



AGOSCI

in focus



This issue ...

Communication - Feel the power
2009 AGOSCI National Conference



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

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Disclaimer

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Editor's Apology

There was a misprint in AGOSCI In Focus November 2008 edition (Issue 27, vol. 2), p. 15. The name of the first author for the article on page 15, Hilary Johnson, was left out. The article's correct title and authors are:

'Out of the Box – Using Technology to Follow Your Dreams.'

Hilary Johnson – Manager, Communication Resource Centre, Scope

Melinda Smith - Community Development, Communication Resource Centre, Scope (msmi5545@bigpond.net.au)

Jo Watson - Specialist services – Scope.

EA – Ed.

Welcome to your AGOSCI 2009 conference edition. The theme for this year's conference, held in Canberra in May, was 'Communication – Feel the Power!'. As AGOSCI's Chairperson, Wendy Webster, has written in her report this edition: "Power is the ability to influence the attainment of goals ... Learning to interact with family, friends, colleagues, authority figures and strangers to achieve this power is so much taken for granted by most until you have to include in this mix communicating another way than speech." We hope those who attended the 2009 AGOSCI conference are still feeling the power of communication: forging ahead in our communities powered by inspiration, networks and knowledge gathered. A huge thank you to the many people involved in organising the conference, particularly Jennie Lindsay and the conference committee.

To refresh your energies, and to energise those who weren't able to attend, we have printed the Governor-General of Australia, Her Excellency Ms Quentin Bryce AC's, Opening Address from the conference and Dr Nicola Grove's keynote address: 'A story

to tell'. In this edition we are also able to offer a forum to share the abstracts of some papers submitted that were not able to be included in the conference programme due to limited room.

Whatever charges you: arts, advocacy, inspirational awardees, travel abroad, access to academia, access to eyegaze technology, academy award nominations, an AC adaptor, alliteration, or all over the above, we hope this edition has something to power you along!

In the next edition we want to hear about the dilemmas and solutions you meet along the way. Please send us your contributions for the next issue with the theme: 'Tricky issues: Positive solutions.' Also keep in mind our regular sections: 'AAC, the Arts and Sport', 'Reviews', and 'Editorial'. Yes that's right – during and/or after the next edition we are in need of a new editor for AGOSCI In Focus as I need to move on to other commitments. Anyone interested in sharing the editorial role with Sheridan Forster in 2010 please get in touch. In the meantime, power to the AAC people! We hope you enjoy this edition of AGOSCI In Focus.

What is AGOSCI?

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

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

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



What are the key areas of interest for AGOSCI?

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

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

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

Who can join AGOSCI?

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

What does AGOSCI offer?

AGOSCI membership offers:

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

How do I join AGOSCI?

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

congratulations!



CONGRATULATIONS! 2009 AGOSCI AWARDS



2009 AGOSCI Award: Service to AAC Melinda Smith

Melinda is an inspiration and source of encouragement to all AAC users, their families and friends. Melinda's efforts as a mentor at Big Mouth Camp, her participation in awareness raising for AAC and her involvement in the international community through ISAAC are greatly appreciated.

2009 AGOSCI Award: Service to AGOSCI Jane Farrall

Jane has been an active member of AGOSCI for many years and during this time has held the role of Chairperson, Conference Convenor and National Tour organiser. Jane's knowledge of AAC, the history of AGOSCI and her willingness to support AGOSCI activities even when not in official roles has benefited many and is greatly appreciated.

CONGRATULATIONS!

Anne McDonald Award for Personal Achievement Australian 2008 National Disability Awards

On the night of the 3rd December 2008, Anne McDonald received the Personal Achievement Award in the Australian 2008 National Disability Awards, which was held at the Australian Federal Parliament House, as part of that year's International Day of Disabled Persons. This was one of the 5 awards received, chosen from 240 nominations.

The awards are held to coincide with International Day of People with Disability, a worldwide celebration of the contributions, skills and achievements of people with disability. Minister for Families, Housing, Community Services and Indigenous Affairs, Jenny Macklin, and Parliamentary Secretary for Disabilities and Children's Services, Bill Shorten, congratulated the winners at the Awards event.

"The National Disability Awards celebrate and acknowledge the achievements people with disability make to our community and recognise the individuals within our community who contribute to the disability sector," Ms Macklin said.

The events' press release stated:

Anne was born with cerebral palsy and at age of three was admitted to the St Nicholas Hospital state institution, unable to walk, talk or feed herself. Eventually Anne learnt to communicate by pointing to letters on an alphabet board and at 18 years old went to court to win her freedom from St Nicholas.

Many who have been inspired by Anne's story and her willingness to share this creatively, through Annie's Coming Out (the book and the movie) and her many discussion papers and presentations, will join the AGOSCI Executive and members in congratulating Anne on the receipt of this award.

AGOSCI is grateful that Anne has allowed us to reprint her acceptance speech for us all to enjoy and ponder.





National Disability Awards

Parliament House, Canberra, December 3rd 2008

Anne McDonald - Award for Personal Achievement - Recipient Speech

Ladies and gentlemen, I'd like to thank the judging panel for choosing me, and I'd also like to thank the many people who've helped me along the way and made it possible for me to be here in Parliament House tonight.

I spent my childhood and adolescence in a state institution for severely disabled children. I was starved and neglected. A hundred and sixty of my friends died there. I am a survivor. That isn't a heroic achievement. Anyone who was put into a large institution in the times when large institutions were sugar-coated concentration camps was as much a hero as I was. They stayed alive when they could and they died when they couldn't. Such heroism is easy to achieve in giant barracks where the prisoners stay alive through being cheery enough to attract a staff member to give them that vital extra spoonful of food.

I wasn't exceptional in anything other than my good luck. I was selected for an experiment. Rosemary Crossley wanted a subject for her Bachelor of Education literacy project. She chose me. The aim of the experiment was to see if I could make gains in my tight-armed pointing to blocks with different colours on them. Rosemary found I could point to colours, then to words, and then to letters. She taught me to spell and to make my wishes known. I made known my wish to leave the institution, and then all hell broke loose. I went to the Supreme Court and won the right to manage my own affairs.

Unfortunately, that didn't mean that the institution offered the other residents the right to manage their own affairs. I was an exception.

Through no desire of my own, I was out front in the struggle to get rights for people without speech. I tried to show the world that when people without speech were given the opportunity to participate in education we could succeed. I went to Deakin University and got myself a degree. That, too, was seen as an exception.

I gave papers and wrote articles on the right to communicate. I set up a website to show that there was hope for people without speech. People thanked me for being an inspiration; however, they didn't understand why there weren't more like me. They continued to act as if speech was the same thing as intelligence, and to pretend that you can tell a person's capacity by whether or not they can speak.

Please listen to me now. The worst thing about being an inspiration is that you have to be perfect. I am a normal person with only normal courage. Some people who should know better have tried to give me a halo. Anybody could have done what I have done if they too had been taken out of hell as I was.



If you let other people without speech be helped as I was helped they will say more than I can say. They will tell you that the humanity we share is not dependent on speech. They will tell you that the power of literacy lies within us all. They will tell you that I am not an exception, only a bad example. Many are left behind. We still neglect people without speech. We still leave them without a means of communication.

It should be impossible to miss out on literacy training, but thousands of Australians still do. As Stephen Jay Gould wrote, We pass through this world but once.

Few tragedies can be more extensive than the stunting of a life, few injustices deeper than the denial of an opportunity to strive or even to hope, by a limit imposed from without, but falsely identified as lying within.

spread the word

Let users of AAC and their families know about AGOSCI

Download a membership form from the internet

www.agosci.org.au



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Wendy Webster

Chairperson's Report

Our conference theme for 2009 is "Communication-Feel the Power". Power is the ability to influence the attainment of goals of an individual or a group. Power is not a characteristic of any one individual, rather, it is defined in terms of relationships and transactions between people. Power is crucial to the achievement of individual goals, the resolution of conflicts, and to communication competency within a group. (Wikipedia)

Learning to interact with family, friends, colleagues, authority figures and strangers to achieve this power is so much taken for granted by most until you have to include in this mix communicating another way than speech. AGOSCI continues to work towards networking those interested in promoting alternative and augmentative communication and related issues. This is done through following a business plan agreed upon at Executive level and is updated each year.

Certainly the strength of AGOSCI continues to be the professional development activities. These may be low key local sharing of information, chat discussions over the list serve or individual connections people make through AGOSCI. In 2008, the National Tour of David Kopenhaver and Karen Erickson breathed new energy into a variety of participants across Australia and New Zealand who have taken hold of the notion of literacy and AAC and the frameworks taught. We tried, for the first time, webcam and a week long intensive, both of these with exciting outcomes. Jane Farrall cannot be thanked enough for the dedication, sweat and enthusiasm she put into making this happen. Jane has offered to manage the 2010 National Tour and Joanne Cafiero, a specialist in autism and AAC, has agreed to visit Australia for AGOSCI.

AGOSCI 2009 Communication Feel the Power has been a joy and many thanks go to Jennie Lindsay and her committed conference committee. It has been wonderful to have two overseas speakers, Luis Estrella and Dr Nicola Grove and the many local presentations to inspire us. Thanks to all who gave of their time and energy and wisdom. AGOSCI for the first time tried the use of a conference manager to support the committee. Thanks to Aghi and her team. There is excitement that Adelaide has agreed to take on the 2011 Conference and will be ably convened by Janelle Sampson.

The combined financial success of FACSIA grant and profits from the National Tour and Literacy Intensive has made it possible to offer scholarships to people who use AAC and family members. 33 of these offers were accepted. This gives AGOSCI great joy as we are all then grounded in the real reason this organization exists.



Portfolios continue to make it possible to make activities of national significance happen. Sally Hunter looks after the website and list serve, Di Symons had the mammoth task of overseeing 40 applications for scholarships. Though not officially on the executive, we continue to be deeply grateful to Emily Armstrong and Sheridan Forster for the wonderful magazines that continue to be published twice yearly. The professional development portfolio is shared between Jane Farrall and Janelle Sampson.

There were efforts to enter into educating government begun this year with information and ideas gathered over the list serve. Submissions were put together for the 2020 Summit coordinated by Meredith Allen and the National Disability Strategy which I coordinated. This has only highlighted that this is an important role for AGOSCI and that there is still a lot to learn about how to present material in the advocacy area.

There are some farewells and welcomes amongst the state representatives. Anne Dixon (NT) has moved south and Marion Mettam has agreed to take over. Tara Wright (ACT) is being a mum and we welcome Kate Jarvis. Melissa Reipsamen and Helen Tainsh (VIC) have handed over to Katie Lyons and Stacy Cohen. Nicole Thompson (NSW) will replace Lisa Hanley as Harriet's offside. AGOSCI is deeply grateful to Anne, Tara, Melissa, Helen and Lisa for their ongoing support at the state level. We welcome new comers to the Executive. Last but not least, there is a need to thank Melissa Bakes, Secretary and Jenny Arthur, Treasurer (and their respective partners) for their ongoing commitment. It is a joy to be part of the AGOSCI Executive.

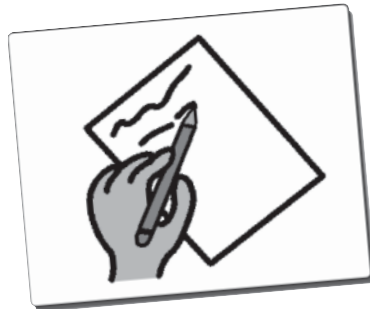
And as I always say..... And all this with volunteers!
Keep seeking the power... and chatting.



Notations ...

