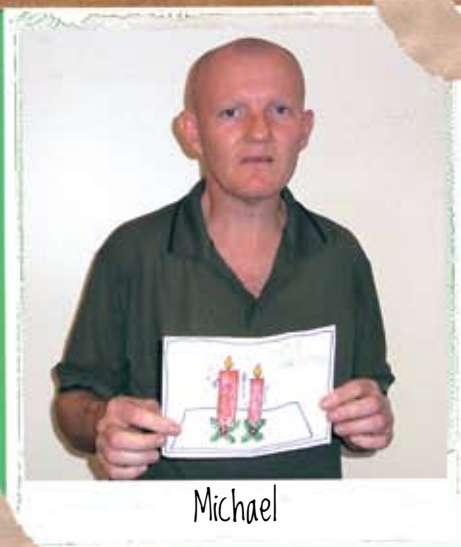


AGOSCI

in focus



Michael

My Name is Michael I am 59 years old and have been living in Brisbane for many years. I enjoy many things including rock-climbing, but my great passion in life is my art. I like to paint, draw and collage. I decorate many things in my home including furniture, and paint on canvas and paper, which is displayed in my house. I also enjoy reading, working on computers and cooking for myself.

People who know me well understand what I am saying most of the time. However, sometimes I need help when communicating. I find that when people are patient and give me time, I can communicate better with them. Sometimes I like to write words and letters to help people understand what I am saying. Sometimes I use symbols or drawings too. This year I am really looking forward to Christmas so I have drawn this picture to celebrate.
Thank you
Michael

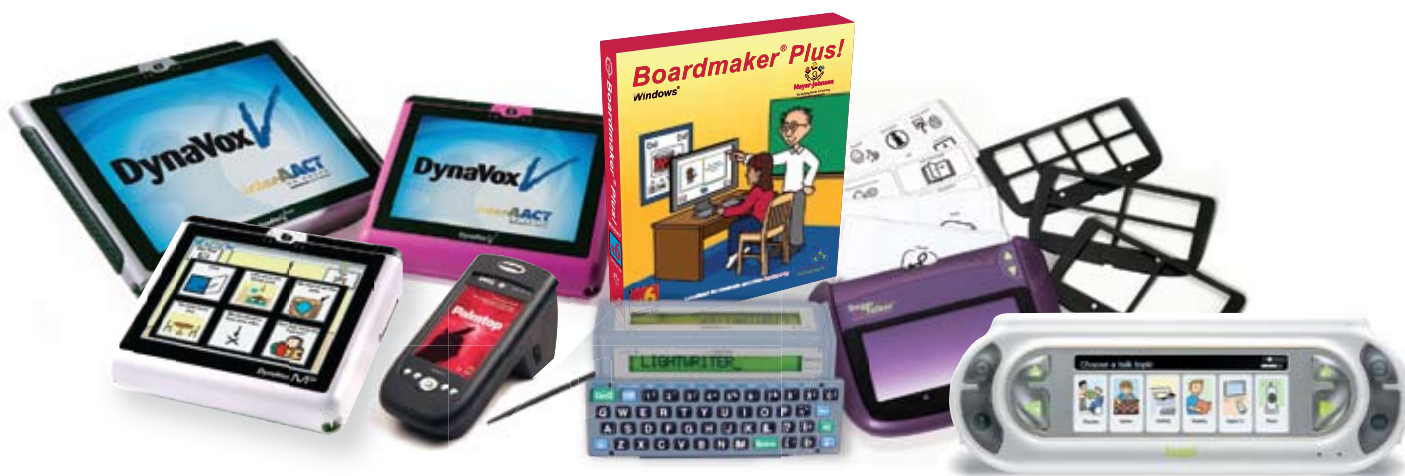
This issue ...

Education for All



Support!

Just one little word – but such an important issue for you once you purchase a speech generating device or AAC software for yourself or for the students, clients or family members that you are supporting.



Spectronics appreciates the need for support both before you have made a decision on which device or software best meets your needs – and after you have purchased a speech generating device or AAC software from us. We understand that it takes a lot of effort to select a range of options that may suit, arrange trials, arrange funding and then make your final selection and purchase. We work hard to be there to assist you during this process and afterwards when you are setting up and using your device or software. We know how important it is to you.

Meet the Spectronics AAC Support Team!



Jane Farrall
Speech Pathologist
AAC Support
Services Manager



Katie Lyon
Speech Pathologist
Speech Language
and AAC Consultant



Charlene Cullen
Speech Pathologist
Speech Language
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Expertly supporting your choice



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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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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.



- Consumer advocacy and stories
- Literacy and AAC.

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).

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



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Schreenan, an AAC user, shares a few words of wisdom for communication partners of people who use AAC. In one of my favourite pieces in this edition, Rebecca Daniloff and John Rynn present how they have educated disability support workers through a combination of professional and experiential knowledge (and perhaps also a small dose of the wheels falling off the cart!).

Learning through different models of service delivery is demonstrated through Janelle Sampson's piece on the SA Statewide CCN Project, through the Out of the Box Project, and from Barbara Solarsh and her teams' work on the communication coordinators situated in adult day services. Angela Klaniscek writes a wonderfully creative piece on the learning process that comes with a device called Mo.

Learning in the classroom is also represented with Jo Shugg and Samantha White writing about the use of Aided Language Displays, and Dariel Rice's piece on growing a love of reading in the classroom. Also in the classroom, but focusing on the learning of teachers is Mark Barber's piece on strengthening the culture around Intensive Interaction. BJ Dee-Price presents a piece about AAC in the kindergarten setting and the challenges that come when policy gaps exist. Her paper also captures the reliance that the AAC field often has on people who are willing to go the extra mile to make things happen for AAC users.

Literacy has been well represented in this edition flying on the wings of the very successful National Tour. Jane Farrall rounds the Tour up, and Helen Tainsh presents her reflections as a participant in the Intensive course. In addition, active Australian research is presented, Naomi Commons pulls together what Australian Universities are doing in AAC (in Speech Pathology courses: I wonder whether AAC features in any other courses?), Susheel Singh writes about her experiences as a Malaysian Speech Pathologist encountering AAC, and a report from the Big Mouth Camp is also included. The executive have also put pen to paper sharing an update of what has been happening in AGOSCI circles, and Darren Trentepohl has slipped in a last minute review.

What an edition, showcasing the talent in Australia. Thank you to all of the contributors and the editorial committee for pulling it all together. The next edition will focus on the 2009 Conference: Feel the Power. We encourage other contributions too, including reviews, AAC in sport and the arts, reports, and new initiatives.

Thanks
 Sheridan Forster
 (co-editor with Emily Armstrong)

Education for All is this edition's theme. We have had a great response with contributors from all over Australia and from many different walks of life. The contributions epitomize the varied ways in which education occurs. When I reflect on my last year I can see that my education has come in many different forms: new experiences (Big Mouth Camp, including breakfast philosophical conversations – thanks Mel), learning on reflection after an event (South Africa IASSID conference/holiday), being a part of a community of practice (Intensive Interaction conference), reading (another five grammar books), practising (my guitar), being challenged (thinking about the different paradigms in child and adult learning), doing something and deciding I wouldn't do it that way again (parts of my PhD research), and having things seemingly fall apart but then move to a new opportunity (with my grandparents going to a nursing home). I also had education through formal means through classes and lectures, but this was only a small part of the learning journey.

In this edition, the richness of learning is represented. Hank Wyllie writes about learning to be an AAC user himself. Mikil



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Chairperson's Report

Wendy Webster

Have you ever been at sea in a dense fog, when it seemed as if a tangible white darkness shut you in and the great ship, tense and anxious, groped her way toward the shore with plummet and sounding-line, and you waited with beating heart for something to happen? I was like that ship before my education began, only I was without compass or sounding line, and no way of knowing how near the harbour was. "Light! Give me light!" was the wordless cry of my soul, and the light of love shone on me in that very hour.

These are the words of Helen Keller. Well we remember the story of her teacher, Anne Sullivan, whose natural curiosity and desire to make a difference for Helen meant that she creatively encouraged Helen towards her own awakenings and interaction.

The Education for All movement took off at the World Conference on Education for All in 1990. Since then, governments, non-governmental organizations, civil society, bilateral and multilateral donor agencies and the media have taken up the cause of providing basic education for all children, youth and adults. (http://www.unesco.org/education/efa/ed_for_all/) The declaration made by the movement challenged educators to move away from rigid, prescriptive education systems of the past and promoted flexible models of education delivery that caters for, and is adaptable to, the needs, culture, and individual circumstances of learners.

I believe the system has a long way to go to achieve this tailor-made education, especially for those who are not able to use speech as their primary form of expression. 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. It is hoped that this will reach those who communicate differently, their family, friends and support persons, professionals involved with issues related to AAC, the wider community and government bodies.

During this year, AGOSCI has been proud to make small steps towards promoting education with the literacy focused intensive and national tour and webinars. Much excitement has been created about the possibilities and now the challenge is to maintain the energy and enthusiasm to implement the learning from Karen Erickson and David Koppenhaver. AGOSCI was also excited to trial use of the internet to carry the message to places we were not able to afford face to face teaching, including New Zealand. We owe great thanks to Jane Farrall for an overwhelmingly successful tour. The Listserve continues to foster healthy information sharing for a wide cross section of the AAC community internationally. The website will have



a few modifications in the near future. Thanks Sally Hunter for your diligence with both of these. And this little magazine continues to create wonderful opportunities for writing relevant information and personal reflections that are highly readable and enlightening. Thanks to Emily Armstrong and Sheridan Forster and the editorial committee. The Conference in Canberra in May 2009 is the next big activity and the Conference Committee, under the guidance of Jennie Lindsay, is working hard to make it all happen for us. And there is lots of discussion about the National Tour 2010. Furthermore, some states have local gatherings.

The opportunity to educate government has been taken by a submission coordinated by Meredith Allen to the 2020 Summit. A subsequent submission to the National Disability Strategy is currently being collated in an effort to highlight the ongoing issues of Australians who do not use speech as their primary form of communication.

The Executive continues to educate and support each other in decision making and allocating tasks, mostly by email. I am grateful for how easy the energy amongst this group of people makes my role as Chairperson. So much happens to educate and encourage and all by volunteers.

spread the word

Let users of AAC and their families know about AGOSCI

Download a membership form from the internet

www.agosci.org.au

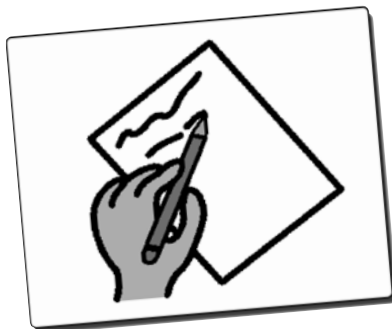


Notations ...

AGOSCI Inc. Secretary's report

Melissa Bakes

Well hi again to everyone, another busy year has come to pass for AGOSCI. We've had a very good year for memberships this year with around 370 members and some from overseas. This is an increase of 120 members from last year which is just fantastic. I think each State or Territory had increases with new members joining. Things will slow down now until early next year. I look forward to a rush of memberships ready for the Conference in Canberra next year and I hope to see some familiar faces there again.



I just wanted to give a big thanks to Jane Farrall and all the Reps who did such a fantastic job in organising the National Tour and the Literacy Intensive held in Melbourne this year. Without them I don't think it would have been the success that it was. So THANKS Jane and Reps! I hope everyone got some valuable information from Karen and David in the area of literacy- I know I did.

Many thanks again to all the members who have joined this year. We value your membership and strive to provide an Organisation that you wish to belong to. I look forward to hearing from you all again next year.

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

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

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

State Reports



Victoria

Helen Tainsh

Hi everyone, I am now the state representative on my own. Melissa Riepsamen had twin girls in September. They are all doing very well!

Term three has been a quiet term following a very successful National Tour. I think many of us have our heads down implementing the four blocks as presented to us by Professor David Koppenhaver and Karen Erickson. Our day in Melbourne was well attended and the feedback was brilliant.

As always, please contact me if you have any ideas / requests for professional development events or training that you would like to see happen in Victoria.



South Australia

Amy Martin and Janelle Sampson

AGOSCI SA has been relatively quiet over the past few months after the busy time during and leading up to the successful National Tour. Amy and I have been busy encouraging SA members to contribute to the AGOSCI In Focus magazine and to submit abstracts for the conference next year. Congratulations to Alice Waterman for her submission to the May 2008 edition of In Focus, and we look forward to some more SA content in the next edition.

In addition, AGOSCI SA has teamed up with the Statewide Complex Communication Needs (SCCN) Project to revive the AAC Special Interest Group. There have been two meetings so far, held in May and August. The most recent meeting had 24 participants including two via teleconference. Minutes of these meetings and information about upcoming meetings are available under the SA page of the AGOSCI website. The next meeting will be held on 22nd October 2008 at the Repatriation Hospital in Daw Park and will have an adult focus. If you would like to attend the meetings, or suggest topic areas for discussion, please contact Amy or Janelle, or you can find details on the SA page of the AGOSCI website.

For those interested in Pragmatic Organisation Dynamic Display (PODD) Communication Books, several groups have arisen from their current popularity in SA. The first is a PODD discussion group developed for those who have attended the 2-day training course by Gayle Porter. This group is designed to allow for group problem solving and sharing of resources and success stories. The second group is a PODD practice group set up following a number of requests from parents, teachers and therapists for specific times to practice modelling sentences with their PODDs.



State Reports (cont)

One final note, we would like to wish you all a great Christmas and New Year, and don't forget your plans for the conference in Canberra in 2009.



New South Wales

Harriet Korner & Lisa Hanley

For AGOSCI in NSW, the highlight of 2008 was hosting the AGOSCI National Study Tour in Sydney on 18 June, with Karen Erickson, David Koppenhaver and Amy Williams presenting on Comprehensive Literacy Training for Students with Complex Communication Needs. We had a wonderful mix of families, teachers, speech pathologists and one occupational therapist attending this course from different areas of NSW, which was fabulous.

Alana Bain (nee Lum) was fortunate in attending the Literacy Intensive, which followed on from the National Tour. Alana is now organizing a Literacy Working Party at The Spastic Centre that aims to consolidate ideas about practice in this area and develop our approach to supporting students with complex communication needs in developing their literacy skills. It is hoped that other organisations may be interested in becoming involved in this working party in the future.

The Children's Hospital at Westmead (CHW) and DADHC Statewide Behaviour Intervention Service are currently conducting two joint projects in the area of intellectual disability and mental health. The first project is a joint initiative to develop a child and family-centred training curriculum for community clinicians. Curriculum development has incorporated a review of literature, analysis of clinical data and a stakeholder survey. The outcomes of this project will be the publication of clinical papers and three training events for clinicians: 16-17 February 2009 in Orange, 16-17 March 2009 in Newcastle (to be confirmed) and 6-7 July 2009 in Sydney (CHW). For further information on the project or training, please contact Donna White, Project Manager and Editor, phone (02) 8876 4000, email donna.white@dadhc.nsw.gov.au.

The second joint project is a pilot intervention program called "Emotion-based Social Skills Training (EBSST) for children (aged 8-12 years) with Autism Spectrum Disorders and Mild Intellectual Disabilities." The program aims to promote the mental health and wellbeing of school-aged children with developmental disabilities through the development of child and parent-focused intervention groups. For further information on the project please contact Dr Michelle Wong, Clinical Psychologist, Department of Psychological Medicine, CHW, phone (02) 9845 2005, email MichelW4@chw.edu.au.

DADHC are currently reviewing their Ensuring Good Nutrition Policy and Information about this review is available at www.dadhc.nsw.gov.au if you are interested. The Nutrition and

Swallowing Checklist has proved to be a very useful resource to assist referrals for assessments and reviews of mealtime management and is used widely in NSW.

Liora Ballin, PhD candidate at the University of Sydney, is conducting research investigating mentoring as a training method for learning to use a speech generating device (SGD). The aim of the research is to develop, implement, and evaluate an SGD mentoring program where adults who use SGDs will act as mentors to new learners of SGDs. Liora is now looking to recruit participants to take part in Stage I of this study, including any adults who use SGDs or speech pathologists who provide augmentative and alternative communication (AAC) therapy. For further information, please contact Liora Ballin lb16064@mail.usyd.edu.au

Makaton NSW has conducted 80 workshops since January 2008 with over 1245 participants trained. In NSW we are finding that Makaton workshops are an effective way of delivering introductory training in AAC and use of key word signing as a strategy. In August, the Spastic Centre ran a Basic Makaton Workshop for Vietnamese Speakers and they had an interpreter translating. During the October School holidays, a Siblings Day was held with an Australian Idol theme that was great fun for all.

Ylana Bloom has established a new service called Autism Central. This is a multi-disciplinary service aiming to work in a holistic fashion with people of all ages who have autism.

There has also been continued interest in PODD's (Pragmatic Organisation Dynamic Display communication books) as an innovation during 2008, following the Introductory PODD Workshop presented by Gayle Porter in March. PODD's is a topic it would be great to further explore in 2009.

We are looking forward to an exciting conference in 2009 with the theme Feel the Power. Canberra will be a great place for us to share knowledge, innovative practice and inspire others to feel the power of communication.

Please let us know if you have other suggestions and whether you would be interested in attending meetings during next year. We can be contacted by email hkorner@tscnsw.org.au, lhlanley@tscnsw.org.au or by phone 02 9757 4322. Have a wonderful break over the holidays.



Australian Capital Territory

Tara Wright

Firstly, I would like to take the opportunity to thank the AGOSCI committee and Jane Farrall for all the hard work they put in to make the National Tour such a success. Here in Canberra we held a webinar session on the 27th of June which was attended



State Reports (cont)

by 10 people (teachers and therapists) from within the ACT. The webinar provided a great opportunity to learn from Karen Erickson and David Koppenhaver, and using this new technology meant that those who attended on the day didn't have to travel to places like Sydney or Melbourne to attend.

I am keen to hear from members in the ACT region to find out what training they would like to see being offered in the ACT, or, alternatively if anyone is interested in forming an ACT AAC interest group – please contact me on twright@tscnsw.org.au with any suggestions.

Remember to keep an eye on the AGOSCI website (www.agosci.org.au) for new information on the upcoming AGOSCI conference on 7-9 May, 2009 here in Canberra.



