people who support their communication with key word sign or with other forms of AAC. In 2009, we changed the focus from staff needs for training to the client's needs. Our clients are invited to bring new staff or friends along to fun Key Word sign sessions where they can work together to improve and understand mutually important key word signs.



MEMBERTALK (cont)...

- Increasing range of functional visual material available to people who have limited literacy skills
- It has been an old complaint that AAC users are very passive communicators. Try a conversation with a student who has been taught to use a PODD and see the difference!
- Increase in peer reviewed research in AAC in Australia

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

I think we have only seen the tip of the iceberg in the work being done for children with Autism Spectrum Disorder (ASD) and Rhett's in relation to movement and sensory disorders.

With ASD, it feels as if we have many people working on small sections of a very big jigsaw puzzle. I hope we can see the whole picture more clearly in the future.

Proloquo2go is the first step in providing a truly generic solution for people with CCN. I hope we see much more technology that is affordable and cool to use, rather than labeling the user as disabled.

We still need to improve early intervention for children with CCN and for adults with acquired CCN.

We still need to work for better school and community inclusion for AAC users including real tertiary education and access to paid work.

AAC on the Radio

By Mark Halupka

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Hi, my name is Mark. I am 21 years old. I can't speak using my mouth, but I can get my message across. When I'm at home with mum, I use my face, noises and my wheelchair tray top communication board to communicate. I also use my Dynavox to speak my ideas. I've had a Dynavox for about 10 years. I like using quick phrases and words to communicate how I feel about things. My favourite word is "probably".

Since leaving school, I've started doing new things. I've always really loved listening to the radio, and last year I started going to a radio station to see how it all works. When I first started going to the station, I would listen to everything that was going on. Now days, I use my Dynavox to talk on air. I still need some help from mum and my support workers to program in messages before I go, but only a little bit of help once we get there.

One of my jobs at the radio station is to interview people. I ask the person questions and they answer. Sometimes the interview is recorded and played back later, and sometimes the interview goes live. The radio station is special and you can only listen to it on the computer.

Sometimes I help choose the music that is played. My favourite song is "Bad Day". One day I'd like to be able to talk on the radio without having to program the words into my Dynavox first. This is called ad-libbing.

Another thing I really enjoy is sport. Mum and I went to the tennis in January. We had great seats. I was able to keep score on my Dynavox when mum was away from her seat. My friend and I also went to the cricket. I kept score and chatted about the game with my friend.

My Mum and my Speech Pathologist think I'll eventually be able to do much more on my own in the community using my Dynavox, but it's going to take some practise..... probably.





Telecommunications Website Project for People with Complex Communication Needs

By Rob Garret, Toan Nguyen and Harriet Korner

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"The term *Complex Communication Needs* is used in this article to refer to people who identify as having a severe communication impairment and / or complex communication needs."

A project is currently underway to develop a community based website / wiki for individuals with complex communication needs and their supporters. Wikis are a way to create collaborative community websites. A wiki is a website that allows the easy creation and editing of web pages, allowing input to the website from the community. This project has been funded primarily by the Australian Communications Consumer Action Network (ACCAN) Grants Scheme, with



in-kind funding and support from the Australian Communications Exchange (ACE), Telstra and Novita. Rob Garrett is the Project Coordinator, working with Toan Nguyen and a reference group of people with complex communication needs and supporters from around Australia.

Telecommunications has often been an area of difficulty for people with complex communication needs. Relying on a speech-generating device when using the telephone has many areas of difficulty, such as the time taken to compose messages, poor sound quality and difficulties with accessing phones. Some people have found recent technology has improved this situation, with touchscreen phones (such as iPhones), texting, Facebook and Twitter providing new options.

The National Relay Service includes options for people who use augmentative and alternative communication, such as speech generating devices and computers with speech and/or text output, as well as for people who have speech that is difficult to understand. However, not everyone who needs these options knows about them. Not everyone who knows about them finds that they work for them. Solutions are often a mix of things that work for an individual.

There is also a need to think about other methods of communication, such as signing and pictures, for people rely on these modes of communication. It is hoped that the website will provide a way for people to share their knowledge, experience and ideas about what is needed across all kinds of complex communication needs.

The website aims to help people succeed with telecommunications – whether this is by using a phone, texting, Facebook or Twitter – “telecommunications” is any form of long distance communication. The website will be interactive and will enable

people with Complex Communication Needs and their supporters to add information on available solutions and to receive directions to known useful resources.

Objectives of this project are:

- to share information about solutions
- to provide individuals with an opportunity to highlight gaps in telecommunications access and information
- to collect information that the community needs and collate it in one space
- to allow a space where individuals can voice their opinions
- to identify actions and funding required to make telecommunications more accessible.

Website design is being lead by Rob Garrett and Toan Nguyen with Shannon Roos from ACE and in consultation with Dr Daniel Woo, University of NSW. The website project reference group is helping to link with the community. Members of the reference group are:

- Darryl Sellwood, a Director of Australian Communication Exchange Limited, University of South Australia Researcher (Honours) and an AAC user;
- Matthew Hesketh, a qualified Engineer (CAD) and website designer. Matthew is studying psychology, has Transcortical Motor Aphasia and works part-time as a builders drafter;
- Hank Wyllie, a fiercely independent and individual person with Acquired Brain Injury, acquired late in life, who communicates by means other than speech;
- Jan Ashford, CEO, Communication Rights Australia;
- Annabel Vasquez, Education and Information Officer WA/QLD, National Relay Service;
- Harriet Korner, Client Services Manager, Independent Living Centre NSW.



TELECOMMUNICATIONS WEBSITE PROJECT FOR PEOPLE WITH CCN (cont) ...

The project is funded for one year up until June 2011. The website is in the initial design phase at present and will then be trialled and improved. This will be an accessible website, aiming to be easy to use with good design, to help answer people's questions and find solutions.

We would like "end users" - that is, individuals with complex communication needs and supporters - to provide suggestions, feedback and advice to make this website useful, practical, interesting, interactive and above all empowering...



The project team wants to hear from you!

Could you let us know about your experience in using telephones and telecommunications

- What works for you?
- What has not worked?
- What are questions you would like to have answered?
- What are good solutions to using telephones that worked for you?
- Are there any issues you'd like to bring up for the website developers to consider?
- Have you any suggestions about what makes a good website?

Let's use the website to build our community, so all the people who have a communication disability, with little or no speech, and their supporters, have great ideas about ways to connect in whatever ways they find can work.

Yes we can ...telecommunicate!

To help with this project, please contact the CCN/SCI Telecommunications Project

c/ Rob Garrett

Project Co-ordinator

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agosci positions

Co-editor:

If you've ever wanted to know what's in AGOSCI in Focus before everyone else, then this job is for you. Work together with Kirsty Holcombe and Dom van Brunschot to help this magnificent publication see the light of day. No previous experience required. Can live in any state. To find out more email Kirsty at agosciinfoocus@yahoo.com.au

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Vision Impairment and the Visibility of Key Word Signs

By Annette Clarke, Speech Pathologist, Royal Institute for Deaf and Blind Children (RIDBC)

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Introduction

Individuals who have multiple disabilities, including sensory, intellectual, and physical impairments, often experience difficulty acquiring speech and may require augmentative and alternative forms of communication (AAC) (Iacono, Mirenda, & Buelkelman, 1983). Key word signing is a commonly implemented form of AAC, particularly for individuals with multiple disabilities (Grove & Dockrell, 2000). As signing is a highly visual mode of communication, adequate visual skills are required to view signs. However, there are no specific guidelines to determine if a person with vision impairment is able to successfully view signs (Glidden-Prickett, 1998). This is problematic as it is estimated that up to 75% of the total population of people with multiple disabilities have vision impairments (Tavernier, 1993).

A review of literature on individuals with multiple disabilities including deafblindness, has found no specific information about visual prerequisites for signing. While the need to consider functional vision is highlighted (Blaha & Moss, 2002; Utley, 2002), no detailed guidelines were found in the literature. Therefore, practitioners such as speech pathologists who are typically involved in implementing key word signs may not have adequate information to determine whether a person with vision impairment will be able to successfully see signs.

Two projects have been undertaken at the Royal Institute for Deaf and Blind Children (RIDBC) that provide information about the impact of vision impairment on the visibility of key word signs.

Project 1: Vision Simulation Booklet

This booklet is a result of a joint Speech Pathology/Orthoptic project and provides information for parents and professionals about the use of key word signs with children who have vision impairment. The booklet contains photos which provide an approximate simulation of vision impairment (reduced visual acuity). The photographs were produced using a Snellan Vision Chart to adjust the focus of a digital camera. The

vision simulation photographs in the booklet cover many key areas that impact on the visibility of key word signs including: lighting, colour contrast, and distance. The photograph below illustrates the effect of reduced visual acuity on sign visibility. Visual Acuity is a standardised measurement for determining a person's ability to see detail at specific distances (Telec, Boyd, & King, 1997). For example, a person with 4/60 VA can see at four metres what a person without vision impairment can see.

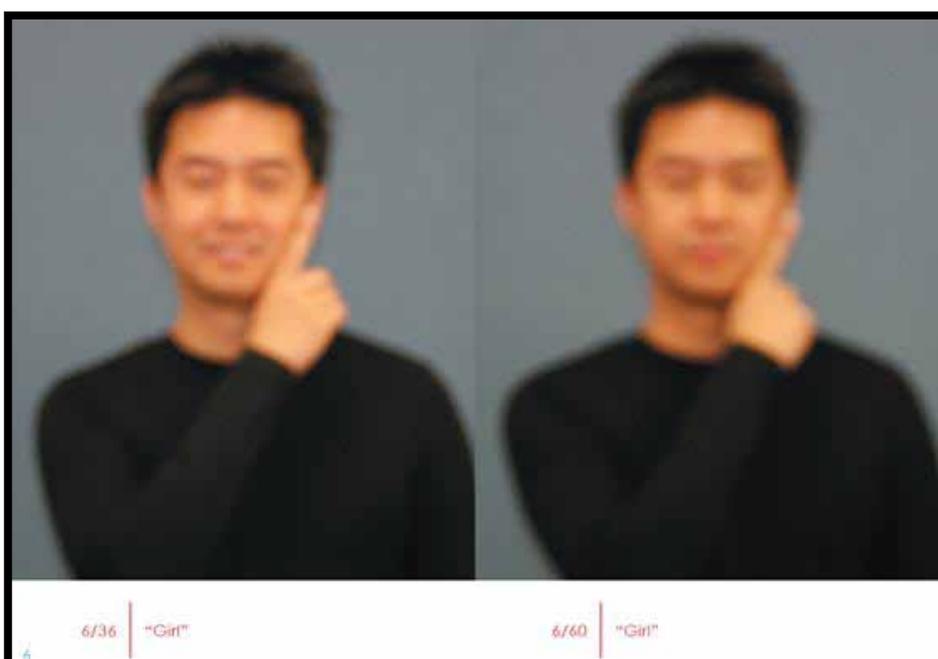


Fig 1.1 Vision simulations for the sign "girl" viewed at a visual acuity of 6/36 and 6/60 at 60 metres. Normal VA is in the range of 6/6-6/9.

