



INTELLECTUAL DISABILITY **A**ustralia

Mates are an essential part of life



Group homes: great gains, some losses. This group of friends has been split up in the move from a boarding house ... read more about Graham, Michael and Bruce inside.

Inside:

- The Development Disability Unit
- IASSID update
- The Importance of Mates
- Where ASSID members work
- What's going on:
 - Conferences
 - Health
 - Health care
 - Research
- State Updates
- Must Reads
- Information Exchange

...and more



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Editorial

It's coming around to conference time of the year again. This means the ASSID National Conference of course (to be held November 12 - 15th inclusive); the most significant annual event on the intellectual disability calendar. Last year's conference was truly inspiring and this year's will be, judging from the experience of more than one ASSID conference, another event not to be missed. So, particularly given the difficulties of the aviation industry, it is worthwhile making your bookings now so that you don't miss out on the best discussion, information, entertainment and networking (not to mention coffee and shopping - it is in Melbourne, after all) that you'll get all year.

Included in this issue you will find considerable discussion of health and medical issues. The impetus for seeking the articles that have been kindly provided by Assoc. Prof. Nick Lennox and Dr Bob Davis and his colleague, Jenny Morrison came about from a phone call I had from Prof. Trevor Parmenter (why do these people all have such impressive titles - it takes ages to type them!). Trevor raised concerns that people with intellectual disability were not, in many instances, receiving medical treatment that accorded with their needs and that some of the background for this was the rejection of what people thought of as the medical model. As a worker myself in the field for the better part of the past quarter century (now that is a shock!) I must say I can only agree with the sentiment that perhaps we threw the baby out with the bath-water. Please read about the Developmental Disability Units at Queensland and Monash Universities and consider the importance of training medical practitioners and allied health professionals who are not only competent but dedicated in the field of intellectual disability support.

I write this a few days after the reprehensible events in the United States. I am sure we were all equally shocked and appalled by what occurred. However, even in the few days since the attacks in New York and Washington, it is apparent that deep divisions within society have been only papered over in recent years. It is sobering to note that a bus load of Muslim school children was stoned in Brisbane very soon after the events. The mid-directed 'retaliatory' action against a group of vulnerable people who could have no association with the perpetrators of terror reminds us how easy it is for the marginalised members of society to be attacked when the 'chips are down'. In the March edition of IDA we reported on radical, and not very welcome changes, to advocacy funding in NSW and while some review of this has occurred, it is timely to remind ourselves that people with intellectual disability are very vulnerable in a world which is ruled by economies and those who can shout loudest. As an erstwhile active member of the Campaign for Nuclear Disarmament myself, I am conscious of the threats that beset us all at the moment; I am also aware that even small organizations like ASSID can play a remarkably effective role in supporting and developing social and professional change; in making the world a better place to live. So, on with the good peace, and see you all at the ASSID conference.

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Ann P.

PS: Don't forget to note that the December issue of IDA will be a special issue on Ethics and Advocacy. **WE NEED YOUR CONTRIBUTIONS:**

penhall@bigpond.net.au

What's going on: Health Care Debates

As Assoc. Professor Nick Lennox – another ASSID member – points out below, there has been considerable debate about whether intellectual disability is, or should be, a specialist medical area and around whether people with disability would benefit – or not – if it were. As we all know, in the past two decades there has been an increasing push to move people with disabilities under generic service umbrellas – not only, of course, in the health care. The motivations for this have been good, of course, but while there are advantages of ‘mainstreaming’, the research is indicating that people with disability are still ‘missing out’, certainly at this stage, in health and well being standards when compared with the general population. The bad press that has been attached to what is very loosely termed the medical model has probably been part of the reluctance to address the specific and particular health needs of people with intellectual disability, but as Nick Lennox notes below, medical practitioners are just another profession struggling to provide quality of care to people with complex needs and it is more than worth considering the successes of the designated Developmental Disability Units and Centres at the University of Queensland and Monash University as they seek to establish support and expertise in developmental disability as a specialist field. – The Editor.

Specialist (Health and Medical) Practitioner Service Models

A personal and professional view from Assoc. Prof Nick Lennox,
Director of the Developmental Disability Unit at the University of Queensland

Firstly ... why is healthcare an issue?

Australian and overseas research indicates that people with intellectual disability die 20 to 30 years younger than the rest of the population and have many unrecognised and/or poorly managed morbidities (Beange, McElduff et al. 1995). One study found people with intellectual disability were 58 times more likely to die before the age of 50 than the general population!

This neglect needs to be addressed... but how? Is one of the answers to develop specialist medical practitioners in the area of health and adults with intellectual disability? The answer, I suspect, lies in a combination of medical centres of excellence, enhanced training of generic health and disability professionals and vigorous health advocacy.

Call for Contributions

Intellectual Disability Australia
Special December Issue, 2001

Ethics & Advocacy.

Do you have something to say about these essential topics? Send your thoughts, ideas, articles to IDA by **November 12th** this year.

Email: penhall@bigpond.net.au
for more info. or to submit.

What we know:

In the UK, there is one learning disability (intellectual disability) specialist (within the discipline of psychiatry) per hundred of thousands general population. On this basis, there should around 200 medical specialists working in the care of adults with intellectual disability in Australia. The reality is vastly different.

There is only one model that I am aware of which has received comprehensive evaluation: the “Morristown model” in New Jersey, USA. This integrates hospital based specialist services with primary care practitioners (Ziring 1987; Pulcini and Howard 1997; Walsh KK, Kastner T et al. 1997). The evaluation found positive results: shorter hospital stays in the coordinated care group; fewer readmissions; less severity of illness on admission and cost savings. The analysis is limited, however, by its retrospectivity, an inability to examine individual outcomes and the authors acknowledge difficulties in generalising from such a study.

Locally, there are strongly held views which vary from the belief that specialists will not contribute greatly, to the view that the only way forward it to develop a similar structure to that in the UK or the specialist training model in the Netherlands. It seems, to me at least, that it is easy to take one perspective and justify a particular opinion, without necessarily having good evidence. And certainly I am happy to indulge myself in this activity!

Service providers:

It is not generally understood that medical practitioners are very aware that they struggle to provide high quality

Continued on page 4

health care to the population with intellectual disability. Surveys of GPs and trainee GPs have found communication difficulties with people with disability and other health professionals, and problems in obtaining patient histories are the two most significant barriers. A range of other barriers have been identified, including GPs' lack of training and experience, patients' poor compliance with management plans, consultation time constraints, difficulties in problem determination, examination difficulties, poor continuity of care, and GPs' inadequate knowledge of the services and resources available. General practitioners have suggested numerous solutions to these barriers, and emphasized the need for increased opportunities for education and training in intellectual disability. GPs have shown an overwhelming willingness to be involved in further education (Lennox, Diggins et al. 1997; Cook and Lennox 2000).

GPs are the medical professionals most commonly in contact with people with intellectual disabilities. The other major providers of medical services are psychiatrists. They and their trainees have also expressed concerns. They have agreed that people with intellectual disability received a poor standard of care, were medicated with major tranquilliser to compensate for inadequate community resources and that disability service providers were not easy to work with. In general psychiatrists hold the opinion that they struggle to provide high quality care under the current system (Lennox and Chaplin 1995; Lennox and Chaplin 1996).

It is common, at the Developmental Disability Unit at the University of Queensland, to get calls from medical practitioners wanting to talk to somebody who is knowledgeable about intellectual disability or the associated morbidity in this population. Although at times there may be little the specialist practitioners can do, the support in this very difficult and complex area is extremely important. Outside the specialist units this support does not exist to any large degree and this lack will continue to make people with intellectual disability vulnerable, unless the system is further developed.