AGOSCI Inc. Secretary's report
Melissa Bakes

It was a busy start to the year with the Conference and with many memberships coming in. Now it is just the usual secretary jobs: banking cheques, forwarding information, answering enquiries etc. etc. I'd first like to congratulate the Canberra conference committee for an absolutely fantastic conference. I had such a great time and picked up some really great ideas. It was great to catch up with many members and the new and past executive committee members. We had a really productive meeting as the new executive. There were lots of wonderful ideas for moving forward.



I have a big task in front of me next up with taking back the role of membership processing and handling of receipts. I know there have been a few hiccups in the past and I thank you for your patience. Hopefully by now you should have your receipts. If not let me know and I'll see what I can do. I have included the minutes from the recent AGM at the conference in this copy of AGOSCI in Focus. We had quite a few laughs at the AGM amongst the serious business.

Just a reminder that with regards to answering phone enquiries, I would just like to say again that if you are leaving a message, that it may be faster if you could leave an after hours number if at all possible or try my email address. As I am at work during the day I don't get to the messages until I get home. That usually means I can't get back to anyone until the next day and sometimes I forget throughout the course of a busy day at work. My apologies to anyone who has had to wait a few days for a reply. Alternatively you can leave a message on my mobile: 0414 369 535.

All I really have to report on for the moment are the membership numbers. At the moment we have around 180 members. That is a little down on last year's figures for the same time of year. I have seen some new names again this time around. So the word continues to get out there. Thanks again to all of those who have rejoined. Your continued membership is appreciated and valued. We continue to grow each year.

Money Matters

AGOSCI Inc. Treasurer's report
by Jenny Arthur

Last year was again a successful year for AGOSCI financially. The Literacy Intensive proved to be a bonus for us because the Australian dollar was a good price when we had to pay our American presenters. These things are difficult to predict and it would be different story if we had to pay them on today's rates. The financial reports were presented at the AGM held during the conference but if any members were not there and would like a copy please contact me.

The conference has been a busy time for me with my role as treasurer and on the organizing committee for the conference but I am excited that the conference went so well. It will take some time for the financial aspects of the conference to be finalized and as this was the first year we had paid conference organizers it will be interesting to see what the final result is on a financial level.

Please remember that your membership for AGOSCI is for each calendar year and the price of the membership has not risen for a number of years so please remember to renew your membership at the beginning of each year. Also, all the people who run AGOSCI are volunteers so please be patient with any enquiries.

Thanks Jenny Arthur

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

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

State Reports



Victoria

No report submitted.



South Australia

Amy Martin

In South Australia we experienced a rise in membership in 2008 with the National Tour. This was well attended by a range of stakeholders including speech pathologists, teachers, school support officers, occupational therapists and parents of children and adults with complex communication needs. During 2008 we also had the Statewide Complex Communication Needs (SCCN) Project running in South Australia. We held a number of interest groups in conjunction with this project, including one at an Adult rehabilitation centre to try to expand AGOSCI's typical membership in SA into the adult sector. We hope to continue these through AGOSCI during 2009.

So far in 2009 we have had a lot of activity locally with approximately 20 local AGOSCI members volunteering to be part of the Conference Committee for the 2011 National conference which will be held in Adelaide. Janelle Sampson has accepted the role of Conference Convener and will also be taking leave later in 2009. This means that Amy Martin will be taking on greater responsibilities in the state co-representative role, while Janelle focuses her energies on the conference.

We are also distributing the "Spot the Difference" postcards that were developed by speech pathology students through SCOPE and CRC and have the order forms and samples available on the AGOSCI website, or by contacting Amy Martin at amy.martin@novita.org.au.



New South Wales

Harriet Korner and Nikki Thompson

Welcome to Nikki Thompson, who has recently taken on the joint AGOSCI NSW representative role. Nikki is a speech pathologist working at The Spastic Centre NSW. We would like to thank Lisa Hanley for the amazing work she has done in 2008-09 to assist the conference committee to organise the wonderful AGOSCI conference in Canberra.

Last year the AGOSCI National Study Tour in Sydney in June 2008 was very successful, with Karen Erickson, David Koppenhaver and Amy Williams presenting on Comprehensive Literacy Training for Students with Complex Communication Needs. We had 49 participants from around NSW.

We are currently planning some events for 2009 in NSW. We are organizing Feel the Power in NSW - AGOSCI Conference Feedback Afternoon for 26th June at 12 noon, The Spastic Centre, Ryde Office.

A Pragmatic Organisation Dynamic Display (PODD) meeting is planned for the afternoon of August 6th, as an opportunity for people who have been implementing PODD's to get together and share their experiences. Please contact Harriet for further information about this.

Dr Melanie Fried-Oken, an internationally renowned AAC specialist, will be visiting NSW in October, presenting on AAC in Hospital and Health Settings.

Makaton NSW has gone from strength to strength, with 110 Basic Makaton Workshops being run in NSW statewide in 2008. Teena Caithness has developed a great poster on Makaton NSW 2004-2008.

The Inclusive Communication and Behaviour Support (ICABS) Project run by Teena Caithness for DADHC in NSW has trained a massive number of direct care workers and support staff working in NSW in the area of practical AAC strategies to assist adults with intellectual disabilities in accommodation and day services. This has been a huge achievement during 2004-2009.

On 23rd April 2009, Liberator: a Prentke Romich Company, presented in Sydney on their new low tech 'Pixon' approach and latest range of high technology products including the Liberator I4, Vantage Lite, Springboard Lite and Chat PC Silk.

The 3rd International Cerebral Palsy Conference was held in Sydney in February 2009. Some of the communication research included: (i) Development of the Functional Communication Classification System (FCCS) by The Centre for Cerebral Palsy, Perth, WA and Cerebral Palsy League of Queensland, (ii) Development of the Communication Functional Classification System (CFCS) by Michigan State University and (iii) Liora Ballin presented on how adults who are experienced users of speech generating devices may be involved in mentoring people learning to use a new device.

Finally, the 9th Biennial AGOSCI Conference 2009 has been incredibly inspiring. We look forward to sharing the power with others very soon! Please come along if you can. We would love to hear from NSW members and will aim to keep everyone informed about events in NSW. Our contact details are: Harriet harriet.korner@northcott.com.au or 02 9890 0923 and Nikki nthompson@tscsw.org.au or 02 9586 1077.



Australian Capital Territory

No report submitted.



Queensland

Melanie Waalder and Paula Hartwig

In Queensland, we had a great turn-out for Dr Karen Erickson & Professor David Koppenhaver's National Tour last year, and it was great to see a large number of Qlders also venture



State Reports (cont)

south to attend the recent AGOSCI conference in Canberra. A number of attendees at the 2008 National Tour requested a return of Karen and David. Keep an eye out for information about the Literacy Intensive, to be held in 2010. These were both fantastic, inspiring events and it was great to part of such exciting professional development opportunities.

In other exciting news, Anne Pearson is awaiting the arrival of her first baby and has decided to step down from her joint role as Queensland AGOSCI representative. Paula Hartwig has now agreed to step into this role. Some may remember Paula from her previous stint as Queensland representative in 2005. We would like to thank Anne for all her hard work and dedication in managing the Queensland AGOSCI role since 2005. Good luck with the baby!

Later this year, we hope to organise some AGOSCI special interest meetings, to give us the opportunity to network and share resources. We are also keen to approach Gayle Porter to travel up to Queensland late 2009/early 2010 for another 2-day introductory Pragmatic Organisation Dynamic Display (PODD) workshop. Don't forget if you have any queries you can contact us by email (agosci@drep@hotmail.com).



West Australia *Sally Hunter*

A small but dedicated band of Western Australian (WA) people attended the Canberra AGOSCI conference this year determined to not only wave the flag for WA but bring back lots of ideas and knowledge. We were also very proud to have Sam Ren over there supporting the National Relay Service in its endeavours to the service to those with complex communication needs. WA membership remains steady although typically membership drops a little in the "non national tour" year. We are looking forward to having Mark Barber visit in June to do a one day presentation. Mark will also be spending some time at Malibu School working with teachers and students there. A local conference supported by Non-Government Centres Support (NGCS) in August will also have a strong AAC stream www.morethangadgets.com.

Having surveyed its members the AAC device interest group convened by The Centre for Cerebral Palsy has expanded its brief to include practices and has had a resurgence of in attendance. The group continues to meet once a school term. Danielle Lampropoulos at The Centre for Cerebral Palsy (TCCP) can be contacted for information regarding future meetings. The Independent Living Centre recently completed a project mapping best Practice in AAC service delivery with a goal of informing the sector of other processes, evaluating the WA experience and raising the profile of AAC. This has been a highly successful exercise utilising an experienced reference group and conducting sector consultations. The literature search and executive summary of the first part of the project can be found on the ILC website www.ilc.com.au.



Tasmania *Diane Symons*

I must start my report by thanking the conference committee for an inspiring conference in Canberra. I and two other Tasmanians attended the conference and will endeavour to compare notes and keep the enthusiasm going at a local level.

Following the successful National Tour last year and my attendance at the Literacy in AAC intensive I held a couple of feedback sessions in the North and North West of the state. These were well attended by a range of people from different professional backgrounds. It is always great to welcome new people into the AGOSCI community.

You may recall that early last year I reported on a submission I wrote to the state parliamentary review into the provision of aids and equipment for people with disabilities. There is currently some media interest into the recommendations of that review which are yet to be implemented. A television interview with a local person with complex communication needs who uses a Pathfinder speech generating device will be filmed in a couple of weeks. I am hoping this will be an opportunity to raise the issue of support for the specialised equipment for people with complex communication needs. I will keep you posted.



Northern Territory *Marion Mettam*

Hi everyone. First and foremost, farewell and a big thank you to Anne Dixon for all her hard work. Anne has been instrumental in arranging fantastic professional development and interest group meetings for the Northern Territory.

As the new representative, there is not (yet!) a lot of news to report on. We were unsuccessful in arranging professional development for the later half of 2008, but are on the lookout for potential professional development for 2009 and 2010.

The first Special Interest Group meeting for the year took place in March and was well attended by Speech Pathologists. We're hoping to encourage a wider range of people to attend future sessions. The next planned meetings will occur in June and September. In other news, Spectronics visited Darwin and Alice Springs in February this year, funded by the Australian Association of Special Education (AASE).

I will continue to encourage people to join AGOSCI, as numbers are down for memberships, but hopefully this will increase. I look forward to working in this role. If any members or potential members in the Northern Territory would like to contact myself to discuss professional development, or potential content for interest group meetings you can contact me on (08) 8922 7271 or email marion.mettam@nt.gov.au.



Opening the 9th Biennial National AGOSCI Conference

National Convention Centre - Canberra, Thursday 7 May 2009

Speech by Her Excellency Ms Quentin Bryce

Chair of AGOSCI: Ms Wendy Webster
AGOSCI's Executive Committee and State Representatives

Conference Convenor: Ms Jennie Lindsay
Ms Agnes Shea, Ngunnawal Elder
Members of AGOSCI and Conference Delegates
My friends

I acknowledge the traditional owners of the magnificent land on which we gather, and I thank you for your warm welcome.

I want you to know how delighted I am to be here for the beginning of your 9th biennial national AGOSCI conference. First and foremost because it allows me to express my sincere admiration and respect for you; to thank you for what you do every single day.

In your different roles as researchers, health professionals and therapists, teachers and special educators, carers, communication partners, parents, and friends, you make an incalculable contribution to Australian society, where one in seven people experiences difficulty in communication. In understanding and supporting them, in your recognition of how essential communication is to all our lives, you add to our sense of cohesion and harmony, to our rich social fabric.