The booklet is called *Understanding Vision Impairment- Vision Impairment and Sign Language* and is available on the RIDBC website www.ridbc.org.au.

Project 2 – Research Study

In 2008, I carried out a quantitative research study investigating the impact of reduced visual acuity on the visibility of key word signs as part of my study on the Masters of Special Education (Sensory Impairment) at the University of Newcastle. The aim of the study was to investigate the effect of reduced visual acuity; 6/36 and 4/60, on the visibility of: (a) sign hand shape, and (b) sign hand movement of key word signs that are formed near the



signer's face.

The study specifically aimed at investigating the visibility of signs formed near the signer's face as these signs incorporate more detailed hand shapes than signs which are formed on or in front of the signer's body (Swisher, 1990). The study investigated two signer to viewer distances, that is, 1.5 metres and 2.3 metres. The study had a sample size of 31 participants. The criteria for selection of participants for this study were: (a) visual acuity (VA) in the normal range, that is, 6/6-6/9; (b) unimpaired imitation skills, as assessed through a short screening criterion; and (c) no formal signing experience. Potential participants were assessed regarding these criteria prior to inclusion in the study. All signs used in this study were selected from the Auslan Dictionary (1998).

Conclusions

Analysis of the results provided the following conclusions:

- Participants with severe vision impairment (VA of 4/60) performed significantly worse than participants with normal VA and moderate vision impairment in their ability to identify sign hand shape ($p < 0.01$) and sign hand movement ($p < 0.01$).
- There was a significant difference between the ability to identify sign hand shape as opposed to sign hand movement for participants with moderate and severe vision impairment ($p < 0.01$).
- Increased distance did not significantly affect participants' ability to identify sign hand shape or sign hand movement for the two distances investigated.

Implications

The results of this study indicate that reduced visual acuity adversely affected participants' ability to recognise aspects of sign phonology, that is sign hand shape and sign hand movement, which are essential to sign recognition. Individuals with severe vision impairment were less likely than those with normal vision and moderate vision impairment to successfully view signs at typical sign to viewer distances. Results also indicated that reduced visual acuity affected the visibility of sign hand shape more significantly than sign hand movement.

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AAC IN HONG KONG – Challenges for “Taking it to the Streets”

By Jordana Vespa, ComTEC, Yooralla

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ComTEC is a service of Yooralla in Melbourne that provides information and advice on assistive technology (AT) to adults and children and their support teams. ComTEC specialise in the following areas of AT: Speech Generating Devices (SGDs), software and hardware for computer access, and environmental control (ECU).

Recently, ComTEC had the pleasure of having a guest from Hong Kong. Fion Tang is a speech pathologist who works at SAHK (formerly the Spastic Association of Hong Kong). SAHK is an organisation not dissimilar to Yooralla. SAHK provides services to children, adults and the aged, including community rehabilitation, outreach, employment services, and residential services. Fion works with adults in a community rehabilitation and outreach setting who have a range of developmental and acquired conditions.



Cath Williams, Fion Tang, Jordana Vespa

For speech pathologists working with both children and adults at SAHK, the majority of their caseload is work in dysphagia assessment and management, with some work in articulation assessment and therapy. Most of the dysphagia work is around the development of oral motor skills. Around 10% of their overall caseload involves Augmentative and Alternative Communication (AAC).

According to Fion, most speech pathologists in Hong Kong work in the area of pediatrics, mostly in special schools and non-for-profit organisations like SAHK. Hospitals are another typical setting, and private practices are becoming more and more common.

Fion's own work with her clients at SAHK is confined to the base. She works in the community rehabilitation centre, generally with clients with acquired conditions (e.g., stroke, progressive neurological disorders such as Parkinson's disease). She also works with clients with developmental conditions (e.g. Down's syndrome, Cerebral Palsy) and this tends to be in their sheltered workshop and residential facility at SAHK. Fion works directly and indirectly with her clients. She plans and provides training to the staff in her organisation around issues on dysphagia and

AAC. She has spent a lot of time creating low-tech aids for clients and appreciates it when she is able to have help from assistants for this (we know how time consuming this can be!).

The Rehabaid Society is a government funded organisation that provides services that include one of the largest displays of AT in Hong Kong. Just as the Independent Living Centre (ILC) does here in Australia, Rehabaid has in its display a large range of equipment for independent living from wheelchairs to support and positioning aids to eating and drinking aids. Rehabaid also includes the AT that ComTEC specialises in. Just like ILC and ComTEC, Rehabaid maintains a comprehensive product database. A closer look at the database reveals a smaller range of products from which to choose when looking at AT for communication, including high-tech AAC. Types of AAC used in Hong Kong

Low tech AAC tools are widely used in Hong Kong. A survey that was conducted in SAHK's sheltered workshop in 2008 found that more than half of the AAC users used both low-tech and high-tech aids at the workshop. However, most people who used one type used low-tech rather than high-tech AAC. High-tech AAC that Fion referred to was mostly software (some of it text to speech) used on a laptop computer, with few dedicated speech generating devices (SGDs).

Fion had never come across dedicated text to speech devices before she visited us here at ComTEC, where she was surprised to see such a range (such as the LightWRITER and Polyana 4). Fiona liked some of the features available on these devices which made the device easier to physically or visually access – such as the keyguard on the LightWRITER or the larger screen on the Polyana 4.

Some of Fion's clients use the Hummingbird communication device, which is a relatively simple SGD with a few levels to store 12 messages per level. The Picture Master Communication System, also commonly used, is computer software that is used for voice output for those who don't have the literacy skills to use text to speech software. One of the reasons for the small range of products such as text to speech software is partly due to



AAC IN HONG KONG - CHALLENGES FOR "TAKING IT TO THE STREETS" (Cont) ...

the lack of development of software in Mandarin or Cantonese. Clients with physical disabilities have the opportunity to use specialised hardware such as switches and joystick mouses to have easier access to their communication.

Fion reported that her organisation is currently exploring the use of communication apps on iPad and iPhone, however this is limiting due to no current Chinese communication apps.

Key word signing is not commonly used in Hong Kong amongst people with communication impairments. Some clients with good fine motor skills are taught the sign language system developed by the Hong Kong Society for the Deaf. For clients with physical impairments, SAHK has developed a modified signing system.

Challenges in AAC in Hong Kong

Funding

Just like in other countries around the world, lack of funding is an issue in Hong Kong. Currently there is some funding available from Rehabaid for people with disabilities to purchase AT but this is limited. Unfortunately, Fion reported that this funding will cease at the end of the year. Therefore a lot of high-tech AAC will be limited to clients who are well off or to organisations purchasing them for clients to use. There is also lack of funding for therapists to work with these clients; therefore time becomes limited and the extent of support for clients and their teams becomes inadequate.

Support

Even though Fion works full time at SAHK, she gets to have contact with her clients about once a week. Because the use of AAC tends to be in specific centres such as SAHK, or hospitals or schools, Fion highlighted the importance of educating staff/caregivers on the rationale, benefits of, and use of AAC with the person. Fion certainly wishes she had more time to spend

on the very important role of education in AAC. At this stage however, in Hong Kong, there is no focus on getting AAC out of these specific environments, where Fion report that the clients "practise" using their AAC, and instead communicating in different community environments.

Space

Space is limited in a place like Hong Kong and this also negatively impacts the use of AAC. Adequate space is required for mounting of AAC and this does not appear feasible to many people who support those in wheelchairs. This appears to feed into AAC users only being able to use the equipment in the specific environments, where educated staff may need to hold the aid in the right position for the person to use.

Summary

We in Australia share some of the challenges as support people of AAC users in Hong Kong do. While some of the funding schemes in Australia are relatively generous in comparison to Hong Kong, such as the Aids and Equipment Program – Electronic Devices Scheme and the Non Electronic Communication Aids Scheme in Victoria, there seems to be similar issues around not having enough resources, such as the number of speech pathologists on the ground to support the process of a trial, set up, implementation of AAC, as well as the provision of education to support people. There certainly isn't the range of AAC or assistive technology available in Hong Kong. However, there are very keen and enthusiastic people like Fion, who understand the importance of AAC and what it means in a person's life, who continue to work with the resources they have to ensure communication is a very real option for people with communication impairments in Hong Kong.

Congratulations ...

To **Camp Have a Chat (QLD)** Who this year ran a successful camp along the theme of "**MISSION IMPOSSIBLE**".

Not only did all involved have fun, learn lots and make good friends, but the camp also got some major media coverage on the channel ten news.

Check it out at:
<http://www.youtube.com/watch?v=xBb4vL6aHfM>

Well done all!

To **Darryl Selwood** (South Australia) for winning the ISAAC Possum Award and **Hilary Johnson** (Scope) for receiving the ISAAC Distinguished Service Award.

It is great to see Australians in the field of AAC recognised internationally. For more information about these rewards check out the ISAAC Australia report in this edition.



The Power of Speech: The Power of AAC

By Meredith Allan

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The following is a presentation by Meredith Allan at the 2009 "Feel the Power" conference.

In late 2006, for World Aids Day, the Aids Trust (USA) produced an advertisement for television. The advertisement simply showed short snippets of speeches by John F. Kennedy, Martin Luther King, Nelson Mandela, and Desmond Tutu, then closes on three words. Those words were *Words are Power*.

Words are power. Even though they show no women in the advertisement, we can use the symbolism in those three words. Words are power.

Introduction

Each of us has a different concept of power and the context in which it is used. Power invokes a sense of inequality. The power of speech, to the AAC community is something we strive to attain. We will never ever have the speech writers or the performance techniques of prime ministers, but we have to make every letter and every word count.

I am going to use Power in many contexts: personal, political, the dominating use of power, disempowerment, and the responsibility of oneself in using the power you have with care.

People who use AAC do not see themselves as having power over people with speech (personal observation only). We will never have that same power unless we get speech devices that work on thought, and I am not sure I want that device.

In a previous paper on self identity, I wrote the following words:

“Language is a very powerful weapon. Very few people, if any, are in a position of power without communicative competence and fluency in the global language of the main culture. I guess, we in our culture, use silence as our weapon, so the words become more powerful. (Allan:2006)

Language and language use, then becomes an investment. The reward for the investment is access to unattainable resources. For those of us in the AAC community, the rewards are far wider than most people imagine. For me, the reward has been employment and being able to attain a life beyond being disabled. (Allan:2006) ”



In another paper I wrote over years ago, on the Language of AAC, I reflected on moving from a non speech device to a speech device. I stated that I am slower on the speech device than the non speech device. However, the speech device was so empowering, I could not imagine my life without it (Allan, 1999).

