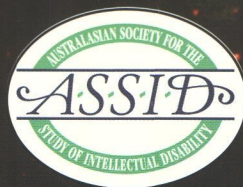


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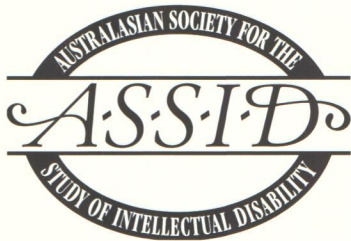
IDA

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Intellectual Disability Australasia

Back to the Future
Cover Feature: Videomodeling using *feedforward*



Magazine of the Australasian Society for the Study of Intellectual Disability



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Front Cover:
Triangulum Nebula -
courtesy of Wikipedia
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Editorial



This issue of IDA offers three very interesting articles that address different topics. Some of you fortunate enough to attend the ASSID conference in Adelaide in 2004 may remember a keynote address given by Peter Dowrick from the University of Hawaii at Manoa. An edited version of this keynote presentation is included in the current issue and describes an innovative technique, feedforward, that Peter has been researching for some years. Modeling and chaining are effective techniques commonly used in teaching new skills to individuals with an intellectual disability. Feedforward combines these techniques in a unique way by having individuals model behaviours they see themselves using but have not yet mastered. Sounds odd, but read the article and you'll discover a novel approach that has wide application for individuals with an intellectual disability.

Jodyne Gianatti and Christopher Coopes present the results from research they undertook concerning the experiences of parents who have an intellectual disability. This is a challenging and thought-provoking article that contains poignant quotes from parents with an intellectual disability about the circumstances of their child's conception and experiences in being a parent and accessing support. Important parallels are drawn between the parenting experiences of those with and without intellectual disability. Some of the unique issues that parents with an intellectual disability encounter are also highlighted and the implications for service provision discussed.

The Independent Accommodation Network (IAN) is a Victorian-based service that matches people with/without disabilities who are looking to share a flat or house. IAN is also an information and resource service that can be accessed by individuals seeking accommodation, service providers and carers/families regarding suitable housing options in the community. There is no cost to the user and the service is fully funded by Harrison Community Services. Details about the operation of this service are provided in this issue of IDA, and include a web site and contact details.

You'll find all the regular features in IDA, including a long list of upcoming events, regional updates, and information about the forthcoming ASSID conference to be held this year in Canberra. With an impressive list of keynote presenters, this year's conference is sure to have something of interest for all our readers. The conference falls a week before Floriade in Canberra so why not take an extra week in our Capital and enjoy the flowers!

Deb Keen

Membership Details



ASSID has 4 types of membership:
Organisational, Individual, Student, and Associate.

To join: download an application form from www.assid.org.au,
or contact the National Registrar at the address below.

Current members please make sure you don't miss out. Keep your contact details up to date.

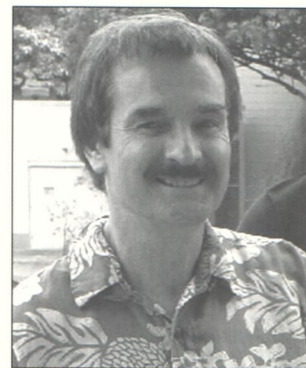
Phone: 1800 644 74 PO Box 84, Rosanna VIC 3084 Australia

Back to the Future

Videomodeling using *feedforward*

Peter W. Dowrick, PhD

University of Hawaii at Manoa



Author note: This article is a partial synopsis of a Keynote Address, Australasian Society for the Study of Intellectual Disabilities, Adelaide, November 2004. Preparation and presentation were supported in part by ASSID and the US Department of Education, Office of Vocational and Adult Education.

Comments and enquiries to Peter W. Dowrick, PhD, Professor of Disability Studies and Graduate Studies in Psychology, University of Hawaii at Manoa, 1776 University Av. UA4-6, Manoa, HI 96822, USA; tel 808-956 8741; dowrick@hawaii.edu; www.creating-futures.org.

Abstract

It is well established that most social learning derives from observation of our own or other people's effective behaviour. This article presents the idea that all observational learning is self modelling – that is, we learn from others only when we see ourselves in them. That gives rise to a notion of selective self-modelness, which explains the pesky fact that we are not influenced by everybody's actions all around us, any day of the week. Furthermore, humans can learn by 'observing' images of their own successful responses – before actually being successful... This principle we call feedforward. That is the opposite of feedback, which tells us about the past, and our errors. Feedforward gives us images of future behaviour. Constructive use of video feedforward has been shown to rapidly alter the likelihood of effective responses to challenging situations for individuals with a wide range of disabilities and talents. I provide a selection of examples to advance these theories and illuminate some of the practicalities.

Wherefore Art the Self in the Model?

Understanding how human beings can learn new and effective ways to respond to challenging situations is a fascinating topic. Modelling and self modelling have much to offer in this respect (Bandura, 1997). I will give explanations of how we learn from observing our own (effective) behaviour, sprinkled with examples. I propose that all observational learning is self modelling – that is, we learn from others only when we see ourselves in them. That gives rise to a notion of selective self modelness, which explains the pesky fact that we are not influenced by everybody's actions all around us, any day of the week. In particular, while acts of terrorism are imitated all too often, there are millions of witnesses who don't imitate – indeed, are more repulsed by the acts than attracted to them.

When we observe a potential model, ourselves or somebody else, we observe an image. That image can

be live, on video, in photos, animated, in stories, or in our heads, where presumably it is stored if memorable enough. Some people with disabilities (e.g., autism, Down syndrome) are much better at thinking in pictures than in words. These talents should not be overlooked in the development of best services. Furthermore, there is an aspect of self modelling that is unique to human beings and some primates: sometimes we learn by observing 'our' successful responses – before we become successful. This principle we call feedforward. That is the opposite of feedback, which tells us about the past, and our errors. Feedforward gives us positive images of future behaviour.

When we are confronted by a challenging situation, our system generates a series of images of potential responses, in a prioritised list. At least, that is what I propose. What video is very good at, is adding to or reprioritising this list. So if I'm annoyed by a half empty jug of juice, instead of (a) tipping it out, (b) throwing myself on the floor and screaming, or (c) pouring the juice over my little brother's head, I relegate such acts to low priority in favour of (A) walking away and going for a *continued page 4*



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Videomodeling using *feedforward*

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ride on my bike or (B) playing my favourite CD even though my brother hates it. The details of this situation are drawn from a real case study, and I will use several other examples to illustrate my point and take the opportunity to discuss some of the practicalities. Why video is highly effective is because not only can it create feedforward, it brings those future images into the present.

