

AGOSCI

in focus



This issue ...

Being a Good Communication Partner



J U N E 2 0 0 8

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!



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Front cover

My name is Katrina Zampech. I am 28 years old. I was born in Toowoomba and now I live in Oxley which is in Brisbane. I like to paint flowers on tables and butterflies. Clare Llewellyn has been a great art teacher for me.

I can't hear speech and I communicate with signing. If the people I meet don't know sign language I write words down for them and they write back to me.

Mum is my very best communication partner but my stepfather, step sister and my brother are pretty good too. I like art, working on the computer, reading, cooking and going on trips. If you ask me what makes a good communication partner I would say "patience".



Katrina Zampech

Disclaimer

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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 and news from overseas.

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editorial

This edition's theme took me back to my first ever lecture of speech pathology at uni. Our teacher asked us to write down a response to the question: 'What is communication?'. It was a definition we speechie students would soon expand until it was of monstrous proportions. Then perhaps, with experience, bring right back to the fundamentals. Fundamentals like what it is to be a good communication partner. I suspect, and rather hope, that the question 'What is communication?' will stay a question. Because, as Helen Curtis said in her article with Meg Irwin, when you're communicating "you never know what you're going to get ... so you go in like you've got to be open for anything" (this edition, p. 12).

With thanks to our editorial committee (particularly our two new members: Naomi Commons and Rod Mackintosh), I am pleased to be sending you an edition of *In Focus* for pondering that communication fundamental: 'Being a good communication partner'. 'Being a good communication partner' is a topic Australian audiences met recently as two exciting movies screened. The Black Balloon and The Diving Bell and the Butterfly each showed us the power of Alternative and Augmentative Communication (AAC) shared with good communication partners. You can read more about these movies in our review section. Also raising the profile of people with complex communication needs (CCNs) in our community, are AGOSCI's submission to the recent Australia 2020 summit and an article from a speech pathologist who attended (p. 34 – 36).

This edition of AGOSCI *In Focus* offers a wide variety of perspectives on what it is to be a good communication partner. We hoped the theme would stimulate submissions from the experts, our AAC users in Australia. And we are privileged to read articles from Alice Waterman giving us a school student's perspective; Joel Barraud on listening skills; and a comment from our cover artist, Katrina Zampech. It's exciting to have our In Focus 'AAC, the Arts and Sport' section make an inspiring comeback in this edition! We have articles from a variety of communication partners too, including: an attendant care worker; a volunteer worker with exceptional interaction skills; education staff; a 'School for Parents' of children 0-4 years; and a medical student.

We hope to hear as rich and diverse a range of perspectives in the next edition of *In Focus*. The theme is 'Education for all'. We look forward to receiving your submissions, due by 8th September 2008. And please keep our 'AAC, the Arts and Sport' section in mind too.

In the meantime, it's been 'education for the editorial team' in the wide world of communication. With each new edition of *In Focus* I add new ideas, tools and viewpoints to my own understanding. I wonder how much richer my response would be now to that question from first year uni: 'What is communication?' I hope this edition of *In Focus* will inspire and equip you to keep on being a good communication partner. Because, as Joel Barraud wrote (p. 15), the "way we grow and mature as human beings is by interacting and conversing with other people."

Emily Armstrong and Sheridan Forster

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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Chairperson's Report

by Wendy Webster

Norman Swan from the ABC Health Report recently reported that the most powerful way to promote positive health outcomes is to be sure that people have the opportunity and the means to make their own life decisions. He also presented a compelling argument that the most powerful way to educate about health issues is to have the issue embedded in the plot line of contemporary media such as soaps. For this reason it was so wonderful to have two big screen movies recently present the power of AAC in the lives of two people. The Black Balloon (proudly an Australian production) relates the tale of a teenager whose new romance is threatened by the challenging behaviour of his brother who could not speak. The Diving Bell and the Butterfly is about the insights of experience after a severe stroke of Jean-Dominique Bauby as related to others via an alphabet board—one blink for yes, two blinks for no. And in each of these movies the caring and the interactive skills of the communication partner were critical to the person who could not speak but had lots to say. The teenage brother, Thomas, confidently communicated with his brother signing with Makaton vocabulary. Bauby interacted with his friend and family, speech pathologist, nurses, all involved patiently spelling letter by letter.

So enjoy celebrating the joy of being a communication partner in this issue.

With the above in mind AGOSCI continues to seek to make information available to those who use AAC, their family and professionals.

A weekend in March was dedicated to the annual executive meeting in Adelaide to discuss amongst other things the updating of the business plan. The plan brings together the portfolios of membership, internet, scholarships and grants, publications, learning and development, lobby/advocate/sponsors/patron. AGOSCI history and awards will be added to the plan.



All portfolios are proceeding well except lobby, advocate, sponsors and patron. Though these are being kept alive (just), we need more bodies to assist with these important portfolios. So HELP! Anyone out there who have ideas; time and energy please contact me.

Perhaps the most exciting step forward is the plan to run a week long intensive and web cast the national tour to rural and remote sights across Australia and New Zealand. For the National Tour and the new innovations I am eternally grateful to Jane Farrall for all the creativity, time and effort she has dedicated to making this a reality for AGOSCI members. THANKS HEAPS JANE!

The Executive welcomes Diane, Tara, Harriet and Amy to our constant email chatter after saying goodbye to Jenni (sort of), Lisa (sort of) and Nathenya and Ruth. Jenny, Melissa, Anne and Melanie, Anne, Sally, Janelle, Helen and Melissa, Jenni and her 2009 conference committee and many local organisers for PD events all serve to keep AGOSCI thriving. And I continue to be very grateful to Emily and Sheridan and the editorial committee for the quality of this magazine. Enjoy reading!

BEEN OUT OF CONTACT LATELY?

If your contact details have recently changed, remember to update your details with your State Representative.

You can also update them on the website or via email ...

www.agosci.org.au

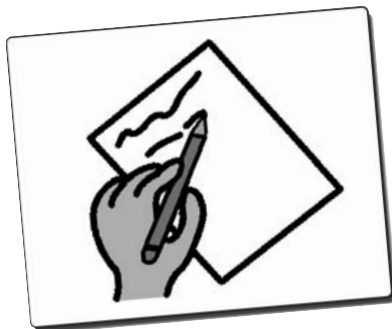




Notations ...

AGOSCI Inc. Secretary's report
by *Melissa Bakes*

It has been a very busy start to the year with memberships to process, agendas to organise and minutes to type. We have had many memberships come through at the moment with the upcoming National Tour. With regards to the National Tour I would just like to give an enormous thanks to Jane Farrall and all the branch representatives for all their hard work in putting this together. I am really looking forward to it as I have heard both David and Karen speak before and they are just fantastic and very inspirational.



Recently the executive met up in Adelaide for our once a year face-to-face meeting. We again had a really productive 2 day meeting with some new faces that have joined the group. There are lots of wonderful ideas for moving forward. I have included the minutes from the recent AGM in this copy of AGOSCI In Focus. We had a few laughs at the AGM amongst the serious business.

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

All I really have to report on for the moment are the membership numbers. At the moment we have around 230 members which is about the same as this time last year. I have seen some new names this time around. So the word is getting out there. Thanks again to all of those who have rejoined. Your continued membership is appreciated and valued. We continue to grow each year.

Money Matters

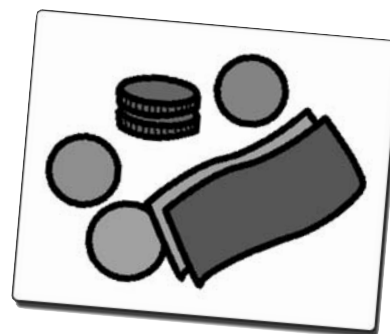
AGOSCI Inc. Treasurer's report
by *Jenny Arthur*

Hi everyone! Another year has past and although the books say we had a 'loss' last year, this was due conference receipts and expenses being spread over 2 financial years.

Overall the conference last year made a profit which goes towards the running costs of our organisation. We have a number of ongoing expenses, such as insurance, printing and distributing AGOSCI in Focus, meeting expenses, equipment etc.

For our next conference we have employed conference organizers, which will increase the costs for the conference, but decrease the stress for our volunteer organisers. We have money in the bank but we need this buffer to pay for our expenses which are increasing all the time.

At the moment I am preparing for the work involved in the National Tour which is a busy time for me and should be a fantastic opportunity for all our members.



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

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

State Reports



Victoria

by Helen Tainsh and Melissa Riepsamen

Hi everyone. Melissa and I have had a busy start to the year helping to plan the AGOSCI National Tour in Melbourne. We are really looking forward to the big day on Wednesday the 25th June, as we know that the presentation from Dr Karen Erickson and Professor David Koppenhaver will be brilliant. There will also be web casts to both Warrnambool and Mildura on Friday the 27th June.

We are also organizing our first AGOSCI Victoria 'catch up' for 2008. Gayle Porter and Sheridan Forster are leading a discussion about smart communication partners. Please also bring some 'show and tell' to share. We are meeting at the Cerebral Palsy Education Centre on Tuesday the 22nd April, 5:00pm until 6:30pm. Please have a look at the Victoria link on the AGOSCI website for further details. We really hope to see a lot of people there. Non-members are welcome.

As always, please contact Melissa or Helen if you have any ideas for an event in Victoria.



South Australia

by Janelle Sampson

First of all, I'd like to welcome a new co-Rep for South Australia. Amy Martin has agreed to join the ranks and has already been extremely helpful in some of the preparations for the National Tour. Amy's first official role in AGOSCI was to attend the face to face executive meeting that was held in Adelaide at the beginning of March and she has already won over the committee members with her restaurant recommendations. Of course, Amy has many other wonderful skills that will come into play over the coming months.

Things are starting to hot up here in South Australia for the AGOSCI National Tour on June 23rd. We are looking forward to hosting Karen Erickson and David Koppenhaver, and registrations are coming in fast. Just a reminder to those who are going for the group registration fees, that everyone in the group must be an AGOSCI member to receive that rate. There are also three South Australians selected to attend the AGOSCI Week Long Literacy Intensive course, which is a wonderful opportunity.

Another plan in place for AGOSCI South Australia is to team up with the Statewide Complex Communication Needs project to host the AAC Special Interest Group, the first being planned for the end of May 2008. For details on these interest group meetings, see the South Australia events page on the AGOSCI website www.agosci.org.au



New South Wales

by Harriet Korner & Lisa Hanley

Welcome to 2008! It has already been a busy year and there is more to come. I would like to welcome to Lisa Hanley, who has kindly agreed to be a joint New South Wales (NSW) AGOSCI representative. Lisa was previously the ACT representative for AGOSCI and has recently moved to NSW. Lisa is helping with organisation of the next National AGOSCI Conference, being held in May 2009. We are looking forward to working together.

Pragmatic Organisation Dynamic Display (PODD)

An Introductory PODD Workshop was hosted by The Spastic Centre on 11-12th March, and there were participants from all over NSW and across a number of organizations, which was great. The two day workshop was inspiring and full of practical information and advice to assist clinicians and educators in their implementation of PODD templates to develop communication systems for the children (and some adults) they were working with. Participants were keen to continue to network with each other and with Gayle Porter in the future to help share information and support each other around implementation issues.

Makaton Australia

The 30 year celebration for Makaton in Australia was held in Newcastle at Hunter Residences (formerly known as the Stockton Centre). Makaton Australia kindly provided the cake, resource packages, and laminated posters for display at the Communication Resource Library at Hunter Residences, Department of Ageing, Disability and Home Care. In attendance were: Michael Arthur-Kelly (Makaton Australia), Kathryn Smith (CEO Hunter Residences), Kim McLellan (Makaton Australia), Leanne Bowie (Nurse Learning and Development Officer), Peter Gardiner (Manager Large Residential Centres), Teena Caithness (Makaton NSW Coordinator) and a whole bunch of staff.

Makaton NSW

The total number of workshops for 2007 was 118 (116 Basic and 2 Refresher), resulting in over 1700 people attending training. With training of NSW Presenters in 2006 and 2007, there has been a greater ability across NSW to provide Makaton workshops, and increased capacity within organizations to supervise first time presenters. The result is that Makaton has grown rapidly and now has active 82 Makaton presenters.

Inclusive Communication and Behaviour Support (ICABS)

This training in Augmentative and Alternative Communication (AAC) has been provided to staff employed by the Department of Ageing, Disability and Home Care (DADHC). This training package was designed in Victoria by the Department of Human



State Reports (cont)

Services. In 2004/2005, 75 staff were trained, in 2005/2006, 125 staff were trained, in 2006/2007, 995 staff were trained and it is planned that over 1,000 staff working in group homes and large residential settings will be trained for the 2007/2008 year. There has been a huge increase in understanding that AAC is important. In 2007 both ICABS and Makaton NSW were nominated for the NSW Premier's Awards.

Black Balloon

Black Balloon is a new Australian film about a boy whose has an older brother who has autism. Aileen Ryan from Makaton NSW was the Sign Tutor for the cast and crew for this Australian film. To find out more go to www.theblackballoonmovie.com.

Building Foundations

Autism: Your Child, Your Family is a 30-minute DVD and detailed manual for families who have recently had a child diagnosed with autism. It features families and service providers talking about their experiences. It provides information about autism to families and the people who work with their children and shows some simple strategies parents can use to help their child. The information includes: 'what is autism?', 'after the diagnosis', 'helping communication', 'play and social interaction', and 'managing behaviour'. The DVD has been translated into 7 other languages including Arabic; Cantonese; Hindi; Korean; Turkish and Vietnamese. It costs \$9.95 including postage. A trailer is available for preview on the Aspect website: www.aspect.org.au/publications/buildingfoundations.asp.

Early Childhood Assistive Technology Project (ECAT)

Northcott CATS has initiated the ECAT project to provide information and support to professionals and families accessing early intervention services across NSW. ECAT is offering free introductory training in assistive technology to families and children with a disability 0-6 years. For further information or to register your interest, you can contact ECAT at the email: cats@northcott.com.au.

National Study Tour

We are very excited to be hosting the AGOSCI National Study Tour in Sydney on 18th June, with Karen Erickson and David Koppenhaver presenting on Comprehensive Literacy Training for Students with Complex Communication Needs. We are very keen to hear from AGOSCI members who are interested in coming to this event. It would be great if members could spread the word to others. For information about scholarships to assist families and AAC users to attend, members can contact me.

Other Items

The Spastic Centre is providing a varied professional development calendar which AGOSCI members may be interested in. Topics include Introduction to Evidence Based Practice, Introduction to Assistive Technology, workshops on Boardmaker, Clicker 5, Makaton and Cultural & Linguistic

Diversity and AAC. The CP Institute will be hosting the 3rd International Cerebral Palsy Conference in Sydney in February 2009, for further information you can go to www.cp2009.com.au.

If you haven't renewed your 2008 membership yet, you can still do this! The National Tour will be a great event. You may want to look into organising a group of people from your organization to all join AGOSCI and take advantage of the group registration option.

A NSW contact list is being updated and we will endeavour to use this to share local NSW information. Please also remember you can send us information to put on the AGOSCI website about upcoming events in NSW.

If you would like to have some other meetings, a chance to network and share ideas, or to explore a topic of interest, then please let us know. We can be contacted by email: hkorner@tscnsw.org.au or lhanley@tscnsw.org.au, or by phone 02 9757 4322.



Australian Capital Territory

by Tara Wright

Firstly, I would like to introduce myself as the new representative for AGOSCI ACT. I would like to thank Lisa Hanley for all the work and dedication she put into the position as ACT representative.

I am a newcomer to the ACT, so I hope that over time I am able to meet all members through such activities as: (a) National Tour Webinar, 9.30-3.00pm Friday 27th June, 2008, Centre for Teaching and Learning, Fremantle Drive, Stirling, ACT; and (b) AGOSCI 9th Biennial National Conference, Communication FEEL THE POWER, Canberra 7-9th May, 2009. Further information about these activities, and more, can be found on the website (www.agosci.org.au).

I am also interested to hear from members about any other professional development events or training they would like to see in the ACT.

Want to know what's happening in your state?

Simply log onto the website and click on the map

www.agosci.org.au

State Reports (cont)



Queensland

by Anne Pearson and Melanie Waalder

Like all AGOSCI representatives, we have been preparing for the 2008 National Tour. Also as with previous years we've received many registrations to attend the Brisbane workshop on the 16th June. We are very excited to be hosting several Webinars of the tour on the 25th June. We will be hosting the Webinars in Townsville, Cairns and Rockhampton. Look out for the flyers for these events.

