

# INTELLECTUAL DISABILITY **A**ustralia

## ASSID members in conference?



*Wherever they are, whatever they do, ASSID members are prepared to work hard . . .* (the Karioke choices required particular attention). Read more about the ASSID/NCID 2000 Conference, **Beyond Business as Usual** inside . . . . .

### *Inside:*

- Conference report with pics
- Working in Partnership with Families
- What's going on - sport
- History of Ausrapid
- What's going on - research
- State Updates
- Must Read
- What's available - resources
- New service for ASSID members?

*...and more*



Intellectual Disability Australia is produced and distributed by the Australian Society for the Study of Intellectual Disability.

The views expressed in this newsletter are not necessarily those of the Australian Society for the Study of Intellectual Disability.

**Editor:**

Ann Penhallurick

**Advertisers:**

Rates are available, on inquiry, from the editor

**Subscription:**

Inquiries to the editor

**Editorial Address:**

28 White Street  
Lilyfield NSW 2040

**Phone:** (02) 9566 4789

**Fax:** (02) 9571 8669

**Email:** [penhall@bigpond.net.au](mailto:penhall@bigpond.net.au)

**Artwork:**

Karen Vance  
[krvt@one.net.au](mailto:krvt@one.net.au)

**Printed by:**

Breakout  
(02) 9281 5100

## Contents

Conference 2000 Report . . .	3
What's going on - sport . . . .	6
Working in Partnership with Families . . . . .	8
State Updates . . . . .	10
Ausrapid. . . . .	12
What's available - resources . . . . .	13
Lay Discourses on Intellectual Disabilities . . .	14
New Service for ASSID members? . . . . .	17
Must Reads . . . . .	18
Letter to the Editor . . . . .	19

# Editorial

This editorial was going to be an upbeat introduction to this edition's contents, to the excellent articles and the notes about new resources from the ASSID/NCID conference of 2000. Those articles are here and I encourage you all to peruse them with attention and interest. However, as I write, I am also conscious that at least two very important aspects of the lives of people with disabilities are, yet again, being circumscribed by attitudes/prejudice and, it seems, ignorance. As most of you would know the International Paralympic Committee has - at least temporarily - shut the doors against people with intellectual disability who have struggled for so long to be included in sport. Only six months ago IDA reported on their inclusion and it is disheartening to see that belated recognition of the skills of people with intellectual disability being reversed - and so quickly. So, in this edition of IDA you will read about the history of AUSRAPID, a major force behind the struggle - both past and present.

It is also notable that advocacy is under attack. The NSW office of Citizen Advocacy has been de-funded, without notice. While the work of Citizen Advocacy is not being completely ignored and some funding remains available for the time being, there is a not too well hidden ideology influencing this decision. It seems to me that this ideology goes something like: people with disabilities should be objects of charity, not recipients of government support, and the people who work with people with disabilities should do so voluntarily and not expect their own tax payer monies to be spent in this area. In other words, working with people with disabilities is not 'real' work and there is no need for this work to be supported by the basic infrastructure of offices and photocopiers and so on. This defunding - without warning and consultation - not only demonstrates how precarious are the gains that have been made in recent years, it throws us back into the Victorian era, where people with disabilities should most definitely never be heard and their advocates should be nice women with a bit of spare time to spend in good works!

Furthermore this is not an isolated incident - not in NSW at least. The (NSW) Department of Aging and Disability has decided to put all advocacy services out to tender and services such as the Western Sydney Intellectual Disability Support Group, an extraordinarily active, lateral thinking and influential family based advocacy group, is one among a number of established and effective services which may be out-bid by far less experienced and less closely connected advocacy groups. In fact, the question has to be raised whether it is likely that soon advocacy will be run by for-profit organisations, as an increasing number of group homes already are.

So, in this edition, read the good news but spare a few moments to pen a letter or two to the relevant government ministers, both federal and state (contact details herein). Every little bit of determined resistance - and forward thinking - helps.

- Ann P.

P.S. Letter to the Ed - see page 19. Don't forget to send your views, too! ◆



This is your editor, carrying someone else's champagne bottle!

# Conference Update



March, 2001

## Key points:

- World renown keynote speakers confirmed
- Earlybird registrations announced – sign up today!
- First call for papers
- Special discounts for organisations purchasing tickets to both State & National Conferences

## Keynote Speakers

A key focus of the 2001 conference will be the involvement of people with an intellectual disability as keynote speakers, participating and running workshops and symposia. The theme of the conference, 'Participation and Citizenship in the Wider World' will be commented upon by reflection over that changes have occurred in the lives of people with an intellectual disability over the last two decades. Currently confirmed keynote speakers are:

### Professor Gordon Grant

Professor Grant is Chair in Cognitive Disability within the school of Nursing & Midwifery at the University of Sheffield, UK and has authored and co-authored numerous books and research articles on topics including: family caregiving and family support; social models of disability and its application to the empowerment of individuals who are disadvantaged or oppressed; educational preparation of nurses in work with older people with learning disabilities; & roles and tasks of community nurses and social workers in their work with citizens with learning disabilities, older people with dementia and carers. Professor Grant has recently completed a study of the coping strategies of families supporting children and adults with disabilities and has helped produce a video training program and practitioner guidelines about needs assessment in family care.

### Dr. Anthony Holland

Dr. Holland is a lecturer and research supervisor at the University of Cambridge, Department of Psychiatry. His major areas of research include: the study of specific syndromes and their relationship to psychiatric and behaviour disorders (including Down Syndrome, Prader-Willi Syndrome, Fragile X syndrome and Tuberous Sclerosis) and offending behaviour by people with learning disabilities and factors contribution to challenging behaviour.

### Professor Gillian Turner

Professor Turner is the Head of the Medical Genetics / Biomedical Science Department, University of Newcastle, NSW. She is also a major genetic researcher for Hunter genetics, Newcastle. Professor Turner is author and co-author of numerous and extensive research articles on genetic abnormalities in relation to specific conditions. She is currently one of the head researchers involved in the Human Genome Project.

A fourth keynote address will be provided by an individual from the South East Asia region, who will identify major issues surrounding the prevalence of developmental disabilities in the region, current initiatives and services provided, and the political framework in which services are provided throughout this region. More details will follow upon confirmation of the speaker.

## Registration Information

The National Conference organising committee, together with the Victorian State committee has endorsed the release of discounted booklets for organisation purchasing four or more tickets to both the State and National Conferences. These booklets, are available prior to June 30 only, at a cost of \$1680, including GST. These booklets contain four full passes to attend

all days of both the Victorian State Conference (July 12-13, Bendigo) and the National Conference (November 12-15). This represents a considerable saving on the cost of purchasing these tickets individually. Work it out for yourself. We're sure you'll agree!

## Call for papers

The closing date for the submission of abstracts is the 31<sup>st</sup> August, 2001.

**Length of Papers:** Presenters of papers will be allocated a 30 minute session. This 30 minutes will comprise 20 minutes for the presentation and 10 minutes for questions and discussion. These times will be strictly enforced.

Paper symposia and any variations to this requirement are available through negotiation with the program committee. Contact the Chair, Program Committee on: (0 3) 9925 7363 or email: karen.nankervis@rmit.edu.au

**Posters:** Presenters will be allocated a time during the poster sessions during the conference. The presenters will be present at the time of the allocated poster session to maximise the opportunity for discussion and interaction with conference delegates.

**Computer aided presentations:** The conference organising committee can not take any responsibility for these presentations and cannot guarantee the availability of such equipment.

**Length of Abstracts:** Abstracts submitted for consideration must not exceed 250 words.

**Submission of Abstracts:** Please forward abstracts by 31st August, 2001 in either of the following ways:

Mail: Karen Nankervis

Chair, Program Committee  
ASSID National Conference  
Dept. of Psychology and Disability Studies  
RMIT University  
P.O. Box, 71  
Bundoora, Victoria, Australia, 3083.

Email: karen.nankervis@rmit.edu.au

See the web for the latest news:  
[www.rmit.edu.au/  
departments/ps/assid/](http://www.rmit.edu.au/departments/ps/assid/)

## Early Registration

**Early Registration** – Must be received by 30th June 2001

Address for receipt:

### Full Conference

- ASSID Member \*  
 Non Member  
 Concessional

Number	Price
_____	@ \$320.00
_____	@ \$370.00
_____	@ \$70.00

Organisation \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Phone \_\_\_\_\_

### Day Registration

- ASSID Member \*  
 Non Member  
 Concessional

_____	@ \$110.00
_____	@ \$135.00
_____	@ \$20.00

### Organisational Booklets

- 10 x 1 Day passes \_\_\_\_\_ @ \$1100.00  
 4 x Full registrations to both State and National Conferences \_\_\_\_\_ @ \$1680.00

Total: \$ \_\_\_\_\_



Names of staff attending (for organisational booklets):

1 _____	6 _____
2 _____	7 _____
3 _____	8 _____
4 _____	9 _____
5 _____	10 _____

Please forward registration and payment to:

Conference Convenor,  
ASSID National Conference  
Department of Psychology and Disability Studies  
RMIT University  
P.O. Box, 71  
Bundoora, Victoria, Australia, 3083.

