

IDA

Intellectual Disability Australasia

*family stress
sexuality and relationship education
the tooth, the whole tooth, ...*

mental

age

financial

physical

emotional



*respite
family funding
in-home support
out-of-home placement*

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research to practice

Intellectual Disability Australasia is produced and distributed by the Australasian Society for Intellectual Disability.

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

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Printed by:
Bloxham & Chambers Printers

editorial



This year's budget delivered some exciting news for people with a disability,

their families and carers and those of us working in the sector in provider and academic roles. The news about the proposed launch of the National Disability Insurance Scheme launch sites was not entirely what we had hoped to hear and there is still a mountain of work and negotiations to occur before anything is settled. But at least, the budget has delivered a promise and commitment that it will be hard for future governments not to deliver. I am sure we will all be watching developments in the coming months.

Some of you may be aware that my term of office as IDA editor is drawing to a close. I am really pleased to be able to confirm that from 2013 we will have a new editor, Doctor Kathy Ellem from the University of Queensland.

Kathy has wide experience in publication of research papers in the area of intellectual disability studies and has published peer-reviewed articles in *Disability & Society* and *Australian Social Work* as well as writing an article in *Intellectual Disability Australasia* entitled "Life Inside Prison for People with an Intellectual Disability" (Vol 32, Issue 2).

Kathy's interest in the field of intellectual disability stems from practice experiences as a social worker in the disability sector in Queensland, and her personal experiences as a parent of a young man with an intellectual disability. She has been actively involved in individual and systems advocacy for people with disabilities, and has professional experience in both government and non-government sectors in the disability field.

She has a wide interest in research with family members who have relinquished care of their son or daughter with a severe disability, has been involved in organising several conferences and also teaches *Foundations for Social Work Practice in Disability* for the University of Queensland

The ASID Board is looking forward to meeting Kathy at the annual ASID conference in New Zealand and welcomes her to her new role with IDA.

In the meantime, the following pages contain some interesting articles drawn from ASID members, and presenters from recent conferences. I hope you find them as interesting as I have.

**Best wishes for now,
Sue**

Family Stress and Adults with Intellectual Disability

by Nick Lennox,
Gloria Wong,
Miriam Taylor,
and Rob Ware

QCIDD

INTRODUCTION

Caring for an adult with intellectual disability can be physically, emotionally and financially demanding. Over 110,000 Australians with intellectual disability have an informal carer; in over 70% of these cases the carer is the parent of the care recipient (Australian Institute of Health & Welfare, 2009). With advances in health care, life expectancy has increased, with the consequence that more elderly parents are carers for adults with intellectual disability (Tucker, Taylor Gomez, Rey-Conde, & Lennox, 2011). Previous studies from North America, Australia and Asia have reported the caring role has a significant impact on the mental and physical health of carers; however, predictors of negative impact were conflicting. Identified predictors include service availability (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009; Knox, Parmenter, Atkinson, & Yazbeck, 2000; Llewellyn, Gething, Kendig, & Cant, 2004), lack of funding (Bigby, Balandin, Fyffe, McCubbery, & Gordon, 2004) and long term accommodation planning (Eley, Boyes, Young, & Hegney, 2009; Minnes & Woodford, 2004). The aim of this study is to investigate the level of stress and burden on family-based carers of adults with intellectual disability and determine which factors are associated with the overall well-being of carers.

METHODS

This cross-sectional study was undertaken among family-based carers of adults with intellectual disability living in the Greater Brisbane area of Australia from August



2002 to August 2003. participants were drawn from a randomised controlled trial that examined the utility of a health promotion tools among adults with intellectual disability who lived in the community (Lennox et al., 2010). Individuals were eligible for inclusion in this study if they were a family-based carer who lived with an adult with intellectual disability in a private residence. The study was approved by the Behavioural and Social Sciences Ethical Review Committee of The University of Queensland.

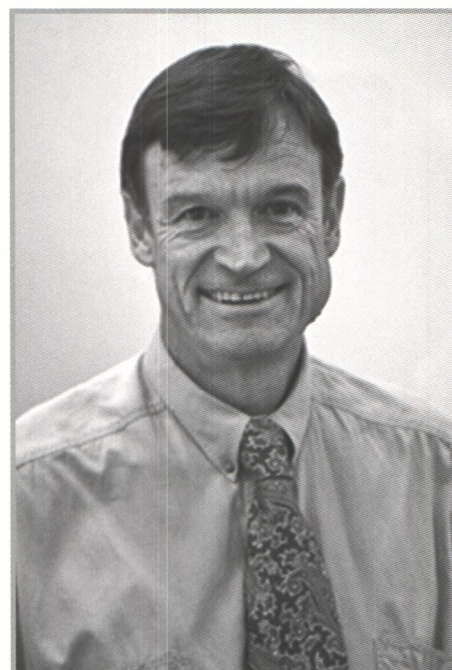
At trial completion all family-based carers were invited to complete a telephone interview. General background information concerning the adult with intellectual disability and their family-based carers including age, sex, level of intellectual disability, education, employment and support services usage status and Barthel score of independent living (Collin, Wade, Davies, & Horne, 1988) was self-reported. Information was collected concerning support services used by the individual with intellectual disability and the carer. Carers were asked to rate their overall health and well-being, and rate the influence of their caring roles on their current physical and mental health compared to when they were not carers.

The carer's burden and stress was measured using the Questionnaire on Resources and Stress (QRS)(Holroyd, 1987). The QRS is a validated fam-

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Family Stress . . .

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Nick Lennox

ily-evaluation questionnaire specifically developed for assessing the impact of chronic illness and disability on family functioning. We used eight of the eleven scales on the short-form of the QRS: preference for institutional care; personal burden for respondent, personal reward, limits on family opportunities, family disharmony, financial stress, cognitive impairment, and lifespan care. The first three subscales measure problems experienced by the person who answers the questionnaire, the next three assess family problems, and the final two assess perceived problems in the individual with intellectual disability;. Each scale comprised six true/false items. A scale score of up to 6 points was calculated and summations gave a total score of up to 48 points. Higher total scores indicate higher levels of stress and burden.