Thanks must go to Wendy Webster, Melissa Bakes, and Paula Hartwig for assisting us with the Brisbane workshop and Webinars. Thanks also must go to Deb Burmester (Rockhampton), Kim Rumble (Townsville), and Kia Morton (Cairns) for organising the Webinars in their local area.

We also have the Learning and Development Portfolio for AGOSCI. We've already been discussing several ideas for the National Tour in 2010 but will do more brainstorming and formal planning after this year's National Tour.

If you have any questions about AGOSCI QLD events or if you would like to suggest a topic or presenter for a local QLD event, please do not hesitate to contact us.



West Australia

by Sally Hunter

Planning is well underway and registrations for the National Tour in Perth are strong. Subsequent to the National Tour registrations opening, WA has experienced a big increase in its membership numbers and plans are underway to retain this membership, with some post National Tour gatherings that hope to be both social and informative. Suggestions for gatherings include discussing topics as Makaton, an Aided Language Stimulation (ALS) sharing workshop, and Pragmatic Organisation Dynamic Displays (PODDs). Please feel free to make further suggestions. The AAC Devices Interest Group coordinated by the Centre for Cerebral Palsy continues to meet regularly, once a term, and information regarding their next meeting can be obtained from Danielle Lampropoulos at the Centre for Cerebral Palsy.

AGOSCI WA and the Conductive Education group in WA are planning a PODD workshop, aimed at training those who are building PODD products, in September, so we are really looking forward to seeing Gayle and company here too.



Tasmania

by Diane Symons

In March 2008, I compiled a submission to the Tasmanian Parliamentary Committee on Community Development's inquiry into the provision of assistive technology and equipment for people with disabilities. The submission highlighted the specialised equipment needs of people with complex communication needs. I have heard via the grapevine that the committee have arranged some meetings with various individuals and organisations that contributed submissions, so hopefully we will hear more from the committee in the coming months.

We have had two interest group meetings in Hobart, the last discussing the challenging issue of vocabulary selection for AAC. I hope to organise something in the north of the state in the latter part of the year.

At the moment it's all hands on deck for the national tour. Tasmania is hosting two webinar sites, one in Hobart and one in Launceston. I've had interest from a number of people who have not been involved with AGOSCI in the past. It's a great opportunity to raise awareness of complex communication needs.

I'm very excited (and a little nervous) about trying the webinar format. It sounds like a great way to spread the knowledge to many more parts of the country. I'm just hoping that on the day the computer says "yes"!



Northern Territory

by Anne Dixon

AGOSCI NT had a flying start to 2008 with the Triple C/ InterAACtion workshop presented by Karen Bloomberg. This workshop was presented by arrangement between AGOSCI and ISAAC Australia. A wide spectrum of people attended including disability support workers, parents, teachers, day service coordinators, occupational therapists, and speech pathologists. The workshop was highly successful and rated at 4.7 out of 5, indicating that the workshop was seen as relevant by all participants whether they supported children or adults and whether they provided support at school, at home, in day programs, or in supported accommodation. Thankyou Karen!

We are in the process of arranging two other development activities for 2008: a web linkup for the Literacy in AAC National Tour with Karen Erickson and David Koppenhaver on 27th June 2008, and the Aided Language Stimulation workshop to be presented by Wendy Webster on 4th October 2008.

The AGOSCI Interest Group is continuing to meet quarterly to network, share information, and discuss issues related to severe communication impairment. Thanks to an increasing membership, the meetings are generally well attended. Information about the dates and location of each meeting is on the NT page of the AGOSCI website. Any suggestions about content for these meetings are most welcome.

If you have any questions or comments I can be contacted by email anne.dixon@nt.gov.au or by phone on 8922 7226.



ISAAC Australia – President’s Report

The Australian Chapter of ISAAC

by *Cathy Olsson*
catherine.olsson@novita.org.au

The Montreal Conference is in the air. Are you going to ISAAC in Montreal? is the question on everyone’s lips. Flights and accommodation are being booked, and lots of thought and energy is going into preparation of presentations and posters. If you are going, remember to come along to the Chapter meeting which will now happen on the Thursday, rather than the Wednesday as was in the initial programme. You will have received the information about how to promote an Aussie identity in Canada by wearing your ISAAC T-shirt with some special additions – look forward to spotting others from down under!

At the recent AGM of the Chapter, some constitutional changes were made in relation to the potential for the Chapter to offer scholarships. As well as providing guidelines about the management of scholarship funds, these changes will support us in our bid to achieve Deductible Gift Reduction status with the Australian Tax Office! It was great to be able to report a healthy financial status for the Chapter, and to have been able to offer a \$500 scholarship to attend the conference – announcement soon in the ISAAC newsletter about the successful recipient.

Preparations are well in train for the next International AAC Awareness Event. The focus this year is on literacy for people with CCN. In addition to the ‘Many Stories, One Voice’ writing competition, there are other ideas about activities that you can do to help promote understanding and awareness, and general information that you can use in publications or discussions. Visit the site to keep up to date with the exciting progress reports from across the world, at <http://www.aacawareness.org/2008events.html>. These suggestions could also be usefully linked with this year’s Speech Pathology Week focus on literacy, so head to the web for some great ideas to use with twice the benefit. Feel free to organise your own activity to contribute to the AAC Awareness event – just email me at Catherine.olsson@novita.org.au if you would like the specific photo consent forms, and with your contribution for the Australian report on our activities for the event.



A mention of some Australian members who have featured in the AAC Journal in December 2007:

- Leigha Dark and Susan Balandin- Prediction and Selection of Vocabulary for Two Leisure Activities;
- Parimala Raghavendra, Juan Bornman, Mats Granlund and Eva Bjork-Akesson- The World Health Organisation’s International Classification of Functioning, Disability and Health: Implications for Clinical and Research Practice in the field of Augmentative and Alternative Communication (with special endnote thanking Cathy Olsson)
- Karen A Erickson, Sally A Clendon, James W Cunningham, Stephanie Spadorcia, David A Koppenhaver, Janet Sturm and David E Yoder- Automatic Word Recognition: The Validity of a Universally Accessible Assessment Task.

Finally, we hope to manage an AAC stream for the IASSID 2nd Asia Pacific Regional Congress: Creating Possibilities for an Inclusive Society to be held in Singapore, 24th to 27th June 2009. The call for papers is now out. For further information, go to <http://www.iassid.org/iassid/content/view/44/60/>. Also looking for people who are prepared to review abstracts and contribute to design of an AAC stream for the conference – please let me know if you are willing to be involved.

I look forward to catching up with a lot of our old and new members at the Chapter meeting, over coffee, on the dance floor and around the ridges in Montreal in August.

Want some information about AGOSCI?

Contact Melissa Bakes
1800 002 950



Being a Good Communication Partner

by Alice Waterman

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Alice is a child from SA who uses AAC. She wrote this on her computer with support from her dad. Alice tells us what she thinks is important to her when she is expressing herself, and what she thinks is important for other people to think about when they communicate with her.

Alice being a good communication partner:

- * Write a whole sentence not just words
- * Look at people in the eye when computer is talking
- * Use expression of my face
- * Always have my device turned on
- * Don't let my mum or dad or carers answer for me.

Others being good communication partners for me:

- * Do not try and finish my sentence for me
- * Give me enough time to finish what I want to say
- * Do not ask my mum or dad or carers to answer
- * Speak to me in language that is suitable for my age
- * Don't think because I am in a chair I am not smart.



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The conference theme is Leadership. Individuals who use AAC for their daily communication have increasingly taken on leadership roles in many different ways. Examples of leadership will be showcased as part of the 2008 conference program.

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For programme details, registration, travel tips and more, go to www.isaac2008.org**



A Communication Partner Reflects on Success

Meg Irwin & Helen Curtis

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Introduction

Many attendant care workers (ACWs) are excellent communication partners for the people with communication needs with whom they work. Meg, a speech pathologist, interviewed Helen, one such ACW, for this article. Most of the words are Helen's as she reflected on her experiences working with Alice.

Alice

Alice is a 48 yr old woman born in northern Europe where all her birth family remain. She and her then partner migrated to Australia when she was about 18 years old. In Australia, Alice had two more partners and had four children. She was 37 when she had an hypoxic brain injury after a benzodiazepam and tricyclic drug overdose in 1996. She now has only very occasional visits from some of her children. She lived in a rural nursing home from 1996 until 2003 when she was moved to the locked psychiatric unit.

This residential unit is for people with acquired brain injuries and behaviour deemed unmanageable in mainstream facilities. In this unit, nursing staff give medication and provide personal care such as showering, dressing, feeding, and continence management. Other aspects of life for residents, such as community access and rehabilitation, are generally left to therapists and Attendant Care Workers who are funded minimally and separately from the ward program.

When Alice came to the unit, a small amount of speech, occupational and physio therapy time and 15 hours per week of attendant care were funded by the Slow to Recover Program [1].

When Meg met Alice in mid 2003, Alice did not use speech and did not appear to understand speech or pictures. She could not move her body or legs and had little control or use of her arms. At times she would vocalise loudly and grimace. She would clap her hands repeatedly and cry out "no no no no" or make a rasping growling sound. We thought the vocalisations were associated with fear or discomfort but we were not sure. Alice frequently regurgitated food. No medical cause for this could be found. She chewed her clothing and ate and smeared bodily substances. Alice would briefly look at bright objects and did not visually scan. She opened her mouth to food and seemed to enjoy eating. Sometimes, she seemed to calm when there was music playing and things were otherwise still and quiet.

Helen

Helen has now worked with Alice for more than four years. In that time she has seen change. Helen rejoices in both the gains Alice seems to have made and in the relationship that Helen experiences with her:

I knew it would be enjoyable. I knew it would make a big difference but it's huge. It's huge! And it's such a tiny thing, but in the scheme of things it's massive! It's huge to have her look at you and actually look at you as a real – in a real way, you know. That she's looking at your face. Or you make her noise and she makes it back. Or you come in and you say hello and she makes a little – I can only interpret it as a – you know – a sort of hello back. It's a gentle sound. It's a sort of warm sound. It's um – it's responsive. You know it's - timing wise - it's sort of correct. That's the way it appears to me anyway. I mean I could – God knows – I could be right off the mark. But - genuinely - I don't feel like I am.

In this Meg sees four things that she thinks make Helen a great communication partner for Alice and others who do not communicate intentionally:

- Helen *wishes for relationship* with Alice
- Helen is willing to *stay with the uncertainty* of what (or if) Alice means
- Helen trusts her *feeling* of what is happening
- Helen has fine-grained *observational skills* (Helen's information about Alice's abilities has been used to develop personal communication dictionaries, sensory guidelines, and other protocols to enable others to support Alice's communication and participation).

A Successful Communication Partner

Listening to Helen's reflections about her work with Alice, the success of a communication partner seems to rely upon three things:

- The communication partner's interaction with the environment of the person with communication needs
- The communication partner's *behaviours* to facilitate communication
- The *attitude* of the communication partner to the person with communication needs

The Communication Partner's Interaction With The Environment Of The Person With Communication Needs

Effective work was assisted by:

- Adequate physical access and aids;
they've changed the two front wheels [on the wheelchair] ...it has made it a pleasure to take her out of the unit again...
- Having the knowledge and skills to operate successfully within the environment;
My confidence... has grown so much...getting to know the clients – getting to know everybody – getting to know how you need to react to other people ... you've got to have your wits about you. I mean the nature of the unit is



A Communication Partner Reflects ... (cont)

that you've got to be aware of other people's triggers...you have to have your wits about you 110% there because of the potential problems you could get into inadvertently.

- Working with others who share the same passion and approach;
Oh Susie's lovely with Alice - you know very gentle and very – and it's so nice to see Alice reacting in the way she does with Susie. You know that makes me very comfortable.
When I interact with Susie (another ACW) and Alice it's different because we both have a definite and similar relationship with Alice so when she and I are talking we're involving Alice... that's probably the ideal scenario.

The Communication Partner's Behaviours to Facilitate Communication

Positive behaviours of communication partners included:

- Working with the person with communication needs over a long period;
You see I'm so used to her now as a person...But that's at the level we're at.
It has taken that long for her to feel comfortable and to communicate with us in the way she does.
- Spending prolonged one-on-one time with the person with communication needs;
From Alice's point of view, she's got used to us carers... because I mean we're the people she has that period of time with when it's very much one-on-one.
People who are better with her...take a bit more time, make the time.
It's that you ...are there just for her and if you stop and make the eye contact.
It's a big difference between spending a couple of hours with her as I do and spending 15 minutes to do a task.
- Removing the person with communication needs from chaotic or threatening situations and following a predictable routine;
If there's something else going on in the unit, you can physically remove Alice from that situation. There's no knowing what out of that she's going to have retained but you have to try to start from a clean slate.
Normally what we do is go to her room and start with a little communicative 'oh hello, and nice to see you and how have you been?'...and then doing face wipe and hands and teeth so you're going through that routine... and then normally I'd try to get out of the unit with her and go for a walk...
- Adjusting one's own communication to meet the person's specific communication needs;
We all speak to people and you may just say hello and that's a genuine thing normally but ... with someone like Alice to do that in a very - not in an unnatural way – but in a very specific way is important...She's definitely one of those people that you've got to go the extra mile with.
- The communication partner using their personal resources

to provide what is required;

I'm the same person ultimately...there's certainly parts of me that I go to her with that I go to my nearest and dearest with. But I don't have the baggage with her that I have with other people.

I would say overall I'm much more patient and would take a lot longer to get snappy with Alice.

I probably listen a lot more - listen in that my senses are a lot more open acute when I'm with Alice. Another thing I do is concentrate a lot more on her...You never know what you're going to get ...so you go in like you've got to be open for anything.

- Learning new skills and trying things
What I tend to do now – especially after I saw the video that you lent me [2] - I just tend to make the noises back. I do speak to her obviously but I'm much more confident about making the noises after I saw that video and sometimes at the same time as she's making her gentle little noises and other times if she isn't, I'll make the noise or I'll say hello verbally then I'll mirror her little noises.

“ I probably listen a lot more - listen in that my senses are a lot more open acute when I'm with Alice. ”

The Attitude Of The Communication Partner To The Person With Communication Needs

The communication partner shows a positive attitude to the person with communication needs by;

- Being prepared to enter the experience of the person with communication needs;
When we've been doing tooth brushing, she appears a lot more relaxed about that...I never got the impression that it was a painful thing she was reacting to. It was more that when someone was going to brush your teeth it is sort of intrusive and literally in your face.
Alice has always seemed to benefit from even the most basic stuff like sitting in the café and the way she'll watch what's going on and watch people going past ...you can tell she's listening...I think she gets something out of it – well it's like different people's voices and different sorts of noises than you'd ever hear on the unit - that coffee machine, and Kath and Stella and Janet behind the counter.
- Wanting to interact with the person with communication needs;
I have to say the nurses who don't want to interact with her - or her and I -don't. And the people who do do. And the majority of those people do it in a perfectly acceptable way in my eyes – hopefully in Alice's eyes – I



A Communication Partner Reflects ... (cont)

can only assume that can't I but...

Let's say the people who interact inappropriately do that with the majority of people and that's just how they are generally...

- Seeing the person with communication needs as a person;

I think it's about people reacting with her in a genuine way. I mean it's really hard to explain it but um treating her one on one as a real person.

[Sometimes people] do that horrible thing of talking to me about Alice as if she's not there. Hmmm. And when that happens I always speak to her directly and then well "No – she's sitting right here with us! What's?" You know. Some of them will - ruffle her hair. Horrible!

- Valuing relationship with the person with communication needs;

But the bottom line is...I know I've built up a relationship with her that wasn't there immediately – no way!

She appears to recognise my voice now – I think.

In a sort of fantasy world I would love to be able to go to see her after a period of time [after she'd moved out of the unit]. I'd wonder if she would recognise my voice or recognise me. That would be mammoth. I mean that's purely totally selfish on my part but I'd love to know if - I'm sure she'd recognise something about me...and it's not what keeps me going -it's just a fantasy thing if you're allowed to have those in your working day. It sounds bizarre. It's the truth I guess.

The other day I was talking to Susie, and Alice sort of turned her head I don't know if she recognised my voice or something ...and that was hugely gratifying...to get something back.

- Working together with the person with a communication need - as a mutual task where both have agency;

Personally between Alice and I - we've worked together for a long time and I think somewhere there must be something about not wanting to give up.

It's that time factor and it's just taken us four years to get to where we are now.

Getting to know each other - it's definitely taken time and it's taken time with her too – I mean I sense it's very much a two way street.