Queensland

Anne Pearson and Melanie Waalder

It's hard to believe we're on the downhill stretch to the end of the year but what an exciting year we've had with Dr Karen Erickson and Professor David Koppenhaver presenting *Comprehensive Literacy Training for Students with Complex Communication Needs* for the AGOSCI National Tour. We were not only fortunate to have them present in Brisbane on the 16th of June to an audience of 82, but webinars were able to be held in Townsville and Cairns on the 27th of June.

Feedback from the Brisbane event indicated that the majority, 99%, of the audience rated the day overall as good to excellent. The majority also indicated that most or all of their expectations were met, with several participants commenting that it had exceeded their expectations. Feedback from the webinars was also generally positive. Despite some slight technical hitches it was evident that the participants appreciated being able to participate in the National Tour and found the knowledge they



Front: Tom Hamilton (successful scholarship applicant)
Back: Dr Karen Erickson, Professor David Koppenhaver and Amy Williams

gained from the webinar presentations as valuable. All venues received really positive feedback, with the majority rating them as good to excellent, so we'll consider this for future AGOSCI events in Queensland.

Thanks must go to Kia Morton for organising the Cairns Webinar and Kim Rumble for organising the webinar in Townsville. Also, thanks must go to Paula Hartwig, Melissa Bakes, and Wendy Webster for helping make the Brisbane event run so smoothly. Last but not least, a big thank you must go to Jane Farrall for bringing Dr Erickson and Professor Koppenhaver out to Australia.

We look forward to 2009 and hope that many of you will be able to attend the National Conference in Canberra. Don't forget if you have any queries you can contact us by email at agosci@drep@hotmail.com or phone Anne on ph: 0413 489 609.



West Australia

Sally Hunter

Locally AGOSCI has enjoyed record membership numbers since the National Tour, which was very successful. AGOSCI WA and the Conductive Education Association also collaborated to hold a 2-day Pragmatic Organisation Dynamic Display (PODD) workshop, presented by Gayle Porter and Helen Tainsh. The event had over 50 participants and was highly successful. I send many thanks to Yvette Theodorsen and Laura Jones for their support with the running of this event.

The Independent Living Centre of WA is currently conducting a project that aims to collect information and develop dialogue in the sector around the current processes and practices involved in funding and supporting AAC. The project began with a literature search and with information gathering from each state as to the funding, prescription and implementation process. A reference group made up of therapists, consumer representatives and policy makers has met locally over a period of several months to discuss and share experiences and points of view, with this information then being taken to a sector information session and focus groups. The information is now being collated and a document reflecting all this information and with some broad recommendations will be produced in the near future. For further information please contact Kelly Moore at the Independent Living Centre of WA.

The list serve has been quiet lately so please join in and share your problems and helpful hints and don't forget to let everyone know if you see someone doing something great!



Tasmania

Diane Symons

When I started to write this I had to look back at my last report and I was worried that I didn't have much to report on since then. Obviously the time around the National Tour webinar was

State Reports (cont)

so busy that I've blocked it out of my mind!

Tasmania hosted two webinar sites. We had 18 people attend in Hobart and 10 in Launceston. I would like to say a big thank you to Tracey Hanigan who coordinated the webinar in Hobart as one of her final tasks before going on maternity leave. Tracey is now "relaxing" at home with her third son. Congratulations Tracey.

Having attended the fantastic week for the literacy in AAC intensive I have tried to sort through the vast amount of information and attempted to share a few gems with others. So far I have presented to a group of speech pathologists in Launceston and I'm looking into running a session on the North West coast of Tasmania.



Northern Territory

Anne Dixon

The Northern Territory had a bit of a breather in the second half of the year after the fantastic workshop presented by Karen Bloomberg back in February. All efforts were made to linkup for the Literacy in AAC National Tour; however technology and facilities unfortunately prevented this from going ahead. Better luck next time!

The AGOSCI Interest Group quarterly meetings have continued and have been very successful, largely due to the efforts of those who have given presentations on topics such as Key Word Signing, the PODD, and Talking Mats. It's a fantastic opportunity for people from different backgrounds and work settings to share information and to discuss the application of the ideas and issues raised to the diversity of cultural contexts, work and home environments encountered in the Northern Territory (NT). Information about the dates and location for each meeting is on the NT page of the AGOSCI website.

We look forward to more AGOSCI events in 2009 with the conference in Canberra set to be a highlight. We hope to have some representatives from the Northern Territory attending.

In the meantime, best wishes for Christmas and the New Year to all AGOSCI members in the NT and elsewhere. If you have any queries I can be contacted by email anne.dixon@nt.gov.au or by phone on 89227226.

Literacy in AAC – the 2008 AGOSCI National Tour and Literacy Intensive

Jane Farrall, Spectronics

jane@spectronicsinoz.com

The theme of this year's National Tour was Literacy in AAC. It was presented by Dr Karen Erickson and Professor David Koppenhaver. Karen is the Director of the Centre for Literacy and Disability Studies at the University of North Carolina. Dave is the Professor of Reading at Appalachian State University. Between them, they have written a large number of articles in the area of Literacy in AAC and have recently written the fabulous resource book *Children with Disabilities: Reading and Writing the Four-Block Way*.

The National Tour began in Brisbane on the 16th of June with a full day workshop. Sydney and Perth followed later that week. Adelaide and Melbourne took place the following week. Numbers at all venues were excellent – with many venues approaching over 100 attendees.

On Friday the 27th, AGOSCI ran its first ever webinar through WebEx. Karen and Dave presented a full day workshop to over 200 people via the internet in Cairns (Qld), Townsville (Qld), Canberra (ACT), Warrnambool (Vic), Mildura (Vic), Launceston (Tas), Hobart (Tas), Auckland (NZ), and Christchurch (NZ).



Participants were able to see the PowerPoint and hear the voiceover from the presenters. There were issues with videos transmitting properly and many of the attendees commented that they would liked to have seen the presenters, but overall our first webinar was a big success and worth doing again with some modifications.



Literacy in AAC ... (cont)

Following up from the National Tour, AGOSCI had another first – our first ever intensive course! The week long Literacy Intensive was also presented by Karen and Dave.

For me, the Literacy Intensive was particularly significant. I had attended a Literacy Intensive run by Karen and Dave in Minneapolis in 2000. That course had changed my practice greatly with improved literacy outcomes for many clients. Since that time I have been keen to bring Karen and Dave out to run a Literacy Intensive here; and this year was the culmination of a number of years of planning and negotiating so that others could have access to the best piece of professional development I have ever attended.

So, in July 2008, 33 lucky people headed up to Rawson in country Victoria for the week long Literacy Intensive. Participants learned how to apply the Four Blocks approach to students with disabilities. Feedback from the course was excellent and many participants are keeping in touch through email, sharing implementation ideas and their successes (and, of course, some less than successful but funny moments too). The course was also taught by Dr Sally Clendon, from Massey University, and by Amy Williams, a PhD student with Dave at Appalachian State.



Overall, the 2008 AGOSCI National Tour and Literacy Intensive were a big success. The feedback forms certainly were extremely positive and the number of requests for Karen and Dave to return to our shores and run more sessions was very exciting. We certainly hope they will return in another couple of years and run another Literacy Intensive for us at the very least!

AGOSCI 2008 Literacy Intensive Report

*Helen Tainsh, Cerebral Palsy Education Centre
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I was one of the lucky 33 participants who attended the Literacy in AAC week-long intensive course at Rawson, Victoria, in July. Well, where do I begin? It was so fantastic. Like those of you who also attended, I am slowly digesting all of the information that was presented to us and gradually implementing things that I have learnt.

Professor David Koppenhaver and Dr Karen Erickson were amazing. I have read some of their articles and heard about their work for a number of years now. It was exciting to have them captive at Rawson, although I think we drove them crazy with our constant questions. They truly were captive. Dr Sally Clendon (from Massey University in Auckland) and Amy Williams (David's PhD student) also presented. They shared many practical ideas with us!

Karen and David shared the belief that all children can learn to read. That sat so well with me as I believe that all children can learn a communication system.

They based all of their work on six conclusions drawn from current emergent literacy research:

- I. The process of learning to read and write is a continuum that begins at birth and perhaps before;

2. Children learn written language through active engagement with their world;
3. Reading, writing, speaking (AAC), and listening abilities develop concurrently and interrelatedly, rather than sequentially;
4. The functions of print are as integral to literacy as the forms;
5. Emergent literacy behaviors are fleeting, variable, and dependent upon text, task, and environment;
6. Technologies, media, and materials can dramatically impact upon children's ability to demonstrate emergent literacy. (Koppenhaver, Erickson, Clendon & Williams. Seminar on Literacy in AAC. June 30 – July 4, 2008.)

Karen and David's work has developed upon the Four Blocks framework developed in 1989-1990 (Cunningham, Hall, & Defee, 1991). They have extended this, based upon their extensive experience with children with severe and multiple disabilities.

Our week was broken into 5 parts: the 4 literacy blocks and assessment.



AGOSCI 2008 Literacy Intensive Report (cont)

Monday was about the *Writing Block*. Karen and David talked about the technology available that assists children to see, hear, and produce print more easily than ever before. They presented why this block is vital for children with disabilities. We discussed the initial challenge: determining the child's pencil. Will this be a low-tech alphabet flip chart or a high-tech system with voice output? We learnt about mini-lessons within this block and the importance of modeling writing using the child's pencil as well as modeling the strategies to develop writing, such as a Word Wall and brainstorming ideas to write about.

Tuesday was about the *Guided Reading Block*. Guided reading is taught in such a way that the student develops reading comprehension, with exposure to a wide variety of text types (e.g. fiction, nonfiction, plays, poetry, and directions). Children are taught how to make meaning from text. Teaching in this block involves repeated readings of the same text, for different purposes, across the week. For example, in reading a book on Monday, the teacher would lead discussion to build, or review, background knowledge needed to read the text. The teacher would then cover the title, read the text, then discuss what the title could be. On Tuesday, the teacher would re-read the text, reveal the title, then compare and contrast. It is important to note that in these sessions there is no right or wrong – merely lots of opportunities for learning. On Wednesday, the teacher may set a purpose, such as “tell me how you think he looks/feels.” This would then be discussed at the conclusion of the text. This would continue with the teacher setting different purposes for reading on Thursday and Friday. By applying reading for a purpose, comprehension is taught. A rich Augmentative and Alternative Communication (AAC) system is vital within this block.

Wednesday was about *Self Directed Reading*. This block is about children reading independently, at their own level, from a variety of text types. Children select from a bookshelf that the teacher has gathered for each child in order to support making choices. We explored alternative text types for independent reading. Self Selected Reading assists building of fluency and a major goal of it is to develop, in each child, a love for reading. We want children to select reading as a leisure activity.

A meaningful quote for me (there were hundreds) was that “time spent reading is the best predictor of the progress a student will make – not time spent doing activities before and after reading.” On reflection of my previous practice, I think I was encouraging too much discussion prior to and after reading. Thursday we focused on the Working With Words Block. We were presented with many strategies to systematically teach skills needed to read individual words. These strategies facilitate learning by teaching how to work out unfamiliar words by using words children know. A couple of the strategies include use of a Word Wall and Making Words activities.



Friday brought the week together with *Assessment*. We need to determine why a child cannot read silently with comprehension at the next level. What is creating the problem: is the breakdown with word identification, language comprehension, or print processing? We worked through many case studies to problem solve this.

By providing daily instruction in each of the Four Blocks, we are providing numerous and varied opportunities for all children to learn to read and write. We are acknowledging the fact that different children learn in different ways.

We were all given the invaluable opportunity to present a case study. I presented a child that I support weekly in a mainstream primary school. It was a bit scary presenting in front of these world leaders, but well worth it. I think that each of us who did this found the feedback and opportunity to ask very specific questions extremely worthwhile.

On behalf of all of us there, THANK YOU to Jane Farrall who was instrumental in finally getting Karen and David over to Australia. We hope that they will be back in two to three years time. I would strongly encourage those of you who work in this field to complete the week long intensive course. It really was brilliant!

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Communication - Feel the Power

AGOSCI 9th Biennial National Conference 7-9 May 2009 Canberra



The 2009 AGOSCI Conference Committee is definitely feeling the power! The number and quality of papers submitted has surpassed our expectations, and while the topics are diverse there is an undeniable common element; they all have a powerful message to share. Thank you to everyone who submitted a paper; with these, the conference promises to be an amazing event.

We are proud to announce our keynote speakers Gus Estrella, Nicola Grove, and Gayle Porter. Gus is an AAC user from Mexico. His presentations are stimulating and provide invaluable insight for practitioners working in the field of AAC. Gus will share his story with us. Nicola Grove is best known for her development of interactive stories and her book 'Odyssey Now' written in 1996 with co-author Keith Park. A teacher and speech pathologist in the UK, Nicola has continued to develop the art of inclusive storytelling and has 30 years experience working with children and adults with learning disabilities. She believes in the power of stories. Gayle Porter is a local favourite. Her resources and strategies empower the person with a communication impairment. She provides a means to communicate and even tell a story.

Are you feeling the power yet? Do you want more power? Our advocacy breakfast will inspire you with ideas to harness the power and promote the needs of people with a disability. Our panel will discuss issues and answer questions on how best to obtain the services and resources you need. Parents, professionals, and other invited guests will share their advocacy experiences: what they did and what they achieved. If you would like to be a member of the panel or would like to recommend someone please contact our conference organisers AMMP at agosci09ammp.com.au.

The conference dinner will be held at Old Parliament House (OPH). OPH is a beautiful venue conveniently located near the centre of Canberra. The committee are busily organising a power filled night of fun and high spirits. We look forward to welcoming you to this event.

Lastly, we would like to introduce ourselves, the conference committee. Jennie Lindsay is our conference convenor. Jennie has a long career in special education, both in teaching and administrative roles, and is currently Principal of Malkara School, one of Canberra's four special schools. Other committee members include Jenny Arthur (Special Educator, Black Mountain School and AGOSCI National Treasurer), Lyn Floyd (Special Educator, Black Mountain School), Renee Wallace (Disability Support Training Officer, Disability ACT), Nicole Zimmer (Deputy Principal, Harrison School), Karin Wetselaar (Principal, Cranleigh School), Alison Frame (Commonwealth Public Service), Lisa Hanley (Speech Pathologist, Spastic Centre NSW), Tara Wright (Speech Pathologist, Spastic Centre ACT and AGOSCI ACT Representative), Sarah Cunningham (Speech Pathologist, Therapy ACT) and Genelle Hood (Speech Pathologist, Therapy ACT). We expect the 2009 National AGOSCI Conference to be an empowering experience for all, and as a committee we are proud to invite you to be a part of it. Mark your diary now – AGOSCI Conference, Canberra May 7-9. Prepare to feel the power!



Meet Sandra, Pauline, Mum and Mo... Education in the Role of ECD Issue

Angela Klaniscek

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Sandra is an 18 year old with a wicked sense of humour and a wild dress sense. She and her mum and best friend Carrie love to go shopping in Savers stores, picking through the racks of clothes and hitting the town in their latest kitsch glad rags. She laughs, chats and makes the most quirky comments about life and she has cerebral palsy.

Sandra has used many different forms of AAC during her 18 years but it has been her Mighty Mo which really excited her, her family and her friends. Sandra received her Mighty Mo in mid 2007 as well as training from the Aids and Equipment Program's Electronic Communication Device's Speech Pathologist – boy is that a mouthful.

Sandra, Mum, Pauline (Sandra's local speechie) and Carrie met at her home for their training session, and some evil hot chocolate, full of expectation of what the future would hold after Mo. The session was very well prepared but casual, interactive and flexible. All the important areas were covered so that all the girls felt comfortable with the device, its capacities, its potential, its limitations, and its quirks. There were questions, laughs, tryouts and lots of jottings as everyone wanted to make sure they got the most out of the AEP speechie's time and knowledge about the new man in their life.....Mo.

Pages and links were made and deleted and the girls fought over whose voice to use...Carrie tried a SJP voice while mum reverted to a Marlene Dietrich style with a very sad accent..... but, did they have a ball. They even found a photo of a very

handsome man with a 70's moustache and decided that he was the inner spirit of Mo.

The devotion to the decision on pages and vocab and photos was like planning for an invasion or a Las Vegas wedding but the glint in the girls eyes said it all....this was for Sandra and we're all here to help. After a week, Pauline dropped in again and they all spent some more time chatting about what they had learnt, made some more changes and tried some new brand of hot chocolate with vanilla extract. Yum was the verdict. Over the following year, there had been changes and modifications as Sandra and the wild ones added and deleted to keep Mo up to date.

When a 12-month follow up was done, Mo was praised for the change it had made in Sandra's world. The whole 'team' of crazy supporters were still there with Sandra, and Mo was being used and abused on a regular basis.

That few hours of training were the spark that ignited the commitment, dedication, and team work. There is continual monitoring of the Mo and the making and deleting pages and links to reflect Sandra's life. Having 'education' around the use and implementation of the device, with a group who would be there on an ongoing basis, made the issue of the ECD successful and opened up Sandra's wide world even more...

MORAL OF STORY- Good friends, good hot chocolate and good education are the key to success when supplying ECD's.



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My Story: My AAC Learning Curve

Hank Wyllie

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I think that I'm among a minority within Alternative Augmentative Communication (AAC) users as I wasn't born with Autism or Cerebral Palsy, but hypoxic (lack of oxygen) brain injury. I woke from a 6-week coma in a darkened room, unable to speak or walk; that scared the hell out of me.

A further 18 months in three different hospitals still gives me the terrors when I visit people to this day.

It wasn't until a number of years later that I learned to walk with assistance and to speak a few words. This was achieved only through the dedication of my wife, Anne, and a virtual *revolving door* of over 200 volunteers, from all areas around Geelong, including church groups, clubs, scouts, and individuals, on a fortnightly roster coming daily to do exercises. The program was through the Institute for the Achievement of Human Potential, formerly in Healesville, Victoria.