My deep lifelong interest in your work, what you do, what you stand for, goes back to my mother – as so many things do for all of us. In the early sixties my mother left her country life to return to her profession as a teacher – to support the education of my sisters and me, which she was passionate about. She taught at the Spastic Centre, as it was then called, in Brisbane at New Farm. Her students were in their primary years, from the city and the country – all with cerebral palsy. She was devoted to them, to their families, to the volunteers who helped with their daily needs, and to the therapists.

They were early years in developing and creating opportunities for children with CP to reach their potential. She was inspired by her colleagues, particularly the Principal, Geoffrey Swan, and by the work of Professor Fred Schonell and Dr Eleanor Schonell, wonderful, generous scholars who pioneered special education.

My mother used to insist that I spend time in her classroom. Then in my teens, I found it awkward and confronting at first but I learnt so much from those experiences – about the struggle



for communication, about difference, about myself. I admired my mother's dedication, commitment and determination. I marvelled at the way she ensured her pupils had access to lovely things as well as learning. She took them to all sorts of special events – ballets and concerts – and sometimes I went with her.

I didn't know it then because we didn't have the words, but I came to understand that what she was doing was translating into practice equality of opportunity, recognition of the dignity and worth of every human being.

When I went to Government House in Queensland I came to know well many of the organisations I was Patron of, particularly disability advocacy groups, at meetings, and special celebrations – on one unforgettable occasion, hosting wheelchair dancing in the sombre Investiture Room.

It meant a lot to me to catch up with some of my mother's former students. They spoke of her with great affection and she loved to hear about their successes in professional and community life, their extraordinary achievements in the face of extraordinary challenges.

I owe a debt of gratitude to her for engendering in me not only understanding but also many enduring and enriching friendships. She handed on to me an ease in reaching out. She taught me that the key to communication, to conversation, to sharing ideas and experiences, to relationships, is in taking the time to listen.

In slowing down, giving our attention wholly and patiently to



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each other, in valuing more what takes longer to arrive. A few years ago I was intrigued by rumours about a worldwide “Slow Movement.” I found Carl Honoré’s book *In Praise of Slow*, and lingered over his sanctions of the slow, the contemplative, the receptive, and the still. He wrote:

In many quarters, ‘slow’ remains a dirty word. Just look at how the Oxford English Dictionary defines it: “not understanding readily, dull, uninteresting, not learning easily, tedious, slack, sluggish.”

Hardly the sort of stuff you want to put on your CV.



All the things that bind us together and make life worth living — community, family, friendship — thrive on the one thing we never have enough of: time. (Honoré, 2005, p9).



In our hyped-up, faster-is-better culture, a turbocharged life is still the ultimate trophy on the mantelpiece.

When we rush, we skim the surface, and fail to make real connections with the world or other people.

All the things that bind us together and make life worth living — community, family, friendship — thrive on the one thing we never have enough of: time. (Honoré, 2005, p9).

His words struck a chord with me, and reminded me of Dr Rowan Williams’ well-known commentary on our “portfolio society.”

In 2004, the Archbishop gave the trenchant warning that in rushing through life, we remain in the shallows. He referred to “the [modern] assumption that jobs, friendships, relationships and ties of birth and kinship are all in flux. The short term is now the only term; if things do not work out, the response is to change the people and the pattern.” He asks how, in such fluidity, you can build “a life that has three dimensions, which has interiority and resonance?”

Though my own life often gets caught and swept off in the swell, I have meditated on these thoughts and found them nourishing.

My friends, for you, I know, they are not new. In the area of complex communication needs, they are part of your mode of being, informing your steady and practiced response to the

challenges of communication disability. Among the many key issues that you negotiate daily – issues of access, opportunity, participation, and wellbeing – is the way people who use augmentative or alternative forms of communication need more time to communicate than our frenetic pace usually offers. They face discrimination when there is insufficient time for them to ask questions, find information, respond to requests, present their work. They encounter exclusion when impatience scuttles the time they need to participate fully.

The irony is that those who are most assiduous in saving time end up with less. Less time, but also less engagement, less openness to the offerings of their fellows and the world around them. We’ve grown used to our age of rage – road rage, shopping rage, internet rage, gym rage. Yet our unseemly haste – what Carl Honoré might call our ‘tempo tantrums’ – in fact leaves us empty-handed, disconnected.

A sublime example of the rewards of patience is the life and work of eminent physicist Professor Stephen Hawking. In his twenties, already recognised as a genius and embarking on his PhD at Cambridge, Hawking developed symptoms of amyotrophic lateral sclerosis – a form of motor neuronal disease that would gradually deprive him of all neuromuscular control. In time, he would lose the ability to walk, speak, wave, breathe, swallow. Later, a tracheotomy left him dependent on a computerised voice synthesizer.

Yet Hawking’s voice – synthetic and monotone – is one of the most important of our generation. He is a global leader in theoretical physics and one of the most effective science communicators: a *New York Times* bestseller since the late eighties. He is philosophical about his disability, and modest about his accomplishments: “It is a waste of time to be angry about my disability. One has to get on with life and I haven’t done badly.”

Indeed the author of the wryly titled *Brief History of Time* is a prophet of the long view. He says “It is no good getting furious if you get stuck... Sometimes it is years before I see the way forward. In the case of information loss and black holes, it was 29 years.” The scientific community would concur that Hawking’s contributions are worth waiting for.

Hawking’s extraordinary gift gives him an international platform and furnishes an audience. Others who share his complex communication needs find it much harder to be heard.

In their paper “Key Principles Underlying Research and Practice in AAC,” published in 2007, Blackstone, Williams, and Wilkins point out that in researching communication disability and designing effective responses to it: “The most important voices are often the hardest to hear.”

Individuals with CCN hold an intensely personal stake in AAC



Opening the 9th Biennial National Agosci Conference (cont)

research and clinical practice; hence the slogan, 'nothing about us, without us'. Their characteristics, experiences, preferences, priorities, opinions, suggestions, and expertise must be sought, respected, attended to, understood, and employed – in the design, development, delivery and evaluation of AAC systems and services. (Blackston, Williams, & Wilkins, 2007).

That principle underpins your conference this week. As you gather to exchange collegial, professional, academic and practical experience, you are listening for the voices of those hardest to hear, eliciting and prizing their part in a crucial dialogue.

Over these three days – full and overflowing as they are – there will be time for each person, for each story to be heard. And I, for one, can't wait to hear what a Blabber Finger is!

I wonder if my final story might contain one? It's about Locky, who is 7. Locky goes to Geebung Special School – a place I grew very fond of in my Brisbane years. One day Locky packed his little knapsack with toys and ran away from home. He quickly became lost, but he had no way of asking for help. He found his way to a police station, but again, he could not explain who he was or where he lived. An officer gave him a pen, but he cannot write legibly and has trouble with sequencing.

Desperate, frustrated, and frightened, Locky suddenly had a brilliant idea. He pulled a toy from his knapsack. It was his Thomas the Tank Engine mobile phone. He began to dial his home number on the fake plastic keys. The officer watched, smiled, and caught on. As Locky patiently dialled the number again, he followed the pattern of his finger until he had the

number right. Mum and dad were called, and clever Locky was restored to his home.

To me, that story captures the spirit, creativity, and courage you find in yourselves and each other every day.

I know you will feel it in spades during your conference, which it's my very great pleasure now officially to open. In doing so, I leave you with the sage advice of Winnie-the-Pooh, who knew all about taking time for the things that matter: "Sometimes, if you stand on the bottom rail of a bridge and lean over to watch the river slipping slowly away beneath you, you will suddenly know everything there is to be known."

My friends, thank you. I wish you all the very best.

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

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

Want to know what's happening in your state?

Simply log onto the website and click on the map

www.agosci.org.au



A Story to Tell

Keynote Speech Friday 8th May 2009

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In the myth of the birth of Taliesin from the ancient Celtic tales of the Mabinogion, the bard and storyteller gains his powers through the inadvertent theft of a brew designed for his half brother Afagddu. The name Taliesin means “shining brow”, where Afagddu means “utter darkness”, and Afagddu is described in the story as malformed, ugly and black. He disappears from the story when the spell is lost. When my company of storytellers with intellectual disabilities came across this tale during our researches into the origin of story, we were in no doubt that we were in the presence of an archetype of severe disability, the marginalised and voiceless shadow side of the successful orator¹.

This is the signature story of Openstorytellers (www.openstorytellers.org.uk) a unique company of professional storytellers who have intellectual disabilities. Our message is that everyone has a story to tell, and that those of us who have a voice and are privileged in society owe a debt to our brothers and sisters who are left on the sidelines, in utter darkness.

Meaning and Narrative

Without narrative, there is no meaning; an insight shared by Terry Eagleton (2009) in his elegant treatise on the meaning of life (2009). In his answer to the question of what life ultimately means, Eagleton emphasises the practice over the end goal – life, like a jazz band, consists of the way in which each player articulates his own theme, harmonising in collaboration with other players, within the constraints of the given form. The process of existence gives it meaning, not the end goal. This focus on the here and now, the unfolding way in which we invest experience with significance by the aesthetic of living, represents – as Naomi Klein points out² – a challenge to the Judaeo Christian apocalyptic story which tells us that life is only given meaning by its telos, its ending and its purpose, and that humanity is essentially constituted by agency and conscious awareness of self. Reinders (2008:52) makes essentially the same point:-

Scholars in the field of disability studies are guided by a concept of human nature that understands human telos in terms of the freedom of the self. But... this concept contributes to the source of the exclusion of people with profound intellectual disabilities.

By contrast, a process focused paradigm asks us to value presence, being and potentiality. So what is the nature of this process? One way of looking at it is as an unfolding narrative.

Narrative and Story in Our Lives

Narrative is in fact the way we live. Each morning we wake to the beginning of a new day, out of a sleep in which we have engaged in very active story making through our dreams. The day unfolds in a sequence of events, contingently and causally linked, until consciousness, and the day's story, ends. And during that day we obsessively engage in the process of story. Each event that we observe is processed, if Mark Turner (1996) is to be believed, as a mini narrative, a “small story of events in time”. We can only recall experience as narrative, with beginnings, middles and endings – or at least, junction points. We constantly rehearse what has happened to us in our heads (often with alternative plots and dialogue!) and we seek out new listeners for our stories as the hunted deer pants for the quenching stream. This compulsion to construct, tell and retell anecdotes appears to be universal. Daniel Everett (2008) describes his life with the Piraha tribe in Brazil who have no history going further back than living memory (two generations). They do not relate or recount any fact or event that has not been eyewitnessed by themselves or at only one remove. But they do relate their personal experiences.

There is however, one group of people who do not engage in shared anecdotal telling – people with severe and profound intellectual disabilities. In the research documented in a 2007 paper, I demonstrated that families, advocates and teachers find it really hard to tell anecdotes about the lives of these individuals, and discussed some of the reasons for this omission (Grove, 2007). I hazard a guess that one contributory factor might be the dominant focus on autonomy and rights in the delivery of services, which sidelines relationships, commitments and friendship in favour of individual choices. By contrast, the Storysharing work that we do in Openstorytellers emphasises the meaning of joint experience that is socially constructed through interdependency (see Grove, in print, 2009). Reinders (2008) makes the same point very cogently when he argues that the humanity of people with profound intellectual impairments does not consist in their agency, but in the relatedness of their lives.