Where to from here?

My view is that people with an intellectual disability need advocates who understand health and healthcare delivery within the healthcare system as well as the disability field. There also needs to be vigorous advocacy from outside the healthcare system by people with intellectual disability, their families and advocates. The role of specialist services is to provide excellence and leadership in healthcare system and to model good health professional behaviour, to be strong advocates as well as support the generic

healthcare system to provide a high level of care.

Prior to the DDU being established in Melbourne, (now the Centre for Developmental Disability Health Victoria), the similar centre in Qld, and the slightly different model of the CDDS in NSW, there was virtually no research looking at the primary healthcare of this population. Also in its wisdom, the disability field had virtually ignored consulting medical practitioners' concerns about caring for this population. It was – and remains – common to hear criticism that is made without having understanding of the primary healthcare perspective.

Some of has come about as a result of a demon-ification of medicine, which came to be seen as responsible for institutionalised care. This view holds that medical practitioners are the group who developed this model and denies a shared responsibility or understanding of the belief systems of the period which produced large congregate care – and fails to consider the available resources of the time. This view also sees specialist medical practitioner as contrary to the principles of social role valorisation and normalisation. However, it needs to be pointed out, that under this logic we would not establish expertise in indigenous healthcare to try to redress the appalling health of this population.

No group, other than people with intellectual disability, in our society would tolerate such poor health status without having in place systematic national health promotion strategies and powerful advocates within and outside the healthcare system. To argue otherwise I think is foolish and, at times, petty.

Clearly there are difficulties assessing and maximising the utility of the healthcare system. The work of the DDU at the University of Queensland, which is described (page 12), is specifically targeted at a more imaginative mechanism to make the current primary healthcare system work better. What is evident from this work, is that healthcare is a combined responsibility which includes the person with an intellectual disability, their family, paid carers and the healthcare service system. To ignore the need for higher level of expertise in the healthcare system, as well as people who can advocate for themselves or can advocate effectively for people with intellectual disabilities, is destined to continue the poor quality of care that currently exists.

There clearly has to be combination of specialist medical practitioners, who are well trained, as well as an improvement in the quality of care provided by generic health and disability service providers. We need strong advocates from within and outside the healthcare system.

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What's going on: healthcare in practice

Professor Parmenter contacted IDA recently, raising concerns that people with intellectual disability were still being poorly serviced within existing generic health services. The Centre for Developmental Disabilities Studies in NSW, based at Royal Ryde Rehabilitation Hospital, has a small dedicated clinic but the need is greater than the service the centre can currently provide. Professor Parmenter stressed the importance of educating the wider medical community in working effectively with people with developmental/intellectual disability and the need to move away from the fears of medicine that arose out of the push for deinstitutionalisation. In this issue of IDA we have outlines of the work of Centre for Developmental Disability Health, Victoria and its sister centre in Queensland. Assoc Prof. Bob Davis and Jenny Morrison from Victoria and Assoc. Prof. Nick Lennox echo Prof. Parmenter's concerns. Read about their work and see what you think. - The Editor.

Centre for Developmental Disability Health Victoria

Dr Robert Davis and Mrs Jenny Morrison.

Good health is an essential requirement for any person's quality of life. Two decades ago the delivery of health services for people with developmental disabilities relied on medical practitioners employed within institutions. As community based models of care developed, the need to have health care provided by accessible generic services became critical. Central to the provision of generic primary health care provision within the community is the General Practitioner (GP).

The Centre for Developmental Disability Health Victoria (CDDHV) is a joint initiative of the Departments of General Practice at Monash University and The University of Melbourne and is funded by the Department of Human Services. The CDDHV's main objective is to improve the quality of health care available to adults with developmental disabilities. Education of medical practitioners through training and clinical services is a key element in the CDDHV achieving this goal. The Centre employs GPs, RACGP registrars, a psychiatrist, speech pathologist, clinical psychologists, developmental disability nurses, human relations' educator, researchers and administrative personnel all of whom have specific interests in developmental disability health.

The literature highlights poor levels of health experienced by people with developmental disabilities compared to the general population and an expectation that they access local health services, including their GP to have their health needs met. GPs have identified barriers to the provision of health services including inadequate training in developmental disability health and difficulties in determining an individual's health needs.

To date there have been few avenues for GPs to learn about the health needs of people with developmental disability and how to best provide quality health care. As part of education and training CDDHV will host the Inaugural National Medical Professionals Seminar in

Developmental Disability on November 8 & 9, 2001 at the Edmund Barton Centre, Melbourne, Victoria.

This seminar evolved from the response to a survey conducted by the Centre into the educational needs of Victorian GPs in developmental disability health. It will provide an opportunity for GPs to meet with local, national and international practitioners and specialists who have clinical and/or research expertise in the provision of developmental disability health care. The conference sessions will also enable GPs to practice new skills in workshops, discuss issues and increase their networks, professional supports and resource base.

Topics to be covered by the seminar include:

- Behavioural and psychiatric issues.
- Syndrome specific medical problems including genetics and the impact of current and future genetic advances.
- Neurological issues, such as epilepsy and spasticity.
- Management of the transition from childhood to adulthood and ageing in the context of medical issues and collaborating with other professionals and carers.
- The role of allied health therapies eg: speech and physiotherapy.
- Human relations and sexuality issues.
- Preventative health and primary health care and complex medical problems as they relate to specific syndromes.

The health care of people with developmental disability requires a broad based holistic approach that takes into account the social context of the patient combined with knowledge and skills in specific areas. GP's are the best placed to deliver medical care to this group. This conference - as well as the other activities of CDDHV offers participants the opportunity to learn from national and

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Where ASSID members work

Community Resource Unit: Brisbane

ASSID member, Lynda Shevellar is one of a team of people who work at the Community Resource Unit in Brisbane. Lynda reports:

The origins of CRU lie in the late 1980s and the air of excitement at this time with many initiatives being taken by the Commonwealth Government, including the establishment of the Office of Disability, the Disability Advisory Council of Australia, the Disability Services Program etc. Despite the exciting events happening around Australia, Queensland showed much less enthusiasm for the initiatives, was slower to sign up to reform and consequently missed out on much funding. Qld Parents of the Disabled (QPD), a small group of parents, workers and people with disabilities were outraged by the loss of opportunities for families in Queensland

and came together around a dining table to plan for the future. The result was a Search Workshop attended by over 100 service recipients, parents, service providers and government officials. Out of this workshop came the need to establish an organisation to work collaboratively with organisations in the disability field. This organisation was CRU. QPD established CRU in 1988 with 18 months of Research and Development Funding from the Commonwealth. Thirteen years later CRU receives no recurrent Commonwealth funding. It receives 10% of its recurrent funds for operational costs from Disability Services Queensland. The rest of its funding comes from membership support, workshops, one-off grants and projects.

The Community Resource Unit continues to aim at challenging ideas and practices which limit the lives of people with disabilities, and to inspire and encourage individuals and organizations to pursue better lives for people with disabilities. CRU's role is to support change that will enhance possibilities for people with disabilities to have lives that are typical of those in the general community. Hence it is a role of change agency rather than one of advocacy or direct service provision.

CRU has adopted a theory of change that emphasizes a change to the heart and mind – as well as changes to social structures. Through its work, CRU places emphasis on

innovation, person-centredness in services, safeguards for quality, positive visions and values, and the need for freely given relationships in the lives of people with disabilities. At the heart of this lies the importance of understanding the vulnerability of people who are marginalized in society.