Self Modelling

Self modelling procedures are being increasingly used in many endeavours, including top level sports. The United States in the Sydney 2000 Olympic games gained an unexpected gold medal in Women's Diving. This is how the winner Laura Wilkinson explained it. Everyday in final training and in competition, lots of video footage was taken of all athletes. At the end of every day, she went through her footage and selected the best examples of important features: her run along the diving board, her bounce off the end, flips and twists through the air, and entry into the water. These clips were edited as a tape of rare and almost perfect exemplars of which she wanted to do more. She watched her tape repeatedly, accompanied by some favourite music before going to bed. There is no proof of cause and effect in her case, but she did win that medal, against the predictions of her competitors.

That kind of approach, drawing upon examples of past success, is called positive self review. And it continues to be popular in Sydney. A few weeks before travelling to Australia for the ASSID Conference, I was intrigued to get email from a mum in Sydney with an autistic child. She started making self modelling (SM) videos for her son at age 4 and has been making both SM and other modelling videos for a range of activities since. With great success, apparently, she started by just taking heaps of footage and clipping the prosocial bits. It was a laborious way to go, and she has since begun to plan and record in ways leading more to feedforward, in which images are constructed of successes not yet achieved (Dowrick, 1999).

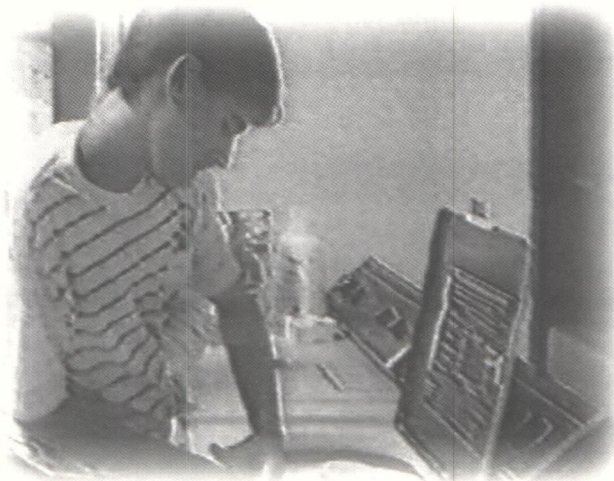
Let me clarify what is self modelling, what is feedforward. Self modelling is simply the process of observing oneself being successful. It's a natural pro-

cess that we indulge in off the screen every day. That is, it's not dependent on video. But video can make it powerful especially for folks with some types of disabilities. Because success is commonplace (having breakfast, walking to the corner, sometimes even finding a parking space), we as practitioners are looking for unusual successes in challenging circumstances: walking to the right corner, when you are confused and harrassed. A powerful way to make self modelling effective, is to emphasize its feedforward aspect, illustrated at the Conference.

Here is a description of a video shown at the Conference and available in the Video Futures Start Up Kit (Dowrick et al., 2003). Autumn was a high school gymnast in Alaska. She was on the team to compete in Seattle, with aspirations for a floor routine including an airborne twist and flip, intended to finish with steady landing, facing back to where she started her run up. I have much footage showing her repeatedly and inevitably falling over every time she landed. No opportunities for positive self review here. She had been stuck at this plateau of performance for 2 months, despite expert coaching and endless practice. Her mother was enrolled in a short course on Videotraining with me, so she and a fellow student made a classic feedforward video. It was in three parts, although to any observer it appears as one complete, sustained floor routine. It takes repeated viewings to see that the first seconds show Autumn's run along the mat; then a cut to side

view of her in the air, with a twist and a flip; then from the back, descent into a perfect, stable landing. This 30 second routine is simply repeated twice more for a minute and a half viewing experience. Autumn watched her tape every day for a week, went to Seattle and did her floor routine without falling (not nailing it, as they say, rock steady, but just moving one foot to retain balance). So, therefore, and thus, feedforward is accomplished through images of success not previously achieved.

Here is a sample of various interventions, mostly with feedforward, for children and adults with intellectual disability. When I met Greg he was in his 20s with a history of classic autism, and a lifetime wish to tie his shoelaces. A graduate student took on the task,



although others had tried and failed with established occupational therapy and behavioural techniques. After 4 months of regular practice and trial videos, Greg progressed from 3 to 14 steps of the 22 steps necessary to tie his shoelaces. But that still left him dependent on someone else. Or velcro, which was not an acceptable option for Greg. The problem seemed to be that when a mistake occurred Greg would continue with subsequent steps in the lace tying. A breakthrough happened when we created a feedforward image of Greg reinserting a lace that fell out of place ... even though the image included a helping finger in the picture. Greg suddenly got the gestalt. He tied both pair of shoelaces, and did it again to confirm it wasn't a fluke. To celebrate, I took him and his mother to lunch. Greg tried his mother's shoelaces in the restaurant. Now he ties bows whenever he can. His next request for a Christmas present was a dressing gown with a sash - so he could tie it with a bow.

Another Gregg (with two G's) was a boy with Asperger's Syndrome in intermediate school. He would extremely overreact to any correction of his work and several times a week have to leave his class to calm down. With a team effort of school staff and suggestions from Gregg, we made a video of him accepting mild criticism and using stress reduction techniques. Within three viewings of his SM video, Gregg's tantrums in class virtually disappeared, and he showed generalisation in the home environment. We subsequently made a SM video to help him deal appropriately with stressful situations arising from substitute teachers.

Other intervention examples include personal safety training (staying safe in public situations), transition to a new school, self-management of annoyances in the environment (juice in fridge being half empty, which others don't find distressing, so annoyed this boy he would tip it out), learning to read, dealing with fear that the fire alarms might go off. Then there was the boy who learned he could calm himself down by blowing a whistle, no matter what upset him. Previously, he would tantrum.

Temple Grandin has proposed that she "thinks in pictures," and that her generalisation is developed from examples (Grandin, 1999). Findings in SM suggest that these processes are more common than she may realise. Using the video medium has distinct advantages for many individuals with intellectual disabilities. Not only does it make ultimately explicit what it is that someone is trying to teach or learn, there is substantial evidence for a preference, even a need,



to think in pictures for some intellectual disabilities, including autism and Down syndrome.

So, thus, and therefore we come to the final section of this article. It is the most advanced theory of self modelling and feedforward. It's in two parts. The first is that all modelling is self modelling, but there are degrees of self modelling. When any behaviour is observed, the degree of self modelling ranges from zero to one. This theory explains the otherwise troublesome phenomenon of so much ambient modelling, so little change.

In the 1950s, so I'm told, an episode of Superman on the radio included the setting of a bomb on a bicycle, intercepted in the nick of time, of course, by the programme's hero. A few weeks later, three teenage boys in Britain, so I'm told, were arrested for the death of a cyclist, to whose bike they had attached a bomb. Superman, of course, was nowhere to be seen. And a debate ensued considering a ban of the radio programme. The debate frequently revolved around the point that at least 10 million teenagers had listened to the radio episode in question, and just 3 had rigged a bomb.