All cheques payable to ASSID Conference Account

# Conference 2000 report

In ways both overt and subtle, **the ASSID/NCID conference held in Fremantle last October** really was the conference which heralded in a new century, if not a new millenium. The presence and participation of people with disabilities, encouraged and appreciated at previous ASSID conferences, reached something of a maturity. People with disabilities prepared, co-ordinated and participated in a major strand of the conference over the full four day period. This in itself was inspiring but perhaps even more so was the fact that it was people with disabilities up on the stage, resting their arms on the lectern, telling the jokes, inciting and exhorting the audience to listen and to listen well. In fact, people with disabilities bossed people without (acknowledged) disabilities around! I can only admit that I was foolish enough not to record Tash's jokes or Ruth's empowering speech - both were brilliant representations of the skills (and charm) that were

demonstrated at the conference. However, we do have a copy of the 'manifesto' of the organising team of the 'About Us' strand and the magnificent words of the song written by a member of that committee, Elisha (see p 5). Elisha's song was performed at the conference and sung with gusto by all the audience. (And an update here, Elisha and Tash are now being formally paid as guest lecturers on a busy WA circuit. Eat your heart out, Bill Clinton!).

The more subtle change was also exciting, inspiring. This change was easier to see at the end of the conference, after the papers and presentations had been listened to, and absorbed as a group rather than as individual abstracts. It was a subtle but definite shift in the emphasis of both research and service delivery towards what I would call (and here I betray my own professional leanings) a more solution focussed approach. Solution Focus,

*continued next page*

## What are HUMAN RIGHTS?

- ❁ HUMAN RIGHTS are ideas and rules about the way people should treat each other.
- ❁ Some HUMAN RIGHTS are written down in the laws of different countries.
- ❁ Some HUMAN RIGHTS are written down in different religious books like the Christian Bible or the Islamic Koran.
- ❁ Some HUMAN RIGHTS are not always written in laws or books like the Bible, but are still agreed upon by lots of people in lots of places. For example, not treating people unkindly by calling them cruel names.
- ❁ HUMAN RIGHTS are about respecting yourself and respecting other people the way you would like them to respect you.
- ❁ HUMAN RIGHTS are therefore all about how we think about ourselves and other people. They are about thinking about other people's feelings, the same way we want to think about ours.

But sometimes, as we all know, people do not always respect our rights and don't seem to care about how we think and feel about things. This is often because they have also been treated badly and have never learned how to care about their own and other people's feelings.

Also, at different times, some groups of people have been badly treated by bigger groups in that community. Jewish people for example in Germany during World War Two, and sadly, Aboriginal people in their own country.

People with a disability have often also been treated very badly in the past, so that in time, communities and their governments have recognised that laws may need to be made to stop bad treatment.

But at times these laws are not enough to protect people from cruel or hurtful treatment, and that the hardest thing to do sometimes, is to change the way some people think.

The good thing is that sometimes when people are educated about their attitudes and behaviour that it is possible they can change.

"ABOUT US" Conference Committee  
ASSID/NCID Beyond Business as Usual Conference, 2000.

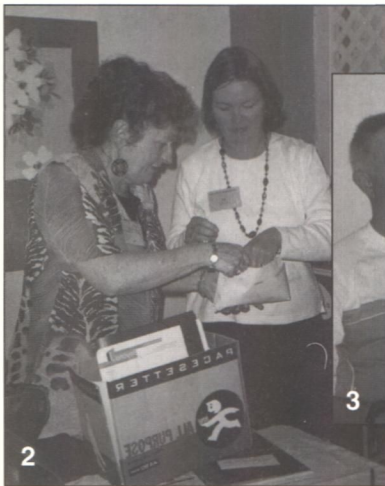
# Conference 2000 report continued



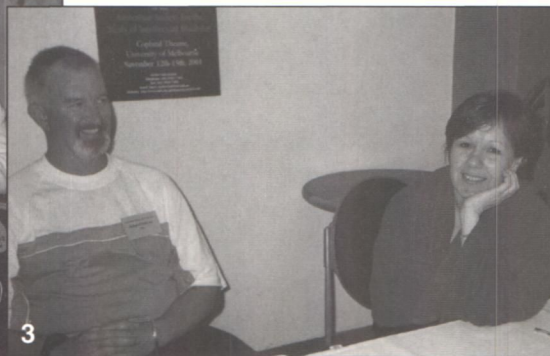
1

when applied to counselling, denotes a systemic, family and/or ecologically orientated approach to providing support and 'directions' for change. It does not seek to examine the details of the past (except for past successes, as SA therapist Michael White has put it), nor to spend much time on detailing the negative aspects of the problem. Solutions for individuals are the outcome, but the means of achieving these very much works against the client as the problem, the past as the problem, the individual as synonymous with the problem and seeks to find solutions in adjustments to systems. In their own ways both Michael Kendrick, speaking on Overcoming Disadvantage and Reverend Tim Costello, addressing Building Community, at **'Beyond Business as Usual'** took

this approach. It certainly underpinned the work of Vicki Cammack and Al Etmanski who are co-founders of Planned Advocacy Lifetime Network (PLAN). There were also number of Australian papers with a leaning towards ecologically or system based solutions – two quite different examples printed here in IDA.



2



3

If the number of questions, the lengths of after-talk queues and the vibrancy of discussion at breaks was anything to go by, the conference held many moments of intense interest for all participants. Steve Beyer's keynote address (Achieving a Good Life – concentrating on Steve's work in open employment) was well received and Ruth Cromer's powerful advocacy-based talk received a standing ovation. Launch events were extremely well attended – particularly that of "When Needs go Begging", the report and life story compilation published by Developmental Disability Council of WA and ASSID's own 'Intellectual Disability and the Law' book launch. The final conference 'round-up' by Playback theatre made a dynamic change to the usual formal speeches.

The fun side of the conference really was terrific fun, too. Great food at the cocktail party (of course none of us drank anything so I can't tell you about the quality



4



5



6

1. Fremantle was a beautiful place to visit.
2. The conference committee were tireless . . .
3. but tired at the end of the day.
4. Some people took it very seriously . . .
5. some even more so.
6. Others made friends.

of the wine) and great singing at the conference dinner (best not to mention names here). Fremantle was a charming place to visit, too, and the quiet, but cosmopolitan area contributed to the overall success of what truly was a fabulous conference.

Congratulations and heart felt thanks to the ASSID-WA conference organisers and to the never-flagging energetic, group at NCID, too. It was a tremendous effort, rewarding for all who participated.

- Ann P. ♦

## Here I am

*I feel scared  
I have the right to feel safe  
I have the right to be heard  
And listened to  
That's no mistake*

*I have the right reason  
To stick up for myself  
The right to hear what is being  
said  
To everyone else*

*I have the right to speak  
I have the right to say  
What's on my mind  
Please respect me  
Can you be that kind?*

*Here I am  
Respect me  
There's no-one in this world  
Who I'd rather be*

*I am very clever  
I am not a bimbo*

*There are some things I know  
Also things I don't know  
And I'll tell you my opinion  
If you ask me so*

*I like to learn  
Participate in things  
Just because I have a disability  
Doesn't mean my mind doesn't fly  
On wings.*

Conference Song by  
Elisha Robinson  
ABOUT US  
Committee Member



7



8



9



10



12



11

- 7. Some just had to have fun.
- 8. We even had some young recruits.
- 9. Some dressed informal,
- 10. others went formal.
- 11. A tired organiser's quizzical smile . . .
- 12. and then on with the preparations for the next one!

## What is going on - sport

# IPC restricts access of sportspeople with intellectual disabilities

As most readers will be aware the IPC (International Paralympic Committee) has recently suspended people with intellectual disability from participation in its events. That suspension followed the discovery that all but two of the team that Spain entered for the basketball at the recent 2000 Paralympics were people without disability. There has been some slight discussion in the mainstream press about the absurdity of the logic of suspending all athletes for the 'crimes' of a few, but the issue has not gained much attention in the past weeks, while the suspension remains. One has to wonder what would happen if the entire US team had been prevented from competing when Ben Johnson was found to be using banned substances: the 'dis-inclusion' of people with intellectual disability is the most extraordinary example of double standards for many years.

Needless to say there are many people and groups trying their hardest to make sure that the suspension does not become a permanent ban. 'Our own' past ASSID (and IASSID) President, Professor Trevor Parmenter has been central to the development of guidelines for the inclusion of people with intellectual disability and may well be continuing in this role. Trevor brought ASSID's attention to this issue through information on ASSID-L. I took up his suggestion and asked **Marie Little, President of Ausrapid** a few questions about where the discussion is currently and about background to the struggle for participation.

