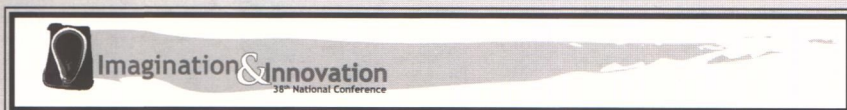


# INTELLECTUAL DISABILITY *Australasia*

## Images: 38th National Conference Brisbane 2003



### *Inside:*

*Interview: Dr Helen Beange OA*

*"It's Time" to change our name*

*Region Reports*

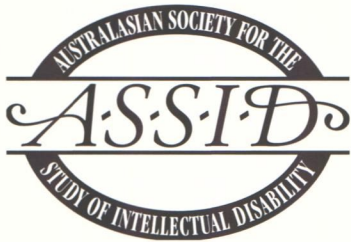
*Mental Health in Adult Developmental Disability: Education & Training Kit*

*Book Review*

*More information on upcoming conferences*

*ASSID Council and Executive List*

*...and more*



Intellectual Disability Australasia is produced and distributed by the Australasian Society for the Study of Intellectual Disability. The views expressed in this newsletter are not necessarily those of the Australasian Society for the Study of Intellectual Disability.

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# Editorial

As the new editor, I am pleased to be bringing you this edition of IDA. Our thanks go to Sue Peden and the Western Australia Regional ASSID Council for volunteering to produce the last bumper edition of IDA during the editorial transition period. A special thanks also to Ross and Karen who work as IDA editorial assistant and designer respectively. They have experienced a number of different editors for the past few editions, from different locations around Australia, and have carried out their roles with great expertise. As incoming editor, I have found Ross and Karen to be most helpful, supportive, and willing to share their knowledge and experience. My thanks also go to the ASSID Board members who have assisted in many ways to help me settle into the new role.



**Deb Keen, Editor**

I wanted to briefly introduce myself to you and mention some ideas I have for IDA over the next three years. I grew up in Melbourne and graduated from Monash University with 4 years of psychology. My first job was as a psychologist at Kew Cottages in 1978. At that time, approximately 900 people with an intellectual disability lived at Kew Cottages. My experiences at Kew were formative. The lives of many who lived there were often harsh, with little to no privacy, and a routine that lacked choice and occupation. The memory of the conditions under which these children and adults lived have often served as a motivation for me in my work. I have continued to work with individuals with intellectual disabilities in a variety of government and non-government agencies, while also undertaking further study. In particular, I have been interested in ways of better supporting individuals with challenging behaviour and those with autism. I am currently employed as a lecturer in the School of Education at the University of Queensland. As part of the new IDA editorial team, I will endeavour to maintain the high standard set by our predecessors. The magazine will continue to encourage contributions from its readers and provide news and information about ASSID activities. Some ideas that we will be exploring for IDA over the next 12 months include:

- the production of an on-line version of IDA for members and subscribers
- the inclusion of summaries of some of the articles published in the ASSID Journal of Intellectual & Developmental Disability (JIDD), and
- a policy watch that provides updates on government policy and legislation affecting people with an intellectual disability.

In this edition, we recognize the contribution of significant people and events that have helped to expand our knowledge and understanding of intellectual disability. We acknowledge the achievements of Dr Helen Beange in the area of health and intellectual disability. Dr Beange's work has been *continued page 3*

Never forget that you are  
**invited to  
 contribute!**

Send your news, views, letters,  
 reports on best practice to  
**[deb.keen@uq.edu.au](mailto:deb.keen@uq.edu.au)**

# An Australia Day Honour for Service and Commitment to People with Intellectual Disability

## An Interview with Dr Helen Beange OA

In this year's Australia Day Honours List, one of ASSID's long-standing and esteemed members, Dr Helen Patricia BEANGE of Turramurra (NSW), was honoured with Membership of the General Division of the Order of Australia. The citation accompanying Dr Beange's honour recognises her for "service to medicine, particularly in relation to the health needs of people with intellectual disabilities, and through clinical practice, advocacy, research and teaching".

Dr Beange is currently the Director of the Developmental Disability Clinic at the University of Sydney's Centre for Developmental Disability Studies (CDDS). In addition to her clinical work she is involved in training other medical practitioners in the field of developmental disability medicine. Dr Beange also takes an active role in CDDS's research programme, and collaborates with other researchers across Australia and overseas. She is much respected internationally as a practitioner and researcher in the field of intellectual disability, and was the foundation co-convenor of the Health Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disability (IASSID). Notably, Dr Beange was the principle author of the IASSID Health Targets for People with an Intellectual Disability.

IDA contacted Dr Beange to find out how she felt about receiving the Order of Australia award.

*Congratulations on your award of an AM in this year's Australia Day Honours. What was your reaction on receiving*

*the award and what does it mean to you?*

"I was shocked first, then thrilled and let out a sort of whoop, which was awkward as I was in a meeting and the letter asked that the news not be revealed until published on Australia

Day. When the shock subsided I wondered who had nominated me for the award, and felt extremely grateful to them. The feeling I had was of increased confidence

in myself: I always knew the work we were doing to improve health in people with intellectual disability (ID) was important, but not that what I personally did was significant. What it means to me is that society is beginning to recognize that doctors have a role to play in our field, and that Developmental Disability Medicine exists as a specialty.

*Your award is "for service to medicine, particularly in relation to the health needs of people with intellectual disabilities, and through clinical practice, advocacy, research and teaching". Clearly there have been many changes that have occurred for people with an intellectual disability during your career. For example, children are more likely to remain within the family home than to live in an institutional setting. How do you feel these changes have affected the health of people with an intellectual disability?*

*continued page 4*



Dr Helen Beange and patient



## Editorial (continued)

formally recognised through the award of AM in this year's Australia Day Honours. We also pay tribute to the contributions made by Phil Forman, Bill Taylor, and Karen Nankervis to ASSID and to the lives of people with intellectual disabilities. Phil, Bill, and Karen are the recipients of 2003 Distinguished Service Citations.

A report on the 2003 National Conference held in Brisbane in November provides an opportunity to appreciate the breadth and depth of expertise and experience that we have in Australia and the exciting work being done to further our understanding of intellectual disability. An edited version of the Conference opening speech delivered by Ian

Boardman illustrates the calibre of speakers at the conference. Information about the national conference for 2004 to be held in Adelaide is also included and we look forward to this event with great anticipation.

While honouring our past, an article by Ian Dempsey asks us to contemplate our vision for people with an intellectual disability and to consider a name change for our organisation. The ideas expressed by Ian may stimulate some of you to respond by writing to the editor of IDA!

**Deb Keen**  
IDA Editor

The changes have probably been beneficial overall to health but we have no means of knowing. Mortality rates have improved for people with ID but also for the general community. Certainly overcrowding in institutions was associated with epidemics of infectious disease and these are now rare. It worries me that people living in the community have become less visible and may be at risk of neglect unless supervised well. An overreaction to the "Medical Model" led to the loss of many good nurses, for instance, and it is not easy for carers to take on this role without some training in medical disorders.

*What do you see as the major health challenges that lie ahead for people with an intellectual disability? Can you comment on how you feel these challenges could be addressed?*

"The major health challenges are the invisible quiet things that creep up on people and kill them or completely disable them. Whereas challenging behaviour gets attention immediately and attracts experts such as psychologists, behaviourists, and psychiatrists (and administrators), we often overlook loss of weight, swallowing disorders, frequent falls and fractures, and chronic pain suffered without complaint. I will cheer when I hear that staff worry more about quiet withdrawn people than noisy challengers.

"The obvious thing staring us in the face is to reduce mortality and morbidity. I am amazed that scientists scrutinize people with ID so carefully about their genetics, & behaviour, and worry about where they should live, without noticing that the subjects of their research have a tendency to get very sick and die wherever they live and under whatever currently fashionable program.