[Walking in the garden]'s something I really enjoy doing...hopefully she picks up on my keenness for it.

- Valuing the inclusion and the potential of the person with communication needs;

The other morning I saw Alice in the dining room having breakfast sitting at the table in her chair having breakfast and that was the first time ever I have seen her in the dining room and they're trying to actually do that now – working to the whole community thing I mean...It was lovely to see!

I'd love to see it now that she is more communicative with us Alice interacting with a family member – one of her kids...see her with somebody else she's got that sort

of bond with how these new [communication] behaviours would transpire with someone like that. That would be the real McCoy to see that.

If she could get the hell out of here...I would love to be able to see her in another situation.

- Being determined and curious;
What sustained me? Not wanting to give up – that idea that you would miss out on something. There have been lots of times when I've thought oh you know – when you don't get any feedback it's very daunting to say the least – but somehow – and the other thing is when the changes have happened - those very slight but in the scheme of things very significant changes – that you think OK I'm going to stick with this because I want to see.
- Accepting that change may be slow or absent;
You know it's taken a long time – it appears to have been very slow but I think that's just the nature of the beast. And for those people who started with her and then left – I'm talking about the carers – have not had any of the benefits that I have because it has taken time.
- Being inspired by the experience of working with the person with communication needs
But it's sort of like if you can stick at it. And then at the end you can see these changes. It's fantastic. It really is... talking to the converted! Someone who's seen it many many times – but I haven't, you see, and for me to have gone through that process with Alice has been huge. And it would also ... give me the courage for want of a better word to work with somebody else who presented in a very challenging way at the beginning and who had behaviours that could maybe initially have put me off but that I stuck with and have seen it through...There's also been almost like - it's been like a revelation actually...to have seen that transition – sort of seen that through – it's been great!"

Conclusion

Alice has made some recovery from a minimally responsive state after ten years. Meg sees her positive relationships with her attendant care workers as one of the very few possible explanations for this recovery!

Footnotes

[1] Alice now has permanent but reduced therapist and ACW funding through the Department of Human Services.

[2] Caldwell, P. (2002). *Learning the language - Building relationships with people with severe learning disability, autism spectrum disorder and other challenging behaviours.* East Sussex, UK: Pavillion.



Seeing the Feelings for Young Adults with High Needs

by Jacquie Cowan

Jacquie presented in February 2008, at the VALID, "Having a Say" conference, in Geelong, Victoria. Jacquie has been recognized by her staff and peers as having excellent skills in interacting with people who have "high support needs." The following is Jacquie's written presentation notes. No changes have been made to the text.

I have a mild disability myself while I cant get my drivers lessons I am not so lucky in that. But I am lucky in lots of other ways if I have a head ache or I am in pain I will tell my staff member at the house or my mum. If something is upsetting me I can talk to my house staff member or my parents. So in lots of way I am very lucky to talk and tell people how I feel.

Working as a volunteer with our high need venues of central Bayside I am lucky in lots and lots of ways some of out high need clients cant always tell staff how they feel or what they feel. And also if they are in pain or upset about something. Some of them will express their feelings in ways such as hitting their heads or hitting their hands on their head or biting their fingers or crying.

But while some of the clients can try and tell us how they are feeling such as using their yes to speck etc. if a staff member asks them do you have a tummy ache they use their eyes to say yes or no. Once for yes and twice for no

So I am very lucky in those ways such as I can tell my staff members if I am in pain or upset or sad or tied to just need my space. But the clients who have the high needs cant tell the staff members how they feel or how they are feeling at that moment so in ways I am lucky.



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Listening Skills

by Joel Barraud

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Listening skills are the key to effective communication. You can't relate to people properly unless you are willing to tune into their views and learn from them.

The only way we grow and mature as human beings is by interacting and conversing with other people. I know myself that it's very easy to forget this and become immersed in your own world.

We start developing our listening skills from the moment we are born. We then spend a lifetime attempting to master them (I must admit that I have long way to go).

Some people in positions of power such as politicians never get them right. Question time in parliament is a perfect example of bad listening skills.

Unfortunately it is not good enough to have two ears that work. Good listening skills require a great deal of patience on the part of both the listener and the communicator.

Very often messages are misinterpreted because the listener and the person relaying the message don't have a good rapport. People with communication difficulties such as people with C.P., like myself, can often encounter this problem. In my experience the best way to overcome this problem is for the listener to take time to tune into the person's speech pattern and for the speaker to remain calm.

I've found myself in lots communication breakdown saturations. For example, when I'm picked up by a taxi driver who doesn't know me quite often when I give them directions I get the feeling that they are not trained to listen to people with C.P. Perhaps this is a good indication that maxi taxi drivers may need more training in communicating with people who have speech problems.

I remember another time when I rang up a disability service and I asked to speak to Stan and they thought I said Sandra. How anyone could mistake Stan for a woman is beyond me.

Listening skills play a vital role in every aspect of our lives. Remember to use them.





Improving Communication Partner Skills: A Pilot Project

By Meg Hinselwood

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If one defines a *good communication partner* as someone who values the mode of communication used, then in order to wear this mantle the person should embrace all forms of augmentative and alternative communication (AAC). Goossens, Crain and Elder (1989, 1999), and Harris and Reichle (2004) (cited in Binger & Light, 2007), suggest that in order for individuals to become effective users of AAC, they must see their mode of communication modeled regularly by other competent communicators. This philosophy underpins Goossens, Crain and Elder's Aided Language Stimulation model, as well as the System for Augmenting Language (SAL) model espoused by Ronski and Sevcik (1996). The Central Palsy League of Queensland launched a project to enhance the ability of people in education to model for and support students who use AAC. This paper outlines the aim of the project, how it was carried out, and the outcomes for participants to date.

In 2007, the Cerebral Palsy League of Queensland was successful in securing a grant to run a Technology Survival Skills Project for volunteers. The project, carried out in Queensland's Gold Coast, targeted people who worked with student users of AAC technology. In research and practice it is recognised that a key reason for device abandonment is lack of support within the user's environment (Hodge, 2007). Fear of new technology and a lack of time to learn about devices may present further barriers to the regular integration and modelling of speech-generating devices by teachers within an educational setting.

The Technology Survival Skills Project involved offering ten days of training in AAC and its technologies in an attempt to boost the confidence and competence of the participants. The trainers endeavoured to cover Light's (1989) four AAC competences: linguistic, operational, social, and strategic competency.

The project involved participants who were teachers, teacher aides, therapists, and a parent. All of the participants were asked to self-rate their competence across a number of AAC-related statements, and to nominate at least two goals they hoped to achieve through training. The programme, developed in response to identified training needs and types of devices used, was then delivered across a six-month period in two schools: a mainstream school with a special education unit and a special school. Training at the mainstream school focused around linguistic and operational competences, while volunteers at the special school requested more support in the areas of social and strategic competences.

Two key types of AAC devices were focused on: *Unity* devices and *Coverage* devices. Unity-based devices were heavily

represented at the mainstream school. Unity is a symbol-based language developed by linguist Bruce Baker and used within a number of speech-generating devices produced primarily by Prentke Romich Company. Whereas many familiar symbol sets (such as the PCS symbols used by popular Boardmaker software) have a different symbol to represent each word, Unity makes use of *semantic compaction* with a limited set of specially selected symbols. For example, the symbol of "apple" represents a variety of semantically linked concepts such as "red", "food", "hungry", or "fruit", depending on how it is combined with other symbols. Students using these devices must learn the Unity language in order to effectively access the vocabulary programmed on the device, however, once this code is learnt users are able to generate novel utterances. In contrast to the mainstream school, the special school AAC users used more *coverage* devices. *Coverage* devices, such as the TechTalk and the Palmtop Impact, generally, must be programmed for the user, who is consequently able to say only what someone else has pre-programmed.

The mainstream school requested and received extensive training in the basics of Unity and how to access the core vocabulary programmed onto the device, as well as how to access features in the device toolbox. Suggestions were provided as to how to make teaching Unity more enjoyable within the classroom. Training related to coverage type devices, for example the Dynamo, incorporated background information on the preparation and use of aided language displays to prepare the group for vocabulary programming. Demonstration and practice opportunities were available for volunteers. The group also received hands on tutorials on the use of Boardmaker in preparation of communication resources, and the preparation of Talking Books.

The programme for the special school involved fewer sessions. They received a tutorial on the use of Boardmaker, and introductory information on the aided language stimulation framework, as a framework for vocabulary selection. Learning goals for this group centred on increasing their ability to facilitate social contact between students and to help them when they get stuck. Therefore, sessions were provided around social and strategic competence, with detailed information about enhancing these skills in students who use AAC. Volunteers received hands on training and assistance with programming and use of the Macaw and the iChat.

The outcomes of the project were evaluated through comparison of self-rating scales completed pre- and post-training. Self-rating of competence improved markedly across most competences post-training in the mainstream school,



Improving Communication Partner Skills ... (cont)

suggesting the participants had enhanced perceptions of their competence as AAC models. At the time of writing, post-training feedback from the special school was unavailable. Project participants will be contacted mid-2007 to determine whether gains they attribute to training have been sustained.

In conclusion, many questions remain to be answered, such as "does this personal competence translate to more regular modelling of AAC technologies and better outcomes for the AAC users with whom the project participants work?" and "are these volunteers better communication partners than they were prior to training?" The completed project will be presented at the ISAAC conference in Montreal 2008, and may be useful in securing further funding to extend the project to other schools, and directing future questions that require to be addressed in AAC projects.

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Technology Survival Skills Project

by Anne O'Leary

Head of Special Education Services, Southport State School

As a school we were delighted to be asked to participate in this project funded by the Cerebral Palsy League of Queensland. Almost all the special education staff (teachers and teacher aides) indicated that they would like to participate, as did two therapists who visited our school weekly.

Our need for training came from the desire to be better communicators with students who used AAC devices, and to assist these students to become more effective communicators through the use of their devices.

The project began with some basic theoretical perspectives on AAC and communication development. Meg Hinselwood (CPLQ) provided us with stimulating information and engaging activities to reinforce our learning over the course of the project. While the project offered 10 days in training, this was delivered across a six month period which contributed to the continuity and effectiveness of the learning (in spite of the late Friday afternoon timeslot!)

“**Our need for training came from the desire to be better communicators with students who used AAC devices...**”

As a team, we were able to determine the areas of training that we wanted. This was directly influenced by the types of devices that our students were using in the school setting. We did branch out on a couple of sessions to develop skills to enhance communication for a range of students (e.g., Boardmaker; talking books) – and these sessions were equally productive.

Each of the staff started from different levels of expertise in the field, however, there is no doubt that we all significantly developed our knowledge and competencies in addressing the use of AAC technology with students. Those of us who worked daily with students using devices tended to develop their skills more quickly, of course; but the consolidated practice in our sessions with Meg provided a strong skill base for all staff. Maintenance of these skills may be an issue for some staff if they do not work regularly with students who use AAC devices, however, I think that, once learnt, these skills will refresh quickly when the opportunity arises.

The best outcomes of the entire project were that we were able to communicate more effectively with AAC users, and encourage greater use of their devices in the school setting. In other words – the best outcomes were for the students we work with.



Considerations When Engaging Speakers who use Augmentative and Alternative Communication (AAC)

by Mel Smith and Karen Bloomberg

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So you are considering asking a person who uses AAC to present a paper for you. This paper has been developed to make it easy for you to do this. It will let you know what to ask and remind the presenter about some of the issues. It is meant as a guide and meant to offer you information to consider. Print this paper off, read the contents and then go to the person who you want to ask and go through the key points with them. Each individual AAC-user may have different issues, the considerations listed are only a guide. Talk to the person, as some people may need less or more time, or types of different supports.

Payment/Expenses

Issues to consider:

- payment for AAC-user (he or she may not have a paid job and may be presenting in their own time);
- travel costs (e.g., taxi to and from venue, or petrol/mileage costs); and
- payment for support worker (if needed).

Topic

Discuss with AAC-user:

- if you are asking the person to prepare a unique presentation then he or she may need 4 – 6 weeks preparation time;
- please be clear about what points you want covered in the presentation by thinking about what is your desired outcome from the presentation;
- provide plenty of prior warning for the AAC-user, if there is any change to the topic content; and
- if the person has presented on a similar topic before, the AAC-user may not need as much preparation time.

Time Factor

(Double the Time Available for AAC-users)

For a speaking person a 25 minute speech plus 5 minute question time is equivalent to 50 minute speech plus 10 minute question time for someone who uses AAC.

Time of Presentation

Consider: AAC-user may have attendant care needs and/or transport issues and not be able attend early morning (e.g. breakfast meetings) or late evening functions.

Travel

Issues to consider:

- what travel time is needed;
- how the will AAC-user get to the venue (e.g., private car, public transport, taxi);
- where is the nearest available train station and do you have a map to the venue;
- what is the availability of a taxi, (e.g., it is difficult to get an MSO accessible taxi before 9.30 am and between 3.00 pm & 6.00 pm as drivers often have prior bookings with a variety of disability services and taxi drivers often change shifts between 3.00 pm and 4.00 pm and so are harder to access); and
- allocating a liaison person to ensure the AAC-user's travel arrangements work smoothly (e.g., make sure the person is able to find a taxi or suitable transport after their presentation).

Venue

Consider:

- access into venue, and
- access to the stage (e.g., is there a raised platform, is a ramp available).

Equipment

Consider:

- what equipment is available (e.g., amplification such as speakers, jacks to link external speakers to Speech Generating Device, flexible microphone);
- set-up time including how much time is needed to set up and to check that all electronic equipment is working;
- is there an accessible stable surface to rest equipment (e.g., laptop, switches);
- might the person need an external power source (e.g., provide an extension cord); and
- allocating a liaison person to help with setting up and for packing up.

Evaluation

Consider:

- feedback to the speaker after the event, and (b) feedback from the speaker about the organisation of the event.



Considerations When Engaging Speakers who use ACC ... (cont)

Checklist Questions for Organiser

Issues to consider:

- do you have a budget to cover the costs of involving an AAC-user;
- have you clearly defined the topic, format, and information that is wanted from the AAC-user;
- have you allocated adequate time for the AAC-user to prepare and to deliver their presentation;
- does the AAC-user have any special needs (e.g., hearing difficulties);
- have you supplied a map to the venue;
- has a liaison person been allocated (in case anything goes wrong on the day and also to help with travel, refreshments, setting up and packing up);
- who will be responsible for booking the taxi?;
- who will be responsible for paying for the taxi or other travel costs incurred (e.g., Cab charge voucher);
- is the venue accessible, including toilet facilities;
- does the AAC-user have a support person he or she likes to use;
- does the AAC-user need extra amplification such as external speakers and/or a microphone;
- are any other equipment or resources needed (e.g., overhead projector, sign interpreters); and
- who is responsible for photocopying material.

Checklist Questions for Speaker

Issues to consider:

- how long is the presentation that is wanted;
- are my costs covered;
- is there any help available, if needed, to put the presentation together;
- how much time has been allocated for questions;
- what sort of format for questions (e.g., yes/no questions only, write down questions with an email address and respond after the presentation, take time to answer questions during the presentation);
- have travel arrangements been sorted out;
- have I received a map for getting to and from the venue;
- what is the size of the venue;
- will there be adequate amplification for the VOCA to be heard;
- do I have a way of signalling for help, if needed;
- have I got a back-up or hard copy of the presentation; and
- is there someone to "read" my presentation on my behalf.

So you have gone through the checklist and it all still seems a bit daunting and you need some support, there a number of places to go and people to talk too for some advice.

Include details of useful contact people here:

PLEASE NOTE: This is a draft of a document designed to make it easier for people with complex communication needs to be involved in some sort of public speaking. We are happy for people to use what they want from it. We are also interested in feedback and comments on the content. Please send any suggestions to: Mel Smith – msmith.crc@scopevic.org.au or Karen Bloomberg – kbloomberg.crc@scopevic.org.au

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Communicating Respectfully

by Sharon Barrey Grassick

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Ten years ago, I wrote an article *CUEmmunication* (Barrey Grassick, 1998), which was very well received at the time and has in fact travelled the globe since then. Although written specific to people with congenital deafblindness or multiple sensory disabilities, feedback over the years from many professionals, including therapists and educators, has indicated that the basic philosophy and resultant strategies have been relevant to, and useful with, many other individuals with a wide range of disabilities and/or medical conditions, and applicable to both children and adults with unique sensory considerations. The core principle of *CUEmmunication* is respecting individuals by using their personalised communication systems in the most meaningful and least intrusive manner. The following article expands upon that basic premise, with a focus upon individuals who use informal or nonconventional communication systems:

Everyone communicates!