**IDA:** Has there been any change in IPC position? any progress in negotiations since January?

**Marie Little:** In order to encourage the IPC to lift the current suspension a working group of reliable and effective INAS - FID Executive Committee members is supporting a Motion to be put by the Canadian Paralympic Committee to the IPC Executive Committee. This Motion embodies several actions, including:

- (1) the issue of the athletes with an intellectual disability, - requesting that the general suspensions be lifted, under the condition that eligibility is proved before Dr Trevor Parmenter, IASSID Member on the WHO, given that athletes who were not involved in the cheating situation at the Sydney Paralympic Games should not be punished for the actions of others.
- (2) the question of the suspension of INAS-FID, be maintained until the Federation is able to prove to the IPC that leadership concerns have been resolved and all proper procedures have been put in place.

We firmly believe that there are many capable and reliable individuals within INAS - FID, the International Sports Federation for Persons with an Intellectual Disability, who are committed to change. It is sincerely hoped that the IPC will provide the opportunity for these changes to occur, by adopting the Motions as described.

We are also encouraging positive publicity and advocacy.

**IDA:** You've been fighting for inclusion of people with intellectual disability for a long time, why do you feel it has been such a tough fight?

**Marie Little:** Yes, the battle for inclusion of athletes with an intellectual disability has been a long one and a hard fought one. There are many reasons for this situation and many anomalies which surround the history of the fight.

Firstly, the thought that a person with an intellectual disability could not understand "competition", and therefore could not compete in sporting event or opportunity. This attitude was reinforced by the philosophy of "Special Olympics" at that time, which promoted the idea that "everyone is a winner" i.e every participant in a track event won a Medal - No First, Second, or Third place winners.

Needless to say this theory was very soon debunked - every facet of our life, whether we have an intellectual disability or not, competition is part of the equation. Putting your hand up first in class, getting to the table before your siblings, getting the best seat on the bus, getting to the toilet before a brother or sister, just being born has a competitive element to it.

Unfortunately the "competition" belief, and other negative attitudes encouraged other disability groups to work actively against the inclusion of participants with an intellectual disability - in fact the wheelchair sports organization, ISMWSF (International Stoke Mandeville Wheel Chair Sports Federation) took up a world wide plebiscite early in the 90s, to discourage their inclusion. Their reasons were many and varied, but the irony was that many athletes with an intellectual disability had been competing for some time in Paralympic and World Championship events. These were athletes who had Cerebral Palsy as well as an intellectual disability (or mental handicap). They competed under the CP banner and were therefore not identified as having an intellectual disability.

For many years it appeared that every time those promoting inclusion eg INAS- FID (formerly INAS-FMH) gained some acceptance there would be another reason why

they were not included. Some of these were "the athletes with an intellectual disability will take away funding, will take away photo opportunities, will lessen the number of events we can compete in." The reasons were never ending but the resilience of those promoting inclusion never abated. As one door closed another opened, and in the Scandinavian countries, the Netherlands, UK and Australia, efforts were constantly being made to ensure that all athletes with intellectual disability were included in the sporting activities of the Nation.

Gradually, after lots of battles and rebuffs, the sporting arenas of the world began to include the previously excluded athletes with an intellectual disability. Harnosand, Sweden hosted the first World Championships in Swimming and Track & Field for athletes with an intellectual disability in 1989. Therefore it was essential to see that these athletes were properly trained, had access to resources, were able to compete in appropriate sporting opportunities and generally gained acceptance as sportsmen and sportswomen as they got their "shot at the sport of their choice." The focus was on the fact that he/she was an athlete, a tennis player etc not "an intellectually disabled athlete" etc.

In Australia, the first such opportunity for inclusion was women and girls into the sport of Netball in SA. In 1979, a pilot program was established at a suburban Netball Club, then the State Netball Association (after much diffidence), provided a Sunday Season played in splendid isolation on the State Courts (no other teams competed on a Sunday), then included 6 teams of players with an intellectual disability into the regular State Netball Seasonal fixtures, playing for the same Club as their sister or neighbor, but in Division/Grade based on their ability. This initiative was repeated in every State and Territory. With the first National Carnival being played in Queensland in 1985.

Other National Generic Sports Organizations have followed suit, so that Athletics Australia, Swimming Australia, Basketball Australia, Tennis Australia, Indoor Cricket and Ten-Pin Bowling National Bodies now all provide competition at National level for athletes with an intellectual disability.

**IDA:** What has been Ausrapid's role in this?

**Marie Little:** AUSRAPID, has been responsible for this development in acceptance, provision of opportunity and the general community awareness of just what is possible. The partnership between AUSRAPID, the Australian Sports Commission, the Australian Institute of Sport and the Australian Paralympic Committee, together with the National Sporting Organizations, has seen hundreds of eligible athletes compete Nationally and Internationally at an elite level.

AUSRAPID, has also been at the forefront of all international lobbying and development since 1988.

We therefore see the current situation as another hurdle which we will overcome to ensure the maintenance of just what we have achieved together

**IDA:** What can ASSID members do to help the continued involvement of people with intellectual disability in international sport?

**Marie Little:** WRITE!

## **URGENT ACTION REQUIRED!**

**Support the inclusion of PWID in all sports**, at all levels. Don't allow persons with intellectual disability to be shut out of the international competitions:

Write immediately to:

President Juan Antonio Samaranch,  
of the IOC, Chateau de Vidy,  
CP 356, 1007 LAUSANNE, Switzerland,

And to

President Robert Steadward,  
IPC, Adenaurerallee 212 -214  
D- 53113, BONN, Germany

**Are you concerned about recent approaches to advocacy** for people with intellectual disabilities? (See Editorial for more information). Do you think there should be more consultation before changes are made?

The Western Sydney Intellectual Disability Support Group and Citizen Advocacy, NSW urge you, whichever State you are in, to write to State and Federal ministers expressing your concern about hasty decisions and about the tendering out of advocacy services.

Write to

The Hon. Fay Lo Po'  
Minister for Community Services  
Government House, MacQuarie St  
Sydney, 2000.

Send a copy to:

The Premier  
The Hon. Bob Carr  
also at Government House.

For more info., contact WSIDSG on 02 9334 0573  
Or Citizen Advocacy, NSW on 02 9369 2411

After the presentation of 'Working in Partnership with Families' at the 'Beyond Business as Usual' conference a long line of excited audience members formed, with parents, advocates, and service providers alike wanting to express pleasure in, and ask further questions about, the presentation. The presentation had described not only the program itself – which is outlined below – but the human face of the program in practice. Pat Palmer, as a parent of two boys with disabilities, told us of the very practical supports that had been put in for his family and described the effect of these. As it turned out, a spa for his water loving child with autism was a more effective intervention than any previous behaviour support programs! Similarly a cleaner allowed family members more time to spend with each other. According to Pat, these interventions, as well as the empowerment of the family being the primary directors of intervention, greatly increased the sense of well being of all the family, thus enabling positive and educative support for his two sons with disability and decreasing some of the behavioural issues that were impacting on all concerned.

So while 'Working in Partnership with Families' does not

describe an entirely unique approach to supporting people with disabilities, it is a highly significant government funded program which exemplifies the much needed shift to more ecologically based funding and practice. Individual service plans, in their various forms, have often meant an improvement in the quantity of service provision to the individual, at the same time they have all too often ignored the impact of the wider world on the client and of the client on the wider world, particularly including their family. The increase in attention to family focussed and system sensitive responses may well be a very positive way into a new millennium.

Below, please find overhead summaries of the points Carolyn Uhlmann made in her part of the presentation 'Working in Partnership with Families'. Carolyn has indicated her willingness to discuss details further. See page 9 for details.

Our congratulations to Carolyn and the team, to Pat and his family and to all the families who were willing to take on a new way of service provision and to Disability Services, Queensland for funding the initiative.

The Ed.

## Working in Partnership with Families

Presented at **Beyond Business as Usual**, by Carolyn Uhlmann, Facilitator – Family Support Program, DSQ and Mr Pat Palmer who, with his wife Lesley is a parent of four children, two of whom are challenged with a disability.

The **Family Support Program** was initially funded as a new initiative of Disability Services Queensland by the Queensland Government in the 1999/2000 financial year.

### Initially two levels of support:

#### Intensive Family Support

- Families with high complex, critical needs, at risk of family breakdown, and/or relinquishment of care.
- Crisis support.
- Building families capacity to care for their children.
- Managed within government sector – Disability Services Queensland.

#### Flexible Family Support

- Families for whom the current service system is unable to meet their needs.
- Often families with a child with high support needs, but usually less complex family needs.