The main activities of CRU include education, training, consultancy, the provision of information, and service evaluation, as well as supporting and advising people who are

themselves providing leadership. CRU has worked with more than 200 groups and agencies throughout Queensland and over 15,000 registrants have attended CRU training events in the last decade. The periodical, CRUcial Times is distributed to over 1700 readers three times a year.

One of CRU's recent

activities has been to release an important new publication called, "Telling the Untold: Families, Disability and Institutions – Stories of Banned and Unrequited Love". This book, woven from narratives that have been told by families for the first time, bears witness to the damage that is done when public policies and service systems ignore the importance of love-relationships within families, by offering institutions as the answer to the problems that families experience. The narratives, and an analysis of them, provide powerful insights into what is really helpful to families in times of need, identifies the characteristics of truly helpful professional practitioners, and stresses the need for policy makers to understand the impact of public policies, especially as they relate to people with disabilities and their families. Three years in the writing, the book will be officially launched on October 12th. It is an uncommon book, speaking as it does about love relationships within families.

Another major activity is the current planning of a three-day conference, called "Relationships and Everyday Lives: Building the Heart of Vital Communities", that is to be held at Griffith University in Brisbane from November 22-24. This gathering will celebrate the efforts and actions of communities that welcome people with disabilities. This conference is for those who are seeking ideas that strengthen communities, who are thoughtful about what



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The importance of mates.

Ann Penhallurick

At the outset, I should note that the following article is a personal one. The opinions and thoughts in it are my own and, although I am the editor of this magazine, do not necessarily reflect those of ASSID - Ann P.

Thursday was pay-day in the medium sized boarding house that Graham, Bruce and Michael lived in for many years. That meant it was fish-and-chip day. These three friends and the rest of their 'group' pooled their money and a couple of people would go down the road to the 'charcoal chicken' and buy a large meal of fish and chips and associated foods for tea. They refused the usual meal and the delicious smell of oily chips overtook the usual bland dining room odour. This weekly event was made all the more possible and enjoyable by the fact that they lived in a smallish town with a very decent local community.

Since then the boarding house has closed (a voluntary closure, rather than a forced one, it probably should be noted). There has been some excellent support put in by government departments and local NGOs – this is not a bad story at all. One of the problems, though, is that the loss of the congregate care facility has resulted in the loss of mates. Friendships that had lasted many years have been broken up as people have been moved into smaller group homes, some in the same area, others quite a way down the train line. Although most people have been able to access a much greater degree of government financial support and have been provided with high quality 'bricks and mortar' accommodation, they have lost out in these essential ways – they have lost friends, networks, the company of people who understood them even if they had a speech disorder, the time with people whose families knew them, the ability to go out independently (because now they have to do it with staff, rather than their mates, some of whom had better road skills), they have lost shared jokes, shared irritations, and those small moments of shared boredom that make communal living possible.

A couple of months ago I put a call out on ASSID-L about research on challenging behaviours and the movement out of congregate care. I received many responses – all of them extremely helpful. I was provided with some articles, spoke with a number of people and have a list of references waiting to be looked up when I have the time. I then put out a second call for information about research into peer networks and devolution of larger facilities. I did not receive one single response.

I was partly, to be honest, being a little disingenuous; I had



Friendships among women are an important aspect of health and well being, too.

already read enough and spoken to enough well-respected researchers to know that issues of peer-support, loss, interaction and so on has rarely, if ever, been considered when researching devolution, challenging behaviours, accommodation supports, employment options or virtually any other area of interest to people with intellectual disability and their advocates. This is not to say that compatibility has been completely ignored, nor that services have not considered who might get on with whom when establishing group homes; but it is to say that it has not been a part of people's lives which has received high priority and the effects on psychological well being of the loss of friendships (sometimes as evidenced by challenging behaviours) has not received a great deal of attention.

Graham and Bruce also used to go and play pool together in the local pub. Now that they live a much greater distance apart they are not able to do this. Considerations of geographic placement of group homes needs to take into account the possibility of continuation of friendships. One of them also now has to deal with a much more protective staff and finds it harder to go out without someone wanting to go with him. This issue of staff-client, staff-resident relationships is a complex one and outside the scope of this small article (there are also greater experts around than I in the area!), but the other side of it – that relationships with staff can preclude or obscure the need for relationships among contemporaries should be noted. It is

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ASSID National Conference: 2001

Special Interest Streams

The 36th Annual Conference of the Australian Society for the Study of Intellectual Disability will be held on the 12th-15th of November 2001 at the Copland Theatre, University of Melbourne. Up-to-date information is available about the conference at www.rmit.edu.au/departments/ps/assid.

Planning is well under way and the conference programme is looking exciting (also see Victorian State Update on p11 of IDA for more details). Registrations are now well and truly underway.

The theme for this year's ASSID Conference is "Citizenship and Participation in the Wider World". Special Interest Streams will continue this theme throughout the four days of the conference.

For further information about the conference itself contact the conference convenors:

Karen Nankervis

Phone: 03 9925 7363

Fax: 03 9925 7303

Email: karen.nankervis@rmit.edu.au

Bill Taylor

Phone: 03 9387 9985

Fax: 03 9459 6146

Email: milparinka@ozemail.com.au

There are a number of Special Interest Streams that will take variety of forms including papers, workshops, case studies, posters, best practice examples and forums. Specific inquiries about the Special Interest Stream can be directed to the convenor or to Carolyn Neville.

I hope to see you in Melbourne at the foremost intellectual disability conference in Australasia!

Carolyn Neville

Special Interest Stream Coordinator

Phone: 03 9925 7975

Fax: 03 9925 7303

Email: carolyn.neville@rmit.edu.au

Ageing

Convenor: Professor Adrian Ashman (QLD)

This stream will consist of workshops and symposia in the important area of ageing with an intellectual disability. If you are able to contribute to this stream, please contact Carolyn Neville (Special Interest Stream Coordinator) on the above details.

Autism

Convenor: Dr David Hamilton (VIC)

This stream is a forum for the presentation of both basic



and applied research on autism spectrum disorders. Reports on research in progress are welcomed, but should include an indication of preliminary findings. Descriptions of innovative curricula, teaching strategies, and approaches to service provision should include an evaluation of outcomes.

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Fax: 03 9925 7303

Email: david.hamilton@rmit.edu.au

Continence

Convenor: Jan Matthews (VIC)

The emphasis in this stream will be on the importance of continence acquisition, and appropriate continence programs, for people with an intellectual disability. Information will be presented on the Victorian government continence initiative, a program funded by the Commonwealth government and recent initiatives in the United Kingdom. Additional papers to be included in this symposium are welcomed.

Phone: 03 9925 7362

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Discourse and Identity

Convenor: Ann Penhallurick

People with disability have been for too long reduced to being their disability. The Identity and Discourse stream encourages the discussion of recent approaches to disability theory and practice - including social construction theories, cultural and discourse analyses. This stream aims

to generate more 'radical' ways of thinking about how disability is created and how the creation of disability impacts on people who are living with 'it'. In raising questions of identity and discourse it is also possible to begin rethinking where the questions that we ask in research and where the approaches we adopt in practice come from – thus opening up a space for innovative theory and practice.

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Dual Disability

Convenors: Professor Trevor R Parmenter PhD(NSW) and Caroline Mohr (VIC)

Professor Tony Holland from the United Kingdom will feature in the Dual Disability Special Interest Stream at this year's ASSID conference. Along with Professor Holland a large number of papers in the area of people with both psychiatric and intellectual disabilities will be presented. This symposia welcomes papers in the area of dual disability for consideration.