Data was summarised using descriptive statistics. Categorical data were summarised as frequency (percentage) and continuous data as mean (standard deviation). For each variable of interest we compared QRS overall and subscale scores between groups of family carers. Statistical significance was defined as $p < 0.05$. All analyses were conducted on Stata statistical software v.11.1 (StataCorp, College Station, TX, USA)

RESULTS

Overall 108 family-based carers completed interviews at trial completion. Characteristics of family-based carers are displayed in Table 1. The majority of carers were female (90%). The median (range) of children a carer had was 3 (0 to 9), and the median (range) of adults living in the residence was 3 (2 to 7). Individuals with intellectual disability had a median (range) age of 28 years (19 to 55) and 54% were male.

There were 61 (56%) carers who rated their overall health and well-being as either "good" or excellent", however a large proportion rated their physical (31%)

Table 1: Demographic and social characteristics of participating family-based carers

| Characteristic | n | % |
|---|----|----|
| Gender | | |
| Male | 11 | 10 |
| Female | 94 | 90 |
| Relationship to person with disability | | |
| Mother | 89 | 83 |
| Father | 10 | 9 |
| Sibling | 5 | 5 |
| Other | 3 | 3 |
| Education | | |
| High School | 43 | 43 |
| Trade / Diploma | 30 | 30 |
| Tertiary | 28 | 28 |
| Employment status | | |
| Employed | 41 | 39 |
| Not employed | 51 | 48 |
| Retired | 14 | 13 |
| Total annual household income | | |
| < \$30,000 | 40 | 41 |
| \$30,000 - < \$60,000 | 41 | 42 |
| ≥ \$60,000 | 16 | 17 |

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Table 2: Questionnaire on Resources and Stress scores for family-based carers of adult with intellectual disability, categorized according to carers' or care-recipients' characteristics.

The overall scale is scored from 0 (lowest stress) to 48 (highest stress). Subscales 'preference for institutional care', 'personal burden for respondent', and 'personal reward' measure problems experienced by the carer; 'limits on family opportunities', 'family disharmony', and 'financial stress' measure family problems; and 'cognitive impairment', and 'lifespan care' measure perceived problems in the individual with intellectual disability. Each subscale is scored from 0 (lowest stress) to 6 (lowest stress).

| | n (%) | Overall | Cognitive Impairment | Limits on Family Opportunities | Lifespan Care | Family Disharmony | Financial Stress | Preference for Institutional Care | Personal Burden for Respondent | Lack of Personal Reward |
|--|-------|-------------------------|------------------------|--------------------------------|------------------------|------------------------|------------------------|-----------------------------------|--------------------------------|-------------------------|
| Overall | n=108 | 20.8 (6.8) | 2.3 (2.2) | 3.2 (1.9) | 5.0 (1.0) | 1.0 (1.5) | 2.8 (1.9) | 1.4 (1.1) | 4.1 (1.2) | 1.1 (1.4) |
| Gender of carer | | | | | | | | | | |
| Male | n=11 | 20.0 (6.9) | 1.4 (1.6) | 3.6 (2.2) | 5.1 (0.7) | 0.8 (1.4) | 3.1 (1.4) | 1.4 (0.9) | 3.5 (1.2) | 1.1 (1.9) |
| Female | n=94 | 21.2 (6.7) | 2.5 (2.2) | 3.2 (1.8) | 5.0 (1.0) | 1.0 (1.5) | 2.9 (1.9) | 1.4 (1.1) | 4.2 (1.2) | 1.0 (1.4) |
| Access overnight respite service | | | | | | | | | | |
| Yes | n=45 | 23.9 (6.1) [^] | 2.9 (2.2) [^] | 4.2 (1.7) [^] | 5.2 (0.8) [^] | 1.1 (1.6) | 3.2 (1.7) | 1.4 (1.0) | 4.6 (1.0) [^] | 1.3 (1.6) |
| No and not seeking | n=49 | 17.5 (6.1) | 1.5 (2.0) | 2.3 (1.7) | 4.6 (1.1) | 0.8 (1.4) | 2.5 (2.1) | 1.4 (1.1) | 3.7 (1.2) | 0.7 (1.1) |
| Care-recipients' level of intellectual disability | | | | | | | | | | |
| Mild/moderate | n=55 | 20.0 (7.1)* | 1.7 (1.8) [^] | 3.2 (1.9) | 5.0 (1.0) | 0.8 (1.2) | 2.5 (2.1) | 1.5 (1.1) | 4.1 (1.2) | 1.2 (1.6) |
| Severe/profound | n=29 | 23.5 (5.9) | 4.0 (2.2) | 3.9 (1.8) | 5.1 (0.7) | 1.1 (1.8) | 3.1 (1.6) | 1.2 (1.1) | 4.1 (1.1) | 1.2 (1.5) |
| Care-recipients' Barthel score | | | | | | | | | | |
| More dependent | n=48 | 24.4 (5.8) [^] | 3.9 (2.0) [^] | 4.0 (1.7) [^] | 5.1 (0.8) | 1.1 (1.5) | 3.4 (1.7) [^] | 1.4 (1.1) | 4.4 (1.1)* | 1.3 (1.5) |
| More independent | n=60 | 18.0 (6.1) | 1.1 (1.4) | 2.6 (1.8) | 4.9 (1.1) | 0.9 (1.4) | 2.4 (1.9) [†] | 1.4 (1.1) | 3.8 (1.2) | 0.9 (1.3) |
| Self-rated overall health/wellbeing | | | | | | | | | | |
| Good – Excellent | n=61 | 18.9 (6.9) [^] | 2.1 (2.2) | 3.0 (1.9) | 4.9 (1.0) | 0.8 (1.6) | 2.4 (1.8) [^] | 1.2 (1.1) | 3.7 (1.2) [^] | 0.9 (1.4) |
| Poor – Fair | n=47 | 23.3 (5.8) | 2.6 (2.2) | 3.5 (1.8) | 5.1 (1.0) | 1.2 (1.3) | 3.5 (1.7) | 1.6 (1.1) | 4.6 (1.0) | 1.3 (1.5) |
| Mental health | | | | | | | | | | |
| Better/no change | n=72 | 18.7 (5.8) [^] | 2.1 (2.2) | 2.7 (1.7) [^] | 4.8 (1.0)* | 0.7 (1.2) [^] | 2.5 (1.9) [^] | 1.3 (1.1) | 3.8 (1.2) [^] | 0.9 (1.2)* |
| Worse/much worse | n=36 | 25.0 (6.8) | 2.7 (2.2) | 4.1 (1.9) | 5.3 (0.7) | 1.6 (1.8) | 3.6 (1.6) | 1.6 (1.1) | 4.6 (1.0) | 1.5 (1.7) |
| Physical health | | | | | | | | | | |
| Better/no change | n=75 | 18.7 (5.9) [^] | 1.9 (2.1) [^] | 2.8 (1.8) [^] | 4.8 (1.0)* | 0.8 (1.3) | 2.4 (1.8) [^] | 1.3 (1.1) | 3.8 (1.1) [^] | 0.9 (1.2)* |
| Worse/much worse | n=33 | 25.6 (6.5) | 3.2 (2.2) | 4.0 (1.8) | 5.3 (0.7) | 1.4 (1.7) | 3.8 (1.7) | 1.6 (1.1) | 4.7 (1.1) | 1.6 (1.8) |
| * difference between categories within characteristic significant at P<0.05 | | | | | | | | | | |
| [^] difference between categories within characteristic significant at P<0.01 | | | | | | | | | | |

