AGOSCI

in focus

This issue ...

AGOSCI 007: Licence to Communicate
2007 AGOSCI National Conference

A**GO**SCI Inc.
www.agosci.org.au

SPECTRONICS News

June 2007 Edition

Technology News

Palmtop3 / iChat3 from DynaVox

Announcing the exciting new Palmtop3 and iChat3 from DynaVox! These truly portable handheld devices pack a lot more power than the previous models and have a range of innovative new features.

Both the Palmtop3 and the iChat3 offer users a range of pre-made page sets which can be modified to suit your needs. Alternatively, there is enough memory to design your own page sets from scratch if you prefer. All 11,000 PCS symbols (as used in the Boardmaker software program) are now included, but both devices also allow the user to select from whole words or to spell words independently.

Both devices are shipped with UK DECtalk voices and some of the new Acapela HQ voices - with both British and American accents. Both now offer improved battery life - using an integrated second battery to provide over eight hours of uninterrupted speech (although typical usage will result in considerably longer battery life).

Differences between the Palmtop3 and iChat3?

The main difference between the Palmtop3 and iChat3 is the different number of communication configurations. The Palmtop3 offers features to assist those who already have good literacy skills to communicate faster using a range of different on-screen keyboards, such as UK spelling word prediction, abbreviation expansion and ambiguous keyboards.

The iChat3 is primarily designed for those who need symbols to communicate and who have minimal or no literacy skills to expand their communication. The iChat3 does not support switch access whereas the Palmtop3 supports single and multiple switch access (with the addition of an optional switch kit).

You can get more information about these exciting new devices from our website www.spectronicsinoz.com or contact Jane Farrall, Spectronics' Speech Pathologist and AAC Support Services Manager on:
jane@spectronicsinoz.com

Coming Events

Inclusive Learning Technologies® CONFERENCE 2008

We have been busy with plans for the next Inclusive Learning Technologies® Conference to be hosted by Spectronics from May 12th to 15th, 2008. Please keep these dates free in your PD calendar! We have booked the stunning Marriott Hotel in Surfers Paradise in Queensland, Australia, for the event and have confirmed that Dr Caroline Musselwhite, Kelly Fonner and Scott Marfilius will be our Keynote Presenters.

While our Inclusive Learning Technologies® Conference will show you in detail the features of many of the inclusive learning technologies available, it will also focus very much on helping you to understand how to APPLY these technologies in your classroom or within your disability support organisation.

We are excited to announce that the first draft of the program for our Inclusive Learning Technologies Conference® in May 2008 is now available!

View it online at:
www.spectronicsinoz.com/conference/2008/timetable.asp or download a PDF file detailing the conference program and session abstracts from:
www.spectronicsinoz.com/conference/2008/pdfs/Spectronics_ILT_Conference_2008.pdf

In brief, the following sessions to be presented by one of our Keynote Speakers have been confirmed...

Dr. Caroline Musselwhite

Full Day Pre-conference Workshop:
WHO`S REALLY TALKING? "Who`s Cute", and Other Social Scripts for AAC Users

Plenary Session:
- POETRY POWER! Using Poetry to Support Language and Literacy

Conference Sessions:
- Emergent to Transitional to Conventional Literacy: Moving through the Beginning Literacy Framework
- PHONICS PHUN or Today is NOT Brought to You by the Short Vowel `O`!
- What`s to Read?
- Communication All Day Long: Communication Circles, Topic Setting and MORE!
- Guided Reading: The Before / During / After Approach!
- Write On, Right Now: Emergent Writing
- Songboards for Language, Literacy and Learning: Theory to Practice!

More presenters, sessions and Hands-on Lab Workshops will be finalised for the program in October 2007 after the call for papers closes on 30th September. Please email Lisa Meyer on lisa@spectronicsinoz.com if you would like to be added to the list of people to be kept up-to-date as our exciting conference plans come together!

contents

Front cover

Pandy Tsimboukis is a 44-year-old man from Adelaide who has been painting for over 15 years. He has cerebral palsy and creates his masterpieces by painting by hand as well as using his wheelchair to make tyre prints. Pandy uses an Emu with 'Windbag' software for communication. His interests include Aussie Rules footy and all things Greek.

Like to Know About AGOSCI Australia?

What is AGOSCI?

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

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

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

What are the key areas of interest for AGOSCI?

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

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

Who can join AGOSCI?

Anyone interested in complex communication needs. 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 List server 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).

AGOSCI Inc.
www.agosci.org.au

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

National Executive

Chairperson
Wendy Webster
Phone: (07) 3357 5952 AH
              (07) 3347 7200 BH
Fax: (07) 3347 7211
Email: wwebster@cplqld.org.au

Secretary
Melissa Bakes
Phone: 0414 369 535
Freecall / Fax: 1800 002 950
Email: in-sain@bigpond.net.au

Treasurer
Jenny Arthur
Phone: (02) 62587596
Email: arthurbandj@optusnet.com.au

State Representatives

Australian Capital Territory
Lisa Hanley
Phone: (02) 6258 8723 BH
Fax: (02) 6258 6847
Email: lhanley@tscnsw.org.au

New South Wales
Nathenya Fall
Phone: (02) 9972 8104
Email: nfall@tscnsw.org.au

Northern Territory
Anne Dixon
Phone: (08) 8922 7226
Fax: (08) 8922 7165
Email: anne.dixon@nt.gov.au

Queensland
Anne Pearson and Melanie Waalder
Phone: (07) 3813 5755
Mob: 0413 489 609 (Anne)
Email: agosciqldrep@hotmail.com

South Australia
Janelle Sampson
Phone: (08) 8182 1000 BH
Fax: (08) 8182 1010
Mob: 0407 603 671
Email: janelle.sampson@novita.org.au

Tasmania
Diane Symon
Phone: (03) 6334 5899
Email: diane.symons@education.tas.gov.au
              diane@ilctas.asn.au

Victoria
Helen Tainsh and Melissa Blazey
Phone: (03) 9560 0700 (Helen – BH)
Email: agoscivic@hotmail.com

West Australia
Sally Hunter
Phone: (08) 9381 0600
Email: sally@ilc.com.au

Do you have a question about AAC but don't know who to ask?

Log onto AGOSCI ListServe – See the website for details

www.agosci.org.au

Stepping out of the RACV Club revolving door in Melbourne last March felt to me like squeezing back out of Narnia's wardrobe.

The wardrobe of Alternative and Augmentative Communication (AAC) may look specific and small from the outside world but inside the AGOSCI conference was a wide wide wonderland! Intricate, mystical, intriguing, uncharted in parts, and peopled with colourful, brave characters and colleagues.

I feel like a junior traveller blessed with wise company on my professional journey. And wasn't it just plain good to dance again with friends and colleagues, old and new, at the conference dinner? Or to sit sipping wine as colourful fish and that big, friendly turtle swam by?

I know Narnia isn't nearly as sexy as James Bond and his shaken martinis but I thought I'd stick to my genre and leave 007 to master agents like Maree Ireland and Ingrid Birgden whose creative writings are in this edition.

Our real journeyers are our AAC users and their families and support people. Read on in this edition of AGOSCI *In Focus* and be energised by some of our action heroes: Maree, Ingrid, Ryan Bright and Dale Gonelli.

While the theme for this edition is our conference, an extra theme seems to have emerged in the articles that came from conference presentations: the rights of everyone to use their competence and communication to access the world as they choose. Accessing local healthcare services and understanding information about voting in elections are two examples of these choices in action. "It is time that people's right to lead lives of their own choosing comes first" writes Jo Watson and colleagues. It seems to me that, in light of our recent conference, if any licences to communicate are to be issued our experienced AAC users could run the tests!

Our appreciation goes to the conference convenor, Jane Farrall, and her committed and enthusiastic committee for a superb conference! And as I embark on this, my first AGOSCI editorial, my thanks also goes to Wendy Webster for her multi-hatted success and endurance with the last two editions of AGOSCI *In Focus* and for getting me started with this edition. The editor role (which I am sharing with Sheridan Forster) is a great opportunity to combine my interest in speech pathology with my ardour for written words. And a chance to get to know a few more of the great people out there in the AAC community! The magical AGOSCI wardrobe door is currently open … Are there any other language loving adventurers among you who would like to contribute more to AGOSCI and join us on the editorial committee?

Sheridan and I are looking forward to your contributions for our next magazine adventure with the theme: 'Alternative and Augmentative Communication and Autism Spectrum Disorders'. Please send us your submissions by 1 October 2007.

So get writing out there – or as they say in AAC circles these days, KILL KILL KILL (Keep Inventing Lively Language)!

Emily Armstrong

CONGRATULATIONS
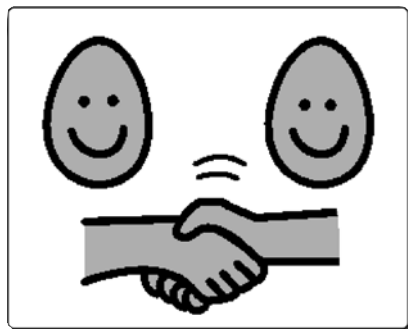
JANE FARRALL
AND HER FABULOUS COMMITTEE
FOR A WONDERFUL CONFERENCE:
'007 – LICENCE TO COMMUNICATE'
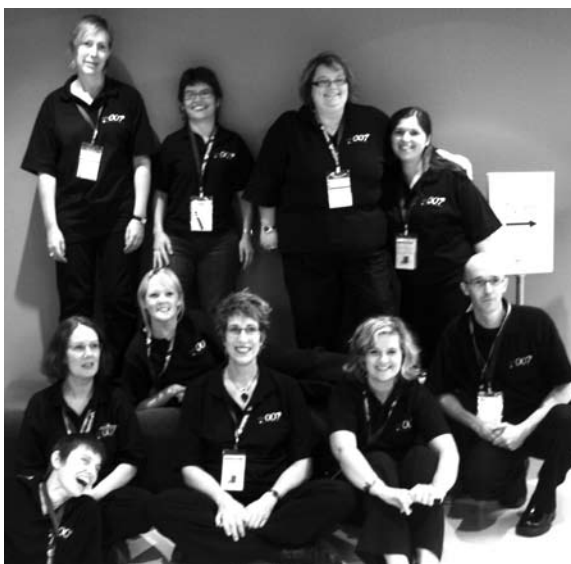
Not-so-secret AAC Agents.
(from left to right)
Back Row: Rosie Miller,
Andrea McQueen,
Jane Farrall, Melissa Blazey.

Front Row: Meredith Allan,
Tracey Bode, Katie Lyon,
Heather Cullen, Marnie
Cameron, Ed Duncan.

AGOSCI Inc. 2007 Chairperson's Report

by Wendy Webster

Once again AGOSCI Inc. can report a year of successful networking with the aim of spreading the word about AAC and related issues throughout Australia, a little of New Zealand and smatterings of Asia.

The Conference "007 Licence to Communicate" gave many of us an opportunity to present, to listen and be challenged by national and international speakers, users of AAC, their families and clinicians and teachers and just have fun with friends. The listserve regularly creates healthy discussion, information sharing and personal reflections. AGOSCI is already gearing up for our next national tour with David Kopenhaver and Karen Erickson and the 2009 Conference in Canberra with Jennie Lindsay as Conference Convener.

The Executive team continues to get on and do what needs to be done, those routine jobs about membership and money, thanks Mel. Jenny and her family have settled into being "The Treasurer", I have really appreciated the suggestions and explanations.

In an effort to make sure that jobs are completed, each state rep has a portfolio. I would like to particularly mention Sally who keeps an eagle eye on the listserve and website, Ruth who looked after the Scholarships and Grants. 20 people were able to attend the Conference with the combined support of the FACS and AGOSCI Grants.

Jennie Lindsay has been working with Meredith Allan to gather relevant information for discussions between AGOSCI and ISAAC Australia. A decision was also made to capitalise on the expertise of the ISAAC Australia members and organise teaching tours to more remote areas in order to teach and encourage membership and create some funds for ISAAC.

It is very pleasing to hand over the role of AGOSCI Editor to a combination of Emily Armstrong and Sheridan Forster. The magazine will continue to inform and inspire under the direction of this dynamic partnership. We have some changes in the State Rep roles. We say farewell to Ruth Chalk (Tasmania) who has handed over to Diane Symons, Jennie Lindsay (ACT) who has handed over to Lisa Hanley, and Hayley Smithers Sheedy (NSW) who has handed over to Nathenya Fall. Many thanks to all who worked hard in these roles. The fact that we were easily able to find replacements is testament to the value of AGOSCI and the time given is seen as worth while. Welcome all new comers.

AGOSCI continues to have dreams of being relevant to a wider variety of interested parties (especially AAC users and their families) moving towards a partnership with ISAAC Australia and much more.

Out of the Box: Using Technology to Follow Your Dreams

There are many people who have little or no speech. Some of these people refer to themselves as having complex communication needs. Computers and speech generating devices can make it easier to participate in everyday life.

Out of the Box: Using Technology to Follow Your Dreams is a course designed to help people with complex communication needs learn how to use technology to communicate better, set new goals and stand up for themselves. The first course is planned to be run in Melbourne in 2007.

It is supported by a number of disability organisations including Scope and Yooralla as well as Diane Bryen from Temple University in Philadelphia. Diane is the founder of a similar course in Philadelphia called ACES. This Online community has been set up for applicants of this course, their supporters and anyone else with a complex communication need who maybe interested in Using Technology to Follow their Dreams. Please join us!

To become a Vicnet user:
1. Go to www.mc2.vicnet.net.au
2. Click on "Join mc2 - it's FREE!" on the left hand side of the screen
3. Fill in the registration form and follow the prompts.

Once you are a registered user you can join this community:
1. Visit the community description page http://mc2.vicnet.net.au/home/ootbox/index.html
2. Click on Join this Group on the left hand side.

If you'd like to see more groups:
1. Visit the Scope project page for a full list of communities http://www.mc2.vicnet.net.au/partners/scope
2. Click on the name of any group that interests you and you can see a description of the group and join it with a single click.

Both Vicnet and Scope can provide training or assistance to help you get connected
You can contact Vicnet help on 8664 7001 or 1800 629 835 or email Scope help on: mc2helpline@yahoo.com.au
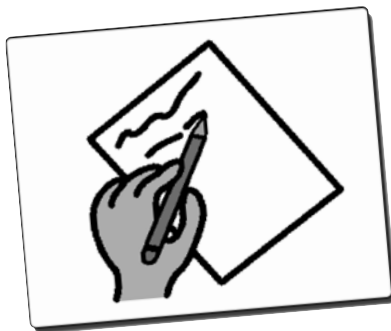
Notations ...

AGOSCI Inc. Secretary's report

by Melissa Bakes

Hi Everyone, It was a busy start to the year with the 007 Conference with many memberships coming in. I think I'm over that hump now with just the usual secretary jobs for now: banking cheques, forwarding information, answering enquiries, etc., etc. I'd first like to congratulate the Melbourne conference committee for an absolutely fantastic conference. I had such a great time. It was great to catch up with many members and the new and past executive committee members. We had a really productive two days, meeting as the new executive. Lots of wonderful ideas for moving forward and I'm really pleased with a focus on rural and remote areas.

I have included the minutes from the recent Annual General Meeting (AGM) at the conference in this copy of AGOSCI *In Focus*. We had a quite a few laughs at the AGM amongst the serious business.

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

All I really have to report on for the moment are the membership numbers. At the moment we have around 226 members. That is up on last years figures at this time of year. I have seen some new names again 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. From a state by state/territory perspective membership numbers are as follows- Queensland 60, Victoria 51, New South Wales 38, South Australia 28, West Australia 13, Australian Capital Territory 15, Tasmania 15, Northern Territory 6, and with 7 members in New Zealand. We continue to grow each year.

Money Matters

AGOSCI Inc.
Treasurer's report

by Jenny Arthur

Hi everyone, I managed to get to the end of my first year as treasurer and the books balanced.

I think that was due to my accountant husband actually, so thank you very much.

It has been a steep learning curve since I took over a year ago but our previous treasurer, Heather Cullen, had put together such good systems, which made it much easier.

Thank you to Heather and to everyone who helped me settle into the role.

AGOSCI's financial position was good at the end of the year and we continue to have a good support base of members.

The national tour with Patti King De Baun was very successful in 2006, both in what we learnt, and from a financial point of view.

We also sponsored quite a few parents and users of AAC to attend the AGOSCI conference last March and I am sure they found as I did that the conference this year was again a fabulous experience.