- Preventative support.
- Maintaining and building the family's capacity to care for their children.
- Managed in the non-government sector.

#### Future Directions (from Oct. 2000)

- One Family Support Program
- Four levels of support: non-recurrent/one off, low, medium, high, support bands
- Managed across Government and Non-government sectors.

#### Family Support Principles

1. Strengthening of families in their parenting roles through:
  - Using a holistic and family-centre approach
  - Tailoring supports to the family's needs
  - Initiating preventive strategies.
2. Fostering and developing children's emotional security and stability by

utilising family based supports and intervention strategies.

3. Promoting and supporting the inclusion of children with disabilities and their families in the mainstream of community life.
4. Supporting the optimal development of each child or children with disabilities including addressing special needs.

#### Family Support Program Aims

- Strengthen the capacity of individual families to meet the day to day challenge of caring for their child or children with disabilities.
- Building formal and informal supports around families to meet the needs and priorities of all family members and increase the capacity of families to maintain the care of their child.
- Increase the inclusion of children with disabilities and their families in the mainstream of community life.

- Develop best practices in working collaboratively and in partnership with families.
- Decrease the need to respond to crises and the incidence of requests for out-of-home care.

#### **How does the program operate?**

Intensive Family Support is based on facilitators working in partnership with families to plan and coordinate supports.

The relationship between the family and the facilitator is based on a partnership and directed by the family.

Families have access (via an approval process) to a source of flexible discretionary funds.

Discretionary funds can be accessed via a variety of payment methods.

The facilitator role can also provide, information resources, advocacy with and for the family, personal support, support through the decision making process, support to develop life and parenting skills etc.

Caseloads are kept low (ten families per full time position).

A facilitator works with the family to identify their strengths, current and future needs and to make decisions about supports that are most appropriate.

Families direct the decision-making process, and decisions are made at the "front end" by families and approval is as close to the family as possible.

#### **Supports focus on the:**

- Needs of the whole family and all individuals, not just the child with a disability.
- Strengths of the family and natural networks and supports.
- Supporting families to be involved in their chosen local community.
- Inclusion of the child with a disability in the mainstream community and services.

#### **The flexibility of the program allows supports to be provided in ways that:**

- Minimise the intrusion into the family

- Suits the family and their lifestyle
- Are responsive and timely
- Utilizes the family's strengths.

#### **Theoretical and Practice Principles, on which practice is based:**

- Eco systems perspective on families
- Family centred practice
- Strengths focused practice, and
- Solution focused practice.

#### **The key beliefs on which practice is based are:**

- Children should be understood in the context of the family.
- The family should be understood in the context of their community.
- All families have skills and abilities as well, as needs and concerns.
- Strengthening families' ability to access informal and formal supports and networks builds their capacity to manage complex situations.
- Families are usually best at identifying their own needs and developing solutions that best fit for their family.

#### **Implications for practice**

- A focus on resources and solutions rather than deficits and problems.
- Providing flexible, responsive and creative support.
- Respecting diversity and difference
- Outcomes are most effective when the family is the key decision-maker.
- Relationships with families based on partnership facilitate change and growth.

#### **The challenges for practice, from a worker perspective:**

- Value base of workers is constantly challenged. What is a family? Presented with a constant need to acknowledge different parenting, family and lifestyle choices.
- What do you do when you disagree with a family's choice or priority?
- Striving to be responsive vs "rescuing" families and creating dependency.

- Developing a close and meaningful relationship with family members, that empowers the family, and does not create dependency.
- Remembering "families know best".
- Remaining in a role of "partnership" not in the role of the "professional".
- Working at the family's pace – allowing them the space and time to develop their own solutions.
- Working with the complexity of issues family's experience, outside of their experience of disability.
- Issues of child protection.

#### **The challenges for practice, from a program perspective:**

- Ensuring that supports and resources are provided in a manner that equips the family and builds the family's capacity to manage more independently in the future.
- Being responsive, in a bureaucratic organisation. Having systems that work which meet families needs.
- Accountability of discretionary funds vs approval process being close to the family and timely.
- Managing/accepting the "risk" associated with supporting families ie. Outcomes unknown, flexibility of resources etc.
- Challenge for a "traditional bureaucratic culture" to put decision making capacity in the hands of the client (this is needed to build capacity and independence).
- Working with the complexity of issues families experience.
- Working across government departments.

#### **MORE INFO:**

[cuhlmann@families.qld.gov.au](mailto:cuhlmann@families.qld.gov.au)

Ph: 07 3818 5133

Mob: 0414 539 283

DSQ

Goodna Area Office

PO Box 354

Queensland 4300



## South Australia

Given that we missed the December 2000 issue, we have some updating to do.

In November we held a well attended event on Genes and Genetics. Our speakers were internationally recognised experts in this field, Professor Grant Sutherland and Professor Eric Haan. They were asked to discuss The Human Genome Project and Genetic Counselling. The provocative question, "Will intellectual disability disappear in the future?" was posed and considered. After enlightening and entertaining presentations a number of challenging ethical issues were raised. Amongst the issues discussed were the disturbing possibilities of 'genetic discrimination', privacy issues and the questions about the need for protective legislation, and fundamental questions about choice and valuing individuals regardless of their genetics. The answer to the provocative question considering the future of intellectual disability was answered in two ways:

- i) There is a multitude of non-genetic causal factors associated with intellectual disability.
- ii) The concept of intellectual disability is essentially a statistical construct: Even if the incidence of particular syndromes associated with intellectual disability were reduced, there will always be those people whose intellectual abilities, when measured and compared to the rest of the population, will fall towards the bottom end of the 'bell curve'. These people will continue to run the risk of being disadvantaged.

Feedback from those that attended was that it was a stimulating and thought provoking event.

At our AGM the SA branch President of the last two years - Jennie Blackwood, resigned, handing over the reigns to Richard O'Loughlin who will seek to keep the SA branch vital and active. The council appreciates and thanks Jennie for her efforts and is grateful for her ongoing support: Jennie maintains a position on the state council. Much to everyone's relief, Ruth Davey continues in her role as state treasurer and Verity Masters continues in her role as secretary. Phil Priest, a man of extensive experience and expertise in the area of intellectual disability, was welcomed on to the state council to 'do his bit' and old hands Wendy Falconer and Richard Bruggeman continue in their state councillor roles.

In planning this years activities we are seeking to tap into some of the 'home grown' local expertise by inviting post graduate students studying in the area of intellectual disability to present on their thesis topics. Approaches are already being made with encouraging responses. In addition to this, we are looking at a "rhetoric versus reality" workshop considering such issues as community living, legislation and access to other service sectors.

## Tasmania

On Thursday 8th March ASSID Tasmania is holding a Hot Topic Night at the Shipwrights Arms in Hobart. The theme is "My Home, or Your Workplace?"

Anna Crotty, a Commissioner for Human Rights will be a speaker, as well as Alderman Mary Guy. This is a contentious issue and should prove to be an excellent night.

The first call for papers is out for our State Conference, which will take place at Wrest Point Casino, Hobart on the 1st 2nd and 3rd August. The Theme for the Conference is "2001 - A Relationship Odyssey". It will encompass the many and varied relationships experienced by people with disabilities and the way they experience them.

Hope this helps!

Virginia Downton  
Tasmanian State Secretary ♦

## Queensland

Hi from Queensland...

Members here can look forward to an active next couple of months. In the wake of the election, we will be meeting the new Minister for Disability Services, Judy Spence, over dinner in Brisbane in March.

In April, members in the South West should be looking forward to a day of workshops at the Warilda Conference Centre. Topics for discussion may include issues around the support of people with a dual diagnosis, communication, service delivery, training needs analysis and/or skills development. More on that anon as details are finalised.

Members in the rest of the State, rest assured, you have not been forgotten, regional workshops are planned for later in the year.

Chris Montgomery ♦

There is no shortage of ideas. The task, as usual, is to find the time and energy to turn these ideas into events that have sufficient relevance and interest to inspire people to attend and participate.

We are anticipating an active and rewarding year.

Richard for the SA Branch  
[rolstmarys@esc.net.au](mailto:rolstmarys@esc.net.au) ♦

## NSW

Welcome to all the new members of the NSW council. We are at full strength this year, with 14 people signing up - and something of a waiting list, which is marvellous.

Our planning day was held by teleconference this year, partly to keep costs down (saved on air fares) and partly to deal with the busy schedule of the members involved.

The meeting was successful and a couple of workshop/seminars are near to completion and should be scheduled in soon. A newsletter will soon let NSW

members know about these and give some more detailed contact information for councillors for

those who want to ask questions, give information etc. The plan is to hold workshop/seminars in regional centres - as well as one in

Sydney - this year. While it is easier, without doubt, for more people to come to a seminar in the capital city, the energy and enthusiasm of regional and rural ASSID members can't be bettered!