Family Stress . . .

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and mental (33%) health to be “worse” or “much worse” than it was before they were carers. Table 2 displays QRS scores both overall and for individual scales. Family-based carers who do not have access to respite services, who provide care to more dependent family members, who rated their overall health and well-being as poor, and who perceived their physical or mental health was worse after taking up their caring role experience significantly more stress and burden (all $p < 0.01$). Gender of carers, care-recipients’ level of intellectual disability and carers’ annual household income were not significantly associated with carer stress level as reflected by overall QRS score.

DISCUSSION

Carers who were not seeking to access respite services, and those who provide care to more dependent family members with intellectual disability experienced significantly more stress and burden. Significant burden was also found in carers who rated their overall health and well-being as poor. A third of carers surveyed they perceived their physical or mental health as worse after becoming a carer. These findings were based on a well validated tool of stress and burden (Allen, Linn, Guitierrez, & Willer, 1994), and confirm the existing literature that life-span care and burden are an important source of stress for families (Erickson, 1992; Salisbury, 1985; Walker, Van Slyke, & Newbrough, 1992). We are unaware of any previous Australian data with which comparison can be made. We found high overall QRS scores amongst carers who rated their overall well-being as fair or poor; other studies have found older female family carers of people with intellectual disability to be significantly more depressed (Chou, Lee, Lin, Kroger, & Chang, 2009), and that carers’ physical health is worse than non-carers in the general population (Yamaki, Hsieh, & Heller, 2009).



Gloria Wong



Miriam Taylor

In Australia, it was estimated that among people (aged under 65 years) with disability who had unmet demand for accommodation and respite services, 85% of them were people with intellectual disability (Australian Institute of Health & Welfare, 2009). Even carers who have access to respite service continued to experience higher stress and burden level (Chan, Sigafos, Watego, & Potter, 2001). This finding suggests alternative arrangements such as in-home support, family funding, alternative accommodation, and person-controlled funding may be necessary to alleviate carer stress and burden and produce positive outcomes (Brown & Brown, 2009; Turner-Stokes, 2007). We must assume

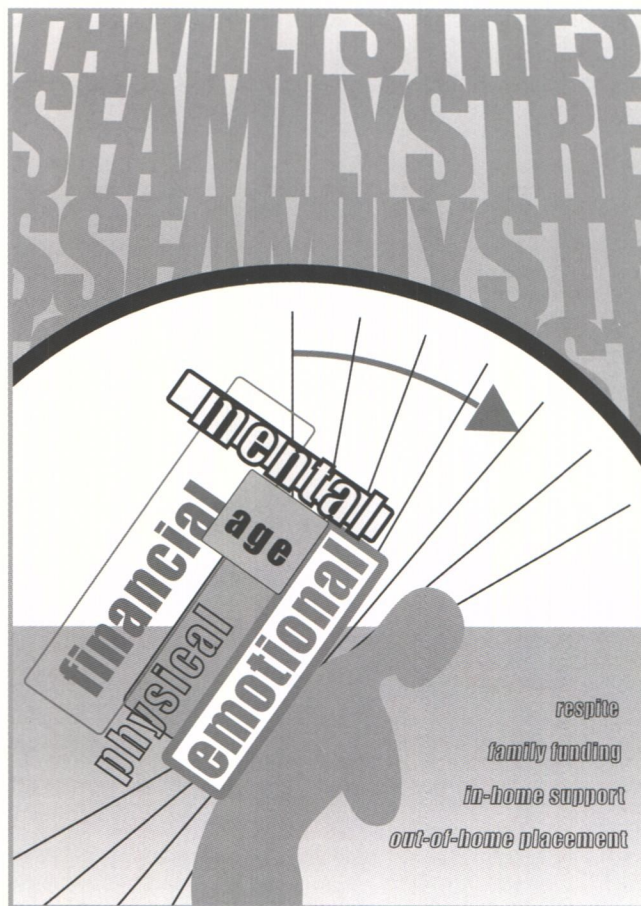
that the current respite model is not the only one, and certainly not useful as a one size fits all. Families are known to have many concerns that contribute to the burden and stress of care including those about the future for their adult children is expressed by carers (Eley, et al., 2009; Tucker, et al., 2011) and the decision-making process of seeking out-of-home placement is a stressful one (Knox, et al., 2000; Mirfin-Veitch, Bray, & Ross, 2003).

It is crucial that these concerns are understood and addressed by professionals and services providers as they may overlook the needs and well-being of family-based carers, especially where the focus of their services are on just the person with the disability. Ongoing evaluation of carers' perceived health and well-being may give service providers a great insight into the burdens of carers, and may assist the identification of those at risk, enabling interventions to be put into place before the situation evolves into a crisis, or strategies of support to be driven by the needs person with the disability seen from the context of their family and community.