1. See <http://www.timelessmyths.com/celtic/mabinogion.htm>

2. Naomi Klein in discussion with Gael Garcia Bernal <http://www.youtube.com/watch?v=2a2W2EXYQWQ>



A Story to Tell (cont)

What We Can Learn From Indigenous Communities

Meaning is elusive. It reveals itself gradually, with time. Often it is only after having shared a story for years that we come to understand what it actually means to us. We can learn from the way in which Lee Darroch, a Yora Yora woman, talks about the remaking of a traditional possum skin cloak. She says that the meaning of the incised symbols she was copying became evident slowly, over time, in the making of it, as a spiritual act³. Meaning is partly inherent, and partly ascribed. The meaning of events for people with profound disabilities is something we have to construct with them. It is a social practice (Middleton and Hewitt, 1999), which contributes to the recall of the experiences at the heart of the story. They are dependent on us, to engage them in experiences that are worth remembering, and to support them to play their part in the telling, duly respecting the affordances and constraints of their natural impairments, yet aware of the possibilities of transcendence. When we create the story together, it develops an identity and a magic of its own – like Eagleton's description of the good life as a jazz group⁴.

Small Stories and Big Stories: Myths to Live By

Our great myths and legends were not handed down on tablets of stone. They are the stories of our own lives, writ large. We take the story of Avagddu to mean that there have always been people with severe disabilities in our society, that they have been loved by parents who tried to get them what they needed⁵. Taking us into the twentieth century, consider Ned, aged 6, a child with "imbecile epilepsy" and Nellie aged 12, "imbecile, ? mongol". These two aboriginal children are mentioned in a 1923 presentation to The Australasian Medical Congress (Bostock, 1924). As they had spent only months in Claremont asylum before they died, it seems likely that somebody cared for them⁶.

Of course our reading of the story also demonstrates the ways in which people with disabilities have been marginalised and left in utter darkness, and how the people of the light have

– maybe unintentionally – abandoned them there. It was not the fault of Gwion Bach that he imbibed the potion meant for Avagddu, but we think that the story tells us that the newly born Taliesin carries a responsibility to voice the story of the brother he left behind.

But perhaps Avagddu has more than this to teach us.

The new kind of story that Klein endorses is the kind of story told by indigenous people, learning from the ancestors who revered the land and saw themselves in relationship with it, rather than as lords of creation who are entitled to exploit it. Western anthropologists and narrative tourists, it turns out, take much the same approach to story as they do to land – that is, they colonise it, tidy it up, remake it in their own image (Le Guin, 1986 and Note 2). In their original form, these stories do not always follow the canonical structure of the hero narrative we so prize. They may not celebrate achievement, winning, conflict and resolution. They meander, they draw us in to another reality, they are about how to be in a specific place at a specific time. The language is circular, repetitive, chant like. It turns out that the new narrative that Klein invokes is actually the most ancient narrative form of all. Dell Hymes, in 1981 developed the idea of an ethnopoetics of narrative, to describe non-Western, indigenous telling. An ethnopoetic score registers the silences, the music of the voice, the use of props, the gestures and sound effects as well as the content expressed in speech. This is very reminiscent of the kind of presence focus that seems to characterise best practice in communication with people who have profound disabilities (see, *inter alia*, Caldwell, 2005; Forster, 2008; Nind & Hewitt, 1998⁷). Perhaps we can learn from people with profound disabilities how to be, rather than to frenetically do, how to honour and value the small things, how to turn away (in the words of Governor General Quentin Bryce, who opened this conference) from the trophies on the mantelpiece, in favour of the people we walk beside.

Conclusion

What Openstorytellers are endeavouring to develop is a narrative culture in services, schools and homes, where reportable events are foregrounded and shared, where each person can contribute something to a story and where distinct community and personal identities are forged through the shared remembrance of what is past.

Cupitt (1991) writes of Scherezade that "she tells stories all night to keep you awake, and thereby saves your life as well as her own". In the act of creating a story, we make and remake ourselves in relation to others. Storytelling helps us all to survive.

7. there are of course many influential practitioners active in the field: Mark Barber, Juliet Goldbart, Jean Ware, Mats Granlund, Cecilia Olsson, Bea Maes, Jim Hogg, Loretto Lambe, Carla Vlaskamp to name but a few.

3. Lee Darroch 2004, video footage to accompany exhibition in National Museum of Australia, Canberra

4. Eagleton credits a colleague, G. A. Cohen, with this image

5. Mithin (1996) cites the case of a Neanderthal skeleton which shows evidence that a man lived for many years, despite horrific injuries which would have left him incapable of surviving on his own (p. 151)

6. they may, of course, have been transferred from elsewhere, particularly in the context of Government policy of forced removal, but McConnochie (1977) provides some evidence that children with disabilities were traditionally cared for within their communities



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Emma's Eye Max Trial

By Toni Green, Cindy Apap, and Emma Green

Mum's Thoughts

My daughter Emma is almost 14 years old. She has severe Cerebral Palsy... and the classic statement that we all know and love, not being able to talk doesn't mean you have nothing to say, is so true of her.

Emma is a very social young woman. She has just begun doing presentations at Queensland University to occupational therapy and speech pathology students. She has attended a number of camps for students who use AAC, and is looking forward to attending another one this year to further develop her skills with her AAC device. Emma attends our local special school where she is in the intermediate class and gets out and about in her local community with the Girl Guides, her friends and family, and our church group. She enjoys travel and hopes to attend the ISAAC conference in Spain next year.

For the last 13 years Emma has struggled with access. She has tried foot switches, hand switches, and finally a head switch. It didn't matter what we did, we could never get the switch position just right for her – her athetoid and dystonic movements meant that there was never any one position where she was able to consistently access her switch. Row/column scan was difficult because she could never quite organize her body in time. ATNR (a reflex that means when Emma turns her head one way, her body tightens up to the other side) and other movement patterns made it even more difficult.

Last year we were able to get Emma a V Max communication device – it's a computer, AAC device, and environmental control in one package. It should have been the answer – no longer having to take a laptop and communication device, lightened the load for the trip to and from school – but the access issues remained. By Christmas Emma was ready to give up and just use low tech (PODD Book) and her eye gaze (which has always been her fastest and most accurate communication method). We put her name down to trial the Eye Max (which connects to the V Max) and waited and hoped.

In February, Emma was able to trial the Eye Max. The speech pathologist and I mounted the device onto Emma's chair, assisted Emma to calibrate the camera, and stood back.

Within seconds Emma was navigating between pages on her V Max, giving cheek to us. She teased her class teacher that hail was imminent, much to the horror of the teacher who had just bought a new car! Emma chatted all the way home and for the next three weeks would talk whenever she was given the chance to do so. Gone was the frustration, fatigue was minimized, and a happier girl began to emerge.

We were fortunately able to get an Eye Max for Emma and she now navigates between three vocabulary sets on her device.

Emma is becoming a happier and more confident communicator. She still has a long road to travel to reach the competency she sees in her AAC mentors, but I am much more confident now that she will get there one day. The eye gaze trial has changed Emma's life.

Speech-Language Pathologist's Perspective

As an Education Queensland speech-language pathologist working with students disabilities for many years, I frequently encounter students with multiple disabilities who require access to AAC. Obtaining the best AAC system and working out all the access issues is typically a time consuming process, which often feels very much like trying to swim through molasses. Working as a team is vital during this process as no single discipline has all the knowledge and expertise necessary for successful device implementation and long term use. Although the combined efforts of the professional disciplines of occupational therapy, physiotherapy, speech-language pathology, amongst others, are vital, I find the most important member of the team is a tenacious and motivated parent. Emma is quite lucky to have such a parent.

“**Emma chatted all the way home and for the next three weeks would talk whenever she was given the chance to do so. Gone was the frustration, fatigue was minimized, and a happier girl began to emerge.**”



In my experience, access to AAC can be the most difficult aspect to overcome when working with people with multiple physical challenges. Emma is one of those people. Although row/column single head switching was deemed the best access Emma had available, her latency of response was just too great for her to have much success using this method. Unfortunately, up until recently, there wasn't really another viable option. Reflective tracker dots, small reflective stickers attached to the forehead or glasses that are picked up by a sensor when the wearer moves their head, work for some people but not for others. Unfortunately, I've worked with many of the 'others' who, because of involuntary head and trunk movement, cannot use the dots. Thankfully, there are now a couple of wonderful AAC devices using eye-gaze technology that work consistently with a minimum of fuss and calibration. Amongst these are the EyeMax, which attaches to the Dynavox Vmax, and the MyTobii.



Emma's Eye Max Trial (cont)

Because of Emma's mum's initiative and follow-up, I was lucky enough to be one of the first speech-language pathologists to get my hands on the EyeMax to trial with Emma's Vmax. Getting the thing on took more hands than I had but, thanks to a helping pair of hands, placement was successful. I calibrated the unit on myself and the fact that I wore glasses didn't seem to be much of an issue. A phone call or two to Spectronics later, and the software was installed and the unit up and running.

Emma's mum put the device on Emma's chair and we started calibrating the unit. Emma was unable to calibrate the device with her head positioned as it was, so her mum held her head more at midline just to get the device calibrated and able to find Emma's eyes. The numbers Emma achieved on calibration were not encouraging and we needed to change her head positioning, and the position of the device, a few times. Because of Emma's difficulty with mid-line head/neck control, as is typical for people with athetoid Cerebral Palsy, putting her head at 90° with the device sitting straight in front of her at 90°, was ridiculously impossible to achieve. Emma's mum and I had a few moments of doubt as we tried to figure out a best set up for her to try the device.

Then a funny thing happened. Despite the poor calibration scores, as Toni and I were discussing how best to improve her positioning, we noticed that the right and left lights, indicating that the device had found Emma's eye(s), were flickering and seemed to be finding her gaze! After a couple of hits and misses, the device was able to find Emma's eyes quite consistently even after Emma had looked away and then her gaze flicked back. We were so excited!

At first Emma mostly mucked around with the device and communication was not generally meaningful. It didn't take long, however, for Emma to get used to the eye gaze and see the power of communication using it. She received such fantastic social rewards from those around her, that her use of non-meaningful language quickly reduced and her use of purposeful communication increased.

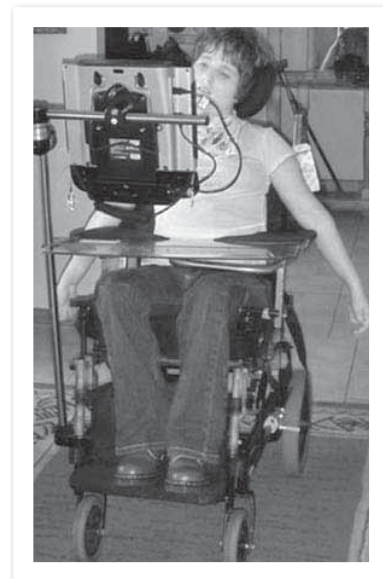
After a short period of time, Emma became increasingly interested in using the device, not only to meet her self-driven social needs, but also to engage with her curriculum. Emma's mum and I both spent some time with Emma's teacher brainstorming some ways Emma would be expected to use her device to enhance her learning. I also spent some time training the teacher on using the device and on basic programming. IEP goals were agreed upon that included the need for Emma to respond, during some specified tasks, via the Vmax/EyeMax. Previously, when head switching, this was something Emma had either been unable and/or unwilling to do.

Slowly, Emma's long-term preference for partner assisted eye-gaze choice-making using objects and symbols began to be shaped into eye gaze communication of a much more complex nature using her AAC device with the EyeMax.

Emma's mum was keen to get Emma her own EyeMax, and I concurred that the access method was more than suitable for her. Within a couple of weeks, Emma had her own EyeMax and off she went.