2001 is the Year of the Volunteer. It is worth remembering that ASSID councillors are volunteers and the contribution made by this work and the involvement of all members of ASSID should be - at least quietly - celebrated. So, hold up your glasses, ladies and gentlemen and here's to 2001.

Cheers, Ann P. ♦

## West Australia

The WA State Council is still recovering from its exhaustion following the National Conference. We have a small but dedicated committee eager to plan an exciting year of events for local members. Ideas include a joint event with the Early Childhood Intervention Association and the College of Developmental Psychologists on the topic of Family-Centred Practice, a speaker on Strengthening and Building Community, our State Conference (yes we think we can manage a very small conference) and dinner and speaker for our Annual General Meeting in late August. Our first choice for our AGM speaker has to be, of course, the new - as I write, unannounced - Minister for Disability in WA.

ASSID members planning to visit WA are always welcome, and we are eager to invite visiting members to talk on their favorite and relevant topic to WA members.

Several new members have been welcomed to ASSID WA, including the latest recruit onto State Council.

We have proposed a new format for planning this year, with a series of subcommittees each taking responsibility to organise an event, meanwhile reducing the number of council meetings so that the work can proceed as efficiently as possible.

Shane O'Connor continues to valiantly complete the books for the National Conference, no further details as yet regarding final figures.

Best Wishes from WA.

Sue Peden. ♦

## Victoria

From all of us in Victoria; a big welcome back from the summer break. Our first State meeting for the year was held in February and found us slowly moving into action as we emerged from the other side of the silly season. Our main focus this year will be the National Conference in Melbourne and we would love as many members as possible involved, so please contact us with your ideas and offers of help. We are bursting to hear from you!

Of course as well as the National Conference in November, there will be the annual State Conference that is shaping up for early July in Bendigo. This conference will be aimed at those who directly work with people with an intellectual disability and be an opportunity for carers to share experiences and ideas and to learn about the latest in service delivery.

There is also every possibility that the Victorian branch will organise a seminar in the Gippsland region, similar to that conducted in the Northern region in November last year. The Gippsland seminar has not been finalised yet and we will keep you posted as it develops.

A further project for 2001 is the establishment of a Research Forum that received a great deal of discussion towards the end of last year. Victorian members are keen for the establishment of an informal avenue for people to meet and exchange ideas about projects and research that is undertaken in the field. Suggestions made so far have included an e-mail network, or occasional meetings and presentations. We would like to know how you think we could establish a research forum? and what aims you think would be important and useful for such a network? Please contact either myself or Daniel Leighton on [Daniel.Leighton@dhs.vic.gov.au](mailto:Daniel.Leighton@dhs.vic.gov.au) with your suggestions and ideas.

Despite the National Conference in November we have many other projects to work on this year and are asking for State members to come and join us in 2001 to organise activities and build on the successes of 2000.

Alex.Phillips

[Alex.Phillips@med.monash.edu.au](mailto:Alex.Phillips@med.monash.edu.au) ♦

## What is going on: sport

# AUSRAPID - a brief history

Since our inception in 1986, AUSRAPID has changed the thinking of many of those working in the sporting and recreational community, which has had a positive impact on the number of mainstream opportunities that have been developed for people with an intellectual disability. This has also been reflected in the mainstream approach many of the other disability groups and the Australian Sports Commission have adopted. With this strong base and the lifted profile of athletes with a disability our role continues to grow in importance and we now have a great opportunity to consolidate and further develop. We have subsequently seen the introduction of many services for athletes with an intellectual disability and in a number of cases other disability groups have benefitted from these links. We have argued since 1986 for the introduction of a Sport Specific model, which is now widely supported e.g. Swimming, Athletics and Basketball.

Our skills in negotiation with mainstream sports for the inclusion of programs for people with a disability are invaluable to the disability area. Our experience in working side by side with mainstream sports to conduct events for athletes with a disability is unique – we do not take ownership. Mainstream organisations should receive the kudos for conducting the events to encourage the further development of necessary infrastructure to provide ongoing support, however this needs to be supported by

adequate advocacy by an effective organisation e.g. AUSRAPID. The element of advocacy is crucial to effective inclusion.

On the international scene, AUSRAPID has played a major part in lobbying for the inclusion of events in Paralympic Games, International Paralympic Committee, IPC World Championships and more recently the Far East & South Pacific Games Federation for the Disabled, FESPIC Games. Mrs. Marie Little, President of AUSRAPID has worked tirelessly since elected as President of the International Sports Federation for Persons with an Intellectual Disability, INAS-FID Asia & South Pacific Region to develop and consolidate the region.

AUSRAPID also plays a major role in determining the eligibility of athletes with an intellectual disability. We have approximately 800 registered members to date.

AUSRAPID has achieved a great deal in a short period of time, effected vast change in the intellectual disability area and can now look forward to the new century with enthusiasm. It is now opportune that we use the model so successfully used and refined in the past couple of years and forge new links with more mainstream organisations. This is essential if we are to give choice to people with an intellectual disability.

**Robyn J Smith**

*National Executive Director* ◆

### 2001 Upcoming events (which include athletes with an intellectual disability)

Mar 2001	Athletics Grand Prix Series	Nationally
Apr 2001	National Athletic Championships	Canberra
Apr 2001	National Swimming Championships	TBA
June 2001	1st European Tennis Championships	Czech Republic
June 2001	Victorian Hardcourt Tennis Championships	Melbourne Park
July 2001	National Basketball Championships	Canberra
July 2001	INAS-FID World Athletic Championships	Tunisia
July 2001	National Indoor Cricket Championships	Adelaide
Sep 2001	Japan Tennis Championships	Japan
Oct 2001	European Basketball Championships	Greece

## What's available - resources:

# Setting the Standards

A number and variety of resources were presented and discussed at **Beyond Business as Usual**. Unfortunately I was not able to attend each and every launch or presentation but one of the advantages of going to the conference is having the detailed program, so I have been able to follow up with some since.

One of the resources that I have caught up with since the conference is the **'Setting the Standards'** video, produced by the South Australian Housing Connexion, Inc. This video was launched in SA in September and nationally at the ASSID/NCID conference. It is a consumer driven project aimed at enabling understanding by people with intellectual disabilities of the National Disability Standards. The video was written by consumers for consumers and acted in by consumers for consumers. So while it is essentially for consumers of services, 'Setting the Standards' could also be an extremely valuable teaching resource for use in disability courses. It conveys not only the sense of the people who made it, but also provides some excellent examples of the importance and efficacy of plain English and brings to the fore the issues that concern the consumers themselves.

For more information or to order the video, contact  
Housing Connexion Inc,  
PO Box 55, Edwardstown, 5039  
Phone 08 82773300.

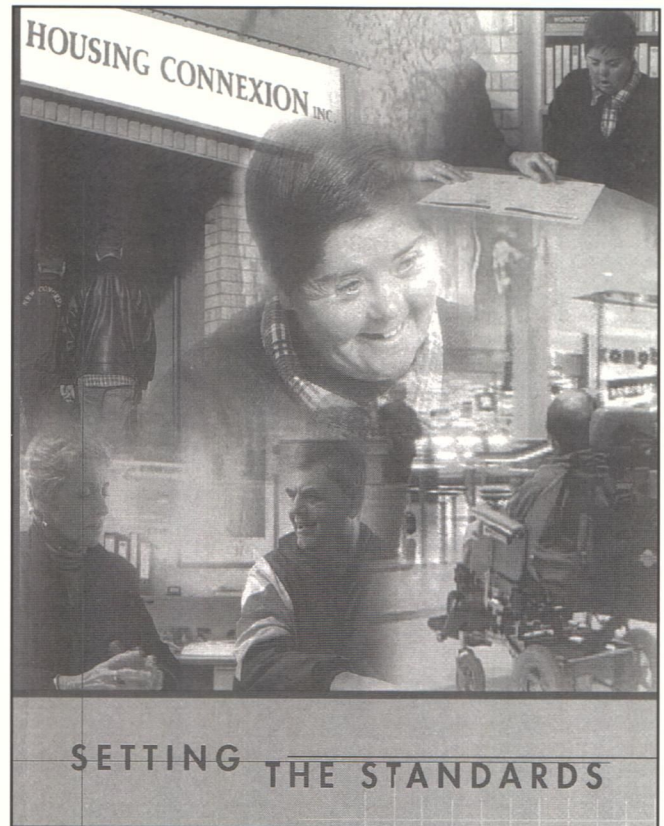
### ANNOUNCING THE OzQOL WEB-PAGE

<http://www.ozqol.org>

This page is a discrete part of the site managed by The Australian Center on Quality of Life <http://acqol.deakin.edu.au>. The site has a separate domain-name access, as you will see from the address. The objective is to enhance and complement the work of the International Society for Quality-Of-Life Studies. Since these sites are maintained by Deakin University, all available information can be scanned or downloaded free of charge. You are welcome to submit additional information or documentation for inclusion at any time.