Professor Trevor R Parmenter PhD(NSW)

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Caroline Mohr (VIC)

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Forensic Issues

Convenor: Associate Professor Susan Hayes (NSW)

The Forensic Issues stream aims at providing a forum for presentation of research results and practice examples, as well as offering opportunity for discussion about people with intellectual disabilities who are involved in the justice system. They may be offenders or victims of crime, participants in family law matters, or involved in issues of guardianship and medical consent. Descriptions of research in progress and evaluation of innovative programs are welcomed.

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Email: s_hayes@bsim.usyd.edu.au

Health Convenor:

Assoc Prof Robert W Davis

This stream will aim to inform conference delegates of the recent developments in health research and services. The stream will consist of papers, workshops and symposia on a wide range of health issues including evidence based clinical practice, reports on important population studies

into health and health care provision and preventative health. A forum of health services and academic centres from throughout Australia entitled "Health, a Happening Thing" will involve presentations on current activities and will be followed by a discussion of health issues, potential areas of collaboration, advocating a national agenda and strategies for health promotion.

Phone: 03 9564 7511

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Email: robert.davis@med.monash.edu.au

High & Complex Needs

Convenor: Tracy Martin-Nixon (NSW)

This is a practical stream aimed at sharing processes and practice to improve the participation and the lives of people with an intellectual disability who have high and complex needs. This may take the form of case studies, papers, posters, Best Practice examples and Round Table discussions.

Phone: 02 9692 7117 (AH 0414 942 092)

Fax: 02 9692 7171

Email: Tracy.Martin-Nixon@community.nsw.gov.au

Human Relations and Sexuality

Convenors: Patsie Frawley (Vic) & John Brown (NSW)

This stream is a forum for the presentation of research, program development and new initiatives in the areas of Human Relations and Sexuality for people with an intellectual disability. Papers and workshops are welcomed on work in progress with preliminary findings, examples of programs and/or policy development and presentations showcasing new initiatives in education, counselling and training with evaluations of outcomes and recommendations for future application. The aim is to create a focus for service providers, researchers and people with an intellectual disability who have an interest in program and service improvement in this area.

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John Brown

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Parenting and intellectual disability

Convenors: Dr. Susana Gavidia-Payne & Ms Robyn Mildon (VIC)

The aim of this stream is to bring together research and practice which address issues pertaining to parents with a disability, and parents of children with a disability. Of

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Queensland

After the successful Sharing the Road conferences in Brisbane and Townsville, things have been relatively quiet here in Qld. But we have a couple of interesting events coming up.

Sharing the Road produced some fascinating discussion, particularly from Disability Support Workers themselves. Especially appreciated in Brisbane was the expert input by Michael Kendrick (USA), Judith McGill (Canada), Asirvatham Jeyabalan (India), Jayne Clapton and Jane Sherwin (Brisbane) and Michael Bleasdale (NSW). It was also very good to see people with disabilities also taking part as presenters and co-presenters at both conferences. Mike Duggan's keynote in Brisbane on disability, oppression and freedom was, as always, inspirational.

A highlight of the Townsville conference was the arrival of

8 Harley Davidson motorcycles, one of which ended up in the auditorium! The members of the local hog group were there to support a man with profound disabilities whom they have welcomed with open arms, not because he has a disability, but because, as they said, "he belongs". Another highlight of the Townsville conference was active participation by indigenous support workers. This is something that I hope will continue.

In September we have our State conference followed by our AGM. The conference is shaping up to be a very interesting event, with topics as varied as the human genome project, epilepsy, advocacy and ageing. Keith McVilly will also be up to talk about his friendship project. Expect more on the State conference and outcomes of the AGM in the next issue.

Chris Montgomery

Western Australia

Our AGM is next month on the 19th. It's an early evening meeting followed by food and a chance to meet and mingle. The guest speaker is Sheila McHale, MLA, Minister for Disability Service. As a lead-in to the AGM an informal meeting of members was held on 9th August to discuss the way forward for the State Branch in the coming year. The final event of the year is the State Conference set for mid to late November following the National Conference. A date will be fixed soon. This is usually a most successful and well-supported event that everyone looks forward to at the end of the year.

Cheers, Janine Smith

NSW

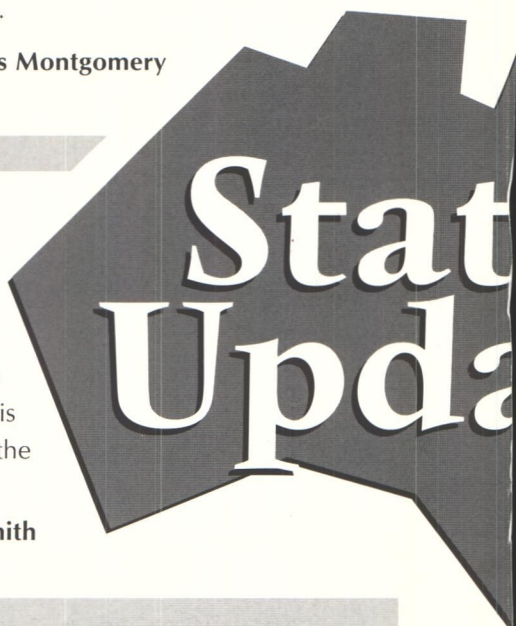
It's been terrific to see ASSID members and their guests eagerly attending two NSW State events in the past couple of months. The seminar on Sex Offenders held in Albury attracted a goodly audience (and not just because of the catchy title) and there was an energetic roomful of people for the first NSW hot topic night held at CDDS in Sydney recently. At this latter we discussed the vexed question of ethics: what are they and where we get them. Dr Tim Griffin (not so long ago, the National President of our organization) provided an informative introduction to the questions that ethics committees must address when assessing the viability of research and then the discussion was thrown open. Enhanced communication and the opportunities for information gathering and exchange appeared to be important issues - the discussion revealing that without these, issues around ethics can be too readily side-lined. Informed consent and the possibilities thereof was another sub-topic that incited discussion. The only problem with the evening was that people did not eat

enough and the committee members had to take home lunch for the next day!

A sub-committee of the NSW State Council is currently working on the state conference for 2002, planned to be in Wollongong. The date is to be early June (final dates and venue to be notified), for a two-day event.

We are also now planning the NSW AGM for 2001. This is to be held on Thursday 25th October, in Sydney. All ASSID (NSW) members are more than encouraged to attend. The past few years have seen some stoic council members willing to volunteer year after year; the years have also seen the increasing presence of new members prepared to put their hands up for council. It is to be hoped that this mix can continue and develop - so members, new or experienced, please feel free to come along and 'join the team' (as they said in the 1980s, I think it was).

Ann Penhallurick penhall@bigpond.net.au



South Australia

The SA branch recently ran an event entitled "Yes, But..." - a workshop on rhetoric versus reality in the field of supporting people with an intellectual disability. The event was chaired by John Harley - the Public Advocate. Panel members discussed a range of areas.

Discussion participants included Richard Bruggemann (CEO of IDSC) on pertinent legislation and implications thereof and Ross Womersley from the Community Living Project, who discussed what had and had not changed in the 20 years since the "Intellectually Retarded Persons Report" was published in SA. Several parents of people with intellectual disabilities discussed their experiences as carers- it was encouraging to hear they had many 'good news stories' to tell.