The importance of having a supportive environment where the key caretakers expect communication cannot be emphasised enough. Emma's mum is fantastic in that, although she is so tuned in to Emma's needs she can practically mind-read the child, she consistently expects meaningful communication at home using the Vmax/EyeMax and has high expectations of Emma's ability to use this device. Her teacher has also been fabulous in supporting Emma to use her device meaningfully across contexts on a daily basis.

Because of the recent availability of high quality eye gaze technology, coupled with a dedicated mother and teacher, Emma's life has been radically changed for the better. Emma's frustration level has decreased, and she is now free to engage more meaningfully across contexts with a variety of audiences reaping a range of natural social rewards. I am confident that Emma has now been provided with the opportunity to engage more fully in her life experiences and I look forward to watching her continue to blossom into the lovely young lady she is, in the coming years.

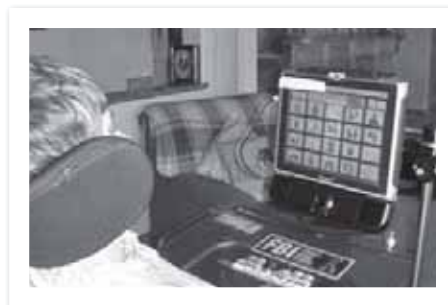




Emma's Eye Max Trial (cont)

Emma's View: Interview with the Editor

- Sheridan: Hi Emma. It's been great to read that eye-gaze has worked so well for you.
- Sheridan: Can you tell me how eye-gaze works?
- Emma: When I look at something on the V Max it's the same as a mouse click
- Sheridan: Is it hard to use?
- Emma: No. But Mum can't get it to work for her.
- Sheridan: How does it compare with using your PODD book?
- Emma: I can do it by myself. (Doesn't need partner assisted scanning)
- Sheridan: Can you use eye-gaze with your computer too?
- Emma: They are still working on the software for that.
- Sheridan: Can you use eye-gaze to write emails?
- Emma: I can write but not send because we don't have a router yet.
- Sheridan: What do other kids think of your eye-gaze?
- Emma: They think I'm clever.
- Sheridan: What's your next goals as a communicating chick?
- Emma: I want to teach other people to use it. Do more talks to fundraise for my trip to Spain next year. (ISAAC 2010).



JOIN THE AGOSCI LIST!



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

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



Agosci Presents: Augmentative & Alternative Communication in Health Care Settings: Supporting Patients from Intensive Care Units into the Community

2 Day Seminars

15th & 16th October 2009 – Melbourne

For further information

Contact Communication Resource Centre

crc@scopevic.org.au

www.scopevic.org.au/therapy_crc_events.html

19th & 20th October – Brisbane

Contact Tricia Chardon qldcpd@bigpond.com

22nd & 23rd October – Sydney

Contact Shirani Gomes shirani@hotmail.com

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

In this seminar, we will discuss the multi-modal communication process, and identify strategies and low-tech and high-tech solutions for each medical setting. Principles of assessment and intervention that have been determined through expert practice will be presented through case studies using videos and clinical reports.

Participants will have hands-on training with the latest speech generating devices, and learn to identify device features that meet users' needs. AAC within the social setting will be stressed, including the role of the speech pathologist as advocate for partner training, policy changes, and funding.

About the Presenter

Melanie Fried-Oken, Ph.D., CCC-SLP

Melanie Fried-Oken is a certified speech-language pathologist and a leading international clinician and researcher in the field of Augmentative and Alternative Communication (AAC). Dr.



Melanie Fried-Oken, Ph.D., CCC-SLP

Fried-Oken (with Dr. Hank Bersani) edited the book *Speaking Up and Spelling It Out*, a collection of essays written by adults with disabilities using speech technology. She has written numerous articles and chapters on AAC for persons with various medical conditions, from the ICU through home health.

Dr. Fried-Oken is an Associate Professor of Neurology, Pediatrics, Biomedical Engineering and Otolaryngology at the Oregon Health & Science University (OHSU), Director of OHSU Assistive Technology Program, and clinical speech-language pathologist at the Northwest Center for Voice and Swallowing.

She has a number of federal grants to research communication technology for persons with dementia, Amyotrophic lateral sclerosis (ALS) and other neurodegenerative diseases, and the normally aging population.



There were many papers submitted to the AGOSCI 2009 Conference. Some papers were not able to be included as there was only so much room in the program. We have included a number of these abstracts in this edition of AGOSCI In Focus: Robinson; Trentepohl; Basterfield & Rezzani; Rezzani & West. Feel free to contact the authors if you have any questions.

Power Equals Whatever!

David Robinson

Steph is a talented young artist with cerebral palsy. A Year 10 student at Sebastopol College Steph has been using the MyTobii computer since the beginning of 2008. The MyTobii is an eye tracking computer which is being used with a button switch for operation. This introduction comes after ten years of having an aide by her side taking notes and assisting in writing for her. In Steph's words

Sometimes the teachers would focus their questions on the aide. They would ask them the questions and then the aide would ask me. When it was time to write something I would tell the aide what to write and often they would fill in extra words and write what they thought they heard. It could be frustrating when they would get it wrong. It was alright. Sometimes it was easy to slack off.

The speed with which Steph has adapted the computer to her education has been a tribute to her approach. Overcoming the operational difficulties has been undertaken by a team of aides who work with Steph daily. The first of these related to the movement and set up of the system around a school environment.

The support frame for the MyTobii as supplied was a clamp requiring mounting to a table, although straightforward the variety of tables within the school often required furniture to be rearranged during the start of classes. In conjunction with this the power requirements would result in less than optimum

placement in some rooms. The transport case used to move between classes limited aides in what they could take along with the computer. The other main constraint in class use was set up and take down time, this could be as much as ten minutes out of classes as short as fifty minutes. Mounting of the system to the wheelchair is currently being investigated although this has proved to be a slow process.

The choice of software to be used in conjunction with the inbuilt programs has been a progression of trial and error. Current programs used include Office 2007 and Adobe Photoshop, each of these has introduced new challenges and opportunities. The hardware has also been supplemented with wireless network access, a wireless keyboard and a digitising tablet for Steph to draw directly into the computer.

Steph's teachers and classmates have all quickly seen the benefits of the use of the MyTobii system and gained a greater appreciation of the contribution she can make to her classes. A debate, essays and exams have all been completed in the first six months and Steph has begun a movie script. Although progress like this is not without its downside as Steph relates;

Now I have to do my own work, its bullshit! Because sometimes I don't have the answer. Sometimes my brain doesn't work. And that is really frustrating. The school work. Like lots of the time I just don't get it in my head. That's the truth.

The Power Of Pragmatics And Parents: Social Interventions for Children with ASD in Queensland

Darren Trentepohl, Greer Maine and Christina Brown
Speech Pathologists, Disability Service Queensland
Darren.Trentepohl@disability.qld.gov.au

Autism Spectrum Disorder (ASD) is a multi-faceted neurological disorder. It is featured by "abnormal and impaired development in social interaction and communication and a restricted repertoire of activity

and interests" (American Psychiatric Association, 2000). Specifically from a communication perspective we see many areas of impairment, from early developmental skills of visual attention to faces and social referencing, to more advanced social skills such as conversations.

In the Family and Early Childhood Service at Disability Services Queensland (DSQ), communication intervention for children with ASD has historically been eclectic, based on best practice.



The Power Of Pragmatics And Parents... (cont)

This has included oral language stimulation (modelling and expansion), naturalistic child led approaches, incorporating play, gesture and sign language, and a plethora of visual communication tools.

Despite seeing development of isolated communication skills in the clients, it was felt there was still a missing piece – the development of genuine affective interactions with family and friends. Research into interventions that target this found three programs that share an aim to promote meaningful and functional interactions between parents and their child through a sequence of parent education systems. These programs are More Than Words, Relationship Development Intervention (RDI) and DIR®/Floortime™.

More Than Words

More Than Words (Sussman, 1999) is an eleven week program that includes eight parent information group sessions, and three individual video feedback sessions. Content includes: being responsive to children, how to model verbal language, incorporating play and books, supporting receptive language, and incorporating AAC. Efficacy research is in its infancy, but is promising. DSQ has now provided 10 workshops to its clients across the state.

Relationship Development Intervention

RDI (Gutstein & Sheely, 2000) is a structured developmentally based program, which focuses on developing an effective 'Guided Participation Relationship' between a child and primary caregiver. This forms the basis for remediating social referencing, co-regulation, flexible thinking, dynamic communication, and episodic memory. It focuses on developing dynamic intelligence over static skills and compensations. Quality of life is a key measure in the effectiveness of the RDI program, and early research is promising. To provide RDI, accreditation is required to become an RDI Certified Consultant, and DSQ has 2 therapists who are in the process of being certified, while other therapists use RDI principles in their intervention.

DIR®/Floortime™

DIR®/Floortime™ (Greenspan 2006) uses a framework based on developmental levels, individual differences and relationships. It targets impairment areas of social reciprocity with a variety of therapies, including sensory-motor, language, social functioning, occupational and speech therapy, along with family support and floortime play sessions; the therapies are tailored to the individual child. To use this approach you need to attend an introductory workshop where you are encouraged to go out and apply the principles, although there is a certification process that can be followed up.

While the evidence base for these interventions is in its infancy, early research outcomes are positive, and so are our clinical impressions. The speech pathologists at DSQ are able to provide interested people with more information on each program, early international research data, how they are being integrated into the DSQ service and their preliminary impressions of the effectiveness of the principles being applied.

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People Power – What Can User Testing Teach Us

Cathy Basterfield & Naomi Rezzani

Speech Pathologists

cbasterfield.crc@scopevic.org.au

Large companies and corporate organisations use focus group testing on their information and advertising before general release to the public.

In the same way, information provided to people with disabilities should be subject to focus group or user testing.



People Power - What Can User Teaching Teach us (cont)

We will discuss the Communication Resource Centre's experiences of focus group or user testing.

The Communication Resource Centre, a service of Scope (Vic) Ltd. has employed people with disabilities as consultants to read documents written in plain or easy English. The consultants read materials such as information leaflets, fact sheets, brochures, posters, and complaints documents, and provide the Communication Resource Centre and their customers with feedback on images, language and concepts.

The principle of this work is grounded in the current literature. This includes the benefits of involving the user early on in the process and that service user consultation enables content to focus on the needs of end users. Word, concept and symbol comprehension should not be assumed, but needs to be tested. Also, readability scores on computer software are not sensitive to grammar or to reader's own contexts.

People with complex communication needs are always involved in the Communication Resource Centre's work. Ward and Townsley (2005) discuss the elements of working in partnership with people to complete user testing. This includes starting early in the process, testing at rough draft stage, getting practical involvement of users and testing the final draft. One of the most important elements is being prepared to make changes to the document! Evaluation of the document after distribution is another important aspect to continually improve the document

and the processes that are used to develop each document. We will discuss some guidelines for conducting user testing, such as, working with experienced/experts on the topic and also with novices, being aware that people might not be used to commenting or criticising information and testing work with a wide audience (age, gender, ethnicity, sexuality, employed, unemployed).

The power of user testing is two-fold. Our consultants enjoy the work and feel empowered in many ways. They are paid for their work, learn about new topics, work on their reading skills and have found new confidence about their rights and therefore feel more confident about speaking up.

Secondly, is the improved final product. The feedback consultants provide information about the vocabulary, grammar, formatting, and image selection to ensure that the product is *Easy to Read*.