Your comments are most welcome and should be addressed to **Bob Cummins**,

[cummins@deakin.edu.au](mailto:cummins@deakin.edu.au)



Other examples of resources presented included

- **'Feel Safe'** (already covered in *Intellectual Disability, Australia, Vol 21 #3*).
- **'Keep Cool'**, an aggression prevention and control program (contact Janine Smith via Disability Services Commission in WA).
- Dr Mary Burbidge's **'Personal Health Records'** - a comprehensive patient/carer held health record (contact Mary at the Centre for Developmental Disability Health, Victoria at Monash University).
- **'When Needs Go Begging'**, the detailed report and compilation of family stories produced by the Developmental Disability Council of WA was also launched, with an impassioned speech of support, by Sir Ronald Wilson at the conference. ♦

**Never forget that you are invited  
to contribute to this newsletter.**

Send your news, views, letters,  
reports on best practice to

[penhall@bigpond.net.au](mailto:penhall@bigpond.net.au)

or see page 2 for post & phone details

# Lay Discourses on INTELLECTUAL Disability: A Critical Analysis

An ASSISD/NCID Conference presentation

by Ruth Quibell

## Introduction:

The conference sub-theme '*Building Community*' poses a difficult question. Exactly how can a stronger community support network be developed? Building community is not just a task for people with intellectual disabilities, experts, disability workers, and citizen advocates. It should also involve the broader community. In particular, it should involve those 'lay' people who have no professional involvement, and limited everyday contact, with people categorised as having intellectual disabilities.

## The Context of Community Education

At present, most social science research indicates that lay people's perceptions of disability and disabled people are negative and discriminatory, and are based on myths, fears, misinformation, and misunderstandings (Oliver, 1990: 1-20; Miles, 1981: 90-116; Goffman, 1963: 1-40; Harris, 1995: 166; Murphy, 1995; Fulcher, 1989; Seymour, 1998). Others go further to contend that 'intellectual disability' is predominately understood in terms of 'lack' within our culture (Fullagar and Owler, 1998). Popular forms of cultural representation are also seen to combine with negative attitudes to result in the exclusion of people with disabilities (Clear, 1999: 6). In short, then, 'lay' people's views appear to present a serious obstacle to building a supportive community.

There have been several large-scale, government-funded public awareness campaigns aimed at changing lay people's attitudes to disability. These include television commercials with 'positive out-take messages' (Community Awareness Campaign, Commonwealth Department of Health and Aged Care, 1998: 3) and publications that offer general principles for speaking and writing about people with disabilities (such as 'A Way With Words' by Queensland's Department of Families, Youth and Community Care, 1999). However, while superficial 'expressed' attitudes may change as a result of such strategies, evidence suggests that a discrepancy between 'newly-acquired' positive attitudes and their everyday (or 'deeper') behaviour may still exist (Small and Associates, 1998: 104). How, then, should we approach this problem? Rather than attempting to simply change the complex attitudes of people we know little about, we must further investigate how and what lay people know as 'intellectual disability'.

## Methodology

I conducted in-depth, semi-structured interviews with thirty young adults aged between 18 and 30 years of age.

There are several reasons for interviewing people of this age cohort. They have lived through a number of legislative and policy changes that make them likely to have attended a mainstream school with disabled students, to have worked and, perhaps, lived with people with disabilities. Voluntary participants, whose professional and everyday contact with disability was minimal, were recruited.

The interview process yielded varied, yet detailed, discussions of disability issues.

## Individualising Intellectual Disability

Most participants commenced their discussions by conceptualising 'intellectual disability' as in the individual. Four discourses were underpinned by this basic view.

### Individualist-Materialist Discourse – 'Functional Limitation'

This discourse constructs disability purely in terms of functional limitation. Participants emphasised loss, damage, restrictions, and functional limitations.

*It probably means that they've had some sort of ... disorder which means that they can't process information at the same ... speed, or in the same manner, or [they do it] in a different manner, I suppose. Which means that perhaps they might move a bit slower, or speak slower, or react differently. (Greg, aged 22.)*

*Intellectual disability, to me, means that your brain... does not function normally. There is some kind of impairment. [I d]on't know where or why, but you might be slower... [It] generally means to me that there is some kind of damage to the brain, and that impairs their mentality. (Phillip, aged 25.)*

*Um, probably someone like you and me but has the mentality of a two-year-old. And slowly learns, but never reaches the point where we've learnt. They process things differently in their heads. (Helena, aged 20.)*

*It means that they can't learn the way we do about things. Um [pause], they probably can't think the way we do... (Alexandra, aged 24.)*

### Individualist-Idealist – 'Special Abilities'

Secondly, and in stark contrast to the previous view, is the individualist-idealist discourse where 'intellectual disability' is viewed as something that could be transcended by either 'hard work' or by other 'special abilities'. This plays down the social and functional consequences that may stem from having an intellectual disability:

*I mean, for example, with 'Graham'...his brain does not function technically normally. He did have problems in certain areas, but in different areas he made up for it. So, um, yeah, um, I'd sort of say to him that it's like having a clumsy leg, you've just got to drag it, or it's not as coordinated as your*

right leg. But you've got to deal with it and learn to live with it. (Phillip, aged 25.)

Um, people like 'John' who is in a motorised wheelchair, he's disabled in a lot of ways because he can't get to things he wants to. So he can't get up stairs, he has to travel everywhere in his little car-thing. That would be a real pain, even when it's raining. [...] I'm trying to think [pause]. The disabled people are largely effected, but they've all got different gifts, and that's what I like about them. Like they can be really 'bubbly' and 'happy'. (Helena, aged 21.)

### Positivist-Medical Discourse – Discovering disability

Here intellectually disabled people are viewed as objects rather than subjects. In particular, there is an obsession with explaining the biological cause of intellectual disability, at the expense of failing to view the common humanity of people with intellectual disabilities:

*Intellectual disability is a mutated gene in the body's makeup which causes people to have less brain capacity, similar characteristics in the face... [I]t's the same gene throughout the body that makes the person look different, act different, talk different, walk different. (Daryl, aged 22.)*

'Intellectual disability' becomes knowable via the language and concept of causality found in scientific explanations. Similarly, diagnostic tools, such as IQ tests, were seen by participants as objective measures to the accurately diagnose the presence of intellectual disability:

*I'm thinking of intellectual disabilities in that they might'en be able to do certain tests, or have only got a low level of intelligence, which is the same as, same thing as having low IQs. (Jessica, aged 24.)*

*I guess if you did an IQ test on them they would be very low. (Amanda, aged 20.)*

### Frankenstein-Apprehension Discourse: 'Us' and 'Them'

It is only the Frankenstein-apprehension discourse that closely corresponds to the overtly negative ways in which lay discourse is usually characterised (Fulcher 1989: 29-30). Overall, this discourse was based on a fundamental dualism between non-disabled people and intellectually disabled people, with the latter being viewed as unpredictable, difficult to know, or unknowable (Johnson 1998: 29). For example, Helena (aged 21) explained how, as a child, she could not make sense of her relative's behaviour:

*I: Do you know anyone who has an intellectual disability?*

*H: I used to when I was younger. She had Down[s] syndrome.*

*I: And how did you come to know her?*

*H: Through family, she was the youngest. She was, you know, it's hard because she was so much younger than me. I didn't really look at her. Like if I saw her now I'd be able to describe her a lot better. I didn't really take that much notice of her than because she made a lot of noise. And I didn't know how to react or be around her, because she didn't know how to act around people. She way just always noisy. (Helena, aged 21.)*

In this instance, the 'enigmatic', inexplicable nature of the disabled relative led to less contact, and thus less understanding in the future.

Similarly, Debbie found it difficult to relate to intellectually-disabled people as people:

*I know, even for me, it's actually really funny because my mum works with people who have both physical and intellectual disabilities, and I'm actually, I know, and as politically correct as I can try and be, I personally know that it is awkward for me to interact with these people. It's kind of like, 'What do you say?' A lot of them can't talk anyway. You know and it's funny, and I would say, on the one hand, you would assume that it's people with a higher level of education that can accept these people better. And someone like my mum, who has a basic year 9 education, who is not academically very trained, can accept these people quite readily. Quite easily and quite willingly. (Debbie, 24 years old, Social Worker.)*

Indeed, feelings of anxiety and apprehension enframed many participants' accounts, such as the following:

*[I]f you are in a public place... and there's a seat next to a person with an obvious, say Down Syndrome or, you know, a person who is mentally ill, or something. And there's a seat next to a guy in a suit. They [the non-disabled person] will probably choose the seat next to the guy in the suit, because there's, I think, people probably, especially mentally ill people, they probably view them as unpredictable. And, um, people aren't sure whether they are going to start talking to them. I mean, you wouldn't expect a normal person to do that. Maybe people sort of worry that they'll be put in this position where they have to talk to them, and they'll sort of be in a situation they don't know quite how to handle. (Alexandra, aged 24.)*

This assumption of unpredictability led to feelings of anxiety, these feelings led to less contact, resulting in more social distance and avoidance, resulting in more fear, and so on. Furthermore, the 'us' and 'them' dualism was reinforced by the use of popular slang terms to refer to people with intellectual disabilities.