Patrick McMurray of Minda Inc spoke on employment, defining employment in terms of that which contributed to 'social capital'. Implications of Commonwealth/State Disability agreement were discussed along with the impact of economic rationalism in this area while Frank Walsh

(IDSC) and Margaret Kyrkou (Child and Youth Health) brought our attention to health issues. Positive steps and proactive strategies were discussed. In all, a thought-provoking event. Including panel members, over 50 people attended, including consumers and their families. A preliminary review of feedback collected suggests that the event met people's expectations.

The SA branch has entered into some correspondence with Adelaide's universities and has been getting a response that flags the possibility of greater levels of mutual support and participation. At the very least we are anticipating some events down the track, with researchers discussing their work.

Planning for the our AGM is proceeding with the SA Branch hoping to recruit some additional energetic individuals to the committee to keep it all happening. Members (and strategically targeted non-members) will be provided with details soon.

Richard O'Loughlin for the SA branch.

Tasmania

Our Tasmanian committee members are enjoying a well earned rest after the State Conference held earlier this month. All present agreed that the Conference was a great success, with the added bonus of good consumer representation, boosted by Self Advocate Roy McAlpine's Keynote Presentation at the beginning of the Conference. In general, this was a good rehearsal for next years National Conference, also to be held at Wrest Point Casino. Watch this spot for more details!

Also taking place at the Conference was our AGM. I was elected State President, with Dee Woods as Vice President. We have a good sized, motivated committee this year, eager to further generate ASSID's good reputation in the State.

Still to come is our State Planning Day, scheduled for October. Some ideas to be kicked around on the day include the possibility of some collaborative research in conjunction with Forensic Mental Health and some work towards expanding support networks for ageing parents of people with disabilities.

With a Hot Topic Night to be held within the next three months, our members don't have much longer to rest before starting work again.

Cheers, Virginia Downton

Victoria

Greetings from Victoria where we are fast approaching the 36th National Conference of the ASSID, held 12 - 15 November in Melbourne this year. Needless to say members of the Victorian branch are busy working towards producing a dynamic conference that includes a wide range of Special Interest Groups, presentations and workshops. In the process two initiatives have been introduced to the conference program.

With support of the Minister for Community Services and the Department of Psychology and Disability Studies at RMIT University, Victorian ASSID is pleased to announce the first Victorian Direct Support Worker Conference. This two day conference will be conducted on Thursday 15 - Friday 16 November and overlaps with the last day of the National ASSID Conference. Linking both conferences together creates the opportunity for workers from a wide range of roles within disability service provision to attend a relevant event and share their expertise. Consequently the exchange of ideas, opportunities to establish networks and the range of programs and sessions to chose from would be enriched by the experience and skills of delegates that reflect the diversity of disability services. For further information please contact Ms Kathy Stebbings on Phone: (03) 9925 7363.

A Cocktail Party Awards Ceremony is another initiative that will be introduced at this year's conference. The

continued on page 14

The Developmental Disability Unit at the University of Queensland

Assoc. Prof Nick Lennox.

This unit was established in Sept '97 with the goal of improving the health and wellbeing of adults with an intellectual disability in Queensland. The Unit divides its time equally between research, clinical work and education. It has a small core budget and includes a Director-Medical Practitioner, a Project Officer and an administrative support person.

Education is provided to people with disabilities, families, a variety of disability and health staff, psychologists, medical students and medical practitioners, including trainee General Practitioners and Psychiatrists. Presentations and seminars cover health and intellectual disability, dual diagnosis and physical healthcare.

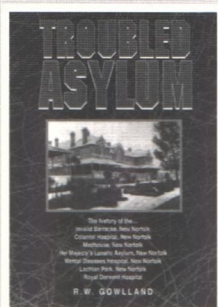
The clinical activities involve a provision of a clinical service, both by direct consultation and telephone consultation. This service is highly regarded by carers and families and works in collaboration with a private psychiatrists and his registrars.

Community Resource Unit *continued from page 6*

we mean by the word 'community', and who wish to understand the threats to community vitality. The conference will go beyond the usual service approaches and suggest another approach; one that is underpinned by the beliefs that without relationships there is no future plan; visions are creations of the heart as well as of the head; and that there is no disability that precludes relationships and deep connections with others. The conference is expected to gather together people with disabilities, families, service workers, activists, and interested citizens.

Thanks to the CRU team - The Ed.

TROUBLED ASYLUM



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

Post your cheque for \$30 (incl. GST) made payable to "ASSID TAS INC." to:

Book Offer

PO Box 572, MOONAH, TAS. 7009

The research of the Unit has been quite substantial and a major success. It has been involved in a significant research projects including -

- The behavioural and medical assessment, which examined the combined implementation of medical and behavioural assessment and management
- An evaluation of the Qld Disability Services Health and Wellbeing Manual,
- An evaluation of the barriers to implementation of the Comprehensive Health Assessment Program in DSQ services, NHMRC funded CHAP project - A randomised-controlled trial of a Comprehensive Health Assessment Program throughout the whole of Qld involving 454 adults with an intellectual disability. The project is the largest of its type in the world.
- Advocacy and Health. A project in assisting people, particularly families and self advocates, to improve their health advocacy skills. These skills are reinforced and used in combination with a 5 year health diary, called the Ask Diary

The Unit also has supported research looking at Helicobacter Pylori and Behavioural Assessment.

The Unit has also been involved in informing Government at a number levels with regards to the health and wellbeing of this population. Most recently this has concerned people with severe challenging behaviour and how the delivery of services can better meet the needs of this population.

In addition, the Director of the Unit, in his former role as Head of the DDU at the University of Melbourne, and while at the University of Queensland, worked with a great many practitioners to publish the first whole of life book on health and intellectual disability in the world. Published in 1999 *Management Guidelines: People with Developmental and Intellectual Disability*, has been extensively used by advocates, professionals and families.

The work of the DDU continues to evolve as we increase our knowledge of the health and well being issues that impact on the lives of people with developmental disability.

For more information:

Management Guidelines: People with Developmental and Intellectual Disability, available through

Therapeutic Guidelines

2/55 Flemington Road, North Melbourne

Free Call 1800 061 260

www.tg.com.au

What's on - research:

Call for contributions: 'Ageing In Place' Disability Services Sourcebook

The Centre for Developmental Disability Studies (CDDS) has received a grant from the Bernard Judd Foundation (The Hammond Care Group) to develop a Sourcebook about good practice in supporting people to 'age in place' or training providers in philosophy and issues of ageing for people with life-long intellectual and/or physical disabilities.

CDDS is seeking nominations from people who may be implementing good practice in 'ageing in place' for people with life-long disabilities. 'Ageing in place' refers to practices which facilitate the person remaining in their own home as they age and their support needs increase.

People with life-long intellectual and/or physical disabilities are living longer due to improved health and community care such that the life expectancy of people with life-long disabilities is not much less than the population in general. This, coupled with the number of people with life-long disabilities in the 'baby boomer' generation means that this group will form a significant proportion of ageing Australians. Because of their disabilities, many adults with a life-long disability will age in formal supported accommodation services, where they have lived most of their adult lives. These people are particularly vulnerable to being placed in institutional care when their support needs increase beyond

the capacity of services to maintain that care.

The purpose of the Sourcebook is to gather and disseminate examples of how best to enable people with life-long disabilities to age in their own community homes. The Sourcebook will be a system whereby services can identify, replicate and support best/innovative practices so they change from being 'isolated best practice' to 'common practice'. The completed Sourcebook will be disseminated actively through workshops and seminars of service providers and will be accessible through the CDDS webpage and newsletter. Its availability will also be advertised through industry newsletters and journals and will be disseminated through appropriate conferences.

If you are currently providing innovative support to people with a life-long disability who are ageing, or if you know of someone else who is, please nominate the practice for inclusion in the Sourcebook.