With my speech device, opportunities have opened up for me. Mainly I could use the telephone, and I could speak to people with no literacy skills. As well as dominate a conversation in my own time and not when someone else interprets.

Way back when I was at university, long before speech output devices were invented, I asked my mother to phone a person for me and pass on a message. My mother refused because she said she could not ring up a male for me. I forget how I resolved it, maybe I did nothing or maybe I had my sister make the call for me. Nowadays, I have the choice to phone or use speech to speech relay or e mail. One day I will have a mobile phone too, so I can text people.

At work, I am able to give clients four alternatives, my phone number with a warning that I speak with voice machine, fax number, email or the postal address. I am able to carry a normal caseload of work. I once phoned a client, the receptionist hung up on me, even though I had said, "Please be patient while I use my voice machine". Very few things disempower me more than someone who should know better hanging up on me. Anyway I phoned back on the TTY relay asking would the person phone me back. Part of the power of AAC is knowing what resources are available to you, and how to use them.

Imagined Communities: Gaining the Power

Imagined Communities often are used in self identity theory and where people from one language culture gradually learn another language. The imagined community becomes the ideal inside the communities' head they all seek to attain (Kanno & Norton,



THE POWER OF SPEECH: THE POWER OF AAC (cont) ...

2003).

When I was at school, some thirty plus years ago, the international language was French. In recent years English has become the language of media, science, and technology. In Norton and Kamal's study of English language students in Pakistan, the students saw the learning of English as empowering and part of their future giving them access to technological advances enabling them to be independent (Norton & Kamal, 2003).

The study by Norton and Kamal came just after the attacks on the World Trade Center (sic) and Pentagon in the United States. The students were hurt by school closures, but still saw the future in learning English and that would help bring them peace (Norton & Kamal, 2003). They were sad for the Afghan refugees who did not have access to the same educational opportunities. The students might have over-estimated their expectations of the value of the English language; they saw the educated rich as having no problems. But, conversely the value the put on their learning should not be under-estimated (Norton & Kamal, 2003; Kanno & Norton, 2003). The students were motivated to learn English and eager to use their literacy skills across countries, using English to connect with the United States and United Kingdom. Pakistan, being caught between India and Afghanistan, has to be able to draw allegiances from a wider community than just their own region (Norton & Kamal, 2003).

AAC operates as a second language culture. The imagined community has to seize the opportunity of using the power to communicate to improve their lives. This includes societal acceptance (Miller, 2000; Quinn & McNamara, 1988).

James Curran, the author of a book called *The Power of Speech*, who analysed the speeches of recent prime ministers of Australia had to admit that watching his young daughter coming to know the power of speech was much more profound (Curran, 2004).

We each have the power of speech, the power of words, but we each need our own motivation to go into the world and use it. It is a self realisation.

Disempowerment

There is nothing like disempowerment to make you appreciate the power in the little things you had. Rose Galvin (2005), in her study of the disability identity, researched hundreds of people who had lost abilities permanently through illness or accident. The identity transformation experienced by people was a complete one hundred and eighty degree turn around. There was a disabling of their identity.

Autonomy and independence came at a cost of having to need assistance. Most of this assistance was not remunerated (Galvin, 2005). People do not realize the chronic shortage of services there is in the disability sector until they themselves enter it.

I was once shopping in a stylish up market retailer. My sister was with me, but she had ducked off to buy a bag. I was buying something, being specific in my choice, telling the sales lady exactly what I wanted on my Lightwriter. The sales lady said

"Aren't you clever", just at that moment my sister came back and piped in, "it's lucky she has two university degrees". The whole thing seemed to totally go over the sales lady's head as she kept serving me. My sister was disgusted at the way I was being treated, whereby I knew I would not see her again, so it did not bother me. What disempowered me was that my sister was hurt.

Cathy Olssen, then ISAAC Australia President, and I were walking down Flinders Street in Melbourne, when a male voice yelled from a doorway, "Hello Spastic". I was glad Cathy was there as I let her take all the hurt and disempowerment. How dare someone with two words, try to shatter my whole being.

My niece, Hannah, has an ambition to join the police force. That way she can lock people up. To her, that is power. In time, she will learn the complexities involved in locking people up. Perhaps I could take her simple philosophy and have the thought police lock up certain people.

A few years ago now, a certain government department, chose a level of funding (\$1500) for communication devices that would have excluded voice output devices. The view taken by the person who decided this was that people did not need voice output. It is not for the voiced person to decide what is right for all clientele. It might be satisfactory for some to have a communication aid without a voice, but for most of us the voice means access to phones, relationships and the verbal world outside.

One disability philosopher stated, "We will find freedom within the contours of the mind and in the transports of the imagination" (Galvin, 2005). Then there is the pragmatic, sometimes radical, Mike Oliver, who advocates the social change model and that other people make barriers (Priestly, 1999; Galvin, 2005). In the power plays of life and as a lazy radical, I believe the answer is somewhere in between. We have to be strong enough in our own minds to deflect the attempt to take power away from us, and society must learn to accept that we have rights to live in their community too.

Using Power

At work, I was secretary of the union in our office. I am always surprised when I intervene on behalf of a member with a third party, how that third party reacts in an almost fearful way to me. Here am I, a voice-less person, not very tall, and physically different, having to face people who earn three times as much as me and command absolute respect. I do not tell them I am just as scared of them as they are of me. In these meetings with members and managers, I do not have to say much, sometimes I do not have to say anything, just watch and observe to see the member is getting a fair hearing. If I do say anything, it is a few chosen words spoken with authority.

Even though voice output communication aids have no intonation, my careful command of the words I use, and the position I hold, exudes the authority. I am not allowed to talk about my work, except to say the position I hold and the knowledge I have has that same authority. When clients talk to



THE POWER OF SPEECH: THE POWER OF AAC (cont) ...

me, they know they have to be very careful and they cannot use my disability against me.

In turn, I have a responsibility, to use my authority fairly.

Adrienne Rich (1978), the great feminist poet, wrote a poem on power. In it she concludes with a few lines about Marie Curie, the Nobel prize winning inventor of the x-ray machine, and enhancer of uranium power.

“ *She died.
A famous woman.
Denying.
Her wounds.
Denying.
Her wounds,
Came,
From the same source as her power.* ”

I have spoken before about the difference between the male and female language (Allan, 2004). In her book *Man Made language*, Dale Spender (1983) concluded that no matter how much you try to empower women, they will always be limited by language in a male dominated society. Women who do break through glass ceilings, will predominantly use the language of a male society. Next time you see a female politician on television, watch the language she uses. It will rarely be her natural language and she will look uncomfortable. Lately, we have been able to watch the Prime Minister, Julia Gillard, change her language to match her new role, which has not gone without criticism.

The AAC community is locked into being marginalized within a marginalized society. We will always look uncomfortable with the language we use. However, we have to use the language of the dominant society to attain a glimpse of empowering ourselves. We have to develop the strategies that we are comfortable with that are accepted within the verbal world.

The marginalized in society will always have less access to educational resources (Norton & Toohey, 2003). Power does operate to reinforce inequality in the classroom and the community at large. Minority communities are expected to assimilate into majority communities (Norton & Toohey, 2003). There is a relationship between power and knowledge (Norton & Toohey, 2003). Technology, as we know in our community of AAC, is an empowering tool which we seek to bring about social change.

We must seize the opportunities that technology brings and empower ourselves. Just as the Pakistani students saw their English language skills as empowering them to make Pakistan a

great and peaceful nation, we have to be motivated in the same way.

Our skills from inside may not be as good as we imagine but they are better than no skills at all. Young people often feel powerless, and sometimes those around them seek to reinforce that powerlessness (Norton & Kamal, 2003). However, if we have strong motivating forces behind us and effective strategies in place, “The force will be with you”, to quote George Lucas (Star Wars, 1977).

The Power of AAC

This next story comes from the ISAAC conference in Dusseldorf, Germany. It is about the power of AAC.

Gabi, from Switzerland, was staying at the same hotel in which I was staying at. She caught a taxi from the convention centre to our hotel. The taxi driver started telling her about the Italian men he had picked up from the convention centre the day before. The taxi driver was from Turkey, he spoke only Turkish and German, the Italian man and his friends spoke only Italian. However it all worked out well said the taxi driver, as one of the young men had a symbol board, so they all were able to communicate.

After ten days in Dusseldorf at the ISAAC conference, I needed to wash my clothes. I was now in Berlin on my way to Warsaw. I did not want to pay hotel for their laundry service. The tour bus dropped me at the launderette. Somehow I managed to start washing machine even without knowing how to read German. I started writing my postcards. A woman walked in to do her laundry. We were there alone. Each of us knew the other did not speak. I assume the other woman had an intellectual disability, then again she probably thought the same about me. My washing finished. I stood there wondering how to get the washing to the dryer in the next room. I did not even know the German language to ask anyone. Without saying a word between us, the woman saw my dilemma and brought me a washing basket from the other room.

The sheer power of communication, needed no words

We live in a verbal world, people with voices will always dominate over people without voices. That is meant both figuratively and literally. Language is an investment to be valued. Somewhere in between; you lose some of the old existence but we cannot remain a child forever. The rewards of breaking into the new world far outweigh the comforts of staying behind.

Power is a funny thing. At university, a student there always ignored me. I tried a bit to break through his barriers. I knew he thought I was not worth talking to, but I wanted to at least show him that his attitude towards me as a person, did not dignify himself greatly. Over the years I have walked passed him in the street, he has still ignored me. He runs for the board of directors of my footy club, I get letters from him saying what a great person he would be for the board. I do not vote for him.

People always get their revenge. I love the power of the vote.



THE POWER OF SPEECH: THE POWER OF AAC (cont) ...

Conclusion

Alice Cooper once asked, "Who has the power?" (Cooper et al., 1974). To which we all answered, "We have!". We danced in the corridors of the Yooralla hostel, shouting, "We have!". No one believed us then, who cared. I believed it, I still believe it.

We have the words, we have the power to communicate. We have the power of speech.

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Taking it to the streets
adelaide 2011

AGOSCI 10th Biennial National Conference

Adelaide Convention Centre
11-14 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.

Taking it to the streets

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: All Occasions Management

Ph: 08 8125 2200 Email: agosci2011@aomevents.com
Fax: 08 8125 2233 Web: www.alloccasionsgroup.com/agosci2011



**AGOSCI Inc.**
www.agosci.org.au



We all have a need to communicate in a variety of situations, both predictable and unpredictable. When you use AAC it needs to be 'Here There and Everywhere'. We asked people who use AAC and their families share their experiences. Here are their stories.