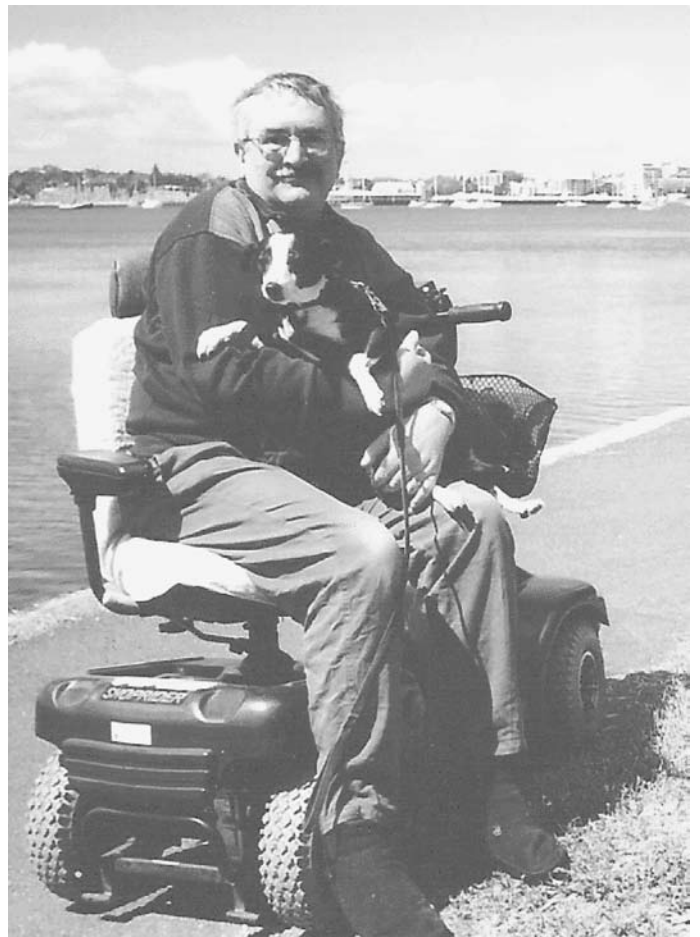
Having *had* speech, then losing it, was my major frustration. The shaking and lack of dexterity or fine motor control caused by my myoclonus (muscle spasms) came a very close second.

At the time, we weren't aware of the knowledge that there is available now. Either it wasn't accessible or we didn't have the contacts to access it. There was speech pathologist support at Grace McKellar Centre (an aged care facility in Geelong where I spent 6 months) but it wasn't very effective and I was not given any advice on AAC.

Before knowing of Scope's Communication Resource Centre (CRC), or in fact that AAC existed, Anne made me a communication board with the alphabet and some words and phrases, but more often than not, people *lost track* of what I was trying to say.

Having been a computer user for many years before, I thought there *must* be a better way! I'm not sure how or when I learned of AAC but I was rapt when I got a LightWRITER from ComTEC (ComTEC is a division of Yooralla in Victoria that supplies electronic communication devices with funding support up to a certain amount).

The LightWRITER opened up a whole new world for me. I then proceeded to try to help other people with speech difficulties to use the telephone. Joining the Telstra Consumer Consultative Committee was my first step, then another step joining the Telstra Disability Forum. The latter would not have been an option without the support of Communication Rights Australia (CAUS: formerly Communication Aid Users Society). I have



since upgraded to a Polyana communication device, as it has some MS Office features that I can use with regular computer functions.

To cut a long story short, I expanded my networks to the Australian Communications Media Authority (ACMA), TEDICORE, and ACIF (now Communications Alliance).

My three years on the Board of the Australian Communication Exchange (ACE is the provider of the National Relay Service or NRS) was a very interesting and diverse learning curve.

I remain very active on a variety of Boards, committees, etc, including the Barwon DisAbility Resource Council, City of Greater Geelong Street Access, and Scope CRC.

Even AAC users can have a say from their local government to a business. Don't let having a seeming lack of communicating stop you – BECAUSE YOU **CAN** COMMUNICATE BY MEANS OTHER THAN SPEECH!



Hope that the Dialogue has not Fallen on Deaf Ears

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My name is Michael Schreenan and I am a severe quadriplegic as the result of a vicious beating in 1987, which left me in a coma for 8 weeks. Upon waking up I have had to come to terms with my new life which eventually included a wonderful device called a Lightwriter. This is a communication aid that has dramatically improved my and other people's lives! As, much to my chagrin, I have become painfully aware of how vital good communication is to everyone's life!

On the other side of the coin, I have discovered how both frustrating and annoying it is when you are trying to say something important and the other person can not understand what you are saying, especially if they just agree, but really have absolutely no idea of what you are saying. If I, writing this article, can achieve one positive it is this: it is my fervent hope that knowing this will prevent people that work as personal carers from doing it! As I have previously stated my Lightwriter has greatly improved my quality of life, namely by allowing me to clearly and succinctly relay what I am thinking. One of its best features, apart from its obvious benefits, is its extremely long battery life.

Whilst on my computer, the best program that I have found is a virtual keyboard called, Click and Type (with the word prediction enabled). But when I am away from my computer I require something else to help me communicate. I have tried many and varied devices for the express purpose of interacting with the general public. By far the two biggest problems I have encountered are too short battery life and an audible insufficiency. As previously mentioned, when at home my primary means of communication is my computer and going hand in hand with that, is the internet, which is

what, speaking from personal preference, would have to be our greatest invention achievement, well anyway in my life, as it has been responsible for dramatically broadening mine and other's lives! I am very sure I am not alone in appreciating a particular beneficial feature of the medium when one is typing / communicating on the internet: it gives the person a great deal of anonymity! As I am sure the reader can appreciate, this is an extremely significant part of successfully interacting with the general populous.

Before my accident I was acutely unaware of the huge importance of both clearly and succinctly conveying one's thoughts or wishes. However, regrettably, I am now painfully aware of their value in productively relating with so called normal people or closer to the truth ignorant people. In particular, some bureaucrats, as has sadly been my experience. Please do not look on my last statement as a cart blanche denigration of the powers that be, because it is not. Unhappily though, and this has occurred on numerous occasions when I have to get somebody to make a phone call for me, the person on the other end of the telephone usually asks to speak to Michael and when they are told "oh he cannot talk", they immediately class me as intellectually disabled. This is a very common misconception some people have when seeing a person in a wheelchair. Along with this they think I can not hear properly. Well, that has been my unfortunate personal experience. Thankfully, however, both attitudes and understanding are changing for the better, particularly in the past five to ten years.



For example, when I was first in a nursing home, some twenty-two years ago (approximately), my day would consist of being put in a recliner chair staring at a wall. As I am sure the reader would agree, this is an all together constructive, beneficial and most of all, do not forget, action packed pastime. However, there are only so many times one can count the number of bricks in a wall! Happily now, my days consist of getting out and about, meeting and conversing with other people. One of my most enjoyable activities, if not my best, is going to the local chess club and, in particular, interacting with my best friend there. He treats me like an ordinary, normal, yes even run of the mill, friend!



Hope that the Dialogue has not Fallen on Deaf Ears (cont)

I shall now endeavour to take this opportunity to unburden myself of a gripe that I have had for quite some years. Namely the misguided practice of a few well meaning members of the public, to single most us disabled people out, for demeaning and patronizing treatment. Some people seem to think that all disabled people are the same and as such should be treated the same (particularly those people in wheelchairs). For some inexplicable reason people feel it necessary to always speak to people in wheelchairs. I, myself, find this extremely condescending and every time it occurs I think to myself "you would not say hello if I was just walking past!". So, in short unless you have some vital information to impart, say nothing! Remember we are all individuals and different. So because you see a disabled person please do not automatically think we are

all the same! Well, that is my gripe off my chest. My only hope is that it is not misinterpreted or thought of as meaning that it is okay to be mean, nasty and or cruel. Because this is not what I mean. Plainly speaking, it is more preferable if you don't say anything rather than being so "sickly sweet" (for the lack of a better phrase).

Well this is just a personal preference, as stated earlier. I shall now climb down from my soap box with the hope that the dialogue has not fallen on deaf ears (so to speak)! In closing, I would like to thank the reader for both their time and understanding.

Out of the Box - Using Technology to Follow Your Dreams

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Overview of the Project

Out Of The Box - Using Technology to Follow Your Dreams is an Australian project based on the Augmentative Communication and Empowerment (ACES) course delivered annually at Temple University's Institute on Disabilities (USA). Out Of The Box aimed to enhance the ability of adults with little or no speech to be leaders and active contributors in their own communities through the use of technology. Training was provided via three intensive workshops over a 12 month period. The three workshops were Daring to Dream, Daring to Use Technology, and Daring to Communicate. Support for individuals was provided between the workshops. The course was designed to meet four sets of core competencies: dreaming and setting goals; access to mainstream technology; communication and the use of a speech generating device; advocacy, empowerment, and leadership.

A unique aspect of the project was a focus on providing opportunities for the skilling of support workers and therapists in new technologies. In addition, all workshops were held in central Melbourne, with opportunities for participants to mix freely in the city. There were many experiences of building positive community attitudes towards people with little or no speech, particularly in the hospitality and retail trade.

In this paper we will describe the journey taken from the commencement of the dream, to the reflection on the outcomes.

Commencement of the Dream (November 2006 - July 2007)

In November 2006, invitations for people interested in participating in the project were publicised. Interviews were held and eight applicants chosen. Preparatory discussions were held with individuals before the first workshop in March 2007. It was called Daring to Dream.

The workshop was run by Professor Diane Bryen from Temple University's Institute on Disabilities, and focused on visualising individual dreams, and setting achievable goals. We opened up this opportunity to two extra people who wanted to learn to dream.

At the conclusion of the workshop, participants were given homework in preparation for the next course. This was to work on their "first wheels," that is, to take the first steps towards their dreams, and to prepare for the workshop on Technology. From March to July, the committee worked on developing a competency-based framework. In addition, a tool was



Out of the Box ... (cont)

developed to guide individual learning called the Australian Digital Independence scale. Time was also spent supporting the participants to organise their travel and support needs for the next workshop.

Daring to Use Technology Skills (August 07- February 08)

One of the original participants decided not to come and a new participant was interviewed and accepted. One of the committee helped him develop his dream before he attended this workshop.

As participants came from a wide variety of backgrounds with a range of experience with technology, a course structure was developed to meet the needs of beginners and those with more advanced skills. Participants were divided into two groups based on their responses on the Australian Digital Independence Scale (see more information about the ADI under resources). The intensive technology workshop was held at a hotel in central Melbourne. Participants stayed at the hotel for two nights with a support worker. Workshops were held over 2 ½ days. Sessions were divided into topics including physical access to technology, software for assistance with reading and writing, telephone use, Internet and email, and presentation skills (e.g. using PowerPoint).

On the first day, each participant had a 1:1 appointment with a specialist Speech Pathologist and Occupational Therapist to try a range of access options and set priorities around technology use. A laptop computer with software and hardware was set up for each participant's use over the weekend. Each person was given a workbook with a list of their priorities and personal goals. Time was spent problem solving how each participant could access various mainstream technologies such as computers and mobile phones. Specialised technologies like eye gaze and infrared pointing systems opened the doors to technology for many. Email addresses were established, and the program's online community <http://mc2.vicnet.net.au/home/outbox/index.html> was explored.

The second day involved more communication, information, and practice on telephones, utilising the National Relay Services. Professor Diane Bryan joined in using Skype from the US, motivating us to continue our learning journey. Participants also spent time learning about the National Relay Service's new Internet based system (<http://www.relayservice.com.au>). Mobile phone technology was also tackled, a necessity for many people with disabilities.

Throughout the weekend, participants were expected to develop a presentation to be delivered in front of the group on the final day. Participants were given a free choice of topic and method of presentation, but the theme needed to be around use of technology, personal goals, or the Out Of The



Box project. Despite the fact that many of the participants had never presented before and were using their equipment for the first time, they embraced this task with surprising enthusiasm. People chose to demonstrate equipment they had tried during the weekend or to share a personal story. One participant even re-drew her "Dream" as she had learnt so much since the original Daring To Dream workshop. Her original dream no longer reflected where she was in her journey. Over the next few months, participants were supported to deliver their presentations in their own communities. Each one was unique and powerful and brought fresh waves of support from their family and support workers. Some participants received offers of paid work; all received a boost to their self esteem.

Daring to Communicate and Final Evaluations (March – August 08)

The final seminar was delivered over 3.5 days in April 2008 at a different central hotel venue. This seminar focused on communication, advocacy, and leadership. The first day included a high tech expo of communication devices and involved presenters from technology companies. Time was spent problem solving how each participant could access communication aids. Specialised technologies like eye gaze and infrared pointing systems were once again explored, this time however exploring how they could be used to access communication devices.

The second day involved more communication, information, and practice on telephones. The afternoon session included a powerful empowerment session on relationships and communication. That night was an early dinner in the City, where communication aids were used, sometimes for the first time, to order dinner. The ability to order a beer for the first time and being understood was a highlight! Wednesday was a treasure hunt where communication abilities were challenged. Each person caught the train to Traveller's Aid and experienced a range of barriers and enablers. One participant had an exquisite interaction with a mime artist. Another tried on a



Out of the Box ... (cont)

\$75,000 ring from Tiffanies. Others were able to demonstrate the frustrations of accessing Melbourne's public transport using a wheelchair. In addition, an informative session on housing options at the Housing Resource Centre was attended by all participants.

The last session on Thursday was led by Scope's person centered planner, Amanda Jones. Each participant chose an animal that represented who they were. Strong positive images such as a tiger or killer whale demonstrated the improvements in confidence and self perception.

It was difficult for everyone to say goodbye; emotions were high. There were smiles, tears, and applause. There was a genuine feeling from all involved that people's dreams will live on, as will the Out Of The Box community. We have all been touched by the experience of Out Of The Box in some way. Friendships have been forged. Dreams have been sown. Although the future of this community is unknown, we are all looking forward to the next chapter.

Evaluation and Outcomes

Although the final individual evaluations are still being collated, the evaluations from previous seminars are very positive from all who attended.

Quotes from two participants are as follows

"I've enjoyed doing out of the box. I would like to do more as I have learned a lot about my rights, new communication devices & how to learn more about my rights on employment as I feel going to day centre is very boring for me"

"I loved it, it was fantastic. I learned so much & have gained so much confidence in myself & what I can achieve"

Quotes from two supporters

"I appreciated the opportunity to meet course participants and supporters. The whole weekend has been incredibly inspiring"

"It has been amazing to see the technology available. I hope to see the people I have supported using these products and services"

Individual Participant Achievements

- One person has taken positive steps towards living on her own.
- Three people have been offered paid work training others.
- All have demonstrated increased confidence and self esteem.
- Melinda Smith, leader community development project worker and person with complex communication needs, was invited to mentor on the 2008 ACES project. There she was awarded the FREE SPEECH NOW award. The ACES Free Speech Now Award is presented to an individual who has actively promoted freedom of speech for individuals with significant communication disabilities. Melinda received this award because she "dared to dream to bring ACES to

Australia and turned that dream into a bold reality."

The 2008 ACES Free Speech Now Award was presented at the Closing Ceremonies of the ACES: Augmentative Communication and Empowerment Supports, held at Shusterman Hall at Temple University on Friday, July 25, 2008.

- Everyone developed a dream and took their first steps.
- Over half the participants logged on to the MC2 community. This community now has 47 members.

Issues and Challenges

There were a number of challenges in this project. The biggest two were time and funding.

Time Restraints

- Forming partnerships that are empowering and develop leadership skills with people who have little or no speech requires extra time.
- Meetings took longer and meetings had to be made at times that fit in with taxis and attendant carer hours. Mealtime and breaks needed to be longer hence there was less time to learn new skills.
- People found some of the new learning tiring.
- The ACES program was two weeks with a year's support, whereas Out Of The Box was three workshops with a total of 7 days, with a year's support. Another workshop would have helped consolidate some of the learning.

Funding Restraints

- Many people had few friends and needed considerable paid support.
- It was difficult to find accessible and reasonably priced venues that cater for a group of people that includes more than three people who use wheelchairs.
- It was difficult to raise funds to pay for the attendant care, professional support, and specialist programme development. Attendant carer hours are not flexible enough to allow participants the "luxury" of attending a weekend course with full support.
- Many of the philanthropic funding bodies considered a target group of 7/8 people too small, even though it was argued that if each person knew only 3 people each the project would affect 24 people. In addition, all the attendant carers, therapists, hospitality and retail staff, all learned new skills. Building the capacity of the community to accept people with little or no speech rippled out far beyond this project. Determining the partnerships that can grow and sustain such projects is a challenge.

Long-term Support

Although participants have come a long way since joining the Out Of The Box journey, like anyone, they have a long way to go. There are funding barriers to ensuring that participants have the necessary supports they need. Specifically, participants are in need of: (1) continued support to lead and become active contributors in their own communities; and (2) continued



Out of the Box ... (cont)

support in acquiring the assistive technology systems and services they need to achieve their full potential, both in the areas of communication and digital independence. This needs to be done not only at an individual level but also systemically, and (3) continued support of participants beyond the acquisition of systems and services. Not only must users learn to communicate to their own maximum potential but they must learn to fully exploit the capacity of the device being used.

This support is vital. In order for any dream to be reached we all need support from our social networks and communities. Unfortunately, this support is something that is sadly lacking for many of the program's participants. Many of the communities the participants are a part of require support and guidance to (a) further develop their understanding, knowledge, and skills in communicating and supporting people with complex communication needs and (b) develop local community networks which are willing and able to embrace the full participation of people with complex communication needs.



Scope's Communication Resource Centre is part of a state-wide network providing information and resources for people with complex communication needs. Within this network, local speech pathology services, called spokes, have a role in building community awareness and supporting community participation. Out Of The Box has highlighted the value of such services locally. The spokes have a clear role in working within the participants' local communities to provide long term support.

Resources Developed

Several resources have been developed from the course. One such resource has been a framework of competencies from which to design the course. An Australian Digital Independence tool (ADI) was used within the course. The tool was adapted from a US Digital Independence Scale (Bryen & Williams, 2006). The ADI scale was designed to be a learning document in that the questions would inform the person about the technology they may not have known about. Questions were phrased as

"I" statements, for example "I can send an email" and "I can use the Internet to look up information." The aim of this was to empower the respondents by giving them a sense that they had the potential to do the tasks. Respondents ticked 1 of 6 set answers, indicating whether they had experience in a particular skill and whether or not they wanted to learn more.