Nomination form is available from Angela Dew at the Centre for Developmental Disability Studies, PO Box 6, Ryde NSW 1680 or request by fax it to (02) 9807 7053. You may also contact Angela on (02) 8878 0513 (leave a message on the voicemail if Angela is unavailable when you call), or email to adew@med.usyd.edu.au

ASSID National Conference Special Streams *continued from page 9*

specific interest are reviews of contemporary topics in these areas, as well as research presentations that report findings about supports and interventions designed for/with parents and their children. Papers for two symposiums and participation in a roundtable are welcome in this stream.

Physical Activity & Healthy Eating

Convenor: Associate Professor Jeff Walkley (VIC)

This stream is a forum for applied research and practice in the promotion of physical activity and healthy eating. Reports on research in progress are welcomed, but should include an indication of preliminary findings. Descriptions of innovative approaches to promoting physical activity and healthy eating should include an evaluation of outcomes.

Phone: 03 9925 7359

Fax: 03 9467-8181

Email: jeff.walkley@rmit.edu.au

Staff & Workforce Issues

Convenor: Dr Karen Nankervis (VIC)

The relationship between staff training, organisational

structure, staff retention and other issues will be explored in this symposium. Papers, Best Practice Examples and Case Studies on staff and workforce issues are sought for this Special Interest Stream.

Phone: 03 9925 7363

Fax: 03 9925 7303

Email: karen.nankervis@rmit.edu.au

VALID Convened Stream

In keeping with the theme of this year's conference, the Victorian Advocacy League for the Intellectually Disabled (VALID) will be convening a stream of the conference promoting discussion on how issues presented in papers at the conference impact on the lives of people with an intellectual disability. This stream will be run on the last two days of the conference. At the conclusion of the conference, people attending this stream can participate in a dynamic keynote address, with delegates from all around Victoria sharing their views on how current practice in the disability area impacts on their lives.

Phone: 0419 377 911

Fax: 03 9362 1141

Email: jonibennett@start.com.au

Must Reads

Handbook of Disability Studies



G. Albrecht, K. Seelman, M. Bury, eds.

Sage Publications, Thousand Oaks, CA, 2001

864 pages. \$US89.95. Available from Sage Publications, email order@sagepub.com.

2455 Teller Rd, Thousand Oaks, CA 91320, USA.

Although this book is not available in your local bookshop, it should be (it can be ordered easily, however). This truly is a 'must read'. It's a big book, one that can be used as a source guide, a reference text and an inspiration for thought and action. The Handbook of Disability Studies is, as the name suggests, a text that should become essential, and possibly definitional, in the growing field of 'disability studies'. Its 34 chapters (plus introduction) are divided into three sections: The Shaping of Disability Studies as a Field, Experiencing Disability, Disability in Context. Clearly it is a text for all disability areas, with Trevor Parmenter providing an excellent discussion for those with a specific interest in intellectual disability.

There are, of course, potential difficulties with including people with intellectual disability under the wider disability 'banner' – many fear the less strident voices of people with intellectual disability and their advocates will not be readily heard, for one. However, perusing the Handbook allows us to see the enormous benefits of

engaging with the wider discussions. Chapters in this book – such as 'Philosophical Issues in the Definition and Social Response to Disability' (David Wasserman) and Tom Shakespeare and Nick Watson's 'Making the Difference: Disability, Politics and Recognition' underline how important it is to approach (intellectual) disability through the critiques of disability as social construct. Intellectual/developmental disability has for too long remained isolated, caught in a negative discourse about what is not working – this book enables us to think beyond categories, paucity of resources and service failures.

The third section of the Handbook, Disability in Context, takes us well beyond theorising and looks at practical effects and issues. Chapters such as 'Support Systems: The Interface between Individuals and Environments' (Simi Litvak and Alexandra Enders) are pertinent across the broad field of disability policy and practice. This whole section is an introduction to an agenda for change.

The Handbook of Disability Studies should be in every university library. It is also worthwhile having on the shelves of individuals. Although it is a hefty cost when translated into Australian dollars it's remarkably good value – there's at least four very expensive books rolled into this one!

- Reviewed by Ann Penhallurick

Victorian state update *continued from page 11*

Minister for Community Services will recognise a number of Direct Support Workers and agencies, whether individually or as a team, for their service to people with a disability and professionalism within the field.

While committee members are currently focussing on the impending National Conference, the Victorian branch has managed to conduct some other interesting events to date. For further information please contact Ms Karen Nankervis on Phone: (03) 9925 7363.

While it seems as though it was an eternity ago, a very successful State Conference was conducted in July this year at Bendigo. Under the dedicated organisation of Ms Kathy Stebbings the conference was attended by over 100 people and provided one of the few opportunities for workers in disability services to gather together from all areas of the state. Last Friday the inaugural Research

Network Meeting was held in Melbourne. The state branch has established this network to promote the exchange and sharing of information relating to research in disability and anticipates that it will be an ongoing event. For further information please contact A/Prof Bob Davis on Phone: (03) 9564 7511.

Finally we extend an invitation to all members for the Annual General Meeting of Victorian ASSID. The meeting will be held at 7:30pm on Thursday 11 October at Art's Project, 116 High Street in Northcote. All members are welcome to attend and if you would like to nominate for a position on the committee please contact me for a nomination form.

See you all at the 36th National Conference and Direct Support Workers Conference in November.

Alex Phillips

Ethics and Advocacy: call for contributions

The NSW State Branch of ASSID recently held an evening to discuss, Ethics: what are they and where do we get them? The impetus for this evening came from a discussion on ASSID-L. It was a lively discussion about an area clearly of interest to all ASSID members. We have decided to pick up this question of Ethics for the December special edition of *Intellectual Disability Australia*, to try to explore what ethics are, and/or ethically should be, in the research and practice of intellectual disability.

WE NEED YOUR INPUT! To make the special edition on Ethics and Advocacy work we need to hear what you are doing, what you or your department/ service area think about ethics. We are particularly interested in ethics in relation to practice – accommodation, day programs, behaviour and communication support and so on. Universities and government departments, as well as professional bodies, have long had ethical guidelines for their staff, but what about more direct care? Should there be ethical statements? What would they say? And in what ways might ethics affect family interactions – and workers interactions with families?

When we think about ethics and people with intellectual disability, many of whom have difficulty readily expressing their needs, we have to also think about the role of advocates and advocacy. We are also seeking articles, information and interest from individuals, families and organizations who support people with disability, who act as advocates. What is your role? What should it be? How could it be improved? Other areas of interest include: informed consent, ethical considerations in research outcomes, ethics and funding and so on.

Opportunity for ASSID members to participate.

Contributions called for the *Ethics and Advocacy Special Edition*. Do you have something to say about these essential topics? Send your thoughts, ideas, articles to IDA by

November 15th this year

Email: penhall@bigpond.net.au

The importance of mates continued from page 7

easy to 'blame' the way that the concepts of normalisation have been interpreted in day-to-day practice for this – and possibly quite rightly so. Even small groups of people with disabilities have come to be seen as abnormal, 'open' employment has been much more highly valued than employment with other people with disabilities, social contact with people without disabilities is the contact that rates on the scales (quality of life) and generally there has been much greater emphasis placed on people with disability going out with people without disability.