Meredith Allan on
holidays at Uluru



Kirrily



Kirrily and the McMahon family had the opportunity to meet Kurt Fearnley. Kurt is described on his website (kurtfearnley.com) as:

“Australian Athlete Kurt Fearnley is the marathon man of wheelchair sports. The two time Paralympian champion has won all around the world, from New York and Chicago to Seoul, Paris and Sydney, he has conquered the world.”

Kirrily had the opportunity thru her Dynavox to congratulate Kurt on his amazing achievements, she then went on to ask him to sign her bike helmet and then suggested they have a bike race one day.

Emma

Emma's photo is so full of fun and enjoyment. We asked some questions around the issues related to communicating with peers.

Emma looks like she is having lots of fun. Big Mouth Camp would give her a lot of opportunities to communicate with peers with similar communication needs and skills, what does this mean to Emma?

BMC is a chance for Emma to focus on use of her AAC both light and high tech, 3 days solid work with speech therapists and SP students, working towards communication goals that we have set as a family. Emma enjoys the chance to meet new young people who are AAC users and catch up with old friends at camp. She especially enjoys the fact that parents are sent off to their own sessions, which allows her to be much more independent in her communication and allows the support team to see where she needs the most help. The adult role models help to provide the motivation to just keep on trying even when it seems hard...



Emma with AJ (Amanda Jean) White communicating using her V Max at Bigmouth camp

Are there any issues / strategies / methods that help or hinder communication with peers?

Able/verbal peers often lack patience with both light and high end communication devices, unless they have really got to know Emma. Her friends that know her well look for her quick communication - eye point, gesture etc... new people are more dependant on the V Max for Emma to communicate with them.

Are there any special messages that she likes to have handy?

Greetings, quick chat, news ,and gossip

Does Emma have any future AAC goals?

Emma is constantly working towards her communication competency... it just takes some young people a little longer.



Morgan

When AAC is used successfully it is often a family affair. In this interview Morgan and her mother Merrell talk about how Morgan uses her Lightwriter to communicate in her very active life. Morgan's thoughts are in black Merrell's are in blue.

You obviously lead a very full and active life. What are considerations around your use of an AAC system given the wide variety of people and environments you interacts with?

I like a system that is easy to use. I like the dual screen on my Lightwriter because people like to be able to read what I am saying. Sometimes people can't hear devices or understand what they are saying so it is good if they can read it. I like being able to send texts.

Having a simple system has been good for Morgan. People aren't intimidated when they see her just type and speak her message.

Do you have any messages that you find particularly useful?

I don't usually use stored messages. I really like having good word prediction, that helps a lot.

Morgan doesn't often use pre-stored messages but the SL40 has very good word prediction and she



Morgan at Mt Hotham

can easily create quickly what she wants to say. She uses natural speech a lot and often just uses her device to clarify a few words. She also uses her iPod Touch or iPad to store lists of things she frequently talks about, such as music/singers she likes. She will often write a list of things that she wants to tell someone such as her medical professionals.

What are your next plans for activities / challenges?

I want my communication to get better and talk more to people. I want to practice my speaking. When I finish school I want to go to college and do a course in childcare and I am going to do work

Morgan on Holidays at Lorne



A Morgan is a para-equestrian: Melbourne Summer Royal 2010 (Lt) Rideability Para-equestrian State Championships (RT)

number of these photos involve you participating in physically demanding activities. How do you ensure that you have a system/s that a robust enough to survive?

I try to look after it, try not to drop it, getting in and out of the car. Mum drops it a lot too.

I take the approach that the technology is there to be used. In reality the Lightwriter gets dropped more during everyday activities than it does when we are doing something more adventurous and taking more care with it.



Morgan ice-skating for her 18th birthday

experience in a childcare centre. I want to still do lots of dancing and riding. I have my two horses Molly and Marley. I want to go to the Paralympics in Equestrian.

Morgan finishes school this year. She would really like to be a better communicator and work on improving her intelligibility, but she also needs to accept that with unfamiliar listeners using her device probably the best option.

Next year Morgan will start a transition to work course with a view to getting part-time work in open employment. She is interested in starting a Certificate in Childcare but she also wants to work on her Maths and English more.

She is good at simple sentences but has difficulty with constructing long and complex sentences. She has a wonderful disability employment adviser who has been assisting us with all sorts of interesting ideas and as someone who has no experience of AAC has been very able to identify the issues and look at ways of

addressing them.

Morgan loves to dance and is thinking of joining a dance company and doing some formal study in dance in ballet and contemporary. She wants to also continue working towards selection for Rio 2016 Paralympics in Equestrian.



Emma Green and Libby Price watching Morgan present at the ISAAC conference in Barcelona

Karim



Karim has been using various communication systems including voice output devices, since the year before Kindergarten. Now 21, Karim recently presented at the "In Control" conference in Sydney. With his mum as an assistant, his presentation focused on how much he is enjoying life after high school in the My Life, My Choice, My Future program. This individualised, self managed package, has provided Karim with opportunities to develop a range of long held interests. It has also supported him to move gradually into adult life in the Community Participation program by developing new roles, interests, and friendships. The conference presentation was a combination of photos, video, and interview with his mum, using a Bespoke to answer questions about what he does throughout his week. Karim's experience with AAC started in 1994 when his speech pathologist, Rosemary Kinna, introduced him to the Message Mate. Over the years, other dedicated speech pathologists have helped Karim with access to AAC. He has been using the Bespoke for the last year, with the support of Megan Legge from ADHC and Alana Lum from the Spastic Centre.



Rachael

Rachael is 22 years old and lives in a group home in Albury. She has a severe intellectual disability, is non verbal and uses vocalisations, pictographs, and keyword signing to get her message across. As well as low tech methods (which she prefers), she uses her VOCA's either a Talara or Macaw, to communicate on the telephone. Here she is talking to her sister, Heather, using her Talara. It is quite funny to watch as she uses vocalisations, her Talara, as well as gestures to communicate with us on the phone. Often the workers are interpreting her gestures to us as we talk to her over the phone. I'm awaiting the opportunity to implement Skype with her but this is a dream in supported accommodation environments at this stage.



Jamie-Lee



Jamie Lee is a 11 year old girl with cerebral palsy who uses verbal communication with her family, peers, and at school. As she becomes older and moves onto secondary education, we are introducing her to the use of augmentative communication so she has skills to communicate with others who will not be familiar with her oral speech patterns.

Here she is combining the use of her iTouch with the low tech board where she points to the initial sound of each word as she speaks.



Doug



Doug is 6 and has a diagnosis of Autism and Complex Communication Needs. Doug has been able to access an iPad using proloquo2go thanks to his local Lions club. Doug who can barely say one word is now using his iPad every morning to request his favourite thing ever, "I want a drink of coffee please. I need a cup thanks mum." He carries it everywhere in his laptop bag & uses it at school for communication and learning (using literacy, maths & science apps). We could not have imagined three months ago that our child would have been able to communicate as he can now. For Doug and his family the iPad has been an affordable and practical communication option.



Kingsley's AAC Journey

By James Henry

Kingsley uses a variety of systems that are individual, tough, and portable - Just the thing for an 8 year old boy who needs to go "Here, There and Everywhere." Kingsley's father, James explains just what it takes to make sure that Kingsley, who has a diagnosis of autism, has communication at his fingertips... wherever he needs to go.

Arm Roll, ABC Sleeve, ABC Beads, and 'First Letter Communication System'

Of all Kingsley's AAC systems, this is the one I most like to share and promote. I believe a lot of kids like Kingsley could make good use of it. It's very simple, very cheap, very versatile, very easy to use and very powerful for a child who has little other means of communication! It also builds a very strong pathway to literacy! We developed this system because Kingsley is a very active and mobile little boy with autism, and he needed a lot of support to communicate. We were using Sign & Gesture, Communication Builder, some PECS, and an 'ABC and Numbers Page' (alphabet board). Kingsley was not literate, it was pre-spelling - the 'ABC Page' was used with 'First Letter System' (eg. 'B' for biscuit, 'HJ' for Hungry Jacks, etc. - it's quite simple for him but relies heavily on 'context' and requires a skilled communication partner to negotiate meaning). These days, although Kingsley independently creates novel sentences on his Springboard or types sentences with support, we still use the 'The First Letter System' with the 'ABC Page', 'ABC Toy', and 'ABC Beads' (and these days, in addition to first letters, he also does some spelling of short words, uses abbreviations, or partial spelling on these systems). The reason we still use these systems is that there are many times and situations during every day that it is simply the best or only way to communicate something at the time (it's about giving him more opportunities to communicate and having more frequent and constant communication).



Arm Roll - this was a soft plastic cylinder that was rotated (with his right hand) to give it extra area to stick on cards or Dymo labels."



ABC sleeve - "this later version didn't rotate, was more convenient and less noticable and is easy on and off with velcro and fit any size."



"ABC Beads" - "he also uses 'pincer grip' to identify each letter (improves fine motor). These's no place that 'ABC Beads' can not go! - swimming, mud, painting, whatever! It's easy to clean, it can't fall off or get damaged, it can only be taken off by skilled fingers."

ABC and Numbers Page

These are used with 'First Letter System' (including spelling short words, partial words, and using abbreviations). This small 'ABC Page' is so easy, simple and robust! It is in a plastic sealed bag (photo bag) with a soft plastic sheet inside to resist folding. I keep other pages inside to use on the back, including spare blank pages to just draw up something on the spot if we need."



ABC Page on the trike and the beach. Easily attached by stickytape and it doesn't mater if sand or water gets inside the bag.



ABC and Numbers Toy

This surprisingly robust 'ABC & Numbers Toy' was the most used communication aid for nearly 2 years! It cost only \$10 but was probably more useful to us than the Communication Builder because not having to worry about dropping it or losing it, not having to design and prepare overlays, or re-record messages or change batteries meant that we got so much more use out of it. The Communication Builder was great too, but speechies who only saw Kingsley in 'their' world and didn't see the bigger picture of his life could not understand that this ABC 'Toy' was also a really functional and important communication aid! It went everywhere and survived everything (except sand and water) without having to worry about damage or loss, and Kingsley would carry it around with him and mostly look after it's needs, himself. Much better than 'ABC Page' because tactile, audible, and beside spelling it also had worthwhile literacy activities. Particularly good in the car (before we started taking Springboard everywhere) because it's audible I didn't have to look at what he was spelling so he could talk to me while I was driving.