Congratulations to Jane and her team for the great job they did.
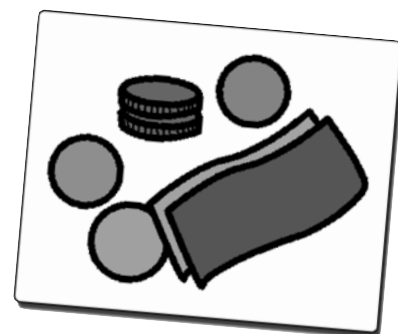
Want to know something about AGOSCI?

Contact Melissa Bakes on 1800 002 950

reports

AGOSCI Inc. State Reports

Victoria
by Melissa Blazey & Helen Tainsh

We have had a very busy few months in Victoria. The National AGOSCI conference in Melbourne in March was brilliant as was the pre-conference workshop presented by Linda Burkhart. The feedback the conference committee received was extremely positive. AAC consumers, their families, carers, teachers and therapists attended and presented on a wide range of topics.

Planning for the national tour for June 2008 is underway. We are very excited to be welcoming Karen Erickson and David Koppenhaver to Victoria. Karen and David will speak on literacy in Augmentative and Alternative Communication. Three webinar sites have been proposed for Victoria including Mildura, Traralgon and Warranmbool. Victoria is lucky enough to be hosting the week long Intensive Literacy Seminar on Literacy in AAC following the National Tour. Only 30 very lucky participants will attend.

We have recently contacted AGOSCI members about resuming a state committee to co-ordinate professional development at a local level. Please contact us if you have any special requests (Melissa Blazey milblazey@hotmail.com   Helen Tainsh tainshes@iprimus.com.au). Look out for details about our upcoming evening when Jane Farrall (Speech Pathologist and AAC and literacy consultant) will discuss AAC and literacy in mainstream classrooms. We know that this will be an extremely practical session.

If you have contributions for the website, or events you would like to add to the Victoria events page, please feel free to contact us. We are really looking forward to seeing you at lots of events.

South Australia
by Janelle Sampson

South Australia was well represented at the recent AGOSCI conference in Melbourne. It's a short flight and when coupled with some high quality shopping time, the 007 AGOSCI conference was a hit for all. South Australia had a good showing at the conference including four families who were successful in obtaining scholarships to attend. Two of our delegates were also teenagers, and one of those teens also presented. All commented on the fantastic organization of the conference, and how valuable it is to attend such an event. Many thanks to the Victorian contingent for such a fantastic and well organized conference. We all look forward to Canberra in 2008.

Prior to the conference, a state event was held to allow a practice run for those who were to present at the conference, but also to give those who were not able to go a chance to hear some of the presentations. It was a successful night with around 30 people attending. We hope to run a follow up evening session soon with a review and feedback from the conference from those who attended.

Membership numbers have stayed strong this year with 27 members in SA. The number of people with AAC and their families on our member list has also increased, which is a very positive step for AGOSCI SA.

If you have any questions or comments, or would like to contribute to AGOSCI SA in anyway, please feel free to contact me. I also encourage you to keep an eye on the AGSOCI website www.agosci. org.au. Our website coordinator has been working hard to update and add information and it's really looking great. If you have contributions for the website, or events you would like to add to the SA events page, please feel free to contact me, Janelle Sampson, AGOSCI SA State Representative, email Janelle.sampson@ novita.org.au or phone 8182 1009.

New South Wales
by Nathenya Fall

2007 certainly kicked off with a bang at the National Conference in Melbourne and things have been on the go ever since. Everyone has been busy putting so many inspiring ideas from the conference into practice. For members in NSW who were unable to make it to the conference in March we are holding a conference feedback afternoon. AGOSCI members from NSW will present their conference papers at The Spastic Centre NSW at Allambie Heights on the 23rd of July.

If you have contributions for the website, or events you would like to add to the NSW events page, please feel free to contact me, Nathenya Fall, AGOSCI NSW State Representative, email nfall@tscnsw. org.au or phone (02) 9972 8104.

Australian Capital Territory
by Lisa Hanley

We had record number of members attend the AGOSCI 007 conference with several parents, teachers and therapists from Education, Therapy ACT and The Spastic Centre.

The planning for the 2009 "Feel the Power" conference is well underway. A conference planning group of 10 - 12 will be meeting regularly. Any further suggestions that people might like to offer would be greatly appreciated. The promotional video for the conference is on the web and promotional coasters are also available to any State Representatives who would like them.

Jane Farrall from Spectronics will be presenting to AGOSCI in August, with a few other events in the pipeline.

Queensland
by Anne Pearson & Melanie Waalder

On the 16th and 17th of April we were fortunate enough to have Dolly Bhargava from 'Innovative Communication Programming' to present in Brisbane and Townsville. Dolly presented on AAC assessment and support for children and adults to 45 teachers, therapists and parents in Brisbane. The participants came from all over South

State Reports (cont)

East Queensland, including Gold Coast, Brisbane, Ipswich, Bundaberg, Gympie, Gladstone, Mt Isa and Roma. The day proved to be a success with much positive feedback received. 83% of participants rated the overall presentation as good or excellent. The majority of participants said that Dolly's presentation met most of their expectations. Mt Ommaney Special School proved also to be a successful venue and the catering was deliciously yummy! Some of the comments received included "Very informative and comprehensive" and "Dolly was very responsive and able to adopt presentation to suggested topics".

Dolly's presentation in Townsville was also well received. The presentation focused on using positive behaviour support to manage challenging behaviour in children and adults with Autism.

We hope to have Dolly Bhargava present in the future due to such great feedback and high participant numbers. We look forward to Karen Ericksson and David Koppenhaver's National Tour in June, 2008. Stay tuned for registration flyer.

West Australia
by Sally Hunter

A small but efficient contingent of Western Australians attended the AGOSCI conference this year and following it much positive feedback has been heard. We were very pleased to see a contribution from rural WA. Laura Coakes (from the UK currently working in Karratha) presented a very interesting study she did on using talking mats with children with socio-emotional difficulties. The conference boosted membership in WA.

The local AAC Devices interest group has continued to meet regularly with the next meeting planned for 26th of July at 3.30pm and interested people can contact Danielle Lampropoulos at the Centre for Cerebral Palsy 08 9443 0211.

As state representative and list server coordinator I am pleased to see great questions and feedback dominating the list conversations and the contributions come from far and wide (both nationally and internationally). Stay tuned on the website www.agosci.org.au for the latest Literacy and AAC Intensive and the National Tour.

Tasmania
by Diane Symons

Several Tasmanians attended the AGOSCI conference in March and returned to our workplaces inspired to implement the fantastic ideas we all picked up at the conference. While we are a small group I believe there is a real commitment to maintaining an active network for those interested in AAC and related issues.

I am hoping to arrange some regional groups for people to get together and share some of their conference experiences. If you have contributions for the website, or events you would like to add to the Tasmanian events page, please feel free to contact me, Diane Symons, AGOSCI Tasmania State Representative, email diane@ilctas.asn.au or phone (03) 6334 5899.

Northern Territory
by Anne Dixon

Firstly, I would like to say a heartfelt thanks to Jane Farrall, the conference committee and the presenters for an incredibly motivating and well-organised conference in March this year. The bi-annual conference is a wonderful opportunity for those of us further a field to network and catch up with recent happenings in the world of AAC. Three people from the NT attended the conference and I encourage people to put Canberra 2009 in their diaries.

Over the past year, there has been a heartening increase in the awareness of and recognition of the rights of people with complex communication needs and the value of AAC by government and non-government services. Services are taking the initiative and asking for assistance to develop AAC strategies that suit people in their particular settings, including schools, family, workplaces, adult day programs and supported accommodation, hospital and rehabilitation services.

The AGOSCI Special Interest Group has been meeting every three months for information and resource sharing, discussion of issues for people with complex communication needs and the difficulties faced by people supporting them. I think we've all found that these meetings inspire ideas and provide much needed support in this area.

Allied health staff and direct care providers working in Darwin, Katherine, Alice Springs and remote areas are looking forward to two workshops to be presented by Professor Justine Joan Sheppard on June 26th and 27th. The Certification Workshop for the Dysphagia Disorders Survey and the Mealtime Management Workshop for Families and Carers have been largely funded by the NT Department of Health and Community Services with co-sponsorship by the Centre for Developmental Disability Studies, University of Sydney.

Want to know what's happening in your state?

Simply log onto the website and click on the map

www.agosci.org.au

ISAAC Australia – President's Report

The Australian Chapter of ISAAC

by Cathy Olsson

I am 'just' back from the fabulous Licensed to Communicate AGOSCI conference in Melbourne. The conference offered great opportunities to catch up with what is new in research, practices, programmes, and devices, as well as to meet up with colleagues from across the nation and to hear more from people with Complex Communication Needs about their experiences and achievements. It is also a delightful opportunity to see each other in a slightly different light at the conference dinner and, in particular, dance. No doubt about it, the AAC community includes some people who love to dance and know how to enjoy themselves!

The conference was also the site for the ISAAC Silent Auction. Thanks to everyone who donated items, to those who bid on them and to those who attended the stall. This is an important fund-raiser for the Chapter and owes its success to the generosity of all involved. With the funds raised from this, the raffle and some donations, the Chapter has now weathered its financial crisis. The generous bridging loan from AGOSCI has now been paid and we are not only still in the black, but should have funds to offer a travel scholarship for someone who uses AAC to the ISAAC Biennial Conference in 2008, to be held in Montreal.

ISAAC thanks the convenor and organising committee for the opportunity to access a little time in the packed closing celebration to draw the raffle and to announce the two winners of the ISAAC Australia Awards for Achievement. Nominations were only received in the School/Organisation award this year, and the decision was made to award to two nominees. Congratulations to Port Lincoln Primary School in South Australia and to the 'First Base' St Albans programme in Victoria for their great work in creating environments that support AAC and the people who use it.

Australians continue to have a very high profile within ISAAC internationally, and it is great to see Australian authors and research being published in the AAC journal. Congratulations to Janet Owens, Jennifer Stephenson and David Trembath who all have had peer-reviewed papers published in the AAC Journal recently.

The working group looking at the relationship between AGOSCI and ISAAC Australia continue to meet. In the interim AGOSCI's fantastic offer to fund and organise professional development to some rural areas using presenters who are prepared to donate their speaker's fees to ISAAC Australia has been enthusiastically supported by ISAAC, with a number of people already volunteering their time. A great idea which has the potential to provide for winners all round.

The Call for Abstracts for the 13th Biennial ISAAC Conference to be held in Montreal August 2 – 7 2008 has come out; hopefully you will have a brochure included in this edition of AGOSCI in Focus. Please consider submitting an abstract to showcase our great work in AAC in Australia and to provide the excuse, or motivation, to attend the ISAAC conference. It is a wonderful experience!

ISAAC is planning an international awareness event, scheduled to occur on October 6th, which is the day that ISAAC was registered as an organisation in 1983. There are a number of creative ideas coming in about what to do, with the focus at this time on running events in schools to promote awareness. A number of people have indicated their interest in being involved and it isn't restricted to ISAAC members, in fact the more the better. If you would like to know more or be involved, please let me know. My contact details are via email: catherine.olsson@novita. org.au or telephone (08) 8172 9216 or mobile 0414 584 348.

Help Make it Happen

International AAC Awareness Day – October 2007

ISAAC is planning an international awareness month in October for AAC. Would you like Australia to be in it? Can we coordinate it to have events in Australia happen on the same day? The plan is to have it in schools – can you help?

How the event might be done

1. The event could be children finding different non-verbal ways to pass a message e.g. acting it out; drawing symbols.

2. Teachers would choose the topic for the class to 'talk' about.

3. After the event the children would express the experience visually. This will allow the experience to be shared across the world; this could be the drawings produced as alternative communication during the event, or drawings of the experience the children make as the closing part of the event.

4. The date would be close to October 6th – when ISAAC started.

How this could be set up

1. Decide which schools to approach.

2. Ask the schools you know if they would like to take part (the Principal's agreement is important).

3. Where people have good connections with local school boards or even broader educational structures (e.g.Minstries of Education) they can approach them to increase the chance of several schools taking part.

How it would be carried out

1. A flyer in pdf form would be given to each organising group to translate into the national or regional language and to print or photocopy to promote the event in the schools and wider community.

2. The press would be contacted with a press kit giving information on this worldwide event and an invitation to run a story on it.

3. T-Shirts with a slogan in English and symbols will be sent to each participating class (or maybe school?) worldwide to wear for the event.

4. The teacher and parent/ clinician/ child would plan the event together and ensure publicity is endorsed by the principal/ school board.

5. Photographs of the pictures of the event would be taken and sent to the ISAAC Information Exchange. Go to http://www.isaac-online.org/ie/

6. The Information Exchange will have a special category "International AAC Awareness Event" for the months of October, November and December to show the pictures and any stories that have been written on the event from around the world.

7. Maybe even a video …

Funding

ISAAC would look for funding for tee shirts. The awareness day is to raise awareness but if you wanted it to be a sponsored event that would be great!

You could also sponsor a silence, an art work etc and donate the money to ISAAC.

At the moment there are lots of ideas buzzing around- but we need someone or lots of people to let us know if they are interested in this happening in Australia?

It doesn't have to be a huge national event – the idea is to start with whatever is manageable for those who want to be involved, and then see how things build in following years. It could start in just one State, or just one school.

If you are interested in being involved, contact Cathy Olsson on 8172 9216 or by email catherine.olsson@novita.org.au after July 9th, or Hilary Johnson on 3 9843 2001 or at hjohnson.crc@scopevic.org.au before July 9th.

isaac
International Society for
Augmentative and Alternative Communication
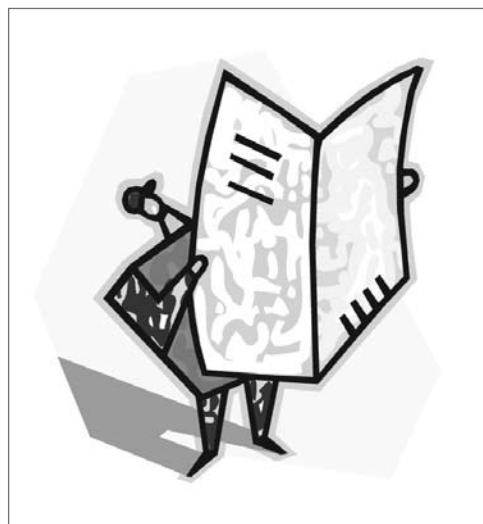
Do you have an AAC user's story for the AGOSCI website?

Contact Sally Hunter:
sally@ilc.com.au

The Makaton Breakfast

by Karen Bloomberg
– Joint National Training Coordinator

National Chairperson of Makaton Australia Bob Conway gives his opening address to delegates at the Makaton Breakfast.

Makaton Australia hosted a very successful breakfast at the AGOSCI 2007 conference. The breakfast and conference took place at the RACV Club in Melbourne. Over 50 people attended the morning discussion that was facilitated by Teena Caithness and Libby Brownlie. The national Chairperson, Bob Conway also attended and gave the opening address.

The Makaton breakfast was a working breakfast where attendees had the opportunity to network with presenters and other people interested in the area of key word sign from across Australia, New Zealand and the Cook Islands.

The early morning workshop was intended to be a forum to address some of the issues in teaching and using signing. The aim was to share ideas and try to problem solve the issues in teaching communication partners key word sign and in supporting them to become effective signers in their workplace and/or with their families. There was also an attempt to grapple with some of the obstacles that can arise in our work to make key word sign a powerful therapeutic tool for our clients.

On arrival, the participants chose a topic for discussion and joined a table where others were interested in the same topic area. There were five tables each with a different topic. After a brief introduction, participants discussed and attempted to problem solve their particular topic area. A scribe was allocated for each table. At the end of the discussion period a list of key points were generated and

given to the facilitators. The key points were summarised and presented at the conclusion of the breakfast. The five topics areas and the key summary points are listed below.

1. How do we support workshop participants to sustain and build on their use of sign in the long-term?

Key summary points:
• Set up a project for Makaton to use in accommodation services
• Ensure Management support
• Use video-taping as a basis for scripting

2. How to build fluency and comfort in the use of sign as effectively and efficiently in the limited time available in a Basic Makaton workshop?

Key summary points:
• Get combinations of signs going quickly by using phrases repetitively e.g. Change one item only in fun games that encourage movement, confidence and fluency.
• Script commonly used phrases i.e. phrases common to the person and to their communication partners.
• Less is more – emphasise that KEY words are the most important aspect.