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Rob Ware

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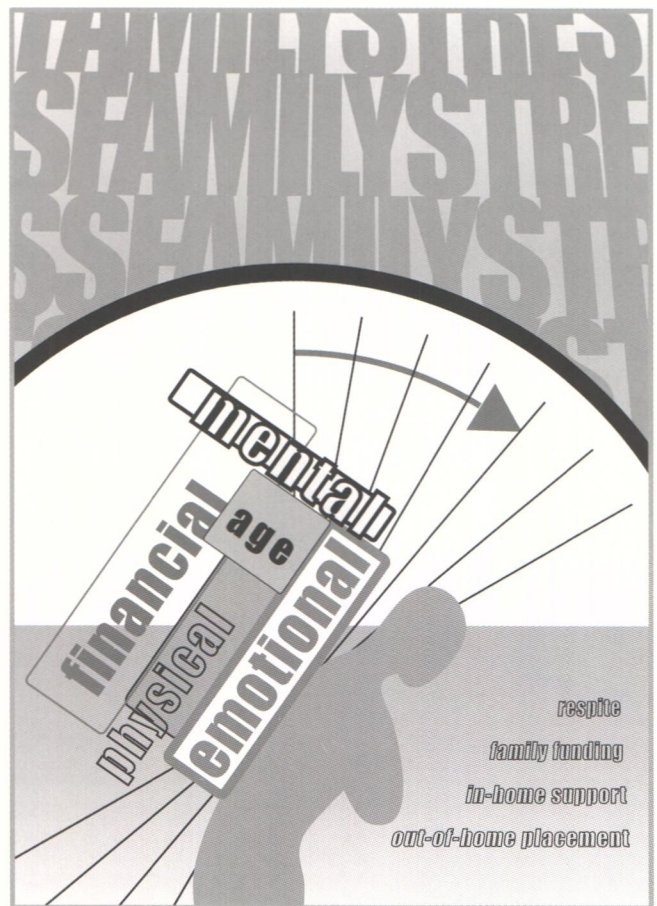
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Queensland

by Nagadeva Higgins

How the months roll on and we wend our way into the Winter period. Here in Queensland we still await any ramifications and impacts on people with an intellectual and service delivery from the new Liberal National Government. There is always a certain amount of post election anxiety over these matters. Watch this space!

The Queensland Committee continue to meet monthly as the nights draw in with the focus more recently being on the planning of events for later in the year. We have decided at this stage on 3 events. The first being a 'Master class' format aimed at providing practitioners with inspiration, skills and information on how to undertake research. The committee are looking to develop a Partnership around this initiative. We are also hoping that such an event could be made available regionally.

The Second event is a one day State conference/Symposium and the third is a pre AGM gathering with Wine, cheese and a speaker (in that order of priority!).

One of the central issues the Committee have discussed from time to time relates to the Boards operational plan. Early in the year during planning we identified the need to spend time in and out of meetings to focus on the operational plan. To that end the Committee divided itself into three sub Working Committees to cover off on some key areas of the Boards plan with regard to Queensland. The sub groups discussed and explored the following topics; ASID as an independent authority; Research to Practice; Strategic Partnerships and Membership promotion.

These discussions opened up areas where more thought, time and action are required locally to address them. Principally the Committee identified a key area with regard to membership. For instance, how can we tailor our events to meet the needs of members when we know little about them? A related question is How can we promote and increase membership unless we know

what (to use the language of business) we know what our offer is? After all, there are many competing organisations and bodies wishing for increased membership engagement and the dollars that come with that. The Boards operational plan offers some excellent strategies in these areas but the capacity of the committee to respond to the work that needs to be done locally in these areas is limited. All grist to the mill for a largely voluntary organisation such as ours but important nonetheless for us to be grappling with!

The Committee is lucky enough to have three regional counsellors and there has been some positive discussion and planning in how to facilitate activities which consider the needs of all regional members. Utilisation of technology is one strategy to ensure, in the first instance, our regional Committee members have some ease with regard to attending meetings remotely. Previously we have had webcasting facilities available for events and we are again reviewing these technologies. Next Committee meeting we are hoping to trial access to the meeting for a regional counsellor through Skype. Not 'high tech' I know but it's important to keep working to reduce the 'tyranny of distance' and bring our colleagues in regional areas closer in mind and spirit at least.

The Committee continue to give attention to our 'Blog' Site as a way of keeping in touch with members in Queensland and to be a one stop shop of relevant information on upcoming events.

On a personal note I would like to thank my colleagues on the Committee for their energy and support in furthering the work of ASID for the benefit of people with an Intellectual Disability.

South Australia

by Denice Wharldall

The local committee is currently organising two Workshops related to Individualised Funding on 19th July. One will be in the evening and the other during the day. We are very eager to both educate and inform

and also share the research findings related to Individualised/Self-Managed Funding.

National Disability Services held a national conference on 3 and 4 May 2012 in Adelaide called Preparing for the New World. The conference was aimed at assisting disability service providers to think through the implications of the major reforms such as the National Disability Insurance Scheme (NDIS) and the National Disability Strategy and provide practical advice on getting ready for change. Over six hundred people attended the conference with a strong South Australian representation. At the Conference the State Minister for Disability, Hon Ian Hunter confirmed the government's commitment to self-managed/directed funding. With major change occurring it is imperative that ASID encourages and promotes research and that research guides our practice. One area of discussion at the conference was the possible unintended consequences of a NDIS such as a resurgence of congregate care.

Western Australia

by Chris Yates

ASID WA got off to a flying start earlier in the year with two sundowner events taking place in February to capitalise on opportunities presented by visiting researchers.

The first sundowner on February 21st focussed on an independent evaluation of the Positive Behaviour Teams operating in Western Australia which was completed by Dr Keith McVilly, Associate Professor at Deakin University in Melbourne. This event was attended by approximately 30 people and after Keith had presented the report there was a lively discussion and a recognition of the excellent outcomes achieved through this program – a real example of research to practice!

Hot on the heels of the first event we hosted another sundowner with Professor Eric Emerson as keynote

leading a prominent panel including Dr Hugh Dawkins, Di Shepherd (parent/advocate) and Sue Morrison (Nursing Services Manager with the Disability Services Commission). The topic was 'Better health outcomes for people with a disability' with the focus on the urgent need to improve the health and wellbeing of people with a disability. This was a very lively event with approximately 50 people in attendance and a great deal of passion in evidence. It confirmed for our regional council that our strategic directions in relation to a focus on health issues for people with intellectual disability.

Looking further planning is underway for this year's conference to be held in September with a likely theme of 'A Healthy Life' or something similar with the aim of picking up on the strongly identified interest in this area.

We are experiencing steady membership growth and also have new members interested in joining the Regional Council which is a tremendous indicator of the interest and enthusiasm of people for issues related to intellectual disability. We are looking forward with a great deal of optimism.