Messy food and liquid on the expensive device - who cares! I've never allowed it to be an obstacle to communication, because meal-times have always been the most effective time to talk. The device has a 'moisture-guard', and extra sticky-tape and plastic (it can even be rinsed under the tap - don't tell the supplier!)



Springboard and Vantage Lite

Increasingly, Kingsley's Springboard goes everywhere that he goes, and he uses it even during very active outside play.

We love it so much we take it to bed with us - another very important place for some of the best communication. In fact, Kingsley tends to communicate most intensely and effectively when he is tired and relaxed just before falling asleep.



The best thing about having an old car is that it serves as a good platform for the device - for taking it to the streets.

In the car is a really good place for Kingsley to use his devices, particularly as there are exciting things to talk about such as where we are going, what we see on the way, directions, etc



The supermarket for us has been a great place for communication, and particularly for literacy! It's highly motivating for Kingsley, so the extra challenges of ramming the trolley into unsuspecting people and the occasional 'meltdowns' are a small price to pay for the benefits.



At playgroup, Kingsley's Springboard was sometimes quite popular with the other kids.



Springboard and Vantage Lite....the more the merrier.



Hiptalk

This is Kingsley's 'Hiptalk 12 with 5 Levels'. I've made a few minor improvements, including adding the shoulder straps. Kingsley is a very busy autistic boy who doesn't like to sit still and is hard to keep up with, so I just love the concept of the Hiptalk- what better way is there to attach a VOCA to him? It's got enough volume to be heard in a noisy room or at a distance and it can go almost anywhere.



The Hiptalk is great for many situations including socialising, but it really comes into it's own in the playground, where it allows communication in situations like this, in which it would otherwise not be possible.



Because we use the Hiptalk in various different situations and places, I often like to add and change some messages to make it interesting and reflect his needs or interests at any given time, for example, a person's name or a new piece of playground equipment. I found that it's quick and easy to write directly onto the paper/card overlays with colored pen whenever the need arises, and Kingsley learned to interpret my crossouts and scribbles. My 'home-made' partly 'spontaneous' overlays were more flexible and functional than completely pre-prepared and laminated overlay

Word Cards

We call them 'Words Cards' because it empowers him with language he can use (instead of disempowering him with jargon). Apart from a functional communication system, it's also a highly motivating learning activity, particularly when we take them off the key ring. Kingsley loves to play with them loose and carry them in a small bucket, and can play games with them, or use them functionally by pointing or giving someone. As with the Hiptalk overlays and other things, I've often made the 'Words Cards' quickly 'in the field' with Kingsley's involvement.



Environmental AAC / Photos

I like to think that signs and everything that we find useful in the environment is a type of AAC. From McDonalds and KFC to all kinds of shop signs, road signs, and street signs, the environment has been and continues to be a very rich and ongoing resource for Kingsley. All the time invested in learning this has been totally worthwhile because everywhere he goes now he is reading and understanding the signs

Kingsley has visual difficulties, typical of many autistic people. Obviously, photos also increase the 'frequency' of his exposure to the target images. Photos have been a motivating and powerful tool for seeing, communicating, and understanding. We have hundreds of photos of local shopping strips, road signs, and street signs. Kingsley loves to play with the prints – to have the individual prints in his hands, to physically manipulate them, (e.g. to put them in favorite places, hide them, mix them up, sort them, play other games). But most importantly, we use the photos as a form of AAC to 'talk about' those places, the signs, the symbols, the words, the ideas, and we also use the photos to extend communication with other forms of AAC including literacy.



This set of cards was quickly made in the playground while following him around to each piece of favorite playground equipment. It was very successful and was used on many other occasions when we visited that playground.



This is a photo of a photo of a photo. It's one way of increasing the 'intensity' of an image.



Environmental signs: These very simple symbols were a stepping stone to more complex symbols and literacy. A lot of his very early reading and spelling was things like 'HUNGRY JACKS', 'SUBWAY', 'CAFE', 'ANZ', 'POST', 'BP', 'Shell', etc. Local street signs have also been a part of this and I love the way he continues to be interested in and tries to read the street signs wherever we go now.



Typing



Typing with our greatly experienced and respected teacher, AAC and autism expert, speech pathologist Leslie Zimmerman. Heartfelt thanks to Leslie and Deal - your hard-work, generosity and determination made it possible for Kingsley to progress. We could not have done it without you. You have been our rock-solid constant foundation of support, encouragement, inspiration and wisdom.

Sign and Gesture

Even with various other forms of AAC including a high-tech device, we still use sign and gesture a lot. Kingsley uses most of his signs or gestures very naturally and often in combination with other forms of communication.



Signing 'Stop!' is great communication at such a distance! (Only problem is, Kingsley was supposed to stop before crossing the driveway, not after it!).



Learning to Finger-Spell Alphabet and Numbers - we were lucky to find this 'Hands Wall' in a playground, it was a great resource to learn finger-spelling



Learning to sign 'K' - drawing on Kingsley's fingers like this was a good way to help him learn this new sign, and others. His severe autism and poor fine-motor skills have meant that it's been a lot of hard work and we've had to invent special teaching strategies like this.



Although Kingsley already had about 70 expressions in sign & gesture, many of these were modified and simplified because of his poor fine-motor skills. Learning finger-spell alphabet and numbers was very challenging but worthwhile



This sign was easy for his hands to do and easy for him to learn.



This sign was very difficult and still is

A Last Thought

I always try to involve Kingsley in making his own communication aids. Here he is making his ABC beads.



Communicate, Participate, Enjoy! Solutions to Inclusion Conference - 2011

21-22 March 2011

Darebin Arts Centre. Preston, Victoria

**Communicate, Participate, Enjoy!
Solutions to Inclusion**

The conference will provide participants with practical strategies to facilitate the active inclusion and participation of people with profound intellectual and multiple disabilities in every day activities and life choices.

There will be two concurrent streams of papers/workshops which have a focus on communication, behaviours of concern, sensory focused practice and active participation.

The conference will be of interest to support workers, health professionals, educators, disability service providers and families.

Keynote Speakers

Dr Jeffrey Chan - Senior Practitioner, Office of the Senior Practitioner (Victoria). Dr Chan's keynote address will provide an overview on restrictive practices and how this impacts on communication and participation.

Associate Professor Keith McVilly - Principal Research Fellow, School of Psychology, Deakin University (Victoria). Keith's keynote will challenge us to think about how to actively support individuals with profound intellectual & multiple disabilities to foster and maintain social relationships.

Other presenters include - Teena Caithness, Mark Barber, Sheridan Forster, Susan Fowler, Nick Hagiliassis, Hilary Johnson, Erinn Miller, Louise Phillips, Mary Rainey Perry, Meredith Prain, Dr Jane Tracy, Mandy Williams, Jo Watson and Sarina Bunnnett.

To register visit: [www. scopevic.org.au/communication](http://www.scopevic.org.au/communication)

For further information please contact:

Scope - Communication Resource Centre

Phone: (03) 9843 2000

Email: crc@scopevic.org.au

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FOR PEOPLE WITH A DISABILITY



Surviving an AVM (Arterial Venous Malformation)

By Marco Borzini

Hello, my name is Marco. I am 27 years old. I am employed by the Department of Human Services (DHS) as an IT Professional and have a university degree in the same field. Even though my work contains a lot of testing and documentation, my primary objective is to support our users.

I very much enjoyed watching sport and especially playing it. This included; badminton, soccer, cricket, and basketball both indoors and out. I used to play basketball every Saturday with my friends from high school.

I woke up a few months ago.

Everything in between seems like a dream. Like a dream I always thought I'd wake up. Each taxi ride home would be the last thing I'd do.

I would return home after certain conditions were met. Upon meeting these conditions, my parallel self could live that life and I would return to mine. So I kept trying to find fault with the world I was in to prove my theory; for example I always thought that: the tree outside my room didn't match those like it, my sister's place of employment was different, and the vegetable patch appeared out of nowhere. I took special note of the 2009 Melbourne Cup winner so I could go back and win myself a lot of money, so my mum could stay home.

I had to and still have to tell myself that this is real and my past life is exactly that; the past, for now.

On the 6th of November 2008, like most other days, I got up at ten to eight and caught the 08:15 train to the city. Then I went to work and the gym at lunch. Upon returning I was very hot. Soon I got too hot and developed a huge headache. I couldn't keep myself cool. I stumbled through the security doors and into the sick bay. There I called our First Aid officer but there was no answer so she must have been out to lunch.

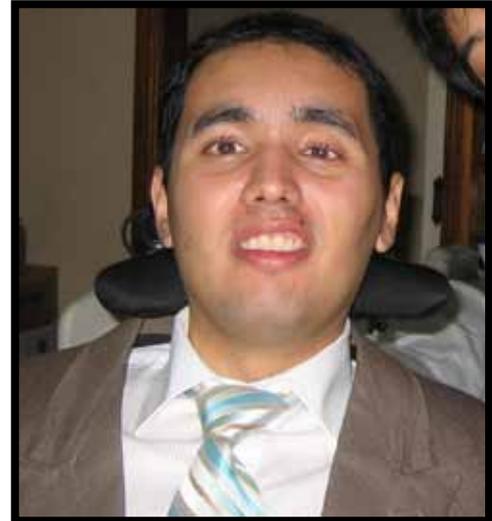
Then I called my mum, with trembling voice I told her that I thought I had a migraine, she quickly offered me a lift home. In her haste she forgot to ask where my building was located.

When I realised something was wrong I called the ambulance.

I tried to keep cool, so I went into the room opposite – the disabled toilet, there I wet my hair and face with cold water. Then I think I passed out and vomited on the floor. Luckily, I left the door open and a passerby found me.

Considering all these things, I believe my God Jehovah had to be assisting me throughout this time.

Thinking it was just a headache my dad came from the hospital where my grandma was admitted with a broken hip two days earlier.



Thus began the vigil of my parents.

When they arrived at the hospital the doctor told them "we don't think he's gonna make it".

After several hours I emerged from the operating theatre in an induced coma and remained motionless.

I had an Arterial Venous Malformation (AVM). Basically, a vessel in my brain was not properly formed at birth. When or after I went to the gym this vessel burst and bled. Because my brain had nowhere to go, the left hemisphere and brain stem were affected. This caused me to lose most if not all of my autonomic functions (this includes eating, drinking, talking, walking, and moving my body. I eat and drink via a small tube which protrudes from my stomach).

After the operation I was moved to the Intensive Care Unit (ICU). Before they moved me out of the ICU, a tracheostomy was performed so that a tube to assist breathing could be inserted. I was rushed back to the ICU when I stopped breathing, this happened on four occasions. The neurosurgeon kept telling my mum "your son is very, very sick. His chances are fifty fifty". This was a very traumatic experience, especially for my parents.