3. Vocabulary selection – do we teach the Interactive Vocabulary, Makaton stages or a different selection?

Key summary points:
• Agreement that the Interactive Vocabulary is the best way to start due to immediacy of use, ability to use across all communicative

environments and its interactive nature. This must be supplemented with the use of scripting in Basic workshops as a means of teaching additional vocab that is specificto the participants.

• RESEARCH IS NEEDED! The aim of research would be to analyse the benefits of the Interactive Vocabulary compared to other vocabulary sets in terms of training context, retention and generalisation of skills for participant.

• Research is also needed that reviews the Interactive Vocabulary and its use with other populations eg. adults, people with a physical disability.

• Rational for Interactive Vocabulary appears sound. Most Presenters do not like the traditional stages as they are not based on sound rational for communication development. Other generated vocabulary sets such as the adult vocabulary and preschool vocabulary are more suitable than stages for extending signing skills

4. Modifying our use of sign and gesture for differing communication and language skills in our clients.

Key summary points:
• It is permissible to modify signs and accept idiosyncratic production however this must be documented. People within the environment must be made are aware of how the signs are different and understand the rationale behind why they are acceptable.

• Signs can be modified for any of the following reasons:

The Makaton Breakfast (cont)

- Sensory skills of individuals
- Physical skills of individuals
- Cognitive skills of individuals
- Cultural reasons
- Existing/known connotations of signs or alternative 'less desirable' meanings.

• Follow the lead of the individual you are signing with as much as possible, offer alternatives and modifications that are within the realms of the individual's skills and abilities.

5. Do we offer different teaching for different populations eg. paediatric versus adult, Culturally and Linguistically Diverse (CALD) groups, people who are deaf/blind?

Key summary points:

• Investigate the translation of existing resource materials.

• Offer training support to Speech Pathologists and others around cultural issues and how these relate to Alternative and Augmentative Communication.

• Develop more ideas around games and activities to use for kids and functional activities for adults.

A comprehensive version of the possible strategies, actions and future directions for people teaching others to use key word sign at home, in day services and in the community can be found on the Makaton web-site at: http://www.newcastle.edu.au/centre/sed/makaton/

This Makaton event was also a thirty-year anniversary celebration. It is heartening to see the growth in the use of key word sign since its introduction to Australia in the late 1970's.

Due to the overwhelming interest from both Makaton presenters and other people interested in unaided communication, the Makaton breakfast will become a regular feature of the AGOSCI conference.

See you in Canberra in 2008!

The Makaton Executive

National Coordinator & Chairperson
Associate Professor Robert Conway
The Director
Special Education Centre
University of Newcastle
Callaghan NSW 2308
Phone: 02 4921 6273
Fax: 02 4921 6939
Email: bob.conway@newcastle.edu.au

Administration Officer
Kim McLellan
Makaton Resource Centre
Special Education Centre
University of Newcastle
Callaghan NSW 2308
Phone: 02 4921 6293
Fax: 02 4921 6939
Email: makaton@newcastle.edu.au

National Training Coordinators
Karen Bloomberg
c/- Communication Resource Centre
830 Whitehorse Rd
Box Hill VIC 3128
Phone: 03 9843 2003 Fax: 03 9899 8684
kbloomberg.crc@scopevic.org.au

National Training Coordinators
Andy Smidt
106 Military Road
Dover Heights NSW 2030
Phone: 0414 301 855
Fax: 02 9371 4066
andy@dart.com.au

New South Wales Coordinator
Teena Caithness
Behaviour Intervention Service
Dept of Ageing Disability & Home Care
Building B, Level 1, 242 Beecroft Rd
Epping NSW 2121
Phone: 02 8876 4021
Fax: 02 8876 4041
teena.caithness@dadhc.nsw.gov.au

Queensland Coordinator
Amanda Hartmann
1749 Wynnum Road,
Tingalpa QLD 4173
Phone: 07 3907 0261
dahartmann@optusnet.com.au

South Australia Coordinator
Amanda Denley
Novita Children's Services
Northern Regional Office
422 Salisbury Highway
Parafield Gardens SA 5107
Phone: 08 8182 1005
amanda.denley@novita.org.au

Tasmania Coordinator
Deborah Davey
(Based at)
Rokeby Primary School
73 Burtonia St
Rokeby TAS 7019
Phone: 03 6212 3514
deborah.davey@education.tas.gov.au

Victoria Coordinators
Karen Bloomberg
c/- Communication Resource Centre
830 Whitehorse Rd
Box Hill VIC 3128
Phone: 03 9843 2003
Fax: 03 9899 8684
kbloomberg.crc@scopevic.org.au

Victoria Coordinators
Ella Keesing
c/- Communication Resource Centre
830 Whitehorse Rd
Box Hill VIC 3128
Phone: 03 9833 3472
Fax: 03 9899 8684
ellapetekeesing@optusnet.com.au

Western Australia Coordinator
Colette Doncon
makatonwainc@hotmail.com

Agents for AAC

2007 AGOSCI National Conference Opening

by Maree Ireland – mareeireland@hotmail.com

Maree Ireland officially opened the AGOSCI 2007 National Conference: 007 Licence to Communicate. "What do we have in common with James Bond?" she asked us. … "More than you might think!"

1. Licence to kill. I wish I had a licence to kill at times but our real licence to KILL is: Keep Initiating Lively Language. It is our right and it is fun!

2. Bond always completed his mission on time.(I had 15 minutes so I got Q-Branch to whip up a human robot to deliver my speech!)

3. Bond used the latest technology and gadgets to assist him in his missions. SMS, emails, wireless communications, Blackberries and video phones are all out there. We should be using this technology whenever we can. Finally the world is communicating the way we have for years, in short message formats that need to communicate so much.

4. Bond insisted on gadgets with style. Why do we have chunky old clunkers?! We should be lobbying communication equipment manufacturers and mainstream providers. I want my Lightwriter to have SMS, email and wireless capability!

5. Bond's weapons did amazing things! He had amazing gadgets that 'empowered him'! Exploding briefcases, rings that cut glass … Why do we often only have boards that say 'yes/no, I want a drink, I want to go to the toilet' etcetera? It's time that people who work with us learn to empower us by programming machines to say sophisticated things! Get your Q-Branch to whip you up some real communication phrases that will empower you!

6. Bond used technology but had a healthy disrespect for it. He knew he also relied on his guts, determination and drive! We are also more than just our communication devices. Don't forget you need to continue to rely on your determination and drive

and KILL KILL KILL. Keep Initiating Lively Language!

7. Bond defeated endless enemies. Bond's enemies continue episode after episode. He defeated them. We face enemies – people who doubt out abilities, intellect and feelings. We need to have faith in ourselves and continue to fight for respect. Remember that non-speech doesn't mean having nothing to say!

8. Bond was well educated! In between missions Bond was always at Oxford doing a course! We must also push the education of people with communication disabilities. Education is the key to your liberation! I have never looked back leaving the workshop and going to University. Encourage someone you know to start a course or start one yourself!

9. Bond reinvented himself regularly! We have seen so many Bonds (Connery, Moore, Dalton, Brosnan and now Daniel Craig). But Bond keeps reinventing himself. We too need to keep reinventing ourselves as times change and we get bored. Take up a new interest, start a course!

10. Lastly, Bond had a great service provider. Bond was effective because he had a great team and service provider in MI6. We too need good service providers if we are to be effective. The disability service sector suffers from a lack of accountability unlike any other service sector. We are part of the problem too! We are not vocal enough in expressing our concerns and moving providers. This needs to change if we are to be as effective in our community as Bond was in his!

In closing:

• Use your licence to KILL (Keep Inventing Lively Language) and communicate.

• Consider new technology and let's push providers toupdate communicators with SMS, wireless and email.

• Ensure our communication devices are updated and the tired old phrases are updated.

• Continue the good fight against our enemies who doubt us. We will prevail eventually like Bond.

• Reinvent yourself, push yourself, consider further education, and let's push for our younger members to have better educational opportunities that we didn't have.

• We need good service providers to make us effective and further work needs to be done on consistency, national standards and accountability.

Maree Ireland has a law degree and works as a Systemic Advocate for Community Living, which is an advocacy organisation.

Maree's powerpoint presentation can be downloaded from the AGOSCI website www.agosci.org.au. (Look in 'Resources' then 'Conference 2007' for the link).

Maree and Stephen Davis (her 'human robot').

007 LICENCE TO COMMUNICATE

Say 'No' to Dr No?
With apologies to United Artists (circa 1962)

by Ingrid Birgden – tingle@internode.on.net

The AGOSCI conference in Melbourne this year had a James Bond theme. This paper is written by a parent who attended the conference with her teenage son.

His name is Bond, James Bond. And here, in his explosive conference debut, the immortal action hero blazes through one of his most spectacular adventures. Laurence B. embodies the suave yet lethal cool of Agent 007 as he battles the mysterious Dr No, a scientific genius bent on destroying the global meta-communication program.

Is that a 1933 Bentley convertible with an inbuilt supercharger in the vestibule of the RACV Club? And a signature Aston Martin? A tall man in a black suit by the bullet-proof panels nods, and with a swipe of a security card, the glass slides apart and Bond enters Mission Control. News of a massive crash in Melbourne's Tunnel, bringing the city's transport system to a stand-still, filters through as the suspense mounts.

Gaining access to Level 2, Bond wheels past the Registration Desk, exchanges pleasantries through his synthesized speech device with Miss Moneypenny, who then hands him his conference dossier and directs him to M.

M disapproves of Bond's choice of weapons. "Nice and light in a lady's handbag", says Q. "From now on you carry a different gun", says M.

Sometimes silence is built into the hero's gun to assist him, but for this mission against the evil Dr No who is so bent on destroying atypical communication systems to further his plans of world domination, silence is "The Enemy".

Enter the MI6 vault and witness with your own eyes the cache of technology used in the War Against Silence, each weapon more powerful and deadly than the next.

In an annexe to the Exhibits Area, 007 is given top-level access to the declassified Eco, a device with the future and Dr No's annihilation in its sights. Because as the world knows, Bond, James Bond, has a licence to kill, when he chooses, where he chooses and whom he chooses.

It's a spine-tingler that takes you from the elegant club-rooms of the RACV to the exotic island nightspots of The Aquarium.

The gaming tables and bar and waiting staff are a formidable back-drop to the 007 conference. The player of this secret agent, in his own words, is "15 going on 16". He appreciates the humour and construct of Maree Ireland's opening address on the Ian Fleming theme. In a session called 'Daring to dream', he responds on his Pathfinder to Diane Bryen's questions about his plans for the future, "University. Science. Build world's fastest car" – perfectly in tune with his alter ego's taste.

Secret agents have come to this venue to exchange information. Bond is greatly affected by the details of Anne McDonald's childhood. "Where her parents?" He startles when Fiona Given mentions Conductive Education. But the real highlight is friend and fellow-teenager Ryan Bright's talk on being an AAC user with a passion for electronic games.

Bond teases Agent Bright when learning of female interest in response to his presentation with: "You did well. You even got a girlfriend out of it". And on the way home in the plane, "Do you have that hot girl's email address?" And so it seems there is more to this story than fast cars, heinous villains and exploding nuclear reactors!

And if you are in Melbourne, what could be more like a Caribbean island than dinner at the Aquarium, sitting in tropical Technicolor and framed by an illuminated wall of floating fish amongst jungle rhythms put out by the resident

DJ? The two agents sit at dinner with their devices, in collusion and communicating animatedly. With typical panache, Bond tucks his serviette in at the neck, and may well request a medium-dry martini with a thin slice of lemon, shaken, not stirred. At one point, he chivalrously turns to his mother and speaks out the display, "Shall we dance?"

Late in the evening the agents are heard discussing the next AGOSCI conference in Canberra, and elaborate on a plan, dare I say, not only to bomb a certain politician with eggs, but naturally to take it to the next level by dropping them from a helicopter.

Outside the Aquarium we again wait for the Access Cab that fails to materialise. Over the three days of the conference we try everything. Our calls are answered by strangely morphing operators as one false piece of information turns into another, such as, "it's only a kilometer away". I get to know the access drivers, who text me with, "try the taxi co. Rob"; "traffic is terrible and I'm gunna be very very very late. Dave"; or, "very sorry. John".

The concierge remembers that he has a mate. He tries. To no avail. That night, as always, my long-suffering brother-in-law retrieves us, forced again to disassemble the Wheelchair-From-Hell with strength rather than logic.

Rosemary Crossley and some other feisty conference attendees help load it piece by monstrous piece into the boot of the coupe. 007 spells out his appreciation, "Michael is the best taxi-driver."

But say no to Dr No?! Who wouldn't do it all again?

That irresistible mix of exclusive clubs, exotic climes and deluxe travel is what Bond fans want, and along with a stock-pile of high-powered weapons and stories to make your hair curl, AGOSCI 007 certainly gave this Bond character a licence to communicate.

Being a Bond Girl

by Katie Lyon – Speech Pathologist, Communication Resource Centre

I was lucky enough to be part of the AGOSCI 2007: Licence to Communicate Conference Committee and I am writing to encourage EVERYONE out there to do the same! I found the whole experience to be a great learning opportunity, not to mention the sense of achievement, (and relief!!!) when everything went so well.

I had been to two Conferences in the past as a participant but had no idea the amount of work that was involved in organising such a large scale event – so my hat goes off to both Sydney and Brisbane for running such fabulous events!

I could not have done this without the support of my workplace, which encouraged me to be involved at the Committee level, but I know the whole experience has and will benefit me personally and my work in many ways. Probably the highlights of being "Behind the Scenes" were:

• Knowledge: Being part of the paper selection process with a team of more experienced clinicians has definitely helped to develop my clinical knowledge of all the inspirational things happening in the field of AAC in Australia;

• Networking: Meeting so many new people from all over Australia and from overseas helps put those "names" that you

'The Bond Crew': AGOSCI 2007 Conference Committee attempting to remain incognito!

hear so much about to "friendly faces" and encourages me to contact the source;

• Organisational Skills: This experience has definitely tested my organisational skills, having to think of so many things in both the lead up and at the Conference will benefit any event that I plan in the future;

• Building Relationships: There is nothing like being on Conference Organising Committee to really get to know and work closely with people from your own backyard. I felt truly privileged to work with the highly skilled people from Victoria on

this Committee and have learnt so much from them in the process.

So – next time you get an opportunity to be part of your State's AGOSCI Conference Committee – please jump at it! After a lot of hard work (and some minor panic attacks) you will not be disappointed!

Good Luck to everyone in Canberra – I look forward to seeing all of your hard work pay off! By the way, I have not been paid to write this article – honest!

Camaraderie, Exposure and Inspiration

by Renee Townson

This years' AGOSCI 007 Licence to Communicate conference was an experience which I am grateful to have had and one which has benefited both me, as a school-based Speech Pathologist, and the children that I work with.

The most noteworthy aspect for me was that I had the opportunity to listen to a number of experienced AAC users communicating so effectively and articulately. This was inspirational because often the students with whom I work are just starting on their journey

with AAC, and it can at times be incredibly daunting and seem like there is a very long road ahead. Despite this, the benefits of using AAC systems are obvious, a fact which was reinforced for me by these powerful speakers.

The variety of presentations on offer meant that I was able to cover a wide range of different areas relevant to my practice. This was terrific because I was exposed to so many new ideas that will help me to revamp the way I work. At the same time, it was also encouraging to hear that my school is generally

on the right track in terms of Speech Pathology interventions.

Finally, I have to say that it was fantastic to meet so many people who are as passionate about AAC, as I am. It is all too easy to feel isolated working in a special school setting, particularly as a sole therapist. I felt a real sense of camaraderie during the three days of the conference and it helped to remind me that I am not alone.

So thank you and congratulations to everyone at AGOSCI for organising such a fabulous, motivational event. See you in Canberra in 2009.

007 LICENCE TO COMMUNICATE

Exploring a world of possibilities

2007 AGOSCI National Conference Reflections

by Amy Martin

A contingent from Novita Children's Services, that included Ryan and Laurence (two teenagers who use AAC), their families and two other parents from Novita, attended the 2007 AGOSCI National Conference in Melbourne.

The group from South Australia have shared some reflections from their time at the conference:

Fantastic facilities, great food, well organized, everyone was helpful, friendly and the information provided was very informative.

Always new developments to learn about, people in similar situations to meet.

I want to go (to the next AGOSCI conference) because I like talking to other users who are like me. And we can make a difference to communication and help other users who are younger ... we can set a good example for them. ... Have an open mind and speak your thoughts, only clean thoughts!

