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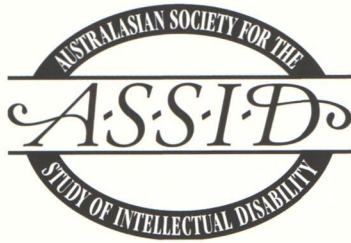
IDA

Intellectual Disability Australasia

Loneliness



Magazine of the Australasian Society for the Study of Intellectual Disability



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Front Cover: by Sue Peden

Editorial



My best wishes to everyone for a safe and peaceful celebration this Christmas. I hope that you, like me, will take some time to review 2008 as well as looking forward to all that the New Year has to offer, with optimism and hope.

This year, as the time arrives to wrap up gifts for family and friends, and decorate the Christmas tree, IDA is focussing on those people for whom Christmas is not a time of cheer, but in fact a time that highlights their ongoing loneliness and isolation. As many of us take annual leave, and services close for a few weeks of well earned rest, many people with disabilities are made acutely aware of their situation.

In March, ASSID, South Australia drafted a communiqué, which is printed in full in IDA. The communiqué explores the issues of loneliness and isolation amongst people with a disability in South Australia. The communiqué was sent to key people in South Australia, for their consideration, by ASSID SA and Flinders University's Department of Disability Studies.

The communiqué is a summary document of the proceedings from a forum held in late 2007. Researchers and service providers from both public and private sectors presented on a range of issues related to the causes of isolation and loneliness, its impact on people with a disability and explored potential solutions and specific questions requiring further investigation.

In printing the communiqué, IDA supports ASSID (SA) and the Department of Disability Studies in raising the issues and presents the recommendations for your consideration.

Dr Roger Stancliffe, and Dr Susan Balandin have written the lead article, also focussing on loneliness, and as you will see, our plain English version of a JIDD paper relates to the same topic.

As 2008 draws to a close, my thanks are due to everyone who has contributed to IDA, with articles, letters and most especially those regional updates every quarter. Thanks must go to Sheridan Forster, for her regular contribution of plain English versions of JIDD papers and thanks also to Ross Tudman, the assistant editor, who manages to get each edition out on time!

Our last edition provided more food for thought on the matter of a name for ASSID. Next year the debate will continue in IDA and perhaps provide some interesting discussions within the regions. And of course there will be many more topical issues that IDA will endeavour to bring to you.

Cheers,
Sue

Loneliness

Roger J. Stancliffe,

University of Sydney

and

Susan Balandin,

Molde University College, Norway



All the lonely people, where do they all come from?

All the lonely people, where do they all belong?

(Eleanor Rigby, Lennon & McCartney, 1966).

At this time of the year, when many people are celebrating with friends and family, some members of our community experience loneliness, not companionship. Sadly, people with intellectual or developmental disability are over-represented among the lonely. In this paper we a) discuss the nature of loneliness, b) look at what research tells us about people with intellectual or developmental disability and loneliness, c) suggest a number of ways to support people to reduce loneliness, d) discuss the effect of loneliness on health and well being, and e) outline two personal stories illustrating different aspects of how people experience loneliness.

Loneliness

Loneliness involves both social and emotional components – aloneness and sadness. Loneliness relates to the subjective difference between people's expectations of relationships and their social experience. In other words loneliness cannot be measured by objective factors such as the number of social contacts or the size of a person's social networks. A person can feel lonely in a crowd, and being alone does not necessarily mean feeling lonely.

Because loneliness is subjective, we should ask individuals themselves about loneliness rather than seek information from proxies. This explains why Chadsey-Rusch et al. (1992) found that staff ratings of the person's loneliness were not significantly correlated with the individual's self-reported loneliness. A number of studies have shown that many (but not all) children and adults with ID can reliably report their own experience of loneliness (Chadsey-Rusch et al., 1992; Duvdevany & Arar, 2004; Heiman, 2001; McVilly et al., 2006; Stancliffe et al., 2007).

What do we find when we ask people with disability about loneliness? Loneliness is a widespread problem among people with intellectual disability. A recent large US study of adults living in community settings outside the

family home found that half of those surveyed said they were sometimes or often lonely (Stancliffe et al., 2007). People with intellectual disability are more likely to report feeling lonely than peers without disability. This is true for school students (Margalit, 2004) and adults (Sheppard-Jones et al., 2005). Likewise, older adults with cerebral palsy are more likely to be lonely than their nondisabled peers (Balandin et al., 2006). Interestingly, these authors noted that adults with high support needs who required more than six hours of support a day were less lonely than other adults with cerebral palsy, possibly because they had company throughout much of the day.

Factors Related to Loneliness

Many people with intellectual and developmental disability report being lonely, so it is important to understand what factors affect loneliness.

Living arrangements. One important issue is living arrangements. Stancliffe et al. (2007) found that – contrary to common expectations – loneliness was not more common among people living alone or in very small settings but, in fact, was significantly more common among those living in larger community settings with 7-15 people. Social dissatisfaction is a component of loneliness (Chadsey-Rusch et al., 1992) and relates to problems with interpersonal relationships. Stancliffe et al. interpreted the greater loneliness in larger settings as arising from incompatibility among residents and consequent social dissatisfaction. Importantly, Stancliffe et al. found that people living alone were not more lonely than those living in two-person households. Therefore, for individuals who choose to live by themselves concerns about loneliness should not be a barrier to living alone. Indeed, some people prefer to spend a good deal of time alone, perhaps because they find social interaction stressful. For example, some people with Aspergers are said to *continued page 4*

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deliberately choose jobs that involve long periods of being alone (e.g., truck driving).