The self modelling explanation is as follows. As the dadarstly bomb setter's actions were portrayed on radio, the degree of self modelling for some 10 million listeners ranged from zero to one. I would like to think, at least as a working hypothesis, that 9.9 million listeners experienced no self modelling at all: the perpetrators were doing something quite foreign to their sensibilities and socialisation. Among the other 100,000, lets say 99,000 saw themselves in the perpetrators, and therefore in the roles of the perpetrators, anywhere from .1 to .9 of the time. That is, some part of themselves felt excited by, even comfortable with participating in some part of this dadarstly deed.

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That leaves 1000 individuals, worldwide, who were potentially 100% self models. But this is where the conditions for modelling, I would say self modelling, to occur, kick in. Go back to Bandura 1969 for details. The self modeller needs to attend to the details, to retain them, to be motivated, and to have the circumstances of opportunity. That quickly reduces the field to three, young men as it happens, who were friends and encouraged each other.

This is where the story really starts: When we meet a challenging circumstance: tying our shoelaces, going to a new school, creating anarchy, we draw up available self models – examples of ourselves coping in comparable circumstances. If adequate self models are not available, we seek the best approximations in other models. When met by a challenging circumstance, we generate potential solutions, that is, images of potential solutions. With suitable intervention, including some elements of feedforward, we can rearrange the hierarchy and change, add, or delete items. Thus, the second part of the theory is that feedforward is a powerful way to change the order in a set of hierarchical responses, and bring the most suitable to the top of the list.

Here are some examples from the development of speech and language. The mum I mentioned in Sydney gave her son examples of how to ask: I want water; I want bikkie – and he ran with it (Smith, 2005). That is, he generalised and asked for other things, like ice cream and \$100 bank notes. By comparison, one of my graduate students in Anchorage Alaska did a fine study of two men with Down syndrome, who had long reached a plateau in their progress with spoken and signed language. One had been a victim of trauma in pre-teen years, so it was physically hard for him to talk. If he wanted something, he would perhaps say a single word (coffee!) or have a tantrum and support staff would have to figure it out. Even saying “coffee!” was too abrupt to get good cooperation in most social settings. The speech therapists tried for months, years even, to get him to use phrases and sentences, to no avail. So Cynthia (the university student) made videos, in which she got him to imitate her phrases (“pass me a coke please”) and she edited them into the context of seeing beverages, asking, receiving, and even saying “thank you” (Bolivar, 1993).

As a good student, she believed the literature that says to teach generalisable skills, you should give lots of examples. So she did: Pass me a coffee please; pass me a cake please, pass me pen, paper, . . . whoa, no! It didn't work. He liked it, he seemed interested; his behaviour didn't change one jot. We decided we need-

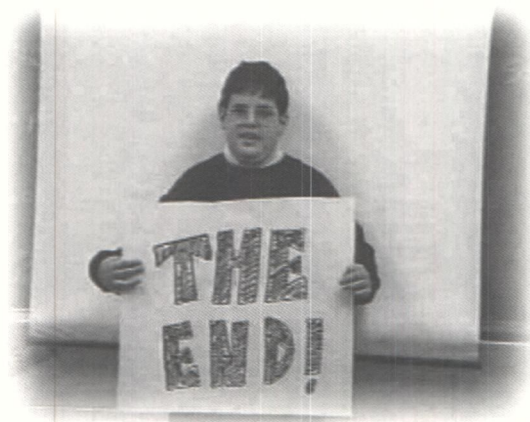
ed to focus - he needed to learn one skill really well. We redid the video to teach him by exact repetition of a single image, and to overteach. See coffee, “pass me coffee please,” get coffee (thank you). See coffee, pass coffee, get coffee, multiple times in a 2 minute viewing, multiple times a day. He got it within 2 days. Then he immediately generalised: pass me a cake please, pass me a pencil please, pass me a \$100 bill ...

These examples each taught a general(isable) skill, with the potential for changing lives.

From the first instance of Greg tying his shoelaces, he tied bows, everywhere. As noted, he tied his mother's shoe laces in the restaurant - a strange environment, and back to front from the way he had learned to tie his own laces. With his new dressing gown, he proudly tied the sash in a bow. He tied bows everywhere he went. He sent me his photo, with a charming message of thanks - and a purple ribbon. Tied in a bow. ♦

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HARRISON

Offering Innovative Accommodation Options

Jane Davoren IAN Project Worker



Uniting Care Harrison Community Services (Harrison) is a Mission of the Uniting Church in Australia (Victoria/Tasmania) providing residential and other services to people at risk of abuse, neglect, exploitation or who are in need of care for other reasons. Harrison manages a number of programs and services for adults with a disability to realize their dreams in the area of independent living. While there are four distinct programs within the independent life styles area they are inter related and complimentary to one another. Harrison is based in the outer eastern suburbs of Melbourne.

Our Values

- People have the capacity to learn new skills
- Empowered people can take responsibility for their choices
- Positive relationships with family, friends and the local community builds individuals resilience
- A professional high morale team provides the best possible service
- We are accountable to those we serve

Independent Accommodation Network (IAN)

As a result of discussions at regional network meetings regarding outreach services a need was identified to connect people with disabilities who were keen to meet with others who had a desire to live independently. Harrison nominated as the lead agency to coordinate a project within the region to provide a matching and referral service to locate potential flat mates/housemates to individuals who registered with the network. An Innovation in Accommodation Grant was applied for through the Victorian State Government which was unsuccessful in the first attempt.

However, IAN was initially funded by the Department of Human Services - Eastern Metropolitan Region for 12 months who saw its merit - but is now totally funded by Harrison Community Services.

The Independent Accommodation Network (IAN) is a free matching and referral service operating Victoria wide. Its aim is to link people with / without disabilities who are looking to share a flat or house. IAN is also an information and resource service for clients, service providers and carers/families regarding suitable housing options in the community.

The network endeavours to match people with similar interests, goals, needs and aspirations so they are sharing in their ideal circumstances. IAN has been operating a web based matching and information system since April 2004 and so far has been successful in matching 25 clients into their choice of accommodation.

The IAN website, currently accessed via www.mc2.vicnet.net.au provides a comprehensive listing of current advertisements from members of the network seeking housemates/flatmates or a suitable property as well as information on housing/disability forums, expos, budgeting, the rights of tenants and landlords, furnishing your own place, privacy, sharing a house, safety in your home and what to do if things aren't working out.