What were your highlights?

• Learning lots from just talking to other people with disabilities.

• Attending the Conference dinner with friends and listening to people with complex communication needs present speeches, their personal experiences, stories, thoughts, opinions and feelings.

• Receiving a private presentation of Ryan Bright's talk (after missing the public version because of taxi troubles!)"

Luckily, for anyone else who missed out on Ryan's presentation, he has shared his AGOSCI conference speech with *In Focus* readers (see pages 16-17).

Part of the South Australian gang at AGOSCI. Front row (left to right): Ingrid Birgden, Laurence Birgden, Ryan Bright and Jo Bright.

What did you learn from going to the AGOSCI conference?

• That there are lots of people all around Australia and overseas who can not speak, but they can still draw an audience and still get the credit they deserve from the audience. Especially some of the presenters, who were amazing.

• The range of equipment available and the importance of Internet, email and chat for people with disabilities.

• That there are so many opportunities for people with communication needs and difficulties and that with the right assistance and support they can successfully achieve their goals and dreams.

Advice for people who are thinking about going to the next AGOSCI conference ...

• Go and see, from the younger children to the older adults who can't speak, that with a device you can communicate and talk like everyone else. And get your knowledge and skills up to date with all the new devices that are available.

• If wheelchairs are an issue, stay in situ – cabs are impossible to come by!

• Plan which sessions to go to – too many can be overwhelming.

What were the best presentations that you attended? Why?

• Hearing Linda Burkhart speak, she was amazing, certainly got you thinking!

• Meredith Allan was another standout speaker.

• Fiona Given's session was fantastic. It made you think that no matter what disability you have everyone can still make it in the work place.

• Hands-on work on Clicker 5. The mother advocating for young people to have alternate accommodation to nursing homes and getting results.

• Ryan Bright. He is an inspirational young man with a great sense of humour. I can only hope my daughter can become half as fluent on her device!

Winter Literacy Intensive 2008

Presented by

Karen Erickson   and   David Koppenhaver

What: A 5-day instructional course which covers theoretical and practical aspects of literacy instruction for children and adults with Complex Communication Needs.

Who: The course is aimed at teachers and therapists who work in the area and numbers are strictly limited to 30 lucky people!

When: 30th June to 4th July 2008

Where: Rawson Village
Approximately 90 minutes drive from Melbourne

Cost: $1700 per registrant, inclusive of course instructional fee, course materials, accommodation in a shared room at Rawson Village (all registrants must stay on site) and all meals for the duration of the course.

About the presenters:

Karen Erickson

Karen Erickson, PhD, is the current director of the Center for Literacy and Disability Studies and is a former teacher of children with significant disabilities. Knowledgeable in literacy, assistive and instructional technologies, augmentative communication, and the learning characteristics of children with significant disabilities, she is in great demand as a presenter, consultant, and program developer. In 2004, Dr. Erickson was awarded the Educator of the Year Award from the National Down Syndrome Congress and the ISAAC Distinguished Literacy Lectureship Award. Her assessment and intervention strategies are described in numerous journal articles and book chapters.

David Koppenhaver

David Koppenhaver, PhD, is the former director of the Center for Literacy and Disability Studies and has worked for the past 20 years with preschool- and school-aged children who have a wide variety of literacy learning difficulties. He currently teaches undergraduate classes in reading methods, special education, and instructional technology. He has written and lectured widely on literacy instruction for children with significant disabilities and was the recipient of the 1998 ISAAC/Don Johnston, Inc. Distinguished Lecturer Award. He collaborated with Karen Erickson and David Yoder in organising a collection of AAC/literacy case studies for the book Waves of Words: Augmentative Communicators Read and Write and co-edited an issue of Topics in Language Disorders on literacy and AAC interventions for persons with autism.

AGOSCI Inc.
www.agosci.org.au

Join the AGOSCI Listserve at www.agosci.org.au for more information or email Jane Farrall jane@spectronicsinoz.com to be added to the mailing list.

007 LICENCE TO COMMUNICATE

It's What you do With it That Counts!

by Ryan Bright

Hello everyone and good morning to you all. My name is Ryan Bright and I'm almost 15 years old. I am here today to talk to you thanks to the scholarship I got from AGOSCI. I have been looking forward to the opportunity to speak at this conference. Today I am going to talk to you about my life and some of my thoughts on devices.

I was born on the 6th of July 1992, in the Lyell McEwin Hospital in Elizabeth, South Australia.

I had a stroke before I was born, and I suffer from cerebral palsy. Which means that the stroke affected my brain causing me to be unable to walk or talk.

I live with my Mum, Dad, and my sister Fiona. I have two dogs called Toby and Zelia. I go to Saint Columba College and I am in year nine. I have had eight operations including Botox but that's not because I have wrinkles. It's because Botox helps my muscles. So I will not have wrinkly legs!

I have an electric wheelchair and, when I was young, I had to get my drivers licence. I have had a few crashes including running over my sister's foot and ramming into a fence. I have become a better driver now.

In my life time I have been to Queensland, Melbourne, Canberra, New South Wales and now Melbourne again.

Some of my favourite hobbies are playing on my X-box, annoying my sister, swimming, and eating while watching footy, cricket and Bathurst. My Mum and my sister think that cricket is boring, but my Dad and I don't care. If it is boring we just keep on watching it, because it is a bloke's thing.

Some of my favourite things are Holden cars, the TV and my two X-boxes. I really wanted two of them because I was sick and tired of playing the same games all the time.

My favourite X-box game is San Andreas. This is because I get to run over all the people and shoot them. I sometimes get in trouble because the game is rated MI5, and there is some swearing on it. So when my Mum comes into the room I turn the volume down so that she cannot hear the swear words.

My favourite foods are cake, hot chips, chicken, Hungry Jacks, MacDonald's and basically all junk foods. Feel free to give me any of these foods. My favourite drinks are fanta, coke and, Bundaberg rum. Ha ha ha, just kidding.

I have some really great friends, who help me a lot. I also have some really great therapists, who help me and get me all this wicked and expensive equipment.

Without them I would not be speaking to you today. Some things I dislike are people who don't laugh at my jokes, people who are mean, and homework. But even if I don't like homework, I still have to do it like everyone else unfortunately.

My favourite movies are *The Fast and the Furious*, and *The Fast and the Furious – Tokyo Drift*. My favourite singer is Usher and I go for the mighty Adelaide Crows.

I have many goals for the future. When I am older I would like to get a job, maybe as an X-box game tester. I would also like to travel around the world.

In the future I will most probably have to have some more operations, and hopefully they can find a way to help me to be able to walk and talk.

Now let's talk a bit more about devices. When I was 18 months old I got my first device which was an Alpha Talker. I also used some communication boards as well, especially when the Alpha-talker broke down.

After I got to be too good for the Alpha talker I moved on to a Liberator, then a Light writer, and then a Pollyanna.

A few years ago I got the Mini Mercury with Speaking Dynamically Pro and up until recently I had a light writer as a back up. I use my device all the time, so I really need a back up device when my battery dies or if the device breaks down.

Usually I use a Mini Mercury device with VS Communicator 3 Pro, but I'm using the computer today for this speech since the Mini Mercury is a little older, and doesn't have the memory capacity to run this new Aussie voice when I do longer speeches.

I have just changed to VS from Speaking Dynamically and like it better because now I'm Aussie Irish, through and through, not a yank thank goodness.

My back up device now is a Chat PC device that I was lucky to get when someone else returned it because they weren't using it anymore.

I love the Chat PC too because it's small and looks cool. It's easy to carry around and people don't notice me using it so much. I think my device is great because I can tell some cool jokes, like this one.

The owner of a pharmacy walks in to find a guy leaning heavily against a wall. The owner asks the clerk, "What's with that guy over there by the wall?" The clerk says, "Well, he came in here this morning to get something for his cough. I couldn't find the cough syrup so I gave him an entire bottle of laxative." The owner says, "You idiot, you can't treat a cough with laxatives." The clerk says, "Really, look at him, he's afraid to cough!"

Here's another one "Why can't a blonde dial 911? Because she can't find the eleven button."

Sometimes I never shut up. Let me tell you about something that happened that can show you how great it is to have a device.

Last year, Mum finally gave me the chance to stay home alone. She arranged to ring me at 3 o'clock to check that I was ok. She called right on the dot of 3.

By the time I got up with my walking frame, got the device, and made it to the phone, the answering machine had already picked

It's What you do With it That Counts (cont)

up and I heard Mum and Fiona freaking out saying, "How come you're not picking up the phone? We're coming home!"

I was worried that my newly found freedom would come to an end so I had to think quick.

I got the address book from the bench and quickly dialled Mum's mobile number and left a message using my device. Mum said she was surprised to hear a Yankee voice telling her, "Mum it's me I am ok but hurry up and get home. I am starving and bring some Hungry Jacks."

Without my device I would never have got the Hungry Jacks I wanted. Sometimes my voice works too but not all the time and not always when I want it to.

One night though Dad and Mum were having an argument because they couldn't find my socks. Out of the blue I said, "my socks are in the bathroom."

I stopped the argument and surprised everyone including me! I also have lots of other ways to talk to people. I use a little bit of sign language, I use e-mail and msn messenger with my friends, and just recently I got a mobile phone so I can text my mates.

It's not all great though. The thing that's annoying about using a device is that people don't want to wait, but want the answer too fast.

Also, Mum, Dad, and Fiona don't like my new Aussie voice because they think I sound like a Pom. They are so used to having an American son, not an Aussie that sounds like a Pom. But I like it and so do my friends so I think I'll keep it.

One other thing that's hard is to keep up and say my bit when I'm hanging with my mates. I wish it was quicker to say those things that everyone else says and crack jokes like they do. I think up some pretty funny (and some dirty) jokes in my head but don't always get a chance to say them. That's probably lucky though sometimes, because Mum or the teachers might hear them and I'd get into trouble.

In the future, it would be great to have a device that would predict what I would like to say. But maybe it could check with me first before it blurts it out! It should be adaptable, to students that are like me who can only type with one hand.

I am left handed, so it is hard to plug in keyboards and the mouse sometimes. It should have a quicker speed and have a longer battery life. A device should be smaller and not too heavy. If I designed it, I would make it cost millions so that I make big profits. But if someone else designs it, then it should be cheap for me to buy. It would have x-box games on it, and the internet for up- to-the-minute sports results. I really need to meet Bill Gates so that I can ask him to design one for me.

If someone asked me how to learn how to use a device, I would say the best thing is to just have conversations. It's the best way to learn. It is also good to watch others who are good at it.

The things I wish for in the future are sports cars and to get a girlfriend. Does anybody have any hints to catch girls? I would also like to get a computer business in America like Microsoft, and then overtake Microsoft "Only dreaming!"

Thank you very much for listening to my speech, I hope that you like my new Aussie voice. Thank you again to AGOSCI for the scholarship, and the chance to come to the conference. It's so nice to have my family here with me too.

Thanks again for listening.

Over and out from Agent Bright ...

Challenging Incompetence - Highlighting Competence

by Jo Watson, Merrin McCracken, Rhonda Joseph, Enaksha Nadarajah & Helen Larkin – jwatson@scopevic.org.au

People with complex and high support needs are increasingly placed in a position of having to prove to others their competence to participate in the sort of everyday activities that we all take for granted. People who work in the disability sector are often placed in the position of being asked for an 'expert opinion'. They are often asked to determine people's competence to participate in activities or their capacity to make informed decisions about them.

At Scope, we recognised that a better understanding of this issue by service users and staff and other key parties was an crucial in ensuring that the people we support have genuine opportunities to live the livesof their choosing. To this end, we have begun to take a fresh look at choice, decision making, risk, and duty of care, all terms with a wide currency in relation to services for people with disabilities.

We are looking at what these terms mean for us and the people we support; the issues that are the most common source of dilemmas for staff and service users; the work being done overseas in this area; and, the structural and attitudinal barriers to decision making. We have found a notable absence of consensus with respect to definitions and theoretical frameworks in this area. At the risk of being perceived as pedantic, we believe that it is vital that these definitions are clearly defined within the specific context of our service provision.

In many arenas there continues to be a diagnostic approach to competence and choice making. A consultation paper issued by the UK Government, Who Decides? (1999), describes decision-making by vulnerable people, including those with a learning disability, in terms of their mental capacity to make a choice.

The first question is whether the person concerned is able to understand and retain the relevant information, including the consequences, not only of deciding one way or another but also of making no decision at all. The second question is whether the disability means that the person concerned is able to use that information in order to arrive at a decision: some people may be unable to exert their will, whether because of delusions or compulsions, or because of susceptibility to influence, or any other reason connected with their disability (Who Decides, 1997, pp 12 –13).

> " *A supported decision making approach has at its heart the notion that everyone is competent in making decisions and that everyone communicates.* "

Behind this statement, there are a number of implicit assumptions: first, that choice is a result of individual psychological abilities, variously referred to as 'able to understand,' 'retain information,' and 'exert their will'; secondly, social influences are irrelevant and unwanted.

The concept of capacity referred to here draws upon an idealised sequence of mental activities, with no reference to the social and environmental supports we all draw upon when making a decision.

Nicola Grove provides us with an alternative view of choice making. She writes about choice from a socio-cultural perspective. She claims that a choice can only be properly understood as a product of social practices that derive their meaning from shared meanings and expectations (Grove et al, 1999).

It is not surprising that when subjected to a diagnostic approach to choice and decision making, many people with intellectual disability are deemed not to have the capacity to give informed consent.

Unfortunately, this bears little resemblance to the way in which ordinary day to day decisions are made and lacks empirical support from research. It is particularly unhelpful as a framework for considering choice making by people with complex support needs, because it emphasises intellectual capacity and explicitly excludes the role which social and environmental factors make to choice (Bach & Rock, 1996).

These social and environmental factors are something that people without disabilities take for granted during a decision making process. In contrast, people with intellectual disabilities are often deemed as not having 'decision making competence' if they require the support of a friend.

We all seek support from the people in our lives that know and love us when making decisions. Some of us simply require more support then others. Interestingly much of the literature equates the absence of social supports in choice making as evidence of independence and empowerment.

An alternative interpretation is that people without disabilities draw upon extensive social resources although these may not always be visible at the point where the choice is expressed. This creates the impression that choices are being made without access to social supports.

Notwithstanding the limitations of this approach, it has proved extremely

Challenging Incompetence - Highlighting Competence (cont)

popular and has had a considerable impact on the way in which staff and professionals provide support to people with disabilities.

We have some strong concerns around the personal implications of deeming someone personally incompetent. What does this do to someone's status and value? Does deeming someone incompetent strip away autonomy, something that makes us uniquely human?

In 2005, Scope underwent a comprehensive process of talking to the people we support and their families. Their insights were invaluable. Here is what some people told us …

"I did not feel I had a say in my own life. I am not able to pursue dreams due to policy or OH&S concerns".

"A lack of choice about everyday routines such as going to bed, showering, mealtimes, going to the toilet, using the phone, not getting to watch the last quarter of the footy because it finishes too late and staff need to go home or finish a shift."

"Not involved in discussions about wheelchair prescription or how I might need to, or more importantly, like to use my own wheelchair."

"Not involved in discussion about manual handling, transport and general health and well-being issues, like being told I am using MY wheelchair in an "unsafe" manner or staff stating they won't push my wheelchair because it is too heavy. Even when I am involved, the OH&S issues are more important that what I think or want."

"Not automatically involved in discussion about medical issues such as pressure care, medication, going to hospital. Needing to insist and be assertive to have a say in these important issues and then I am still not always listened too or the information is not given to me so I can understand it. If I can't understand it I can't make a decision about it."

"Nagged constantly about lifestyle issues such as smoking, diet, weight management, usually by smoking, overweight staff."

"Sex, well what can I say, just to have a relationship is a major issue, let alone sex. I can't get agreement about gaining support from staff in this area of my life; one person will support one person won't and no-one wants to talk about it!! I am usually told it is an 'OH&S or Duty of Care issue'. I think staff hide behind this so they don't have to help."

"I went and did travel training, yet still I had to see the psychologist to prove I was competent to travel on my own. The staff were not sure if I understood about the risks, yet they happily take those same risks every day."

> ❝
> *We have some strong concerns around the personal implications of deeming someone personally incompetent. What does this do to someone's status and value? Does deeming someone incompetent strip away autonomy, something that makes us uniquely human?*
> ❞

"I got a mobile phone, it was great I could text people without staff listening in to my conversations, but I forgot to pay one bill, so the phone was taken off me and I am not allowed to have one. I have been told I might have to get a financial administrator. My brother has a mobile phone. When he first got his, it was cut off every second month, this only happened a few times and he learned to remember to pay his bill. Isn't he lucky he doesn't have a disability, cos you are not allowed to make mistakes. That was five years ago and I am still reminded of it every time I want to buy something. I guess I am just not responsible."