Other aspects of living arrangements are related to loneliness. Stancliffe et al. (in press) found less loneliness among adults living with their family (40.2% were lonely) versus outside the family home (46.4%). For people living outside the family home, those who chose who they lived with were less lonely than those who did not choose their living companions (no choice = 51.7%, full choice = 44.8%). Ballin and Balandin (2007) noted that people with cerebral palsy sometimes were lonely in their group homes as they had little in common with other residents and often were able to communicate easily only with staff. Finally, other features of the home or local community can greatly influence the experience of loneliness. Stancliffe et al. (2007) found that being afraid at home or in one's local community was strongly associated with greater loneliness. Experiencing such fear and not having the support or positive companionship to overcome it may be experienced as loneliness.

Overall, these findings suggest that loneliness is reduced when you can choose where you live and who you live with, including living by yourself. Feelings of loneliness are also reduced if you feel safe at home and in your community. People living in large-group settings or institutions are more likely to feel lonely.

Relationships and friendships. Stancliffe and Lakin (2006) found that people with more contact with family and friends were less lonely. Families often maintain contact with a family member with a disability long after the person has moved out of the family home. For example, Stancliffe and Lakin found half of their participants, who had an average age of 45, continued to have contact with their family 6-monthly or more often, even after almost three decades of institutional life. These authors also found that institutional closure and relocation to community living resulted in increased or renewed contact with family in many cases.

Older people with cerebral palsy noted that their families were important in mitigating feelings of loneliness (Ballin & Balandin, 2007). Some participants noted that they felt very lonely and upset if families did not make contact or excluded them from family get togethers, for example at Christmas or family birthdays.

Support for maintaining social contacts and reducing loneliness

There are a number of areas in which people with intellectual and developmental disability can be supported to help them maintain friendships and avoid loneliness.

Phone skills. Fees, Martin, and Poon (1999) found that having frequent conversations with friends on the telephone was an effective way of decreasing loneliness. Morris (2001) reported that not being able to talk to friends on the phone increased feelings of social exclusion for young people with disability and high levels of support needs. People with disability may have difficulty using the telephone independently. Phone skills training, easy-to-use phones (e.g., one-touch dialling), and support with phone use can all assist with reducing these difficulties. However, this support needs to be given sensitively. People who need support to use the telephone may find that their support workers 'take over' phone interaction thus increasing feelings of loneliness, and exclusion. (Cooper, Balandin & Trembath, in press).

Internet skills. Despite advances in web sites that are accessible to people with disability, including screen reading technology, people with intellectual and or physical disability still experience barriers to accessing the internet. Furthermore, families and staff may be concerned that people with intellectual disability are vulnerable to exploitation when accessing virtual worlds that are increasingly popular venues for making 'virtual connections' and friendships that sometimes lead to friendship in the 'real' world. In addition, physical disability such as cerebral palsy, or poor literacy skills each can impact negatively on computer access unless an individual has a range of assistive technology available and the support to learn how to use and maintain this equipment.

Interpersonal problem solving. Keith McVilly's research on friendship and people with intellectual disability revealed that some lonely individuals experienced the breakdown of valued relationships but did not know how to rebuild that relationship (McVilly et al., 2006). Sensitive personal support in these situations can help avert permanent loss of a previously good friend.

Social skills – meeting people. Adults with cerebral palsy who have complex communication needs have noted that communication difficulties are a barrier to developing friendships in the community (Ballin & Balandin, 2007, Cooper et al. in press). Communication difficulties are also common for people with intellectual disability, yet there is little information on the impact of communication interventions on friendships and loneliness.

Maintaining or resuming friendships. Friendship requires personal contact and opportunities to spend time together. Some people with intellectual disability need help with the practical aspects of bringing about these contacts. Practical assistance with telephoning friends and family, exchanging cards and presents on special occasions, inviting a friend to go out or to visit, all can

contribute to maintaining an existing friendship or resuming contact with an old friend. Likewise, support with transport, money management and personal schedules can all assist with enabling these activities to occur. McVilly et al. (2006) found that people with intellectual disability identified these issues as matters where they wanted practical assistance. Similarly people with physical disability have noted that transport costs and poor access to public transport are major barriers to keeping in contact with friends who have moved to a range of community living options over the years (Ballin & Balandin, 2007).

Pets. Feelings of loneliness may be moderated by having a pet (Banks & Banks, 2002; Smith, 2004). Smith, a woman with cerebral palsy, commented that having a dog increased her participation in the community and also provided satisfaction and self-esteem as she trained and managed her pet. Yet although some people with physical disability use assistance dogs, to date, there have been no studies on the use of pets to alleviate loneliness for people with disability (Ballin & Balandin, 2007).

The effect of loneliness on health and well-being.

Personal relationships are fundamental to quality of life and provide social, emotional, and practical support, as well as information and advocacy (Robertson et al., 2001). Relationships and personal support also provide important safeguards against stress and psychological illness (Duck 1991). Conversely, loneliness can have detrimental effects on the physical and mental health of adults (Hopps et al., 2001). Creecy et al. (1985) reported an association between loneliness and the increased depression, suicide, peptic ulcers, asthma and other respiratory conditions, as well as diabetes and coronary disturbances. Among people with intellectual disabilities and in the wider community, loneliness is significantly associated with suicidal thoughts (Lunsky, 2004) and depression (Heiman, 2001; Lunsky, 2003).

Personal stories

Two personal stories illustrate some important issues about loneliness.