Everyone communicates in some way. There are far too many horror stories of parents being told their children will “never communicate.” This is simply untrue. Communication has many shapes and forms. Communication is not necessarily speech, sign language, or symbols. Communication can be a blink of an eye, a slight movement, or change in body positioning, or a stilling. As parents, educators, therapists, and service providers, it is our responsibility to learn what that vital communication may mean, and a particular movement or effort may have, different meanings, depending upon the situation. It is our responsibility to learn that communication: in all its informal and nonconventional shapes and forms. Behaviour is communication.

Imagine: A man named John, who is deafblind and lives in group accommodation... John has a few basic signs, learned over many years. He has been observed on numerous occasions to hit his wrists together repetitively and quite vigorously. Staff at his residence are quite sure this means he is really distressed; however, staff at his workplace are equally certain he does this when he is very happy or excited about something! Is it possible that this same, highly affective gesture has different meanings? Yes, of course, depending upon the situation at the time, this same gesture may have two totally different, yet equally emotive meanings. Consider a ‘typical’ hearing-sighted person who may cry when ecstatically happy or laugh nervously - even hysterically - when distraught. Careful observation and negotiation of a shared meaning of a particular behaviour can help to establish what an individual may be trying to communicate at any point in time. Always remember – behaviour is communication!

Negotiation of Shared Meaning

Rodbroe and Nafstad (1999) emphasised the importance of co-creating communication by negotiating a shared meaning for a particular behaviour, action, or gesture. Through shared experiences and imitation of an individual’s communicative efforts, shared meanings can be co-created. Video documentation can be an invaluable tool in reviewing and analysing this process.

Effective communication partners must start with the communication system of an individual, using any combination of movement, touch cues, gestures, object cues, symbols, pictures, speech and/or signs, etcetera that have meaning for the person.

Imagine: Sue has learned Deafblind fingerspelling and is keen to use her skills...

She meets John, who is deafblind, so she fingerspells onto his hand; however, John has never learned fingerspelling and has no idea what Sue is trying to do. She is using a system she knows, with someone who does not yet have a formal communication system. Sue thinks she is ‘communicating’, but she is certainly not communicating with John. To communicate, the same system must be shared by both communication partners. Communication is not one-sided and must reflect the interactions understood by an individual. All communication efforts need to be acknowledged and their meaning/s negotiated to co-create a shared communication system.

Consistency

Consistency in whatever communication system is used with an individual is important. However, consistency is not synonymous with rigidity. It must be emphasised that any strategies suggested in this article are not intended to be regimental or implemented rigidly, as communication strategies must be personalised, based upon a particular individual’s communication system, and adapted as situations may change and as a communication system develops or evolves.

We still have so much to learn in the area of communication development. If at any point we think we know it all, it’s time we left the field! Learning is an ongoing process, not a destination.

‘He, who knows all the answers, has not yet been asked all of the questions.’
Author unknown

Approach: Making Contact Respectfully

One of the most fundamental and essential components of communicating respectfully, is approaching and making contact with a person in the least intrusive and most meaningful way



Communicating Respectfully... (cont)

possible. Some children and adults with multiple disabilities can be very difficult to accurately assess in regard to functional hearing and/or vision. Therefore, it is important to continue to give opportunities for a person to use any functional hearing and/or vision there may be.

The following steps are easy to learn, can become automatic within a very short period of time, and require only seconds to implement. This is not rocket science!

1. Approach from the front, at eye level, to enable person to use any functional vision there may be.
 - a. If you are aware of better vision in one eye, approach from the front, but slightly to the better side.
2. Say the person's name as you approach, for example "Charlie...", to enable the person to use any functional hearing there may be.
 - a. A person's name is probably the one word heard most often and therefore likely to be better recognised than any other word, so more likely to get attention.
 - b. Using good inflection in your voice may enhance interest.
3. Say your name, eg. "Charlie, hi, Sharon here."
 - a. If you are aware of better hearing on one side, adjust your approach accordingly.
 - b. Note: A better ear or better eye may not be on the same side! Therefore, approaching from the front centre may be the best option.
 - c. Always use your voice to give person opportunity to use any functional hearing.
4. Make contact by placing your hand firmly but gently on back of person's hand and leaving it there until person responds to your presence in some way, for example, turns towards you, seeks your hand, or vocalises.
 - a. Keeping your hand in contact with the person assures them of where you are; a tap or pat is fleeting and may be confusing or even startling.
5. Identify yourself with a personal signature or sign name. A sign name is a hand sign or initial/s used to represent a person's name (e.g., tapping the letter 'g' onto back of a person's hand is my sign name; a colleague uses a combination of the letters 's' and 'c'; another uses the sign for 'white' as it is her last name).
 - a. If using a signature, make sure it is something that you always wear or have with you, for example a particular ring or a moustache (that you never intend to shave!)
 - b. If using a sign name, make sure it is not a formal sign that could eventually be introduced to the person and have a different meaning.
6. Proceed, using person's individualised communication system.
7. Remember to let person know if you are leaving, if even for a very brief time; use a consistent cue and always reintroduce yourself when returning.
 - a. A squeeze on the shoulder could be a touch cue for "be right back", for example leaving for a brief

period; if used consistently, the person may learn to associate this cue with expecting your return; however, any association may take many repetitions for a person to learn what a cue represents.

- b. The cue for "be right back" should differ from a cue or sign for when you are leaving for the day (e.g. the natural gesture of waving goodbye would be appropriate for when leaving for an extended period; if little or no vision, adapt by waving your hand under the person's hand).

Imagine: How many other people could a person with sensory disabilities have contact with in any one day?

Teachers, speech therapists, physios, OT's, education and therapy assistants, volunteers, specialist and visiting teachers, other specialists, administrators, doctors, nurses, student teachers, other visitors, residential carers, other staff, other students or residents, bus drivers, relief staff, parents, siblings, neighbours etc. We must never assume that a person, who is deafblind or has multiple/complex sensory disabilities, knows who we are when we have returned, even if only after a very short period of time. It is simple respect to reintroduce ourselves to let a person know who we are. And it's so easy! Please reread above...

Hearing is Not the Same as Understanding!

Hearing sounds, for example, responding or reacting in some way to environmental sounds, is not the same as hearing and understanding words and spoken language!

Imagine: You are sitting in a café and at the next table people are speaking a foreign language.

You can hear what they are saying, but you cannot understand what they are saying, because it is not a language you share: not a language you have yet learned or are familiar with. This is the same for many children and adults with sensory or multiple disabilities who may respond in some way to environmental sounds, and even some spoken words, by attending or turning to a sound or person speaking; but they may not yet have the language to understand what the sounds or words mean. Just because a person reacts in some way when he hears someone speak does not mean he understands what is said. For example, an adult observing a child turning his head to a knock on a door or a dropped pot (both relatively loud sounds and well above speech perception levels) may assume that this child not only can hear, but can also understand spoken language. This is a common, and often erroneous, assumption. However, this does not mean we stop speaking! It is important to use spoken language to supplement personalised communication systems. Always give the opportunity for a person to use any functional hearing there may be.



Communicating Respectfully... (cont)

Even if a person does not understand a spoken language, they may still be able to pick up some useful information from voice inflection, intonation, pitch, or accent. Therefore, always use voice when interacting with a person who is deafblind or has multiple disabilities.

Hand-Under-Hand

Barbara Miles' excellent article *Talking the Language of the Hands to the Hands* (1998) has had a profound effect upon the thinking of many educators in the field of deafblindness. The strategies proffered have been found to be relevant to individuals with a range of disabilities, not only people with deafblindness. Offering our hands, sharing experiences, taking the lead of the child/adult and acknowledging communication efforts, are all integral to interacting effectively and developing communication in a highly respectful manner. This article is highly recommended reading.

Offering

Interaction, assistance, and communication can occur more respectfully and effectively by using hand-under-hand, rather than manipulating and controlling hands. Hand-under-hand is a concept that is difficult for some educators and therapists to grasp, as shaping and moulding hands has been a long held trend in working with children with multiple disabilities. However, Deafblind educators have found that the combination of offering and waiting results in children taking far more initiative; individuals also begin to realise that they have the power to be able to do things for themselves – and the power to communicate!

Waiting

This vital technique cannot be underestimated. Giving a child or adult time, firstly to process and then to respond, is essential. Too often we rush, push, prompt, direct, prod, control, manipulate or do something for or to an individual, rather than setting up the environment, providing the stimulus or information and then waiting giving the person time to process and initiate their response. Sometimes we forget that real learning is about the journey rather than the destination (e.g., student outcome statements and progress reports so often rule the day, rather than the time actually spent interacting and communicating). Somewhere along the line some educators have forgotten that learning is an ongoing process and not a prompted response or a tick on a form! Learning and journeys take time. Waiting is not easy! However, the benefits of waiting for an individual to respond are invaluable!

Waiting for an individual's response is one of the most important elements in fostering the development of effective communication. Deborah Chen's *No Freebies* (Chen, 1998) reminds us not to jump in and do things for a child, but to set up the environment to enable and encourage a child to communicate what they want or need. Waiting for a response gives the time needed for a person to process, plan, and then respond.

Respecting Behaviour as Communication

As parents, educators and therapists it is our responsibility to observe and learn what a child may be trying to tell us, through a particular behaviour or pattern of behaviours.

Dr. Tim Hartshorne, highly respected psychologist and authority on challenging behaviours, has extensive expertise with children with CHARGE Syndrome¹. Children with CHARGE have complex sensory and medical conditions, including cranial nerve damage, which could impact upon and influence behaviour. Most children with CHARGE will learn to communicate using formal methods such as speech and/or sign language; however, it is possible that some of the quirky or challenging behaviours often observed in children with CHARGE Syndrome are another form of communication.

"He has no communication...he just screams!" How often have some of us heard that? Renowned deafblind educator, David Brown says, "All behaviour has a purpose." If a child is screaming, he is trying to tell us something. By acknowledging this behaviour as communication and trying to discover what the behaviour may mean, we can then respond in a way which may help to modify the screaming into a more desirable form of communication. For example, some children may not yet have learned another way to communicate, so they scream as they have learned that screaming gets attention or what they want. Firstly, always check any possible medical concerns, eg. blisters on feet, constipation, pain, etc, particularly if a behaviour is new or exacerbated.

Imagine: A TAFE² student, who also happens to be a bus aide, came up during a break one day expressing concern over so many of the children on her bus-run, who have communication challenges. Apparently, one child never spoke or made eye contact and didn't like physical contact of any kind; however, she made repetitive vocalisations. I suggested that the child's vocalisations may be her way of communicating something and that it was our job to try to tap into what those vocalisations might mean, and the same vocalisations may not always have the same meaning for that child. As a start, I suggested the bus aide imitate the girl's vocalisations...and wait. The very next week this (very excited!) bus aide/student said the child had made eye contact and smiled for the first time after she imitated her vocalisations! We then discussed how the bus aide could again imitate the girl's vocalisations, always with a smile, and then add the child's name. The next week, bus aide/student rushed into class to say that the child had responded to her name by turning to the bus aide and even reaching out for her!

Obviously, the role of a bus aide is not to teach communication! However, this is a great example of how all of us can help to facilitate and expand communication in every possible environment.

Predictable Routines

Establishing predictable routines (Axelrod, Condon, Durkel, & Wiley, 1993) is a highly effective way of helping to develop



Communicating Respectfully... (cont)

communication through consistency and structure. Routines can give shape and form to a world that can otherwise be very fragmented, frustrating, and confusing.

There are many ways that everyday routines can provide a basis for communication.

Imagine: Jimmy needs a nappy change...

Wherever Jimmy is before his nappy change, he is given a natural touch cue/gesture, for example a pat on his upper thigh near his nappy.

Jimmy is then taken into his nappy change area, where his nappy is patted again; then, a clean nappy is brought into his field of vision, offered near his nose for him to smell clean nappy and then offered under his hand to feel before the old nappy is removed. Once the old nappy is removed, a cleaning cloth or tissue can be offered under his hand before wiping his bottom to indicate he is about to be wiped. Before the clean nappy goes on, his thigh is again patted. This routine gives Jimmy the opportunity to anticipate what is about to happen. Anticipation is an important element of language development. In this situation the clean nappy is the object symbol. Eventually, the nappy could be reduced in size to an object-symbol of just the nappy tab.

Calendar boxes or a tangible timetable can be very effective in giving structure to a day. Depending upon an individual's hearing, vision and communication system, a set of objects, object-symbols, photos, drawings, print or Braille can be used to represent activities throughout the day, presented in sequence. Each symbol is taken to the corresponding activity, and then placed into a finished box at the end of the activity. This routine provides clear beginnings and endings to activities.

In Summary

These strategies are simple to learn, easy to implement and most important of all - respectful.

Imagine: "But, we don't have time to do all this!"

Response: Time yourself! Approaching, identifying yourself and letting a person know where you are going by providing a touch cue, object symbol, picture or sign, takes approximately 8 seconds!

So how can these strategies be effective with individuals who are not deafblind?

It is our responsibility to constantly think of the messages that we are, or are not giving to the people entrusted in our care. The strategies offered on these pages can help let children like Charlie know who we are, where they are going and what is happening in their world. This is not a huge task; it is simple respect.

- 1 CHARGE Syndrome is becoming a leading cause of congenital deafblindness in developed countries.
- 2 Technical and Further Education; Auslan Studies – Deafblind Communication modules

Imagine: Charlie is not deafblind; he has 'typical' hearing and vision. However, Charlie has a severe physical disability which greatly restricts any voluntary movement; he is in a wheelchair for most of his day.

Suddenly, without a word, someone pushes Charlie's wheelchair from behind; he doesn't know who it is because he is unable to turn his head to look.

"But he knows me!" Does he at that point in time? Remember in a previous section how many adults there may be in and out of a classroom on any one day? How can Charlie be expected to know who it is at any one point in time, if we don't give him that information?

Charlie is then pushed into an unfamiliar area, and just as suddenly as he was whisked from his room, he is left in a strange environment, staring at a wall...

Although Charlie has hearing and vision, he doesn't know who brought him, where he is, or why he is there.

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Supporting Parents to Become Effective Communication Partners Through ‘School for Parents’: A Holistic Model of Early Intervention Using the Principles of Conductive Education

by Laura Jones (Teacher-Conductor) and Yvette Theodorsen (Speech and Language Specialist)

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School for Parents

The Conductive Education Centre at Carson Street School runs a holistic early intervention service known as School for Parents. The service includes once or twice weekly half-day programmes for groups of 0-4 year olds with physical and/or multiple disabilities such as Cerebral Palsy, and for children whose physical development (and often global development) is delayed such as children with Down's and Angelman's Syndromes. The service is known as School for Parents (SfP) because the young children attend these groups with their parents and the emphasis of the intervention is on both children and parents learning together. Workshops are also held throughout the year to provide parents and their extended family or support network with greater insight into the strategies and activities used within the programmes.

The SfP services, coordinated by a Teacher-Conductor and Speech and Language Specialist, are underpinned by the principles of Conductive Education and therefore have a pedagogical rather than clinical perspective (Withall & Cotter, 1996). The central tenant is an open expectation of human potential and a belief that all individuals can learn (across all areas of development) if given appropriate conditions. The ultimate goal of Conductive Pedagogy is for individuals to see themselves as people who 'can', who have active, independent, problem solving personalities (Hari, 1996; Kozma, 1995) – essentially, individuals who have the capacity to meet the demands of their daily lives (Hari & Akos, 1988). Clearly, the ability to be an effective, active and competent communicator is critical to the development of an active 'can do' personality. The vast majority of children attending SfP groups have severe communication impairments (97%). In order to learn the skills necessary for competent communication it is imperative that these children have good communication partners around them who can support their language development effectively. The Conductive Education Centre at Carson Street School promotes the use of aided language stimulation strategies (Goosens, Crain & Elder, 1992) across all of its services in order to support communication development. In our experience, implementing aided language stimulation (ALS) within the SfP groups and providing training on ALS for parents and their extended support networks is essential if we want those in our children's

every day environments to become better communication partners.

Aided Language Stimulation (ALS)

ALS involves a combination of strategies which expose children to the use of aided symbols within meaningful, purposeful communicative interaction. When describing ALS strategies within our workshops, we use the acronym MORSE to help participants remember the range of strategies, explaining that we need to create Opportunities for MORSE - Modelling, Observing and Responding, Scaffolding and Expanding (Porter, 2007).