References

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Communication Partners Have the Power: A Model for Capacity Building Services

Naomi Rezzani & Denise West

Communication Resource Centre
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The Victorian Government is committed to ensuring that disability supports focus on assisting people with disabilities to live in the community and participate in activities of their choice, in ways that are meaningful to them. (Victorian State Disability Plan, 2002 - 2012)

The Communication Resource Centre (CRC) is a service of Scope (Vic) Ltd that forms part of the Hub and Spoke Model in Victoria for people with complex communication

needs. This Hub and Spoke Model was funded through the Department of Human Services, Speech Therapy Initiative in 2002. The Communication Resource Centre provides information, advice, resources, and services relating to the many different aspects of complex communication needs. Adults with complex communication needs and their communication partners frequently have limited access to speech pathology services. Clinicians often have to prioritise services offered and direct speech pathology services are often short term, time limited and episodic in nature.

The Communication Resource Centre receives many requests from large organisations (both residential and day services) to provide consultancy speech pathology services. The focus



Communication Partners Have the Power... (cont)

of these requests is often to improve the communication environments and skills of communication partners within these services. Many of the agencies requesting support provide services for up to 100 people with a disability. In response to these requests, the Communication Resource Centre has developed a model of service, with an emphasis on training the whole team. This model aims to enhance the capacity of others to effectively communicate with a range of adults who have varying communication skills and abilities.

This paper will describe and outline features of this training model, which utilises and embraces capacity building principles. The focus is on the primary communication partners who support adults with communication difficulties to communicate and therefore participate fully in life. Staff employed in disability

services have a key role in facilitating successful communication for the people they support. Research has also found they also have a critical role in fostering peer relationships, providing opportunities for social activities in the community and they have a direct responsibility for supporting people with programs and activities. (M. Sherlock, 2004).

The Communication Resource Centre has implemented training model over the past 5 years. The model has several elements including planning, pre training evaluation and information collection, and implementation. In addition, the evaluation, follow-up, and long term sustainability will be discussed. Each element will be described and critical indicators of success will be presented.

AGOSCI In Focus Editor needed!

We need another language loving, communication advocate to edit AGOSCI In Focus.

This role is shared with Sheridan Forster, to begin November 2009 or May 2010 edition. Each editor receives an honorary payment of \$1000 per edition.

We'd love to hear from you - please contact:

Emily Armstrong (emilyarmstrong.ea@gmail.com) or Sheridan Forster (sheridanf@yahoo.com).

From the AGOSCI Listserve: Karen Erickson and David Koppenhaver Coming Again in 2010 for AGOSCI

Date: Tue, 19 May 2009 19:46:16 +1000

From: janef@spectronicsinoz.com

To: listserve@agosci.org.au

Subject: [listserve] Karen Erickson and David Koppenhaver coming again in 2010 for AGOSCI

Hi all,

I know many of you saw Karen Erickson and David Koppenhaver present in 2008 when they travelled around Australia during the AGOSCI National Tour.

We had overwhelming feedback that people would like to see Karen and Dave back again – and we also had a lot of people contacting us asking us if the Intensive Literacy Week that Karen and Dave ran at the end of the National Tour could be repeated again.

So we are very excited to announce that Karen and Dave are coming out again in 2010 to run the Literacy Intensive once more for AGOSCI.

The Literacy Intensive is a fabulous 5 day course, which covers theoretical and practical aspects of literacy instruction for children and adults with complex communication needs. People who attended last year found the course incredibly valuable.

In 2010 the course will be run from the 5th to the 9th of July at Rawson Village campsite in Victoria – about 90 minutes drive from Melbourne. The course is appropriate for teachers and therapists and also parents of children with complex communication needs. Numbers are strictly limited to 30 lucky people.

Further information and the application forms are available from www.agosci.org.au – just click on the link on the left hand side to the Winter Literacy Intensive 2010. You can also email me if you have any questions. All applications for this course are due in by the 15th of November 2009.

Cheers

Jane

Jane Farrall
AAC Support Services Manager
Speech Pathologist
SPECTRONICS



From: Polly Morgan
Sent: Sunday, May 31, 2009 2:32 PM
To: listserve@agosci.org.au
Subject: RE: [listserve] Karen Erickson and David Kopenhagen coming again in 2010 for AGOSCI

Hi all,

It's great to hear that Karen and David are coming back. I have read the postings over the year and have promised that I too will write something...but never seem to have the time.

The Literacy Intensive was a transformative week- it had a huge impact on my teaching practice. Sam White and I took information, tips and strategies back to Glenroy Specialist School and organised professional development for the whole school. We developed a series of rotating workshops (4 in all) across a curriculum day introducing staff to the 4 Blocks. Some of our school staff also attended the day seminars- so we had some very inspired converts on board. One of the teachers who attended the day seminar (who also leads the Literacy Professional Learning Team), approached the principal to come out of the classroom for a year to coach/mentor staff in relation to implementation of aspects of the 4 blocks across the school. Our school has a very diverse student population, all of our students have a physical disability, most of our students have associated communication, cognitive and sensory impairments as well. So our Literacy coach has a very big role! She has done an amazing job to date- working with a handful of classes to get staff up and running with curriculum ideas/resources etc. Our Speech Paths have also supported her with this. The biggest shift I believe is the inclusion of more sensory based learners in literacy programs. The school has purchased MeVile to WeVile and introduced Gretchen Hansen's print alphabet charts to enable students who have not historically participated in writing activities to do so. Staff attendance and participation at the day seminar and Winter Literacy Intensive gave us greater insight, determination and energy to ask for changes that would increase student opportunities for literacy and thus have greater impact on their learning.

On a more personal level, I believe my students now get a better literacy deal from me. I have had to reconfigure my timetable to ensure that I can fit as much opportunity for literacy in as possible. Sam and I work closely together to ensure we can do this. This is no mean feat. When you consider all of the other curric requirements and personal needs...I think we have managed to get it in as much as we can. Last year I was working with a very different classroom-all early communicators with complex issues. This year I am working with 7 students who are following a more mainstream curriculum - we are operating guided reading groups (3 different groups for 3 different levels), 3 writing sessions per week (we are now looking at targeting software to take away some of the physical and cognitive load), Working with words and Making words sessions are built in 3-4 times across the week. Each guided reading group has their own word wall. We have not honoured the colour coding stuff (I didn't have the time to do this). These are going well. We have serial reading twice a week and have set up self selected reading boxes and an opportunity during lesson time to indulge in reading. My students are all borrowing from the self selected reading boxes. I am very lucky to have Sam working with my class and access to an OT who has great knowledge in relation to assistive technology. Note, that does not mean you get it set up any quicker.

It is very early days, however I believe my students are making huge gains in their comprehension of texts. The purposes set in guided reading vary to exploit different strategies and understandings. I constantly refer to my 4blocks texts and the articles on the little white thumb drive. I haven't got it all right... I misunderstand aspects of it then have big 'a- hah' moments. I am not really impressed with my writing block at the moment- even though the students are doing more and learning more about writing than they ever have before. However, I think it's been the best piece of professional development that I have ever done and I believe will have the most far reaching results on my students lives.

So if you ask me if it's worth it.....I'd have to say YES!!!
PS Sorry for the long blurb

Polly Morgan
Teacher
Glenroy Specialist School



University Education and Speech Impairment – Slipping Through the Web?

Grant Meredith

Graduate School of Information Technology & Mathematical Sciences

University of Ballarat

g.meredith@ballarat.edu.au

People with complex communication needs may find the thought of entering into higher education rather daunting and fraught with doubt not knowing how they can be supported and accommodated throughout university life. During late 2008 I conducted a web-based content study of 39 Australian universities. The aim of the study was to look at each university's dedicated internal disability services site and to survey some of the content which was contained there while looking through the eyes of a prospective student who stutters. I put myself into the mindset of a potential higher education student who stutters and who wishes to have some form of help from disability services to undertake study. I endeavoured to see if I could have an understanding of how Australian universities could address my speech based disability throughout my potential academic life and in turn then I could make an informed decision to enroll. I soon realised though that the results had implications not only for stutterers but also to those with complex communication needs. The findings have been summarized throughout the following paragraphs.

It was decided to survey web-based information rather than paper-based on campus information because the Internet has a perceived omniscient and constant presence which is available 24 hours a day, 7 days a week, and 52 weeks a year. Such an informational avenue could be proposed to be very appealing to a communication impaired person who could be anxious about normal face to face communications and/or more willing and able to access online information.

This study did not look beyond the internal university site or its associated links to find information. I assumed the role of a web browser as defined by Dacor who is a user type who usually browses the contents of a site using only the obvious links available, as opposed to a web searcher who is more inclined to use onsite search facilities (Dacor, 2009). The web browser is the most common type of Internet user.

I first looked to see if each university acknowledged the Disability Discrimination Act of 1992 (DDA) whose part main objective is "To eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of: work, accommodation, education" (Disability Discrimination Act, 1992).

Therefore it may be thought that it is in a university's favour to advertise the fact that they at least acknowledge the DDA and to give a brief understanding of its importance. It was pleasing

to see that a large percentage of universities did mention that they acknowledged the DDA and its legal obligations in some fashion.

Secondary to the acknowledgement of the DDA was the search for existence of a university's Disability Action Plan (DAP). A DAP is a proven, effective tool for organisations to plan and implement changes that remove barriers to access for people with a disability (Victorian Office for Disability, 2008).

It must be made clear at this point, though, that a DAP is purely a voluntary approach to compliance with the DDA. Thus universities are not compelled to have one and are at no legal fault by not having one in action but it does however advertise that facts about how proactive they may be towards addressing disability issues.

This study indicated that only close to 60% of universities advertised the fact that they had a Disability Action Plan and, surprisingly, some of those had broken links present. A broken link means that the document that the text is referring to is inaccessible.

The next step in this investigation was to establish whether or not a website offered public access to any form of official guides for staff concerning the teaching and assessment of disabled students and, more specifically, speech impaired students. Nearly half the universities studied indicated access to disability-related teaching information though not all of these sites though allowed the general public to access this information. Sometimes the information was password protected for staff and/or enrolled student access only. These guides in general covered more commonly promoted disabilities like hearing impairment, sight impairment, mobility impairment, mental health conditions, and even heart conditions. The found guides at times seemed to assume that speech impairment was in general a result of another condition all together and was not treated alone.

Only a very small number of the sites surveyed advertised some form of teaching and assessment guide with sections specifically focused on speech impaired students and, even then, the information that was presented was very general and was not as well thought out or given as much text space as that of other disability types. Some of the dot point information was entered into the popular "Google" Internet search engine and they were found mirrored in content and phrasing in the exact



University Education and Speech Impairment ... (cont)

same form elsewhere in the world. Perhaps this is a sign that not much effort or thought has been put towards this student type and that someone had simply copied the guidelines from an external source?

The university sites were also surveyed for information concerning alternative assessments and reasonable adjustments. A speech impaired student who was concerned about how their needs could be flexibly met would be highly interested in such information. The information found ranged from some very basic information to that of full blown policies. A large number of universities advertised this information in some form. Having this information present in some form could give a prospective student some confidence in the fact that the university would be flexible to suit their individual needs.

Scholarships are an important consideration for some students and perhaps even more so for disadvantaged students. Each site was scanned for links and information to scholarships for disabled students. These scholarships did not have to be solely for a disabled student but they had to be advertised via the disability site. Under a third of all universities gave students some form of information and links to either university specific disability scholarships or those in the same vein, external to the school. Perhaps to encourage more disabled students to enroll into a university course then more scholarships should be advertised and be made available? For some disabilities the associated costs associated with attending the university could very well be an issue that prevents their participation.