Choosing who you live with. Joanne (assumed name) had lived in a large, isolated private residential where she had a close relationship with her boyfriend. When the residential closed most people were offered the chance to move into four-person group homes in various locations. Joanne moved to a group home but was not close friends with any of the other residents there. Unfortunately her boyfriend had become ill and was placed in a nursing



home many suburbs away, and it was very difficult for her to visit or even to telephone him. Joanne reported very often feeling lonely, not because she was alone – she lived with three other people in a home with 24-hour staffing – but because she was unable to be with the person she most wanted contact with; her boyfriend. This case is a sad example of the importance of being able to choose who you live with and its relationship to loneliness.

Living alone. Another woman, Doris, (assumed name) from the same private residential had a different experience. When the residential closed she too moved to a four-person group home (she actually lived in a self-contained granny flat at the group home) close to where her family lived, although her preference had been to live alone with support. There were fundamental incompatibility issues among the group home residents which resulted in continuing aggressive behaviour by Doris, who was clearly anxious and unhappy. The situation came to a head and eventually Doris moved to her own place to live by herself with support. She was much calmer – “like a different person” - and she was still near her family so there were no serious issues of loneliness. For Doris, living alone was far preferable to living with others. Living alone she could interact with others (or not) on her own terms, whereas being required to interact by virtue of living together was distressing for her.

Conclusion

Loneliness is a widespread problem among people with intellectual and developmental disability. It causes real distress and can contribute to physical and mental health problems. To find out about each person's experience of loneliness we need to ask the person about this issue. Most people can talk about such feelings and can highlight the support they would like to help with social contacts and friendships. We identified a num- *continued page 6*

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ber of factors that affect loneliness, ranging from living arrangements to practical supports for contacting friends and family. However, support workers and families do not always recognise the importance of these issues and, as the personal stories show, sometimes unintentionally create situations that result in greater loneliness or interpersonal conflict.

Future research. With Christine Bigby (La Trobe University), we are joint recipients of an ARC Linkage Grant, starting in 2009, entitled Transition to retirement by adults with chronic disabilities: increasing community capacity. Retirement from work or day activities is a time when people with disability are at risk of social isolation and loneliness. With our industry partners AFFORD (Sydney) and St John of God Accord (Melbourne), we plan to investigate opportunities for participation in retirement – like retirees without disability – in community groups and voluntary work, by:

1. identifying the opportunities for and barriers to participation in community groups and voluntary work by older people with chronic disability;
2. using these findings to design and trial a training package to enable community groups and voluntary work settings to achieve greater participation by older people with chronic disability;
3. determining the benefits to the well-being of people with chronic disability.

We will assess the effects of this approach on loneliness and other aspects of well-being. We look forward to sharing our findings with IDA readers in the coming years.

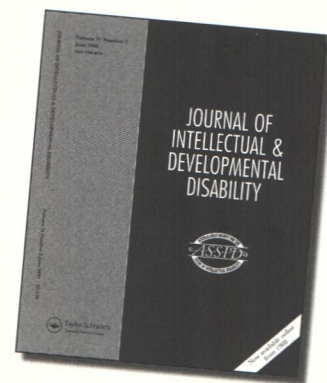
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What Older Adults with Cerebral Palsy Say About Feeling Lonely

*A Plain English translation by Sheridan Forster of:
Ballin, L., & Balandin, S. (2007)*

An exploration of loneliness: Communication and the social networks of older people with cerebral palsy
Journal of Intellectual & Developmental Disability, 32,315-327



Feeling lonely means different things to different people. Researchers generally agree that feeling lonely includes having problems with relationships and it is a sad feeling. Sometimes people feel lonely even when they have lots of people around them. People do not feel so lonely when they have good friends around them. Older people can feel more lonely than young people. They might feel lonely because they have left work or moved house. They may be feeling sick too. Older people's friends might die. Their husband or wife might die. This can make people feel more lonely.

People with cerebral palsy get old too. Many people with cerebral palsy have difficulty communicating. This can make it harder to have good relationships.

The researchers in this study wanted to find out more about older adults with cerebral palsy.

What did the researchers do?

First, the researchers asked their university if it was okay for them to do this research. Then they contacted seven adults with cerebral palsy. The researchers asked the adults if they would like to be interviewed about feeling lonely. They all said yes. The youngest adult was in his forties and the oldest was in her sixties.

The researchers interviewed the people twice. They had long conversations about feeling lonely. The researchers taped the conversation and then wrote down what was said. They looked at all of the different ideas talked about by the person. The researcher asked the person if they had got the right idea about feeling lonely.

What did the people say about feeling lonely?

Two main ideas came up. The first idea was about communication. The second idea was about the different people in the adults' life.

Communication

Communication had a big impact on feeling lonely. Sometimes problems with communication made people feel more lonely.

The adults felt more lonely when people could not understand what they said. They felt that some people

did not know much about communication. They felt that sometimes people did not give them enough time to communicate. Talking with support staff made them less lonely.

Six of the adults felt that talking on the phone was good. But two people found it hard talking on the phone. Some people also communicated on the internet.

Different people in the adult's life

Feeling lonely was affected by the different sorts of people in the adult's life. The adults felt better when they had a good family. Some people really liked spending time with other people's children. One of the adults had two children.

Two of the adults had a partner. The other people felt lonely without a partner. They missed touch and having someone close. Everyone thought that friends were really important.

The adults also talked about staff who were friends. Some people found it hard when staff left them. Only one person said that their housemates made them feel less lonely. Most people didn't get along with their housemates. Some of the people talked about having pets and how this made them less lonely.

Outside of their house, some people felt good about their neighbours. Many of the adults felt that the attitude of people in shops and other places made them feel lonely. A couple of people went to clubs and church. Most of the adults felt that going out with people made them feel less lonely.

What did the researchers learn?

The researchers found out that the adults with cerebral palsy were like other older adults. The same sorts of things made them feel lonely. But some things made the adults with cerebral palsy more lonely, like having trouble communicating.