We also spent some time listening to others in the field that are grappling with some of these issues. Here's what they had to tell us …

"The risk that is the focus is more often the potential risk to the organisation than a risk to the individual."

"The number of court cases and the level of actual litigation in the community services area are negligible yet the level of fear is huge."

David Sykes (Office of the Public Advocate): "Risk management strategy needs to include the risks of denying client rights as a risk category in the same way as managing risk to data, staff, property etc."

David Green (LaTrobe University): "Is the way in which we rightfully or wrongfully apply duty of care the new form of manacled straight jackets?"

Julian Gardner (Office of the Public Advocate): "Is the way we manage OH&S the new form of paternalism?" "Is OH&S, the new walls of institutions?"

Based on this consultation process, we are attempting to redefine our approach to decision making, choice, risk management, and duty of care.

In the past, we had a duty of care to 'protect, comfort, keep safe, take care and watch'. We believe that our current duty of care is much more than that.

We have drafted a working definition which we believe reflects our current thinking and practice: 'One person supporting another in a way that does not cause harm, injury or loss (including loss of opportunity) that could be reasonably predicted because of something someone does or fails to do'.

At the core of these proposed changes is the adoption of a model of supported decision making. A supported decision making approach has at its heart the notion that everyone is

Challenging Incompetence - Highlighting Competence (cont)

competent in making decisions and that everyone communicates.

The question that needs to be asked is not around an individual's decision making competence, but rather, the assumption that every human being is communicating and that this communication will include preferences.

With support, preferences can be built up into expressions of choice and these into formal decisions.

From this perspective where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices.(Beamer, 2001).

It has become clear to us that the crux of any supported decision making process has as its foundation the need to truly listen to people in whatever 'language' they are using (words, objects, symbols, idiosyncratic body movements, behaviour).

We need to not only listen to people in terms of what we perceive as important for them, but also what is important to them. This is a delicate balance for any of us.

For many people with disabilities this see-saw is often very heavily weighted to what is important FOR them. The

outcome being that their life is not all that fulfilling. Everyone grapples with this balance.

As a result of this realisation we have developed a model of supported decision making in an attempt to provide a framework for truly getting to the heart of people's desires, preferences, and dreams. Each phase will have different emphasis according to who is using this model.

> *It is time that people's fundamental human right to lead lives of their choosing comes first over barriers such as occupational health and safety, and outdated perceptions of duty of care.*

It is a framework to be used in supporting very early communicators to make choices and decisions, and should be seen as such, merely a framework.

Supported decision making should be a fluid, not a prescriptive process. There is no denying that supported decision making is a complex and multifaceted process not easily articulated in one model or set of guidelines.

In conclusion, it is clear to us, that if service providers such as Scope, are to

embrace models of practice to which they aspire, fundamental changes to policies and processes in relation to decision making and choice need to be made.

It is time that people's fundamental human right to lead lives of their choosing comes first over barriers such as occupational health and safety and outdated perceptions of duty of care.

While acknowledging that we have work to do, we believe as an organization we have made great strides in this area and are feeling optimistic about the much of this rhetoric around decision making and choice becoming reality.

References

Bach, M. & Rock, M. (1996). Seeking consent to participate in research from people whose ability to make an informed decision could be questioned: The Supported Decision-Making Model. Ontario: Roeher Institute.

Beamer, S. (2001). Making decisions: Best practice and new ideas for supporting people with high support needs to make decisions. London: Values Into Action.

Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See what I mean: interpreting the meaning of communication by people with severe and profound intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 12, 190-203.

Harris, J. (2000). Choice and empowerment for people with a learning disability. Kidderminster, UK: British Institute of Learning Disability.

Lord Chancellor's Department (1997). Who decides: Making decisions on behalf of mentally incapacitated adults. London: HMSO.

Rawlings, M., Dowse, L., & Shaddock, A. (1995). Increasing the involvement of people with an intellectual disability in choice making situations: A practical approach. International Journal of Disability, Development and Education, 42, 137-153.

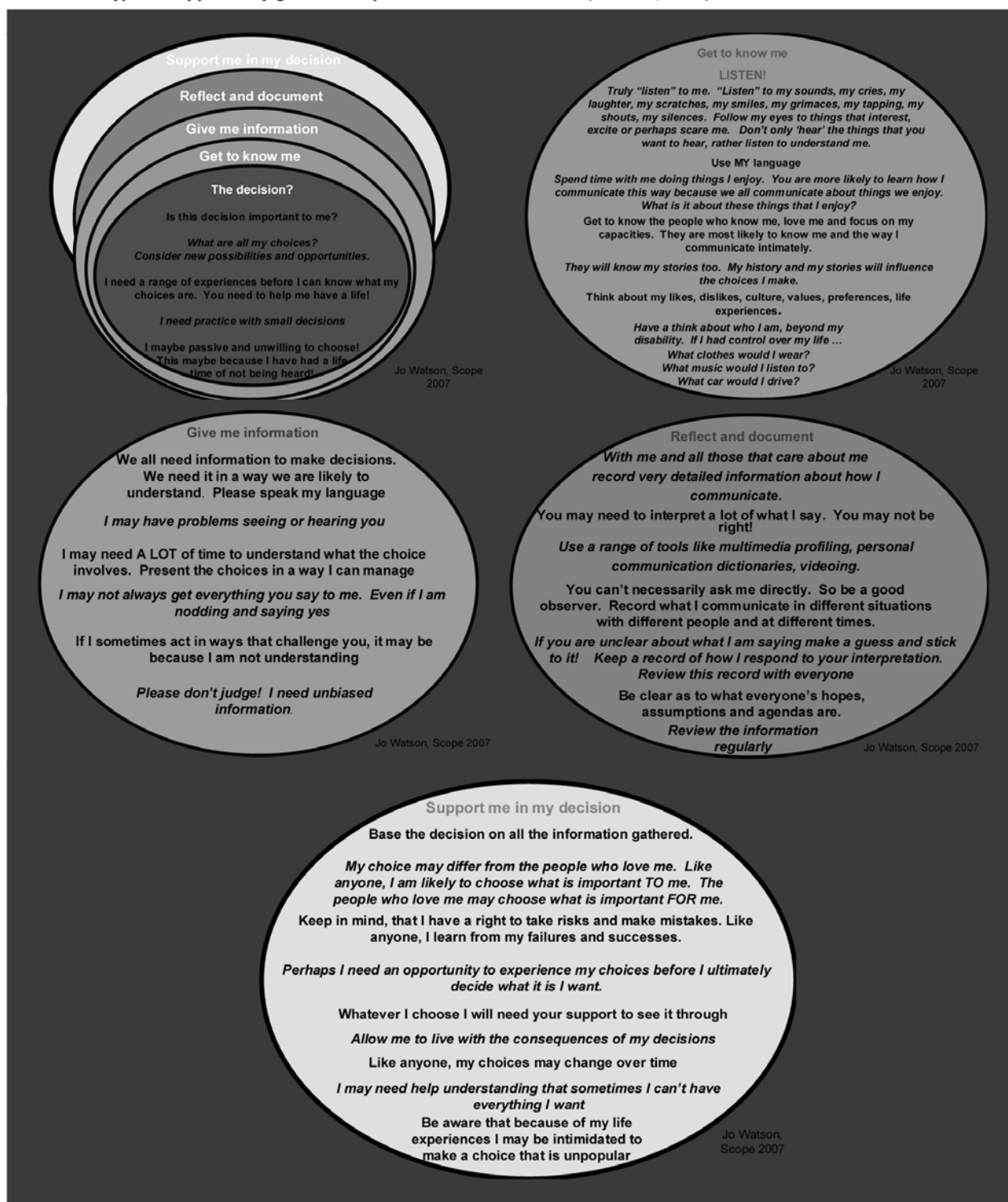Statewide Specialist Services, Scope (2004). Decision making and choice for people with high support needs.

Challenging Incompetence - Highlighting Competence (cont)

Figure 1

A Supported Model of Decision Making
Jo Watson 2007

The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices. (Beamer, 2001)

Support me in my decision

Reflect and document

Give me information

Get to know me

The decision?

Is this decision important to me?

What are all my choices?
Consider new possibilities and opportunities.

I need a range of experiences before I can know what my choices are. You need to help me have a life!

I need practice with small decisions

I maybe passive and unwilling to choose!
This maybe because I have had a life time of not being heard!

Jo Watson, Scope 2007

Get to know me
LISTEN!

Truly "listen" to me. "Listen" to my sounds, my cries, my laughter, my scratches, my smiles, my grimaces, my tapping, my shouts, my silences. Follow my eyes to things that interest, excite or perhaps scare me. Don't only 'hear' the things that you want to hear, rather listen to understand me.

Use MY language
Spend time with me doing things I enjoy. You are more likely to learn how I communicate this way because we all communicate about things we enjoy. What is it about these things that I enjoy?
Get to know the people who know me, love me and focus on my capacities. They are most likely to know me and the way I communicate intimately.

They will know my stories too. My history and my stories will influence the choices I make.
Think about my likes, dislikes, culture, values, preferences, life experiences.

Have a think about who I am, beyond my disability. If I had control over my life …
What clothes would I wear?
What music would I listen to?
What car would I drive?

Jo Watson, Scope 2007

Give me information

We all need information to make decisions. We need it in a way we are likely to understand. Please speak my language

I may have problems seeing or hearing you

I may need A LOT of time to understand what the choice involves. Present the choices in a way I can manage

I may not always get everything you say to me. Even if I am nodding and saying yes

If I sometimes act in ways that challenge you, it may be because I am not understanding

Please don't judge! I need unbiased information.

Jo Watson, Scope 2007

Reflect and document

With me and all those that care about me record very detailed information about how I communicate.
You may need to interpret a lot of what I say. You may not be right!
Use a range of tools like multimedia profiling, personal communication dictionaries, videoing.
You can't necessarily ask me directly. So be a good observer. Record what I communicate in different situations with different people and at different times.
If you are unclear about what I am saying make a guess and stick to it! Keep a record of how I respond to your interpretation. Review this record with everyone
Be clear as to what everyone's hopes, assumptions and agendas are.
Review the information regularly

Jo Watson, Scope 2007

Support me in my decision

Base the decision on all the information gathered.

My choice may differ from the people who love me. Like anyone, I am likely to choose what is important TO me. The people who love me may choose what is important FOR me.

Keep in mind, that I have a right to take risks and make mistakes. Like anyone, I learn from my failures and successes.

Perhaps I need an opportunity to experience my choices before I ultimately decide what it is I want.

Whatever I choose I will need your support to see it through

Allow me to live with the consequences of my decisions

Like anyone, my choices may change over time

I may need help understanding that sometimes I can't have everything I want
Be aware that because of my life experiences I may be intimidated to make a choice that is unpopular

Jo Watson, Scope 2007

Making Written Information Accessible:
Voting in Victorian State Government Elections

by Cathy Basterfield (Communication Resource Centre – Scope) & Peta McCammon (Victorian Electoral Commission)

The Victorian Electoral Commission's (VEC) primary responsibility is to conduct State government, and local government elections in Victoria. As part of the Commission's commitment to providing accessible voting services, the VEC undertook a consultative process in 2005 to update its Disability Action Plan.

Through this process, it was identified that the VEC needed to provide accessible written information to those Victorians who have historically not been engaged in the voting process, such as those with lower levels of literacy. This in turn would increase the capacity of the community to make informed choices, and to become more engaged with the voting process for the 2006 Victorian State Election.

The VEC had previously recognised the value of engaging in organisational partnerships to develop new directions and initiatives and has previously done so with regard to accessibility issues, eg: Vision Australia.

In considering making written information accessible, the VEC developed a partnership with the Communication Resource Centre, SCOPE Victoria, to develop an Easy English resource. The Communication Resource Centre provides organisations with training and consultancy to develop their Easy English resources.

The VEC approached the Communication Resource Centre to learn about making written information accessible. The entire Communications team at the VEC undertook a half day training workshop to build internal capability and acceptance of an Easy English writing style.

Increasing the capacity of the whole VEC communications branch ensured it would be able to support the production and distribution of the new document. It also assisted in identifying and prioritising other publications and signage that could be developed into Easy English.

In 2005, the Communication Resource Centre was asked to produce some Easy English material for the local government elections. This material was placed on the VEC's website. The response was extremely positive and encouraged the VEC to consider the publications and signage for the 2006 State government election.

> *... it was identified that the VEC needed to provide accessible written information to those Victorians who have historically not been engaged in the voting process, such as those with lower levels of literacy.*

The primary product for the 2006 State election was a draft booklet in Easy English, which was based on part of an original document from the VEC – 'Your Voice Your Future.' The two organisations worked together on multiple drafts to develop the final document, 'Voting in Victoria: State Government elections.' The drafting process included some feedback from the target group.

The document had two print runs within the first six weeks of its release, and over 2000 copies were distributed. The majority were distributed in response to requests including schools, Members of Parliament, and disability agencies.

In addition, the VEC learnt that those who accessed the booklet represented a broad range of communities; such as those whose spoke English as a second language and Indigenous Victorians.

Internally the VEC developed some Easy English signage to display at voting centres, with the Communication Resource Centre providing some minor comments. This internal capability will be further utilised when looking at other options at voting centres at future elections.
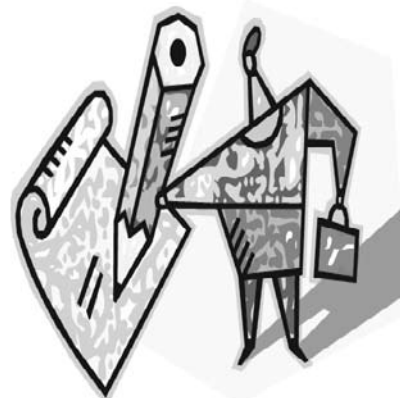
For further information please contact:
Cathy Basterfield
Communication Resource Centre
Scope
830 Whitehorse Rd
Box Hill VIC 3128
cbasterfield.crc@scopevic.org.au

Peta McCammon
Victorian Electoral Commission
Level 8, 505 Little Collins Street
Melbourne VIC 3000
peta.mccammon@vec.vic.gov.au

Accessible Local Healthcare Services

by Andrea McQueen (Inner South Communication Service, Vic – amcqueen@cbchs.org.au)
and Penny Jordan (MetroAccess, City of Kingston, Vic – penny.jordan@kingston.vic.gov.au)

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being.[1] People with disabilities have the same rights to access local healthcare services as other people in the community. They also have the right to the same health outcomes as people who do not have disabilities.

Throughout Australia and beyond, government health policies are moving away from a centralised, specialist model of health care for people with disabilities, towards inclusive local services. The Victorian Disability State Plan 2002 – 2012 states that "The Victorian Government is committed to ensuring that all people have access to high quality health and community services in their local communities."[2] The Commonwealth Senate Standing Committee on Community Affairs, in revising the Commonwealth State Territory Disability Agreement (CSTDA), said that "Access to generic services should continue to be a priority for the next CSTDA, particularly access to health care services".[3]

Inherent in this policy shift is the assumption that local health services are accessible (physically and in terms of communication and information) and that health professionals within these services are prepared, skilled and resourced to manage the health needs of people within their communities who have disabilities.

Anecdotal evidence tells us that this is not the case. Stories from both people with disabilities and health care providers indicate that the road to the local health service is a bumpy one, at least in some cases. We embarked on this paper as a means of exploring the accessibility of local health care services for people with disabilities, and particularly those with complex communication needs. Our aim was to identify the barriers (if any) and to research potential strategies for overcoming these barriers.

Along the way we discovered that there is not a lot of research in this area and much of what does exist comes from overseas. Although there is a body of work on the relationship between disability and health, information about the relationship between disability and the use of health services is harder to come by.