Creating Opportunities

Within SfP we ensure the learning environment supports the implementation of ALS and therefore supports aided language acquisition. Aided language displays (ALDs) presenting appropriate vocabulary across a range of communicative functions (including comments, requests, questions, objections and exclamations etc) are readily available across the whole daily routine. ALDs for specific activities are kept where those activities take place. In so doing, we have tried to "engineer the environment" (Porter & Kirkland, 1995, p.97) because we recognise that communication needs to occur in all activities in all positions (Burkhart & Porter, 2006). By ensuring the ALDs are always available, we are not only supporting the children's progress towards communicative competence but also the parents' progress towards being a good communication partner – they have plenty of opportunities to practise using the ALDs within the supportive context of the group and can seek help easily if they need it. They are able to learn from the models provided both by the staff and other parents in the group using the ALDs. By 'engineering' the group environment (Goosens, Crain & Elder, 1992), we provide ideas to parents and their support networks on how they can similarly set up their child's other environments to create ongoing opportunities for communication development.

We provide varied, meaningful, fun activities that encourage and entice communication – not just for the children but for families too. Depending on the needs of the groups, we will focus activities to stimulate particular communicative functions



Supporting Parents... (cont)



(such as asking questions or making comments on new toys, encouraging requests for a turn, developing metacommunication skills within pretend play etc).

The ALS workshops we provide for parents, who are encouraged to bring siblings, extended family members, carers and other professionals involved with their children, create excellent opportunities for participants to learn about and be exposed to ALS in action.

Modelling

It is important that good communication partners remember that competent communication is not innate, rather it must be learnt, and to be learnt, it must be taught (Light, 1997). All children need huge amounts of receptive input before any expressive output is achieved in language terms and children who need to learn to use AAC methods must equally be exposed to high quality examples of their AAC system of language in use. As we know children learn to communicate in the way they experience their system of communication being used (Beukelman & Mirenda, 1998; Porter, 2007; Porter & Kirkland, 1995).

Throughout group sessions, we emphasise to families the need to model multiple modes of communication so that their child can learn to be flexible, adopting whatever communication tool will allow them to be most effective and efficient at that particular moment. The group situation allows families to become confident that the use of AAC will not prevent speech developing and that the use of symbols will not discourage signing, as they can learn from the experiences of other families within the group, as well as information provided by the Teacher-Conductor and Speech Pathologist.

We model the use of aided symbols by pointing to the appropriate symbols as we speak – on ALDs and in multi-level communication books. We use 'group' communication books

based on the 'Pragmatically Organised Dynamic Display' (PODD) templates (Porter, 2007) which include pragmatic functions and activities used specifically within the group sessions. The group books are matched in their vocabulary and visual presentation to the general needs of the children in each group, taking into account their current communication skills and those they need to develop. We also model the use of partner-assisted scanning to demonstrate to both children and their communication partners how to use these methods to access the children's own individualised PODD books. We often use small torches to further highlight and draw visual attention to the symbols as we point.

Modelling is also applied to the use of voice output communication aids, including simple single message devices, multiple message devices and more complex dynamic display devices because access to technology itself is not the answer (Jones, 2007; Millar & Aitken, 1996). Input must be provided to enable children to use these technologies for competent communicative output. On all displays, low or high tech, we always seek to provide enough vocabulary to meet the children's current communication needs, as well as to enable communication partners to model vocabulary for further development. Group sessions allow parents to learn how to model a range of devices from the group leaders as well as other parents and, more importantly, they have the opportunity to practise this skill in a supportive environment.

When providing workshops, we show videos clips of communication partners modelling and children using various types of PODD communication books, ALDs and voice output devices taken from current and previous SfP groups, and a training package from Education Queensland (2001). We allow time for parents to practise saying messages whilst modelling the appropriate symbols on ALDs and in various communication books, so they experience modelling in a non-confronting way.

Observing and Responding

We teach parents that, in order to be able to observe their children's communication and potential for development, we need to start with a system that can be easily modelled by all communication partners across all environments and aspects of their daily routine. For example, when a child first comes



Supporting Parents... (cont)

to a SfP group, we would immediately begin to expose them to modelling of Makaton signs and symbols on ALDs (with 12 symbols on a display). This enables all communication partners to observe the children's communicative responses and the group leaders can make appropriate modifications (e.g. using a torch, increasing the contrast of symbols, using 'pull-off' symbols to decrease visual complexity without compromising on providing sufficient vocabulary). Within a few weeks of attending SfPs, parents, as their child's primary communication partner, are able to start modelling with ALDs at home, across their child's daily routine, and make their own observations of their child's responses.

Through modelling and dynamic observation of how children respond to the varied ALDs and devices, it can be determined

to assist the parents in learning how to effectively model different ALDs or PODD books and how to be effective as a communication partner for someone needing partner assisted scanning. For example, in one activity, workshop participants form pairs, and one adult takes on the role of a person using auditory / visual scanning to communicate. They are given a set message to communicate, and the other adult has to provide scanning to allow them to access the communication book. We actively observe the participants and respond by providing feedback as needed, such as always starting at the first page of the PODD book, scanning through in the correct order, reading aloud the symbol label only rather than adding in extra words, and so on.

Scaffolding

Many AAC users are passive communicators, making few requests, initiations, asking few questions and tending to rely on single function, non-verbal responses rather than using their AAC device (Clarke & Kirton, 2003). Good communication partners scaffold or structure situations to entice more initiations and more in-depth responses. Porter (2007) describes many varied scaffolding techniques including both verbal and non-verbal cues which we discuss with parents during the ALS workshops. All of these techniques are implemented throughout SfP sessions, not only to develop the children's communication skills, but also to teach parents how to scaffold their child's communication attempts within their daily lives, further improving their skills as a communication partner.

Expanding

We expand on the messages of both the children and their parents to demonstrate how to build longer, more specific messages, by combining words on a page and modelling additional pathways in their PODD communication book. For example, when a parent is modelling with a 'painting' ALD, they may point and say 'more', in which case we could show them how to expand this by adding 'paint' (i.e. 'more paint'). Similarly, if a child presses 'food' on their voice output device, we may model pressing the combination of 'yummy' and 'food' to encourage commenting. When children are given a new PODD book, we support both children and their parents to use a larger vocabulary by expanding their messages, helping them learn to navigate new pathways in the book and deliver more complex and specific messages. As with modelling and scaffolding, good communication partners use expanding across all communication modes and systems.

How Successful Are We?

A measure of our success in supporting parents to become better communication partners are their own comments on how confident they feel to support their child's communication development.

The following comments were made by parents after attending at least one training workshop on ALS:

- The underlying rationale has really helped me understand



what access method best suits each child. This information can be used to prepare individualised PODD communication books. However, the process of observing and responding does not end here. Every communication partner needs to use responsive, dynamic observation continuously when interacting with the children so that every new skill the children display can be expanded and developed further.

We apply the same principles of responsive observation when leading the parent workshops. We adapt our level of support





Supporting Parents... (cont)



- the need to follow the process rigorously
- It gave me an understanding of the background of the system, my son's current need and the future objectives.
- I feel better informed about how to implement ALS and supports needed. I feel everything is possible!
- I am going to try and remember the prompts and be involved in scaffolding eg to pause, use prompts, wristbands etc.
- At home, I am now going to use ALS as much as possible throughout the day and provide more opportunities for purposeful communication – conversation as opposed to question/answer activities.
- It was useful to appreciate that although my daughter can sign, has started to talk, she can't tell me if she had a bad day at day care etc. I feel with this system she will be able to do that.
- Video footage was very encouraging, great examples of what is possible.

In Conclusion

We have learnt that we will only see significant improvements in our children's ability to communicate with us if ALS with the child's own communication systems is being implemented consistently by their family and other members of their support network. As early intervention service providers it is our professional duty to keep abreast of all developments that can enable our students to gain greater autonomy in their learning, to develop active, problem-solving 'can do' personalities. For young children with complex communication disorders it is our experience that these personalities have the best chance of developing if parents, professionals working with the children, and ideally the wider community understand what it takes to be a good communication partner and are empowered to become good communication partners through explicit training in and frequent, regular exposure to the strategies of aided language stimulation.

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Reflections of a Medical Student: Communicating with People with Intellectual Disabilities in a Healthcare Setting

by Ka Lip Chew, Dr Jane Tracy and Dr Teresa Iacono

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This article was authored by Ka Lip Chew under the supervision of Dr Jane Tracy and Dr Teresa Iacono, Education and Research Directors at the Centre for Developmental Disability Health Victoria.

Over the past year, I have been on placement at the Centre for Developmental Disability Health Victoria (CDDHV), studying communication in relation to people with intellectual disabilities. As a medical student, my interests focused on communication within medical consultations. In this article, I explore the different communication methods used by people with intellectual disabilities and strategies recommended for medical practitioners to enhance communication in this marginalised group. I also discuss the issue of informed consent, and several legal and ethical considerations. Healthcare decisions are not always made only by patients themselves. Patients with intellectual disabilities are often accompanied by one or more carer(s) to medical consultations, who may influence the healthcare process. In this article, the term carer refers to a parent or relative of the patient, or a paid disability support worker primarily responsible for supporting the patient in their daily life. This article is based both on the current literature and on my own experience while working at the CDDHV.

Communicating with People with Intellectual Disabilities

People with intellectual disabilities have various levels of cognitive impairment and communication skills. Augmentative and Alternative Communication (AAC) is used by some people with intellectual disabilities. AAC consists of a number of strategies used to enhance communication when a person is unable to use speech, or where their speech does not meet their daily needs (Burbidge & Iacono, 2005). It includes non-aided communication, such as gestures and the use of key-word signs (Makaton vocabulary), and aided communication such as using photos, pictures or symbols to facilitate understanding, as well as electronic devices (Burbidge & Iacono, 2005). One individual may use several forms of AAC, the choice of which depends on the context of the communication. Some people without speech may use informal modes, such as facial expressions, body language or vocalisation either as their only means of communication or in addition to some speech and/or aided or unaided AAC systems.

An individual with borderline or mild intellectual disability may be able to use everyday speech, but have difficulty with higher level language skills. The person may therefore have some difficulty understanding information or expressing him/

herself. Some strategies suggested to medical practitioners include simplifying the language used (and avoiding the use of medical jargon), and speaking at a pace comfortable for patients (Murphy, 2006; Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004). Patients may require additional time to process information and formulate their responses (Iacono & Johnson, 2004). It is therefore important that patients not be interrupted, and medical practitioners develop an awareness of the importance of pauses in the conversation (Iacono & Johnson, 2004). Extended appointment times promotes good communication by providing the patient with more time during the consultation to communicate effectively (Iacono & Johnson, 2004; Murphy, 2006; Ziviani et al., 2004). It has also been recommended that medical practitioners try to ascertain patients' understanding throughout the consultation, and clarify as many issues as is necessary. The use of visual aids such as pictures, photos, or models to aid explanations and improve patient understanding has also been suggested (Iacono & Johnson, 2004; Burbidge & Iacono, 2005; Ziviani et al., 2004).

Communication within medical consultations typically involves verbal communication: and therefore relies on the ability of both the patient and doctor to engage in a spoken conversation. The situation becomes more complex when the patient does not use speech or has limited speech skills, and uses either informal means of communication or an AAC system to communicate instead. Some AAC systems may be relatively straight-forward to understand (e.g. picture books, symbols, electronic devices). Other AAC systems, such as key word signs, may require skilled communication partners for those systems to be effective. It is recommended that medical practitioners establish some familiarity with individual communication styles of patients with intellectual disabilities to improve communication (Iacono & Johnson, 2004). Medical practitioners are also advised to ensure that patients' communication devices (where applicable) are available and ample opportunities to use those AAC systems provided (Iacono & Johnson, 2004).

In situations in which people with intellectual disabilities rely on informal methods to communicate there are implications for medical practice. Obtaining self-reported information from patients may be more difficult or impossible. Even when medical practitioners have had extensive experience with a particular patient, they may need to elicit patients' medical histories mainly from patients' carers rather than directly from patients themselves. This is particularly problematic if the accompanying carer does not know the patient well enough to



Reflections of a Medical Student... (cont)

provide the medical practitioner with the detailed information required for an accurate medical assessment. In these cases it can be very difficult or impossible for the medical practitioners to get a comprehensive overview of the health issues of the patient.

In consultations in which the dialogue primarily occurs between the medical practitioner and the carer, it has been recommended that at least some of parts of the conversation should still be directed towards the patient (Iacono & Johnson, 2004; Ziviani et al., 2004). Some people with intellectual disabilities have better receptive communication skills than demonstrated expressive communication skills and hence may respond to parts of the conversation or even to accompanying nonverbal communication of the medical practitioner. People who may not understand the content of the conversation may still respond to the social and emotional cues of being included. People who demonstrate limited communication ability should therefore be greeted and involved in ways that are meaningful to them.

“**People who demonstrate limited communication ability should therefore be greeted and involved in ways that are meaningful to them.**”

Doctors should also inform patients prior to an examination occurring. This is particularly important prior to the conduct of intimate examinations, such as breast, vaginal, testicular, or rectal examination or when a procedure such as Pap testing is required. For people with difficulty understanding the spoken word, the touch that the doctor uses can be a powerful way of communicating. For example, touching the person under their arm may prompt them to raise their arm, or a gentle touch on the person's shoulder may calm him/her in an unfamiliar environment. Touch can, however, also be perceived as inappropriate, confronting and even threatening so an awareness of the patient's perception of the situation is extremely important.

Informed Consent for Medical Treatment

An issue regarding people with intellectual disabilities in a healthcare setting is how much control patients with intellectual disabilities have over decision making. Providing informed consent to medical treatment may be challenging, or not possible, given the communication difficulties that individuals with intellectual disabilities may have. Under Victorian law, a person is unable to provide informed consent if s/he is: (a) “incapable of understanding the general nature and effect of the proposed procedure or treatment” or (b) “incapable of indicating whether or not he or she consents or does not consent to the carrying out of the proposed procedure or treatment” (Guardianship and Administration Act, 1986, S. 36 (2)). The

first requirement then is to ensure that the patient is provided with sufficient information to make an informed decision. This may not always occur, as was demonstrated by Law, Bunning, Byng, Farrelly and Heyman (2005): In an interview, a woman with intellectual disability reported previously undergoing a “smear test” without knowing what it was. Assuming medical practitioners provide all the information that is reasonable, several different scenarios may occur with regards to informed consent and patients with intellectual disabilities. These scenarios are discussed below.

The patient is capable of understanding the information provided, making a decision, and communicating that decision. Regardless of whether speech or an AAC system was used, the patient's decision must be respected. Even if the patient should make a decision that the doctor feels is detrimental to the patient's health, that decision must be respected as the patient has the capacity to make their own decision on their healthcare. If, however, the doctor carries out an examination or procedure against the express wishes of the patient, the action is inappropriate, violates his/her human rights, and from a legal perspective, could be considered assault.

The patient is capable of understanding the information provided and making a decision, but has difficulties communicating that decision. A patient may understand more than what they can express. For example, a person with cerebral palsy may have no intellectual disability but have difficulty communicating clearly due to his/her motor difficulties. In some cases, someone who knows the person well, a friend, family member or carer may be able to interpret the intention of the person and check that they have understood the person's wishes correctly using yes or no questions. Difficulties may arise if the patient's carer is unable to interpret the patient's communication attempts.

The patient is unable to understand information provided and thus is unable to make an informed decision. Formal informed consent is not needed for emergency and ‘minor’ medical procedures (OPA, 2006a). Examples of minor procedures include visual examinations, first aid treatments, and prescription drugs. For many other examinations and treatments however, informed consent is a necessity. If a patient is unable to provide his/her own informed consent, the patient's legally defined ‘person responsible’ may be able to make a decision on his/her behalf. The ‘person responsible’ is usually the patient's closest relative based on a hierarchy beginning with the patient's immediate family to the patient's extended family (OPA, 2006a). The ‘person responsible’ may also be someone appointed by law (legal guardian) but is never a paid disability support worker. Paid carers are specifically excluded from acting in this decision making capacity. If however, the doctor is unable to locate a ‘person responsible’ to provide consent on behalf of the patient, the proposed medical treatment may still proceed if the following conditions are met, as outlined under Section 42K of the Guardianship and Administration Act (1986):



Reflections of a Medical Student... (cont)

- The doctor has made reasonable attempt to locate and contact the 'person responsible'
- The proposed treatment is in the best interests of the patient
- A notice is submitted to the Office of the Public Advocate, with the patient's details, supporting the medical practitioners proposal to provide treatment.