"Minority health engages interest whether it is the indigenous population of Australia or people living with HIV. There is no objection when it is suggested that such groups should have enhanced access to health resources. For reasons I cannot understand the poorest and most vulnerable group in our society at present has no such access, and it is time it did. We need more nurses assisting the staff of group homes, improved primary health care and specialist clinics to assist general practitioners in delivering primary health care. Hospital admissions should be monitored and assistance given to patients who are unable to express their needs. Finally deaths should be notified to a public authority and efforts be made to identify preventable deaths. People with intellectual disability have the same right to life and health care as we all do. Professional advocates can help self advocates to achieve these rights.

For those who might be interested, there follows a bibliography of some of Dr Beange's more recent publications.



Dr Helen Beange OA

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# 39th ASSID Annual Conference

Adelaide, 9-12 November, 2004

## Visions and Realities

The 39th Australasian Society for the Study of Intellectual Disability Inc Conference: Visions and Realities is to be held at the Adelaide Hilton, South Australia in 2004.

**Visions and Realities - The way things are and the way things should be.**

**Empowering people with intellectual disability and supporting their families in the 21st century.**

The SA branch of ASSID has secured a range of keynote and plenary speakers, have convened the Programme Committee and are currently working on ways to ensure that people with intellectual disability and their families

have the opportunity to contribute and fully participate in this year's conference.

Publicity and adequate sponsorship are the other significant challenges they are currently working through.

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[www.plevin.com.au/assid2004](http://www.plevin.com.au/assid2004)

**39<sup>th</sup> Australasian Society for the Study of Intellectual Disability Conference**  
9-12 November, 2004

**Visions and Realities** ✱

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***Please keep your ASSID contact details up to date***

with your State Councils at the main ASSID database.

**Phone: 1800 644 741 PO Box 3241, PUTNEY, 2112, NSW**

# "It's Time", To Change Our Name

by Ian Dempsey

Centre for Special Education and Disability Studies

University of Newcastle

ian.dempsey@newcastle.edu.au

I recently read an article in the December 2003 issue of *Access*, the regular newsletter published by the Australian Institute of Health and Welfare (AIHW). The article profiled Dr. D'Arcy Wood, a long-standing member of AIHW's ethics committee. Among other things, Dr. Wood discussed the universality of ethical principles and the extent to which there are cultural differences in these principles. In addition, he argued, and I agree with him, that if the Universal Declaration of Human Rights were written today it would probably be a very different document to the one that was framed 50 years ago.

What does this have to do with the name of our Association? Well, the relationship between the two issues extends to the arguable assertion that if our Association happened to be established today then its name would be different to its current name. This suggests that there may be something wrong with the present name of our Association, which there is. From my perspective there are at least two problems with the nomenclature of the Australian Society for the Study of Intellectual Disability (ASSID). I'll describe each of these problems and suggest some alternatives.

## 1. Our name reflects our history, and not our vision for the future.

Until the mid 1980s, the Association was known as the Australian Group for the Scientific Study of Mental Deficiency (AGSOMD). The group was formed in 1964. The name reflected the dominant professional thinking of the 1960s and 1970s about the best way to assist people with intellectual disability and the popular terminology of the time. However, for nearly 20 years the Association has been known as ASSID, which continues to convey the notion that our professional organisation is primarily about "studying" intellectual disability.

The Macquarie Dictionary defines "study" variously as, "putting of the mind to gaining knowledge ... deep thought... , and, ... to examine carefully and in detail". So, to what extent does our Society continue to "study" intellectual disability? To my mind, this is not what the Association is primarily about, and a useful way to demonstrate this is to reflect on the issues that are covered in ASSID's journal, the *Journal of Intellectual and Developmental Disability (JIDD)*.

Phil Foreman (1998), the then editor of *JIDD*, completed a content analysis of the Association's journals (the *Australian Journal of Mental Retardation* was first published in 1970), and came to the following conclusions:

- There had been a strong move away from hospitals and training centres to universities in the professional affiliations of Journal authors.
- The most marked changes in content were significant increases in quality of life and community support issues, and significant decreases in medically oriented papers.

I don't believe that these changes have diminished in the six years since Foreman's analysis. In addition, these changes are also reflected in the content of papers presented at ASSID's annual conferences. In short, our Association is primarily about supporting people with a disability in a wide variety of community and diminishing institutional settings.

## 2. Our name sends an unfortunate message to people with intellectual disability, and to their advocates.

I'm afraid that two negative images come to mind when I consider the name of our Association. First, I'm reminded of the "stuffy" and elitist colleges of professionals that flourished during the 19th and early 20th centuries that reflected a desire to understand and to tame the natural environment. Second, our name creates an impression of controlling and dominating a group of members of our society that we wish to enable.

Criticism of the status quo is easy; providing constructive alternatives is harder. While it's difficult to speculate on where the terminology in this area may head, it must be said that the principle of "people first", and the term "intellectual disability", continue to be supported in Australia. Consequently, I offer the following suggestions as a vehicle for further discussion of the issue in this and in other forums.

A minimalist alternative – change the word "study" to "support". Thus, our group would become the Australian Society for the Support of People with Intellectual Disability. Advantages are we get to keep an acronym that many of us seem to enjoy. Disadvantages may be that our name confuses our role with that of

*cont. on page 7*

# Mental Health in Adult Developmental Disability: Education & Training Kit for Professionals & Service Providers

Edited by:

**Niki Edwards, Nick Lennox, Geraldine Holt and Nick Bouras (2003)**

This is a unique Australian resource that comprehensively links research, best practice and clinical experience to the needs of adults with a dual diagnosis (co-existing intellectual disability and mental illness). The Kit is a blend of international, national and local Queensland experience, as it draws upon the expertise of its editors and contributors.

The Kit was just launched by the Queensland Centre for Intellectual and Developmental Disability in conjunction with ASSID, at the last ASSID National conference in Brisbane. The launch was a huge success and much interest was shown by conference attendees.

This Kit is the first of its kind in Australia. "Mental Health in Adult Developmental Disability" aims to improve the mental health needs of adults with an intellectual disability by providing education, training strategies and resources to professionals and service providers who come into contact with this population. The Kit includes a comprehensive set of units that cover a broad range of topics outlining how to work with an adult with a dual diagnosis. The contents are as follows:

**Unit One: Introduction to Intellectual Disability**

- Module 1: Understanding Intellectual Disability
- Module 2: Aetiology of Intellectual and Developmental Disability
- Module 3: Health and Well Being

**Unit Two: Mental Health of Adults with an Intellectual Disability**

- Module 1: Mental Health Problems and Disorders

- Module 2: Promoting Mental Health and Well Being

**Unit Three: Diagnosis of Mental Health Problems in Adults with an Intellectual Disability**

- Module 1: Understanding Assessment of Mental Health
- Module 2: Screening for Mental Health Problems

**Unit Four: Challenging Behaviour**

- Module 1: Assessment of Challenging Behaviour
- Module 2: Intervention and Prevention of Challenging Behaviour

**Unit Five: Therapeutic Interventions**

- Module 1: Non-Pharmacological Treatment and Intervention
- Module 2: Psychopharmacology

**Unit Six: Staff and Organisational Issues**

- Module 1: Staff Stress and Coping Strategies
- Module 2: Service Factors
- Module 3: Legal and Ethical Issues

**Unit Seven: Advanced Clinical Practice**

- Module 1: Ageing and Intellectual Disability
- Module 2: Pervasive Developmental Disorders
- Module 3: Epilepsy

See [www.sph.uq.edu.au/qcidd/](http://www.sph.uq.edu.au/qcidd/) for more information about the Kit, the authors and the Queensland Centre for Intellectual and Developmental Disability. The kit costs only \$550 and can be purchased through QCIDD. All enquiries to (07) 3840 1538 or email [m.moloney@sph.uq.edu.au](mailto:m.moloney@sph.uq.edu.au)

## "It's Time", To Change Our Name

continued from page 6

other peak groups (e.g. National Council on Intellectual Disability), and that it may convey a welfare/dependency mindset.