Adults with cerebral palsy may need lots of different types of help to stop loneliness. Everybody needs education. People need to be able to choose who they live with. Services need to be good at helping people keep good friends as they get older. ♦

Queensland

by Madonna Tucker

ASSID Qld has been through some changes in the last couple of months. We recently held our AGM and dinner regarding the Carter Report and the outcomes of that report entitled: "Challenging Behaviours – Bringing the Dream to Reality". There was three speakers at the dinner– the Hon. Bill Carter (who spoke about the Carter Report), Ron Joachim (who presented upon the new Restrictive Practices Legislation), and Robert Heron (recently appointed as Director of Learning and Development in The Centre of Excellence for Behavioural Support, who spoke about his vision for the Centre regarding learning and development issues). All three presenters discussed the journey of challenging behaviours from the dream (report) to reality (the Centre).

At the AGM Madonna Tucker took over as ASSID Qld President. Thanks to Janene Suttie who did a fabulous job last year. We also have three new committee members: Ankica Melbye as Secretary, Cindy Nicollet and Julie Kelly who have joined us on the committee. Then we have the committee members who are back for another year: Lyn McPherson as Treasurer, Lisa Fraser as Board Rep, Karen Grogan and Paul Grevell as committee members and finally Hamish Millard (Board Rep) who has not written this update because he is on his honeymoon! If we are lucky he might give us a photo for the next IDA update.

South Australia

by Richard O'Loughlin

The SA branch will have held its AGM on 12 November. It will have already occurred by the time this magazine goes to print. Lynn Young - the Executive Director of Disability SA will be our guest speaker. Lynn will be talking about the Department for Families and Communities' vision for the future of services for people with an intellectual disability, their families and carers in South Australia. At this stage, there is every indication that we shall have a large turnout.

We anticipate a Christmas event for ASSID members where we will have one of our prominent members talking about his recent experience at an orphanage in India that provides care to children with a disability.

We have plans for 2009 that include following up with our membership in the Northern Territory (what assistance can we provide them in getting some local events happening?); looking at how we can involve people with an intellectual disability in both developing and disseminating resources on their rights; and continuing our efforts at engaging with the universities that are doing research in the field as part our ongoing effort to bridge theory and practice.

Given the theme of this issue of IDA is Loneliness and that we are approaching the end of the year - a time of year that involves celebration for those of us who have family and healthy social networks, I hope that we all maintain an awareness of those individuals who do not have

these critical supports, and what role we can all play in supporting these people to become more part of the community.

Seasons greeting to you all and as always if you have any concerns, passions or areas of interest that you believe that it would be of benefit for ASSID to run a forum event or some other type of event on, please contact me on richardoloughlin@bigpond.com.

Tasmania

by Craig Jones

October saw our third annual Celebrating Support Workers conference take place in Hobart. The theme of the conference was "Celebrating our Client Networks" and was our first two day conference. Attendance was fantastic and the feedback from delegates was that they were very happy with the event. Our keynote speakers were Jane Warlow and Maria van Ravenstein. Jane spoke about flexibility, control and independence in relation to funding and services and how as a service user, she operates as her own employer based on an individual funding package. Maria is a young lady with down syndrome who has packed more than a life times experiences into her short 30 years. She delighted the audience with her address on the supports she received in being able to achieve her goals and then enthralled delegates with her dance performance.

The 44th ASSID Conference, Power and Passion: Progress through Partnerships being held in Hobart in 2009 was officially launched at the 43rd ASSID Conference in Melbourne. We have a number of keynote speakers already confirmed as well as a very active social program. We look forward to seeing you all at the conference and invite you to submit an abstract. Details are available in the Call for Abstracts brochure included with this edition of IDA.

Victoria

by Louise Mountford

The ASSID Vic committee have been overwhelmed by the number of registrations for the 43rd Australasian Board Conference and the 8th Annual Disability Support Worker Conference (DSW08), with both of these events now booked to capacity. Whilst the whole committee have been busily preparing for these events, none of this would have run so smoothly without the organisational skills of Sue Mason working hard to put it all together.

The 43rd Board Conference was held on the 24th-26th of November at Melbourne University with the theme 'Principles, Policy and Practice: The Search for Evidence' There was a full and interesting program featuring keynotes from: Professor James A. Mulick, Bruce Tonge and Laraine Masters Glidden.

DSW08 was held directly after the 43rd Board conference on the 27th and 28th of November. Keynotes for the conference included: James Mulick, Laraine Masters Glidden, and Doug Boer. The conferences theme 'Working Well: on Paper and in Practice' was highlighted by the return of the popular panel session. This year the panel of experts, headed up by Mr Andrew Hollo, placed themselves 30 years into the future and reflected on the practices of today.

The debate was robust and lively!

The ASSID Vic AGM was held in October, where we were lucky enough to hear from Mr Jeffrey Chan about the progress of the Office of the Senior Practitioner (OSP) and their work addressing restrictive practices, as well as from Mr Sanjib Roy the new CEO of Yooralla and his initial reflection on the sector and Victoria's largest community service provider. The new Victorian committee was also elected, with Samuel Murray returning as president, Alyson McKenzie as Vice President, Glen Jose as Treasurer and Paul Tomaszewski as Secretary. We are confident that they will lead the Vic branch of ASSID through another productive year.

New South Wales & ACT

By Tina Purdon

ASSID NSW is pleased to announce that at the AGM held Friday 31.10.08. The following new Committee Members were elected:

President – Tony Harman
Vice President – Vivienne Riches
Secretary – Linda Ward
Treasurer – Dennis Robson

General Committee Members – Ian Marinner, Laura Hogan, Mark Blanks, Sheila Frater, Trish Wetton and Tina Purdon

We warmly welcome Ian, Laura and Mark, who are new to the NSW Committee.