Assuming the recommended treatment proceeds (whether with the consent of the 'person responsible' or otherwise), two outcomes are possible:

- (a) *The patient indicates assent to treatment/intervention, and does not resist attempts to administer treatment.* Though it may seem that intervention should be continued, one ethical question is raised: Should medical procedures be performed on individuals who appear not to understand the process?
- (b) *The patient indicates dissent to treatment/ intervention, and resists attempts to administer treatment.* In this case, it may be difficult for the intervention to continue. Assuming the decision made is in the best interests of the patient, an ethical and legal decision needs to be made. Should the doctor do what is (presumably) best for the patient's health and proceed with the intervention albeit forcefully? On the other hand, should the doctor respect the patient's 'decision' even though the patient may not understand the current circumstances and is likely to become more ill? If consent has been obtained from the 'person responsible', it may or may not be overruled in consideration of the patient's reaction. It may be advisable for medical practitioners to contact the relevant authorities regarding specific cases. The Office of the Public Advocate (OPA) (Victoria) has an advisory service that can inform medical practitioners and service providers about the options in particular circumstances (OPA, 2006b).

The 'person responsible' may also decide not to proceed with the treatment. In such a case, should the doctor believe that treatment should not be withheld, the doctor may make an application to the Guardianship List of the Victorian Civil and Administrative Tribunal (VCAT) for treatment without the consent of the 'person responsible' (OPA, 2006a). Should the 'person responsible' continue to insist that treatment be withheld, the 'person responsible' must then make an application to the VCAT, giving reason for their objection to treatment. The VCAT will then make a decision on whether or not treatment should proceed (OPA, 2006a).

Given the significant consequences of communication difficulties that may arise with patients with intellectual disabilities, it is important that medical practitioners and patients' carers actively support their communication. This may be difficult for people with severe intellectual disability and/or those whose communication is difficult to understand. However, in most cases, it requires only allocation of additional

time and collaboration with carers who know the person well to optimise communication with the patient. Good practice may also require medical practitioners (as well as carers) to familiarize themselves with individual communication styles including AAC systems. It is also essential that medical practitioners familiarise themselves with legal issues regarding informed consent and guardianship to promote good practice. Collaboration between medical practitioners, patients and their carers may not completely remove all communication barriers, but will go a long way in affording people with communication impairments opportunities to be active participants in decision making in relation to their own health and wellbeing.

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Saliva Control & the Medical Solution: Two Personal Views

by Meredith Allan & Fiona Given

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With concluding remarks by Hilary Johnson

Earlier this year Meredith was asked her personal views about operating on the saliva ducts that help stop saliva uncontrollably flowing from the mouth. Meredith asked Fiona her opinion as Fiona had had a different procedure to Meredith. Both Meredith and Fiona felt that their stories and views should be shared.

This is a sensitive issue in the AAC community. We hate the embarrassment our saliva causes. Within the AAC community, we are relaxed about it as it is something we accept. However once outside our community, it is socially unacceptable for a person over the age of two years old.

Meredith

Each person has two sets of saliva ducts. In 1975 as a teenager, I had my two parotid ducts diverted. They were diverted to flow the saliva back down the throat. Theoretically, I have the same amount of saliva but most of it flows directly down the throat. I still "dribble" (I hate that word) especially when concentrating hard on something.

Life changed.

In 1976 I successfully integrated into a 'regular' secondary school, then proceeded to university and finally the workforce. Socially I was also accepted.

During the years immediately following the operation, I remember being thirsty. I mainly drank at night. I gave up salt in the early 80's which helped me not feel so thirsty.

It is hard to remember how bad the saliva was before the operation. One account I do remember was when my grandmother visited me at the hostel where I was boarding. My grandmother had brought me new serviettes. When she left me an hour later, the serviette was sopping wet.

After the operation to divert the saliva ducts, I was warned that removing my wisdom teeth would be difficult. In 1992, I eventually had my four wisdom teeth removed but there was no problem. My dentist did check with my primary surgeon before referring me to the dental surgeon to have the wisdom teeth removed.

I do have fillings. My nieces and nephews think filling are strange things (fluoride generation). Most of my fillings were between 1971 and 1975. I have been pedantic about my dental care since 1975. Of course, there are always repairs to be done. I am very grateful to my dentist for her patience, care and for always listening to what I say. Mind you, I pay the bills too.

Recently, I have had a very dry mouth at night. I ignored it at first thinking it was hayfever. After a few months of waking up every night with a dry mouth, sometimes up to four or five times a night, I knew it wasn't extended hayfever. Gradually, I realised it might be related to my saliva ducts.

My dentist has me on dry mouth gel and tooth mousse. The tooth mousse is a calcium and phosphorus formula which

protects my teeth due to the lack of saliva at night. They cost \$34 each and should last me three months. All very expensive. Fiona has also suggested I try Oral Balance.

I have no regrets about having the operation to divert my saliva ducts. It has allowed me to have a better quality of life than I would have had without it.

Fiona

I was only 6 years old when saliva control really started to bother me. My chest was always wet and from memory I got a lot of colds.

I had independent discussions with the head speech pathologist at Mosman Spastic Centre about my options. She said my options were bibs or surgery.

So I tried bibs for a while. Mum made bibs that blended in with my clothes. However, I still hated wearing them. I thought I looked like a baby.

This is where the freak child comes out. In 1984, aged 6, I decided to have my right submandibular gland removed accompanied with a left tympanotomy.

My parents obviously agreed because I was below the age of consent.

However, since I have started to get into health law, I have reflected upon this and have discussed it with my lecturers and they have said I possibly would have been competent to have made the decision. So I guess this is an illustration of how children with disabilities can be involved in decision making.

Following the operation, my dribbling reduced considerably. However, like Meredith, I still dribble a bit. I need to have a hanky with me all the time to wipe my mouth.

I have had similar side effects to Meredith. I get a dry mouth and have to drink constantly. I use Oral Balance at night and have water beside my bed.

Dental problems have been a bit of a nightmare since my early twenties. I have had my wisdom teeth removed, fillings and root canal treatment. Every time I need dental work, I require full general anaesthetic. This has happened five times in the past ten years.

I am meant to use tooth mousse. However, I am not as disciplined as Meredith and most nights I'm too tired to bother. My dental nurse, who I have had for a very long time says, "Please Fiona try to use tooth mousse and do not leave it too long between dental visits." If I do, she is on the telephone and then I know I am in big trouble! I would like to thank the dental clinic at the Spastic Centre for the service they provide.

I agree with Meredith that the saliva control surgery was successful. If I had not had it, I don't think I would have been able to go to a mainstream high school or university, let alone practice law.



Saliva Control... (cont)

Comments From a Speech Pathologist: Hilary Johnson

I have worked as part of a saliva control team at the Royal Children's Hospital, Melbourne, since 1987. I salute Meredith and Fiona for writing about this topic which causes so much distress to people with disabilities and their families. At the saliva control clinic our evaluations rely on parent and family feedback as the children are young or often cognitively unable to respond. Personal in-depth accounts by the recipients of surgery are rare but immensely valuable to future decision making.

Rather than enumerate the forms of treatment, I want to focus on some of the aspects of saliva control mentioned in Meredith's and Fiona's article.

There have been various types of saliva surgery over the years with the current surgery being relocation of the submandibular ducts (plus excision of the sublingual ducts) and ligation of one parotid duct (Scott & Johnson, 2004). The rationale behind including the excision of the sublingual glands arose from post surgery follow-up (Webb, Reddihough, Johnson, Bennett, & Byrt, 1995). Post surgery evaluations indicated thick ropery saliva deposited in the lip and corner of the mouth which was difficult to remove. As the sublingual glands produced thicker saliva and were also occasional ranula sites, these glands were excised. The surgery has two main aims; first to maintain the oral health and hygiene by targeting only some of the glands, and second to reroute the submandibular ducts in order to reduce the amount of saliva in the mouth while redirecting the saliva to hydrate the gastro intestinal tract.

The transtympanic neurectomy was less successful over time and it was thought that the nerves regrew. During the operation, the chorda tympani was cut which provides taste to the posterior two-thirds of the tongue. Surgeons commented that after the operation patients ate foods they refused prior to the operation (Mullins, Gross, & Moore, 1979). It would be interesting to see if Fiona remembers a change in reaction to the taste of foods.

The saliva clinic team has always involved a dentist and care is taken to ensure good dental health. For children with reduced tongue movements, extra saliva is beneficial for dental health and the surgeon is very keen not to produce an over dry result. Where children have caries or gum disease, build up tartar quickly, or live in non fluoridated water areas, parents are counselled about the importance of regular cleaning, flossing, sealants on molars, topical fluoride applications, regular dental checks and tooth mousse. These children can access regular dental cleaning under anaesthetic. We know there are long waiting lists for dental service for adults with severe disabilities and we do not know the long term outcomes for children once they become adults.

The saliva clinic team have always hoped that through research we would be able to establish the criteria that make for successful saliva surgery. This has not proved possible. Over

75% of children benefit but only about 5% are totally dry. Some children experience a short lived improvement and return to using medications particularly for important social occasions. Last month a young woman with cerebral palsy came into the saliva clinic a month after surgery. She thought the result was fantastic and she was delighted. I would welcome hearing other experiences of adults who have had the surgery when they were young in order to be able to inform parents and children in the clinic of any possible sequela in later life.

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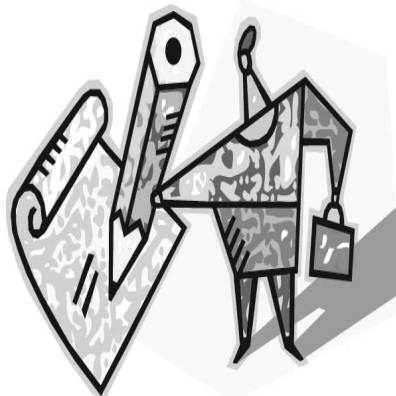
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Conference Report

by Hilary Johnson

Chair of the ISAAC board

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6th Augmentative and Alternative Communication Eastern & Central European (ECE) Conference Prague, Czech Republic Nov 29-30th 2007



In November 2007, I attended the 6th AAC Eastern and Central European Conference in Prague. Prague is a beautiful city despite the -2C temperatures in late November. I arrived to a light covering of snow. Much of the city is covered with small cobblestones, however I saw several electric wheelchair users who seemed to have no problem negotiating them. There is an efficient subway system but only some of the subway stations are wheelchair accessible. Many of the homes and apartments were five storeys, but very few had lifts.

I was invited to this conference to talk about ISAAC (International Society for Augmentative and Alternative Communication) and the membership benefits for Eastern and Central Europeans. Lucie Laudova, the conference convenor, opened the conference with support in sign and gesture which was followed by a welcome from a representative of the Czech Republic Ministry of Special Education, Youth and Sport.

There were 110 participants from 15 countries including Belarus, Czech Republic, Denmark, Finland, Hungary, Israel, Latvia, Poland, Romania, Russia, Slovakia, Ukraine, USA and the UK. The conference language was English and a simultaneous translation was available in Czech. Some participants had also brought their own interpreters. Many of the countries represented at the conference were only beginning to use AAC. People using wheelchairs attended this conference in spite of some physical access issues. There were two AAC users; one from Poland and one from Hungary.

The number of countries in Eastern and Central Europe becoming emerging AAC nations is growing. Some groups, like those from Poland, have developed some excellent resources and practices. The variety of local languages is a considerable challenge and as each country starts its AAC journey there are no materials available in their language. The journey does not start with AAC, but with general attitudes and policies in relation to disability. Two participants from the Ukraine reported that children with disabilities cannot attend school so there is no access to any educational program.

ISAAC has been instrumental in supporting some of the participants to enhance their international perspective. Alina Smyczek, from Poland, received a Bridge school/ISAAC award several years ago. Lia Kalinnikova, from Russia, received financial assistance to attend the 2006 ISAAC conference in Düsseldorf. Both of these people presented at this conference. Alina gave a very impressive history of the development of AAC in Poland. AAC commenced with a Bliss centre in Warsaw 20 years ago. Ten years later, lectures in university started and 7 years ago an AAC post-graduate study was added. Makaton training commenced only 3 years ago and there are now 5000

people trained in its use. People are writing their own books including one about the Polish experience of teaching and using AAC. Also in Poland, a family program with Polish resources relating to AAC has been developed. There are now 55 special schools that make use of AAC technologies. The country now has its own AAC organisation "Speaking Without Words" with 107 members and an ISAAC chapter.

Also at the conference was Lia Kalinnikova, the only Russian ISAAC member. She is from Archangelsk near the White Sea. She will be hosting the 7th AAC Eastern and Central European conference in early July 2009. In her geographical area there are several large institutions of over 500 people, with social work services only in early stages. She is involved in an education project to establish AAC in Minsk and Belarus, which is financed by the Swedish Eastern European Committee, the Swedish Institute of Education and Pomor University. Project participants will be parents and professionals in the areas of disability and AAC. The project will begin with 60 participants being introduced to the social model of disability and AAC. The second level of training will focus on the development of an educational course and resource centre by 30 specialists and special education teachers.

There were also two presentations that involved people who use AAC. Ania Kazimlczak and Maja Adamczyk told us their AAC story. Ania gave a moving personal account of her increasing use of a voice output aid. This process was enhanced by her growing friendship with Maja, a young woman of her own age, who programmed the device in her own voice. Maja is the daughter of Ania's speech pathologist (Aldona Mysakowska-Adamczyk). As part of her presentation, Ania also included a photo of Meredith Allan (an Australian ISAAC member) who had inspired her on a visit to Poland.

Attila Pal Pager and Richard Faher, from Hungary, provided a joint presentation which focused on Richard's talk to secondary school students in a mainstream school. In order to get to the room they had to carry him in his wheelchair up the stairs.

There were many highlights from the conference, including the dinner in a lovely restaurant complete with a piano accordion player. Everyone was very friendly and supportive. I also met with Dorothy Fraser, an ISAAC member from Scotland, and her colleagues from a school in Romania. They are hoping to form an ISAAC group utilising a program called *5 plus 5*. Dorothy has bought a house in Transylvania and is offering accommodation for anyone interested in visiting or supporting their project. Finally, thanks in particular to Lucie Laudova and Jana Sarounova for their amazing organization and hospitality.

2020 Summit Submission

Introduction by Wendy Webster

The Prime Minister of Australia Kevin Rudd convened an Australia 2020 Summit at Parliament House on 19 and 20 April to help shape a long term strategy for the nation's future.

The Summit brought together some of the best and brightest brains from across the country to tackle the long term challenges confronting Australia's future – challenges which require long-term responses from the nation beyond the usual three year electoral cycle.

To do this, the Government brought together 1000 plus leading Australians to the national Parliament to debate and develop long-term options for the nation across 10 critical areas:

1. The Productivity Agenda – education, skills, training, science and innovation
2. The Future of the Australian Economy
3. Population, sustainability, climate change and water
4. Future directions for rural industries and rural communities
5. A long-term national health strategy – including the challenges of preventative health, workforce planning and the ageing population
6. Strengthening communities, supporting families and social inclusion
7. Options for the future of Aboriginal and Torres Strait Islanders
8. Towards a creative Australia: the future of the arts, film and design
9. The future of Australian governance: renewed democracy, a more open government (including the role of the media), the structure of the Federation and the rights and responsibilities of citizens
10. Australia's future security and prosperity in a rapidly changing region and world.

In addition to those participating in the Summit, all Australians were invited to make submissions on each of the 10 future challenges. These were submitted to the Department of Prime Minister and Cabinet which acts as the secretariat for the Summit. ISAAC Australia and AGOSCI would like to thank Meredith Allan for putting together a submission after collaborating with (Dr) Bronwyn Hemsley, Karen Bloomberg, Hilary Johnson, Melinda Smith, Wendy Webster and Cath Gunn. It was decided to submit under the "Strengthening communities, supporting families and social inclusion" section and defined the topic as: *How we provide practical support to families to combine the tasks of work, raising children and caring for ageing parents.*

How we provide practical support to families to combine the tasks of work, raising children and caring for ageing parents.

Approximately 1 in 500 people in Australia have Complex Communication Needs (Perry et al. 2003). Complex Communication Needs (CCN) is defined as:

Communication problems associated with a wide range of physical, sensory and environmental causes which restrict/limit their ability to participate independently in society. They and their communication partners may benefit from using Alternative or Augmentative Communication (AAC) methods either temporarily or permanently.

This means there are a number of people who struggle with speech and cannot use speech alone to get their needs met. Many people with CCN also have other associated physical, intellectual, sensory and social emotional issues that impact on their ability to participate in the community.