Apart from formal academic practices it was thought of interest to see if disability services offered a prospective student links to campus based disability social avenues. A majority of universities linked the visitor to disability related social activities beyond academic premises. These ranged from blogs, discussion groups, newsletters, and news reports. This simple action could surely help encourage disabled people to study and in some cases to keep studying.

In conclusion it can be seen that Australian universities need to consider more their available web-based information that they have present for speech impaired students about how they address, cater for, and adjust for disability in terms of content, richness, and accessibility. These three factors seem to be lightly and haphazardly regarded and individually or combined could serve to hinder speech impaired students and students with more complex communication needs from enrolling.

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Introducing Augmentative Communication to China

Rosemary Crossley
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2008 Visit

In November and December 2008 I spent nine days working with twenty-eight children with cerebral palsy (CP) or autism in Putuo Hospital and Shanghai Pearl Hospital (and one special school), showing their therapists how Augmentative and Alternative Communication (AAC) strategies could be adapted for use by children with different abilities and needs.

Hands-on computer training sessions were held for speech therapists at both hospitals, together with an in-service for staff at the special school, demonstrating how they could use cause and effect software and Powerpoint books with a switch-adapted mouse. At least one switch-adapted mouse and switch was left at each location, along with PDFs of basic communication boards in simplified Chinese, which the therapists could print and laminate.

An International Seminar on Speech Therapy was scheduled at Putuo Hospital over the weekend of November 29-30. I delivered two two-hour presentations on the use of AAC with children with CP and autism to more than a hundred local therapists, together with students and family members.

As it was important to show the therapists what people without speech could achieve, my first Powerpoint included graduation photos and information about well-known AAC users who have jobs. There was some muttering and my interpreter whispered "They don't believe you." Given that Chinese children with severe CP do not have appropriate wheelchairs (see below), do not attend school, and have had no access to AAC, this was understandable.

Fortunately I had a short video from the Pittsburgh Employment Conference, so the audience could see people conversing using devices. I had to play the video several times before they could see that the speakers were not moving their lips, but were moving their hands or eyes. They were also really impressed by the motorised wheelchairs used by the participants, never having seen any before.

After each presentation I was literally mobbed by therapists desperate to get the laminated communication boards I had available to give away.

Equipment

The difficulties with language, lack of funding and the therapists' lack of experience meant that it was necessary to present a different selection of equipment from that which we would typically use here. Dynamic display devices were out, both for

reasons of cost and because it was impossible to reprogram the captions, not to mention the absence of manuals in Chinese. Electronic scanning was not feasible because of the lack of equipment and the inexperience of the therapists.

Low-tech cards, boards, and indexed folders were fine, and could easily be translated using Boardmaker v5 (NB, Boardmaker v6 has a glitch affecting translations, and whatever system you use, it is important to get a native speaker to check the translations, as the Boardmaker versions are sometimes insufficiently colloquial or impolite.)

Low-tech could also be used for eye-pointing systems and manual scanning and coded access. All of the systems were simple, with no more than 10 pages in an indexed eye-pointing or direct-access folder.

High-tech was restricted to cheap, easy-to-use overlay-based devices, with translated overlays recorded by Chinese speakers. A Bluebird was very useful, as the way it uses a booklet of numbered overlays that match the numbers on the level keys, makes it obvious how you can program multiple overlays on one device. The Bluebird could also be set up with overlays that exactly matched a simple indexed communication folder. I had carried many laminated boards with me; thanks to the generosity of QANTAS, which doubled my baggage allowance as its contribution to the children. But it was still necessary to print more, and to produce individualised aids, and that meant I had to buy a printer. Ironically, Chinese-made printers cost much more in China than they do here, even after haggling, and obtaining genuine printer cartridges as opposed to non-working rip-offs involved major research and, finally, a taxi trip across town to the only Canon outlet in Shanghai.

With the printer, and with the assistance of the wonderful team of tertiary students who were my interpreters, we set up a cottage industry in my hotel room. We generated many personalised aids, including indexed communication books and eye-pointing folders. Clear pocket folders were readily available fortunately, and boards could be laminated at the hospital. I left the printer behind with CDs with PDFs of the displays so the Shanghai therapists could print more as needed.





Introducing Augmentative Communication to China (cont)

A major US communication equipment manufacturer interested in marketing communication aids in China was in regular phone contact during my visit, and sent over some bilingual laminated Pixon communication boards for me to distribute at the seminar, in addition to the Picsym boards I had made. Professionals from this firm will visit China in June, and hope by then to have a basic dynamic display device programmed in Mandarin ready for trial.

Some of the little things we take for granted were quite unknown to the Shanghai therapists. Blotack, for example, was a real hit, along with Velcro dots and mini-white-boards. On my next visit I will carry extras, along with a stack of printer cartridges. Before leaving Shanghai I set up a small library of communication equipment at Putuo Hospital for use by all the therapists. This included several different Go-Talks, a range of folders and laminated boards, and switch-adapted mice, switches and software.

Seating - Size Does Matter



Every child who couldn't walk who came to see me was carried by a parent, regardless of the child's age or size. Questioning established that the government does supply wheelchairs, but one size fits – or doesn't fit - all. A 5-year-old with extensor spasm gets exactly the same off-the-shelf wheelchair without straps as an adult who has a broken leg.

I spoke with the Rehabilitation Director of Yue Yang Hospital about the need for appropriate seating, which they recognise and are working on, but a rapid resolution is unlikely. Given the environment and the poverty, an adjustable insert for the standard funded chairs might be the quick and dirty solution. Currently this is still on my wish list. It will be a top priority in June, and any ideas will be welcomed.

With My Right Foot

During the December visit I met many fascinating people, including Yi Lin, a smart young lady of 15 with cerebral palsy

who can walk, just, and talk, just (very unclearly). She cannot use her hands. She has never been to school, and her mother is dyslexic. Nonetheless, she's learned to augment her dysarthric speech by writing with a pen held in the toes of her right foot.

Obviously, Yi Lin needs a computer system.



A few years ago that wouldn't have helped her, but the mobile phone has changed everything! Today young Chinese are incredibly rapid text messagers using predictive Pinyin, the phonetic representation of simplified Chinese using the roman alphabet. Similar software is also available on laptops, making it possible to type Chinese characters and words far more quickly than previously while using a standard QWERTY keyboard.

I gave Yi Lin a Pinyin textbook and lined up her 14-year-old brother to teach her Pinyin. With an expanded keyboard (which she'll use with her toes) attached to a laptop, a keyguard to stop her hitting two keys at once, and a screen reader or text-to-speech program (yes, they do exist for simplified Chinese) to read aloud what she types, she should be able to type and talk.

Generous sponsors from Brussels and Dubai have donated funds for this equipment, and in June I hope to deliver it and show Yi Lin and her family how to use it.

And Finally

At the end of my June visit to Shanghai I will fly on to Beijing to participate in the Second China International Conference on Speech Therapy, which for the first time has an AAC stream, so the word is spreading.

During both of my visits to Shanghai I was looked after spectacularly well by Professor Sun Kexing and his colleagues and students. And of course the food was wonderful. I also wish to thank the Australia-China Council of the Department of Foreign Affairs and Trade for making my 2008 and 2009 trips to Shanghai possible.



Closure of the Statewide Complex Communication Needs Project (SCCN)

Janelle Sampson

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Many of you will have read about the South Australian Statewide Complex Communication Needs (SCCN) Project in previous editions of *In Focus*. Sadly, the time limited project closed on Feb 28, 2009. The initial funding was only promised as one-off, and despite a highly successful project and numerous appeals, the state government was not able to provide ongoing support for such a program.

The demand for the variety of services offered by the project was extremely high, with referral and enquiry data showed an ongoing need for such programs. Although continuation of the services long term was the ideal outcome, many aspects of the project have created an impact on the augmentative and alternative communication (AAC) community within South Australia (SA) beyond the closedown date. These have included:

- Increased awareness of service provision needs and preferences of people with complex communication needs (CCN) in SA. This awareness has increased for the general public, service providers, senior management, and government.
- Processes, documentation, and guidelines established in the project continue to be used within other areas of service provision for people with CCN. This includes device trial evaluation forms, assessment guidelines, training and information packages, and resources created or purchased within the project.
- Development of client advocacy and peer support through social networking events. Some clients and families established links throughout the project that continue to exist today.
- Data collection and outcomes measurement from the project are now used for additional funding submissions.

It is hoped that the outcomes of the SCCN project will continue to impact on service delivery for people with CCN in South Australia and other states. Managing the SCCN project was an incredible ride. The entire team worked at a frenetic pace to squeeze as much as we could into the limited time available for such an undertaking. My goal at the outset was to reach the end of the project with the feeling that I did everything I could to ensure improved services and outcomes for people with CCN in SA. Although continued funding was not available, I feel that, as a team, we did everything possible and left no stone unturned, that we ourselves had the power to move. Looking back, I can now see the longer term impacts we achieved and also accept the limitations of pilot projects and

funding constraints. My new mantra: You can't always get what you want, but you take what you can get, and use it to continue to move forward.

As a final note, I'd like to acknowledge the dedication and skills of the project staff. All staff worked beyond the call of duty, and displayed an holistic attitude and true dedication to optimise services for people with CCN. Project staff included: speech pathologists, Claire Della Torre, Peita Petersen, Bridget Manning, and Sandra Stewart; occupational therapist, Helen Parkyn (nee Dawkins); therapy assistant, Cassie Manuell; and project administrator, Tara Comas. In addition, I would also like to acknowledge and thank the overwhelming support and guidance provided by Lloyd Walker throughout the project.

(Editors comment: Most of all, the key person in the team and author of this article, Janelle Sampson, deserves huge thanks for the success that was the SCCN)

No Voice No Choice

To our knowledge, history was made in Adelaide on the 9th of December 2008, with a rally. Those affected by the decision to not continue to fund the Statewide Complex Communication Needs (SCCN) Project took to the streets with "NO VOICE-NO CHOICE" placards. This type of action is usually the action of those who know they are at risk of losing something very valuable and are feeling desperate. AGOSCI *In Focus* would like to honour these brave and committed people who took the time and effort to let government know that a well organized and resourced service to provide communication options is a vital part of a disability service by publishing photos and articles relevant to this action.





My Story

Drew Serisier

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Here is the challenge.....

You have recently been appointed in a drama teaching position within a primary school for children with disabilities. Ninety-six children attend the school, with several classes operating mainly off-site in various local primary schools. The children all have an intellectual disability and may also have a sensory or physical impairment as well.

The school concert is approaching and you need to be central in its production. Having access to most of the students through your drama program, you feel encouraged to move away from separate class concert pieces to a whole school performance.

The story needs to draw upon the Going Bush unit of work, and be both relevant to the children and reflective of life in the Territory. It also needs to be communicated in a clear and accessible way, in order for students to gain an understanding of the sequence of events, humour, and messages conveyed. You have less than six months, so what are you waiting for..... YIKES!!

This was the challenge I set myself at the beginning of the school year. I took a few weeks to establish class based drama programs with the groups I was working with and channelled most of my energies towards getting to know the children. As time slipped on, I could no longer ignore the looming voice inside my head asking; "What about the school concert?" As you could imagine, I was a bit freaked out by the magnitude of this challenge and for several days did everything to quieten that voice.

Finally I decided to jump in! To start with I decided to write an original story as I believed that it was the most effective way to make the story both relevant and accessible to the children participating. This was also the easiest way for me to draw upon and integrate skills and techniques that I used in my daily drama program into the story. Another reason was that I couldn't find a children's book with 90 plus characters. As all of the students wanted to shine on the night and wouldn't settle for roles as extras, I needed to create an ensemble worthy of a Robert Altman film!