L-R Standing: Viv Riches, Tina Purdon, Dennis Robson, Mark Blanks, Laura Hogan, Sheila Frater

Seated: Linda Ward, Tony Harman, Trish Wetton

The newly elected Committee would also like to acknowledge the efforts of Trish Wetton who has held the role of Secretary for a number of years and thank her sincerely for her contributions to NSW ASSID during this time.



'You are Valued', was an informative and motivational session held immediately prior the AGM. Approximately 30 people were entertained by Deborah Frith from the Royal Rehabilitation Centre, Sydney, as she spoke about her experiences working and supervising staff in the Human Services Sector.

We are very pleased that Deb was able to share her insights with us on this occasion and thank Deb for her engaging and enthusiastic presentation. ASSID NSW would also like to recognise the support of all Organisations who sent participants along on the day.

The first meeting for the new Committee will be held on Friday 5th December. We again encourage any interested persons from Regional NSW areas to contact the Secretary – lindaw@ucsl.nsw.uca.org.au. ASSID NSW has made a commitment to assist involvement of ASSID members from Regional areas.

By the time this issue of IDA is distributed, the 43rd ASSID Conference will have been completed. We are looking forward to catching up with our interstate colleagues in Melbourne at the Conference and wish ASSID Victoria all the best with the Conference and also the Direct Support Worker Conference to be held the same week. ASSID NSW appreciates the mammoth task that organising these events constitutes and we put forward our appreciation.

As this will be the final IDA issue for the year, we would like to wish all our ASSID colleagues a healthy, happy and safe Christmas and a fabulous New Year ahead. We keenly approach 2009 and the prospect of regrowing ASSID NSW to a strong, recognised body within the Australasian Association and also within our own State.

Finally, the Committee would like to thank Sue Peden for her work as the IDA editor. Without Sue's emails and reminders, and calm encouragement, IDA would not be the newsletter that it is.

New Zealand

by Sharon Brandford

We held our annual conference in Wellington, on the theme of Lifetime Health and Well-being. We had 3 excellent keynote addresses:

- Dr Rosie Marks, a developmental pediatrician, discussing transitions from childhood to adulthood
- Dr Stephanie duFresne, giving a very reflective presentation on her life long observations as a psychiatrist working to enable people with disabilities to have a good life,

continued page 10



region update

continued

- Christine Bigby, giving a powerful overview of the context in which adults with disabilities, their families and services must plan for later adult life.

Excellent presentations from across the country made this yet again an important conference event, this year marked also by an all day stream devoted to mental health issues, as part of an increasing involvement with mental health professionals in NZ committed to people with intellectual disability.

Professor Jeff Sigafoos held a one-day seminar in Dunedin in August on Communication and Behaviour issues for people with ASD. It was well attended and generated positive discussion and feedback.

NZASID hosted a Launch event of the ASSID Code of Ethics at a joint meeting of the country's residential and vocational service providers. There has been much interest and activity as a result, including several positive discussions with trade unions, who see this as a tangible opportunity to strengthen the role of direct care workers.

We are collating papers from presenters at our national conference and will disseminate these to interested people as soon as they are available.

Our annual Planning day with the incoming Council will be held in Wellington on December 5th. All members are welcome. Contact NZASID President.

While not an ASSID event, we in NZ were proud to hear that Dr Olive Webb, an inaugural member of NZASID, was awarded the Honour of NZ Order of Merit for her services to people with disabilities.

We sadly mourned the passing of Dr Anne Bray, former Director of the Donald Beasley Institute, whose life-long commitment was to the meaningful and sound research

that advanced the lives of people with disabilities.

As NZ faces a General Election in November we await with some great interest its outcome, and hope for continuing commitment from our elected representatives to make living in NZ a disability better. We are pleased to see that our Government has ratified the UN Convention on the Rights of Persons with Disabilities, and look forward to seeing the ink used to sign off some action plans.

Western Australia

by Angus Buchanan

The recent ASSID Western Australia Annual General meeting saw some changes within the Western Australian Committee. Associate Professor Buchanan took over as Regional President from Chris Coopes, who deserves a well earned rest after two years of dedicated work. During his tenure the successful 2007 ASSID Conference and two State Conferences have taken place plus numerous other events and initiatives. ASSID WA sincerely thanks Chris for all of his commitment and hard work and leaving things in great shape. The new Western Australian Committee is:

Angus Buchanan (President), Nicole Hicks (Vice president), Sue Peden (treasurer), Jill MacKenzie (Secretary), Chris Yates, Chris Coopes, Mauricio Sanabria, Sandy Komen. The WA ASSID Committee reminds members that they are welcome to attend committee meetings. Contact Jill MacKenzie for meeting details ill.mackenzie@dsc.wa.gov.au

The WA ASSID Committee continues its focus on building a depth and diversity of membership and over the next 12 months will be working to build partnerships with the university/education and the non government sectors, hosting workshops/seminars and will run the annual State Conference. ♦

Full-Time PhD Scholarship Opportunity

La Trobe University,

Melbourne, Australia

(Preliminary announcement)

This Australian Postgraduate Award – Industry (APAI) is funded via an Australian Research Council (ARC) Linkage Grant: ***Transition to retirement by adults with chronic disabilities: increasing community capacity.*** The investigators are: Associate Professor Roger Stancliffe (University of Sydney), Professor Christine Bigby (La Trobe University), and Professor Susan Balandin (Molde University College, Norway).