Yet, when I spoke with Graham and Bruce and Michael and their friends before they moved out of the boarding house, they consistently identified 'mates' or 'friends' as being of great value to them. They did not identify staff or a particular type of housing or being able to participate in the domestic work as being important. They continue to consistently identify being with friends as important and to identify missing friends as a cause of dissatisfaction. The services that are now providing accommodation for them have made some attempts to redress these problems but it is almost impossible to do so within the current model of accommodation which insists on small houses integrated (or do we mean isolated?) in mainstream areas and day programs where the emphasis is on skill development out

of the home, rather than on hanging around and having visits with mates.

Since being away from his friends Graham in particular has been very anxious. He has become more dependent on staff and saddened by missing his erstwhile regular pool games and fish and chip nights. I, for one, don't think that this is good enough. I think it is time that all government and non-government organizations listened to people with disabilities themselves and developed policies and procedures which matched people for more than statistical similarity (age, gender and not much more). The seeking of detailed history from a person where possible and of a person where they cannot give it themselves is essential – and this should not be simply a set of tick boxes filled in by a staffmember who has known someone in one circumstance for a few months (there are real debates about the reliability of proxy reporting for starters). The planning of group homes – their geographic position, their resident composition, their out of hours activities – must only begin on the basis of known likes/dislikes, established friendships and family networks, activities that are valued by the person who will live there. There is no shame in being seen with a person with a disability – even if you have one yourself!

IASSID Update

Professor Trevor Parmenter, Immediate Past President, IASSID.

Montpellier Congress

Following the highly successful Seattle Congress held in August 2000, an energetic Program Committee, led by President-Elect Professor David Felce, is busily laying the foundations for the next Congress to be held in June, 2004, in Montpellier, France.

In conjunction with the IASSID Council meeting to be held on 27th September, 2001 in Berlin, Germany, the Program Committee will formally meet to progress the planning processes, including the content of the First Announcement. One of the priorities on the agenda of the Council meeting, President Neil Ross has indicated will be an examination of the Business Plan for 2001-2004 proposed by the Immediate Past President, Trevor Parmenter.

Special Interest Research Groups (SIRGs)

Negotiations are proceeding with the World Health Organization (WHO) to process the position papers prepared by the Quality of Life, Physical Health and Mental Health SIRGs. The joint publication by WHO, IASSID and INCLUSION International of the Ageing SIRG, Ageing and Intellectual Disabilities, Improving Longevity and Promoting Healthy Ageing was launched at the Seattle Congress. It is hoped similar publications will follow the acceptance by WHO of the remaining three position

papers that were part of the collaborative work plan established through the Non-Government Organization Status (NGO) that exists between IASSID and WHO. Copies of the special issue of the Journal of Applied Research in Intellectual Disability that contains the papers from the Ageing SIRG will be available for sale at the Melbourne National Conference of ASSID in November.

There is now a wide range of SIRGs within IASSID, in addition to those mentioned. These include: Empowerment & Citizenship; Ethics; Family issues; Nursing; Parenting; Forensic; Employment; Individuals with multiple disabilities and Social integration. Ageing, Ethics and QoL SIRGs held Roundtable talks earlier in the year and Physical Health and Mental Health will have meetings in September, 2001.

Regional Groups

Council has also approved the establishment of Regional Groups. A new Regional Group, IASSID-Europe has just been instituted under the French Charitable and Voluntary Organizations Law, 1901, which is celebrating its centenary in France this year. The inaugural conference of IASSID-Europe will be held at the University College, Dublin, 12-15th June, 2002. It is hoped that many Australians might be able to participate.

Preliminary discussions have been held concerning the development of an Asia-Pacific Regional Group. This proposal will be discussed at the Ageing and QoL SIRG Roundtables to be held in Japan in March, 2002.

INCLUSION International Congress, Melbourne September 22-26, 2002

IASSID has been invited to participate in the Congress Program. This is an excellent opportunity for ASSID members to be involved as one of IASSID's major organizational members. It is anticipated there will be an IASSID Council meeting held in conjunction with the Melbourne Congress. NCID is helping to host this important Congress.

Individual Subscribing Members

There is a growing number of people around the world joining IASSID as individual subscribing members. The cost is modest (despite our weak dollar). Benefits include subscription to the Journal of Intellectual Disability Research, Newsletter, and reduced registration for IASSID Congresses. Contact Treasurer and Membership Committee Chair, Dr Matt Janicki for further details mpjz@aol.com OR iassidoffice@aol.com

What is IASSID?

The International Association for the Scientific Study of Intellectual Disabilities (mental retardation and related developmental disabilities) is an international and interdisciplinary scientific organization that promotes worldwide research and exchange of information on intellectual disabilities. The association (originally named the International Association for the Scientific Study of Mental Deficiency) was founded in 1964 and has sponsored eleven World Congresses. IASSID is the first and only world-wide group dedicated to the scientific study of intellectual disability. The President of IASSID is Dr. Neil Ross

ASSID's involvement with IASSID dates back many years with active members of ASSID gaining prominence at the international level. Professor Trevor Parmenter is the Immediate Past President of IASSID. Trevor has provided us with an update on current IASSID activities. ASSID also hosted the extremely successful international conference in 1992.

What's going on: conferences

One of our very energetic Victorian members, **Daniel Leighton** attended the Forensic Disabilities Conference recently. IDA has observed (using qualitative rather than quantitative methods) that this an area of interest to the membership of ASSID and so asked Daniel for some feedback from this conference, which he has kindly supplied.

Report on Forensic Disabilities Conference: Challenging Systems, Challenging People

Victims and offenders with disabilities: Prevention, Detection, Investigation & Intervention.

Melbourne, 23rd & 24th August, 2001.

ACSO, the Australian Community Support Organisation (and ASSID Organisational Member) hosted this important conference as an opportunity to bring together professionals from around Australia and New Zealand to network and swap ideas as to how best improve the quality of forensic services for all. The conference was well attended, attracting over 150 advocates, outreach workers, justice personnel, prison officials, psychologists, solicitors, barristers, social workers and students.

A well designed program allowed for participation, thought and debate and was designed to provide practical and theoretical advice. The two days were divided between papers, workshops & plenary sessions. Topics that were examined at the conference included: Fitness to plead issues (from WA, New Zealand and New South Wales); Dual diagnosis (including the intersection between psychiatric services and disability services); Sexual offending (including identification of people at risk

There is also a new category of New Member – Research Centre – the fee for which is \$125 per annum. See web site for details.

IASSID Web site

Visit the Web site at www.iasid.org

Australian Council Representatives

Council members from Australia are Professors Phil Foreman, Bob Cummins and myself as Immediate Past President.

Relationship with organizational members

I have urged Council to increase its communication with organizational members. Reciprocally, ASSID might consider sending copies of its publications to Executive members of IAASSID.

TREVOR R. PARMENTER

of offending, social skills training, and psychotherapeutic group treatment); Court diversion programs; Police interviews (rights of the suspect; witnesses with intellectual disability & independent advocate systems for offenders and witnesses); Prison services for offenders with intellectual disability; Forensic social work issues; Community treatment orders and an examination of some creative service responses within Victoria and other jurisdictions.

The idea behind bringing together people in this area is one of merit, and I hope to see it repeated again next year. The conference happy hour provided a good opportunity to re-acquaint with old colleagues, as well as meet and share ideas with new ones. Personally, I enjoyed the opportunity to meet with representatives from New Zealand and discuss the service system that they operate under, particularly with the looming introduction of the Intellectual Disability (Compulsory Care) Bill. Perhaps the biggest disappointment of the conference was the noticeable absence of any police forces either as presenters or delegates.

For those that were unable to attend, a number of participants are planning to present at the ASSID National Conference in November as part of the Forensic issues special interest stream. I look forward to it.