The scale was designed to establish what respondents did or did not know and set individual goals accordingly. Participants were not expected to complete or have the skills to complete every task on the list, but it enabled us to set priorities and give them a list of tasks and skills to keep pursuing after the training weekend.

Each question had a teachable response too. For example, if the respondent said that he or she could not send an email, the teachable response would be to look at a range of email programmes suitable for the individual, make sure they had an email address, and give them the opportunity to send an email.

Future Directions

Out Of The Box – Using Technology to Follow Your Dreams has huge potential for positively changing the lives of people with complex communication needs and their supporters. The 18 month pilot described in this paper is testimony to that. As has already been discussed, the program faced many challenges along the way, the most significant being the provision of sustainable avenues of funding. The committee, in recent months, have done some soul searching and based on the many triumphs, hurdles and lessons learnt along the way, have developed a vision for the program's future.

The committee agree that this project should be given an opportunity to 'spread its wings'. There is a sense amongst all involved that the project, its participants, supporters and potential should survive. The committee have a vision for the project living and flourishing outside of the confines of disability organisations such as Scope and Yooralla. With support from the current Out Of The Box community, the committee envisage it being housed and supported by a non-disability specific organisation: an educational institution such as a University or TAFE, a community based organisation such as a neighbourhood house, or perhaps a leadership organisation such as Leadership Plus. Although this would not immediately overcome the challenges of finding funding, the committee believe it may open the doors to alternative funding sources not currently available to the project in its current form. Additionally, those that have been a part of the program since its conception strongly believe that a project such as this is far greater than 'disability services', and should have its routes strongly placed within the mainstream community. Melinda Smith, Libby Price, and Jo Watson, all members of the committee who have participated in the ACES program in Philadelphia, strongly agree that one of the many positives of this program is that it is housed within a University rather than within a disability organisation. A 1995 evaluation of the



Out of the Box ... (cont)

ACES program backs up this observation (Bryen, Slesaransky & Baker, 1995).

The committee agree that a program such as Out Of The Box would be well placed within the transition stage of a young person's life. Specifically, they are referring to the transition of young people with complex communication needs from school to whatever they choose to do, including conquering the world.

The committee intend to 'wrap up' Out Of The Box with a view to handing the program over to a welcoming and nurturing new home, outside of Yooralla or Scope. To this end, they plan to develop a handover package containing material such as a CD-ROM, the resources described above, and a training manual,

which will be useful to the program's new driver(s). A forum is also planned, where potential new drivers and or funders of the program will be invited.

If an appropriate home can be found for the program, the committee will be available to mentor and provide guidance to ensure that the seed that was planted back in Brazil, at ISAAC in 2004, by Melinda Smith and Diane Bryen will not only stay alive, it will flourish!

Sponsors

We would like to thank our sponsors for making this dream a reality. These were Friends of Australian Communication Exchange Support program (FACES), the National Relay Service, and Scope.



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Training Together: Incorporating the Client Perspective in the Training of Carers

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The following paper was presented at ISAAC 2008. It has been adapted by the authors for AGOSCI In Focus.

In an attempt to maximise the goals of a mealtime management training package for carers of people with a lifelong disability, an AAC user was approached to retell his personal journey in transitioning from oral to non-oral nutrition. The Speech Pathologist and the AAC user joined together to present both clinical and personal perspectives of mealtime management. Active involvement in the training has enabled the AAC user to develop a leading role in the area of mealtime support. This paper will discuss the development, benefits, and value of the joint training partnership and will highlight the leading role an AAC user can play in advocating for others with a lifelong disability.

John's Introduction

Hello. My name is John and I'm going to take you on a journey.

I want you to think.

Think for a minute.

Do you have any idea of what it is to stop eating?

Do you?

Really?

Okay. Stop right there.

I want you to think of your last good meal. Think about it. Savour it. What if, just as the first lovely mouthful was on its way up to your mouth a speech pathologist burst into the room with a fierce look and told you that you were never allowed to eat any thing ever again. The last meal you had was the very last thing you would ever eat. From now on your food would consist of a vanilla liquid food you have to ingest in one long slow motion through a hole in your stomach; drip, drip, drip.

I am John. I'm a writer and artist, an advocate, and sailor. I hope you enjoy what I have to say. Before I hand you over to my colleague there is something I would like you to do if you can. While you read this paper, I want you to imagine that you've just been told you are now NIL BY MOUTH.

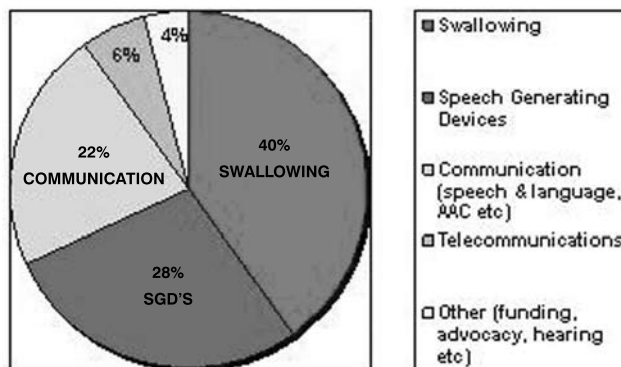
Rebecca's Background

This paper will discuss how a client-driven approach to mealtime management facilitated a collaborative working partnership

between a client and a therapist which, through the use of John's personal narrative, was then used to further improve and enhance current mealtime training of our organisations' staff. Our work together has come out of my admiration for John as he underwent the difficult and uncertain transition from oral to non-oral means of nutrition. This largely undocumented and life changing experience led us to form a partnership based on the conviction that all care givers must be properly prepared and trained in adequately supporting all facets of mealtime assistance. Our chief purpose was to bring knowledge and communication to the area of swallowing difficulties, mealtime management and non-oral nutrition, and, particularly, to enhance the quality of life for people with lifelong disabilities.

Both John and I are from the Cerebral Palsy League of Queensland, based in Brisbane. Our organisation currently supports 1655 adults with cerebral palsy and related disabilities, as well as over 1400 children, 105 of whom are currently transitioning into adult services. Services offered may include accommodation, employment, community access and therapy support to name a few. There are 2 Adult Therapy and Social Work teams covering the state, with one Speech Pathologist assigned to each team. At times therapists are required to travel over 1000kms to see clients. Due to the large case numbers, and at times vast travelling distances, services are often consultative in nature.

Over a 12 month period, there may be close to 550 active referrals requiring an adult speech pathology service. In 2007, swallowing related referrals accounted for 40% of the total active case-load (see graph 1).



Graph 1: Breakdown of 2007 Speech Pathology Referrals



Training together ... (cont)

Current literature in the area of disability suggests that dysphagia related illness and death are highly prevalent. Kaatze-McDonald (2003) in completing a Australian state community review, reported that respiratory related illness was the most common cause of death in people with a developmental disability. The literature and our own referral statistics suggest that the area of swallowing and mealtime management is a critical issue requiring an urgent action within the speech pathology service. There appears to be many people with a lifelong disability who are having difficulties with swallowing, of which John's is just one story.

John's Perspective

I was born in Australia in Bowen, a two day freight car ride away from Brisbane. Bowen has farms and a fishing industry but is most famous for its mangos, which is interesting because today I want to talk about food. I just love mangos, but then, I love many sorts of food. Food is one of the great pleasures of life. We talk over a meal, we take time in preparing it, and we talk endlessly about it. Look at the number of television shows devoted exclusively to it. In my mailbox I have seen whole forests cut down just to advertise it. I love the taste. I love the smell. I love its fabulous textures.

But, you see, the problem is that I was born with cerebral palsy and I have always had trouble eating. I was always skinny. We Rynn's all are. But I had trouble getting enough food. In the 60s, when I was eleven they tried forcing me to feed myself. You know, if it wasn't for good kindly Sister English, who had a sense of proportion, I would have starved. Nowhere in my life was my eating difficulty more obvious than in 2002 when my speech pathologist and her videofluoroscopy told me that my eating days were over. She said I would need to have an enteral feed device inserted. I was 48 with a life time of eating behind me.



The great celebration of food, one of the last great pleasures in my life and one thing that really linked me to the rest of humanity was about to be downgraded to a vanilla flavoured liquid I could only taste if I burped.

Well, all this put me on an emotional roller coaster. I've read that a lot of people experience a sense of loss with this diagnosis. I need to confide in you, it wasn't just loss, it was grief. You see the big problem is not only giving up eating but all the other things that go with it. You know the ages spent gathering it, preparing it, and feasting on it etc. But, most importantly, as a species, humans socialize around food. We are at our most relaxed and at our very best around the table.

Hey, how's that exercise I gave you going out there. Tummy rumbling? Feel a bit freaked out? Remember, you are still in society but it's different, isn't it? My attachment to food was a big one and even though I survived the transition from oral to enteral, giving up food was like seeing a friend die. I have never stopped wanting food, never. While it fills a hole, enteral food never really satisfies.

And John's Baggage...

There is some baggage I would like to get off my chest.

Early in life I had had one expert telling me I needed a brain operation to cure my cerebral palsy and it didn't. Then another comes along and tells me I have to learn to feed myself when I never did, I never have, and I never will. So, here I was, in 2002, a grown man being told by yet another therapist that I had to give it all up for science again and stop eating.

How do you think I felt?

Luckily, Rebecca approached the whole thing differently and this made all the difference. For a long time she had been talking about my eating but it just went in one ear and out the other. I did not want to know. But it was crunch time. She told me how worried she was about food and drink going into my lungs. She predicted that over time I would get sick. You may not think so but I needed to hear her talk this way. On my board I spelled out my past experiences with therapists and mealtime interventions. Rebecca saw what was going on. She went through the whole thing with me patiently and caringly. This made a whole world of difference.

When the results of the video fluoroscopy with a modified barium swallow came back the verdict was "nil by mouth." Let me tell you, loud and clear, that was the last thing I wanted to hear. The good thing is that Rebecca seemed to sense how important it was to get all this off my chest. I don't think she really knew what she had let herself in for. In fact, she had uncorked a riot. The more I talked the more it helped. I went out to any one who would listen: people at church, people in



Training together ... (cont)

my family and those who were on my care team at the time. My personal carers were horrified. Every one of them. My friends at church said they felt sad for me because they knew how much I loved eating and I always bought up big on sweets at church fetes! My family were very sad; my brother exclaimed, "No!" One young lady who knew me was so sad she sobbed tears all over me. I felt I just had to hug her. I felt like saying, "Look, this doesn't affect my kissing."

A key moment was with Peter, a lifelong friend, who had gone through a similar intervention years before and who had a PEG. When I saw his PEG for myself, and how it had affected his life for the better I saw how happy he was with it. That made me feel much better about the decision I had to take. I could accept the reality. This helped me give permission for it to happen. That's how it should be. After all, it's our bodies that end up being the meat in the proverbial sandwich. It is our lives. If able, people can make their own decisions, why not me? Freedom, self-respect and "choosability". Now there's a word for you. Those are the things democracies are supposed to protect. Well, I know why.

Rebecca's View on The Training Process

Many people supported by our organisation may be supported by up to 5 or more different services each week, with countless numbers of different staff assisting with every meal. Most providing this support were doing so with little to no formal training. New staff were expected "to know" how to recognise when the person they were supporting was having swallowing difficulties, but had never been given the skills to do this properly. New staff were learning this information via word-of-mouth (from other staff members) and often the wrong information was being given.

As a result, I noticed a number of reoccurring myths regarding mealtimes, namely:

- If it's going down, everything must be okay;
- It's okay for adults with cerebral palsy to have low weight (body mass index below 19);
- It's okay for adults with cerebral palsy to experience coughing and/or choking as part of a regular mealtime experience.

A mealtime training package was developed in an attempt to: (1) address the organisation's current lack of training in the area, (2) improve the skills of the large number of staff providing mealtime support on a daily basis, and (3) address and dispel the common and dangerous myths surrounding mealtimes.

Initially, the training was in danger of becoming a 2 hour "do's and don'ts" session with a list of rules and regulations, which could easily be forgotten within a couple of days. We'd established that a good mealtime management practice was one where the individual and the therapist worked together with the individual driving the process. It became apparent that this

model could also be beneficial in the training of staff. Stepping back to look at John's journey and how he was supported allowed the recognition of the value this information had in the training of others to better assist the people they supported. I approached John in the hope that he would be willing to present the personal side of swallowing difficulties in an attempt to make a lasting impression on training participants and bust some of the complacency around mealtime management as a whole.

With this in mind, the following formal aims were developed:

1. To raise awareness of the prevalence of dysphagia in people with cerebral palsy
2. To challenge and reduce acceptance of swallowing difficulties for adults with cerebral palsy and dispel common myths
3. To emphasise the role the individual/client plays in their own mealtime management
4. To raise the awareness of the carers role in mealtime management
5. To raise awareness of the Speech Pathologist's role within mealtime management
6. To equip trainees with the necessary skills to identify possible occurrences of swallowing difficulties and strategies to ensure safe mealtime experiences.

The training aimed to meet these goals by providing both the clinical and emotional side to swallowing difficulties and mealtime management. In running the training we attempted to allow the attendees to take on board the seriousness of poor mealtime management and then incorporate skills to provide sensitive support of the mealtime process. By incorporating John's very human perspective to the topic we were hopeful those attending the training would become better advocates and even role-model themselves.

John: Between a Rock & a Hard Place

After the operation I had to find a way of letting my feelings out. I didn't have the Aussie tones of "Lee" (my Pathfinder voice) then. My dear old Liberator device lay stone cold dead in the cupboard and I desperately needed to express myself. The only effective way I knew of letting it out was on paper. So using Stone Age technology, aka a carer, I wrote "Between a Rock and a Hard Place." After such a big experience it seemed clear to me, especially where there is communication impairment, that the person's side of the story must be told.

Rebecca loved the ideas in my story. She felt that by working together we could help.

Now, everyone praises the training we do. The feedback I get tells me it is badly needed. There just isn't enough knowledge around. People express a lot of relief during the sessions. The interplay between us creates an informal and enjoyable



Training together ... (cont)

atmosphere. People are not afraid to ask questions. I think this is really important. People can open up without fear and offer their own experiences. A lot of feelings are let out.

The thing they most want to know is how I was after the operation. They want to know how I felt and how I still feel even now, from day to day. They want to know whether or not I am happy and especially whether or not I miss food. They are always very grateful that I spoke to them. Nearly always, they tell me how much better they feel after listening to what I have to say. It's like it comes from a voice they can trust. I know that's exactly how I felt when I spoke to my friend, Peter. I knew that what he told me was from the school of hard knocks.

Concluding Together

Feedback received from those who have attended the training has been more than positive, with all attendees commenting on the impact of having the personal as well as the clinical perspective presented.

We feel that this training package is of an enormous benefit to services and staff currently providing mealtime support.

However, this training continues to be sporadic in its delivery due to a severe lack in funding and the current inability to attract further funds. We continue to try to lobby for additional funding to increase staff coverage, but also to better value John's contribution. Further funding would also allow for the expansion of the scope of the target audience to include medical students and other health professionals, in an effort to improve the quality of service for individuals with a lifelong disability.

We would like to highlight that only through open communication could such a potentially negative experience develop into such a positive partnership. For any issue, the need to listen, to provide a means of open communication and to have equal concern and respect for the individual is crucial to build a true partnership, rather than an "I know what's good for you" perspective. Further, we believe that the use of a personal narrative of an individual can be of an enormous benefit in the training of staff and is a valuable tool for any therapist.



AGOSCI 2009 Awards



Nominations close 5th of March 2009

In 2009 AGOSCI will once again have awards as part of the conference closing ceremony. These awards are designed to recognize both contributions to AGOSCI and contributions to Australian AAC.

If you know someone who has made an outstanding contribution to AGOSCI you can download the nomination form from our website at www.agosci.org.au. Then click on the Grants, Scholarships and Awards link and download the Nomination form for the AGOSCI Award for Service to AGOSCI.

If you know someone who has made an outstanding contribution to Australian AAC you can download the nomination form from our website at www.agosci.org.au. Again – you need to click on the Grants, Scholarships and Awards link. You can then download the Nomination form for AGOSCI Awards for Service to AAC.

If you have any questions please contact Sally Hunter on sally@ilc.com.au



The OWLs, the Child and the System - AAC Integration in a Mainstream S.A. Kindergarten: A Parent Perspective

B-J Dee-Price

It's a spring morning in 2008 and we drive into the car park at the kindergarten. An ice-cream lid with a felt-tip drawing of the 'disability symbol' strapped to a little chair tells us that this is our park. My four year old son and I are met at the gate by an early childhood worker (ECW) from the Department of Education and Children's Services (DECS) and a registered nurse (RN) from the Child Youth and Women's Health Service (CYWHS). They carry the bags and market trolleys: one for medical equipment and the other for my son's communication system. I carry the most precious package. In my mind, I also carry the DECS Curriculum Framework, Disability Legislation, the Communication Bill of Rights, a high regard for speech pathology, and a belief in the ability of individual teachers to overcome systemic gaps or, at least, their willingness to try. Borne also is the weight of risk; this being the emotional development of a child in a setting not really ready to integrate him.

We weave our way into the kindergarten and I tumble my son into his Tumble-Form (Tumble Forms Paediatric Rehabilitation Equipment) chair.

The Child

This is a small Adelaide inner city public kindergarten of approximately 20 students. It welcomes a rich diversity of children from different cultural backgrounds, as well as those with additional needs. It is the educational setting for my four year old son who, with athetoid cerebral palsy, experiences severe physical barriers affecting almost all dimensions of his movement, including swallowing and speech. Without the ability to sit or walk independently, to take food orally, or to talk his needs, challenges are presented in the kindergarten setting.

There is a range of service providers who assist him. In addition to receiving support from the ECW and RN, there are visiting therapists such as a speech pathologist from Novita Children's Services, which is a non-government agency providing services for children with physical disabilities.

Despite the significant barriers to his daily life, he is a typical four year old boy in his thinking and interests. As a young child striving for self-expression, he has a strong desire to learn and socialise and, for these reasons, a mainstream kindergarten is

the most appropriate setting for him.