A more dramatic change – Australian Association for Intellectual Disability. Advantages are its brevity and clarity. Disadvantages are that the name may not convey an understanding of the purpose of the group.

Whether you agree or disagree with the alternatives I've proposed, I'd encourage you to reflect on the name of our

Association. Much has happened in the two decades since it last changed its name. It's now time to change our name to better demonstrate our group's vision for people with intellectual disability in contemporary society.

Reference: Foreman, P. (1998). Publishing about intellectual disability: an analysis of the contents of the Journal of Intellectual and Developmental Disability, and its predecessors. *Journal of Intellectual and Developmental Disability*, 23, 3, 187-198.

# Report on the 38th ASSID Conference, "Imagination and Innovation"

Held in Brisbane November 17th - 20th, 2003

*Steve Bristow, State Vice-President and Australasian Treasurer on behalf of the Conference Program and Organizing Committees.*



The morning of the 17th of November saw the tireless work of the conference organizing and program committees, come to fruition with the birth of the 38th ASSID conference.

The fear of the "what ifs" that had raced through the committee members' minds in the days leading up to the conference were all but forgotten as the conference took on a life of its own, with the exception of a little fine tuning, some tweaking and the management of a few opus! It was now time for the committees to enjoy the fruits of months of work.

The theme for this year's conference had evolved from many hours of creative thinking from within the conference committee and from the need to provide a conference theme that engaged delegates and presenters in the debate of possibilities. The program committee labours brought together a rich tapestry of papers, workshops and keynote speakers. Traditional streams such as "Disability & Ageing" or "Dual Diagnosis" combined with themes of "Policies, Paradigms & Law", "Individuals, Families and Communities", "Services, Supports & Practices", "Health & Wellbeing", "Learning and Personal Development" and "Research". The development of the conference streams was designed to continue the conference theme and provide different and new ways of looking at the concepts and ideas presented. An international flavour was introduced with the inclusion, thanks to the hard work of Dr Jayne Clapton, of an IASSID Special Interest Research Group (SIRG) on Ethics and Intellectual Disability.

## Day one

The first morning of the conference commenced with a traditional welcome to the country conducted by the Turrbal People, the traditional owners and custodians of the conference site. This official welcome shared the journeys of the Turrbal people,

the concept of oppression and empowerment. This concept of oppression was also evident in the opening address given by Mr. Ian Boardman, Public Advocate for Queensland. Ian spoke of the imbalance of power between individuals with an intellectual disability and their support systems. An edited version of Ian's presentation can be found in this edition of IDA.



Post morning tea delegates were entertained by the talented Conbrio music group and then heard from Marcia Rioux speaking on "International Trends in Policy and Research". This presentation provided a global picture and some challenging thoughts in relation to research and the hidden message that I took away from the presentation was the need for policy but the potential for policy to hijack the direction and ultimately the outcomes for individuals with an intellectual disability. To lead into the lunch break, Gary and Roz Cooper provided an inspiring account of Gary's work in helping to raise funds for the Fred Hollows Foundation.

The afternoon session opened with a keynote from Gordon Grant about 'Resilience in Family Care: Perspectives on Ageing and Life Course'. Gordon's method of presenting his paper softly spoken and nearly story telling in style left

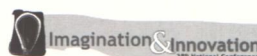
delegates with much to think about as they move into the final afternoon session. Delegates chose to attend one of six streams. I attended 'Policies,



*cont.inued on page 9*

# 38th ASSID Conference Report, "Imagination and Innovation"

continued from page 8



Paradigms and the Law' with papers from Mark Rapley and Jo Ann Sower leaving me to reflect on how I conceptualize the concept of Intellectual Disability and the subsequent support systems needed. With presentations finished for the day the first of many social occasions commenced with invited delegates being hosted at Government House by Her Excellency the Governor Ms Quintet Bryce.

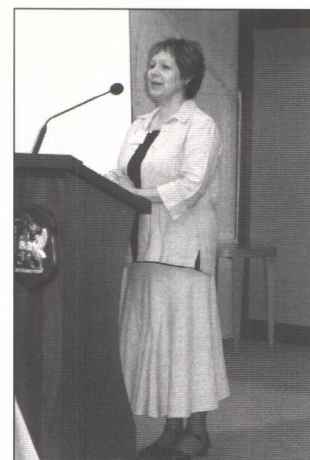
## Day two

Day two began with delegates reflecting on the social functions of the night before or with the challenge of choosing from the concurrent papers on offer that day. Nick Bouras enlightened delegates with his keynote paper that reflected European experiences. The focus of the paper was on models of support for Adults with Dual Diagnosis (Intellectual Disability and Mental Health issues). This paper identified positive approaches that can be taken in supporting individuals and challenged my thinking about the relationship between intellectual disability and mental health issues. Does one necessarily lead to the other or do support models that exhibit power imbalances or oppression contribute to the issues raise? This may not have been the intended message of Nick Bouras' paper and my reflections on the paper may do a disservice to the information presented.

Lunch on day two presented more choices for delegates: Do I dine on the fine food provided by the conference venue, stroll in the magnificent Queensland environment on South-Bank or attend the launch of the "Dual Diagnosis Kit or the launch of an art exhibition by artist with a disability from Cascade Place. After lunch on day two delegates were again inspired via Geraldine Holt's keynote examining autism and related disorders. Having set the bar for the afternoon sessions delegates moved from Geraldine's keynote to one of the six streams on offer.

The evening of day two, brought on the official "Welcome reception" This reception was hosted by the Queensland Government in the parliamentary Annex directly across the river from the conference center. Mr. Frank Rocket Director General for Disability Services Queensland officially hosted the reception on behalf of the Queensland Government.

This reception struggled to maintain the balance between officialdom and meeting the delegate's social needs. The reception began with an enthusiastic welcome from the Director General Frank Rocket. Then came the moment many members on both sides of the Tasman had been working hard to achieve. Sue Peden, National President of ASSID, officially marked the birth of the Australasian Society for the Study of Intellectual Disability. This was the product of the determination of several dedicated members to not let foreign languages, geographic borders or notorious sporting moments prevent the formalization of the organization. What happens when technology fails? Dr Roger Stancliffe, Editor of the Journal of Intellectual and Developmental Disability, was on hand to present the Editor's awards and



was forced to manage one of those periods in time when the dreaded data project developed its own challenging behaviors! The reception also saw the launch of the Special Edition of the Journal of Intellectual Disability Research. Hans Reinders, Guest Editor for the edition, launched the edition and was able to use his wit and humor to motivate the delegates after what had been a long welcome reception packed with a little too much officialdom.

## Day three

Day three commenced with a keynote address by Professor Carl Haywood titled 'A Transactional Perspective on Intellectual Disability'. This address examined definitions of intellectual disability and changes that have taken us beyond IQ to looking at a comparison between intelligence and cognitive processes and the implications for cognitive development based on motivation. Professor Haywood compared those who are intrinsically motivated to those individuals who are extrinsically motivated and their subsequent cognitive development.

After a session of concurrent papers and lunch, Tim Stainton used his personal experiences to examine the labyrinths involved in meeting *continued on page 12*



## South Australia

Since the last edition of IDA, the SA branch conducted an event in October 2003, in conjunction with ANGOSA (Association of Non government Organisations of South Australia), with Professor Robert Cummins from Deakin University speaking on: "Quality Services, Individualised Services and Quality of Life." The event was well attended and well received.

We continue to receive a steady stream of orders for our Roy Brown monograph – *Disability and Society: Challenges in the 21st century*. (See September 2003 edition of IDA for review). Contact any SA office bearer for details.