If a person is seeking a housemate/flatmate or indeed a property they are asked to complete a registration form and return it to the IAN Project Officer. Once details have been received about what type of accommodation is being sought, the preferred suburbs/location, the amount of rent available and some information that the client is willing to share about themselves and their likes, dislikes and interests then we can then begin the matching process.

This search may take some time so clients need to be prepared to wait until someone suitable and appropriate to their needs is found. Once we've found someone who has similar needs/wants/interests contact is made via phone, email or letter. Initial contact will be made with the nominated case manager/advocate and the client.

Following phone calls and/or possible meeting up with potential housemates/flatmates somewhere that is convenient to all then everyone decides whether sharing would work or not. These initial contacts are an opportunity to ask many questions of future potential housemates/flatmates such as How much rent can you afford to pay? What do you do during the day? What are your interests/hobbies? Are you a smoker? Do you do your own cooking? IAN can also assist people who prefer not to share and wish to live by themselves.

Shortly, there will be a new website for IAN : www.harrison.org.au which will be far more accessible for users, particularly those with disabilities.

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Queensland

By Lesley Chenoweth

The Queensland branch is planning a wine and cheese evening in July with guest speaker Sally Murray the new head of Intensive Behaviour Support teams at Disability Services Queensland. The issue of so called challenging behaviour continues to be one which always attracts interest from ASSID members and poses considerable challenges for service providers and families. Details will be circulated to members when we confirm a venue and date. We are also planning another evening with Assoc Prof Nick Lennox as the speaker later in the year. Watch for further updates.

We will also be surveying our members by email to canvass needs and ideas for future events in the forthcoming weeks. The meetings of the executive are now being held in the offices of BlueCare, 56 Sylvan Road Toowong and are scheduled for the following dates starting at 6.15 pm.

June 8th, July 6th, 10th August, 7th Sept, 5th October, 2nd November. Please contact Lesley Chenoweth for details at l.chenoweth@griffith.edu.au

South Australia

by Richard O'Loughlin

The event held in March "South East Asian Perspectives" involving a Developmental Educator describing her experiences working with children with developmental disabilities in Vietnam, was successful and popular (despite it being held on a Friday afternoon before a long weekend).

Our next scheduled event is a breakfast meeting on 31st May (likely to have already occurred by the time this update goes to print). Professor Bruce Tonge will be presenting on the LifeSpan Project – a major South Australian research project aiming to provide information on: the mental health status of adults with an intellectual disability; the prevalence of and nature of mental illness within SA's population of adults with an intellectual disability; the mental health problems of particular groups such as indigenous Australians and older people with an intellectual disability; and the mental health problems in adolescents with an intellectual disability in their transition from school into adult life. It is a collaborative project involving Monash University, the public sector agency in SA (IDSC), the Education Department and Minda (a large NGO providing accommodation amongst a range of other services to people with an intellectual disability).

Other news in SA is that there are major changes underway in the way that disability services are organised and provided in SA. IDSC as a public sector corporate body will be dissolved. The new government agency will be Disability Services SA. The rationale underpinning the changes are about clearer service pathways for people with a disability, and a more person centered approach, increased agency accountability, and effective partnerships. The imminent changes are of a scale that has not been seen since the inception of IDSC in 1982. ASSID(SA) will need to give some consideration to how it has input into the ongoing process of change.

The SA committee has range of other events and project in mind and welcome any suggestion or request from its membership. Send your suggestions to richardoloughlin@bigpond.com

Victoria

by Daniel Pennefather and
Alexandra Phillips

You may remember that the past couple of years in Victoria have seen debate between disability organisations, other key stakeholders and government about redevelopment of the Victorian legislative framework. We are pleased to report that the position advocated by Victorian members in submissions made to the review process, is on the whole reflected in the draft legislation released by government. In general, members welcome the decision by government to make a draft of the proposed legislation available for further public comment and applaud the inclusion of a complaints mechanism that is independent of government. The submissions can be accessed by following the link to the Victorian branch at www.assid.org.au and the draft legislation and further information about the review process is available at www.dhs.vic.gov.au/disability

This month signaled a change of the guard in the Victorian committee, with President Alex Phillips stepping aside to focus on completing her PhD. Vice President Claire Vissenga stepped up to the plate, and will act as regional President until the AGM later this year. The committee thanks Alex for her years as Regional President and welcomes the fact that she will remain on the committee as a general member. We also welcome Claire Vissenga to the role of acting Regional President.

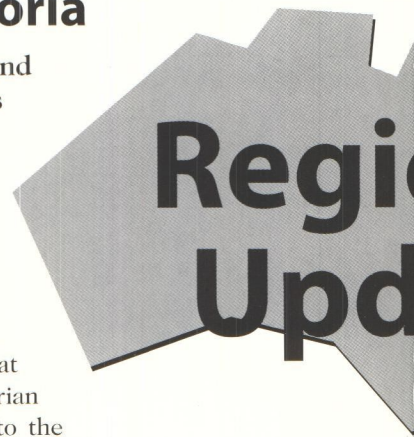
In other news, preparations for the Disability Support Workers Conference (Nov 16 & 17) are well underway. Forums are being conducted with Disability Support Workers to identify specific areas of interest for this year's program. A conference website is also being established that will be updated as preparations progress. Committee members are also working to offer a seminar about Evidence Based Practice in addition to a seminar to showcase student research in the disability area.

NSW & ACT

by Tony Tinlin

At present all energies of the NSW & ACT Branch are focused on the September conference. The conference is shaping up to be a fine event with the Keynote speakers arranged, and conference organizers who are making our life much easier. The following Keynote speakers have been confirmed:

- Kristjana Kristiansen,
Norwegian University of Science and Technology
– Norway
- Dr Levan Lim,
National Institute of Education – Singapore
- Professor Gwynnyth Llewellyn,
University of Sydney
- Robert Martin,
IHC – New Zealand
- Professor Jeff Sigafos,
University of Tasmania



on
ate

- Professor Tony Shaddock,
University of Canberra
- Dr Roger Staneliffe,
Centre for Developmental Disability Studies,
University of Sydney
- Dr Stuart Todd,
Cardiff University – Wales

Information about the conference is available on www.assid.org.au or contact can be made using the following email address assid41st@confeo.com.au

A submission has been prepared in an attempt to obtain some funding to assist people who have a disability attend the conference.

Tasmania

by Donna Venn

ASSID (TAS) is off to a busy year. We held our Strategic Planning Day in March and since then have made progress across a number of areas. We are planning a joint conference with ACROD (Tasmania Division) for Support Workers on October 18th and have Keynotes confirmed already. This should be a great event and hopefully the first of many. We are starting small with a single day conference but are having an Awards Ceremony the evening before which will be hosted by the Governor of Tasmania at Government House. The committee is also busy organizing the launch of our new (revised) Student Award which we have been given consent to name. This will be launched within the next few months and hopefully well received by the Tasmanian community.