Tasmania

by Ben Crothers

After extensive consultation, the new legislation governing disability service provision in Tasmania has been released. The Disability Services Act 2011 replaces the previous act from 1992 and includes a broader human rights perspective – more information is available at: http://www.dhhs.tas.gov.au/disability/tasmanian_disability_services_act_2011

The Hobart NDIS Rally held at Parliament House Lawns on April 30th was very well attended including representation across the political spectrum voicing support for change in disability funding. It was encouraging to hear the voice of intellectual disability loud and clear at the rally.

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Victoria

by Sam Murray

Apologies to Victorian members for the omission of the Victorian report for the first quarter.

A new Regional strategic plan for 2012-2015

With the 2008-2011 ASID (Vic) Strategic Plan expiring, the Regional Council met in early January to prepare an action plan for the coming years. With discussions emerging from the Australasian Board's 2011-2020 plan, there were some stimulating and energising dialogue around the local strategic direction. Whilst the ASID (Vic) 2012-2015 Strategic Plan is still undergoing some final wording edits and revisions, we are excited to have a renewed focus within the Region. The plan will be posted shortly on the ASID (Vic) webpage (<http://asid.asn.au/Regions/Victoria.aspx>), and will take effect as of the March 2012 meeting. In the meantime we gladly share with you a snapshot of the direction in which we are heading.

The goal is for ASID (Vic) to be a 'meeting place of ideas' for the coming together, expression and contribution of all perspectives interested in people with an intellectual disability. ASID (Vic) will be:

- Starting to set in motion new activities and ways of doing things consistent with goal for ASID (Vic). When there is opportunity to, 2012 is to be a year for experimenting, trying new things, evaluating and reviewing
- Ensuring that ASID Vic in all its operations and activities, including the Region Committee, is more inclusive of all constituent groups throughout Victoria, including people with an intellectual disability.
- Establishing ASID (Vic) as a point of reference and credible source of comment about issues relevant to people with an intellectual disability. This will be achieved through varied approaches to communication and participation relevant to different constituent groups; furthering research to practice initiatives, based on supporting a research program relevant to constituent groups, wide ranging activities to disseminate information for constituent groups.

- Ensuring the Region committee adopts an approach to implementing the action plan based on defining a rationale, then cycles of plan, implement and review of all actions.

The DSW Conference office is moving!

After many years of calling RMIT 'home', we are happy to announce a new location for Sue Mason, DSW Conference Coordinator. Sue will be moving down the road in late February, to La Trobe University (Bundoora Campus) where she will lead the conference planning and other ASID (Vic) activities. More information will be posted on the ASID (Vic) webpage (<http://asid.asn.au/Regions/Victoria.aspx>) when they come to hand.

We'd like to take this moment to also thank RMIT for the many years they allowed us to use their office space and resources.

Condolences

ASID (Vic) was saddened to hear the news that one of its members, David White, passed away suddenly just before Christmas. David had attended numerous ASID (Vic) events and was a great supporter of our Region. Our sympathies to his wife and family.

NSW & ACT

By Tina Purdon & Laura Hogan

A recent voluntary survey was conducted across NSW utilising Survey Monkey to gain an understanding of the professional development needs and professional association memberships of rural and metropolitan professionals employed in the disability sector in NSW. Limited results from this survey, capturing current and potential ASID members only has been providing by Laura Hogan (ASID NSW / ACT Board Member).

The following professions participated in the survey:

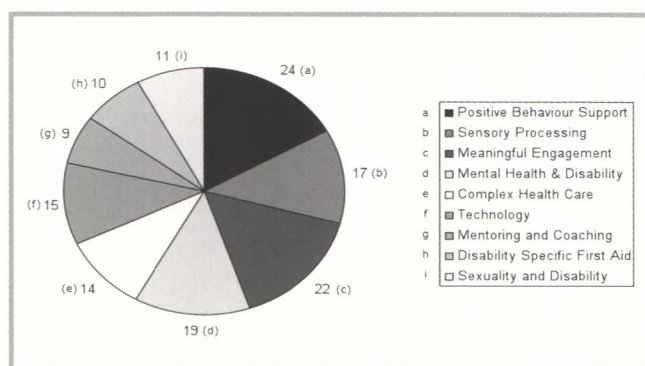
- Nursing
- Psychology
- Occupational Therapy
- Speech Pathology
- Special Education
- Management
- Disability Support Work

- Social Work
- Case Management
- Youth Work
- Social Educator

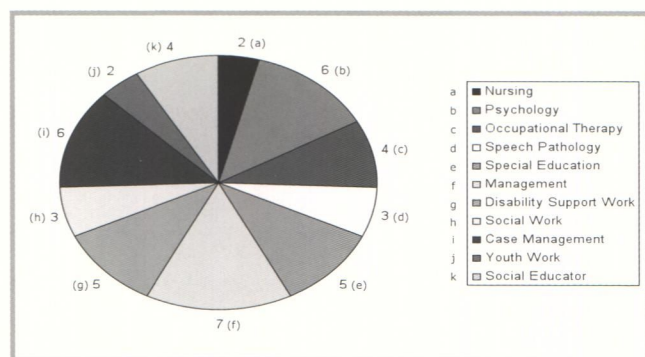
Total number of respondents: 234

Number of respondents who are either current ASID members or who would consider becoming an ASID member should they know more about the Association: 47.

Respondents were asked to list their top 3 professional development needs (unranked) these have been grouped and the chart below represents the key areas of professional development needs of the 47 ASID related respondents.



The graph below shows the percentages of respondents from each of the professions surveyed.



In response to these survey results, coupled with feedback from our 2011 conference and workshops, ASID NSW/ACT are working toward new exciting training opportunities in 2012 to address some of these needs

and promote ASID Membership across NSW.

We will also be using these results to look at how we can better engage with regional members and non-members to increase membership and member satisfaction.

The Streams for the ASID NSW / ACT 2012 Regional Conference *Through the Looking Glass – putting the talk, research and planning into action!* will cover many of the topics identified in the survey. As well as looking at how people across the sector are implementing supports under individualised funding, self managed models and other person centred supports.

The Committee thanks all who submitted Abstracts submitted for this event and are working to finalise a fabulous program. Please check the ASID website for registration information and take advantage of Early Bird discounts.

ASID NSW / ACT has continued our partnership with University of Sydney, Centre for Disability Studies to support a series of one day interactive workshops in September by **Bob Bowen – The Mandt System Inc.; trauma informed positive behaviour supports and complex behaviour.** And recognising our commitment to providing access to research and training in rural and regional settings as well as in metropolitan areas, we will be working with local partners to provide as many statewide opportunities as possible. Registration information for these workshops will be distributed to all regional members shortly, or check the ASID website.