Everyone with a CCN is part of a family unit. The communication problem therefore does not just impact on the individual but also on individual's communication partners. Whether the communication disability is developmental, acquired or progressive the impact significant as communication is fundamental to all aspects of daily living and quality of life. People with CCN often rely upon augmentative and alternative forms of communication (AAC). Alternative and augmentative communication (AAC) refers to an area of research, clinical and educational practice. AAC involves attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restrictions of persons with severe disorders of speech and language production and/or comprehension, including spoken and written modes of communication. (2005, p.1)

Issue that impact on these individuals include access to:

- Appropriate education –including early intervention services, non-segregated primary and secondary schooling, post-school options



2020 Summit Submission (cont)

- Appropriate housing and accommodation options
- Appropriate communication support services
- Appropriate communication aids and technology
- Appropriate attendant care support
- Meaningful daytime activities – including paid and unpaid employment

Solutions include:

- Valuing unpaid carers: keeping people with high support needs with their families. Increasing the carers allowance in line with increases in the CPI.
- Increasing the time available for respite
- Offering respite in a variety of models eg. In-house respite
- Building more respite facilities – that are physically accessible and communication accessible
- Increasing the disability pension
- Increasing the number of speech pathologists trained
- Including training in AAC (Alternative and Augmentative Communication) to disability support staff
- Funding to adapt worksites to become more “communication friendly”
- National funding for non-technological communication aids (based on the Victorian NECAS – Non-electronic Communication Aid Scheme)

- National funding for technological communication aids (based on the Victorian Aids and Equipment Program)
- Adapting worksites to ensure workers with disabilities have access to employment

Employment

Most people with CCN have mobility disability, so employers, like the rest of the community, see not one disability but multiple disabilities. There is or will be a severe worker shortage in Australia. Both employers and potential employees with CCN have to be able/allowed to see the possibilities.

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A Speech Pathologist at the 2020 Summit

by Juliet Vanyai

Speech Language Pathologist, Education Department Tasmania

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When the idea for the summit was first publicized I remember saying to my husband “There should be a speech pathologist at that!” I think he’s known me long enough to nod and agree with statements like that but I really felt passionately that our profession has such a valuable contribution to make to early childhood care and education. I briefly considered making a submission which involved writing about yourself and your idea and paying your own way to Canberra but shelved the idea as the busyness of day to day life took over. So when I saw the opportunity to make a submission to the Mercury newspaper in Hobart and attend the summit all expenses paid I wrote 50 words about the importance of early oral language skills particularly in the transition to written literacy and the next thing I knew I was on my way to Parliament House.

The whole experience was so interesting on many levels. Sure it was exciting to rub shoulders with so many people in the public eye (I walked past Hugh Jackman at a social function but decided against interrupting his conversation with another “summiteer” to retain any professional credibility I may have had!) But even more satisfying was to participate in discussions





A Speech Pathologist at the 2020 Summit (cont)

with the group of 25 in my sub-stream of early childhood and schooling. There were several others making similar arguments for putting resources into early childhood development such as Professor Frank Oberklaid, a pediatrician from the Royal Children's Hospital in Melbourne, who warned that it was a "pay now or pay later" question.

There were many challenges such as convincing the other sub-streams within the Productivity stream that without an emphasis on early childhood, there would be a much poorer outcome in terms of numbers and skills of employable workers. The other challenges were condensing my point to make it punchy enough to get across to politicians or people who don't work in health or childhood education. I was even lucky enough to have a chat with Kevin Rudd who to his credit was interested in what it was like working in schools "at the coalface". I tried to stress the

importance of interactions between parents and children and of allied health professionals such as speech pathologists in his proposed "one stop shop" parent child centres. He seemed to take that on board but he was also interested in the size of my HECS debt!

Another topic that deserved more of a mention that it received was disabilities. There was a lot of emphasis on disadvantage but this minority group didn't seem to be a priority.

All in all it was a very exciting peek at some of the workings of government. I do think our profile as a profession needs raising as it was hard work sometimes to help people to understand why a speech pathologist might be concerned with children's educational outcomes. I was fortunate enough to come away with some contacts to pursue and a real sense of pride in our profession and our use of evidence as a base for what we do.

Mountains and Molehills: The South Australian Statewide Complex Communication Needs Project

by *Janelle Sampson*

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Due to a generous allocation of South Australian State Government funding, the diverse range of services required to fully support people with Complex Communication Needs (CCN) is finally on the map in South Australia.

In 2007, the State Government announced funding for a period of 12 months for the Statewide Complex Communication Needs (SCCN) project, managed through the NovitaTech Division of Novita Children's Services in South Australia. The aim of the project is to enhance the communication opportunities and participation of people from 0-65 with CCN in South Australia. The expected outcomes of the project are:

1. Assessment, prescription, provision and follow up of cohesive and effective total augmentative communication systems for people with CCN.
2. Development of community knowledge, skills and attitudes to support enhanced opportunities and participation of people with CCN.
3. Enhanced social networks for people with CCN.
4. Investigation of potential service models to support the development of an ongoing, state-wide 'community' of people with CCN, their caregivers and service providers.

With much excitement and an equal amount of trepidation, I took on the role of Project Manager in November 2007. I am completely aware that to achieve such aims and objectives is a long term and complex process requiring a multitude of partnerships, programs and approaches. This is the mountain that we face and with only 12 months of funding available it may seem an impossible mission. However, for such a good cause I was willing to give up any sense of control over my work-life balance and take this on with the hope that we may create a foundation, or shall we say a molehill, on which to

build this mountain. In the past, services to people with CCN in South Australia have varied in terms of availability, funding and expertise dependent on age, diagnosis and geographical location. It is hoped that even a molehill can seed a more comprehensive and equitable approach to these much-needed services.

As I write this article, the project is approaching the half way point. This is a time to panic of course, but also to look at what we have accomplished and hope to still achieve. There are still many challenges ahead as well as future planning for services for people with CCN at the completion of this project.

Achievements to Date

Personally, my most important achievement to date as Project Manager has been the recruitment of a dedicated and energetic team. Without their understanding and acceptance of this challenge, and their enthusiasm, even a molehill would be unachievable.

As a team, we have placed our initial focus on the first two expected outcomes listed above – communication solutions and communication partner/service provider training. These were the primary drivers of the funding and the most acute and pressing needs. From this, we are averaging 4-5 new referrals per week since the beginning of February, and 7-8 enquiries per week to our information and advice service. Our current referral statistics show a predominance of male (82%) over female (18%) and an almost equal number of children (53%) to adults (47%). Primary referral groups in order of frequency are people with Autism Spectrum Disorders, Motor Neurone Disease, Cerebral Palsy, Stroke, Head Injury and Intellectual Disability. We are also receiving referrals from a diverse range



Mountains and Molehills... (cont)

of service providers (11 different agencies to date) including disability agencies, schools, hospitals, not for profit agencies and community health services. The communication solutions service to date has been developed as a support to primary therapists, rather than taking on clients individually. The reasoning for this is that although many agencies are finding it difficult to meet the demand for services, all clients eligible for the project are also eligible for services from an existing agency. If the SCCN Project were to take on clients without the involvement of these agencies there is potential for disconnected and inequitable services, as well as contraindications to the prioritisation and workload management practices used by these agencies. Additionally, it is more beneficial to support therapists through the process of developing communication solutions for their clients with resources and/or expertise, rather than taking over. The aim of this is to build the capacity of existing agencies to provide more efficient services during and beyond the timelines of the SCCN Project.

The trial and loan program has also shown a positive outcome to date. The project funding has allowed for a wide range of communication equipment to be purchased or created (both electronic and non-electronic), that is available to clients and therapists. Client loan is a priority; however there have been many requests for loan of the equipment by therapists for familiarisation, comparison and demonstration to their clients. The client loan of equipment is available in order to achieve a comprehensive trial prior to allocation for long term funding. During the trial period, SCCN can assist with:

- modifications to the equipment
- providing client and communication partner support
- evaluation of the trial by the client, primary communication partners, and therapist.

Following evaluation of the trial, equipment may be recommended (or not recommended), a different item may be loaned for trial, or an extension of the existing trial may be negotiated. Although there are only a small number of referrals at the point of equipment provision so far, this program has already resulted in a few changes to the type of equipment that was originally suggested.

Several training and information sessions have been held to date and many more have been requested and scheduled. Recipients include people with CCN, their communication partners, service providers, allied health students and the general public.

We have also completed two additional grant applications for programs that will support people with CCN but were not listed as our core deliverables for the project this year.

Other Project Plans

Although our focus to date has been on communication solutions, equipment, and information/advice services, we are eager to allocate time to capacity building activities. These capacity building activities will focus on training for communication partners and service providers, resource development, social networking events and public awareness activities. One part of this is a joint initiative with AGOSCI SA to establish an AAC (augmentative and alternative communication) Special Interest

Group, the first of which is scheduled for the end of April 2008. Resource development will also be particularly important as these resources may be useful and time saving to others beyond the life of the project. Social networking events will be organised based on the Club Yacky Yack model developed by Novita Children's Services but with a wider eligibility criteria and age range.]

Challenges

Clearly the biggest challenge has been the time limitations of the project. The impact of this are the decisions we must make about which tasks are must haves, highly desirable, or just beneficial to have. We must consider not only the needs of the here and now, but how to allocate our time to ensure the sustainability of the project beyond the end of the funding period. We must also accept the obvious pitfalls that come when processes are developed in haste. It is important to view the project as a testing ground for such processes and programs rather than the final or ideal solution. To this end, modifications, inclusions and exclusions are ongoing and based on client feedback and an increasing awareness of unmet need and new challenges.

Other challenges have been the corresponding timing of the restructure to both Novita Children's Services and Disability SA. Additionally, the diversity of the client group in both age and type of disability and the diverse range of AAC experience of referring clinicians has required flexibility and creativity in service delivery and resources.

Future Plans

High priority is given in the project to partnerships and collaboration with existing agencies as well as the involvement of people with CCN in the determination of the types of services and recommendations for the future. Our hope is that some of the processes and resources developed throughout the project will be utilised by other agencies and that partnerships and collaboration across service agencies continue. We also hope that the involvement we have had through client referrals, consultation or training with other service providers will raise awareness and understanding of approaches to communication solutions and ongoing support for people with CCN. A major aim for the sustainability beyond the project is to develop a sense of community and collaboration between stakeholders.

There is of course so much more and so little time but with such a fantastic and dedicated team, and the support and enthusiasm of our stakeholder group we hope to at least build a molehill that will grow up to be a mountain.

For more information on the SCCN project or to join the mailing list, visit the website www.novitatech.org.au/sccn or contact us:

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AAC, the Arts...and Sport!

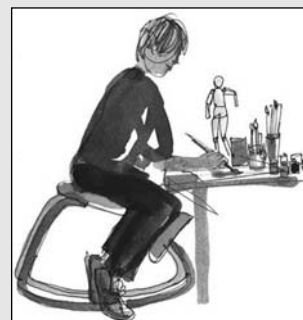
“Art is communication.”

People everywhere express and receive messages through the arts. Creative works hang on walls of our houses, play on the radio, line our bookshelves, and show at local movie theatres. It is important to acknowledge the potential impact of the arts on the lives of AAC users. Music, painting, sculpture, writing, drama and dance convey a range of ideas, thoughts, and feelings. Often the arts can express emotional messages with more depth than traditional modes of communication. The arts can be important to all of us because they provide:

- A source of enjoyment
- A vehicle for self expression
- A means of escape from daily routines
- A way to relax
- Meaningful leisure activities
- Opportunities for socialisation
- An avenue to learn the experiences and feelings of others
- A forum to foster independent thought and divergent thinking
- Access to new experiences.

(John McCarthy in Augmentative Communication News Dec 1997)

For this reason AGOSCI In Focus would like to encourage artists (and sportspeople!) to contribute their works of art and articles related to their experiences of art or sport to the magazine. This will also highlight creativity and expression of personality beyond the AAC interaction. There will be a \$50 payment for each item published so please forward your articles to the Editors. We are also on the lookout for artists to feature on our cover! (Payment is \$250). If you're interested please send the editors a photo of the artwork (high resolution jpeg, 300dpi, 10cm x 15cm), a short bio and a photo of yourself, the artist.



Rosebud and the Elves

by Samantha Rogers

My name is Sam (Samantha), I learnt to do Facilitated Communication about three years ago. I love to write stories and I love fairies at the moment. People thought I was stupid, but I just couldn't talk. I like being able to do Facilitated Communication because I can make my wishes known now. It is a great feeling! I hope you like my story. Sam

One day Rosebud looked out and saw the birds singing and the flowers blowing in the breeze. She was happy to be alive on such a lovely day.

She decided to go and visit her friend Lilac Fairy. "I think I will take her a present of some sweets" she said. I know she likes candy so I will make her some.

She got out all of the ingredients and started to make the sweets. She mixed the sugar and other things in a big bowl. She mixed and stirred away to make nice sweets. When she finished she put them in pretty papers. She put them on the table to set and then went to get ready.

Some naughty Elves had been watching her. They sneaked in and took the sweets and ran away and hid. They ate all the sweets and felt very full. They had very sick tummies and wished they hadn't eaten so much.

Rosebud came out all dressed to go out. Then she screamed "where are my lovely sweets?" Where could they be! She looked everywhere for them. Then she sat down and cried big tears. What am I going to do she thought? She thought and thought. I'll never find them now. Then she heard a little squeak near her. I don't know what to do she thought.

The Elves were hiding in the woods. They did not care that Rosebud was sad. They only wanted to eat the sweets.

Rosebud dried her eyes and looked down and there was a tiny mouse. She smiled at the mouse. It knew what had happened to the sweets but could not tell her. It made a noise to try and help Rosebud. It squeaked and squeaked. The Fairy knew it was telling her something but she couldn't understand it.

Then she saw a bird flying overhead. It was making a noise too trying to tell her about the Elves. Then another Flower Fairy called Lucy came up to her. "I can understand the bird language" she said to Rosebud. "The bird is saying the Elves took the sweets and ate them all" she said. "They are hiding in the woods and have sick tummies".

"Let's look for them" said Rosebud to Lucy. Soon they were walking to the woods carrying big sticks. "We will chase them away" she said "they are naughty". They found them and chased the naughty Elves away.

I will make more sweets now and stand guard till they are set nicely. Then I will invite all my friends over to share them. Rosebud had a lovely party and they were all very happy.

The End



It's Not Rude

by Melinda Smith

In my workplace, I've learnt
To step in, contribute to conversations
Without feeling guilty
For interrupting someone else –
Though sometimes I feel bad
Deep down – it's like I'm rude
And I need to be
If I want to keep up, to
Conversations around me.
I'm passionate about communication,
I love to listen
I love to talk...
My chances to talk
Have never been natural, years of hard work
Years of practice
To make my voice.
I've gone through the process of being
Left behind,
Judged for being too slow,
Too quiet
Too polite...
I've gone through enough
To make me realize,
It's my voice and this is how I talk
This is how I participate
I don't need to wait for a break
To speak and miss out,
I want to engage
I want to share small talk
I want to be able to contribute
My view
My opinion,
Face to face
In meetings, and cafes
I only need a bit more time,
Consideration,
Even fairness
From my communication partners –

To recognize it's not because I'm rude
I've pressed the button,
I need to speak too.

Being a Leader in a Leader-less World

by Melinda Smith

As an AAC user, it's not natural to be a leader,
In a world that speaks, there's a lot to look up to.
In a world that doesn't speak, there's a lot to learn from.
By changing the regularity of ground rules to give someone
more time
Means opening up the chance for an AAC user
To learn new skills for building confident and Self worth,
To experiment what self expression is about.

I used to feel intimidated
I used to feel powerless
I used to worry about my hearing
I always said sorry to people
I used to be bothered by slowness
I used to get upset when people didn't understand
I used to not make the effort to tell people my thoughts
I used to make excuses for conversations

In 2005 the leadership course shifted my thinking
Empowered me to speak for myself,
Took me on a different direction in my journey
As an AAC user
In my workplace
The leadership course was not just about me
It was about engaging with society
Communicating with other communicators
Turning my life
Around
Making me a participator
With my talker.

My struggles still exist, but not as personally demanding
I know my feelings more
Crying for help when it gets too much,
I'm not tough and I don't let out anger much,
But I know my voice
Through learning to express

Who I am.



Go the Broncos!

by Scott Stephenson

Scott Stephenson loves sport. He might be a spectator and Broncos supporter while the activity happens on the footy field, but being a Queenslander he loves to get onto a surfboard.