For the purposes of this paper, "local health services" include a range of health services available within the community, including community health centres, hospitals, dental clinics and general practices. "Disability", as defined in the Disability Discrimination Act, includes "physical, intellectual, psychiatric, sensory, neurological, and learning disabilities, as well as physical disfigurement, and the presence in the body of disease-causing organisms".[4]

Health is a major issue for many people with a disability. "People with a disability experience significant health inequalities and are at higher risk of health problems, particularly conditions that relate to lifestyle, including poor nutrition, low levels of physical activity and limited social networks. Therefore, people with a disability also have a higher prevalence of heart disease, diabetes, osteoporosis, obesity and mental health problems when compared with the Victorian population".[5]

A study in the Netherlands identified that people with intellectual disability appeared to experience 2.5 times more health issues than people without an intellectual disability. Some health conditions are often related to the individual's diagnosis, such as epilepsy and sensory impairments being more common with individuals with Down Syndrome. Other conditions such as diabetes seem more related to external factors such as lack of information, lack of exercise, poor mobility, poor eating habits, medication use, etc.

Figure 1 (below) shows that the more significant the level of restriction a person's disability imposes the greater the number of additional health conditions they will experience. A person with a profound disability is likely to have three to four health conditions where as someone with no disability is likely to have less than two conditions.

1.   World Health Organisation, 2006, p1
2.   Department of Human Services, 2002, p42
3.   Commonwealth State Territory Disability Agreement, 2007, Recommendation 23
4.   Disability Discrimination Act, 1992, section 4
5.   Department of Human Services, 2006

LEFT: Figure 1 – Mean number of health conditions by disability status and age group.
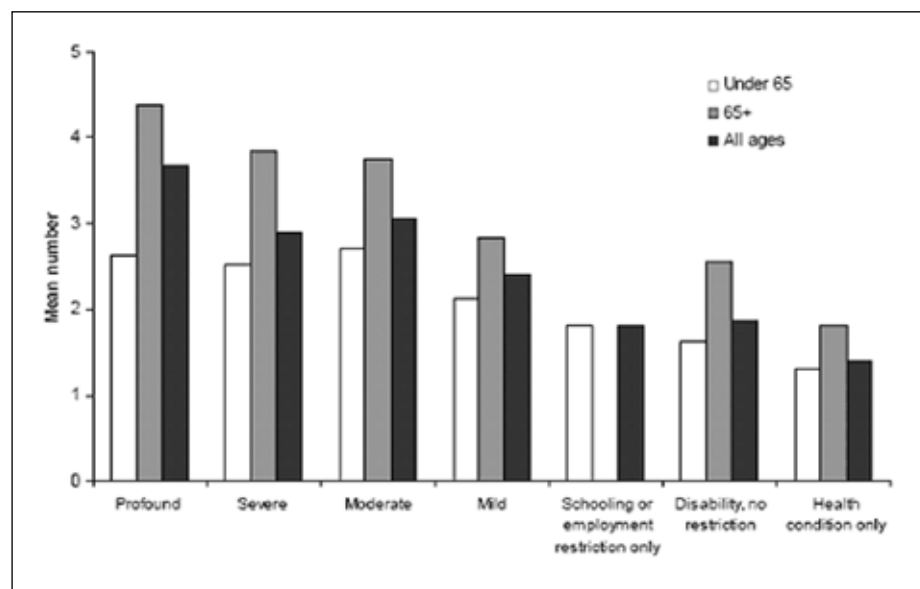
Accessible Local Healthcare Services (cont)

What are the barriers to local health services faced by people with disabilities and complex communication needs?

Beukelman and Mirenda's Participation Model[6] (see Appendix I) is widely used throughout the world as a key component of individual augmentative communication assessments. It provides a means of analysing the barriers to participation and identifying solutions. Although it is more often applied to individuals, the Participation Model also provides a useful means of analysing the barriers to participation within a broad social context such as the healthcare system.

For the purposes of this paper, it is assumed that the barriers identified are "opportunity" rather than "access" barriers – that is that they are limitations of the system, rather than of each individual's skills and communication methods. Again we would like to emphasise that much of the evidence of these barriers existing in Australia is anecdotal or from very small studies, however the conclusions are supported by more compelling studies that have been conducted overseas.

Difficulties with the appointment making process

The processes used for making an appointment can be difficult to negotiate, particularly for people with complex communication needs and those for whom telecommunications are difficult. This issue can be influenced by both policy and practice.

Transport issues

Access to transport is an issue that is bigger than the scope of this paper and certainly has an impact beyond the healthcare arena. This is considered a policy barrier, with public policy and infrastructure planning having a big impact here.

Physical accessibility

This is another policy barrier where accessibility for people with vision, hearing and cognitive impairments, as well as for those with physical disabilities, is not always adequately considered in the design of public facilities. It is, however, an area in which some progress has been made over recent years. The availability of accessible equipment, such as height adjustable examination tables, is also limited.

Communication in appointments

Anecdotal evidence shows that people with disabilities, particularly those with complex communication needs, report health professionals often communicate with others present during the appointment, such as carers, and not with the patient who has a disability. People also stated that they were not provided with adequate time to communicate and that they felt guilty as they took longer to communicate.[7]

Focus groups conducted by CAUS Inc in 2005 into the experiences of individuals with communication and speech impairments found that communication or speech impairment was sometimes exacerbated by their health issue, reducing their ability to communicate with the health professional.

A study in the US, of 384 people with disabilities surveyed, showed 59% of individuals with learning disabilities and 64% of individuals with cognitive disabilities reported that their health providers communicate with someone else in the room rather than directly communicating with the patient.

Almost 80% of individuals with cognitive disabilities report receiving too little time to communicate their symptoms to the provider and ask questions of the provider that are necessary to ensure effective communication.[8]

The whole area of effective communication is affected strongly by the attitude, skill and knowledge of the health professional.

Stereotypes and awareness of disability

Respondents to a study completed in the UK, showed that many individuals with Cerebral Palsy and Multiple Sclerosis were dissatisfied with assumptions made about intellectual disabilities based on an individual's communication style. This could result in decreased provision of information and involvement in decision making. From the perspective of the health professional, it was reported that many felt a "fear of the unknown" and felt that they did not know how to relate to people with complex communication needs.[9]

This area also relates to the attitude, skill and knowledge of the health professional.

Accurate identification of health issues

If a health professional is not competent in communication with people with complex communication needs, these patients may have difficulties in accurately communicating their health issues and symptoms.[10] For people with intellectual disabilities, another issue that may occur is having limited insight into their own health, and therefore being less likely to identify and follow up on any health issues. Diagnosis Overshadowing may also occur. This refers to a health issue being wrongly attributed to an individual's disability.[11] This barrier is affected by the skill level of the health professionals.

Information provision

The provision of information in accessible formats including Easy Read, Braille or audio cassette is rare in health services. This results in difficulties for individuals in understanding what services are available and what their rights are. It also means that many health promotion activities are not accessible. This is, again, a policy and practice issue.

Appropriate services

The perception that specialist medical and allied health services exist for people with disabilities, and that these are preferable to generic local services, continues in the community. This may be a knowledge barrier - many health professionals are simply unaware of the lack of specialist services for people with disabilities. It can also be an attitude barrier - the assumption being that people with disabilities are not entitled to choice of service provider.

6.   Beukelman & Mirenda, 1995
7.   Focus groups conducted by CAUS Inc in 2005
8.   Markwalder, A. 2007
9.   Shapiro, J, et al., 2003
10. Schrojenstein, et al., 2000
11. Human Rights and Equal Opportunity Commission, 2004

Accessible Local Healthcare Services (cont)

This results in many generic health providers not seeing that there is a need to develop specialisation or appropriate skills.

Funding shortfalls and the tyranny of the waiting list

There is a policy element to these issues – funding is stretched and waiting lists are an unpleasant reality. Individuals themselves have limited finances to cover additional health related expenses. "However, there is also an attitude barrier element to this issue. The perception is that people with disabilities are "extra" consumers – an additional demand on an already stretched system rather than part of the broader community.

What is being done?

With most issues being affected by more than one opportunity barrier, analysis clearly shows that strategies to overcome these barriers will need to have multiple strands:

- Training to target knowledge and skill barriers
- Policy changes, and
- Resources to support these changes and developments in practice.

There are a number of innovative projects underway which aim to address some of the barriers we have discussed. Often these projects are small-scale – addressing one or two services on a localised level. We have chosen to highlight a few projects of particular interest.

Training

- Listening and Communicating with Everyone (LACE) is a project targeting frontline staff (reception and intake teams) within community health centres. The aim is to provide reception staff with the skills and resources they need to communicate successfully with people with complex communication needs. A similar program for health professionals is currently in development. This should impact upon barriers such as appointment making and information provision, as well as communication in appointments and disability awareness. This project was initially only a localised project targeting the Inner South Metropolitan Region of

Melbourne and will be spreading to other regions of Victoria.

- A number of services offer "peer support" as a way of supporting health professionals to develop skills needed to treat people with disabilities. Victoria's Eastern Regional Communication Service has recently had success in supporting local physiotherapists and speech pathologists to work with individuals with disabilities. This has been a process of negotiation, taking into account the concerns and limitations of service providers as well as the needs and rights of each patient.

This approach too should increase disability awareness and more effective communication in appointments, however again it is limited in the breadth of its impact.

- On a broader scale, the Centre for Developmental Disability Victoria has input into the undergraduate training of future medical practitioners. Some of Victoria's Regional Communication Services are also involved in doctor training.

Resources

- CAUS – Communication Rights Australia – has developed a "hospital kit" for people with complex communication needs to take and use during hospital stays to improve communication with heath staff and more accurately identify health issues. This kit has been distributed throughout Victoria, however health professionals are not always aware of how it operates.

- The LACE program provides shared communication boards for use at reception desks in health facilities. Boards and other communication resources have also been developed by the Communication Resource Centre for a variety of disciplines, including pharmacists and dieticians. These useful resources to improve appointment making and communication are again limited to various locations throughout Victoria.

- A project is underway creating easy-read versions of the mandatory written information used by Victorian health services. This includes the Service Co-ordination Tool (SCoT),

privacy brochure and rights brochure. This will improve provision of essential information markedly.

- Outside of Victoria, the University of Queensland Centre for Intellectual Development Disability has developed a multi-pronged approach. The Comprehensive Health Assessment Program promotes a more thorough health assessment and review process by GPs. This has resulted in massive increases in identification of health issues such as a six-fold increase in identification of vision impairment. This centre also runs a training program for adolescents with intellectual disability in identifying and reporting health issues utilising a variety of communication tools, including an 'Ask Diary' where interactions and issues can be recorded to report to and discuss with GPs. This tool has also resulted in increased empowerment and advocacy of people with disabilities and their families in the health system.[12]

- Height adjustable tables are rarely used in Australia. A survey of general practices across Australia in 2003 showed that in Australia there were 14,008 fixed height tables as compared to 719 adjustable tables. There is a push for increased purchase of adjustable tables in practices to improve physical access. In some areas such as the Northern Territory only 4 out of 168 couches were reported as being adjustable. Similarly the survey showed that in Victoria out of 3581 examination beds identified only 120 were adjustable.[13]

- The Inpatient Functional Communication Interview (IFCI)[14] is a functional assessment tool developed for use by speech pathologists in acute hospitals. The IFCI provides useful information about a patient's communication skills and methods – maximising the success of interactions for people with communication difficulties within the acute hospital environment.

12. University of Queensland, 2007
13. HREOC, 2006
14. O'Halloran, R. et al, 2004

Accessible Local Healthcare Services (cont)

Policy changes

• There are limited Australia wide changes being made to decrease opportunity barriers, however one such action is the recent introduction of a new Medicare item number that will allow for longer GP consultations for people with intellectual disabilities from July 2007. This will enable people with communication and speech impairments longer time to communicate and also allow GPs to conduct more thorough health assessments.

• The new Victorian Disability Act 2006, which will come into effect on July 1st this year (2007) will stipulate that public sector bodies, including many health services, must develop a Disability Action Plan that will: reduce access barriers to goods, services and facilities; promote inclusion; reduce discriminatory attitudes; and promote employment of people with disabilities.[15]

Conclusion

The current push away from specialist disability health services is placing demands on generic health services, which are under-resourced and not well trained to meet the needs of this population. Although there are numerous small scale, localised projects occurring, there are limited national initiatives.

There have been significant gains in providing supports for people with disabilities, such as stronger access to Auslan interpreters for people who are deaf or who have hearing impairments, however limited gains have been made for people with complex communication needs in receiving support for communication assistants.[16]

Through the implementation of the new Disability Act here in Victoria, a strong series of policy requirements should be put in place to promote the change to a more equitable health service system. However for the policies to be successful, they must be supported by training and resources.[17]

When a similar move was made in the UK with "Equality Duty", which came into place in December 2006, resources and support guides were produced for all health service providers about how to meet requirements of the Disability Discrimination Act. This guide also provided information and encouragement about making changes beyond what was legally required and how to make these changes in a simple and low cost manner. They also produced fact sheets for all front line workers on the needs of people with disabilities.[18]

A health forum convened by the Human Rights and Equal Opportunity Commission in Sydney, focussing on the needs of people with disabilities, provided recommendations for improving access to generic services for people with disabilities. A primary push from many involved in this forum was that for any initiative to be successful people with disabilities needed to be involved in developing strategies, particularly those around health promotion.[19]

If people with disabilities are to achieve "the highest attainable standard of health"[20], they must have access to a full range of appropriately resourced, trained and welcoming health services. There is a need for comprehensive national initiatives, beginning with policy development, with strong support through training and resource provision. Only then can optimal health outcomes become a reality for Australian people with disabilities.

15.   Disability Act 2006, part 4, section 38.
16.   Australian Association of the Deaf, 2004
17.   Women with Disabilities Australia, 2001
18.   National Health Service, 2004
19.   Human Rights and Equal Opportunity Commission, 2004
20.   World Health Organisation, 2006, p1

References

Australian Association of the Deaf 'Access for Deaf people to health services', 2004, http://www.hreoc.gov.au/disability_rights/health/AAD.doc.

Australian Institute of Health and Welfare, Disability and its relationship to health conditions and other factors, Canberra, 2004.

Beukelman, D. & Mirenda, P. "Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs". Third Edition. Baltimore: Paul H. Brookes 1995

CAUS Inc focus groups, 2005 , unpublished.

Commonwealth State Territory Disability Agreement, 2007 , http://www.aph.gov.au/Senate/committee/clac_ctte/cstda/report/b01.htm

Department of Human Services, Health Promotion Strategies, Volume 6, Number 3, August 2006

Department of Human Services, State Disability Plan, 2002

Disability Discrimination Act, 1992, http://www.austlii.edu.au/au/legis/cth/consol_act/dda1992264/

Disability Act 2006, http://nps718.dhs.vic.gov.au/ds/disabilitysite.nsf/sectiontwo/leg_policy?open#new

HREOC, 2006 , http://www.hreoc.gov.au/disability_rights/health/couch.htm

Human Rights and Equal Opportunity Commission, www.hreoc.gov.au/disability_rights/health/notes.htm, 2004

Human Rights and Equal Opportunity Commission, http://www.hreoc.gov.au/disability_rights/health/couch.htm, 2006

Markwalder, A. 'A call to action: A guide for managed care plans serving Californians with disabilities. Retrieved June 14th 2007, from http://www.dralegal.org/downloads/pubs/call_to_action.pdf

National Health Service 'You can make a difference', 2004, www.drc.org.uk

O'Halloran, R. et al. "Inpatient Functional Communication Assessment". 2004 University of QLD

Schrojenstein, H., Metsemakers, J., Haveman, M. & Crebolder, H. 'Health problems in people with intellectual disability in general practice: a comparative study'. Family Practice, 2000:17, 5, 405-407. www.fampra.oupjournals.org

Shapiro, J., Mosqueda, L. & Botros, D. 'A Caring Partnership: expectations of ageing persons with disabilities for their primary care doctors'. Family Practice, 2003:20, 6, 635-642. www.fampra.oupjournals.org