Daniel Leighton



**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

Avoiding viruses, keeping contact: Make ASSID-L work.

Recently a spate of viruses saw a number of people unsubscribe from ASSID-L. I am urging you all to rejoin and encouraging all those stayers out there to begin using our email list more energetically so that it can truly become a discussion forum.

Viruses do happen and ASSID-L is safer than most lists from them. Monash University – where ASSID-L is ‘housed’ - has updated its virus protection since the recent problems and it is very unlikely that a virus will spread through our list. However, the salient lesson is also that it is imperative that every PC has its own virus protection and that this is regularly updated. This is not difficult or

particularly expensive to do, it avoids a lot of problems and means that each of us can feel comfortable in contacting the other.

I was, I admit with apologies to anyone to whom I inadvertently passed the virus to, part of the chain of virus which spread like those letters that came around when we were kids; ‘send this to ten friends within the next 24 hours and you will receive 6 million post cards from the most exotic places in the world’/ or ‘if you don’t you will have 24 years of bad luck’ (and so on). The only good thing about it for me was that my teenage son was away and I had to solve it myself – which I did, despite Telstra telling me that it wasn’t even a virus (they said it was their own server problem, no less) and the fact that I am PC illiterate (I am a dedicated Mac user but the email is on a PC of some disreputable sort).

Although the computer ‘fixers’ I contacted warned that I would have to have my hard drive erased, I solved my virus problem without any loss of data, without cost and with a great deal of increase in my knowledge. Part of this was due to the excellent advice provided by (Dr) Bob Davis, the ‘web-master’ (I think he deserves that title even if it is not quite apt) of ASSID-L. Bob provided much better information than any of the overseas or local experts that I was able to contact. In other words ASSID-L can be of great use to us all!

ASSID-L has had some excellent discussions over the past few years but recently has been very quiet. It is important to use ASSID-L as a way of interacting with colleagues from all over the country – our practice is better for it and the quality of lives of our clients is enhanced because of it. So, back to the computer, one and all; life is a never ending learning curve!

-Ann P

ASSID-L

A mailing list for people with an interest in intellectual disability. Access to this list is included as part of “Australian Society for the Study of Intellectual Disability” membership and is intended to improve communication between us all.

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

To subscribe, send a message to ddu@med.monash.edu.au, leaving the subject line blank. In the body of the message, type ‘subscribe ASSID-L (your email address)’ - making sure you put your email address in! Then, sit back and smile, you will be notified in a couple of days.

The life and activity of ASSID-L depends on its members. Use it to search for research collaborators, to discuss disability-related news stories, to recommend new literature etc.etc. You’ll receive early notification about conferences and about the contents of ASSID’s journals and magazine.

Centre for Developmental Disability Health Queensland *continued from page 4*

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What is citizenship?

This is a central question to the theme of the ASSID National Conference, 2001 (Melbourne, Nov 12 - 15th). The 'Budapest Declaration' of 1999 states that citizenship:

- Constitutes a lifelong learning experience and a participating process developed in various contexts: in the family, in educational institutions, in the workplace, through professional, political and non-governmental, organizations, in local communities and through leisure and cultural activities and the media, as well as through activities for the protection and improvement of the natural and man-made environment,
- Equips men and women to play an active part in public life and to shape, in a responsible way, their own destiny and that of their society,
- Aims to instil a culture of human rights which will ensure full respect for those rights and understanding of the responsibilities that flow from them,
- Prepares people to live in a multi-cultural society and to deal with difference knowledgeably, sensibly, tolerantly and morally,
- Strengthens social cohesion, mutual understanding and solidarity
- Must be inclusive of all age groups and sectors of society.

The goal of full citizenship for those who are without power in society can be achieved only through sustained effort of those who are in power: come to the National Conference and demonstrate your solidarity with people with disability. (see back page for details)

Centre for Developmental Disability Health Victoria *continued from page 5*

international experts in the field and make a difference in the delivery of health care to this marginalised group of patients

Further information

For further information about CDDHV and for registration details for the Inaugural National Medical Professionals Seminar in Developmental Disability contact:

Jenny Morrison,

Centre for Developmental Disability Health Victoria
Suite 202, 3 Chester Street, OAKLEIGH

Telephone: (03) 9567 1518

Facsimile: (03) 9564 8330

E-mail: jenny.morrison@med.monash.edu.au

Web address:

www.med.monash.edu.au/generalpractice/units/cddh

Information exchange

In this column we will try to keep ASSID members up-to-date with fellowships and calls for papers and other items which might be of benefit to them in developing their expertise in the area of intellectual disability.

If you know of any item that may be of interest to your fellow members please let us know: penhall@bigpond.net.au or fax: 02 9571 8669

Fellowship

The Rosemary Dybwad International Fellowship Trust has announced a new round of requests for project proposal for its 2002 funding cycle. The announcement is posted on the IASSID website at <http://www.iassid.org/communication/dybwad.htm>. Individuals who wish to apply for travel/study grants of up to \$4000 are most welcome to apply and the deadline is December 1, 2001. The criteria are posted on the website. Applications are taken from any country in the world for travel to any other country in the world.

Calls for Papers:

Special Issue on Family Research in the Journal of Intellectual Disability Research.

Submissions are invited concerning family research pertaining to intellectual and developmental disabilities across the lifespan. Submissions are particularly welcomed which include: reports of empirical quantitative and qualitative research concerning families; cogent and timely research reviews related specifically to family research; and theoretical, methodological or philosophical critiques of the family research literature. This special issue on family research will be published in early 2003. Deadline for submissions is Friday 21 December 2001. Early submission is encouraged.

Send three copies of each submission, following

APA format to: **Dr Chris Hatton**

Institute for Health Research,

Lancaster University

Lancaster, England LA1 4YT

Email: c.hatton@lancaster.ac.uk

Submissions are encouraged in Word and on a 3.5" floppy disk (or electronically via email as an attached document). Contributing authors are referred to the information to contributors section of JIDR for further information on the format of submissions. Instructions for authors.

Upcoming Events . . .

October 12 - 21, 2001

Awakenings Performing Arts Festival

(a wonderful event, participation for all!)

Horsham, Victoria

Contact: 03 5382 6789, Fax: 03 5382 1566

Email: wimnet@netconnect.com.au

November 8 & 9, 2001

Inaugural National Medical Professionals' Seminal in Developmental Disability

Melbourne

www.med.monash.edu.au/general-practice/units/cddh/education/
or Jenny Morrison

Centre for Developmental Disability Health Victoria

E-mail: jenny.morrison@med.monash.edu.au

Telephone: (03)95671518

Facsimile: (03)95648330

November 12 - 15, 2001

ASSID ANNUAL NATIONAL CONFERENCE

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

Participation & Citizenship in the Wider World

Copeland Theatre,

University of Melbourne

Contact: **03 9925 7363**

Facsimilie: **03 9925 7303**

E-mail: karen.nankervis@rmit.edu.au

Website: <http://www.rmit.edu.au/departments/ps/assid/>

November 15 - 16, 2001

Victorian Direct Support Worker Conference. (overlaps with the last day of the National ASSID Conference). Melbourne.

Info: Ms Kathy Stebbings on Phone: (03) 9925 7363.

November 22 - 24, 2001

"Relationships and Everyday Lives: Building the Heart of Vital Communities"

Griffith University, Brisbane

More info: lyndashevellar@cru.org.au

November 29 - December 1, 2001

International Society for Quality of Life Studies (ISQOLS)

'How to Measure Quality of Life in Diverse Populations

Washington DC,

info: <http://www.cob.vt.edu/market/isqols>