However, in South Australia we are currently primarily focussed on planning for this year's annual Australasian conference. (See elsewhere in this edition of IDA for 'first call for papers'). We have secured a range of keynote and plenary speakers, have convened the Programme Committee and are currently working on ways to ensure that people with intellectual disability and their families have the opportunity to contribute and fully participate in this year's conference. Well timed publicity and adequate sponsorship are the other significant challenges we are currently working through.

In addition to conference planning the SA branch recognises that we need to also consider other events for the year. More news on this as arrangements 'firm up'.

*Richard O'Loughlin, SA President, rolstmarys@esc.net.au*

## Victoria

The Victorian Regional branch wishes everyone a Happy New Year and invites members to take part in activities planned for 2004. The first event this year is a dinner in March to present Distinguished Service Citations to Mr Bill Taylor and Dr Karen Nankervis in recognition of 24 and 15 years respectively, of active involvement in ASSID. In May the regional branch aims to present a debate to raise awareness of issues related to a topic that may be causing some confusion and discussion in the disability sector. The topic has yet to be decided and should be confirmed over the next few days. A state conference will be held in the city of Melbourne on Friday 27 August and the 25 and 26 November of this year will find the regional council busy conducting the fourth Disability Support Worker Conference to be held again at The University of Melbourne. Victorian council welcomes Dan Pennefather to the committee this year and acknowledges that although Bill Taylor and Karen Nankervis are not officially on council they continue to be involved through support of council members and the Victorian team.

*Alex Phillips*

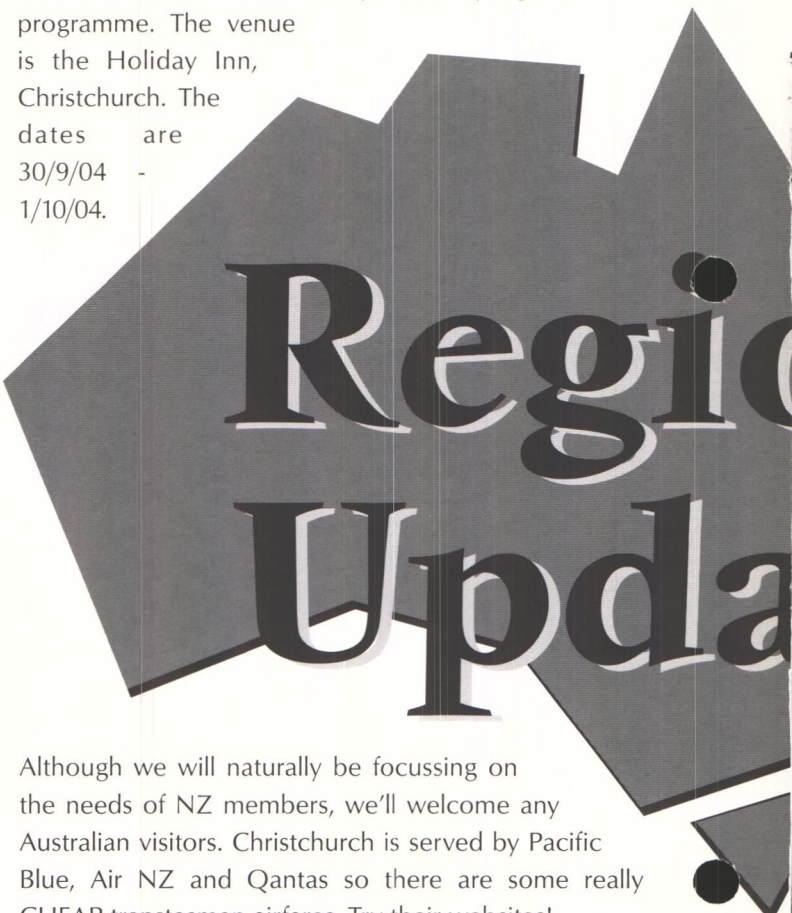
## New Zealand

Following our successful Auckland Regional conference in October 2003, NZASID has been exploring ways of increasing membership numbers. One obvious way of doing this is by offering potential members exciting Conferences and training opportunities as well alerting them to the excellent services available now that we are a regional member of ASSID (Journals, ASSID-L etc).

The conference committee for the next regional conference has been busy developing the programme. The venue

is the Holiday Inn, Christchurch. The

dates are  
30/9/04 -  
1/10/04.



Regional  
Update

Although we will naturally be focussing on the needs of NZ members, we'll welcome any Australian visitors. Christchurch is served by Pacific Blue, Air NZ and Qantas so there are some really CHEAP transtasman airfares. Try their websites!

The Committee for the 2005 ASSID conference to be held in Auckland has met on a number of occasions and programme planning is coming along. Tricia O'Brien is currently in the UK meeting with potential Speakers.

In April the NZ Prader Willi Association ([www.pwsa-nz.co.nz](http://www.pwsa-nz.co.nz)) is hosting the PWS International conference. Speakers include Professor Tony Holland, who has a chair in Developmental Psychiatry (Learning Disability) at the University of Cambridge, UK. Tony has kindly agreed to give 2 Public lectures for NZASID during his time in New Zealand.

A number of NZASID members are hoping to make Montpellier and some will also be coming to Adelaide in November.

*Angus Capie*

# Education Disability Studies



## Graduate Certificate in Educational Studies

CRICOS Code: 027431K

## Master of Disability Studies

CRICOS Code: 045140E

## Master of Disability Studies (Honours)

CRICOS Code: TBA

The Disability Studies coursework programs provide a mix of theoretical and practical content and are designed for professionals who are either working, or who aspire to work, in the disability industry in either a "hands-on" or a managerial capacity. The awards are offered by staff from the Centre for Special Education and Disability Studies, who have demonstrated expertise in the disability area.

The Master of Disability Studies (Honours) program is available as an additional 40 unit research strand.

### How long will it take me?

The Graduate Certificate can be completed in one semester full-time or part-time equivalent.

The Master's program can be completed in one year full-time or part-time equivalent.

The Honours program can be completed in one additional semester full-time or part-time equivalent.

(It is recommended that students in full-time employment attempt only one course per semester).

### On-campus or distance learning?

All courses are offered by distance learning and courses marked with an \* are offered on-campus also. Distance courses commence three weeks after the on-campus semester dates to allow for distribution of teaching materials.

All courses offered are at the Master's level. Please note that not all courses are offered each semester.

### What qualifications do I need?

For entry into the Graduate Certificate applicants must have satisfactorily completed a three year diploma from a recognised tertiary institution or equivalent qualifications. However, applicants who hold other relevant qualifications together with appropriate high level work experience are encouraged to apply for recognition of prior learning (RPL).

For entry into the Master's degree, applicants must have satisfactorily completed a relevant three year degree. Applicants who do not satisfy the requirements for direct entry to the award are required to complete the Graduate Certificate prior to entering the Master's award.

In both awards, the assumed knowledge for study would be equivalent to two years relevant professional experience.

For entry into the Honours program, applicants must have satisfactorily completed the Master of Disability Studies award.

### What happens when I am finished?

On completion of the Graduate Certificate, graduates will be eligible to apply for entry into the Master of Disability Studies, and seek up to 40 units in that award, or exit with the Graduate Certificate.

On completion of the Master of Disability Studies, graduates will be eligible to apply for entry into the Master of Disability Studies (Honours), and seek up to 80 units credit in this award, or exit with the Master's degree.

### How much will it cost me?

For cost details Australian students should visit the website [www.newcastle.edu.au/study/australian/fees/postgradcw](http://www.newcastle.edu.au/study/australian/fees/postgradcw)

A General Service Charge will also apply. Course fees may be a legitimate tax deduction as a self-education expense. Prospective students should seek independent advice in relation to taxation issues regarding fees. You may be eligible to use the Postgraduate Education Loans Scheme (PELS) which is an interest-free loans facility for fee-paying postgraduate students undertaking non-research courses. It is similar to the deferred payment arrangements available under HECS, and is operated by the Commonwealth Government. Information can be obtained by visiting the website at [www.hecs.gov.au/pels.htm](http://www.hecs.gov.au/pels.htm) or calling the PELS enquiry line on 1800 020 108.