UQ study gives young Australian's with intellectual disabilities a healthy start' University of Queensland. Retrieved June 14th 2007, from www.medicalnewstoday.com/medicalnews.php?newsid=32248
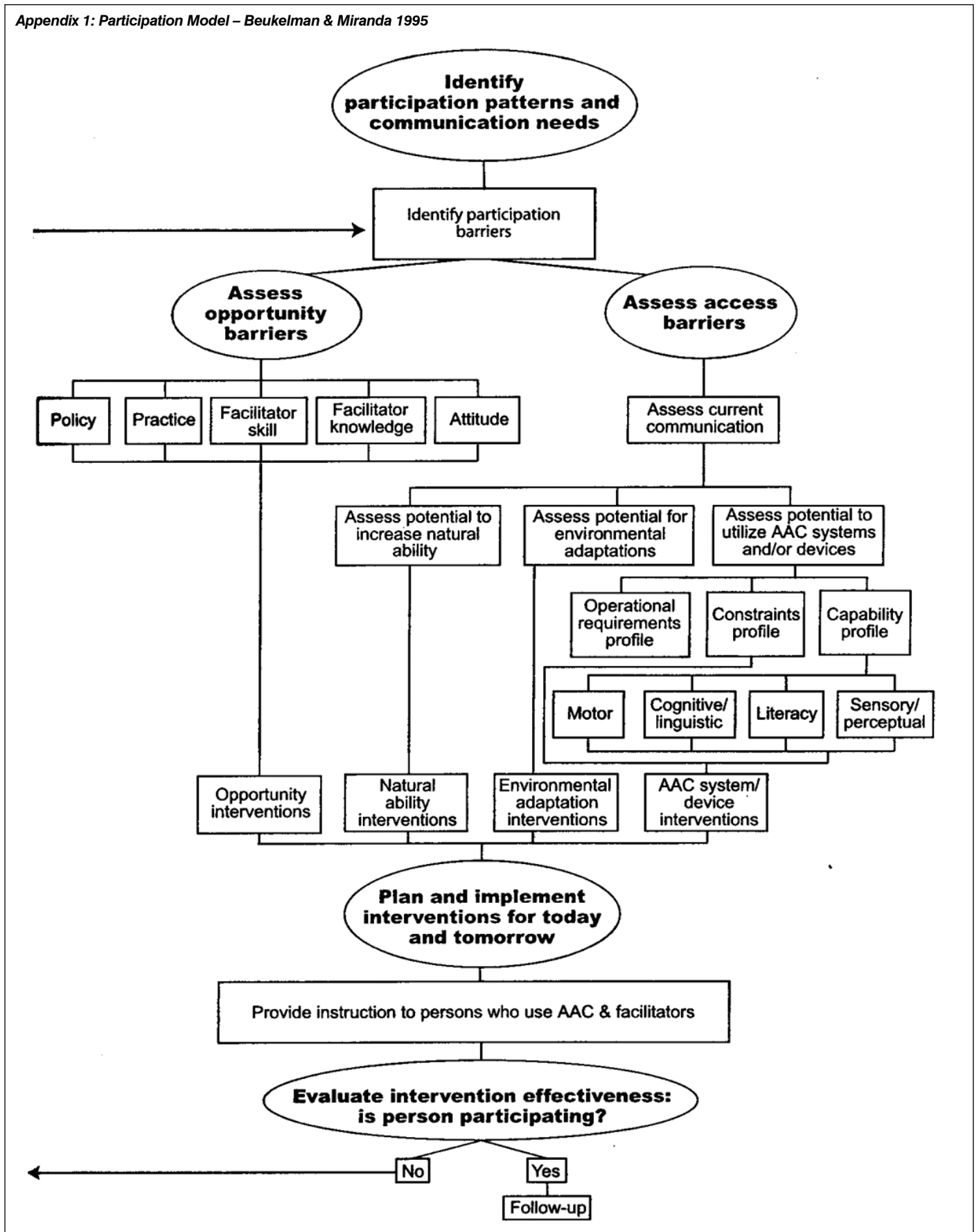
World Health Organisation – Constitution. 45th Edition. Supplement 2006.

Women with Disabilities Australia 'Going inclusive: access to health care for women with disabilities' 2001, http://www.wwda.org.au/inclusive.htm

Accessible Local Healthcare Services (cont)

Appendix 1: Participation Model – Beukelman & Miranda 1995

Identify participation patterns and communication needs

Identify participation barriers

Assess opportunity barriers

Assess access barriers

Policy | Practice | Facilitator skill | Facilitator knowledge | Attitude

Assess current communication

Assess potential to increase natural ability

Assess potential for environmental adaptations

Assess potential to utilize AAC systems and/or devices

Operational requirements profile | Constraints profile | Capability profile

Motor | Cognitive/linguistic | Literacy | Sensory/perceptual

Opportunity interventions | Natural ability interventions | Environmental adaptation interventions | AAC system/device interventions

Plan and implement interventions for today and tomorrow

Provide instruction to persons who use AAC & facilitators

Evaluate intervention effectiveness: is person participating?

No | Yes

Follow-up

People With Complex Communication Needs Have a Right to Good Mental Health Too!

by Jo Watson, Mark Di Marco, Hrepsime Gulbenkoglu, Nick Hagiliassis, Teresa Iacono – jwatson@scopevic.org.au

Background

For some years now, Psychologists working with Scope, have provided counselling and other psychological services to people with complex communication needs. In reflecting on their practice, they have continued to be inspired, but also challenged, by working with people with complex communication needs. A question that they continue to ask is "How they make counselling accessible to people with complex communication needs, whilst not compromising the integrity of the counselling process?" It is this question that was the catalyst behind the development of the Bridging Project.

The Bridging Project is a collaboration between Scope Victoria and the Centre for Developmental Disability Health Victoria, Monash University. This collaboration is made up of two Speech Pathologists and three Psychologists all of whom are experienced in supporting people with complex communication needs.

People with complex communication needs and people with mental health issues often feel hidden within the community and believe that others do not readily understand the difficulties that they experience or the problems that they have accessing necessary services. However, when people have both a complex communication and a mental health need, these problems are significantly compounded. The Bridging Project is attempting to build bridges between specialist and community providers of mental health services in relation to people with complex communication needs.

Historically, the focus of psychological intervention for people with disabilities has been at the behavioural approach level: to cease or control behaviour and reduce the likelihood of behaviour recurring. Adjunct approaches have also implied the principle of 'controlling': e.g., medication, restraint and seclusion practices. However, today there is an increased (and welcomed) focus on understanding "why people behave the way they do". The positive behavioural intervention framework (LaVignia and Willis 1995), marked the beginnings of this change. Although it uses strategies such as reflective listening and teaching coping and tolerance skills, the focus continues to remain at the behavioural level. The role of approaches, such as counselling, that allow for exploration of the emotional factors that contribute to a person's psychological wellbeing continues to be overlooked.

> **The Bridging Project has as its mission, to progress the knowledge and resource base to ensure those individuals with complex communication and mental health needs have access to quality services.**

Everyone has a need to address and resolve specific problems, make decisions, develop personal insight and knowledge, work through feelings of inner conflict or improve relationships with others. Therefore, everyone, including those with disabilities such as complex communication needs, should have access to quality counselling services.

The Bridging Project has as its mission, to progress the knowledge and resource base to ensure those individuals with complex communication and mental health needs have access to quality services. The project has two streams, Building Evidence and Building Capacity. Each stream works with the other to support the overall mission statement and assist in informing the project development at all stages.

What Does the Literature Tell Us?

Published literature on the effectiveness of counseling for people with complex communication needs is decidedly lacking (Di Marco & Iacono, 2007). The main focus in this area has been on examining the question of counseling effectiveness with people with intellectual disability and although there are some inferences that can be drawn from this literature, more work is needed in the area of complex communication needs.

The only identified study to examine people with complex communication needs directly was by Crawford in 1987. He described individual counseling for seven people with complex communication needs. The results of the study indicate that the response of these people to therapeutic intervention using AAC generally was positive. The study is relatively flawed methodologically due to a lack of robust data, and the failure to describe the psychotherapeutic model and strategies employed. However, Crawford's study does highlight the viability of psychotherapeutic intervention for people with complex communication needs. He makes the point that despite the challenges that can arise in using AAC in a counseling context, access to AAC enables the therapy to occur.

What Barriers Have Been Identified to People with Complex Communication Needs Receiving Quality Mental Health Services?

Counselling is often excluded as an option for people with complex communication needs. One of the reasons for this may be that most leading models of counselling are based on speech and listening processes (Hagiliassis, Di Marco, Gulbenkoglu, Iacono, & Watson, 2006). It is speech that primarily guides counselors in gaining understanding of clients' thoughts, feelings and responses. This reliance on speech can obviously result in major challenges when providing counselling to people with complex communication needs.

Diagnostic overshadowing can be a disturbing reality for many people

People With Complex Communication Needs ... (cont)

with a disability. A mental health issue may be misinterpreted as a manifestation of their disability. For example, a person with autism, whose thinking becomes more rigid in the context of a deteriorating mental state, may have their behavior simply interpreted as a symptom of their autism.

Behavioral overshadowing can be another reality for people with a disability. Responses are regarded as a behavioral response to environmental factors and labeled as "challenging behavior" This is when a symptom that is normally ascribed to a psychiatric illness, such as loss of interest in pleasurable activities as in the case of depression, is interpreted at strictly a behavioural level, "the person is not engaging in that activity or program, therefore, we must fix the environment to be more stimulating". While that may assist, it may not be getting to the heart of the matter, the person's depression.

Diagnosis of psychiatric illness in people with disabilities is fraught with difficulties. Complex communication needs add an additional level of complexity to the process. Complex communication needs make information about symptoms such as hallucinations difficult to express. So even when people present to mental health services, conventional diagnostic processes may have little value, and it may be impossible to reliably ascribe a clinical diagnosis to a presenting issue.

Additionally, there exists a common assumption that people with disabilities somehow do not posses the intellectual or personal capacity to be affected by everyday psychosocial stressors and, therefore, are not vulnerable to psychiatric illness. This assumption is deeply concerning as it implies, incorrectly, that people with disabilities can not be impacted upon emotionally.

As members of the Bridging Project, we collectively have decades of experience in working with people with complex communication needs. We therefore draw a lot of information from our anecdotal experiences and observations. One such

observation is that 'people with disabilities are less likely to self refer' (Hagiliassis et al, 2005). Many (perhaps the majority) of referrals for the clients we support emerge from staff and family members, rather than from clients themselves. This links to the issue of empowerment and opportunity for self-referral. It also links to the issue of the accessibility of referral mechanisms, which themselves imply a degree of verbal and written communication ability.

For example, some services have moved towards a request-based system of referring to specialist services, which requires either a telephone-based referral contact, or a written and then faxed referral. We ask the question, what proportion of the clients that we support have the communication capacity to self-refer under such systems?

> *Diagnosis of psychiatric illness in people with disabilities is fraught with difficulties. Complex communication needs add an additional level of complexity to the process. Complex communication needs make information about symptoms such as hallucinations difficult to express.*

Another barrier appears to be a disdain or discomfort about working with this group. Bender (1993) argued that there has been an historical disdain towards therapy and research into its effectiveness for people with intellectual disability. He charted the history of this bias from Freud (1904) to Rogers (1951), each of whom stated that clients must be of average intelligence and able to communicate using speech to benefit from client-centered therapy. Cognitive-behavioural therapists have also suggested that their model of therapy may not be applicable to people with below borderline levels of intellectual disability (Hollon, 1984). According to Hurley (1989), no

real evidence is available to support these views. In fact, Hurley, Pfadt, Tomasulo, and Gardner (1996) argued that although the evidence has been patchy and intermittent over the years, the results, generally, have been positive, as is evidenced by a number of studies (Hagiliassis, Gulbenkoglu et al., 2005; Silvestri, 1977; Taylor et al., 2002; Willner et al., 2002).

An assumption for which there is no evidence is that people with disabilities are unable to benefit from counseling. Specifically, according to this view, people with disabilities lack the capacity to resolve specific problems, make decisions, develop personal insight and knowledge, work through feelings of inner conflict or maintain meaningful relationships with others. These all are important aspects of counseling.

There are limited assessment tools for practitioners to use when working with people with disabilities, specifically those with complex communication needs. Most assessment tools are based on staff reports, using behavioral indicators of mental ill-health. There are no existent tools that involve self-report that are accessible to people with complex communication needs. Most assessments require complex verbal responses, or involve complex concepts that can be a barrier for people who experience comprehension difficulties.

Another obvious barrier is the need to modify or adapt counseling to make it accessible to people with a range of verbal and/or cognitive abilities. This is an obvious challenge for the Bridging Project, however, we believe that the Guidelines we have developed provide some clear direction in this area.

The Bridging Project have identified that there is an under-identification of mental health problems in people with complex communication needs. We hypothesize as to some reasons for this. That is, there is poor early detection of emerging mental health condition and mild-to-moderate cases tend to be overlooked entirely. For example, a person with early signs of depression, or a mild form of depression,

People With Complex Communication Needs ... (cont)

whose primary presenting symptoms may be withdrawal and intermittent teariness, may not be readily referred for treatment, until their depression worsens and their symptoms are more evident and they result in significant functional impairment.

Similarly, a person who is in the early, prodromal phase of a psychosis, who may have emerging delusional or hallucinatory symptoms may not be identified and referred for treatment until they are clearly in a psychotic state, and symptoms are so severe so as to draw the attention of those that support them.

Guidelines for Practitioners

The Bridging Project has developed a set of Guidelines for practitioners providing counselling services to clients with disabilities and complex communication needs (Hagilliasis et al., 2006)[1] .

The intention of the Guidelines was to focus on symbolic communicators. While acknowledging that the strategies that counselling practitioners use with non-symbolic communicators may need further modification and development, the principles/hallmarks of counselling remain the same, whether someone is using formal communication or not. These hallmarks include empathy, positive regard and genuineness, all principles that can be present within any counseling relationship regardless of one's expressive or receptive language skills.

The guidelines describe approaches for making counselling maximally accessible to people with complex communication needs, whilst maintaining the integrity of the counselling process.

Importantly, these guidelines are not approached from the perspective of a specific theoretical orientation, but rather reflect approaches that can be generalised to a number of current models of counselling.

This resource provides practitioners with both general and specific guidelines for providing counseling services to people who use augmentative and alternative communication. The general guidelines

are drawn from our collective experiences of communicating with people who do not use speech. Although they appear obvious to those of us who have regular contact with people who use AAC, we anticipate they will be invaluable to counseling practitioners who may have little experience interacting with people who don't use speech. Some of these general guidelines include …

- Become familiar with the person's AAC system;
- Use the person's established form of communication;
- Where appropriate consider involving a communication assistant;
- Prepare to allow the time needed;

> " *The intention of the Guidelines was to focus on symbolic communicators. While acknowledging that the strategies that counselling practitioners use with non-symbolic communicators may need further modification and development, the principles/hallmarks of counselling remain the same ...* "

- Ask clients where they would like you to be positioned;
- Be aware that AAC users are often passive communicators, which may interfere with client-directed counseling;
- Practice overtly pausing and asking clients if they have something to say;
- Signal changes in topic;
- Be honest if you have not understood a message;
- Clients may not have had opportunities to practice social rules so pay attention to their signals to change topic etc.;
- Use and accept all methods of communication;

- Be comfortable with silence – use it as a therapeutic tool;
- Be aware of physical reflexes and don't mistake them for intentional communication;
- Be aware of fatigue;
- With permission involve others;
- Become familiar with client's values;
- Check accuracy of interpretations regularly;
- Employ client's own words/phrasing where possible;
- Be aware of the need to unpack certain words/phrases. This is particularly important for people who have a limited message set available;
- Check congruency between AAC communication and non-verbal communication.

The Guidelines also detail some specific recommendations, full detail of which is beyond the scope of this article.

One specific recommendation is the need to adapt the technique of 'open questioning'. Counseling practitioners rely on pen questioning as an important feature of person centered counseling.

Open questioning ensures that the direction of the counseling process remains with the client. The client is able to respond in their own frame of reference. We know however, that unless someone has access to an AAC system which provides the ability to develop generative language that this technique is going to be difficult.

To overcome this challenge 'closed question openers' are often used. These are questions which open up further client directed dialogue, using a yes/no response option format. For example, the question, 'Is there anything else that is bothering you?' provides an opportunity for clients who rely on yes/no to alert the counselor to additional issues.

I. *These Guidelines can be found on the Bridging Project Website www.bridgingproject.org.au. A hard copy can also be ordered there.*

People With Complex Communication Needs ... (cont)

Another clear recommendation outlined in the guidelines is the involvement of AAC specialists in the process of vocabulary selection and use, particularly in relation to those who don't have access to unlimited message and rely on pictorial systems, both expressively and receptively. AAC specialists have a clear role to play in ensuring clients' have access to vocabulary, whether it be within a device or within a low tech system. They also have a clear role to play in the use of visually based techniques such as 'Talking Mats' (Murphy & Cameron, 2001). The guidelines also discuss the role that additional pictorial resources play in assisting the client in moving beyond the 'concrete and the safe', something that is important in most counseling relationships.

Nick Hagiliassis and Hrepsime Gulbenkoglu, members of the Bridging Project, have developed some pictorial templates that can be used within a counseling context.

AAC specialists also have a clear role to play in assisting practitioners to accommodate for the difficulties a client may have in understanding language, particularly concepts that are abstract in nature.