The successful applicant will receive a tax-free stipend and will conduct their research under the supervision of Professor Christine Bigby at La Trobe University and the co-supervision of the other two investigators. The industry partner in Melbourne is St John of God Accord, and small number of the older day-program service users will be invited to participate. The PhD student will use qualitative research methods to investigate the processes for placing and supporting people with severe intellectual disability in community settings as they transition to retirement.

A formal announcement and call for applications will be made in the coming weeks. For more information, interested individuals should contact:

Professor Christine Bigby
C.Bigby@latrobe.edu.au (03-94791016)

Associate Professor Roger Stancliffe
r.stancliffe@usyd.edu.au

Loneliness, Isolation and Not Belonging

Workshop Communiqué



While we may be heading towards a civilization which may have little further use for the "social", for the time being it seems as though this problem is the cause of considerable pain and suffering.

Professor Adrian Franklin

On Wednesday, 17th October 2007 the Australasian Society for the Study of Intellectual Disability and the Department of Disability Studies, Flinders University, conducted a workshop "Loneliness, Isolation and Not Belonging". This workshop, conducted to address what has been described as the "emerging crisis of loneliness" within Western societies and, in particular, the effect on people with disabilities, attracted 52 participants from a broad background.

Dr Lorna Hallahan, Lecturer from the School of Social Work in the Faculty of Social Science at Flinders University and recently appointed Chair of the Ministerial Advisory Committee on Disability, was the keynote speaker. Lorna set the scene for the workshop by describing the role seemingly assigned to people with disabilities in our societies and how our attitudes exacerbate the isolation of people with disabilities. Lorna also spoke on the need for community development and systems that put people more in control of their lives and destinies.

Dale Hassam, who recently retired after 45 years in the field of Intellectual Disability, spoke of his experience of managing the Department for Community Services' relationship with the boarding house sector. He spoke of lives impoverished by a lack of friends, plans and hope for the future. Rather than homelessness being a cause of the problems in an individual's life, it is much more likely to be a manifestation of "lives without hope". Dale spoke of the need for new ways to include people with disabilities and the limitations of the service system which often had a preoccupation with accommodation, not recognizing the sustaining capacity of friendships and a purpose in life.

He also spoke on the "Wraparound" model which has been successful in Canada in bringing these important components into a holistic view of the individual.

Mr Ross Womersley, Executive Officer of the Community Living Project, spoke on his organisation's experience in implementing a "Circles of Support" program. This program entails finding significant people in the life of an individual who will meet with the individual to develop a friendship group and support the development of future plans. Ross showed a film that had recently been developed to demonstrate what the "Circles of Support" could offer to people with disabilities. There is no doubt that this initiative has insured that people with disability, that have participated in this process, have a group of people

who are interested in supporting them on a long-term basis.

Ms Cassie Quigley, Teen Companion Coordinator of Interchange, spoke of the Teen Companion program. In this program, a young person with a disability is matched with a young person without a disability who shares the same interests. The two then meet on an agreed basis to do things that are of interest to both of them. Cassie mentioned that although they are able to recruit about 50 teen companions a year, they currently have a waiting list of 250 people with disabilities who are seeking a companion.

The discussion at the workshop ranged across a number of topics but some key issues emerged:

- There is a need to find out the degree of isolation amongst people with disabilities. As this has generally not been 'on the radar' of service providers, it will be necessary to ask people with disabilities themselves.
- The situation of people living in institutions needs to be examined. There is a view that many people with disabilities have a rich and varied range of relationships with other people in institutions and that when down scaling projects occur, these relationships need to be taken into account.
- There is a need to support people with disabilities to speak for themselves and to talk about the things that are important to them. Such organisations as "Our Voice" (a self advocacy group) should be supported so that the actual views of people with intellectual disabilities can be obtained.
- Community development initiatives are imperative. We need to find out where communities gather and work out strategies as to how those gathering places can include people with disabilities. It is interesting to note in passing that some venues are already very inclusive of people with disabilities e.g. football clubs.
- We need to recognise that if people with disabilities are truly integrated within the South Australian community then they have to have opportunities to contribute to the community. Many already do this through service clubs, their employment and through volunteering. These programs need to be supported and expanded.
- Developing the infrastructure to support these options for people with disabilities is well worth funding. Many are essentially volunteer models and do not require a high outlay of funds for a significant benefit to a potentially large number of people with disabilities. For example,

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... and Not Belonging

Workshop Communiqué

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once established, "Circles of Support" can be potentially self-sustaining.

- There is no panacea for the accommodation crisis or the overall substantial underfunding of disability services. Group home models of service are not cheaper than institutions. There have been a number of attempts recently, e.g. home boarding, that have not only been more cost-effective but have also given the individual an alternative family.
- The underpinning of addressing loneliness and isolation in people with disabilities will also address this growing problem in the wider community. We don't live in neighborhoods in a way that we once did. The majority of people drive to most places because public transport is not user-friendly. Children are transported to school and even if the supermarkets are close by, which is not likely in many of the newer housing estates, we invariably take our cars. These are all issues that will need to be addressed as we move to a society that has to pay more for its energy and transport.
- There are real economic costs to social isolation not only for people with disabilities but indeed all vulnerable people. It is those people who are usually unemployed whom we see as not making a contribution to the community. These people will be at greater risk of mental illnesses such as anxiety and depression. They will add to what epidemiologists call the community's "burden of disease". These are the people who are more likely to find themselves vulnerable to a gambling addiction, substance abuse and exploitation by others. These are also the people who are most likely to find themselves before the courts on minor charges such as shoplifting and disorderly behaviour.
- Some participants expressed concern at the attitudes of other workers in this field often alienating families and controlling the person's contacts. Such programs as "Community Visitors" could have a substantial effect in ensuring that there are substantial other people in the lives of an individual.