It was four weeks before my eyes opened. It was another two weeks before my eyes began to track. My eyes tracked for the first time when I heard the Top Gear music. I smiled for the first time when one of the physiotherapists told me a joke, this happened nine weeks after the operation.

To the relief of my parents, the tracheostomy was finally removed on the 16th of March 2009. Upon receiving their approval my parents and I went outside every day.

Early in April 2009, a patient next to me told my parents excitedly that I had spoken during the night. My mum was very happy and said I had tried to say hi a few times, but my dad found it hard to believe as I hadn't spoken since the operation.



SURVIVING AND AVM (cont) ...

A few weeks later another patient opposite me told my parents one early morning in May that I had spoken a full sentence in my sleep. The next day he told my parents I had spoken again during the night. This time another patient also heard that. As happy as my dad was, I was still not talking when awake. This started to happen slowly in the following months.

Afterwards, I went to an additional occupational therapist and got access to an electric wheelchair. I also got to use a whiteboard and a PC. My parents got permission to take me to the gardens across the road every day. I remember the big Elm trees and the cool shadows they cast. The big fountain had its water turned off in a bid to save water. The occupational therapist also arranged for me to go see an exhibit at the Museum.

I remember a trainee nurse telling me "With an Italian father and a Chinese mother you've got nothing to worry about". How true her words have proven and are proving to be.

It was very refreshing to have younger nurses looking after me with such a high standard of care, love and personal interest. For example; one nurse who only worked on Saturdays always came to see me and encourage me. He came to see me go to rehab the day before even though it was his day off.

My parents can't thank them enough.

I spent nearly nine months in hospital.

Before this, during the early stages of my hospitalisation, the hospital rehab consultant came to assess and referred me to a rehab center. She never came back again. Despite the recommendation of my surgeons I was still sent to the 'rehab' center she chose. We realised what a colossal error she'd made after just three days.

The center I was referred to was ill prepared and ill equipped for rehabilitation purposes. I didn't have a bed extension. The 'training' supposedly organised for my parents to use the hoist didn't happen. Some of the nurses were nice, the rest were crusty.

When I arrived, we asked for a wheelchair to go outside but the 'rehab' center didn't have any, so despite my parent's pleas, I was left in bed for three weeks.

The center's physiotherapist and occupational therapist only came once. This happened even though the occupational therapist said "We'll start up a program and come back tomorrow". The dietician and the speech pathologist who both helped me a little, left for the rehab center suggested by my surgeons.

During my hospitalisation I was given a Slow to Recover (STR) package. With this I got a case manager, three therapists: a physiotherapist, a speech pathologist and an occupational therapist and a carer. Six weeks into my stay in 'rehab', to our great relief the STR team moved in. They busied themselves

into getting me home; for example my occupational therapist arranged a lot of equipment for me to try. She organised my wheelchair when she first saw me.

When I got a wheelchair my parents took me outside every day. I only stayed inside when it was too hot.

The best thing about the 'rehab' center was its shared courtyard which ran across its side. It was made up of three levels. The top level went outside and to the vegetable garden behind one of the asbestos-vacated buildings. The second, or ground level circled the lowest level. On one side it led to the fronts of the medical and 'rehab' centers as well as a big tree, under whose shade I often rested. On the other, a gazebo overlooking the lowest level which the nurses used to smoke in and a grassy area behind the medical center. The lowest level had a dried up waterfall and fishpond it fed into as well as some benches under some small trees.

The building opposite, open Monday to Friday, had a very nice flowerbed full of flowers and a path which meandered through it. It was the ideal place to improve driving my wheelchair.

When it rained I would sit under an eave and watch the rain fall and the lightning strike.

I didn't like that place. It was more like a nursing home. All I wanted was to go home.

But I couldn't. Otherwise the 'rehab' center would appeal to the Tribunal saying that I wouldn't have the appropriate care. In order to get me home, my case manager had my parents enquire about the application for an Individual Support Package through the My Future My Choice Program submitted over eight months before by the hospital social worker.

Soon thereafter my parents and case manager had a meeting with two people from DHS who were in charge of the program. Basically they said my application had been approved and was put on the waiting list. They get a different amount of funds each year and these are divided and apportioned to those who most need it. They could not say when the funding would be available. In desperation, my parents appealed to the big wigs who would have a say about my plight.

The person responsible for purchasing equipment at STR was on leave. The person placed in her stead apparently agreed to purchase everything requested. Very quickly she ran out of money. None of my equipment could be purchased.

On the 27th October, I went back to the hospital for my first check-up. Upon seeing my progress, my neurosurgeon said "you've come a long way". Then he told us how serious my condition previously was: "if you had've come from Spencer Street¹ you wouldn't have made it" then he said "nine out of ten with your condition don't make it". He then arranged for a series of tests be performed on the same day.

¹ Spencer Street (main street and railway station in Melbourne) is only a few blocks away from where I work.



SURVIVING AN AVM (cont) ...

One day while I was resting under the shade of the big tree dad got a phone call from my case manager who sounded very excited. As usual, dad kept a straight face. Once mum arrived, I got news that I was given a substantial package. I was then able to go home. However, it would be another two months before I would be discharged (on the 18th of January 2010).

During this time I developed insomnia and couldn't sleep there anymore. One morning as soon as my parents walked into my room I exclaimed "I've had enough"

On another occasion I joked to one of the nurses and said that I wanted to escape.

"But you don't know the security code to get out".

"Yes I do" and repeated it to her.

"We'll put a bright orange T-shirt on you and tell the police to 'Use extreme caution' when they approach you".

"Oh" I replied.

"Anyway, you can't escape during one of my shifts or I'll have too much paperwork to do".

Another nurse came and said the same.

Between them they worked the whole week. My escape plan was foiled.

On the 27th of November, I had an EEG and a MRI scheduled. My mum went upstairs to say hello to my former nurses and told them I was in the hospital to have an EEG and MRI done. During the last part of my EEG, all of the nurses present excitedly took turns (so as not to leave the ward empty) to see me. Among them were my physiotherapists and occupational therapist. I asked them many things and told them how much I'd missed them.

Shortly after, all of the team doctors walked in, my surgeon said "Marco, we heard that you were here so we've come to see you". The head surgeon shook hands with me then he asked my mum about my feet. "Good Marco. In a few months time you'll be able to stand and walk".

It was very comforting for my parents and I to hear such a positive comment. My mum treasures his statement in her heart.

While waiting for my MRI a heavily pregnant lady came running (as best she could) towards me. It was my speech pathologist. She told me she was very disappointed not to have seen me on my first check-up. It was her last day; she would start her maternity leave the following day. I asked her about the name of her baby but she said it was a secret.

I don't think any of us will ever forget that day.

As scheduled, dad called my neurosurgeon a week later for the results of my tests. He was very happy. He took me off my few remaining medications and said the swelling had gone down. Best of all, I would continue to progress.

Getting DHS to use even a portion of the money given to me has been like pulling teeth. Big and healthy teeth with long and strong roots. DHS stipulate that I have to have a completed and approved plan². The plan has yet to be completed, let alone approved and it is already two whole months late. Although it has paid for some equipment (bed, air-mattress, hoist, sling, and the small modifications to my shower) it did this a few weeks after I had come home and begun using them. It hasn't even paid for my electro-acupuncturist, even though he's treated me half a dozen times.

My dad often says about my rehabilitation, it took six months to get in, three days to realise our mistake, and another six months to get out.

My STR team come to me even though I'm at home. My physiotherapist is helping me to move my body, currently I am learning how to sit and stand. My speech pathologist is helping me to talk, swallow and to navigate and use a PC using a modified keyboard and mouse. My occupational therapist is helping me to live by teaching me to use the objects in my environment.

On the 17th of March 2010 I began to successfully swallow a tiny bit of peanut butter mixed with vanilla ice-cream, on the 18th I sat unassisted for the briefest of periods, on the 23rd I stood up for half an hour (with the aid of a standing frame) and on the 25th I helped make some coffee.

My family, friends and workmates (both past and present) have visited me regularly in hospital, 'rehab' and at home.

Above all, my parents have been with me every day for the duration of my ailment (sixteen months³, thus far).

I am deeply honoured and privileged to have such caring people around me. I can never repay them for all their kind deeds. I cannot begin to express my gratitude toward these.

I am glad things turned out the way they did as I am not sure who of my family or friends would have survived like I have.

Finally, I know that I will look back at these things that have happened to me but won't be able to call to mind for the former things will be but a distant memory.

I plan to get better quickly and cook⁴ some Katsu Curry⁵ for my parents and little sister. If I can be even a fraction as good as mum is in the kitchen I'll be very happy.

I plan to make a full recovery, actually, I plan to be better than before and I believe that I have a team which will let me do this.

2 DHS state that this plan should not take more than sixty days to finish.

3 As of March 2010.

4 Something I never used to do.

5 A Japanese dish.



Augmentative & Alternative Communication in North West Melbourne

By Karyn Muscat & Kym Toressi, Speech Pathologists, North West Regional Communication Service, Victoria
 karyn.muscat@isispc.com.au, kymt@nchs.com.au

Augmentative & Alternative Communication (AAC) in the local library, AAC at the leisure centre and in the pool, AAC at the council offices and train station, AAC here, there and everywhere – that’s our aim; along with communication partners who are skilled at using forms of communication other than speech.

The North West Regional Communication Service (NWRCS) is part of the Communication Access Network (CAN). CAN is a network of speech pathology services based across Victoria that, in conjunction with the Communication Resource Centre (Scope, Box Hill), aims to support the community to be more inclusive of people with communication difficulties (CRC, 2010).

The NWRCS is staffed by two speech pathologists, and services the north-west metropolitan region of Melbourne. We work in partnership with people who have communication disabilities, councils, community organisations, and disability service providers on community based projects which enables the community to be more accessible for people with communication disabilities.

Requests for community projects come from many places including; individuals who are experiencing difficulty accessing a service in their local area due to communication barriers, community organisations or other professionals who are working in similar fields (such as MetroAccess officers or Access for All Abilities officers). We also work with the Communication Resource Centre on more diverse statewide projects. In these projects we act as the local contact and provide support and resources for consumers and services in the north-west region.