Finally we take our hats off to all the Regional Committees who have been involved in planning and conducting an Australasian Conference. As we work through this process for the 2013 event, we acknowledge the massive commitment and dedication of our Regional colleagues – who are probably breathing a sigh of relief as their turn is over for a few years!

New Zealand

by Adrian Higgins

All steam ahead for the conference in November. Make sure you check out the website. ●

Sexuality and Relationships Education (SRE) to Support Young People

by Georgina Livingstone
Family Planning Queensland



“I liked learning about my body and how it works. I know who I can talk to if anyone touches my body in a way I don't like. I know about safe sex too.”

Quote from a young person with a disability who has been part of a SRE program in a school.

Since 1972 FPQ has been actively promoting the right of people with a disability to access effective SRE programs, resources, information and clinical services that meet their sexual and reproductive health needs.

SRE involves developing knowledge and understanding about sexual development, reproductive health, relationships, affection, intimacy, body image and gender roles. SRE supports people to develop the skills to communicate effectively and make responsible decisions. All of this reduces a person's vulnerability to abuse and assault and promotes a healthy approach to sexuality and relationships.

Although all people have the right to effective SRE, there often seems to be the need to justify why young people with a disability should receive this education. We should not have to justify why it is important for young people with a disability to receive education that supports their basic human right to access information that can help them to make safe and informed decisions about sexual health and relationships.

We do though need to make sure that the SRE that is made accessible is of the highest quality, is evidence based and meets genuine needs. When thinking about what constitutes effective SRE for young people with a disability it is important to think about the strengths of the young person. How do they like to learn? What types of resources will be needed? How can you create

a safe learning environment? Most importantly learning about sexuality and relationships is a life long process, and as a parent, carer or professional, talking about sexuality is an ongoing conversation and not just a 'one-off' talk about 'the facts'. Research suggests people with a disability benefit and learn more from sexuality information that is repeated and reinforced both in the home, school and in support services.

Some young people with a disability may not have access to or receive information about SRE in the same way as their peers. It could be that literacy skills impact on the ability to read about topics such as **puberty** or **where I came from**. Some young people with a disability take information literally, which can lead to misunderstandings. A conversation about babies being delivered by a stork or being found in the cabbage patch takes on a whole new meaning when interpreted literally.

For some it may be difficult to distinguish between public and private places and behaviours. For young people (and adults) with an intellectual disability and high personal care needs there could be a variety of people (family, paid carers etc) that assist them with personal care tasks such as showering or going to the toilet. For some young people this can be confusing: on the one hand we are saying that the penis, testicles, vulva, vagina and bottom are private however for some young people many others see and touch their private parts. This can be confusing if there has never been a conversation about why this occurs or a clarification of the where, when and the who of the situation.

Parents and carers are key partners along with schools to help ensure that young people with a disability are receiving relevant information that meets their needs.

"I really think it is important for me to be able to not only give my child the information they need to say no to sex but to be brave enough to help them to know how to say yes and to know how to say yes safely. Even though this is scary for me...it's something I want to do in partnership with teachers and other key people in my child's life. If we truly want the best for her, I don't see that we have a choice."

Quote from a parent of a young person with an intellectual disability, 2011

A recent survey commissioned by FPQ and conducted by Footprints Market Research, clearly demonstrates that parents and carers of young people want to be active partners with teachers in the delivery of sexuality and relationships education (SRE). 85% of parents surveyed believed that SRE is a responsibility that is best shared between parents and teachers.

This being said though, many parents do not know where to start and for some the topic of sexuality can be a difficult one to discuss. Sometimes this can be even more challenging for a parent of a young person with a disability. Some parents express apprehension about whether their child will understand the information and how to provide the 'right' type of information. Others want to feel more confident to have and continue the conversation. Most parents do want to be able to share information about SRE with their child with a disability and they want relevant resources to help have these conversations. 9 in 10 parents (90%) feel that receiving information about sexuality and relationships would encourage them to discuss the topic with their school-age children.

Case Study:

A parent based in a remote town in central Queensland contacted FPQ to ask about ways she could give her daughter information about growing up. After talking with another parent at her daugh-