SUMMARY

Loneliness and isolation are emerging problems in South Australia and not only for people with disabilities. The emphasis on the need to be first and foremost consumers rather than citizens has resulted in many in our society being disconnected, lonely and unhappy. Our "new toys" seemingly do not give us the happiness the "market" promised us in its seductive messages. These problems will be exacerbated when those living in ill-planned and infrastructure-poor suburbs are hit by the effects of the looming energy shortages and price increases.

The issues raised in the forum and documented in this communiqué present a significant challenge to all people who are concerned about the circumstances of people with disabilities and their families. The range of constraints (e.g. budgetary) on the responsible public sector agency - the Department for Families and Communities - appears to result in the department responding in a way that is more reactive (responding to crises) rather than putting in place proactive programmes that may address issues causing and resulting from isolation and loneliness. Strong leadership is required.

The Australasian Society for the Study of Intellectual Disability (SA) and Flinders University's Department of Disability Studies recommends some urgent activities by the South Australian Government including:

- Research on the causes and nature of loneliness and isolation.
- Research on the effects of fuel shortages on our communities.
- Talking to people with disabilities about their lives.
- Providing opportunities for people with disabilities to contribute to our community.
- Giving high priority to community development initiatives.
- Research on the social cost of isolation.
- Some innovative programmes that demonstrate how people with disabilities can be included in the fabric of the community.
- Research on how power is given back to people with disabilities. ♦

ASSID membership details

4 membership types:

Organisation / Individual / Student
/and Associate

to join:

download a form from www.assid.org.au,
or
contact the registrar at the address below

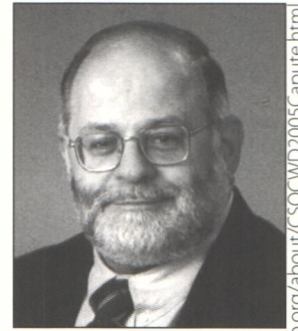
to current members:

please make sure you don't miss out
keep your contact details up to date

registrar:

phone 1800 644 741
PO Box 84 Rosanna VIC 3084 Australia
assid.national@bigpond.com

Capute and Accardo's Neuro-developmental Disabilities in Infancy and Childhood



Editor:
Dr Pasquale J Accardo

www.medicalhomeinfo.org/about/CSOCWD2005Capute.htm

3rd Edition, published in 2008

Review by: *Denise Luscombe and Raewyn Courtney*

Disability Services Commission, Western Australia

This is a two volume set with Volume I titled Neuro-developmental Diagnosis and Treatment and Volume II titled The Spectrum of Neuro-developmental Disabilities. Editor Pasquale J Accardo. The chapters are written by many different contributors. The two volumes together total over 1400 pages.

Volume I is divided into five sections titled Introduction, Scientific basis, Etiologies, Assessment and Practice Issues. Volume II is divided into seven sections titled Spectrum of Motor Dysfunction, Intellectual Impairment, Genetic Syndromes Associated with cognitive Impairment, Communication Disorders, Autism, Disorders of Learning and Disorders of Attention and Hyperactivity.

The introduction to Volume I includes sections on the neuro-developmental perspective on the continuum of developmental disabilities and human brain development.

The section titled 'Scientific basis' has chapters covering the Epidemiology of Developmental Disabilities, Genetics, Metabolic Diseases and Developmental Disabilities, Neonatal Encephalopathy, Genetic Intellectual Disability – neurobiological and clinical aspects, Human Behaviour Genetics – implications for Neurodevelopmental Disorders.

The Etiologies section covers prematurity, Congenital infections, Children born to Drug-Dependent mothers, Foetal Alcohol Syndrome and related disorders and Plumbism – Elevated lead levels.

The Assessment section has eleven chapters covering topics such as the developmental history, the dysmorphology examination, the Amiel-Tosin and Gosselin Neurological Assessment from birth to six years of age, Neonatal Neurodevelopmental assessment, Neurodevelopmental assessments of infants and young children and school

age children. There are also chapters on Developmental screening – the pathway to early identification and Functional assessment in neurodevelopmental disorders, visual impairment and neuroradiology. There is an interesting chapter on family functioning. When the impact on families is discussed it is not clear as to whether there was any input from families. There is nothing on working with families in a practical sense for practitioners in the field.

The Practice issues section contains a chapter on Early Intervention and its efficacy. Different disabilities are described in this chapter and at the end of each section there is a section on efficacy of Early Intervention for these different groups. There is also an interesting conclusion to this chapter about Early Intervention and some useful references. This chapter on Early Intervention and its efficacy is worth reading.

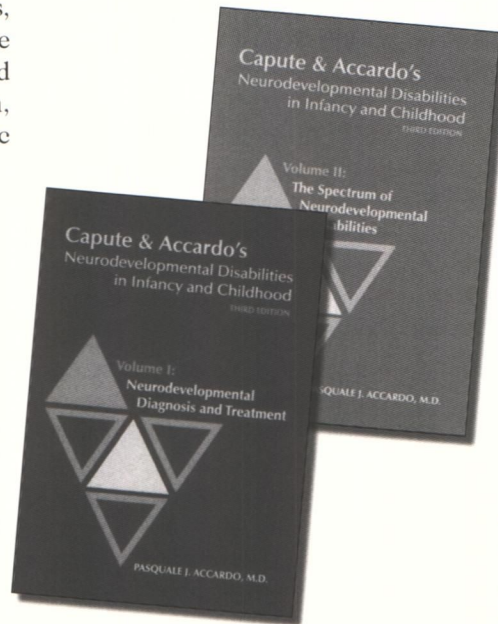
ing.