One example of a state-wide project being supported at a local level is the pilot project ‘The Inclusive Leisure Initiative’. The



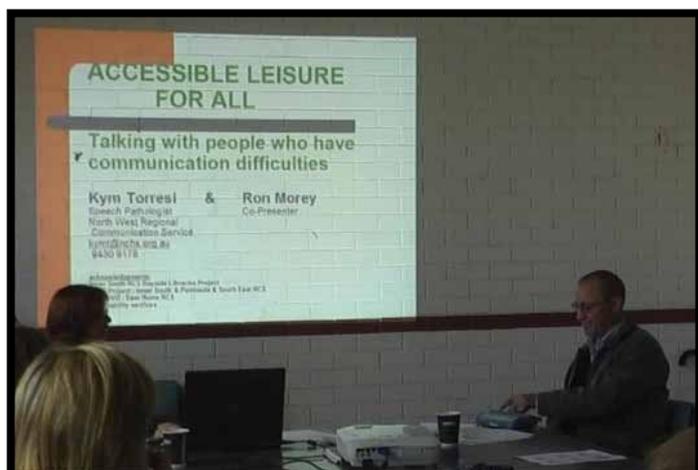
Inclusive Leisure Initiative (ILI) aims to assist leisure centres to be accessible for people with a disability (ILI, 2010) and includes specific strategies to improve communication accessibility. Many ILI leisure centres now have AAC options at their front desks. Some sites also have communication aids in the cafe or in the pool with lifeguards and swim teachers. AAC everywhere: even in the pool!

The NWRCS is currently supporting a number of leisure centres in the north-west who are involved in the ILI. These leisure centres include Kensington Community Recreation Centre, Carlton Baths Community Centre, Broadmeadows Leisure Centre, and Richmond Recreation Centre. There are further leisure centres where we are involved; it’s always a good idea to look at our latest newsletter for full details of where we are currently working.

The process we undertook with the local ILI centres was similar to other local projects. First, we conducted a communication accessibility audit to look at both the strengths and the areas requiring improvement regarding communication access in individual services. This led to us setting project goals with management and identifying required resources. In the future, we would like to have a person with communication difficulties who accesses the service complete the audit with us.

Once we have identified the main communication barriers, we identify ways that these barriers can be removed. We liaise with management about any environmental changes that could be made, e.g. lowering counters, decreasing noise levels, staff coming out from behind glass barriers etc.

We also conduct staff training. The training focuses on aims of the project, the rights of people with communication disability and the idea that ‘Communication disability does not just belong to the individual. It belongs to the entire environment of which





AUGMENTATIVE AND ALTERNATIVE COMMUNICATION IN NORTH WEST MELBOURNE (cont) ...

the individual is a focal point" (Sandwell Communication Aids Centre). The aims of the training sessions are that staff will:

- understand the challenges faced by someone who has difficulty communicating
- be aware of and develop confidence using different ways of communicating
- develop some communication aids for their service
- know how to use those communication aids effectively.

A big positive that staff report about our training sessions is that we co-present with a person who uses AAC. The NWRCS has been fortunate to have an ongoing partnership with Ron (a man who uses AAC after having a stroke a number of years ago). Ron has presented a number of training sessions with us using his Lightwriter in combination with computer technology to educate staff about interacting with people with a communication disability. Ron has just finished filming a DVD with us to showcase his work and encourage other people with communication difficulties to become involved as co-presenters.

Ron's involvement in our presentations is invaluable and staff always comment that his parts are not only the most entertaining but also the most educational. Recent feedback from staff about Ron's presentations has included:

'Absolute gold having Ron there for firsthand experience / insight' – staff member at Carlton Leisure Centre.

Another integral component of the training session is talking about communication boards that the venue can develop and have available for people to use. In the ILI, communication board templates were developed by the Communication Resource Centre in conjunction with people with communication difficulties across the state. The NWRCS then set about helping the local leisure centres adapt these standard templates to their needs and educating them about how to use the boards effectively. In other more localised projects we seek local service users to help create and evaluate the communication boards.

Once the training has been completed and the communication boards are in place we need to evaluate how 'communication

friendly' the venue is for the community. We invite someone to become a mystery shopper, this means going and using the service and then commenting on how communication accessible it was.

As mentioned above, we have recently finished filming a DVD of Ron presenting at Broadmeadows Leisure Centre. We aim to show this to other people who would like to become involved. It showcases Ron using his Lightwriter to educate staff about life with a communication disability and what they can do to make their venue more communication accessible. We have also filmed an interview with Ron about his experiences with presenting the training sessions. Ron explains on the DVD that he enjoys educating people about what it's like to have a disability.

The NWRCS is always looking for people to be involved in our projects. You can:

- tell us where we should be focusing our work
- create and evaluate communication boards
- evaluate communication access at a venue in the planning stages of a project and as the mystery shopper, or
- present staff training with us.

If you live in or access services in the north-west region of Melbourne and would like to become involved please feel free to contact us.

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CAMP HAVE A CHAT 2010: Mission Impossible

By Meg Hinselwood



Annika and mum Mona at Camp Have a Chat



Mark and Mona with Maureen (Liberator)



Kate chatting using her device



Ed talking with Mary and Rohan

The Cerebral Palsy League's annual Camp Have a Chat took place this year at Kindilan Outdoor Education and Conference Centre in Redland Bay. Camp Have a Chat ran in the second week of the September-October school holidays. It spanned four days and three nights and was enthusiastically attended by 14 students with complex communication needs (CCN), along with varying numbers of family members and therapists. Students were aged between eight and 18 years, and came from the Gold and Sunshine Coasts, Rockhampton, Toowoomba, Warwick, Townsville, and Brisbane, and used a wide range of augmentative and alternative communication systems.

Camp Have a Chat is assisted by the Commonwealth government through Commonwealth Special Education Programme Non-School Organisations funding. It consists of a programme of art and drama activities that is carefully designed by community artists. This year Scotia Monkivitch (from Helicon cpr) and Tamara Kirby (from Struth Arts) put together and facilitated a wonderful programme titled Mission Impossible. Students workshopped a mission that they could tackle as a group, and created their own secret agent identities and dossiers, as well as some ingenious gadgets that could assist them in undertaking their mission. Among the more creative efforts was Kate's 'dog poo bomb': I'm very grateful I didn't get in the way of that one!

Each year Camp Have a Chat features different highlights. Some of this year's highlights included:

- Telling ghost stories around the campfire, followed by an outdoor disco and limbo competition
- Creating our own amusing 'avatars' using digital photos of ourselves and Switchit Facemaker software
- Being visited by a couple of adult AAC users who talked to us about the value of communication
- Having Channel 10 News do a story on us on the second day, that we watched that evening.

Students at camp were able to have a chat while exploring and interacting with the exciting art and drama theme. Long-standing friendships were renewed, and new ones were formed. Parents learned to perform some new tasks on their children's devices, and talked to one another about different aspects of communication. Students and parents exchanged phone numbers and e-mail addresses, and promised to add one another as friends on Facebook. Six student speech pathologists also attended and learned an enormous amount through spending time with families, and helping students with CCN engage with the programme activities.

If you would like more information about Camp Have a Chat or other initiatives offered by CPL's complex communication needs programme, please contact the coordinator, Meg Hinselwood, on 07 3347 7200 or by e-mail on mhinselwood@cplqld.org.au



Annika using the camp book



Scotia with Jens



camps



Photos from Camp Big Mouth
September 17 - 21 2010 Rawson Village, Victoria



BOOK REVIEW: Rules by Cynthia Lord

By Amy Langley and Janelle Sampson

A while ago I borrowed a book from the lovely Amy Furze (SA State Rep for AGOSCI). It was a very quick but enjoyable read and so I went out and bought myself a copy. Several months later I loaned the book to my 13 year old niece, also called Amy, who wrote the following book review about it for a school project. She was happy for me to share her work with AIF readers.

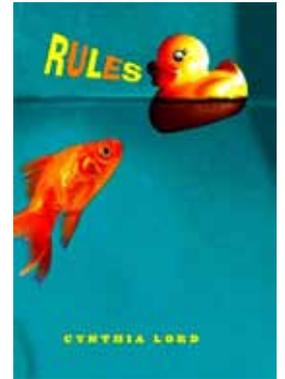
Personally, my favourite aspect of the book is the relationship between Catherine and Jason (a boy who uses AAC). From Catherine's perspective, the book describes the process by which Catherine gets to know Jason, and how she goes about selecting and drawing vocabulary to go in his book. The following quote is particularly insightful "She (Jason's mum) takes a little card and a pen from her purse. Watching her, I wonder how that'd feel, to have to wait for someone to make a word before I could use it. And to have all my words lying out in the open, complete strangers able to walk by and see everything that mattered to me, without even knowing my name (pg 43)"

The book is definitely worth a read. It was essentially written for younger readers but "older" readers will not be disappointed.

Book Review by Amy Langley

The text that inspired me is a book called Rules by Cynthia Lord. This book is set in America and is about a lonely sister of a boy who has autism. "Twelve-year-old Catherine just wants a normal life. Which is near impossible when you have a brother who has autism and a family that revolves around his disability"

the blurb says. Catherine feels that her parents don't pay any attention to her and often uses the phrase "I matter too". Her parents don't see this as they are far too busy caring for David and use her more as a tool to help them rather than helping her themselves. Catherine also loves to draw. She's very self conscious about David and tries her best to hide him from everyone she knows; any strange behaviour from him makes her drag him inside or run away from the scene. Catherine meets a boy called Jason who goes to the same clinic as David. Jason is in a wheelchair and can't speak, so he uses word cards to express what he wants to say. As Catherine and Jason spend more time together, Catherine makes word cards and draws pictures for Jason. She uses simple words to start off with and then as she goes on, uses words that express what she feels towards her parents and David. David loves rules (hence the title of the book). If he doesn't stick to a rule it turns out very badly. Some examples of this are "No toys in the fish tank", "Sometimes people laugh when they like you, other times they laugh to hurt you", "a peach is not a funny-looking apple", "Keeps your pants on in public" and "If you can't find the words you need, borrow someone else's". As the book progresses, Catherine finds that she doesn't need to hide her brother to be liked and takes control over the situation with her brother, her parents and with Jason. I loved this story because it paints an amazing picture of the way people look, feel and relate to each other. The way the book is written in the first person really personalises the moral of the story.



DVD Review

The Mounting System Toolkit

Produced by: ComTec – Disability and Communication Technology Solutions (<http://www.yooralla.com.au/comtec.php#resources>). Price: \$44.00

Review by John Pashen, Assistive Technology Adviser - Occupational Therapy, Cerebral Palsy League of Queensland
jpashen@cplqld.org.au

The Mounting System Toolkit is an essential resource for all therapists prescribing Speech Generating Device (SGD) mounts. This DVD provides a comprehensive overview of the many factors which need to be considered when recommending a SGD mount for a client.

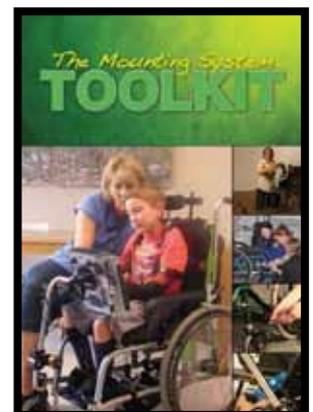
The Mounting System Toolkit provides a step by step instruction for the set-up of three SGD mounts available in Australia: the Daessy Rigid mount, the Monty mount and the Mount n Mover.