I decided to write a story promoting safety and environmental awareness through a series of events at a camp site. Titled, Our Camping Adventure, the story was to focus on the activities of several families camping in the bush and how their actions could easily impact on the native animals and their habitats. To engage the students, the story needed to be highly motivating. It therefore required humour (fart jokes of course!), lots of action (dangerous driving, snapping crocodiles) and a few scares (a campfire ghost story).

I am a very visual learner. So to build the story, I began sketching small illustrations to cement the idea in my mind. I presented the first draft at a staff meeting and received great support and constructive feedback. Being inspired by the new ideas presented to me, I began work immediately on a second draft of the story. As most of the children I work with are also visual learners, I decided to spend more time drawing the images for each scene to convey the ideas more comprehensively. Many of the children find it difficult to think abstractly, so I began to draw the children dressed as their characters. This immediately enabled the children to see themselves in the story and, in turn, understand their role better. Also, when children were required to interact with the audience, I included the crowd in the illustration. This not only guided those specific children in what actions they were required to do, but also gave all of the students the concept that they would be performing in front of many people.

After a busy week of drawing (60 pages in total!), I was ready to present my second draft to the staff. It was enthusiastically received, which was a big relief as they were the key to making this story a success. A copy of the story in power-point was made available for staff to read through with the children in their classes. In the days that followed, it was comforting to be approached by many students expressing their excitement about the story and their individual roles. One student told me I was a "genius writer"! I decided to ignore the fact that genius was one of his favourite and most used words and accepted the glowing praise whole heartedly!

As many of the students don't use speech as their main form of communication, staff are presently exploring ways to make the concert accessible to all of the different communication needs. For example, in the high needs classes in which students have profound learning difficulties, staff are using sensory exploration. Students are provided with experiences that immerse them in smells, tastes, sights, sounds, and textures that capture what it is like to be in the bush. The children can smell the gum leaves, taste freshly cooked damper, listen to bird's singing, feel the cool surface of water, and gaze around a classroom that has been transformed into a forest. In other classes, students have been provided pictographs to assist them in comprehending the story and learning their role. For example, the children in the ghost story section of the concert have a visual timetable with all of the monsters pictures placed in the sequence they appear on stage. Other techniques used by staff to communicate to the students and to ultimately empower them to access the story independently include music to indicate the start and finish of a sequence, modelling of actions, movement and emotions, and verbal prompting through the narration of the story.



My Story (cont)

Discussion is currently taking place amongst staff on ways to use the story in language based classroom activities. Some suggestions include removing words from the text and encouraging children to choose from a list provided the most appropriate word for the passage. Another idea is for illustrations to be taken out so that children can hear a section of the story and draw what they imagine. Also, pages can be jumbled for students to then sequence them in the correct order. Not only will activities such as these help the students to familiarize themselves with the story, but they will also present the children with opportunities to build upon their literacy skills. Now that the story is complete and is being embraced and absorbed by the school community, we have only one small task to do.....bring this story to life..... YIKES!!!



As the sun rose higher into the morning sky, a family of kangaroos came into the campsite looking for a quick snack. It didn't take the kangaroos long to find the breakfast scraps the kids had left out and were soon eating them up!



The kangaroos became very excited by this different food and began to party. They played instruments and all sang together, "WE WILL, WE WILL, ROCK YOU!"

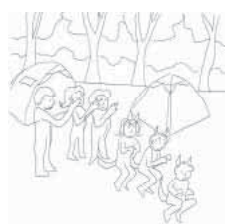


After the party the kangaroos began to feel very sick from the food. They rolled on their backs and held their stomachs.



The children were still fishing when they heard a big MOANNN from the campsite.

They saw the sick kangaroos and remembered the snacks. Quickly, the children filled up bowls with water and took them to the kangaroos.



The kangaroos felt much better after the drink. They said goodbye to the children and hopped off into the bush. The children picked up all of the remaining scraps from the campsite and put them in the bin, closing the lid tight. They then went to find their mum to tell her what had happened.



"WHO, WHO knows that food humans eat can sometimes make wild animals sick?", asked the wise old owl.



AAC in the Arts

Andrea McQueen
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The 2009 Art of Difference Festival took place in Melbourne in March. The festival steering committee was keen to make it an accessible festival in every possible way. There were Auslan interpreters at the Symposium sessions (workshops), venue staff were offered training in disability awareness, and there was a communication expo in the foyer of Gasworks Art Park.

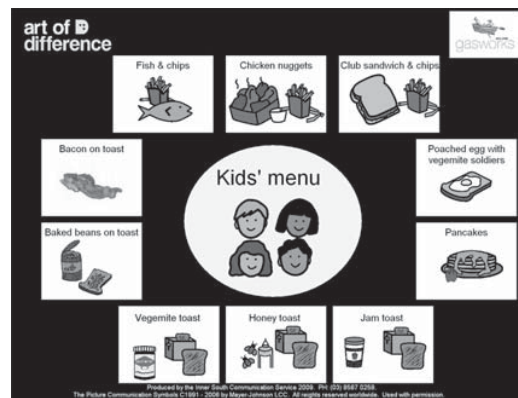
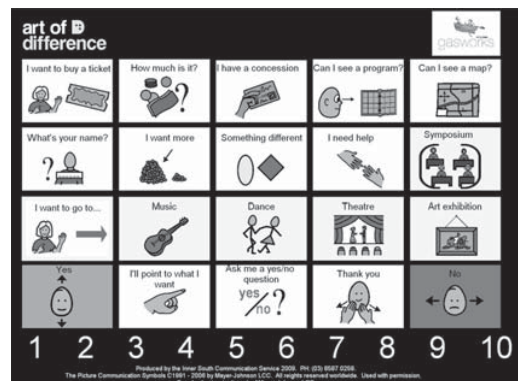
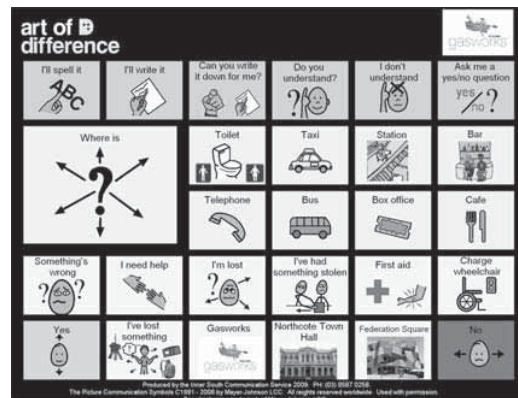
Festival organisers enthusiastically approached the Inner South Communication Service to provide some communication boards which people attending the festival could use. In consultation with the organisers we produced communication boards for diverse parts of the festival – from the box office to the bar to a kids' menu for the café. We also developed some simplified fliers for the Symposium sessions.

It was great to be part of such a vibrant festival, and to have the opportunity to see and hear famous artists and performers (with disabilities) such as Tom Shakespeare, Emma J Hawkins and Sandy Jeffs. It was also exciting to see AAC systems being prominently available at the festival.

Unfortunately due to time constraints, we were not able to provide training to go with the communication boards, and this may have limited their use by festival staff and volunteers. Training is certainly something we would look at for next time. It would also be great to add symbols to the printed and online programs for future festivals.

It would not have been possible to produce such a range of resources for the festival if it hadn't been for the work of many other people. Some of the communication boards were based on those originally developed by Elizabeth Gale from the West Loddon Mallee Regional Communication Service for the Mildura/Wentworth Arts Festival. Boards developed for the Talking Taxis project were used on the festival buses.

The Art of Difference communication boards are freely available to anyone who may be able to use them. Please contact me, amcqueen@cbchs.org.au, if you would like a copy.



DVD Reviews - Autism is a World

by Darren Trentepohl

(Discipline Senior – Speech Language Pathologist, Disability Services, Department of Communities, Qld Govt)

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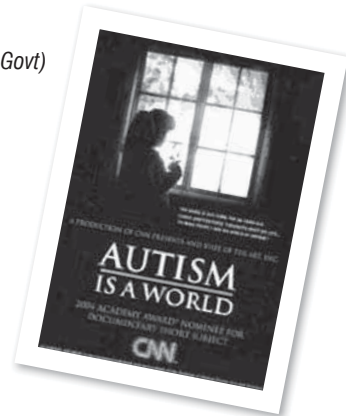
and Peter Rowe

(artist, poet, writer, and AAC user)

If you need a video that is going to make people stand up and maybe even cry a little (apart from *The Wedding Singer*), *Autism Is A World* could be just what you are looking for. It is a DVD that will inspire people to go forth and treat people with ASD differently. Made in 2004, it is not a brand new release but I only recently saw it for the first time and have come across other people who have not heard of it.

Co-produced with Cable News Network (CNN), this documentary stars and is written by Sue Rubin, a woman with ASD. *Autism Is A World* provides a snippet of Sue's daily life and is also a brief summary of her life journey so far. It was only at the age of 13, when she was introduced to Facilitated Communication, that she could start to communicate to others. Sue now no longer requires physical support for typing, giving evidence to the idea that communication skills and needs change over time. I watched in amazement hearing Sue talk about her fixation on spoons, difficulty moving through doorways, and how she is trapped in her Autism. But her achievements are far more powerful: moving out of her parent's home; education; and gambling!

This movie was nominated for the 77th Academy Awards for Best Documentary Short Subject. It has won a range of awards and I can see how. "Rubin is one of a number of individuals whose stories make it clear that at least some individuals with ASD who are labelled has having significant ID (intellectual



disability) can develop high level language skills and can learn to read, spell and write" (Mirenda, 2008). Sue's story is becoming more widespread.

Autism Is A World is available from Amazon.com for US\$27 and there are also snippets on You Tube and Video Google. This is a powerful movie, I liked it a lot and I'll give it 4 ½ stars. Over to you Peter.

This was a good film. I think Sue's attitude is really strong. She shows the struggle of being Autistic. I do think that I could recommend the film to others. I think it is a great film for showing about Autism. I would give it 3 ½ stars.

References

Mirenda, P. (2008). *A back door approach to Autism. Augmentative and Alternative Communication, 24(3), 220-234.*

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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. And submissions for our AAC, the Arts and Sport section. 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 November 2009 issue is "Tricky issues: Positive solutions".** We also have regular articles such as reviews. 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 (MS Word preferred).

All major articles are reviewed by two people. 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

Use two levels of headings. 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 headings to make it easier for the reader to understand.

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 etc.) 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. Australian Group on Severe Communication Impairment (AGOSCI).

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>

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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.

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AGOSCI pays \$250 to the artist who provides our cover artwork each edition. Article writers who use AAC receive \$50 for each contribution to AGOSCI *In Focus*.

Contact Sheridan Forster:

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or Emily Armstrong:

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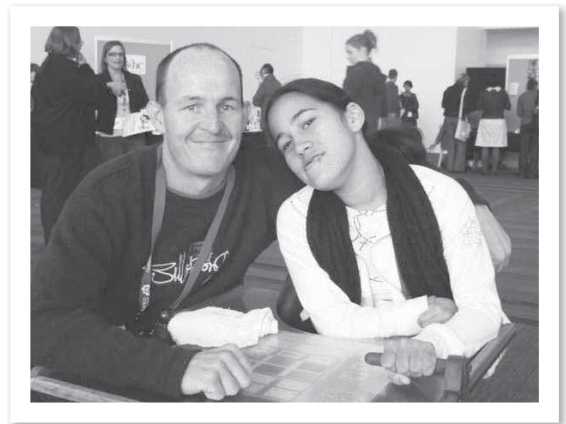
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Dr Gretchen Hanser

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



Ian Bean “Mr Priory Woods”

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

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

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