The ability to communicate underpins all dimensions of learning and socialising. It is the most important element of successful, and inclusive, integration of an extraordinary child into a mainstream setting. Needless to say, as a family, we have invested considerable time and effort working closely with our son's speech pathologist to enable the best possible communication opportunities.

Without the ability to vocalise or gesture to communicate, there is a large gulf separating his receptive language (understanding of information coming in) and expressive language (his ability to communicate outwardly). Alternative and augmentative approaches to communication (AAC) are therefore integral to addressing this gap.

The OWLS

In line with the Observing, Waiting, and Listening (OWL) acronym of an effective communication partner (Pepper & Weitzman, 2004), our son's communication is promoted by a committed ECW and RN team who have enthusiastically embraced AAC. They are the natural OWLs who watch and interpret his expressions, provide time for him to respond, and use whatever tools and strategies that are made available to them through the speech pathologist. They also adopt creative solutions to enable participation and communication, for example using the Big Macs to enable our son to play the role of 'the troll' in Billy Goats Gruff, and to direct the counting for his peers in the game of hop-scotch. Rarely have these workers left the kindergarten at the scheduled end of their shift; to bridge gaps, they have also given their time.

We have been fortunate, also, to have received the skilled intervention of a committed speech pathologist who has promoted our learning as well as provided training, information, and support to kindergarten staff. These tasks have often been performed in an implicit context of *no right to expect any ideas or strategies to be accepted or incorporated by the kindergarten*. There are no policies, procedures, or interagency agreements ensuring that any of the interventions, strategies, or resources provided by a therapist, should be adopted. The Negotiated Education Plan (NEP) is the only vehicle to ensure some level of accountability. Yet, as a static document, a NEP is not an



The OWLs, the Child and the System ... (cont)

adequate tool to ensure that the evolving recommendations from therapists are incorporated. In addition, after nine months of kindergarten we are still yet to receive a copy of this plan. It is, therefore, almost left entirely to the discretion of the Kindergarten Director and the relevant staff to value this material and find the additional time to learn and implement AAC.

At this point, there is also ambiguity surrounding the pragmatic role of the kindergarten teacher, which is reflected in minimal use of AAC, often because AAC use is viewed as the role of support staff. There is, however, a commitment and willingness to move forward. A few weeks ago, AAC training was squeezed into the most practical time slot: staff lunch hour. The unquestionable giving of this time, and their full participation, demonstrates their commitment. We shared a pizza and watched a video of an American mainstream kindergarten with fully integrated AAC. Not only were the teachers in this video using AAC, but all of the students had adopted AAC as a supplementary form of communication in the classroom. This video established a standard in the minds of all present, but also highlighted the reality of systemic gaps impeding the possibility of these types of practices being enacted in our kindergarten.

The System

The system here refers to the key organisations mandated to support the inclusion of our son into the mainstream kindergarten. These are predominantly the Department of Education and Children Services and the non-government therapeutic services with their policies, procedures, interrelationships, governance, and political responsibilities.

Despite the functions of the DECS Disability Co-ordinator, the NEP, and the vital role of the ECW, there are pervasive systemic gaps which pose barriers to the successful integration of AAC. At this macro level it is interesting that these gaps are as much about communication and strategy, as they are about unmet resource need. There is a profound absence of curriculum implementation strategies, curriculum supports, supported access to staff training, effective interagency communication and partnerships, quality assurance, evaluation, and the resource documents of the experiences of children, however different, which may act as roadmaps to assist children, families, and workers, on the path to inclusive education.

It has been perplexing to realise that, at this early entry point, our pathway to inclusion has sat within the murkiness of absent procedures and somewhat tenuous systemic relationships. It seems ironic that one of the roadblocks to the successful integration of AAC within this educational setting is the interagency communication problem. Without memorandums of agreement between agencies, defined roles

and responsibilities of educators, supports for educators, action plans, implementation strategies, and curriculum resources, there appears to be many ends left loose and a relentless re-invention of the wheel. We are not the first family to have walked down this pathway; so why does it feel as though we are?

Due to these problems at strategy and planning levels, it appears to be left to the grass-roots service provider to cut through a jungle of confusion; to decide their level of involvement, to risk the consequences of making decisions and taking action that falls outside of their responsibility, to forage for resources they are not authorised to access, and to sometimes attempt activities which exceed the scope of occupational health and safety.

Our experience has brought to mind a conversation I had two years ago with a mother of a teenage daughter with significant physical disabilities. She provided what I had thought was a biased account of mainstream schooling describing access like this: "They'll tell you, you have the right to collect some water from the well but don't expect the rope and the bucket."

Hopes and Dreams

What began as an expectation of inclusion has become somewhat an illusion. Despite this, we still harbour a hope of our child receiving an inclusive education in an integrated system committed to narrowing the gap between his receptive and expressive communication.

Many systemic gaps can be addressed. Finding ways to build interagency communication and partnerships is one strategy. This relies heavily on the time and commitment of senior management to claim their position of stakeholder and, thus, see the investment in collaborative intervention. Another key strategy is to pursue inclusion through the doorway of teaching diversity; this is an obvious invitation to develop innovative curriculum resources, even if inclusive curriculum development poses too big a challenge.

Until then, our personal pathway forward continues to be heavily reliant upon the willingness, skill, and determination of service delivery staff to find ways to bring a semblance of meaning to the rhetoric of inclusion. Until then a four year old boy, his parents, the kindergarten staff, and the support workers must act as pioneers in an education system so familiar, yet so elusive.

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Reading Rocks

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One of the most important emergent literacy skills is the association of books with pleasure (Musselwhite & King De Baun, 1997). For this link to be established, the young child needs to be exposed to books. Often, for typically developing children, the journey to become literate individuals begins in infancy. For children with special needs the journey sometimes isn't even contemplated until the commencement of formal education, due to the myriad of other needs that must be addressed in day to day care (Musselwhite & King De Baun, 1997). Supporting the teaching of literacy to students sometimes isn't just about teaching them to *read*, but rather that books are full of wonderful things and can be shared with the student at whatever level they are able to enjoy them (Musselwhite & King De Baun, 1997). This short article is about just that: taking the books to the students, and enjoying their personal journey toward literacy alongside them.

St Ann's Special School is a co-educational Catholic school in Marion, South Australia. St Ann's educates 53 students aged from 5-20 years of age. The curriculum is based on the South Australian Curriculum Standards and Accountability (SACSA) framework, delivered through three groupings: the Early Years, Middle, and Senior clusters. The students at St Ann's have moderate to profound intellectual disability, with various co-diagnosis of Angleman syndrome, Ataxic Cerebral Palsy, Autism, Myotonic Dystrophy, Cri Du Chat syndrome, Dravett syndrome, Down syndrome, Epilepsy, Global Developmental Delay, Lennox Gastuat syndrome, Smith Magenis syndrome, Sotos syndrome, Tuberous Sclerosis, and William syndrome. St Ann's employs teachers, education support officers, bus drivers, administration staff, and a fulltime speech pathologist and occupational therapist to support the delivery of the educational programmes of the school.

As the speech pathologist, I work across the school in all of the clusters, seeing every student in the school at least once a week. The allied health service is delivered via SPOT groups (combined speech pathology and occupational therapy groups) and groups targeting more discipline specific areas in the learning space of the students. There is also an amount of time spent consulting and collaborating with teaching staff, in regard to individual student needs, in the areas of mealtime support, augmentative and alternative communication, and positive behaviour support. One of my areas of interest at St Ann's is the support of literacy teaching to further reinforce the notion of a *total communication environment*. This year has provided an opportunity for me to work closely with a member of the teaching staff on a Key Literacy Project supported by Catholic Education South Australia (CESA). This project has formed part of professional development opportunities for new key literacy teachers. We have attended courses on early



literacy development, and the use of the Early Years Assessment tool used by mainstream schools across the state (Marie Clay Observation Survey of Early Literacy Achievement, Clay, 2002). Currently we share this key literacy position.

Participating in this course has provided me with valuable insights in regard to the teaching of literacy in mainstream schools. My colleague and I have learnt much from our mainstream counterparts, but they have also taken away valuable understandings as to how learning is supported for students with special needs. Our project has taken the form of an extended *show and tell*, with teachers from other schools showing an interest in how we write stories, adapt stories, use technology, and other aids to involve and engage our learners in literacy experiences.

Literacy at St Ann's looks like - well - a lot of fun actually! Emphasis is placed on facilitating the development of beginning and emergent literacy skills:

- Orientation to the book- where a story starts and finishes
- Which way the print proceeds
- Development of 'reading' like behaviours, i.e. turning pages of book (either by hand or activating jelly bean switch for computer)
- Recognising familiar texts
- Recognising a 'favourite' text & being able to request it (using existing communication style)
- Able to 'read' familiar text (relying on memory and information from pictures)
- Beginning to link text with pictures
- Beginning to match written words to spoken words
- Beginning to develop sound/letter correspondence.

A variety of strategies are used focusing on access and opportunity; access to a variety of text and opportunity to explore that text. When planning for story telling sessions, the last thing I am worried about is whether the books will be pulled apart or sucked on. The students need to hold the book and explore the book by getting up close and personal with it. Books are often completely dismantled, photocopied (you can do this without breaching copyright as long as you own a copy



Reading Rocks (cont)

of the book and only reproduce it once), laminated, and put back together with the coil binder. To aid little fingers, or other fingers that have difficulty turning pages, small squares of foam are glued to the corners of pages to bulk them out. Covering a book cover in soft contact, and then all the pages, is also helpful in extending the life of picture books.



Here are some of the ways we *do* literacy at St Ann's:

Adapting an existing text

Make colour photocopies of the pages of the book, laminate, and stick a square of rough hook Velcro on the back of the picture. Students choose a picture and match it to the page in the story by placing on a wonder-wall/felt storyboard. This can be further supported by the use of a Step-by-Step communicator for the repeated line in the text. *Boo to a Goose* is a particular favourite at St Ann's.

Re-writing an existing text

Sometimes the story is too wordy and needs to be reduced down to its basic elements. Identify what you want to tell the students and the language elements you want to teach (i.e. nouns, verbs) and rewrite accordingly. Visual supports and Step-by-Step communicators can be used to further reinforce these elements and engage the students.

Writing books about the students

Two of our classrooms have interactive white boards which have been used with great effect to create stories about the individuals in the class. The students have participated in the writing of these stories, have chosen the pictures to illustrate the pages, and are able to access them on the classroom computers or on the white board itself. Copies of the stories have also been printed off and laminated for the students to take home and share with their families.

Power point stories

This is a quick and easy way to write a story about an excursion or school activity using photos of the student in the particular context. Power point stories can also be quickly printed off and sent home.

Microsoft Photo story

Photo story is used by many classes at St Ann's to record special events at the school, such as masses, liturgies, and other such celebrations that have a high level of student involvement. Photos of the event can be inserted into the story and linked to music, which plays whilst the story plays.

Commercially available audio-visual material

There are some wonderful recordings on CD and DVD of many books being read by various celebrities. They have come a long way from the tapes and that annoying ringing bell that tells you to turn the page! Look out for *Hooray for Fish* by Lucy Cousins. The DVD is just beautiful, a wonderful accompaniment to a good, well written story.

Visual supports and props

Puppets, musical instruments, and monster masks: the list goes on! Basically anything the students can touch, feel, and smell that assists in the telling of the story. It did take a while to find plastic versions of all of the food that *the very hungry caterpillar* worked her way through, but I did it!

Single message devices

These devices are such invaluable pieces of equipment that engage and motivate not only the non-verbal members of the group, but everyone else as well.

Bookworm Literacy tool

This device is made by Able Net and essentially, turns a storybook into a talking book. A book is read into the device's memory module (each module can store four books) and





Reading Rocks (cont)

coloured stickers are stuck to the edge of the right hand page. The book is clamped to the device and the student *reads* the book by either pushing on the sticker, which corresponds to the page of the book, or by activating a switch (e.g. jellybean). The student needs to turn the pages of the book or can be facilitated in doing this.

In 2007, the school participated in the South Australian Premiers Reading Challenge. The challenge was to read, or in our case *experience*, 12 books, commencing in March and concluding in September. Students completing the challenge for the first time received a certificate. Students then received a medal for each challenge completed thereafter: bronze, silver, gold, and platinum. We have 15 students receiving their bronze medal this year, and another 19 who will receive certificates for completing the challenge for the first time. Extra certificates were awarded to those students who *extended* the challenge with their families and experienced extra books. I awarded certificates to two students who had experienced a total of more than 60 books with their families! To celebrate the achievements of our students and their families, we had a huge morning tea and organised our certificates to be presented by Sascha Hutchinson, children's book author and illustrator. It was a wonderful morning and one that was quite emotional for all involved. Parents, carers, and the extended families (we had quite a few nannas and pops in attendance) were so very proud of their children. Teachers were proud of their students and I was proud of our whole school community, who didn't look at me like I was crazy when I said I wanted to register our school for this literacy initiative; who instead, whole-heartedly took up the challenge. This year, we have 34 participants who will be recognised for their achievements. I think I am going to have to organise two celebrations, as our school library can't accommodate all those extra people!

The sharing of a book with another individual is a very special experience. By taking the time to sit and read a story to someone or to have the experience of another reading to you is telling that person that you respect them, enjoy them, and want to share this particular thing with them. A favourite book is, in essence, a part of who we are as individuals. What a great gift. Yes, sometimes, adapting and rewriting books can be

time consuming and a bit fiddly, but when you sit down with a student and share that book with them, in *their* way, respecting their journey toward becoming literate individuals, it is certainly well worth the effort. Erikson, Koppenhagen, and Yoder (2002) took this to another level, highlighting the importance of books in the lives of all individuals regardless of ability or diagnosis when they wrote the *Literacy Bill of Rights* which states that "All persons, regardless of the extent or severity of their disabilities have a basic right to use print." Reading, well and truly, rocks!



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Access for All to the Curriculum Using Aided Language Displays

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Introduction

Glenroy Specialist School (GSS) is a school for students with physical disabilities. Students have varying levels of communication, cognitive, sensory, visual, and hearing impairments, as well as complex medical issues. The school has over 150 students aged from 5-18 years.

Therapy services (speech pathology, occupational therapy, and physiotherapy) at GSS are provided by Yooralla. Yooralla is a not-for-profit organisation that provides disability services for Victorians. These therapy services are predominately provided to the class as a whole, within the students' school program.

Most students at GSS have a severe communication impairment, and Augmentative and Alternative Communication (AAC) is used by students and staff extensively in the school. Students make use of both light and high technology systems such as electronic communication devices, multi level communication books, Pragmatic Organisation Dynamic Displays (PODD), and Aided Language Displays (ALD) to communicate. Students access these systems through a variety of methods such as direct access, one or two switch scanning, eye gaze, and partner assisted auditory/visual scanning. Makaton (key word signing) is also modelled consistently throughout the school.

This article will explore the use of ALDs at GSS to enable Access for All to the curriculum.

Curriculum

One of the main roles of the therapists at GSS is to work with the teachers to ensure that the curriculum is accessible to all students. The school follows a modified version of the Victorian Essential Learning Standards (VELS) Curriculum. Individual Education Plans (IEP) are developed at the beginning of the school year for each student by their team (i.e. family, teacher and therapists). These plans contain specific measurable goals relating to the components of the curriculum. Therapy goals are integrated into the IEP resulting in the goals being addressed in every session across the day, including those not attended by therapists. Checklists are developed and completed by all staff (teachers, therapists, and assistants) to enable recording of students' progress on their goals in each session. The IEP is reviewed twice yearly and goals are modified with new goals developed mid-year as required.

Aided Language Displays

An ALD is a board of pictures that contains words that may be used by a student in a specific context. The ALD is used as a part of the Aided Language Stimulation approach, in which the



more experienced communication partner points to the picture as they are talking to the student. In this way, the student has somebody speaking to them using a method by which they can respond back (i.e. pointing to their message too). For example, during mealtimes the student may reach for their sandwich. Their communication partner would then point to the pictures I WANT SANDWHICH while also saying the sentence "I want a sandwich."

The speech pathologists, in conjunction with teachers and other therapists at GSS, have developed a number of direct access (displays that students point to with their finger) and eye gaze (displays that students look at to indicate what they want to say) ALDs for use within the curriculum. Sessions where students are positioned without their usual communication system setup (e.g. gross motor programs and morning circle sessions where students are positioned out of their wheelchairs on the floor) or when students require greater physical space to participate actively in tasks (e.g. during cooking and art classes) are enhanced through the use of ALDs, as these allow the students to access language and the curriculum. Without access to the session specific ALDs students are limited in their ability to communicate during these sessions.

ALDs are used within the school setting to support receptive and expressive language development, as well as targeting literacy skills. ALDs are also used with students who are at the pre-intentional level, during their interactions in the classroom, to provide consistent models of language and concepts that they are learning. The primary aim of this is to develop the student's understanding of how symbols can be used to communicate for real purposes.

To ensure consistency across the school in the ALD layout, core vocabulary and the symbols being used when making ALDs, the speech pathology team are currently developing a list of rules and guidelines to enable teachers, school staff, and other therapists develop ALDs for use by students/staff. For example,



Access for All to the Curriculum ... (cont)

having the displays organised so that sentences can be formed from left to right (the way we read), ensuring verbs, as well as nouns, are included, and keeping core vocabulary in the same position on each ALD, are encouraged. This facilitates memory, speed of communication, and the development of motor learning patterns. These guidelines ensure that there is activity specific vocabulary available as well as vocabulary that allows the students to make a range of comments and requests during the activity to interact with others.

Training has been provided for staff and families/carers in the development and use of ALDs. Several in-services have been conducted to large groups focusing on Aided Language Stimulation and the use and development of ALDs. Smaller practical workshops have also been held where participants have had the opportunity to develop and practice use of ALDs in functional settings.



Discussion

There are many different AAC systems and access methods used by students throughout the school. There may be numerous different AAC systems within a class of students. Teachers and parents have provided feedback to us over the years informing us that they prefer to use activity specific ALDs for some specific classroom and home activities. They have said:

- The ALD supports working with students within the same class who have varying levels of communication, cognitive, and access abilities. In particular, using the ALDs reduces the complexity of using multiple communication systems in a class with minimal assistants.
- The ALD's ease of use allows for modeling using the same system resulting in other people using ALDs during interactions with the students. The ALD facilitates peer learning, in which students can see their classmates using the same systems of communication.