The clinical decision making flowchart and practical examples of what to include in your own assessment toolkit, make this

resource invaluable for therapists who would like to become more involved in the SGD mount prescription process.

There are many components of a successful SGD mount prescription. It is reassuring to know that there is now a resource available that will support therapists with this process and ultimately provide better outcomes for individuals who need a mount when using their SGD.

Well done Comtec.





AAC Research in Australia

Collated by Sheridan Forster

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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. Unfortunately due to the number of projects being undertaken we are not able to print the whole document. We have printed the titles, and have placed the full synopsis up on the AGOSCI website (www.agosci.org.au). If you want to find out more about any of the research I encourage you to contact the researcher directly.

Accessible Depression Tool – Bridging Project (www.bridgingproject.org.au) Teresa Iacono (teresa.iacono@med.monash.edu.au), Nick Hagiliassis, Jo Watson, Mark Di Marco, & Hrepsime Gulbenkoglou, Monash University and Scope Victoria

Children with Cerebral Palsy (CP) and Complex Communication Needs (CCN) Communicating in Hospital: The views of children who use AAC Bronwyn Hemsley (b.hemsley@uo.edu.au), The University of Queensland, Communication Disability Centre

Children with Cerebral Palsy (CP) and Complex Communication Needs (CCN) Communicating in Hospital: Views of Community-based Health Professionals Views (Honours Project Sabrena Lee) Sabrena Lee, Bronwyn Hemsley (b.hemsley@uo.edu.au), & Bronwyn Davidson, The University of Queensland, Communication Disability Centre

Children with Cerebral Palsy (CP) and Complex Communication Needs (CCN) Communicating in Hospital: The views of hospital-based allied health professionals and nurses. (includes Honours Project Kate Munro) Bronwyn Hemsley (b.hemsley@uo.edu.au), & Kathleen Munro, The University of Queensland, Communication Disability Centre

Children with Cerebral Palsy (CP) and Complex Communication Needs (CCN) Communicating in Hospital: Parents' Views (Honours Project Melissa Kuek) Melissa Kuek, Bronwyn Hemsley (b.hemsley@uo.edu.au), & Nerina Scarinci, The University of Queensland, Communication Disability Centre

Stories Of Adverse Events in Hospital for Adults with Communication Disability Maryanne Wernicke, Bronwyn Hemsley (b.hemsley@uo.edu.au), & Linda Worrall, The University of Queensland, Communication Disability Centre

Communication During Hospitalisation: The Path to Better Health Care Bronwyn Hemsley (b.hemsley@uo.edu.au), & Linda Worrall, The University of Queensland, Communication Disability Centre & Susan Balandin, University College Molde, Norway

Communicating Pain Marie Huska, Nick Hagiliassis, Sheridan Forster, & Jo Watson (jwatson@scopevic.org.au), Scope Victoria

Communication in the Social Networks of Adults with a Severe Intellectual Disabilities Hilary Johnson (H.Johnson@latrobe.edu.au), La Trobe University

Interaction Between Pre-symbolic Children with I Disabilities and Family Communication Partners Susheel Joginder Singh (skjogl@student.monash.edu), Teresa Iacono & Kylie Gray, Centre for Developmental Disability Health, Monash University

Interactions Between Adults with Congenital Deafblindness and the Staff Who Support Them Meredith Prain (Meredith.prain@ableaustralia.org.au), RMIT University

Interactions Between Disability Support Workers and Adults with Profound Intellectual and Multiple Disabilities Sheridan Forster (sheridan.forster@med.monash.edu.au), & Teresa Iacono, Centre for Developmental Disability Health Victoria, Monash University

The Use Of Internet-Based Social Networking and 3D Virtual Environments by Children and Adolescents with Physical Disabilities and Its Impact on their Social Participation 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

Making Music Through Movement: The Efficacy of the Virtual Music Instrument (VMI) for Developing Early Communicative and Play Behaviours in Children with Severe and Multiple Disabilities Pammi Raghavendra (parimala.raghavendra@novita.org.au), Sonya Murchland, David Hobbs (Flinders University), Prue Shiosaki, Renee Jose, & Breanna Worthington-Eyre (Disability SA), Novita Children's Services

Outcomes of the Non-Electronic Communication Aids Scheme (NECAS) for Adults with Complex communication Needs Teresa Iacono (teresa.iacono@med.monash.edu.au), Denise West, & Katie Lyon, Communication Resource Centre, Scope

Participation Profile of Children With Physical Disabilities With and Without Complex Communication Needs: Association Between Social Networks, Communication, Activity Engagement and Time Use Pammi Raghavendra (parimala.rahavendra@novita.org.au), Rachael Virgo, Dr Alison Lane (Ohio State University, USA), Catherine Olsson, Dr Tim Connell (Disability SA), Novita Children's Services

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 Abi Thirumanickam, Pammi Raghavendra (parimala.rahavendra@novita.org.au), & Cathy Olsson, Flinders University & Novita Children's Services

Partner Training and Communication Outcomes for Students with Multiple and Severe Disabilities Phil Foreman, Michael Arthur-Kelly (Michael.Arthur-Kelly@newcastle.edu.au), Deone Bennett, & Judy Neilands, The University of Newcastle

Professional Learning for School Personnel: Impact on Communication of Students with Severe Disabilities

Using Speech Generating AAC Devices 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

Speech Generating Device (SGD) Mentoring with Adults Experienced in Using SGDs As Mentors To New Learners Liora Ballin (lbal6064@mail.usyd.edu.au), Susan Balandin, Leanne Togher, & Roger Stancliffe, The University of Sydney

Supported Decision Making – Listening to Those Rarely Heard Jo Watson (jwatson@scopevic.org.au), Erin Wilson, & Nick Hagiliassis, Deakin University

The Experiences of Grief and Loss of Older Adults with Cerebral Palsy and Complex Communication Needs Leigha Dark (leigha_dark@hotmail.com), Susan Balandin, Lindy Clemson, & Leanne Togher, The University of Sydney

The Transition of Care from Ageing Parents: Achieving Flexible Relationships Between Adults with Cerebral Palsy, Their Siblings and Service Providers Angela Dew (angela.dew@sydney.edu.au), Gwynnyth Llewellyn, & Susan Balandin, The University of Sydney

The Prevalence of Drooling in Children with Cerebral Palsy Jenny Mc Cutcheon (jmccutcheon@students.latrobe.edu.au) Hilary Johnson & Sue Reid, Latrobe University

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Writing an Article for AGOSCI

AGOSCI In Focus is published twice a year in May and November.

Articles in AGOSCI In Focus should inform others about all areas of complex communication needs. We particularly encourage articles on augmentative communication, literacy, mealtimes, and saliva control. Articles may be in the form of research, personal stories, artworks, conference reports, video, book and technology reviews, and great ideas. Generally we have a theme for each issue.

Upcoming Issues

You are encouraged to submit articles with the theme in mind. The theme for the May 2011 issue is 'Taking it to the Streets' in line with the upcoming conference.

If you want to write an article, feel free to contact the editor and talk about it. Before you write an article please consider the following style tips. Adhering to the style requirements will make the article easier for the reviewers to read and more likely to get printed.

General

The articles that you submit must be your original work. If you have published it elsewhere you must put this on the article. If you are quoting other people's work you must reference their work.

Articles must be submitted by email or on disc (Word preferred).

All major articles are reviewed by the editorial committee. The reviewers may make some changes so that the article is clear and concise. You may be contacted to make some changes to the article.

Length

Articles should not exceed 2500 words, including the references. This is equivalent to 11 double spaced pages.

Format

All articles should be double spaced. Include a title, authors name, and contact details (email and phone number). Use one space after punctuation.

The first paragraph is flush. And all subsequent paragraphs are indented, with no extra spacing between them.

Use two levels of headings to make it easier for the reader. For the first level heading use all capitals, centred with one line space above and one below. For second level headings use a capital letter for the first letter of each word, centred with one line space above and one line space below, for example:

FIRST LEVEL HEADING

Second Level Heading

Writing Style

Use short sentences and plain language.

Include pictures or photos that add to the meaning of the text and add interest to the article.

Photos need to be at least 10cm x 15cm and preferably high resolution jpeg files. Please label

all pictures, tables, graphs etc. If you would like to include a reprint of any previously published material (e.g., diagrams, graphs) you need to seek permission from the author/publisher first.

Acronyms should be used only after the full term has been written and is followed by the acronym in parentheses, e.g. Complex Communication Needs (CCN).

References

Full references should be included at the end of the article.

References should be in American Psychological Association (APA) (1994 or 2001) style. The reference list is organised alphabetically, with italics, overhanging indent, and punctuation as shown in the following examples for journal articles and books.

Bloggs, J. (1999). The relationship between red wine consumption and tooth decay. *Journal of Teeth and Wine*, 34, 99- 909.

Bloggs, J. & Bliggs, S. (2001). *Correlates of lifestyle and health*. Melbourne: Big Banana Publications.

Bloggs, J. (2000). Conversations at the bar. In S. Bliggs (Ed.), *Professional conference activities* (pp. 10-25). Sydney: Bigger Banana Publications.

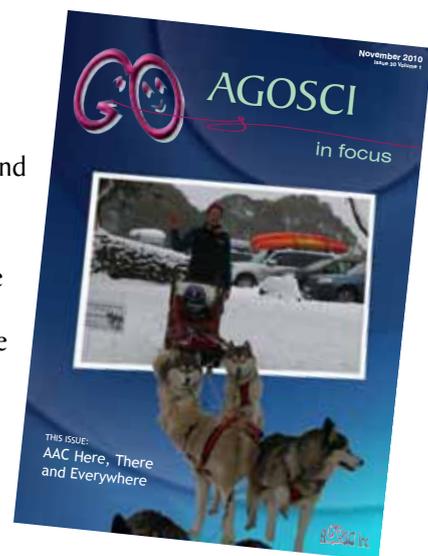
Bliggs, S. *Chocolate Myths*. Retrieved June 11, 2007, from <http://chocolaterocks.com.au>

Article Submission

Do not be daunted! If you want to write something and are not sure what all this means contact the editor and ask for help. We want to encourage you to write and share your experiences.

Contact agosciinfocus@yahoo.com and see www.agosci.org.au for more details.

Thanks to ACQ for permission to adapt their "notes to authors" guidelines. Go to website for full details.





Zytec is an Australian company specialising in speech generating devices for people needing alternative/augmentative communication systems. We also offer environmental control units. Zytec provides nation-wide direct sales, equipment to try, support, training and repairs. We also distribute through resellers around Australia.

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