The promotional CD that our committee developed last year has been in use at various RTO's over the past couple of months and I have had the pleasure of talking with a number of students in disability courses about ASSID (who we are and what we do) and I am hopeful that not only will this assist to raise our profile but also increase student membership. Darryleen and I are attending the mid-year meeting in Melbourne at the end of this month and looking forward to catching up with our Australasian colleagues over that weekend.

New Zealand

by Marleen Verhoeven

The first NZASID newsletter was emailed to our membership recently and was well received. The NZ council held a strategic planning meeting in Auckland on 28 April. The meeting was well attended by council members, which included self-advocates and people of diverse cultural and professional backgrounds.

A brainstorm resulted in a multitude of opportunities for development of our young organization. These opportunities were developed into goals and targets. Overall the organization has a keen council with creative ideas. Some of them are basic improvements like colour coding conference rooms so self-advocates have an easier time finding their preferred presentation. Other ideas are utilizing and being available for the media. We also discussed future workshop and con-

ference opportunities, for example training in the use of diagnostic tools for Autism Spectrum Disorder.

Ongoing challenges are our membership and corresponding financial position. The membership has improved greatly since the Auckland ASSID conference last year, but could still improve if more people would see the benefit of joining NZASID. All in all it was a well structured and productive meeting, and the ideas will hopefully make a positive difference for our membership.

NZASID conference, Wellington, 2-3 November. Theme: "Getting the message: living, learning and playing". The theme allows for real people and real stories of things that made a difference. Two keynote speakers have been confirmed: Anne Bray of the Donald Beasley Institute, New Zealand and Mark Barber (Australia) discussing communication with people with severe disabilities. Coping skills training based on dialectic behaviour therapy: pre-conference workshop by Marleen Verhoeven.

Western Australia

by Chris Coopes

On the evening of the 19th April, there was the first of three presentations this year by the "ID NETWORK". This Network is a joint initiative of the Developmental Disability Council (DDC) and ASSID (WA). The aim is to strengthen the focus in WA on intellectual and other developmental disabilities, to stimulate debate and innovation and to promote opportunities for families, agencies, professionals, academics and all those committed to a better life for people with developmental disabilities to work together. Over 55 people attended after work and it was a very successful evening.

The topic was AUTISM: Some International Perspectives and Ways Forward. The presenters were Sue Peden (ASSID WA Treasurer and immediate past president ASSID) and Dr Angus Buchanan (co-convenor of the Planning Committee for the 2007 National ASSID Conference which is to be held in sunny Perth). Sue and Angus are joint recipients of the Hon Ray Young Scholarship and recently visited the United Kingdom and Canada to research current approaches to autism policy, funding and interventions.

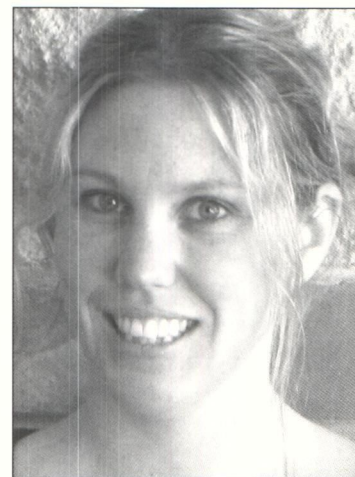
We have a small group of State Council members planning the ASSID State Conference this year in late September with Keith McVilly as keynote speaker. We hope that this will be even bigger and better than the 2005 conference.

The Planning group for the 2007 National ASSID Conference which is to be held in Perth was established in the early part of 2005 and planning is now very advanced. The co-convenors are Danni Stehlik and Dr Angus Buchanan. The group members have representatives from a range of agencies and there are also a range of ASSID (WA) Council members.

The ASSID State Council is very active on a number of fronts and includes several new members. The Council members are Sue Peden (treasurer), Janine Smith (secretary), Craig Glasheen (vice president), Kate Randall (immediate past president and acting ASSID secretary), Jill McKenzie, Chris Yates (who travels from the country to attend meetings), Shane Mauger, Angus Buchanan and latest member is Kelly Linley. All are committed and involved and I feel privileged to be a member of this group...my thanks to them all. Craig Glasheen will be acting president when I go on sick leave from the end of April for a couple of months.

Personal Experiences of Parents with an Intellectual Disability

By *Jodyne Gianatti*
and *Christopher Coopes*



Background to the Project

In September 2002, the Disability Services Commission in Western Australia commenced a survey project into the needs of the population of parents with an intellectual disability residing in the Perth Metropolitan area. The first Phase involved data being obtained from service providers (in particular, Local Area Coordinators involved with these families) through the use of a structured questionnaire. By the end of Phase one, information pertaining to 41 families where at least one parent had an intellectual disability had been collated and demographic information, service and support utilisation and perceived need areas had been identified. More details of the findings from Phase one can be found in an article printed in the Magazine of the Australian Society for the Study of Intellectual Disability, September 2003 edition.

After the completion of phase one a second phase was undertaken, whereby a sample of families identified in the first phase were invited to participate in a semi-structured interview to comment on their experiences of parenting. Under the direction of the Reference Group to this research study, it was decided that only families who had children currently at home and in their care could be included in this study. This excluded 13 families, and of the remaining 28 families who did at least have one child at home in their care, 16 chose to participate in the study.

Methodology

In Phase 2 families were sensitively approached to participate in a semi-structured interview seeking to obtain information about: 1) family experiences with respect to family planning 2) general experiences of being a parent with an intellectual disability, and 3) parents experiences of supports and services utilised.

16 families chose to participate in the interview process, and families were encouraged to choose the venue of their choice for the interview, and were given the option of having a support person present during the interview. The majority chose to have the interview conducted in their own home, and a few families chose to have a support person present.

The demographic profile of the 16 families was similar to the demographic profile of the 41 families identified in Phase one, and can therefore be classified as a representative sample in this sense.

The interviews ranged from 1 1/2 to 2 1/2 hours in

length, and answers were recorded manually, with tape-recording also being used with the express permission of each participant (tapes were erased after being transcribed). Issues of confidentiality and privacy were discussed with each participant, and families were invited to choose pseudonyms for themselves and their children. These pseudonyms were then incorporated into the interview transcripts and report process and are used throughout this article.

Interview transcripts were analysed thematically, and were independently rated by the presence of these themes. There was 90% agreement between the two raters.

Data Limitations

The sixteen families who participated in the interviews represent a relatively small sample of the population of parents with an intellectual disability (identified at forty-one in Phase 1 of the study). All sixteen families interviewed had at least one of their children at home in their care.