We have also had feedback from parents, that the student's home environment is often busy and chaotic, making more complex communication systems difficult to manage. Therefore they prefer specific ALDs for home activities. For example, an individual ALD for bedtime, bath time, mealtime, story time, and play time. Parents can use these systems easily to model language used in their interactions with their child, as well as expanding on communication attempts from the child.

Additional benefits of using ALDs in both the home and school environments are:

- Consistency in the use of symbols, that is, the same symbols are used to represent specific areas of the school curriculum;
- Consistency in the way symbols are taught throughout the school;
- Symbols are taught in relevant functional settings rather than in isolation;
- Students see their system of communication used interactively by other people to communicate a range of real messages in real situations;
- Students have their messages expanded by other people, using their system of communication;
- Consistency in the way communication is modelled. It is well documented that children learn to communicate in the way that they experience their system of communication used;
- Students can experience a consistent approach to language exposure across the curriculum (e.g. in library, art, music, mealtime, English);
- Ease of use in the busy home environment.

Summary

Aided Language Displays can be a good adjunct to other AAC systems in school settings for students who have a range of communication, cognitive, and sensory abilities. Students in classes that have peers with mixed abilities, and minimal support staff, can continue to have functional communication modelled to them in a consistent manner.

Having a user friendly system accessible to the students and their teachers, families, and assistants result in an increased use of the system by all, therefore allowing the student to meaningfully interact with not only the curriculum but also their home and school communities.

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Creating Cultures of Intensive Interaction in Australasian Special Schools

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This article gives an overview of an approach to working with students who experience profound intellectual and multiple disabilities (PIMD), which is attracting the attention of an increasing number of special educators, as well as adult services in Australia and New Zealand. Because of the range of staff who use this approach (e.g. teachers, classroom support workers and assistants, therapists, workers in adult services) the term practitioner will be used throughout this article. Also in the article is an outline of measures used in a number of schools to promote cultures of professional reflection and discussion, which is contributing to improved learning outcomes for this challenging group of learners.

Intensive Interaction: Background

Intensive Interaction was developed in the UK in the 1980's as an approach to working with learners of all ages, who are at the very earliest stages of communication, and those who might be described as hard to reach. The approach is used with learners who are not communicating with intent; who take no meaning from symbols, signs, words, or any other formal method of communication, many of whom spend prolonged periods of time involved in repetitive, or self oriented, cycles of behaviour. Since the first publication of *Access to Communication* by Dr Dave Hewett and Dr Melanie Nind, a growing number of books and peer reviewed research articles on the use of the approach have contributed to developing a breadth of insight into the effectiveness of the approach (e.g., Nind, 1996; Nind & Hewett, 1994, 2001, 2006; Nind & Powell, 1996; Kellett & Nind, 2003; Barber, 2007).

The aims of Intensive Interaction include developing:

- cognitive abilities including social cause and effect and predicting and exploring the behaviour of others;
- fundamental communication abilities including eye contact, facial expression, turn taking, and engagement; and
- sociability, including the desire and ability to be with others, taking part in and initiating social contact, and understanding the ways in which social encounters can be enjoyable.

Intensive Interaction is characterised as a naturalistic approach to promoting communication which focuses the practitioners' attention on what the learner can do rather than on perceived deficits. It is not a behavioural intervention with a focus on decreasing targeted behaviours; rather, it seeks to promote communication. As one of what have become known as the Interactive Approaches (Collis & Lacey, 1996), Intensive

Interaction focuses on the understanding that "the quality of a learner's attention is substantially greater when focussed on events of their own choosing, than to events chosen by someone else" (Warren & Yoder, 1998).

Intensive Interaction is an approach that uses behaviours that the learner will recognise as their own in order to develop a two-way dialogue, through which fundamental communication skills and enjoyment of social interaction can be learnt. In essence, the approach harnesses features that are seen as crucial and inherent in the interactions between caregivers and typically developing infants, although it recognises that the learner has the experience and established preferences that are associated with more mature learners. Practitioners of Intensive Interaction emphasize the importance of learning about being a communicative agent, and they propose a style of interactive teaching based on the skilled partner taking the lead from the learner, rather than the learner being led by the skilled partner. One of the tenants of the approach is that no matter how idiosyncratic the behaviour, it needs to be interpreted as having potential for interaction (Nind & Powell, 2000).

“**Intensive Interaction is characterised as a naturalistic approach to promoting communication which focuses the practitioners' attention on what the learner can do rather than on perceived deficits.**”

Starting to use Intensive Interaction involves an initial period of observation to identify the student's preferred sensory foci and attentional inclinations. The observations become the reference point for practitioners' initial attempts to engage the learner's attention. Where learners are routinely focussed on repetitive, self-oriented or ritualistic behaviours, the practitioner might join in with them. Alternately, the practitioner might suggest an interaction to a sentient learner, based on characteristic mannerisms, movements, or sounds that were noted during their observations. Once the learner's attention is engaged, the practitioner uses a palette of non-directive responses or intrigues to support an open ended interaction.



Creating Cultures of Intensive Interaction ... (cont)

As interactions progress, the learner begins to experiment with a range of contributions to investigate the responsiveness or apparent rules of the game. The practitioner responds using topics or conversational openers closely related to what the learner does, to open up communicative possibilities for the learner to explore, if they so choose. In this way, communicative routes (e.g. turn taking, reciprocity, anticipation, imitation, social prediction) are investigated allowing mutually responsive dialogues to evolve within the repertoires or the sensory language that the learner recognises as their own.

Within conventional teaching approaches for many learners with severe-profound intellectual disabilities and autistic spectrum disorders, much of their experience of communication involves responding to directions, or requests for compliance. Many teachers report that the majority of their interactions with high needs learners involve them in responding to (their interpretations of) student expressions of needs, and communicative exchanges which might be generalised as functional and finite. Intensive Interaction opens up the communicative arenas of joint attention and social interaction, which, while being acknowledged to be of equal importance to the development of communication as the more universally addressed request function (e.g. Bruner, 1981; Bates, 1979) are all too frequently absent in classroom interventions (Light, Parsons, & Dragar, 2002).

Challenges to Implementing Intensive Interaction in School Contexts

Profound levels of intellectual disability catastrophically disrupt the learners' understanding of the events they are experiencing. This often occurs to the point where the learner demonstrates insurmountable difficulty in achieving what are, for typically developing learners, the most automatic intellectual separations. For many learners, separating the presence of their teacher from the other competing, ambient, and pervasive sensory events which simultaneously compete for their attention, is an overwhelming challenge. Unless the activity or sensory focus is already coded or recognized by the learner, the vast majority of conventional teaching activities, or indeed group lessons, become apparently random sequences of confusing experiences for the learner. Indeed it could be said that, for the many learners who have few means of challenging, controlling or changing the experience, they frequently freefall through the events of the lesson as it engulfs them. Learners with these complex and interacting disabilities do not necessarily learn what is being taught, but acquire further experience of passive recipients and learned helplessness as they are physically prompted through tasks of whose purpose is obscure and, all too often, totally unrelated to their perception of the world. At these levels of learning, both selecting meaningful learning outcomes from an arbitrary hierarchy of skills, as well as measuring performances with a criterion of success, might be judged as somewhat unrealistic.

The challenge for special educators using Intensive Interaction is to reconcile the perceived tensions between the dominant culture in Australasia, of prescriptive and predictive objectives-led-curricula, with a learner-centred style of teaching and promoting communicative involvement. It is certainly not controversial to state that for learners with PIMD there are no existing standardised tests available for a valid estimation of their intellectual capacity (IASSID). Neither is it controversial to suggest that, for many of these learners, their presence on curriculum hierarchies is frequently based on their physical presence in the activity rather than their active involvement in it.

The first hurdle to be overcome for improving education for these learners relates to the practice of writing predictive targets for pre-intentional learners. This culture leads to framing our strategies on the basis of what we want rather than how the learner senses and perceives their world (Collis & Lacey, 1996). Indeed, it could be argued that objectives that make specific behavioural predictions about the learning progress of a student whose interactions with the environment are at a preintentional level, are largely wish lists. While meaningful progress can be monitored and recorded, it cannot be predicted, and while drilling these learners, through series of actions, might produce increased compliance or physical performance of patterns of action, it does not produce understanding, cognitive gains, or learning.

Intensive Interaction and other Interactive Approaches (Collis & Lacey, 1996) present a rationale for teaching which challenges the dominant behaviourist culture which seeks to fix perceived deficits. Although the need for collecting evidence and rigor in teaching is recognised, the Interactive Approaches re-orientate practitioner's attention from focusing on what learners cannot do, to giving them more control over what they can do.

Professional Development in Intensive Interaction: A Process Focus

Best practice in Intensive Interaction requires practitioner reflection and the recording of interactions. This section describes a process in development focusing on practitioner reflection.

Beginning in 2004 at Bayside Special Developmental School, Moorabbin Victoria, a culture of professional reflection and a process of group moderation of progress has been developing. More recently, the initiative has spread to several other schools: Arohanui School, Auckland, NZ; Patricia Avenue School, Hamilton, NZ; St Anne's Special School, SA; St Patrick's Special School, SA; and Kilparrin Services SA.

The purpose of this initiative has been to:

1. develop a culture of robust reporting on the communication development of learners by reaching inter-observer agreement about evidence of changes in levels of communicative involvement,



Creating Cultures of Intensive Interaction ... (cont)

2. provide an arena for teachers and support workers to reflect on their use of the particular communication skills developed when using Intensive Interaction, and
3. continue this development through professional collegiate practices.

Robust Reporting

Video footage of students and practitioners involved in Intensive Interaction is regularly filmed during the school year. This becomes a resource to enable professional discussion about progress demonstrated by the student across the reporting period. The video can also be assembled as a digital portfolio or record of the learner's school life, for parents.

The initiative involves the formation of a group of involved practitioners at each school. The group commits to meeting on a regular basis for discussion. At the beginning of the recording period a process of moderation begins for establishing the levels of communicative involvement that the learner demonstrates initially. This moderation process follows a set format. Firstly, a piece of video (chosen by the staff member) is shown of a learner and staff member engaged in Intensive Interaction, in which the student is judged to be at the top of their game. The group then engage in discussion about the nature of the involvement that the learner demonstrates. The frame of reference used to make these statements is the document Framework for Recognizing Achievement which underpins the P Levels in England's QCA Planning, Teaching and Assessing the Curriculum for Pupils with Learning Difficulties. Discussion, and eventual agreement, allows the group to arrive at a descriptive statement based on the Framework's levels, which characterises the student's level of communicative involvement.

This moderated statement is then used by the practitioner to write open ended goal statements describing the supportive contributions that they currently use in interactions, the manner in which interactions typically take shape, and the types of settings (i.e. curriculum areas) in which interactions will occur.

Throughout the year, teachers record brief narrative notes on interactions, sketching out or describing new developments, contributions, emerging responses, the appearance of new initiations, as well as emerging trends in interactions. These notes contribute further evidence of the processes in development during Intensive Interaction, but also, importantly, inform the mid and end of year reporting process.

At the end of the reporting cycle, another recent video is shown, and the process is repeated.

Progress across the year is agreed through comparison of video footage and the moderated statements. Evidence of progress is subjected to a robust discussion, occasionally requiring more

video evidence to be collected. These discussions prove to be crucial for the development of a shared understanding of the process of communication and for developing a common language to describe the learning taking place. Central to the reporting process is the recognition that horizontal progress is just as important as vertical progress.

Through collegiate practice and agreement, a much more robust level of reporting and recognition of progress is achieved than when conventional criterion of success is used. No longer is the criterion of success a matter for the opinion of a single practitioner; it becomes an agreed position taken by a collegiate body or community of practitioners. More importantly, this process does not attempt to report on the performance of a skill, rather on the involvement in a process.

Developing Professional Reflection

The second part of the initiative involves staff coming together for a process of professional reflection and feedback from their peers about their own interactive skills. This process occurs in a bi-weekly rhythm of in-house professional development. This has become an intrinsic part of the professional culture of the schools committed to developing their use of Intensive Interaction.



The processes also promote professional support networks and a shared ownership of educational endeavours.



Using protocols adapted from the Australian National Schools Network, and the Intensive Interaction Reflection Tool (Williamson and Barber, 2006, in Barber, 2007), the video footage provides a resource for structured and collegiate reflection and discussion about the skills of practitioners. At meetings, staff select video showing themselves involved in an interactive encounter and invite discussion with their professional colleagues about features of the video they present. The format of the feedback, and indeed the entire reflective process, is governed by protocols that both support the video presenter and ensure that all of the group contribute to the process. The process results in a range of warm and cool feedback being given to the practitioner by their peers. The feedback is always given in a style which affirms good practice, while facilitating further reflection and contributing to the continual process of improved pedagogy.

The establishment of these protocols has contributed to a continual process of development of knowledge of Intensive Interaction, but also regularly provides increased insights into the experience of consciousness of our students. This is of



Creating Cultures of Intensive Interaction ... (cont)

vital importance when assisting learners with these levels of intellectual disability, and those whose perceptions of the world are disrupted by autistic spectrum disorders, to learn.

Conclusion

Both of these collegiate processes have the effect of opening the classroom door to collegiate learning for teachers whose practice has frequently been isolated from all but a small classroom team. The processes also promote professional support networks and a shared ownership of educational endeavours. Furthermore, the processes have contributed to more consistent responses to individual students on an informal basis as encounters occur across the school campus. Most importantly, students begin to notice that other people begin to speak their language.

Ultimately, Intensive Interaction and the processes that have been established to sustain it, advance improvement in student learning outcomes, facilitate improved understanding, and contribute to improved quality of life.

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Growing a Culture of Communication: the Communication Coordinator Network

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This paper was presented at the Australasian Society for the Study of Intellectual Disability (ASSID) Disability Support Worker Conference in 2007.

Dr. Barbara Solarsh is the Speech Pathologist in the Southern Loddon Mallee, Regional Communication Service. This is part of the Victorian Speech Therapy Initiative, which is a hub and spoke model, delivering speech pathology services to adults with complex communication needs in Victoria. There are eleven Regional Communication Services across Victoria.

Dr. Solarsh has established a network of nine trained Communication Coordinators (one in each day service) who have the role of creating a culture of communication within their disability services. The Communication Coordinator network in the Southern Loddon Mallee region of Victoria is an example of an innovative service delivery model.

This is a demonstration of AAC in education in three ways:

- 1) Disability support workers gaining knowledge and skills to become Communication Coordinators in the day services in which they work,*
- 2) Communication Coordinators sharing skills and offering communication support to other support workers in their services, and*
- 3) Communication coordinators presenting the model to other disability professionals at a valued and recognised conference.*

Communication, like the air we breathe, is essential for life. The air we breathe surrounds us wherever we are. Similarly, communication occurs wherever we are, irrespective of the time of day, the function we are performing, the people we are with, the state of our health, or our ability to communicate verbally. We all need to be able to communicate effectively, just as we all need air in order to survive.

For people with little or no speech, there are a wide range of options which could facilitate effective communication. We may interpret the person's gestures or behaviours, use object or picture-based symbols, use signing and gesture, and voice output devices of various levels of complexity may be used. In order for these communication options to enhance quality of life for people with little or no speech, they need to be a part of every communication event that may occur.

When this happens, we will have grown a *culture of communication* for people with little or no speech.

However, achieving this provides us with enormous challenges. These challenges include ensuring that all communication partners:

1. value communication as a human right
2. understand how critical communication is to each person's humanity
3. feel confident in their own skills as effective communicators
4. recognize the power of each communication aid, no matter how simple
5. recognize the importance of independent communication (even when we think we *know* what the person wants to say)
6. appreciate the empowerment provided by each successful communication event.

If we can meet these challenges our tasks in Person Centred Planning and Life Planning will translate into lifestyles that people really want. With it will come enormous satisfaction for the individuals with whom we work, as well as for us as service providers.

The Communication Coordinator Network, Loddon Mallee is a positive response to meeting the challenges posed above. The primary task of the nine Communication Coordinators is to create a culture of communication within their disability day services. They are support workers who embody the six qualities above, and who have become agents for growing a culture of communication within their services.

The Communication Coordinator Network offers a capacity development strategy for embedding communication skills in the day services. It:

- Makes effective use of the limited number of speech pathologists,
- Delivers services to a greater number of people,
- Delivers services over a wide geographical area,
- Makes use of local service providers who are trained as communication coordinators,
- Enables services, and the people who use them, to access the Communication Coordinators' knowledge and skills,
- Enables people with a communication disability, staff, and families to take greater responsibility for successful communication,
- Is more than a speech pathology services or a consultancy model, and



Growing a Culture of Communication ... (cont)

- Is capacity development and a systemic approach.

The day services, the Regional Communication Service, and the Communication Coordinators make a commitment to the training program and follow-up meetings. Participation involves:

- The release of Communication Coordinators for 6 days of training,
- Attendance of Communication Coordinators at four Network meetings per year,
- Commitment by Communication Coordinators' services to release communication coordinators for dedicated communication hours, and
- Commitment by the Regional Communication Service for ongoing support and training of current communication coordinator.

The Communication Coordinator has knowledge and understanding about communication and its importance for maximising quality of life for people with Complex Communication Needs. They display an attitude towards people with Complex Communication Needs that recognizes that everyone has the potential to communicate. Table 1 shows many of the roles and functions required of Communication Coordinators.

Table 1: Roles, skills, and functions of Communication Coordinators.