International students should contact International Admissions (email: [international-admissions@newcastle.edu.au](mailto:international-admissions@newcastle.edu.au)) for details of international study and in-country training costs.

For cost details International students should visit the website [www.newcastle.edu.au/study/international/fees/postgradcw](http://www.newcastle.edu.au/study/international/fees/postgradcw)

### What do I need to do?

As all courses are not available in a given semester, prospective applicants are advised to consult a Program Officer or the postgraduate handbook at [www.newcastle.edu.au/faculty/educ-arts/programs/postgrad-c.html](http://www.newcastle.edu.au/faculty/educ-arts/programs/postgrad-c.html), prior to enrolment.

#### Graduate Certificate in Educational Studies

To qualify for the Graduate Certificate in Educational Studies students must complete 40 units. Students who are interested in Disability Studies may wish to complete four courses from the following: EDUC6001, EDUC6002, EDUC6003, EDUC6004, EDUC6083 and EDUC6087 (brief course descriptions below).

#### Master of Disability Studies

To qualify for the Master of Disability Studies students must successfully complete 80 units, made up of 40 units of compulsory courses and 40 units from the elective courses listed below.



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of NEWCASTLE  
AUSTRALIA

## Compulsory Courses

### **EDUC6001 Disability Studies: Perspectives on the individual, family and community\***

Provides an introduction to the study of disability, its definitions and social construction, and its impact on the individual, family and community.

### **EDUC6002 Disability Support and Services: Management and evaluation**

Provides an overview of the philosophical basis for disability services, the legislation associated with disability services, and the implications of both for the management and evaluation of disability services.

### **EDUC6003 Programming for Support in Disability Services: Issues and strategies\***

Provides an introduction to the area of programming principles and strategies used in the design of support programs for people with disabilities.

### **EDUC6004 Collaboration, Planning and Interpersonal Skills in Disability Services**

Examines interpersonal communication processes, which are required for collaborative/planning roles in disability services. In particular, skills will be developed in the areas of listening, interviewing, conflict resolution, and collaborative problem solving.

## Elective Courses

### **EDUC6051 Industry/Work-Based Project\***

Conducted in a workplace, the project provides students with the opportunity to design, conduct and analyse research focusing on an issue of concern to them in an in-depth manner.

### **EDUC6083 Communication Intervention**

Introduces theory, research and implementation protocols, which support the design and evaluation of communication interventions and programs for challenging behaviour for individuals with high support needs.

### **EDUC6084 Community Service Provision for People with a Disability**

Examines recent research associated with a range of community services for people with a disability, (e.g. accommodation, employment, advocacy), and issues that are relevant to the provision of these services.

### **EDUC6087 Education of Students with Developmental Disabilities\***

Overviews a number of common developmental disabilities, examines the social, emotional and physical health issues of these disabilities, and critically analyses contemporary approaches to the support of individuals with a disability.

### **Master of Disability Studies (Honours)**

To qualify for the Master of Disability Studies (Honours) award students must successfully complete a total of 120 units made up of 80 units of coursework as specified for the Master of Disability Studies and the 40 unit Research Strand.

## Research Strand

### **EDUC6048 Introduction to Research Methodology\***

Provides an introduction to qualitative and quantitative research methodologies, contemporary perspectives in research, and in particular focuses on developing a range of skills involved in formulating a research proposal, including framing research questions, reviewing the literature and choosing appropriate methodologies for different types of study.

### **EDUC6049 Educational Research Methodology 2: Qualitative\***

Provides a generic introduction to the knowledge, skills and tools that a student will require when undertaking a qualitative research study. In particular, the course focuses on the areas of data collection and analysis.

OR

### **EDUC6050 Educational Research Methodology 1: Qualitative\***

Offers students skill development in quantitative methods of the collection, analysis and reporting of research data, including introduction to the statistical software package SPSS. Analyses of data and hypothesis testing are undertaken using basic descriptive and inferential statistical procedures.

### **EDUC6026 Minor Thesis A and EDUC6027 Minor Thesis B\***

Provides the opportunity to undertake research in an area of interest to the student. The research may take the form of an empirical study, a review of the literature or another research format in discussion with the supervisor.

Please be aware that this program outline is subject to change.

## How do I apply?

Australian Citizens and Permanent Residents must lodge an application via UAC for entry into these programs. For details visit the UAC website at [www.uac.edu.au](http://www.uac.edu.au). If you do not have access to the web, return the attached Request for Postgraduate Booklet, which includes an application form.

### **Australian Citizens and Permanent Residents seeking entry after the UAC closing date should contact the Faculty Student Services Office.**

International Students wishing to study in Distance Learning mode should download a Distance Learning Application form which can be found at [www.newcastle.edu.au/study/forms/](http://www.newcastle.edu.au/study/forms/)

International Students wishing to study in Australia should contact [international-admissions@newcastle.edu.au](mailto:international-admissions@newcastle.edu.au) for details of application procedures, or visit the website at [www.international.newcastle.edu.au/index-flash.html](http://www.international.newcastle.edu.au/index-flash.html)

## Need a Postgraduate Booklet?

Please send me the 2004 UAC Postgraduate Booklet.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_ Postcode: \_\_\_\_\_

Phone: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Want more information?

For more information on these professional development programs please see our program information website [www.newcastle.edu.au/faculty/educ-arts/](http://www.newcastle.edu.au/faculty/educ-arts/) or contact the Faculty Student Services Office.

## Who can I contact?

Faculty Officer  
Faculty Student Services Office  
Faculty of Education and Arts  
GP1-22 General Purpose Building  
The University of Newcastle  
Callaghan NSW 2308  
AUSTRALIA

Phone: 02 4921 5314  
International: +61 2 4921 5314  
Fax: 02 4921 6997  
International: +61 2 4921 6997  
Email: [education-arts@newcastle.edu.au](mailto:education-arts@newcastle.edu.au)  
Web: [www.newcastle.edu.au/faculty/educ-arts](http://www.newcastle.edu.au/faculty/educ-arts)

## New South Wales

New South Wales commences another year with an energetic committee. Unfortunately the annual planning day had to be postponed, but will be held in the near future. The committee has decided not to hold a State conference this year. However in an attempt to provide educational opportunities for people across the State a number of seminars are being planned for Northern New South Wales and the Australian Capital Territory. If any members have suggestions for seminar topics of interest contact a member of the committee.

The committee has commenced early planning for the 2006 National Conference with the decision that it will be held in Canberra. The very energetic Linda Goddard has agreed to take on the role of conference organiser. The other projects identified in the State plan are moving forward.

It was with delight that we heard that one of the original members of ASSID in New South Wales, Dr Helen Beange, was awarded an Order of Australia for her contribution to medicine and people with disabilities. Helen's quiet determined approach has ensured that the health needs of people with an intellectual disability are seriously attended to. Helen has been an inspiration as well as a good friend and colleague to many of us, and her award is well deserved.

*Tony Tinlin*

## Queensland

With new committee members and refreshed and invigorated after a successful national conference, there is another busy time ahead for Queensland with two dinners, three conferences and some hot topic nights/breakfasts planned for the year.

Our events start in April with an invitation to the newly appointed Minister for Disability Services Queensland, Warren Pitt, to join us for dinner. Then it's off to Rockhampton and Toowoomba for some periodic local hot topic discussion in the evening and to Brisbane for the

same at breakfast - topics and speakers yet to be confirmed. In October we will invite Steve Moss of Manchester University to join us as our dinner guest. More on that as the time approaches.