If families who had none of their children in their care had been included, the information obtained may have been considerably different; however the fact that several families did have DCD involvement and some children removed from their care, does suggest that some similar issues may have been included in this report.

In addition, of the twenty-eight families eligible to participate in the study, the sixteen who chose to participate may have had specific reasons for doing so, and this may have biased the results in some way. It is not known however, whether families chose not to participate, or if they were not advised of the interview opportunity by their Local Area Coordinator.

Demographic Findings

Of the 16 families who were interviewed, 50% were two-parent families where the mother had an intellectual disability, 25% were single-parent families where the mother had an intellectual disability and 19% were two-parent families where the father had an intellectual disability. The majority of parents interviewed were aged between 40 and 49 years (55%), followed by 30% of parents being aged between 30 and 39 years.

The 16 families interviewed had a total of 35 children, over half (54%) of whom were of school age, and just over a quarter (29%) of whom were under 6 years of age. Almost half (40%) of the children had a formal diagnosis of intellectual disability or global developmental delay, and a further 14% were identified by their parents as being delayed but not formally diagnosed.

Parental experiences with regard to Family Planning

Of the 16 families interviewed, three quarters (75%) stated they had not deliberately planned the birth of at least one of their children (however the definition of 'planning' varied between couples).

"Travis was planned, but was a surprise too. I wanted to have him, but later" - Sheryl, a mother of two school-age sons, both with an intellectual disability.

Many of the women (62%) stated that they had not had any information about contraception prior to the birth of their first child, and almost a third of the women interviewed (31%) stated that they had received pressure from family members or professionals not to have children.

"Actually, when I got pregnant with her [my second child], I had to go see [my Doctor] because of the... Syndrome [that my first child had]... They wanted me to have an abortion with her - the Doctor [did]. Maybe they thought she would be like [my first child]. But I never did but. They thought I might have a 50/50 chance. I already had [my first child] so I took the chance... She doesn't have it." - Debbie, a single mother of three adults, two with an intellectual disability.

"My Mum had a funny feeling that [my son Chad] would turn out like me [with a disability] because what you are is what the kids are. She stopped me from getting my license and from doing a lot of things, and held me back". - Ruby, a mother of six school-age children, five with an intellectual disability.

Just over a quarter of women (31%) shared their experience of losing a baby through miscarriage, still birth or abortion, and two women shared experiences of being forcibly raped and the impact that had on their lives.

Molly, a mother of two younger children shared *"Kylie was conceived through rape by my ex-husband, but I'll never tell her that. My Mum and all my friends*

were happy [about the pregnancy] except for me cos I knew how she was conceived. I didn't have anyone to talk to. I had to work through it myself and it was so bad that the doctor said that I couldn't have any more kids."

Parental experiences with regard to being a Parent in general

The vast majority of parents (75%) found parenting difficult, challenging and harder than expected, but more than half (56%) also described it as being rewarding.

"It's difficult at times, and rewarding. The kids have their moments. I do get rewards from them and I do get stressed with them. I mean, every parent would, wouldn't they?" - Kylie, the mother of 3 school-age children.

Several parents (31%) stated that having a child with a disability made parenting even harder, as did having a disability yourself.

"I didn't know it was going to be hard. In my case, you see your brothers and sisters have kids you know, and you think that... you're not with them all the time and when you see their kids you think that doesn't look too hard. [My daughter, Olive] she's very like, how you say? Always on the go... very hypo!" - Quisha, the mother of a five year old daughter with global developmental delay.

"It's hard work. A lot of hard work. And I'm not anywhere near the field of a normal mother. So just imagine how they're doing it. They'd find it easier I guess cos they've got more knowledge up here [points to her head]". - Kylie.

Winonah, a single mother of a four year old stated *"It's hard for parents to admit that the kids have got a disability. When I found out that Derek had one I bawled my eyes out. I said, 'no Mum, they've made a mistake. Please tell me they've made a mistake'. You know? I've had one all my life and kids can be so cruel. I grew up at school and I felt like the odd one out"*.

Winonah also candidly recounted her experience with post-natal depression and how the difficulties of parenting sometimes seemed too much.

"The first two years it took me a long time to get over what had happened, um, and um... then I went into the stage of having baby blues and um... then I was suffering from an eating disorder" continued page 12

Personal Experiences

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cos anything yummy I'd eat it straight away... my comfort. Then I went to the Doctors and said I'm suffering from depression, I can't handle the stress anymore. I had Derek, I wish I never had him – you know sort of thing?.. I had a screaming baby and I remember putting him in the cot a few times and telling him to 'shut up'. I'm being honest here... 'cos of the stress of my bub. A few times I wanted to actually get my hands around his neck and start squeezing because I just wanted him to shut up, but now if I... I can't even try to do that to him now because I... if I even think of doing it I just couldn't imagine... his little eyes looking at me... you know?"

Several parents shared about the necessity to "learn as you go along" with respect to caring for their children.

"Sometimes it's hard, other times it's alright. You go with the flow. The hardest thing about parenting is being on the pension, cos I can't give her what I want to give her. But I'm getting used to being a single mother. I think my girls have done alright. Emily has gone right through school – through to year 12 and has a job. She wanted to finish in year 10 and I told her 'no!'... I thought it was going to be easy, but it's not. That's what I thought at first. But I found out the hard way – after the first one! With your first baby you don't know what's wrong when she cries. You learn as you go along". - Wanda, a single mother of two children, one with an intellectual disability

"It's funny. Someone working for childcare for such a long time would have known better... [but] after I gave birth to Derek I said 'where's the manual?' so I could read and know what's the deal and what to do!" - Winonah

Others shared about their experiences on how others treat them as parents and people. Over half of the families described experiences where others were critical, judgemental, excluding and generally non-supportive of them as parents, and of their children.

"For some reason, my kids are always the ones that get picked on. I do not know why, unless they can pick up that there is something wrong with them. I don't know. But they're so cruel sometimes... [We've been] in tears most of the time cos the kids were getting bullied and picked on and stuff like that. And then there were things that used to get pinched..." - Molly

"Timothy [my husband] said I don't look after my children so good, but I try very hard." - Casey, a mother of two teenagers, both with an intellectual disability.

"We used to go to this church thing... and there'd be a whole group of 20 or 30 people talking on a high level and as soon as we'd enter we noticed the level dropped. I don't know how you pick it up or what. No-one else talks to us when we go. We're more or less pushed to the corner [like] rejects. And we don't like it but what can we do? We've had a few people in the past come for a meal... they've never come back. We've invited them, we open our hearts to them and they just run away." - Kylie

Experiences of current and recent services/supports being received.