- Skills to analyse the different levels of communication including use of the Triple C (Checklist of Communication Competencies)
- Collaborate with a speech pathologist or other staff to identify, prioritize, and implement appropriate intervention strategies for each level
- Skills to design communication aids for people who have limited verbal communication
- Monitor, review, and when necessary, make changes to communication strategies for a client
- Awareness that sensory interventions may be applicable and have knowledge of how to refer for further support around such interventions
- Basic knowledge of Makaton signing
- An understanding of the range of non-electronic communication aids that may be suitable for people with Complex Communication Needs
- An understanding of basic electronic communication aids and how to access further information about them
- Skills and knowledge to implement communication strategies for individuals within community settings
- Foster a spirit of understanding between clients who are verbal and those who are not verbal
- Develop an approach to recording activities and report writing

- The skills to coordinate a *whole of service* communication strategy so that communication strategies are consistently implemented in all components of the service
- Acknowledge the importance of developing one's own computer skills and proficiency with Boardmaker so that these skills may be passed on to other staff members where relevant
- Skills and knowledge to develop a communication support plan which may include the development of a multimodal communication system, and to foster these skills in other support workers
- Skills in supporting developing a strategy for an integrated approach to communication in a range of settings and environments, including day services and residential services
- Skills and knowledge to be a resource to other support workers in the development of communication plans and the development of communication aids
- Skills and knowledge to coordinate and deliver training within the services, and to support staff to be confident communicators
- Acknowledge the importance of being an active member of the Communication Coordinator Network
- Have an understanding of the *scope of practice* of the communication coordinator in relation to the speech pathologist.

A recent survey of day service managers and CEOs has indicated a very positive attitude to the importance of communication and the valuable contribution that Communication Coordinators are making to people who attend the services.

For more information about the Communication Coordinator Network and other activities of the Southern Loddon Mallee, Regional Communication Service, please contact Barbara Solarsh.

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Would you like to submit an article
for
the next AGOSCI
In Focus?

Contact Emily Armstrong
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or Sheridan Forster
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Educating South Australians About CCN and AAC

Janelle Sampson

janelle.sampson@novita.org.au

The Statewide Complex Communication Needs (SCCN) Project is a South Australian Government funded initiative. The objectives of the project are not only to assess and prescribe communication equipment, but to also develop a range of additional services that meet the needs of people with complex communication needs (CCN) in South Australia. In line with the philosophy of Novita Children's Services, the project plan is based on the *Life Needs Model* developed by King et. al. (2002). The services provided by the SCCN Project, and the allocation of time for each team member is spread across the three spheres of the Life Needs Model: personal, interpersonal, and external.

The external sphere of the Life Needs Model addresses the community's needs for information and education. Services in this sphere aim to: (i) foster positive attitudes, (ii) reduce environmental restrictions, (iii) encourage availability of programs and services in the community, and (iv) foster policies and legislation that support people with disabilities (King et al. 2002).

Within the SCCN Project, activities focused on the external sphere have included advertisement in community newspapers, information sessions to student groups, presentation of a WEA (Adult Learning Centre) evening course, and representation at community awareness events (e.g. National Aphasia Day, Special Education Expo).

For people with CCN, there are many barriers to participation that exist within this external sphere. Many of the barriers noted in the *Participation Model* by Beukelman and Mirenda (1998) are related to opportunities, or the lack of, provided by the individual's environment and/or communication partners. These specifically include policy, practice, attitude, knowledge, and skill barriers. An increased public awareness of the nature of communication challenges and strategies that enhance communication is aimed at reducing these barriers. Evidence of the impact of this approach has been noted in feedback comments from the sessions we have conducted to date. As an example, the WEA course was successful in reaching those in the community who had no, or minimal exposure, to augmentative and alternative communication (AAC) strategies in the past. The majority of registrants learned of the course through the WEA calendar, which is distributed to every resident of metropolitan Adelaide, and included people with just a general interest, parents, spouses, teachers, nursing home employees, a disability studies student, and an instructor of the riding for the disabled program. Feedback from this course included comments such as "I learned of resources, ways of interacting, and how to 'begin'". In addition, one participant offered to work

as a volunteer for the project, and another requested training sessions for care support staff within their organisation.

Representation at events such as the National Aphasia Day, *Wednesday Without Words* and the Special Education Expo has also led to an increased awareness by attendees of AAC strategies and resources available. Many attendees have requested further information or copies of resources, and numerous therapists have subsequently referred clients to our service for development or review of their AAC system.

An additional outcome of participating in these public awareness activities has been the opportunity to inform some people that solutions and services to support people with communication challenges actually exist. 'Drumming up business' has not been necessary, given the overwhelming response to the project, but we have been surprised at the large number of people accessing these public awareness activities who were not aware of AAC strategies. The result of an advertisement in the community newspapers was an especially high number of information and advice calls regarding services available or communication options. There are also currently 486 people registered on the SCCN mailing list who receive information on upcoming education and training sessions. Some information and advice enquiries from have required only a simple strategy or suggestion, and others have led to a full referral to our communication solutions service. This important outcome of being able to provide information and support to those within the community who didn't know that such communication solutions existed, has been one of the significant rewards for the SCCN Project team.

As many of you are aware, it is often difficult to prioritise these types of activities within existing programs given the emphasis on 1:1 assessment and intervention services (personal sphere of Life Needs Model). Although this is also the case for the SCCN Project team, we acknowledge the vision and advocacy of those who developed the original project proposal that incorporates outcomes related to the external sphere of life within the project brief. With this direction, the SCCN Project plan has allowed for allocation of specific time to these much needed public awareness initiatives. Each team member is allocated roles and responsibilities across all 3 spheres of the Life Needs Model, and places equal value on the services we provide at the level of the interpersonal and external sphere for people with CCN. People with CCN and families who have been involved in these activities also support and value them. We believe that for every hour spent in service delivery at these levels, there are wider reaching outcomes and increases to efficiency for services within the personal sphere. These outcomes and



Educating South Australians About CCN and AAC (cont)

efficiencies may not be immediate or directly obvious, but over time less opportunity barriers should lead to increased participation for people with CCN. This is the overarching aim of the SCCN Project. There is still a very long way to go but every little step makes a difference to at least one person and that is a very worthwhile outcome.

For more information on the SCCN Project, see AGOSCI In Focus, May 2008.

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Augmentative and Alternative Communication in Malaysia

Susheel Joginder Singh

susheel_29@yahoo.com

My name is Susheel. I am a speech pathologist from Malaysia. I graduated in 2007 and worked as a speech pathologist for a year in Malaysia. I have now come to Australia to pursue postgraduate education in communication problems in children with cerebral palsy.

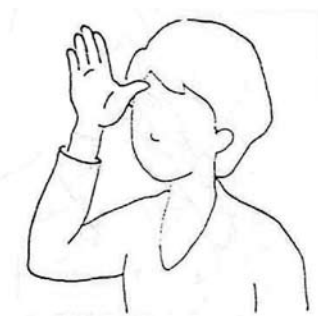
Speech therapy is a relatively new field in Malaysia. It has now been around for about two decades, with the majority of speech pathologists (SPs) working in public and private hospitals. Other SPs provide services at centres for people with disabilities or in private practice. Being a relatively new field, limited research has been carried out in Malaysia in the area of speech pathology. In the past few years, more research is being conducted on different aspects of speech, language, and communication, however, there have been few published articles related to Augmentative and Alternative Communication (AAC) in Malaysia. This article will give an overview of AAC in Malaysia based on my own experience as a clinician and information from fellow SPs working in Malaysia.

There are several types of AAC that have been introduced to clients in Malaysia. The most common have been MAKATON, Picture Exchange Communication System (PECS), and Picture Communication System (PCS) in the form of books and boards. Many SPs are familiar with these forms of AAC and are comfortable using and recommending them to clients who are in need of alternative modes of communication.

Like elsewhere, AAC is introduced to many different populations ranging from children to adults. It is often used with children

with developmental disabilities such as autism and cerebral palsy, as well as those with speech language impairments. Adults who have acquired speech and language impairments due to aphasia, apraxia, or dysarthria, are also introduced to AAC. The SP carries out a series of assessments to determine if the individual needs AAC and then decides which form would benefit the client best. For some populations, especially people with hearing impairment, SPs have suggested the use of sign language (Bahasa Melayu Kod Tangan –BMKT) or cued speech, depending on the individual's schooling.

MAKATON in Malaysia appears to have used some signs from BMKT and incorporated some signs from other countries as well. For example, the sign for toilet is like pulling a high toilet chain (hence, quite different from Western signs for toilet), and mother and father are signed by spreading fingers and pointing thumbs to either the forehead (father) or chin (mother). Some other signs, such as for biscuit and apple, are signed similarly to the signs used in Australia.



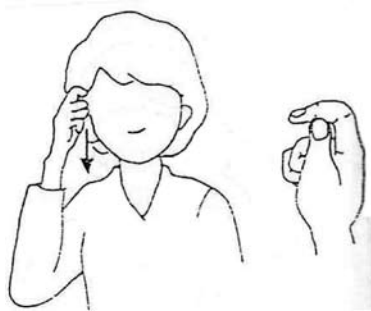
Father



Mother



Augmentative and Alternative Communication in Malaysia (cont)



Toilet

In my short time working as an SP, I have seen several successful cases of AAC being used. One was a child with autism who was progressing so well with PECS that he could produce sentences with it. Another was an adult patient who had made his PCS communication book a part of his life and used it to communicate efficiently. I have also seen MAKATON used by children to convey clear messages to others.

AAC, however, has a long way to go in Malaysia. There are several confounding factors to effective implementation of AAC. One of the major problems faced by SPs working with individuals who require AAC is lack of knowledge and resources. Most SPs are familiar with some forms of AAC but are lacking in knowledge and experience about other forms. In my experience, MAKATON, PCS, and PECS are the only three forms of AAC that I have seen used in Malaysia. The use of more advanced high technological devices, such as those with voice output, is not common. The main factor that is confounding the use of such devices is the lack of training for SPs in these devices. Besides that, the lack of exposure to the different types of AAC, be they aided or unaided, also contributes to SPs staying with those they are familiar with. A SP friend working in a hospital once asked me if I knew what a Lightwriter was. I asked her why she wanted to know. She said that she had been working with children with severe Autism and wanted to find out more about the different forms of AAC for them. She had been using PECS with most of the children, but felt the need to explore other options. However, she didn't know where to look for advice and guidance. She is certainly not the only therapist faced with this dilemma. There are many other SPs in the same boat as her: all seeking information but not knowing where and who to get this information from.

Another daunting task faced by the SP is encouraging caregivers to consider using AAC. Many parents find it difficult to consider that their child may not talk. The thought of having to carry a communication book around wherever the child goes does not seem very appealing to them. Many parents feel that in going to a SP, their child should be able to start speaking. Parents feel that once they accept a certain form of AAC, it would mean that the child is doomed to a non-verbal life. This is a scary thought for most caregivers, especially parents whose children are very young. In such situations, SPs play an important role in convincing parents that AAC is not necessarily the

end of speech, but can aid in the development of speech and communication. Sometimes parents may accept the suggestion of AAC for their child, but they may, for many reasons, be reluctant to encourage its use in the home.

Steps are currently being taken to improve AAC use in Malaysia. More hospitals are starting to get high tech AAC devices and hoping to train SPs to be proficient in using them. The main factor limiting use of high-tech devices is the cost of the device. Most high-tech AAC devices are very expensive and families aren't able to afford them. Some private organizations that work with individuals with special needs have been able to support families to have high-tech devices for their children. Workshops are also being held about different types of communication devices. Both parents and SLPs are encouraged to attend these workshops to improve their understanding and increase awareness.

While this is a good start to the development of AAC many other steps can be taken. A particular area of need is improving SP networks and knowledge of AAC. Recently, in a web-search, I found out about Malaysian Information Network on Augmentative and Alternative Communication (MINAAC). Increasing awareness of such groups would certainly be beneficial, and I look forward to finding out more about the organization when I return to Malaysia. SPs need these forums for discussing concerns regarding supporting people to use AAC, sharing knowledge, and learning about new systems and approaches for people with communication impairments.

Furthermore, I think it would be good to compile a collection of locally made videos of successful AAC users to serve as a form of inspiration for parents. They would see how AAC has been successfully used by other people with communication impairments. They might then be more willing to consider AAC and be more motivated to implement the system suggested to them if they have seen it used successfully by someone in Malaysia itself.

Enhancing AAC in Malaysia would also include improving practices in the assessment and provision of AAC. Best practice in AAC provision highlights the value of assessment being conducted by interdisciplinary teams that include the individual and their family in decision-making. Such inclusive practices may assist families in being active contributors to the AAC learning processes.

Speech pathology has a long way to go in Malaysia. With improved healthcare systems, more people are becoming aware of therapy and the role of therapists in helping individuals with communication problems. It will, however, take more time for AAC to be accepted as a part of speech therapy in Malaysia.

Images used with permission from Ms. Khor Ai-Na, Executive Director of the Asia Community Service, trainer of Makaton in Malaysia.



AAC Education in Australian Universities

This is a snapshot of AAC education in four Australian Universities.

For information on Speech Pathology Accredited University courses, go to www.speechpathologyaustralia.org.au.

We would like to know more about the AAC education provided to students in Australian universities.

Please contact: Naomi Commons, Ncommons.crc@scopevic.org.au, 03 9843 2010

Victoria

Latrobe University, Bundoora

The Faculty of Health Sciences, School of Human Communication Sciences offers Bachelor of Speech Pathology, Bachelor of Speech Pathology (Hons) and Masters of Speech Pathology. AAC is a five credit point course for 3rd year speech pathology students. Students attend one 2-hour lecture per week. Lecture notes are also available on WebCT.

This course introduces students to a variety of augmentative and alternative communication (AAC) strategies for people with developmental, acquired and progressive disabilities. Students learn about the procedures involved in the selection and application of AAC for people with complex communication needs.

Assessment includes one group report of an interview with a person who uses AAC, one group assignment focusing on appropriate vocabulary selection for an AAC strategy and one problem solving assignment.

This course in its current form will be offered until 2010 when the transition from a 4 year degree in Human Communication Sciences will be made towards an undergraduate degree in Health Sciences and specialisation into Speech Pathology at a master's entry level.

Thankyou to Karen Bloomberg and Hilary Johnson for providing some of this information.

New South Wales

Charles Sturt University, Albury

The School of Community Health offers Bachelor of Health Sciences (Speech Pathology).

Students are given a range of experiences in 2nd, 3rd and 4th years of the course to ensure they have a broad understanding of complex communication needs and AAC.

2nd Year - AAC is covered in the Disability and Lifelong Communication subject –

Semester 1

- **Parents as tutors program**

Groups of students (4-5 per group) spend time with a family of a child with a disability. Usually the child will have profound and multiple disabilities or serious life threatening illness. The students receive insight into the family's perspective of what life is like when a child has a complex disability and the challenges they face.

Semester 2

- **Lecture content:** This includes WHO classifications of disability types, the participation model, assessment and strategies, including AAC.
- **Practical experience** is a 2 day site visit to Specialist Service in NSW, Victoria, Canberra or Hobart eg. ComTECH or Spastic

Society. Students also visit local services in the Albury-Wodonga region

3rd Year –AAC is covered in a number of their Clinical Experiences

Students are asked to build on the theory they have developed in second year through diverse practical experiences in the third year of their course.

They are encouraged to reflect on their own attitudes and about the language and terminology they use in relation to people with complex communication needs and who may use AAC as we feel this is an important 'first step' for students developing confidence and skills in using AAC. There is a focus on the life experience of people with a disability. This enables students to reflect on their own examples and personal experiences when they learn the theory of assessment and intervention.

Clients as Tutors

- Students spend time with an adult with a disability to find out about the person's individual journey. Many of the tutors use AAC resources for some/all of their interactions in community.

Community Partnership Projects

- Coolinda Partnership:** Students work with local clinicians and families of children with Down Syndrome – in homes or school environments. Many of these families are using elements of AAC to support communication in one or more contexts.
- Learning Exchange:** Students do a 13 week 'Learning Exchange' with a local service for people with a disability. Services include early intervention, community based day services for adults and residential services for adults. Students are assigned a client to work with over 1 semester. Students must assess the functional needs of the person and develop 1 AAC strategy (low technology) through consultation with the client and all significant others. Typically the clients are "difficult to assess" and significant problem solving and skill is required of the student.

Thank you to Sarah Nicolson for this information.

University of Sydney, Lidcome

The Discipline of Speech Pathology offers Bachelor of Applied Science (Speech Pathology) and Masters of Speech Language Pathology.

Students enrolled in the undergraduate and Masters level program at the University of Sydney learn to work with people with complex communication needs through a combination of applied theory and clinical practice. Starting in their first year, students work through real life case studies involving clients with a range of communication difficulties associated with physical and intellectual disability including clients with cerebral palsy,



AAC Education in Australian Universities (cont)

Down syndrome, and autism. This represents a departure from the traditional model of teaching characterised by the delivery of a series of topic based lectures. Although content relating to working with people who use AAC is infused across the curriculum, with the intention of supporting students to develop generic attributes and competencies, it also forms the basis of a dedicated subject. In this subject, students work through multi-disciplinary case studies generated through collaborations with the Spastic Centre and other organisations. The case study materials are discussed in lectures and released gradually to the students via an online learning system. Students are also lectured by experts who themselves have lifelong disabilities and complex communication needs. Flexible learning is encouraged, with all core lectures recorded for students to review following class.

Students have the opportunity to further develop and apply their skills in working with people who use AAC through a range of clinical placements. These include the opportunity for undergraduate students to undertake a three week inter-professional clinical placement at the Indian Institute of Cerebral Palsy, and for masters level students to complete a three week inter-professional clinical placement in Ghana each year. The need to ensure that all students gain experience in working with clients who have complex communication needs is now identified as a priority at the University.

In addition to the clinical program, students have the opportunity to complete advanced studies in the area of lifelong disability during their final year of study and the opportunity to undertake honours research with staff who specialise in the in the field of

lifelong disability and AAC. The University also offers postgraduate study in the field of disability including a masters by coursework program, a masters by research program, a graduate diploma in developmental disability, and a PhD program.

Thankyou to David Trembath for providing this information.

Western Australia

Curtin University of Technology, Perth

Human Communication Science, School of Psychology, Faculty of Health Sciences offers Bachelor of Science (Human Communication Sciences) and Master of Science (Speech Pathology).

The students are provided with 9 hours of lectures on AAC including introduction, assessment, system design and strategies for implementation, covering all ages across the lifespan from early intervention to adult for both developmental and acquired communication disorders. Students also receive 3 hours of lectures on Makaton. We invite guest speakers in to present on these topics who have specialist knowledge and skills in AAC use.

Students enrolled in our Human Communication Science degree at both an undergraduate and post graduate entry level Masters program receive the lectures. Learning is generally didactic and case based. Students are also required to complete a case based assignment on AAC which requires them to develop an appropriate AAC system.