Our conferences will happen in July and August this year, with Sharing the Road again taking central stage. With the theme The Fire Within: Exploring Commune-ity the conference will explore the deeper relationships within community and the relationships that people with disabilities and their support workers have with themselves and the rest of the world. These discussions will happen in Brisbane from July 19-21 and in Cairns from August 11-12. For further details contact Chris Montgomery at [cmontgom@disability.qld.gov.au](mailto:cmontgom@disability.qld.gov.au) or by phone on (07) 3404 3086.

The State conference will be convened on Sunday July 18 at the Sharing the Road site (Griffith University) and will incorporate a student stream. A theme and keynotes have yet to be confirmed, more on that and our other events anon.

*Chris Montgomery*

## Tasmania

Early in October 2003, the annual state conference was held with Matthew Bowden, Di Brokenshire and Keith McVilly providing keynotes. The conference entitled "Different Abilities" focused on all people's differing abilities rather than disabilities. This meant we went outside the intellectual disability arena and had some different perspectives to think about.

As anticipated The Institute for Applied Behaviour Analysis (IABA) training seminars entitled Positive Approaches to Solving Severe Behaviour Analysis held at the Old Woolstore Theatre on the 14th, 15th, 16th and 17th of October 2003 were highly successful. Many departmental staff and 3 non-government staff went on to further longitudinal training that will continue well into 2004.

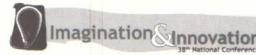
In December, 2003 ASSID Tas were successful in receiving a \$5000.00 grant from the Tasmanian Community Support Levy to purchase a laptop and data projector for our training/workshops and conferences. This has proved to be great asset already.

Tasmania has just held it's annual planning day where we reviewed our Strategic Plan and did some planning for this years ASSID events. This planning attracted a few non-committee members which was good to see and provided the committee with some good discussion about where ASSID Tasmania is heading and what we should be concentrating on in the future.

*Darryleen Wiggins, Tasmanian President*

# 38th ASSID conference report, "Imagination and Innovation"

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individual needs and the incongruence of disability policy and politics. His ability to use technology to enhance the power point presentation ensured all delegates remained alert throughout the afternoon session. A Tim star war now has new meaning. The final session again allowed delegates to select from concurrent papers.



As the formal program for day three closed the social program again commenced with the "Conference Dinner" held at the Gabba, home to the reigning AFL premiers. The night was a resounding success with individuals having the opportunity to dance away the night to the sounds of the Chardonnay Sippers.

## Day four

Professor Brendan Glesson, School of Environmental Planning at Griffith University, began the day with a paper that examined the concept of disability through the eyes of environmental theory and policy. Brendan's urban perspective on intellectual disability encouraged delegates to examine their concepts of disability. From morning tea through to afternoon tea delegates again were able to feast on a variety of quality papers via the streams on offer. Afternoon tea became the penultimate event leading to the plenary session. No ASSID conference can come to a close without a word from one of Australia's sages on issues of disability. The sage in question is our own Professor Trevor Parmenter. Trevor was both able to pull the conference to a close and present us with an image for the future without inflicting death by powerpoint on those gathered.

Trevor's closing signaled the end to an event that had been many years in the planning and it would be inappropriate to close a report on the 38th conference without thanking those involved. Our thanks are extended to the sponsors of the event Queensland Government via Disability Services Queensland, Kimberly Clark, Taylor and Francis, ACE, the Public Trustee, Endeavour. Queensland's three major tertiary institutions, University of Queensland, Griffith University, Queensland University of Technology for the support provided to the conference organizing and program committees. Thanks also to the IASSID special interest group on ethics for the extra dimension and depth they brought to the conference. A special thanks to presenters, keynote speakers and delegates for participating in the conference.



Congress Patron The President of the French Republic  
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12th  
**IASSID**  
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June 14-19, 2004

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[www.iassid.org](http://www.iassid.org)

# Distinguished Service Citations, 2003 to Professor Phil Foreman, Dr Karen Nankervis, & Mr William Taylor

*Distinguished Service Citations are awarded to individuals who have made a distinguished contribution to ASSID which has enhanced ASSID's profile and/or operation. Individuals must be nominated for the award which is presented by the Australasian President at the National Conference or by the Regional President at an appropriate local event. In 2003, three individuals received citations in recognition of their significant contributions to ASSID.*

## **Professor Phil Foreman**

Professor Phil Foreman is Professor of Education, Head of School, and Dean of Education at the University of Newcastle. He has a PhD from Macquarie University and is a Fellow of the Australian Psychological Society.

Phil has been involved in Special Education and Disability Studies for many years and is the outgoing Editor of the Journal of Intellectual and Developmental Disability, having been Editor for over 10 years. He is also the Editor of a widely used University textbook, Integration and Inclusion in Action and has published extensively in the area of disability and special education. He is Australian delegate on the Council of the International Association for the Scientific Study of Intellectual Disability.

Phil is also currently involved with provision of services for adults with a disability. He is Foundation President of Newcastle and Hunter Community Access, which provides services to over 100 adults with a disability through six different programs, and is Foundation President of Disability Advocacy Service Hunter.

## **Dr Karen Nankervis**

Originally a Mental Retardation Nurse and Psychiatric Nurse, Karen worked as a Nurse Educator in a Victorian institution before moving to Phillip Institute of Technology in 1988 (now RMIT University). At RMIT Karen established one of the few disability degree programs in Australia and continues as head of the undergraduate and postgraduate programs.

For fifteen years Karen has encouraged and supported academics, researchers and students to take part in the organisation and provision of ASSID events. Involvement in these activities, while of enormous practical support to ASSID at the time, have also raised the profile of the society, strengthened links with the university, research community and the service sector.

Karen's contributions to ASSID can be characterised by the establishment and development of new and innovative

activities and the development of long term relationships that continue to benefit ASSID today. While providing leadership through positions of National President, Vice President and other executive positions on council, Karen undertook additional roles that were essential for ASSID to meet the needs of its growing membership. From 1994 to 2001 Karen was the inaugural editor of Intellectual Disability Australia, (later Australasia) with her first edition representing the first time it was produced as a quarterly magazine as distinct from its original newsletter format. More recently, Karen's work for ASSID has focused on two significant contributions, (1) the re-inclusion of New Zealand as a regional entity of the national association and; (2) the Victorian Disability Support Worker Conference.

## **Mr William (Bill) Taylor**

When William (Bill) Taylor first joined ASSID, it was called the Australian Group for the Scientific Study of Mental Deficiency (AGSSOMD). A short time later in 1980 Bill was employed at an institution for people with intellectual disabilities, significantly as the first non medical Superintendent in Victoria. With a background in special education, Bill represented the beginning of a policy shift in the care of people with intellectual disabilities and the membership of AGSSOMD that had primarily been medical personnel. Bill's vision and enthusiasm for community care and normative practices in service delivery lead him to take an active role in the society where he advocated for change to the care of people with intellectual disabilities and raised the profile of AGSSOMD.

In 1986 Bill took part in a significant members' vote that changed the name of the society to the Australian Society for the Study of Intellectual Disability (ASSID). By this time Bill was one of an increasing membership that reflected professionals from a wide range of disciplines, and heralded the need for further development of the organisation. His involvement in debates of strategic direction, the establishment of more formal processes, the organisation of conferences and dissemination of information meant

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# Innovation through Insight

*by Ian Boardman, Public Advocate, Queensland*

**This is an edited version of the opening speech for the 38th ASSID National Conference held in Brisbane 17-20 November 2003**

The life and work of an advocate is somewhat akin to the life and work of the creative artist. Our job is to challenge and to cause discomfort. We value our freedom and independence above everything else, and will sacrifice much in order to protect that freedom. What we resent above anything else is the thought that the mainstream system and its power elites - with which we necessarily have a relationship of tension and sometimes even estrangement - that that system might seek to restrict in any way our capacity to communicate.