Future Directions

1. Further research into the types of psychosocial stressors experienced by people with complex communication needs, and the impact of these stressors on mental health outcomes;

2. Development of Psychological assessment and intervention tools that are accessible to people with complex communication needs and that reflect the range of needs of people with disabilities;

3. Bridging the divide between generic and specialist health services;

4. Further focus on the counselling needs of people with limited literacy skills;

5. Further investigation of the use of approaches such as Talking Mats within a counselling context;

6. Further focus on the development of vocabulary sets around psychological counselling for people who do not use a generative AAC system;

7. The development of accessible fact sheets around mental health specifically for people with disabilities;

8. The development of guidelines for people with complex communication needs to embark on the counselling process;

9. Investigation of online counselling for people with complex communication needs;

10. Development of training supports and materials for Practitioners;

11. Develop a conceptual framework for a model of service delivery, specifically for people with complex communication needs who have mental health needs.

References

Crawford, J. (1987). Individual psychotherapy with the nonvocal patient: A unique application of communication devices. Rehabilitation Psychology, 32, 93-97.

DiMarco, M., & Iacono, T. (2007). Mental health assessment and intervention for people with complex communication needs associated with developmental disabilities. Journal of Policy and Practice in Intellectual Disabilities, 4, 40-59.
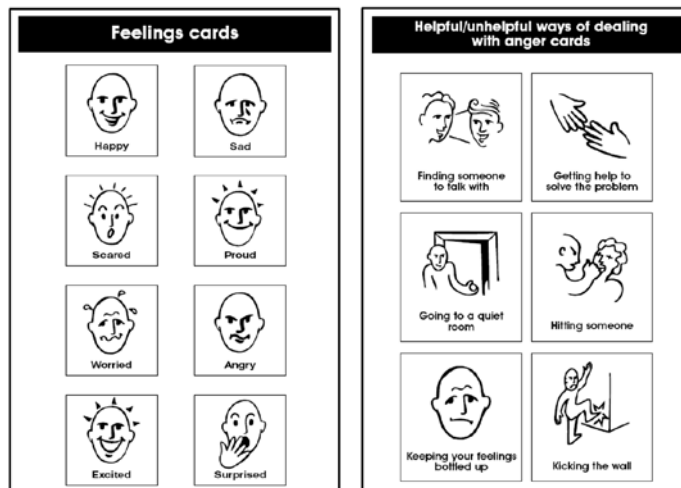
Gulbenkoglu, H., & Hagiliassis, N. (2006). Anger Management: An anger management-training package for individuals with disabilities. London: Jessica Kingsley.

Hagiliassis, N., DiMarco, M., Gulbenkoglu, H., Iacono, T., Larkin, H. & Watson, J. (2006). Beyond Speech Alone: Guidelines for Psychologists Providing Counselling Services to Clients with Disabilities and Complex Communication Needs. Scope: Melbourne.

Hagiliassis, N., DiMarco, M., Gulbenkoglu, H., Iacono, T., Larkin, H. & Watson, J. (2005). The Bridging Project: Physical Disability and Mental Health, The Bulletin of the Australian Psychological Society, 27(4), 22-24.

LaVigna, G. W., & Willis, T. J. (1995). Challenging behavior: A model for breaking the barriers to social and community integration. Positive Practices, 1(1), 8-15.

Murphy, J., & Cameron, L. (2001). Talking mats and learning disability. University of Stirling, AAC Research Unit: Stirling, Scotland.

ABOVE: Anger Management Training Package: Gulbenkoglu & Hagiliassis, 2006) (reprinted with permission from Scope)

Want some information about AGOSCI?

Contact Melissa Bakes
1800 002 950

Student Placements in AAC

by Cassie Byers – cbyers@scopevic.org.au

In my final year of the Speech Pathology course at La Trobe University Bundoora I was fortunate enough to have a wide variety of experiences in the specialist area of disability. I had two placements in the disability sector. The first was with Yooralla in an adult day centre and the other was with SCOPE. This particular SCOPE facility provided services to both early intervention clients and adults with disabilities.

It wasn't until third year of our course that all students had the opportunity to learn about Augmentative and Alternative Communication (AAC). This subject introduced students to the types of AAC that were available (including both high and low tech devices), and required students to problem solve in terms of who these particular devices may be appropriate for. Although some devices were brought into the occasional lecture there was not enough time allocated to really explore the communication possibilities these devices opened up for people with disabilities.

Throughout my placements I was presented with a number of different AAC devices and options for client use. My placements provided me with the opportunity to start right from the beginning. This meant assessing the client and speaking to family and staff who knew the person well to establish their strengths. Once the client's strengths were known to me I was able to begin research to find viable AAC options for enhancing the client's communication capabilities. This ranged anywhere from the use of gesture to requesting a high tech device such as the MightyMo.

As a student I was provided with the time to apply for a low tech communication book from NECAS. This was an excellent opportunity to problem solve with the client on issues such as text size, vocabulary choice, picture use (photos, COMPIC, PCS), and access methods, just to name a few. Clear instructions on the books size and appearance were vital in ensuring NECAS understood what was needed for the client.

In terms of the more high tech devices, time was provided to explore the communication possibilities of many speech output devices. Client's with devices such as the Minimo, MightyMo, Lightwriter, Palmtop Impact, and others, were more than happy to share their knowledge about their own devices with me. Client's were happy for me to observe how they used there devices, many of which provided word prediction which was a great tool for those with decreased mobility or spelling difficulties.

When working with these clients I found that it was not only about giving the client an alternative or augmentative means by which to communicate. There was another integral part to the partnership of communication. I learnt how I needed to be in order to communicate with the clients I was seeing. For some this simply meant using many gestures to accompany my speech to assist their understanding, for others this meant using touch and different sounds to communicate as they do.

At the completion of my placements I had come to recognise that although I had a lot of knowledge to offer the clients, they also had a lot to offer me. A placement in disability is an excellent opportunity to gain a more in depth knowledge of the possibilities for AAC use and the changes that AAC interventions can have on a person's communication capabilities.

Sensory Stimulation

Sensory-focused activities for people with physical and multiple disabilities

Fowler, S. (2007) London: Jessica Kingsley

Reviewed by Sheridan Forster – sheridanf@yahoo.com

It's hard to believe that it's been ten years since a small group of people with multiple disabilities and I, down at Kingston, Tasmania, first explored together the Spicy Hot Chocolate, smelling the cinnamon, listening to the chocolate, and tasting every part of the process. In 1997, Susan Fowler first launched "Sensory Stimulation" through the Spastic Society of Victoria (now SCOPE Vic.). Over the next ten years it became a favourite guide for practitioners working with people with profound and multiple disabilities, a concrete resource in a desert of texts, providing practical recommendations for engaging with adults with severe difficulties with engaging with the world around them. Stocks soon ran dry as growing numbers of people were asking Susan how they could get hold of the book.

Now the book is available again, published by Jessica Kingsley, and more widely available. The original edition has been expanded upon with more theory and more ideas for practical application. There are more guides for assessment and recording outcomes.
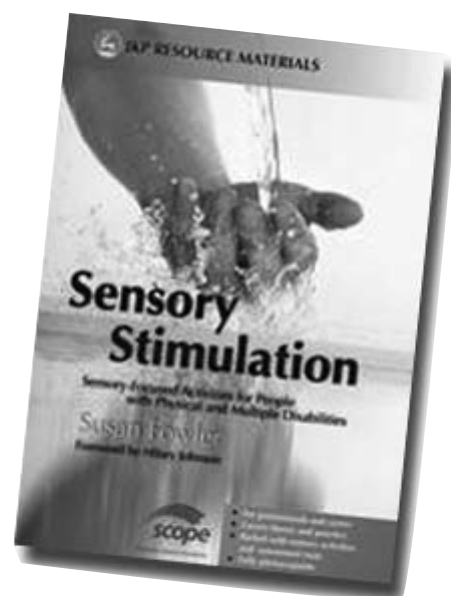
Sensory Stimulation is written for both residential and day service disability workers. However, it is also a resource of value for therapists and educators.

The book is presented in two key sections: theory of sensory focused practices and the activity section. The theory section covers the meaning of sensory stimulation, theoretical frameworks, maximising participation, assessment, evaluation and structuring sensory-focused activities. Fowler presents a brief overview of frameworks influencing sensory-focused activities today. These include Bunning's', Individualised Sensory Environment, Dunn's Sensory Profile, Knickerbocker's Learning Continuum, UK National Curriculum's Framework for recognising Attainment, the Affective Communication Assessment and Triple C – Checklist of Communication Competency, Intensive Interaction, Snoezelen, and finally, O'Brien's five service accomplishment and Person Centred Planning. The explanation of O'Brien's five service accomplishments is particularly rich with examples situated within sensory focused practice. Fowler then brings the frameworks together, explaining how they relate to each other, parallels of which help the reader integrate the different perspectives into a clearer understanding of people.

In presenting the theory of sensory-focused practice, the author at times brings in terms that may be unfamiliar to the reader. Some of these are explained in a glossary (in the back of the book), however, at times, the explanation of the terminology occurs in several sections after the term was first introduced, or are given in inadequate explanation for the term given it's relative importance. At times, the text could be interpreted as a bit "therapy centric" with an assumption that readers will have access to an Occupational Therapist or Speech Pathologist to provide further information. Unfortunately, many disability support workers do not have access to such services. An example of limited explanation of terminology and assumptions of access to therapy is in discussions related to "co-active assistance." Co-active assistance plays a central role in enhancing participation for some people with profound and multiple disabilities, and more detail was necessary to know how to do it, particularly if you do not have access to an Occupational Therapist who could show you what to do. Similarly, although people who have been in the industry for a long time may understand the meaning of a "switch," people who are new to the area may not know about switches, switch boxes, and how to go about purchasing these.

Fowler clearly states guidelines for planning sensory-focused activities, with examples of how to enact the guideline. For example in thinking about making each step sensorily stimulating she discusses getting people to touch the cold container coming out of the fridge, and smelling and tasting the milk. There are over eighty activities in the categories of drinks, food, personal and household care, and art and craft. Some of my favourite activities include the soy banana thick milkshake, the Indian samosa filling, and the Bird cake (minus the bacon rind), which once made can then be used outside, as participants watch the local birds enjoy the feast. Most of the activities are written onto a single A4 page that are photocopiable. Each activity is presented with the aims, ingredients and equipment, and the method, with steps of how to involve the person.

I believe that this book is a must-have for services supporting people who have profound and multiple disabilities. However, if I could recommend one change to the book, it would be to make it more of a sensory experience, at it is test dominated. For example, theoretical perspectives could have been reinforced through diagrams and tables (such as a diagram explaining sensory thresholds), techniques portrayed with more illustrations, and photos used to help people "see" how people with the most severe level of disability be involved in activities. Maybe that's a next step; Sensory stimulation, the DVD!

Writing an Article for AGOSCI

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

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

Upcoming Issues

You are encouraged to submit articles with the theme in mind. The theme for the November 2007 issue is 'Alternative and Augmentative Communication and Autism Spectrum Disorders'.

However, we also have regular articles such as reviews. If you want to write an article please 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

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. Use two levels of headings.

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. Please label all pictures, tables, graphs etc. Acronyms should be used only after the full term has been written and is followed by the acronym in parentheses, eg: 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.

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.

Ylana Bloom

9 Oaklands Avenue, Beecroft, NSW. 2119
Phone/fax: (02) 9876 3568
Email: bloom@iinet.net.au

Softpics Professional and image library
Softpics is a flexible and easy to use software package for creating stunning Augmentative Communication Displays. It contains over 1800 images and a large range of design tools, which allows you to create displays that can be tailored to individual needs. It has been designed by Australians for Australians and has images associated with the disability standards.

The Softpics images can be used in Boardmaker, Writing with Symbols 2000 (using the JPEG version) and Microsoft platforms eg Word and PowerPoint. It is also possible to import images from other packages into Softpics. It is possible to buy the full Softpics Professional package or just the images as an image library.
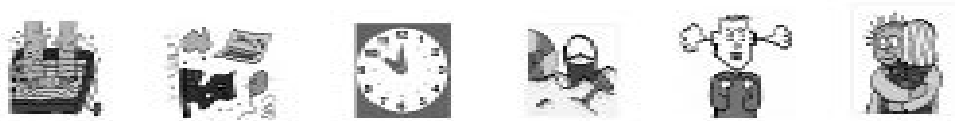
Let's Talk Together – The Great Ideas Manual for Creating Augmentative Communication Support – Ylana Bloom and Sue Treloar
'Let's Talk Together' is a user friendly resource which offers simple and functional communication ideas for people with complex communication needs. The original manual is currently being updated to include many more ideas for people of all ages including classroom, home, and community.
 The manual includes a section for developing a communication profile, a testing and teaching section offering useful ideas for ensuring that appropriate communication support is available for people

**Let's Read Together Part 1 – Using commercially available books to promote literacy**
Ylana Bloom and Dolly Bhargava
This literacy package has been created specifically for children with intellectual as well as additional disabilities (such as hearing impairments, physical disabilities, Down syndrome and Autism.) We have included a variety of practical augmentative ideas to assist your child with limited verbal skills to participate actively in the literacy learning process. The Let's Read Together literacy package is presented on a CD that can be used on both Windows and Macintosh.

Let's Read Together Part 2 – Using commercially available books to promote literacy
Ylana Bloom and Dolly Bhargava
This literacy package has been created specifically for older children and adults with intellectual as well as additional
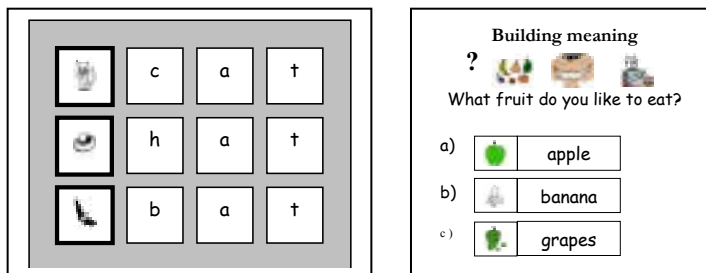
disabilities (such as hearing impairments, physical disabilities, Down syndrome and Autism.) We have included a variety of practical augmentative ideas to assist the individual participate actively in the literacy learning process. The Let's Read Together literacy package is presented on a CD that can be used on both Windows and Macintosh

The Participation Through Communication Guide - Ylana Bloom and Dolly Bhargava
The PTCG is a user friendly manual designed to assist communication partners with ideas on how to successfully interact with pre-intentional communicators. The guide has an assessment and intervention section The assessment section explores the individual's cognitive, receptive, expressive and social skills. The intervention section focuses on developing these skills using daily routines, preferred and sensory activities.

AGOSCI

Announces the 2008 National Tour

Literacy in AAC
Presented by
Karen Erickson and David Koppenhaver

Tour Dates

◇ Brisbane 16th June 2008
◇ Sydney 18th of June 2008
◇ Perth 20th June 2008
◇ Adelaide 23rd June 2008
◇ Melbourne 25th of June 2008
◇ Webcast 27th June 2008
  (at remote sites, to be announced.)

About the presenters

Karen Erickson

Karen Erickson, PhD, is the current director of the Center for Literacy and Disability Studies and is a former teacher of children with significant disabilities. Knowledgeable in literacy, assistive and instructional technologies, augmentative communication, and the learning characteristics of children with significant disabilities, she is in great demand as a presenter, consultant, and program developer. In 2004, Dr. Erickson was awarded the Educator of the Year Award from the National Down Syndrome Congress and the ISAAC Distinguished Literacy Lectureship Award. Her assessment and intervention strategies are described in numerous journal articles and book chapters.

David Koppenhaver

David Koppenhaver, PhD, is the former director of the Center for Literacy and Disability Studies and has worked for the past 20 years with preschool- and school-aged children who have a wide variety of literacy learning difficulties. He currently teaches undergraduate classes in reading methods, special education, and instructional technology. He has written and lectured widely on literacy instruction for children with significant disabilities and was the recipient of the 1998 ISAAC/Don Johnston, Inc. Distinguished Lecturer Award. He collaborated with Karen Erickson and David Yoder in organising a collection of AAC/literacy case studies for the book Waves of Words: Augmentative Communicators Read and Write and co-edited an issue of Topics in Language Disorders on literacy and AAC interventions for persons with autism.

Join the AGOSCI Listserve at www.agosci.org.au for more information or email Jane Farrall jane@spectronicsinoz.com to be added to the mailing list

AGOSCI Inc.
www.agosci.org.au