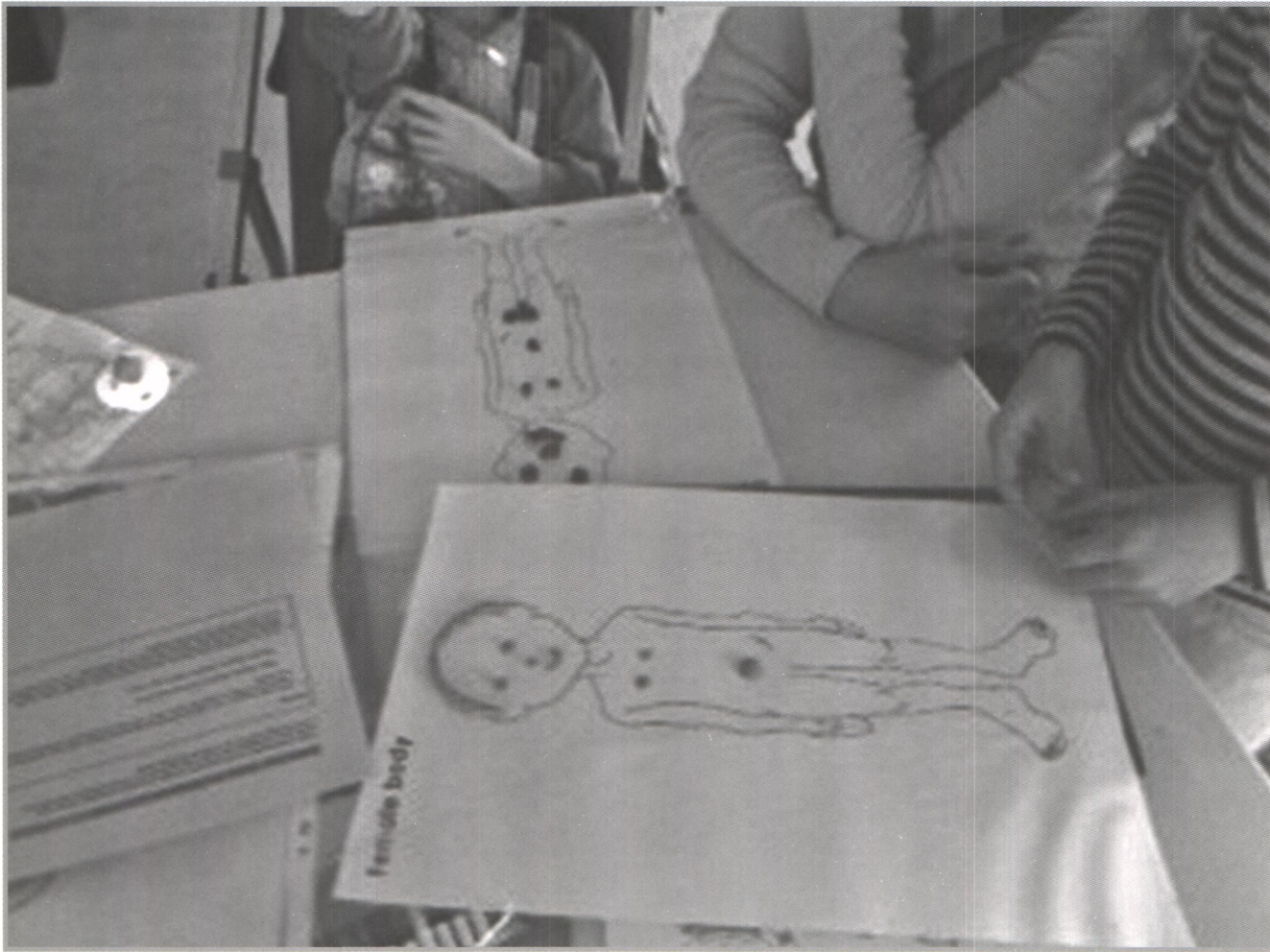
ter's school she realised she had never spoken with her daughter about puberty, periods or sexual relationships. For this parent the major stumbling block in her words was "how to break the ice" and that maybe it was too late to start talking about this "body stuff", as well as not being sure how much her daughter would need the information, let alone take it in. The parent and her daughter were invited to be a part of FPQ's **Creating Conversations** project. The project provides parents and carers with valuable information and resources to be able to talk with their children about relationships, the changes that happen with puberty and to practice personal safety skills.

The parent attended an initial group education session along with other parents and carers and was able to connect with other parents and carers who could share similar experiences she stated after the session that it was "...good to hear that others had the same concerns as me, although we were all different and our children all had varying levels of ability – we all wanted our children to be happy, healthy and safe and if that meant stretching a little outside of our comfort zones, we would try."

The aim of the parent/carer session is to support parents and carers to develop their own approach using a combination of strategies that are suggested from other parents and carers as well as FPQ facilitators. Over the coming weeks parents/carers and young people with a disability attend family education sessions together. These provide opportunities to practice SRE conversations in a supportive environment and enable these conversations to continue once families return home.

The feedback from the parent after coming along to sessions with her daughter was overwhelmingly positive and the parent was surprised (as is often

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Sexuality and Relationships Education . . .

continued from page 15

the case) by how much her daughter already knew but also how much she was able to communicate about sexuality and relationships. At the end of the sessions the parent was keen to continue the conversations at home: "I now intend to try and teach my child more about her body and be able to talk more freely about her growing up." For this family the ice has well and truly broken. Acknowledging that most parents and carers have the skills to have ongoing conversations about growing up, bodies, relationships, safe sex and personal safety enables professionals to work together with parents to improve sexual health outcomes for young people with a disability.

Family Planning Queensland works with families, schools and other organisations to help them to have conversations about SRE with young people with a disability, as well as helping to source relevant and appropriate resources to have that conversation. A conversation does not always have to be verbal. It could involve using signing or pictures, a communication device or other resources.

Resources to support parents/carers and professionals

To view resources that could help you start a conversation visit www.fpq.com.au

References

can be obtained from the author at glivingstone@fpq.com.au ●

“The tooth, the whole tooth, and nothing but the tooth!”

by *Dr Isabelle Livings*
(Clinical Psychologist)



Oral health refers to the care of a person’s whole mouth, including their teeth, gums, tongue and cheeks. Oral health is an important aspect of a person’s health, yet it can often be overlooked for people with intellectual disabilities (ID). In fact, it has been found that people with ID have seven times more oral health problems than the general population.

Oral health problems can occur when there is a build-up of bacteria in the mouth. The most common oral health problems include dental cavities, gum disease, infections, and loss of teeth. Many people are unaware that if the mouth bacteria are not eliminated through good oral hygiene practices (such as daily brushing), then the bacteria can enter the blood stream and contribute to more serious health problems such as bacterial pneumonia, cardiac disease, and Diabetes. Poor oral health can also have a detrimental effect on other aspects of a person’s life, such as their ability to eat, their physical appearance, their comfort and cleanliness, their breath and interaction with others, and their overall wellbeing and quality of life.

It is not clear why people with ID seem to have more oral health problems than the general population. However, it is possible that some people with ID have impaired communication skills, and that they find it harder to express themselves, to let others know that they are having trouble with their teeth or let others know that they are in pain or discomfort. Some people with ID may have a limited understanding of the importance of oral health, and the rationale for routine teeth cleaning and attending dental appointments. Some people with ID may also have impaired planning and

decision-making skills, which may affect the quality and frequency of their oral hygiene practices. Furthermore, some people with ID may have co-existing disorders which may bring about additional challenges for achieving good oral hygiene. For example, some people with ID may have co-existing physical disorders, sensory disorders, psychiatric disorders, neurological disorders, or pervasive developmental disorders.

In 2009, a Perth Special Needs Dentist approached the Disability Services Commission (in WA) about the concerns just mentioned. As a result of contact from this Dentist, Disability Services Commission’s Accommodation Services Directorate (ASD) set up an Oral Care working party in 2009. The outcomes from this working party was the development of three important documents to assist direct care staff to improve the oral health care of all ASD residents.

The first of these documents was the ‘Oral Health Care Checklist’. This is a monitoring tool which assesses the condition of the mouth and looks at many factors including daily care (how many times teeth are being brushed), whether the toothbrush is new or in need of replacing, the colour/condition of the lips (pink, dry, chapped), the colour/condition of the tongue (pink, furry), the colour of the gums (pink, red, bleeding), whether the breath is normal, whether the resident has complained about their teeth, and the general cleanliness of the mouth (ie. whether there is any scaling or plaque). The purpose of this checklist is to allow staff to monitor a person’s oral health over time, and to put strategies in place if needed. Within ASD it is completed by a staff member every 2 months.