Service and support utilisation differed somewhat according to the age of the children in the family – a general trend being that families identified more support from formal services and informal supports during the child's early years, but that this support frequently diminished as the child's age increased. Supports and services identified by families included family, local area coordinators, friends/neighbours, Disability Services Commission (the Commission), parenting groups, the Department for Community Development (DCD), Schools, Daycares and Tutors, Financial Counsellors, Medical Staff, Respite services, Ngala and Mofflyn.

Having supportive people around was described by families as making a difference in their role as parents. The kinds of support that was valued the most included practical support such as babysitting, providing transport to appointments and financial support, however information and advice was also valued when given constructively and in a non-judgemental way.

"[My mum] usually talks to me and all that, and you know, calms me down and gives advice. She knows Olive is so active and that she's delayed and all that. My Dad doesn't think in his head... He doesn't believe Olive's delayed." - Quisha

"My mother, if I ring her up gives me advice... She used to help me, but she's not much into mothering or giving advice cos as far as she's concerned like she's had her day, that's it... She did give me one bit of advice – a stern talking to on the phone about me giving food and money to [my neighbour] and not spending it on my daughter. My daughter's important, my daughter comes first, not my neighbour or friends" - Harold, a single father of a teenage daughter with learning difficulties.

Role clarification and consistency within those roles also appeared as a common theme addressed by families. Some services appeared to be clearly defined by families (such as therapy & training services) while

with other services, families were unable to identify the purpose and role of service providers.

"Don't really know what she does. Talks a lot. But she's on time and well-mannered. She listens very carefully, which is good" - Ruby

Through further discussion however, the service purpose and role soon became apparent to the interviewer, although this was still not recognised by the parent.

Formal services most commonly accessed by families included Commission services, the Department for Community Development, parenting groups, cleaners and schools/daycares. In general, these services were viewed positively; however several issues were mentioned as being frustrating to families. These included...

- **Frequent staff turnover & the lack of notification to families.**

"I ring up for one person and they'd say, 'that person's not working here no more, you've got such and such' and then like I'd be, 'Ok, no worries'. I've found that I don't get along with a lot of them very well" - Quisha

- **Unreliability.**

"I'm not very satisfied at the moment, because when she says she's going to turn up she doesn't. She doesn't give me a call when she says she's going to turn up. She's unreliable lately. And that could be due to her sickness. I'm not blaming her. [I would like] someone a bit more reliable" - Kylie

- **Not helping practically but only giving information.**

"When you ring him up, he gives you the phone number first and asks you to approach them. The approach is that he leaves it all up to you, and if you can't solve it, [pause] sometimes he doesn't like it if you can't solve it. But what I meant was, we've got to ring up all these places and he just gives us phone numbers to call, and Ray says, 'why can't he do it, a little bit more for us?' instead of him just laying it off on him. But he can't understand that. He doesn't want to be involved" Ruby

- **Nagging, Criticism & Judgmentalism.**

"This young bird used to come in and tell me how to do this with Mary - put her to bed without a bottle. Used to boss me when Mary was little. And I said, 'no, you try and put her to bed without a bottle... you want her screaming all night? You go to college, you think you know this, this, this and this' and I said, 'you know bugger all'. And she said, 'you've no

need to speak to me like that'. I said, 'look, you've got no bloody kids and it's a 24 hour job bringing up kids, normal kids, let alone special needs. You know where the door is'. She said, 'yeah' and I said 'piss off and don't come back'." - Tracey, single mother of a young adult with an intellectual disability.

"They were very abusive, in slander, running us down, making fun of us. Snappy, no patience. I had to get things done in their time... And I had to do about four things at once, and they were doing it deliberately to make me snap, to put me in the loony bin. They looked at me as an unfit mother and told... that my kids should be surrendered" - Kylie.

Qualities which families valued that contributed to a positive service relationship included being positive and constructive, flexible and creative in problem solving, having good listening and communication skills and providing a balance of practical support and information.

Another quality highly valued by families included taking extra time as needed. For example one mother, Wanda, recalled a specific incident when her daughter Toni (aged 4 months at the time) had surgery for a heart murmur. Wanda remembered that at this time a service provider *"was good enough to sit with me to support me. I knew she didn't have to, but she did"*. This support meant a lot to Wanda who was teary when recounting it.

Summation

Like the majority of parents in the general population, parents with an intellectual disability frequently find parenting challenging and difficult (as well as rewarding). The experiences shared by these parents touched on issues such as financial hardship, difficulties with schools, post-natal depression and other issues no different to those experienced by the general population of parents. Thus, their support needs in many respects are not dissimilar to that of general parents.

However some of the other experiences shared revolved around issues of social exclusion, attitudinal discrimination and in essence highlighted the vulnerability of these families who may have more difficulty in recognising and expressing their needs when faced with this.

While good communication and listening skills are crucial for any human service profession, when providing a service to people with an intellectual disability, poor communication can have greater implications, as people with an intellectual disability may be less likely to ask for further information about an issue they are confused about, or they *continued page 14*

Personal Experiences

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may be unlikely to make complaints when dissatisfied with a service.

Furthermore the attitudes and communication of those attitudes by society in general, family members and friends and service providers/support agencies go a long way in shaping the type, amount and frequency of support that these parents/families access both formally and informally. Negative attitudes and communication subsequently lead to minimal supports being accessed (or existing support relationships breaking down).

Within Western Australia, there are several formal service provider and support agencies available for families to access that are able to provide practical assistance and support as well as relevant information. When these services and supports are constructive, encouraging and advocate with and for families, they are more likely to be positively accepted and regularly accessed.

In addition, when formal, practical services are utilised regularly by families, potential risk issues

(such as those associated with financial factors, home cleanliness and/or familial stress) may be minimised, particularly if services are accessed before these risk issues escalate.

Consistency of support is also crucial: consistency in staff; consistency in frequency; and consistency over the child's life phases. By nature, informal supports tend to have a longer involvement with families than that of paid services. Hence, services that work with and alongside informal supports and that seek to build upon these by assisting them to continue to support families (rather than replacing them with paid support) may help to maintain positive and long-term relationships between families and their natural informal support-givers.

Clearly, while many experiences and subsequent support needs of these families are similar to those of parents in general, there are specific issues that are distinctive to these families and require further consideration when providing a service or support to a family where a parent has an intellectual disability. ♦

HARRISON

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Individual Development Program

The Individual Development Program supports adults with a disability to develop their independent living skills while residing in a five bedroom house. Each resident spends twenty weeks "living in". Skill development activities are individually designed and implemented in the areas of cooking, cleaning, budgeting, shopping, paying bills, making appointments, community access, self advocacy, social skills, problem solving, communication skills and learning to live with other people. Thirteen clients per annum access the program and support is provided by four staff and a lead tenant.