### Intellectual Disability as a Social Problem

#### Collectivist/Community-Welfare Discourse

This discourse is characterised by an emphasis on civic responsibility and concerns about the welfare of people with disabilities. Those constituting the community-welfare discourse maintained that people with intellectual disabilities do have important differences, but that these differences only become meaningful within a given social context:

*You could see that they will never reach what society expects of people, and how their life might be different. And how social pressures are going to make it hard for them. Not so much the fact that it's different, but what people make of that. (Genevieve, aged 23.)*

Genevieve stresses the powerful roles that 'social context' and non-disabled people occupy in giving meaning to intellectual disability. This discourse, however, is a far cry

*continued page 16*

from disability consumer, activist, and social model discourses which emphasise concepts of empowerment, rights, discrimination, and 'wants' as opposed to 'needs' (Oliver, 1990: 9; Hazelton, 1993: 151-152; Fulcher, 1989: 30-31).

### **Intellectual Disability as Invisible**

The final set of discourses render 'intellectual disability' invisible or concealed, by normalising, homogenising, or minimising intellectual disability.

#### **Relativist Discourses – 'Perfectly normal to me'**

People with intellectual disabilities were effectively homogenised as having just another 'variation', 'difference' or 'different life challenges':

*I'd have to say with a case like Down's syndrome in most cases I think they're born like that. It may be a hereditary thing. And than again, maybe I'd just say that these people are not ... evil, they're not freaks, or anything. They're only different from us... You know, maybe needing a little more help with things. (Frank, aged 22.)*

Relativistic-normalising discourse appears to share much in common with practices of 'normalisation', or positive 'labeling' (as popularised by Wolfensberger, 1975). Some participants even resisted labeling people whom they knew as 'intellectually disabled', such as children with Down's Syndrome, despite acknowledging the difficulties they may experience. Whilst relativist discourses potentially create the space and understanding for an inclusive community, they are also problematic. They accept the status quo by failing to acknowledge the unintended and conservative nature of the practices that they promote. They foster the expectation that people with intellectual disabilities will 'pass' as non-disabled (Goffman 1963: 73-91). This prevents lay people from creating new understandings of 'intellectual disability', 'difference' and life experiences that vary from one's own.

#### **Politically Correct Discourse – 'I can't say that'**

The politically correct discourse is the most complex identified in the data. Rather than it being identified by what participants said, it was what they left out that alerted me to its presence. Whilst only one participant openly

acknowledged that he was worried about coming "across as discriminatory" (Greg, aged 22), many participants spent considerable time searching for the 'right' word or phrase, and were anxious when they could not recall it.

It could be argued that the politically correct discourse demonstrates the success of community education strategies in changing lay attitudes, we also need to consider whether participants may have drawn on this discourse tactically (Fulcher 1989: 4; Macdonnell 1986), in order to conceal their real views – discriminatory or otherwise – or simply to conceal their ignorance. Certainly, this seems to indicate the potentially obscuring, and hence problematic, nature of politically correct discourse.

### **What is at stake?**

This analysis and identification of varied lay discourses on intellectual disability reveals a number of important points for self-advocates, community educators, disability workers, and so forth. Firstly, and in contrast to the generalised theoretical assumptions which are often made about lay attitudes towards disability, this study reveals that lay people's discourses about intellectual disability are not uniform. Furthermore, their views are not completely based on negative fears, myths, misinformation, and ignorance.

Despite their diversity, however, lay discourses remain problematic, posing and fostering problematic partial and fragmented understandings of intellectual disability. We now know that public awareness campaigns have not offered lay people sufficient tools to break through the fear and anxiety cycle that is reinforced each time they avoid a person with an intellectual disability. We now know that individualist-materialist and positivist-medical discourses, which view intellectual disability as in the person, result in an emphasis on lack and functional limitation. The identification of these discourses can potentially facilitate the development of specific strategies that target the limitations of a given discourse and rework, counter, or reverse it (Weedon 1987: 109).

It is the concealing discourses that render intellectual disability invisible which appear to me the most harmful of all the lay discourses identified. These appear to be a direct outgrowth of, or reaction to, normalisation practices concerning people with intellectual disability in recent years. These politically correct and relativist discourses appeared to be a vocabulary that was self-consciously drawn on by participants in order to obscure or hide other their everyday ways of speaking, rather than actually changing them. Whilst the presence of these discourses may be taken by some as indicative of positive social change, they appear only to have ensured that "disabled people pass the threshold to invisibility" (Mitchell, 1999: xiii).

For more information about ASSID or for membership forms to give to your friends and colleagues, contact Wendy in the secretariat on  
Phone: 1800 644 741  
Fax: (02) 4921 7151  
Email: [scwbg@alinga.newcastle.edu.au](mailto:scwbg@alinga.newcastle.edu.au)

## NEW SERVICE FOR ASSID MEMBERS?

ASSID has always offered its members a forum for the exchange of information and ideas. The conference is a major vehicle for this, and in recent times the email list ASSID-L has enabled people to discuss as well as send each other references and notes. In short, one of the major functions of ASSID has been to enable its members to access information on the best research and practice available in the field of intellectual disability.

The Publications Committee of ASSID is presently discussing whether this function could be expanded or enhanced for the membership. We have been 'batting around' ideas about whether members might benefit from the opportunity for an experienced researcher to conduct web searches and/or some level of library search. Now is your chance to tell us what would be of use to you. PLEASE find the time to answer the following simple questions. (We know that it is not necessarily a good idea to pull out part of your magazine - so please photocopy; the questions will also be posted on ASSID-L for you to reply to).

1. If you were offered one free web search - annually, with your membership - on a topic of your choice by an experienced researcher, how likely would you be to take up this offer?

Very likely                       Perhaps                       Not very likely.

2. If you were offered additional web searches at a small fee (eg \$30) how likely would you be to take up this offer?

Very likely                       Perhaps                       Not very likely.

3. If you were offered more detailed library and web searches at a fee how likely would you be to take up this offer?

Very likely                       Perhaps                       Not very likely.

4. Would you mind nominating two or three interest areas that you might like to have more information on:

1. .... 2. ....  
3. ....

5. Do you know other people you think would like to have such a search service made available to them?

Yes                       No

Please post responses to The Editor, *Intellectual Disability Australia*,  
28 White St, Lilyfield, 2040, or fax to 02 9571 8669, or fill in the form on ASSID-L.

### Acknowledgements

I would like to thank Damon A. Young for his comments on this paper, and Ann Penhallurick for her editing finesse.

### Major References

**Fulcher, G.** (1989), *Disabling Policies?* London: The Falmer Press.

**Johnson, K.** (1998), *Deinstitutionalising Women*,

Cambridge: Cambridge University Press.

**Oliver, M.** (1990), *The Politics of Disablement*, London: MacMillan.

**For more information contact Ruth via:  
Rquibell@swin.edu.au**

**Detailed references published on ASSID-L the  
same week as publication of IDA.** ◆

## Must Read: Book Review



### **Moving On Without Parents: Planning: transitions and sources of support for middle-aged and older adults with intellectual disability.**

**Christine Bigby**, *MacLennan and Petty, Sydney, 2000*

In his foreword to Bigby's well researched, *Moving on Without Parents*, Matthew Janicki claims the book to be 'unique'. Claims to unique-ness abound today but, in the case of this particular work, seem to be well-founded. Janicki defines the unique qualities of Bigby's work as 'so rich in detail and drawn from actual experience, (the book) goes far to help us better understand the life histories, circumstances, and challenges of men and women with lifelong disability as they age' (pvii, *Moving On Without Parents*). It is this integration of research detail – sourced from many years of her own and others' work – combined with 'real life' stories of people who have faced the aging process which make the book more than an extremely useful resource for researchers, advocates and practitioners in the field. *Moving On Without Parents* shows the human face of aging in what is largely a poorly prepared world.

*Moving On Without Parents* is divided into three sections: 'The context', 'The nature and success of parental planning' and the third 'Sources of support in later life for people with intellectual disabilities'. In 'The context' the reader is brought up to date on studies (most relatively recent, most UK or US based) around aging in the often hidden population of older adults with intellectual disability. Connections to formal and informal supports systems, caregiving relationships of older parental carers, the diversity and size of the population as well as physiological and psychological aspects of aging are just some of the topics covered in the four chapters of this first section. The chapters themselves are well organised, allowing for readers who have precise needs to easily find where to go as well as facilitating a 'good read' from beginning to end. Each chapter is divided into major headings and sub-headings with a very helpful summary at the end of the chapter. At the presentation level, the text is well set out, with readable headings and well spaced lines, so that the information is never overwhelming and it is easy to come back to a section, to check or re-read or confirm.