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The second document developed by the working party was the 'Oral Health Care Tipsheet'. This tipsheet provides information and strategies about oral care from a number of allied health professions including psychology, speech pathology, physiotherapy, dietetics, and nursing. This tipsheet was provided to every group home within ASD so that staff could be aware of the potential issues that could occur during oral health, and could follow the advice provided by the different allied health professionals.

The final document developed was the 'Individual Oral Health Care Plan'. This is a person-centred plan that documents an individual's specific oral care needs and procedures. The philosophy behind this document is that every individual has their own needs, abilities and preferences, and that the "one size fits all" approach is not appropriate. Therefore a person-centred plan is developed in consultation with the individual themselves (if possible), their family, direct care staff and other professional staff. Every individual within ASD now has their own person-centred oral health care plan.

The Individual Oral Health Care Plan provides information on the following areas for the person with an ID:

- Dental considerations eg. bad breath, gum disease, reflux, teeth grinding
 - Level of independence in oral care eg. whether the individual needs verbal prompts, physical assistance, or is independent in some areas
 - Special dietary requirements eg. modified food/fluids or diet plans
 - Method of consuming food eg. peg, orally, NGT
 - Difficulties with swallowing, aspiration risks, food pocketing (and if so, whether there is a referral to a Speech Pathologist)
 - Factors that may influence effective brushing e.g. bite reflex, tactile defensive, sensory issues, reflux
 - Strategies required to support the individual eg. manual handling/ positioning, whether physical assistance is required, the best time/place for oral care, the person's likes/dislikes, the person's preferences including equipment etc.
 - Step by step procedure for oral care
- PRN protocol (ie. whether there is one or whether one may be needed)
 - Psychology referral (ie. whether the individual is showing resistance or behaviours of concern around teeth-brushing)

Since 2009, the DSC Accommodation Behaviour Support Team (ABST) has also been accepting referrals from the Special Needs Dentist when ASD residents have been resistant to having their mouths cleaned. The Psychologists have responded to these referrals by conducting assessments and providing support and strategies for staff and residents to reduce and minimise resistance, and to reduce or eliminate the use of restraint.

The use of 'restraint' has often come up when ABST Psychologists have responded to oral care referrals. Direct care staff have often expressed confusion about what constitutes 'physical assistance', and what constitutes 'physical restraint'. The ABST psychology position is as follows. Examples of physical assistance are the gentle holding of an arm to comfort or reassure someone in an unfamiliar clinic, or the 'cradling' of someone's head while staff brush their teeth. These examples are NOT considered physical restraint. However, where the person becomes so agitated or distressed, that they require considerable physical force to comply with the procedure, then that is considered Physical Restraint. Physical restraint can be dangerous and life-threatening for some individuals, and is not recommended. There are two alternative options in this situation:

- (a) The medical or dental practitioner may consider prescribing a sedative for the individual prior to any procedure being attempted again, OR
- (b) A referral for Clinical Psychology services could be initiated

According to the Office of the Public Advocate Position Statement on Restraint (2010), "the appropriate use of drugs to reduce symptoms in the treatment of medical conditions such as anxiety, depression or psychosis, does not constitute restraint." As many ASD residents experience severe anxiety during dental treatment, medication prescribed by a medical/dental practitioner

upcoming events

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|-----------------------|---|
| 9 - 14 July 2012 | 2012 IASSID World Congress Halifax Canada |
| 8 - 10 Aug 2012 | 10th Biennial Early Childhood Intervention Australia Conference Perth, Western Australia |
| 17 Aug 2012 | ASID NSW ACT Conference 2012 <i>Through the looking glass - turning all the talk, research and planning into action</i> Liverpool Catholic Club, Sydney www.asid.asn.au |
| 26 - 29 Aug 2012 | 2012 International Conference on Special Needs Offenders Ottawa, Canada etownson@specialneedsoffenders.org |
| 11 - 13 Sept 2012 | Disability Studies Conference Lancaster University www.lancs.ac.uk/disabilityconference/ |
| 1 - 2 Nov 2012 | 23rd PANDDA 2012 Conference venue to be confirmed Professional Association of Nurses in Developmental Disability Australia. www.pandda.com |
| 7 - 9 Nov 2012 | 47th ASID annual conference Wellington New Zealand www.asid-2012.org.nz |
| 21 - 22 Nov 2012 | 12th ASID (Vic) Disability Support Worker Conference <i>" Working Together "</i> Melbourne Cricket Ground www.asid.asn.au or vicevents@asid.asn.au |
| 29 - 30 April 2013 | Pacific Rim International Conference on Disability and Diversity Hawaii www.pacrim.hawaii.edu |

If you want to advertise your conference in IDA's upcoming events section,
please e-mail: susan.peden@dsc.wa.gov.au

to address this so that a procedure can be carried out is considered acceptable in such circumstances.

In conclusion, the Accommodation Services Directorate (ASD) at DSC has put a number of organisational strategies in place to address the issue of poor oral health in residents with intellectual disabilities. This appears to have increased the awareness of oral health issues amongst ASD staff and professionals, and it appears to have improved oral care outcomes for many ASD residents. It is hoped that Disability Sector Organisations will consider adopting a similar approach for addressing this very important issue.

References

- Residential Services Practice Manual (2009), Department of Human Services, Victoria.
- Oral Health Information for People with an Intellectual Disability (2008), Dental Health Services Victoria.
- Position Statement on Restraint (2010), Office of the Public Advocate, WA. ●

asid

research to practice

Conference 2012

Wellington, New Zealand



UNITY IN DIVERSITY
Kotahitanga ki rō Kanorau
Different Perspectives : Common Purpose

Australasian Society for Intellectual Disability (ASID) 47th Annual Conference 2012

**Wellington Convention Centre, New Zealand
Wednesday 7 to Friday 9 November 2012**

Registrations will open on
Wednesday 6 June 2012

Register online at www.etches.com/asid2012

Early Bird registrations close on
Friday 7 September 2012

Pre-conference workshops will be held on
Tuesday 6 November – details still to be confirmed.

Further information is available at
www.asid-2012.org.nz

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