The program has developed innovative teaching/independent living skill aids that are tailored to each individual's support needs and increase the client's ability to generalize skills. These aids are discreet, high quality and provide clients with confidence when interacting in community settings.

Community Support Program

The Community Support Program assists adults with a disability to develop their independent living skills in their current living situation or local community. Skill development activities are individually designed to support people to achieve predetermined goals. Currently the program supports 51 clients with 4 staff (3.6 EFT).

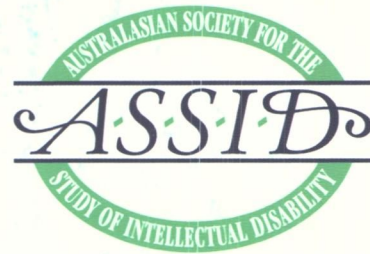
Recycled Manses

Former Uniting Church Manses are being used as transitional accommodation for adults with a disability who will eventually move on to more independent share accommodation. Currently four manses are utilized with individual client support through the Community Support Program, with one manse having a dedicated part time worker on weekday evenings. Aims of the manse program are to provide each individual with developmental opportunities to increase independent living skills within a local community environment, to support and encourage each individual to develop and access generic community networks, to provide each individual with opportunities to develop problem solving skills and take on responsibility for decision making and life choices. Other aims include to orientate individuals to long term accommodation options, source appropriate community based housing and to provide an environment for individuals to experience living in a shared house by developing interpersonal skills and appropriate communication skills. This unique program provides a stepping stone to independent living which is not available elsewhere.

If you would like further information on the Independent Accommodation Network (IAN) or any of the other Harrison Community Services Disability Programs please contact : Jenny Tomlin or Jane Davoren on 03 9887 1055 or via email : jenny.tomlin@harrison.org.au or jane.davoren@harrison.org.au. ♦

UPCOMING EVENTS

2 - 6 July 2006	<p>International Society for the Study of Behavioural Development 19th Biennial Conference</p> <p>To be held at the Carlton Crest Hotel, Melbourne. Further information http://www.issbd2006.com.au/</p>
4 - 6 July 2006	<p>4th International Conference on Developmental Disabilities: Policy, Practice and Research</p> <p>To be held at the David Intercontinental Hotel, Tel Aviv. Pre Conference Workshops will also be held 2-3 July 2006. Further information http://www.ortra.com/beitissie</p>
2 - 5 August 2006	<p>2nd Europe-IASSID Congress: Bridging Research, Policy and Practice.</p> <p>To be held at the University of Maastricht, Maastricht, the Netherlands. Information on the Congress, as well as information on lodging and registration arrangements can be found at the Congress website: http://www.unimaas.nl/congresbureau/e-iassid2006</p>
1 - 3 Sept 2006	<p>National Conference on Autism Spectrum Disorders (Hosted by Autism New Zealand Inc)</p> <p>To be held at the Duxton Hotel, Wellington, NZ. Further information at http://www.autismnz.org.nz/.</p>
5 - 8 Sept 2006	<p>Australasian Society for the Study of Intellectual Disability (ASSID) 41st Annual Conference: Risk and resilience: Hope for the future.</p> <p>To be held at the National Convention Centre, Canberra, Australian Capital Territory</p>
6 - 8 Sept 2006	<p>The Association of Competitive Employment (ACE) Conference</p> <p>to be held in Perth. Further information at http://www.acenational.org.au/</p>
7 - 8 Sept 2006	<p>From Tolerance to Respect: Cultural Competence in Practice.</p> <p>Conference hosted by the Multicultural Disability Advocacy Association of NSW and the National Ethnic Disability Alliance. To be held at the Novotel Hotel, Sydney Olympic Park, Sydney. Further information from Theresa Clark, Conference Coordinator Theresa.clark@mdaa.org.au or www.mdaa.org.au</p>
30 Sept - 2 Oct 2006	<p>Australian Association of Special Education (AASE) National Conference: Learning together: Leading practice in inclusive education.</p> <p>To be held at the Hyatt Hotel Canberra, ACT. Further information at http://www.aase.edu.au/2005_National_Conference.htm</p>
15 - 17 Nov 2006	<p>Centre for Developmental Disability Studies and Australian Association of Developmental Disability Medicine: The Right to the Right Health Care: Evidence, Ethics and Health in People with Developmental Disability.</p> <p>To be held at the Sydney Masonic Centre. Further information www.cdds.med.usyd.edu.au</p>
16 - 17 Nov 2006	<p>6th Annual Conference for Disability Support Workers: Meeting the Challenge.</p> <p>To be held at the University of Melbourne. Further information phone (03) 9925 7211 or email dswconference@rmit.edu.au</p>



Australasian Society for the Study of Intellectual Disability 41st Annual Conference

Risk and Resilience : Hope for the Future

4 - 7th September 2006

National Convention Centre, Canberra, Australian Capital Territory

CALL FOR PAPERS

The theme of the conference is linked to the challenges that have occurred over the last twenty years in the lives of people with disabilities, their families, service providers and professionals. A strength of ASSID is that it involves a range of individuals - service providers, parents, researchers, clinicians, professionals and others - so the conference provides an annual update on what is happening holistically across the life span for people with disabilities and their families.

Presenters should ensure that their paper or poster addresses the conference theme. We encourage presenters to be innovative in their approach and forward thinking. Papers should be evidence-based and, where appropriate, provide recommendations for the future.

We encourage experienced and new presenters to present their work in a way that allows all participants to gain insight into the many issues and challenges people with intellectual disabilities are facing each day.

Presenters may nominate their paper for consideration for the peer-reviewed stream of the conference. Presenters whose papers are accepted into this stream will have the opportunity to have their abstract published in a forthcoming issue of the Journal of Intellectual & Developmental Disability.

Proposals for papers, posters, symposia should be submitted by 30 June 2006 and be submitted by email to: assid41st@confco.com.au following the guidelines - available at www.assid.org.au

Intending presenters will be notified by 30 July 2006 on whether their paper has been accepted.

Conference Committee:

Linda Goddard, Convenor: lgoddard@csu.edu.au Tel: 02 6051 6875
Tony Tinlin, President ASSID NSW: ttinlin@bigpond.net.au Tel: 02 6023 1800

Confirmed Keynotes:

- Kristjana Kristiansen, Norwegian University of Science and Technology – Norway
- Dr Levan Lim, National Institute of Education – Singapore
- Professor Gwynnyth Llewellyn, University of Sydney
- Robert Martin, IHC – New Zealand
- Professor Jeff Sigafoos, University of Tasmania
- Professor Tony Shaddock, University of Canberra
- Dr Roger Stancliffe, Centre for Developmental Disability Studies, University of Sydney
- Dr Stuart Todd, Cardiff University – Wales