The second and third sections are similarly organised as the first. The second section, 'The nature and success of parental planning', contains many more references to and quotes from what people with disability or their caregivers have had to say. This section is essentially the results of Bigby's study and analyses the processes of transition from parental support and the life changes thereafter - and it makes fine reading. Difficult topics such as 'late life development' – people with disability can be shown to learn far longer than is generally assumed, Bigby argues, and many go on to learn and enjoy and lot more after they live the family home – are taken on. As one of the participants in Bigby's study, Bronwyn, succinctly puts it 'She wouldn't let me go out. She didn't think I was as old as I am. She wouldn't let me be friends with anybody. She wouldn't even let me talk to anybody' (p115). This second section lets the reader know that there can be positive changes with aging, as well as providing a wealth of useful detail on the difficulties and struggles involved for people with disability, their parents, siblings and caregivers.

The third and final section takes the reader beyond the often tight circle of family support and considers the informal support networks introduced in 'The context'. Again Bibgy relies on what people with disability have themselves had to say and again she faces some of the harder questions and issues, such as the lack of flexibility in many (usually formal ) support services and the vulnerability of the informal support networks to loss and to change. The strength of this section is in a gathering of information and an analysis which enables identification of the 'potential for support, gaps that need to be bridged and maintenance action that may be required to ensure support continues' (p125). Thus this final section takes the reader into the future.

*Moving On Without Parents* also contains an impressive bibliography section which would be helpful for anyone wanting to read further. In all is a comprehensive and readable book, providing an extraordinary wealth of detail in a volume that is a comfortable 252 pages long (including the index). The book is well organised, written in clear language and is notable for the importance it places on the real voices of the real people it seeks to 'serve'.

*Moving On Without Parents* is published by  
**MacLennan and Petty** and is available from them  
through mail order – write to:

Suite 405, 152 Bunnerong Rd,  
Eastgardens, 2036.

# Letter to the Editor

Dear Ed.,

I must comment upon Chris Bigby's concerns about the recent IASSID Congress held in Seattle.

As one who has been active in the last three Congress Program Committees, and Chair of one, I am in a reasonable position to comment upon how keynote speakers are selected. The practice has been to invite suggestions from a wide variety of sources. The criteria are that persons nominated should be eminent in their field; with disciplines, gender, and countries of origin being as balanced as far as possible. Selected speakers are asked to give a tutorial type presentation that provides an overview of the state of research in their field. While not all speakers follow this suggestion, we have had reasonable success in attracting speakers who have been able to present their work in a manner that can be comprehended by a diverse audience.

Chris also expressed her disappointment concerning the "excessive bias towards medical research" in the keynote addresses. I would maintain that there was an extremely balanced set of topics, delivered by people eminent in their field, representing the integration of the biopsychosocial elements of the disciplines that inform our work.

A quadrennial congress is a good opportunity for various approaches to be debated in a scholarly manner, so that the field may advance to new levels of understanding. We may not necessarily agree with the views of all presenters. The bottom line, nevertheless, is to what extent are their views backed by good research evidence.

How their findings are applied is obviously open to debate; a good example being the advances being made in the area of the human genome. We would be derelict in our responsibility of these, and similar scientific discoveries, were left to molecular biologists alone to debate how the discoveries should be applied. The same could be said of people who take an exclusively social construct view of disability.

Censorship of views, however, would be a retreat to an age when discoveries you did not agree with, were suppressed. In the case of the Seattle Congress, I believe the program was balanced, and great credit must be given to the Program Chair, Neil Ross, who had the task of organising over 1300 presentations into a coherent program involving up to nineteen parallel sessions.

**Trevor R Parmenter, PhD**  
Immediate Past President ◆

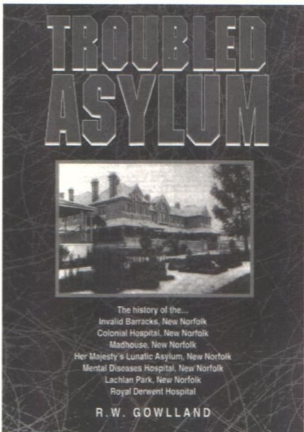
## Chris Bigby has exercised her right of reply –

Reply to (Prof.) Trevor Parmenter

Firstly, my comments about the reasons why the key note speakers were selected were not intended as a slight on their credentials or the abilities of those choosing them but rather the failure of the conference program to provide any information about these speakers. Unlike usual programs the backgrounds of the key note speakers were not included and indeed the abstracts of their addresses were not differentiated from the hundreds of other abstracts.

Secondly, my comments do not in any way advocate censorship of any views and curtailment of debate. However, I think all speakers from whatever discipline must adhere to the basic principles that underpin current approaches to disability, one of the most fundamental of which is respect for the dignity of people disabilities. In that respect I consider that referring to "my favourite syndrome" is offensive to people with disabilities.

(Dr) Christine Bigby ◆



To commemorate the closure of The Willow Court Centre in Nov 2000 ASSID TAS INC is offering a reprint of:

### TROUBLED ASYLUM

*A reflective view of institutions for people with intellectual and psychiatric disabilities up until the 1960's.*

This book is a purely historical account of care at the complex know as Royal Derwent Hospital and Willow Court Centre.

You are invited to travel through time with Ralph Gowlland as he examines the dynamics of the service, the buildings and the lives of people who have resided at the complex over a period of 141 years.

Post your cheque for \$30 (incl. GST) made payable to "ASSID TAS INC." to:  
"Book Offer"  
PO Box 572, MOONAH, TAS. 7009

SEND YOUR LETTERS TO THE EDITOR AT  
[penhall@bigpond.net.au](mailto:penhall@bigpond.net.au)  
or Fax to (02) 9571 8669  
or send to 28 White St. Lilyfield NSW 2040

# Upcoming Events . . .

**22-28 April 2001**

**First International Conference of the Specific Learning Difficulties Association (SA) Inc. Dyslexia - What's New?**

Adelaide. Contact: SPELD (SA) Inc. PO Box 83 Glenside SA 5065

Phone: 08 8431 1635

Fax: 08 8364 5751

Email: [info@speld-sa.org.au](mailto:info@speld-sa.org.au)

Website: [www.speld.sa.org.au](http://www.speld.sa.org.au)

**20-23 May 2001**

**Speech Pathology Australia National Conference**

Melbourne. Contact: Gina McInnis

Phone: 03 9642 4899, Fax: 03 9642 4922

Email: [gmcinnis@speechpathologyaustralia.org.au](mailto:gmcinnis@speechpathologyaustralia.org.au)

Website: [www.speechpathologyaustralia.org.au](http://www.speechpathologyaustralia.org.au)

**25-27 May 2001**

**Australian Group on Severe Communication Impairment (AGOSCI) National Conference: 2001 A Communication Odyssey**

Adelaide. Contact: Helen Currie

Email: [helen.currie@cca.org.au](mailto:helen.currie@cca.org.au)

Phone: 08 8243 8261

**29 August - 1 September 2001**

**International Rural and Remote Allied Health Professionals Conference**

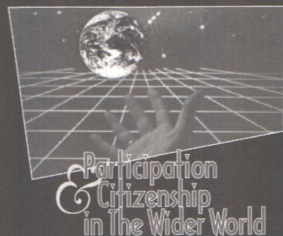
Cairns. Contact: The National Rural Health Alliance

PO Box 280, Deakin West ACT 2600

Phone: 02 6285 4660, Fax: 02 6285 4670

Email: [conference@ruralhealth.org.au](mailto:conference@ruralhealth.org.au)

Website: [www.ruralhealth.org.au](http://www.ruralhealth.org.au)



**36th Annual Conference**  
of the  
**Australian Society for the  
Study of Intellectual Disability**

Copland Theatre,  
University of Melbourne  
**November 12th-15th, 2001**

Further information:  
Telephone: (03) 9925 7363  
Fax: (03) 9925 7303  
Email: [karen.nankervis@rmit.edu.au](mailto:karen.nankervis@rmit.edu.au)  
Website: <http://www.rmit.edu.au/departments/ps/assid/>

**Third International  
Respite Care  
Conference**

**Sydney  
11-14th September**

Conference Theme

**"Global challenges,  
Local Solutions"**

Hosted by  
**Interchange NSW**

For those interested in  
presenting a paper or wishing  
to receive further information  
please contact:

**Interchange NSW**  
02 9789 1348  
[interchangensw@one.net.au](mailto:interchangensw@one.net.au)