Thankyou to Amanda Bolton for providing this information.

AAC Research in Australia

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

Researchers: Project name:	Main aims:
Phil Foreman, Michael Arthur-Kelly (Michael.Arthur-Kelly@newcastle.edu.au), & Deone Bennett The University of Newcastle	
Partner Training and Communication Outcomes for Students with Multiple and Severe Disabilities	We are investigating the impact of a program of mentor-modelled professional development on the observed behaviour states of students with multiple and severe disability and the reported and observed changes, if any, in teachers and aides who interact with these students. Using a multiple baseline design we plan to implement the program first in special schools then replicate it in inclusive situations.
Hilary Johnson (H.Johnson@latrobe.edu.au) La Trobe University	
Communication in the Social Networks of Adults with a Severe Intellectual Disabilities	The aim is to examine the process of communication between adults with a severe intellectual disability and members of their social network. The data will be collected through participant observation and interviews. Data will be analysed using a grounded theory approach and a model of the communication process will be developed.



AAC Research in Australia (cont)

Gwynnyth Llewellyn, Susan Balandin, & Angela Dew (a.dew@usyd.edu.au) The University of Sydney	
The Transition of Care from Ageing Parents: Achieving Flexible Relationships Between Adults with Cerebral Palsy, Their Siblings and Service Providers	To explore the relationships between people with severe CP aged 40 years and over and their nondisabled siblings in order to identify the support services required to facilitate the transition from parental to other care. To develop a model for achieving optimal relationships between the adults with severe CP, their siblings and service providers.
Sheridan Forster (sheridan.forster@med.monash.edu.au), & Teresa Iacono Centre for Developmental Disability Health Victoria, Monash University	
Interactions Between Disability Support Workers and Adults with Profound Intellectual and Multiple Disabilities	Adults with profound intellectual and multiple disabilities, who live in residential services, primary interaction partners are disability support workers. Despite the recognition that the interaction influences quality of life, little is known about what happens when these two people sit down together. The aim of this study is to investigate what happens in everyday interactions within this dyad. Coding of video recordings will be used to describe the nature of the interactions.
Pammi Raghavendra (parimala.raghavendra@novita.org.au), Alison Lane, Cathy Olsson, Tim Connell, & Rachael Virgo Novita Children's Services	
Participation Profile of Children With Physical Disabilities With and Without Complex Communication Needs: Association Between Social Networks, Communication, Activity Engagement and Time Use	The aim of this project is to develop detailed profiles of participation in daily activities and communication interaction of children with physical disabilities with and without complex communication needs and children without disabilities. The outcomes of the project will provide us with a better understanding of children's participation and the factors that influence participation of children with physical disabilities, especially children with CCN.
Abi Thirumanickam, Pammi Raghavendra (parimala.raghavendra@novita.org.au), & Cathy Olsson Flinders University & Novita Children's Services	
Participation Profiles of Primary School Children With and Without Physical Disabilities and Complex Communication Needs: The Relationships Between Communication Abilities, Social Networks and Involvement in Activities	The purpose of this study is to construct a comprehensive description of the participation and social network profiles of 6 – 9 year old children with physical disability and complex communication needs and compare it with their typically developing peers. The aim is also to determine the association between communication abilities, physical abilities, social networks and participation in activities outside school.
Pammi Raghavendra (parimala.raghavendra@novita.org.au), Sonya Murchland, David Hobbs, Breeanna Worthington-Eyre, & Prue Shiosaki Novita Children's Services	
Making Music Through Movement: The Efficacy of the Virtual Music Instrument (VMI) for Developing Early Communicative and Play Behaviours in Children with Severe and Multiple Disabilities	The Virtual Music Instrument (VMI) is an innovative musical software program developed at Bloorview Kids Rehab in Toronto, Canada. The VMI system creates an augmented environment that allows the simplest movements to be translated into music. The aim of this project is to study whether the consistent use of the VMI with children with severe and multiple disabilities has an impact on two key developmental areas – their play and communication.
Julie McMillan (julie.mcmillan@flinders.edu.au), Pammi Raghavendra, Cathy Olsson, & Margaret Lynch Flinders University, Novita Children's Services & Department of Education and Children's Services	
Professional Learning for School Personnel: Impact on Communication of Students with Severe Disabilities Using Speech Generating AAC Devices	This project aims to provide professional development in the use of SGDs for teachers and professional support staff in schools through the use of a collaborative team approach. Student communication skills are measured across phases, including generalisation in the home or community. In addition, support team self-assessment and the teaming approach to supporting students with CCN are investigated.



AAC Research in Australia (cont)

Ralf Schlosser (Ralf.schlosser@neu.edu), Jeff Sigafoos, Gunther Eysenbach, Pat Dowden, Pammi Raghavendra, Sarah Blackstone, & EdTECH NE University, Boston; Victoria University of Wellington, New Zealand; Univ. of Toronto; Univ. of Washington; Novita Children's Services ACN, California.	
EVIDAAC: A Database of Appraised Evidence in Augmentative and Alternative Communication.	The project aims to develop EVIDAAC, an accessible and usable database of appraised research evidence in AAC for practitioners of allied health, special educators, rehab. engineers and individuals using AAC. EVIDAAC will provide pre-filtered evidence by critically appraising studies of various research designs and systematic reviews. This will save time and reduce the skill-burden associated with having to appraise evidence.
Leigha Dark (leigha_dark@hotmail.com), Susan Balandin, Lindy Clemson, & Leanne Togher The University of Sydney	
The Experiences of Grief and Loss of Older Adults with Cerebral Palsy and Complex Communication Needs	Older age is often a time of loss and grief, particularly in terms of bereavement, changes in physical, cognitive and communicative abilities, and changes to accommodation arrangements, social networks and sources of support. At present there is little information on the types of loss experienced by older people with cerebral palsy and complex communication needs or the experiences of managing loss and working through grief. This qualitative study aims to explore experiences of grief and loss through in depth interviews and describe arising themes.
Natalie Berg (nber5765@mail.usyd.edu.au), Susan Balandin, Leanne Togher, & Roger Stancliffe The University of Sydney	
What's it Like to Live in a Nursing Home? Exploring the Experiences and Residential Preferences of People Under 65, Their Families and Nursing Home Staff	An increasing number of younger people with severe disabilities are utilising nursing home care due to a lack of accommodation options that support their high level care needs. Aims: To explore the experiences and accommodation preferences of younger people living in nursing homes, their families and nursing home staff who provide care. Recommendations will be made to assist government departments, policy makers and service providers in their attempts to move this group of younger people back into the community.
Liora Ballin (lbal6064@mail.usyd.edu.au), Susan Balandin, Leanne Togher, & Roger Stancliffe The University of Sydney	
Speech Generating Device (SGD) Mentoring with Adults Experienced in Using SGDs As Mentors To New Learners	Adults who use SGDs may be well placed to mentor others who are learning to use a new device. The aims of this research will be to develop, implement, and evaluate an SGD mentoring program with adults experienced in using SGDs as mentors to new learners. In the first phase of this research, qualitative methods will be employed to explore a) learning to use an SGD and b) how adults who use SGDs can be involved as mentors in an SGD mentoring program.
Teresa Iacono (Teresa.iacono@med.monash.edu.au) & Marnie Cameron Communication Resource Centre, Scope	
Speech Pathologists' Perceptions and Experiences of Augmentative and Alternative Communication in Early Childhood Intervention	The aim of this qualitative study was to explore speech pathologists' perceptions of AAC, and the extent of its use in early childhood services. We were particularly concerned with exploring the knowledge and application of best-practice in AAC within early childhood intervention, and barriers to its implementation.
Kate Anderson (kate.anderson@usyd.edu.au), Susan Balandin, Sally Clendon, & Bronwyn Hemsley The University of Sydney	
Friendship Experiences of Children Who Use Natural Speech with Peers Who Use AAC	In this small interview study we are investigating the friendships that develop between children who use natural speech and their peers who use AAC. Exploring both the barriers and benefits to these friendships may help to inform social inclusion programs for children with complex communication needs within the community.
David Trembath (D.Trembath@usyd.edu.au), Susan Balandin, Leanne Togher, & Roger Stancliffe The University of Sydney	
The Experiences of Volunteers Who Use Augmentative and Alternative Communication	Our aim is to explore the experiences of people who use AAC who act as volunteers in order to identify (a) their motivations for volunteering, (b) the benefits they receive through volunteering, (c) the barriers they face, and (d) strategies that individuals and organisations can use to promote and support volunteering amongst people who use AAC who want to volunteer.



Big Mouth Camp 2008

Charlene Cullen, Spectronics

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Faster than a speeding bullet. More powerful than a locomotive. Able to leap tall buildings in a single bound. Is it a bird? Is it a plane? No - and it's not even Superman. It's Kung Fu Panda! Yes, the theme for Big Mouth Camp 2008 was Superheroes.

The Big Mouth Camp has been running since 2003. It is a residential camp for school aged children using speech generating devices, and their families and carers. The primary aim of the camp is for the children using the devices to increase their device use, and become more competent communicators in a fun and relaxing atmosphere.

Heroes teleported themselves to Rawson Village on September 19th for five days of amazing activities, learning, and super-laughter. Thirteen families attended the camp this year including 23 parents, 13 children with disabilities, and 17 siblings. Approximately 25 staff including speech pathologists, occupational therapists, students, and teachers and assistants, came along to share their knowledge and skills with the children and their families.

During the morning sessions, children with electronic communication devices were divided into smaller working groups for some intensive therapy blocks provided by speech pathologists, occupational therapists, and students. Activities included designing a superhero logo, deciding on a superhero name and power, making Batmobiles and creating Camp Super Scrapbooks to showcase some of the camp highlights and memories.

The parents participated in information and training sessions about programming and vocabulary selection that were presented by therapists from Spectronics and the Cerebral Palsy Education Centre. Siblings were involved in their own recreational program that involved kite making, the ropes course, and braving the flying fox.

Melinda Smith joined the superhero ranks, and as always, was fantastic as the camp's "role model." She spoke to children

and parents about her personal journey using augmentative and alternative communication, and made a huge impact on everyone attending camp.

All parents, children, and therapists came together in the afternoons and were involved in a number of group activities that, this year, included making super-ted biscuits and slime, controlling Kung Fu Panda's mind, and launching rockets. Everyone thoroughly enjoyed competing for pointless points in the scavenger hunt and the opportunity to create a panda trap, as the superheroes banded together in an effort to fight for truth and justice. Then there was the Batmobile Racing, where many dads and kids showed their super strength and competitiveness in getting over the finish line.

During the evenings, super activities continued with divas dancing at the disco, a movie night, and the amazing final night concert. Creativity flowed into the captivating costumes, sensational scripts, and singing. Who ever would have thought that chocolate cake is the superhero solution to someone who has turned into gold?!? It was an "Incredible" night!

Many of us were reluctant to leave – and we look forward to Big Mouth 2009!

The Big Mouth Camp is auspiced by the Cerebral Palsy Education Centre. The 2008 Big Mouth Camp was funded by the Grosvenor Foundation and the Melbourne Welsh Church, and supported by Spectronics Inclusive Learning Technologies and the Communication Resource Centre (Scope). The Independent Living Centre, ComTEC, and the Aids and Equipment Program Electronic Communication Devices Scheme also loaned equipment, without which we couldn't have run the camp.

Congratulations to everyone who helped make the 2008 Big Mouth Camp such a memorable event and a BIG thank-you to all the volunteers and families without whom camp wouldn't be possible.



education for all





The Best Race of my Life – Inclusion at its Best

Marlena Katene

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Why aren't people with a disability included? Included in things properly like school classrooms or school sports. I believe all people with a disability should be included in ALL parts of school life. In the last month I have had a few dramas with my school. A school which is a mainstream one with an SEC attached to it. One excuse they have seemed to use has been they do not have the right amount of aide time and they think I get more than my fair share of the allocated time. They say they do not have enough resources. So the story I am about to tell you kind of shows what can happen with positive attitudes and no extra amount of teachers aide time.

I am not the fastest person alive but on the day of the race I really believed I would go ok. When I found out my school was having a sports carnival I decided I would sign up for the grade 10 girls 100 metre race. I thought it sounded great even though I knew the competition would be tough. I wasn't too worried though because for years I did this race at the annual sports day for people with a disability, held at Griffith university. I am pretty good at this race and a few others but I just wanted to do the one race. At least my mother thinks I am pretty good. She went and framed all my medals and ribbons. They take up one whole side of my bedroom wall. It reminds me of the scene on the movie "Meet the Fockers" where they have a wall of their sons achievements. I am proud of my wall of achievements but on this day I got something so much better: "Included".

As I lined up on the starting line I knew that I would not win the race. The girl beside me was a sports freak and was really, really good - she would probably win. This was ok though because I thought I still may be able to get a place. So we all started going up to the line and everybody got ready to race. I started to look towards the finish line.

On your marks I started to get nervous.
Get Set my body started shaking.
Go!

Now up to this point everything was ok, but this is what happened next.

After the teacher said get set, my body shook. This may be ok for all the other girls but for me it made the race a little bit harder. I have cerebral palsy (Athetosis) and am in a wheelchair. Then the starter gun went offBOOM.

Well that didn't help my movements one bit. I had taken my hand off my joystick and my body was half out of my chair. By the time I had sorted myself out and got off the line the rest of



the girls were half way down the field. How Embarrassing! To make it worse once I did get going my chair was a lot slower than I thought. I thought I blew it but what happened next was just beautiful. I finally got it together and then I heard someone say "Come on Marlena". A group of friends started cheering for me then some more people joined in, some people I didn't even know. They were cheering for me like I was coming first even though I was coming last. I wasn't used to coming last but I did not lose the race. As I crossed the line people congratulated me and were clapping. There is a line on "Meet the Fockers" that says "I didn't think they awarded ribbons for 7th place." Well guess what, they don't, or if they do I missed out on mine. No ribbons.....no medal..... but did I lose? No way. The sporty girl game up to me and said well done and they even gave my house a point because I entered the race. This was the race of my life. I was not put in a special race for the special people in a special wheelchair. There was nothing "SPECIAL" about me that day. Believe me, nothing at all.

Inclusion isn't always about extra aide time or extra pieces of equipment. I think inclusion is more about attitude and respect. I did not win my race but I did not lose it either, even though I came last. With the right attitude and respecting people are different, all people with a disability can be included in all parts of life.

Thanks, Marlena Katene.

I am 15 years old and have cerebral palsy. I have many ways to communicate. Those who know me well use Facilitated Communication to point to a word and alphabet board on my wheelchair tray. With others I use a colour code system to indicate words and spell. I also use a Dynavox 4 with voice output for some situations. I love email and chat rooms to keep in touch. I also have a website www.marlena.com.au. I would love to write as part of my career when I finish year 12. If anyone would like me to write my thoughts on certain subjects feel free to email me marlena_katene@hotmail.com. I believe writing articles for newsletters like AGOSCI In Focus will help me in achieving this goal.



DVD Reviews - More Signing Stuff

Darren Trentepohl

Discipline Senior in Speech Language Pathology

Disability Services Qld

If your Makaton Nursery Rhymes videos, made by the Variety Club of Tasmania, are wearing out, or wearing you out, then you might like to add a few others to your library that my team have found useful over the last few years.

The first is *Something Special*, a series put out by Makaton UK, featuring a local actor and his clown character. There are six in the series, featuring topics such as Where I Live, Out and About, Animals, and of course Nursery Rhymes. They include simple songs, stories, show and tell, and community access - so a lot like Play School really. They are gently paced, making it very suitable for young children with special needs, and for the age range 1-5. They are colourful and simple, clear and fun. They are, however, using British Sign Language, but I reckon there must be about 40-50% correlation with Auslan.

I have given it to a few client families to review, and they loved it heaps; none were too concerned about the lack of full sign compatibility. There are sections where children with special needs go into the community to reinforce the concepts learnt, which surprisingly did not include any use of the signs - at which I suggest to my families to use this opportunity to model the use of the Auslan signs to their kids. Feedback from families was that the kids loved the DVDs, and the parents appreciated the support of the Makaton culture in their home.

All are available from the Makaton UK website www.makaton.org, and are 17.99 English pounds each. Maybe there is an idea for an Australian entrepreneur to do similar?!?! ★★★★★



The second is our own *Wiggles in Hoop-Dee-Do it's a Wiggly Party*. Unfortunately it includes Greg, which may confuse some of the next generation, but the songs are cool and make it difficult to remain still in your seat. This is one of their standard commercially available videos, but has been modified to include Auslan signing in a box in the corner of the screen. So the weakness of this video is that it is not key word signing, which makes it difficult for most of our clients using Makaton to learn; however, client families who have borrowed this have commented it was good to see signing linked with a universally loved kid's product, and felt it again supported the Makaton culture of their home. Kids of all ages will love it, especially the 2-7 age range.

It is available, along with other Wiggles translated DVDs, from www.bilby.net for \$30. If I'm sacked, I'll be happy to be the next Wiggle. ★★★★★

PODD: Intensive Advanced Workshop

The first intensive advanced workshop teaching Pragmatic Organisation Dynamic Display (PODD) Communication Books will be held at the Cerebral Palsy Education Centre in Melbourne Monday July 6th until Friday July 10th 2009. Attendance at a 2 day workshop is a pre requisite.

This will be the only intensive advanced workshop held in Australia in 2009.

Keep a look out for more details in the next issue of AGOSCI In Focus. Please contact Gayle Porter at podd@cpec.com.au if you would like further information.



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 May 2009 issue is 'AGOSCI 2009 Conference: Feel the Power'. 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>

Article Submission

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

Contact Sheridan Forster:

sheridanf@yahoo.com

or Emily Armstrong:

emilyarmstrong.ea@gmail.com

and see www.agosci.org.au for more details.



Thanks to ACQ for permission to adapt their "notes to authors" guidelines. Go to www.acq.org.au for full details.



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COMMUNICATION – Feel the power

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The 2009 AGOSCI conference committee is definitely feeling the power!
The number, quality and diversity of papers submitted has surpassed our expectations.

We are proud to announce our keynote speakers:

- Gus Estrella
 - Nicola Grove
 - Gayle Porter
-
- Advocacy breakfast and panel
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**Want to know more?
See page 11 for more details**