Scott has recently acquired a Vanguard 84 and is learning to communicate with scanning and auditory cueing... which is no mean feat with all that remembering what is on "Row 1" "Row 2" etc. His memory does not let him down!

Here is his story about meeting Darren Lockyer written with the support of his Mum, Sue.

Through a wish granted from the Starlight Foundation, Scott met his footy hero Darren Lockyer (Lockie). It was the day before the Cowboys versus Broncos game at Suncorp stadium, and Scott went to watch the Broncos' train at their home ground.

Everyone in Scott's family are Broncos supporters and their favourite thing is to watch is Lockie in top form. Grandma, Pop, Matthew (brother), and Sue (mother), went with Scott to check out the Broncos.

They watched the boys train and practice their touch football manoeuvres. At the end of training, Lockie came looking for Scott.

Scott is 15 years old and had recently got a Vanguard communication device. He had only been using it a few weeks. Scott uses a head switch to select the items on the device and has to wait for the device to scan to the area for selection (it scans down the page and then once the row is selected, scans left to right). He uses auditory prompts via a pillow speaker (a small speaker) near his head rest to hear the options softly, as his vision is not great.

The night before the meeting, Scott and his mum had prepared 3 things for Scott to say to Darren. These were stored in the quick hits section of the activity row. Scott had to select the correct row using his head switch when the device scanned down the screen and by listening to the auditory prompt from the pillow speaker, and then had to select again using the head switch to select the correct item to say.

Lockie was very patient as Scott selected what he wanted to say.

This is what Scott had to say:

1. "Hi Lockie, it is great to meet you. I love to watch the footy on TV."
2. "We love to watch you play and we yell at the TV, 'Go Bronco's!'"
3. "We were sad when you hurt your knee. We are glad you have recovered and look fit and ready to win. My family and I are coming to watch you play tomorrow."



Lockie was very impressed with Scott talking using his device. While Darren stayed and talked to the group, Scott used his device to repeat several times (unprompted), "Hi Lockie, it is great to meet you. I love to watch the footy on TV." Each time, Darren would stop talking and say it is great to meet you too.

It was a fantastic visit. Scott and his family also got to watch the Broncos thrash the Cowboys the next night. It was the first time Scott had been to a large event with so many people. There were fireworks every time the Broncos scored, lots of cheering, a mascot horse and, of course, the cheer squad. It was a fantastic night for the whole family. I have not seen Scott so happy in a long time. We hope the Broncos continue to have a great season!





Movie Review

The Diving Bell and the Butterfly

by Cathy Willmott

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“I decided to stop pitying myself. Other than my eye, two things aren’t paralyzed, my imagination and my memory” (Jean-Dominique Bauby, 1997).

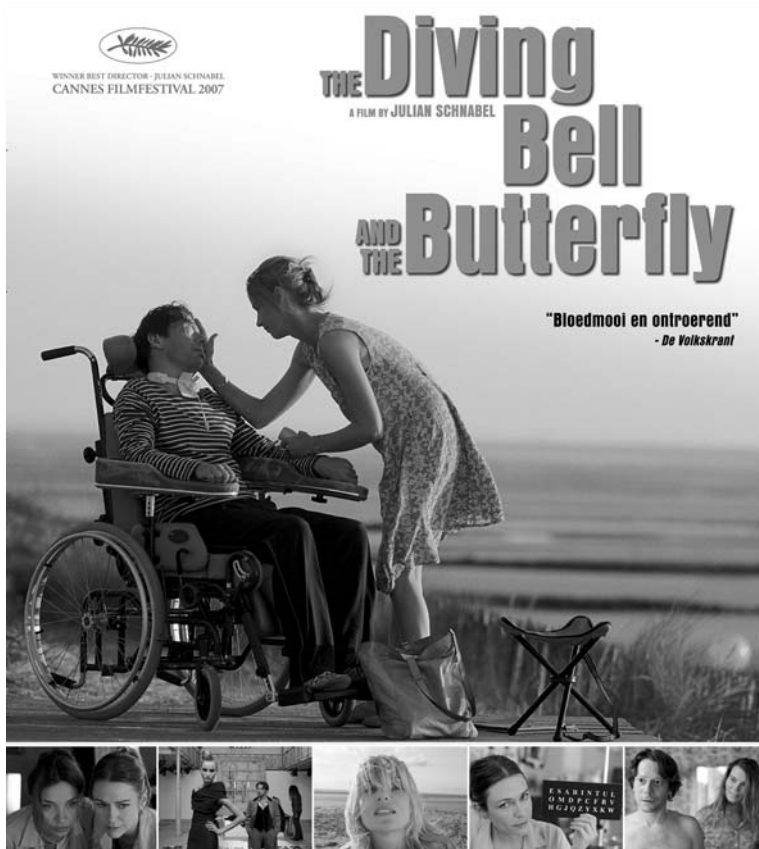
Based on Jean-Dominique Bauby’s 1997 memoir of the same name, “The Diving Bell and the Butterfly” (“Le Scaphandre et le Papillon”) by director Julian Schnabel, tells the story of Bauby’s experiences of life with locked-in syndrome. At age 43, Bauby, then editor-in-chief of the fashion magazine “Elle”, suffers a devastating cerebral vascular accident. Awakening from a coma, Bauby finds himself imprisoned within a body he can no longer move or control, but with a mind that remains free and unaffected. Thus, the metaphor of the heavy diving bell and the light butterfly is used by Bauby to powerfully contrast the new actuality that is his body and mind.

While locked-in syndrome dispossesses Bauby of his ability to communicate verbally, the relationship between the viewer and his character quickly develops, as we alone are privy to Bauby’s incisive and often sardonic inner thoughts (subtitled for those of us who do not speak French!). This intimacy is further heightened by the fact that a significant portion of the film is shot from Bauby’s perspective. We, as the viewer, awaken in the hospital with Bauby to the confusion of blurred images and sounds, and when advised of the medical advances and resources that have made it possible to save his life, it is only we who hear Bauby’s impassioned response “This is life!?”

Through this sharing of perspective with the viewer, Schnabel is able to portray some of the moments of true horror detailed in Bauby’s memoir. However, while these horrific moments do exist, they do not define Bauby’s existence, and are tempered by his ability to build beautiful images of his life, both real and imagined. There is loss, but there is also Bauby’s tenacious spirit and determination, which sees him accept the previously unimaginable, drawing strength from memories of his life before his stroke, and from the imagination which frees him from the confines of his body. It is this tenacity which sees him, with the assistance of his speech pathologist, learn to communicate again with the outside world. Using his left eye (the only part of his body he is able to control after his stroke), Bauby painstakingly blinks messages letter by letter to his family, friends, and staff at the hospital where he is interned. It was this method that Bauby used over a period of 14 months to dictate the brilliant and moving “The Diving Bell and the Butterfly”.

The end result of Schnabel’s sensitive interpretation of Bauby’s text is a film that is extremely moving and engaging, while managing to avoid degenerating into a condescending or saccharine retell of Bauby’s experience. “The Diving Bell and the Butterfly” is raw and authentic, it is as humorous as it is sobering, and at 112 minutes, it is well worth dedicating the time to become acquainted with the indomitable Jean-Dominique Bauby.

Note: supplies of tissues and chocolate are highly recommended!



The Black Balloon

by Aileen Ryan

Aileen Ryan is well known as a major contributor to the following Makaton Australia resources, "The Makaton Vocabulary – Australian (Auslan) Edition (2001)", "Key Signs: a supplement to The Makaton Vocabulary Auslan Edition (2002)", and "Let's play with sign (2006)".

In addition to these books Aileen has published her own resources "Sing and Sign with Me (2002)" and "Tiny Hands (2005)". Aileen is an experienced teacher of sign. She began to conduct sign workshops in 1996 for staff supporting her daughter, Elysha, who has Down Syndrome and is hearing impaired. At that time, the need for information, publications and education in the use of Key Word Sign was paramount, as Aileen tried to find books and courses for her daughter's early childhood staff. Aileen runs her own business "Hands Can Talk", is a Makaton Presenter and is the Sign Liaison Officer for Makaton NSW. Her collaborative role with the stars and crew of *The Black Balloon*, has ensured that the film's gritty and realistic plot has been further strengthened by the authentic approach to the use of Key Word Sign.

Simple concepts for authenticity were crucial, such as Charlie's mother (Toni Collette) was the one who signed the most fluently, that short sentences and phrases were used when talking and signing with Charlie, that Charlie did not use accurate sign production and that signs used in Australia were used in the film. These ideas became central to the film story and are the subtle touches that are easily recognizable for those who support individuals who have complex communication needs and use Key Word Sign.

The following is Aileen reflection on being involved with "The Black Balloon." It has been adapted with permission from Aileen Ryan's report on <http://www.handscantalk.com.au/>

In January 2007, Aileen was contacted by producer Tristram Miall in reference to assisting the cast with using sign language in the movie "The Black Balloon." At the time Aileen was on holidays and, not being truly in the mood for work, thought Tristram was a student producing a small movie but she said she was pleased to out. After getting off the phone Aileen mentioned to her family what was happening, "Tristram had mentioned an actress - ummm Toni ??? Yes that's right Toni Collette." Now everyone was getting excited. Aileen looked up Toni Collette and talked to friends and family who, of course, had seen her in quite a few movies and thought she was fabulous. Aileen watched some of Toni's movies and could see what all the hype was about -Toni was great at what she did!

First Meeting

Aileen went to Holsworthy, the house being used for the movie, and met Tristram (Producer), Elissa (Screenwriter & Director), Toni (the mum), Erik (the dad), Rhys (the brother) and Luke (Charlie "the brother with autism"). Aileen's comments at the time were: "it was fun meeting everyone", "relaxed and casual

and they all picked up the sign language easily", "we used bits of Makaton, Auslan and Signed English" (as the books available at the time that the movie was set in were only the Signed English and early Makaton book) . A few times in the movie signs were used that were more readily available now through Auslan.

Second Meeting

Aileen again met up on set and practiced with the cast. Having parts of the script to work from made it easier to plan and try to keep everything looking natural and not overdone. Aileen was then filmed doing the signs to help everyone with revision and Gemma (girlfriend of Rhys's character) was able to do all her practice thru the video clips.

Third Meeting

Aileen went back and took Elysha with her to meet Rhys, or better known to her as Luke from "Home & Away". Elysha was wrapped of course and only interested in LUKE!! She had photos with him, saw him on set, and had lunch with LUKE.

Finally

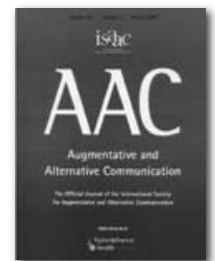
It was hard for Aileen to not talk about the movie to all around her, but finally the movie is released and you can read reviews from those who have already seen it, or look at a trailer, and read short pieces on the cast.

Aileen said she did not want to be paid for her involvement in the film and fitted in with cast and crew time-frame. Aileen got involved simply because someone asked her to and the thought of a film being made and sign language being included (therefore improving and increasing people's understanding of the use of sign language for people with speech and/or developmental delay) was all the incentive Aileen needed.

Go see the film, it's brilliant! Elissa (the Screenwriter and Director) should feel fantastic. What a tribute to her life growing up with two autistic brothers. Every actor in the movie gave their utmost and shone through.

AAC - ISAAC's Professional Peer Reviewed Journal

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



If you are interested in subscribing to this journal, please see the information in the ISAAC Membership forms, included with this edition.



Book Review

The Communication Access Toolkit

Reviewed by Kathryn McKinley

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Parr, S., Wimborne, N., Hewitt, A. & Pound, C. (2008). The Communication Access Toolkit. London: Connect – the communication disability network.

Price: \$500, includes toolkit and two-day training course

The Communication Access Toolkit is a new resource designed by Connect, a UK charity working to promote effective services, new opportunities and a better quality of life for people living with aphasia. This new toolkit was published in January 2008 and is the product of a three-year project undertaken by Connect. The toolkit is sold as part of a 2-day training course, run by trainers at Connect, titled "Making Communication Access a reality".

The toolkit has been designed to be used as a resource to help clinicians raise awareness of communication access issues in health and social care settings, as well as voluntary sector settings. The resource provides step-by-step guidance on how to plan, run and evaluate the training. Communication access training is aimed at all service providers, from professionals and clinicians to assistants, administrative staff and volunteers – anyone who has day-to-day contact with clients with a communication disability.

The aim of the toolkit is to equip the clinician and the service providers they train, with the skills, techniques and resources to make their service accessible to people with a communication disability. The toolkit provides the clinician with everything they need to plan, prepare, run and evaluate the "Making your service accessible: communication matters" training programme. The toolkit includes:

- the trainer's book, for the clinician to use, which contains background information, the training program and extra resources (e.g. how to plan for the training, resources required)
- a CD, which has all the Power Point presentations required to do the training, a set of tools to help with course administration (in PDF and Word templates e.g. a certificate for course participants, an agenda for the training day) and pages of the trainee book so that they can be printed and given to the trainees
- a DVD, which has video clips about communication access to be used in the training, and
- a bound copy of the trainee's workbook.

The training program works through eight modules including:

- Thinking about communication access
- What is a communication disability?
- What is communication access?



- Making interactions accessible
- Making documents accessible
- Making environments accessible
- Communication access stories
- Action planning

Whilst the toolkit training program was developed by and with people who have aphasia, the principles of communication access hold true for other groups including people with intellectual disability, developmental language delay, dyslexia, depression, anxiety, or other mental health conditions affecting communication, and other communication difficulties i.e. no or limited English.

The toolkit gives ideas regarding course structure, and can be adapted to be run as a one-day session, two three-hour sessions, three two-hour sessions or six one-hour sessions, allowing for the training to be delivered flexibly to suit trainees' work patterns and shift requirements. The toolkit also provides the clinician with practical ideas for setting course dates, attracting potential trainees, recruiting trainers, choosing a venue, equipment and resources, and support and follow-up.

The training programme uses Kagan's (1995) "Supported conversation for adults with aphasia" as a framework for their training, particularly when discussing making interactions and documents accessible. However, Connect have moved away from using terms such as supported conversation, read easy, or aphasia friendly, towards the term communication access which can be readily used for all people who have a communication disability. The training has the potential to be used across a wide range of settings, from hospital and community health to disability and education.

As the toolkit has been developed in the UK, there are some parts of the training that need adapting to be used with an Australian population. For example, the UK's Disability Discrimination Act is discussed in one of the modules and this part would need to be changed to discuss our local state and federal disability acts.

This is a great resource, and one that is ready for busy clinicians to start using, with all the hard work done! For more information, visit Connect's website www.ukconnect.org or email lukechamberlain@ukconnect.org.



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 (see page 39 for more details). 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 2008 issue is 'Being a Good Communication Partner'.

However, 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 Emily Armstrong:
emilyarmstrong.ea@gmail.com

or Sheridan Forster:
sheridanf@yahoo.com

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

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



COMMUNICATION - *Feel the Power*

AGOSCI 9TH Biennial National Conference
7 - 9 May 2009 CANBERRA AUSTRALIA

The 2009 AGOSCI Conference Committee invites you to be a part of the next national AGOSCI conference being held in Canberra from 7-9 May 2009. ***Feel the Power*** of exchanging information and ideas with like-minded people from around Australia and overseas!

The conference will offer delegates a rich menu of learning and sharing through concurrent programs focusing on the latest strategies, developments and research assisting people with a complex communication need. AGOSCI conferences are uplifting, stimulating, fun events that invigorate delegates to return to their lives or place of work armed with the latest know-how and a heap of new friends, experiences, networks and information.

If you live with someone with a complex communication need (CCN), work in the area of augmentative and alternative communication (AAC), or have a CCN yourself, then:

1. mark the conference dates in your 2009 diary
2. look out for registration and sponsorship information at www.agosci.org.au
3. flag with your organisation's Professional Development Committee that you will be submitting an application to attend this conference in the near future!

The Call for Abstracts is out and is available at www.agosci.org.au with a closing date of 1 August 2008. Could you contribute a workshop, presentation or poster?

HOT NEWS HOT NEWS HOT NEWS HOT NEWS HOT NEWS



The Committee is delighted to announce that Mr Gus Estrella will provide the keynote address. An AAC user, Gus' presentations are always thought-provoking and powerful.

Read his biography at www.agosci.org.au or one of his speeches at www.aac institute.org/Resources/PrentkeLecture/1997/GusEstrella.html.

Other significant practitioners and researchers will also be on the program. More information will be provided as soon as details are confirmed.

Hope to see you in Canberra in 2009!

Jennie Lindsay
Conference Convenor

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