The quality of the day to day life of a person with an intellectual disability lies most often in the hands of family members and direct support staff. Their longer term fate lies not only in the hands of those who control policy and budgets, but also in the outcome of various discourses, some of them almost entirely philosophical in their nature, that can determine the fate of whole populations of vulnerable people. Human history is replete with these disasters, for disasters they mainly are, where ideology killed millions, among those millions being people living with an intellectual disability.

It is meritorious then, that so many gathered here are dedicated to the study of intellectual disability and to the well being of those citizens who live their life through the prism of that particular experience.

It is especially important that those of us who have what is taken to be full intellectual capacity, spend some time getting to know people who do not. It is important because

it helps to balance the relationship, a relationship that is typically characterised by an imbalance of power between the parties, and that far too often has the classic hallmarks of a relationship of oppression.

It is not widely appreciated that in such relationships, it is the oppressed who know and understand the oppressor, far more than the oppressor understands the oppressed. Yet the reasons why it is so, are fairly obvious.

Firstly, regardless of their best paternalistic intentions, the oppressor needs to dehumanise the oppressed simply to live comfortably with themselves. Let me illustrate. Most of us would have difficulty sleeping at night if we fully accepted the humanity of the people we were locking away - as we have done, so often in the past - or that we otherwise segregate and isolate from any opportunity to live a full life. What we tend to do therefore, is to minimise the humanity of the person; and it is very difficult to do that when we really know them well.

Secondly, all of us are motivated to seek out information about other people or things to the extent that that person or thing can have an impact on our well being and prosperity. For instance, many more middle class Australians nowadays, are seeking to inform themselves about the vagaries of the real estate market, because they perceive that their well being is reliant upon that market by virtue of their recent investment in it.

Similarly, oppressed people know that the chief determinant of their grief, and equally *continued page 15*

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## Distinguished Service Citations, 2003

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that Bill made an invaluable contribution to the advancement of the organisation and its objectives, while embracing and guiding ASSID through significant change.

Over 24 years of active participation in ASSID Bill has earned the respect and admiration of his colleagues. Not least of Bill's achievements by the late 1990's was the leadership he provided as President on both the national and state branches of the society. Equally as important to the ongoing development of the organisation were the roles he held over the years on national and state councils as registrar, secretary and treasurer. Perhaps at no other time was Bill's dedication to ASSID more apparent, than when for a few years during a 14 year term as State

President he, together with friend and colleague Dr John Annison, were the only two members of state council and they held meetings to ensure the ongoing existence of the Victorian association.

More recently, Bill has played a key role in the 2003 name change to the Australasian Society for the Study of Intellectual Disability (ASSID). While New Zealand had once been a distinct group within ASSID, declining numbers meant that they could not maintain their group status. Together with Dr Karen Nankervis, Bill was instrumental in the re-inclusion of New Zealand as a regional entity of the national organisation.

their well being, is the oppressor. So they make it their business to study the oppressor, to know his or her motivations, foibles and concerns.

The oppressor on the other hand, has little incentive to study the oppressed, because the oppressed has little apparent impact on the oppressor's well being. The main issue for the oppressor is to maintain control over, and malleability in, the oppressed. It is practically certain therefore, that oppressed groups know far more about their oppressor than their oppressor knows about them.

Thus, for all of the anthropological studies conducted by Western trained researchers, Indigenous Australians know far more about white Australia than white Australians know about them.

The sum of the average white Australian's knowledge of Indigenous Australians is titbits of information picked up from newspaper articles, and almost wholly mythical notions that, be they negative or positive, bear little or no relation to the lived experience. How could it be otherwise when the majority of white Australians have never met an Indigenous Australian, let alone sat down and had a good old chinwag.

A similar analysis applies to people who have a mental illness, and equally to people who have an intellectual disability. They already know what we are like. They cannot afford to have any illusions about us. Their survival depends on their being able to accurately gauge what our actions and reactions are likely to be, and to the extent that their disability prevents them from accurately doing so, to this precise degree they are vulnerable to abuse, exploitation and neglect.

Those of us who study intellectual disability, and who do so with the best of intentions, do not ourselves live with that disability. So the question should be asked: to what extent can we really know what is the lived experience of someone who has an intellectual disability? How much of our own wish fulfilling subjectivity is inadvertently injected into the exercise, regardless of our ethical framework and the checks that we build into our methodology?

By way of example, in kidnap or terrorist situations, it is known that highly intelligent hostages can journey in a relatively short period of time from fear and loathing of their captors to, not just acquiescence, but full blooded support for whatever cause the terrorist is espousing. One must wonder therefore, what an equal desire to please, what an equal level of suggestibility on the part of the person with disability might do, in terms of distorting research findings and obscuring the truth of the person's lived reality? This would be even more so when the person

with a disability has been socialised by the experience of living an oppressed life.

The challenge for all of us as we journey through the extraordinarily diverse and interesting intellectual landscape that is on offer here, is to keep in the forefront of our consciousness that it all might be a very convincing, but nevertheless will o' the wisp illusion.

We might not be helping anybody. We might not be contributing to a field of knowledge, but rather participating in a gigantic group think that is fully aware of all the intellectual traps, that prides itself on its diversity of views, and that nevertheless is so constrained by twentieth and now twenty first century cultural and intellectual paradigms, so blinded by a centuries long bias in favour of intellect over intuition, of material reality over spiritual truth, of cognition over what we have come to call emotional intelligence, that it simply cannot see the dangerous path down which we are all travelling.

I do not want to seem alarmist, and the alarming picture I paint is simply to highlight the absurdity of the larger world in which we are living and from which we all tend to draw our sense of what is sane. I consider the absurdity of what passes for national and international leadership in these troubled times, and the absurdity of the triumphant posturing of the latest empire, and the apparent ongoing victory of power over love, and the profound failure of moral intelligence to which these indicators point.

It is true that no one person can take all of these things on board and make sense of them. There is both merit and common sense in being less ambitious, in limiting ourselves to a more manageable area of study.

For we know that the more we learn the less we seem to know. And we know that the acknowledged greatest minds of even this materialist era have almost without exception surrendered their intelligence, and the product of their intelligence, to a greater and higher power, one where potency and compassion can coexist.

Now it does not take a great mind to surrender in this way. Millions of alcoholics over the past fifty or so years have done it on a daily basis through Alcoholics Anonymous.

It is the humility of the reformed drunk then, which I commend to you. A humility that appreciates its own lack of mindfulness, its own disability of the both the intellect and the spirit; a humility that knows that the smallest of ordinary human acts of kindness mean more to a person – whether they have an intellectual disability and are lost in an impersonal service system, or are intellectually brilliant and lost in a strange city – than all the arguments in their favour at a philosophical or policy level.

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## Book Review:

# Ageing with a Lifelong Disability: A Guide to Practice and Policy Issues for Human Services Professionals

**Author: Christine Bigby, 2003**

**London: Jessica Kingsley. 319pp. Aus \$51.95  
ISBN 1-84310-077-0**

**Review by: Marie Knox,  
School of Humanities and Human Services,  
Queensland University of Technology,  
Brisbane m.knox@qut.edu.au**

It is widely recognised that Australia's population, along with that of many developed countries, is ageing. This growing population of older people includes a small but increasing number of people with a lifelong disability. It is this group of people who are the focus of Dr Bigby's book.

Bigby is an internationally recognised expert in the area of ageing and people with a lifelong disability. The book is meticulously researched and is reflective of the high quality and extensiveness of her prolific research and involvement in this area over many years. The reference list of some 22 pages is but one indicator of this thoroughness. Yet at the same time, the volume is immensely readable – making it appealing to a wide audience. Bigby shows a capacity to describe quite technical and complex issues in an easily understood manner.

Throughout the book Bigby continually emphasises the importance of enhancing quality of life for this group of people, the need for flexibility in approaches to achieving this goal and for the utility of person-centred planning strategies in ensuring that this group of people lead rich and fulfilling lives.

The book opens with a foreword by Professor Gordon

Grant in which he gives a particularly eloquent overview and critique of the book.

The book itself consists of five sections. The first section ("Perspectives on Ageing") comprises two chapters, the first of which explores issues around the concept of "successful ageing" and its relevance to older people with a lifelong disability. The second warns of the vulnerability of these people to discrimination on the basis of their age and argues for and describes the use of individualised planning and case management approaches to address this issue and to ensure that supports are tailored to individual's needs.

The second section ("Physical and Psychological Needs") comprises 2 chapters and looks at the risks factors associated with poor health of older people with a lifelong disability - particularly in terms of factors that many experience over their lifetime – poverty, poor nutrition, lack of healthy lifestyle to name but a few. It also explores several issues that are specific to particular groups of people with a lifelong disability. An Appendix ("Age-related Biological Changes and Health Risks") is included with the book that gives an overview of the biological changes associated with ageing and the health conditions that impact on all older people. This provides a useful supplement to the issues raised in this section.

The third section ("Social Dimensions of Ageing") comprises three chapters. The first of these chapters explores the vital role played by informal support networks for this group of people. The vital role for support services of fostering, nurturing and building a breadth of informal relationships is stressed. This section also explores the

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## Innovation through Insight

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Our study then, needs to include some strange research questions: how to introduce kind heartedness into a service system? How to appreciate disability as an expression of divine creativity? How to deal with our own lifelong lack of insight and perception?

Our study also requires that our imagination be sufficiently informed by these questions that it can move us toward

genuine insight. For it is out of these magic moments, that our creativity and capacity for innovation grows.

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GPO Box 149  
Brisbane; Queensland  
Australia 4001  
ian.boardman@justice.qld.gov.au

## **Ageing with a Lifelong Disability: ...**

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concept of retirement for this group of people, in terms of supporting lifestyle choices for people with a lifelong disability as they grow older. Bigby raises the question of 'retirement from what and retirement to what'. She then warns of retirement for this group of people being used as a mechanism for managing demands on the service system. Here Bigby argues for the reframing of day programs in terms of lifestyle support. She advocates the provision of continuing support adapted to an individual's changing needs rather than have the person transition to a fundamentally different sort of service as they grow older.

This section also explores changing housing and support needs for this group of people. Bigby advocates broadening visions of possibilities in this area when parental support is lost, as well as flexible creative use of funding. She also points out that the area of housing and support is the biggest area where stereotypes and age discrimination abounds in the lives of older people with a lifelong disability.

Section Four ("Older Parental Carers of Adults with a Lifelong Disability") comprises two chapters. The first of these explores the circumstances surrounding older parents who have cared for their now aging son or daughter with a lifelong disability for the vast majority of their lives, their connections to formal services and their relationship with their adult son or daughter. The challenge of planning for the future in these circumstances is well described. The resilience of these parents and their adaptation to and satisfaction with the interdependent relationship with their son or daughter are particularly well brought out by Bigby. The following chapter then uses this material as a basis on which to explore means of working with older parents in terms of preparation and planning for quality lifestyles. Inter alia, this chapter includes an interesting discussion on the relevance of family focussed approaches prevalent in working with younger families to working with older families

The final section ("Service Development and Policies for Successful Ageing") explores the policy and systemic issues around concerns of older people with a lifelong disability. It explores the questions on responsibilities of the aged care and disability sectors, policy and program issues for both older people with a lifelong disability and older carers. It argues that the formulation of individual or person-centred plans is the lynchpins to developing a good quality of life for older people with a lifelong disability. To this end, program planning and community development must occur in tandem. In the final pages of this section, Bigby reminds us that the voices of older people with disabilities are rarely heard in debates on this topic and argues for a research priority that focuses on exploring the perspectives of this group of people. She also notes the lack of clear understanding of "what works well and what doesn't", and on this basis calls for a shift from a descriptive to an evaluative stance in research efforts.

Each chapter of the book concludes with a summary of the chapter's content and reference list for further reading on the topics explored within the chapter. A particularly appealing feature of the book is the inclusion at the end of sections one to four of a series of vignettes. These vignettes present "case studies" of the relevant issues covered in the section and a set of related discussion questions. These questions provide an interesting basis for further debate and reflection.

In all this book is an essential addition to the library of service provider organisations, policy makers, researchers, and families and all who wish to share in ensuring the well-being and quality lifestyles of this growing and emerging group of citizens. I see this book as a seminal text in this area.

# ASSID-L

***A mailing list for people with an interest in intellectual disability.***

Access to this list is included as part of "Australasian Society for the Study of Intellectual Disability" membership and is intended to improve communication between us all.

ASSID-L operates in the same way as any e-mail list.

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For information please contact:

The Editorial Assistant,  
Intellectual Disability Australasia  
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# Upcoming Events . . .

4/6/2004 - 19/6/2004

## 12th World Congress of the International Association for the Scientific Study of Intellectual Disabilities

Place: Montpellier, France  
Website: [www.iasid.org](http://www.iasid.org)

21/7/2004 - 24/7/2004

## One World: Many Childhoods - Strengthening Early Childhood International Links

Place: Melbourne, Vic  
Contact: The Meeting Planners,  
91 - 97 Islington Street, Collingwood, Vic 3066  
Phone: (03) 9417 0888  
Fax: (03) 9417 0899  
Email: [omep@meetingplanners.com.au](mailto:omep@meetingplanners.com.au)  
Website: <http://www.omepaustralia.com.au/>

*This is the XXIV World Congress of The World Organisation for Early Childhood Education will be a unique opportunity to highlight OMEP's concern for early childhood development across the world. and will provide opportunities to explore issues such as children in difficult circumstances, innovation in service delivery, indigenous children's needs and services and children's health and social services.*

25/7/2004 - 27/7/2004

## Sixth Biennial National ECIA Conference - Broadening the Vision: Building Cohesive Communities for Children and Families

Place: Melbourne, Vic

*The Victorian chapter of Early Childhood Intervention Australia (ECIA) invites participants to the 6th biennial National Conference which will focus on the benefits that the provision of inclusive, positive, community oriented opportunities bring for children with additional needs and their families.*

28/10/2004 - 29/10/2004

## Medical Conference "Well Beyond 2004"

Place: Bardon Centre -Brisbane QLD  
Contact: Jude McPhee  
Phone: (07) 3840 2496  
Email: [j.mcphee@sph.uq.edu.au](mailto:j.mcphee@sph.uq.edu.au)

*The Australian Association of Developmental Disability Medicine (AADDM) in association with Qld Centre for Intellectual & Developmental Disability (QCIDD) is holding a two-day national medical conference for all specialist and generalist medical practitioners and allied health professionals with an interest in child and adult developmental disability. Keynote speakers include Prof Nick Martin (genetics and behaviour); Prof. Frank Bowling (metabolic disorders); Prof Bruce Tong (ASD); and international keynote speaker Dr Steve Moss (Psychiatric Assessment). The topics covered will include: mental disorders, gastro-enterology, metabolic disorders, ADHD, severe behavioural problems, epilepsy and autism spectrum disorders.*

9/11/2004 - 12/11/2004

## 39th ASSID Annual Conference

Place: Adelaide, SA

**The upcoming events column can only be filled if ASSID members let us know what is going on. Any conference or event – local, regional, state based, national, international, ASSID or not – can be notified free of charge in the upcoming events section.**

Just email [deb.keen@uq.edu.au](mailto:deb.keen@uq.edu.au) and put 'IDA:upcoming events' in the subject line and it will be passed to the IDA editor to go into the next available edition.

Include name/title of event, date(s), time(s), venue(s), contact details and a few words – a very few words – of information. It's a great way of reaching potentially thousands of workers in the field of intellectual disability and in allied areas.