The practice issues section also contains chapters on Behaviour management, Psychopharmacology

– an approach to management in Autism and Intellectual Disabilities, traumatic brain injury, Acquired Spinal Cord dysfunction, Neurorehabilitation, Sensory integration, Assistive and Augmentative Technology for individuals with Developmental disabilities, non standard therapies in Developmental disabilities, Ethical issues in disabilities, Legislative directives and trends, international adoption and supports for families of children with disabilities.

Following the chapter about assistive and augmentative technology there is an appendix of information about devices and software, organisations and resources about assistive technology and other organizations related to different disabilities and funding sources. Unfortunately for Australian readers, this information

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2008 Australasian Research Prize

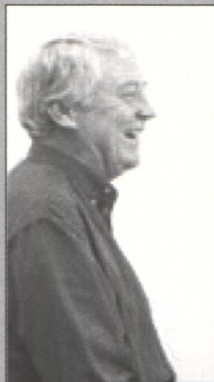
(for a paper published in JIDD during 2007 and judged to be the most innovative contribution by an Australasian author/s resulting in positive life changes for people with an intellectual disability):

2008 JIDD Editor's Prize

(for the paper judged to be the most outstanding contribution among all papers published in JIDD throughout 2007)

This year both the 2008 ASSID Australasian Research Prize and the 2008 JIDD Editor's Prize go to **Alan Hudson, Christine Cameron, and Jan Matthews** for their paper published in JIDD 33(2): **"The wide-scale implementation of a support program for parents of children with an intellectual disability and difficult behaviour"**.

This is the first time one paper has received both awards.



Alan Hudson



Jan Matthews



Christine Cameron

book review

Capute and Accardo's

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relates mainly to American organizations and sources of funding.

All information related to legislative directives and trends discussed in chapter 36 is American and therefore not applicable to the Australian setting. In the chapter of Supports for families there is resource material for families which again is all American, so its relevance to the Australian context is questionable.

In Volume II section one titled "Spectrum of Motor Dysfunction" contains thirteen chapters which cover from the Epidemiology and Etiological Spectrum of Cerebral Palsy to the Neurophysiological basis for the treatment of Movement disorders to Spina Bifida to Tourette Syndrome and associated Neurobehavioural problems.

Section two called Intellectual Impairment contains two chapters one on the spectrum of Cognitive adaptive developmental disorders in Intellectual Disability and one on Psychological assessment. In section three there are eight chapters describing Genetic syndromes associated with cognitive impairment including chapters on Down Syndrome, Prader-Willi Syndrome, X-linked Intellectual disabilities, Williams Syndrome, Turner Syndrome, Smith-Magenis Syndrome, Velocardiofacial syndrome and Epilepsy and Developmental disabilities.

Section four examines Communication disorders and hearing loss. There are chapters on the child who does not speak, assessment of speech and language disorders

in children, Hearing loss and Audiological assessments of infants and children with Neurodevelopmental disabilities.

The section on Autism has chapters on an overview and diagnosis of Autism Spectrum disorders, Etiologies of Autism spectrum disorders, Treatments for children with Autism disorders and a chapter on Rett Syndrome.

Section VI contains three chapters on disorders of learning and Section VII contains six chapters about Disorders of Attention and Hyperactivity.

These are comprehensive American texts that have a target audience of Paediatricians and Allied health Professionals working in the Neuro-developmental area. The major focus of these texts are diagnosis, aetiology, epidemiology of conditions described and sometimes treatment. There is a medical, clinical and evidence based focus in both volumes of the text. The treatment model described is the Medical model.

In general these volumes are relatively easy to read with short focused chapters. The chapter order is difficult to follow but it is presumed that these books are not meant to be read sequentially from front to back. The volumes provide a reasonable background on a diverse range of topics in the area of neurodevelopmental disabilities. These volumes are reference texts, they do not have a lot of practical information for the practitioner in the field. ♦

upcoming events

4 - 6 Feb 2009	<p>"Having a Say 2009" The Victorian Advocacy League for Individuals with Disability Inc to be held at Deakin University campus, Geelong</p>
7 - 9 May 2009	<p>AGOSCI 9th Biennial National Conference 2009 Communication FEEL THE POWER For more information email agosci09@ammp.com.au</p>
19 - 21 June 2009	<p>3rd International Cerebral Palsy Conference to be held at the Sydney Convention Centre, NSW For more information email cp2009@meetingplanners.com.au</p>
24 - 27 June 2009	<p>2nd IASSID Asia Pacific Conference "Creating possibilities for an inclusive society" to be held at the Furama Riverfront Hotel, Singapore For more information go to www.iassid.org</p>
20 - 22 Aug 2009	<p>Asia-Pacific Autism Conference "Connecting Today: Inspiring Tomorrow" will be held at the Sydney Convention and Exhibition Centre</p>
4 - 6 Nov 2009	<p>44th ASSID Conference "Power and Passion, Progress through Partnerships" will be held at the Wrest Point Convention Centre, Hobart, Tasmania See back page of IDA for more details</p>

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

IDA Advertising

- Display advertisement:
 \$176 (incl. GST) for quarter page (artwork supplied), where ASSID has to arrange art work, + \$70 (incl. GST).
- Pre-printed inserts:
 \$242 (incl. GST). Weight restrictions apply, contact editorial assistant for details.

For information regarding closing details for receipt of advertising material, please contact:

The Editorial Assistant, Intellectual Disability Australasia
 email: krvt@optusnet.com.au

Note: acceptance and publication or distribution of material does not indicate endorsement of a position, program, material or product by the Australasian Society for the Study of Intellectual Disability.

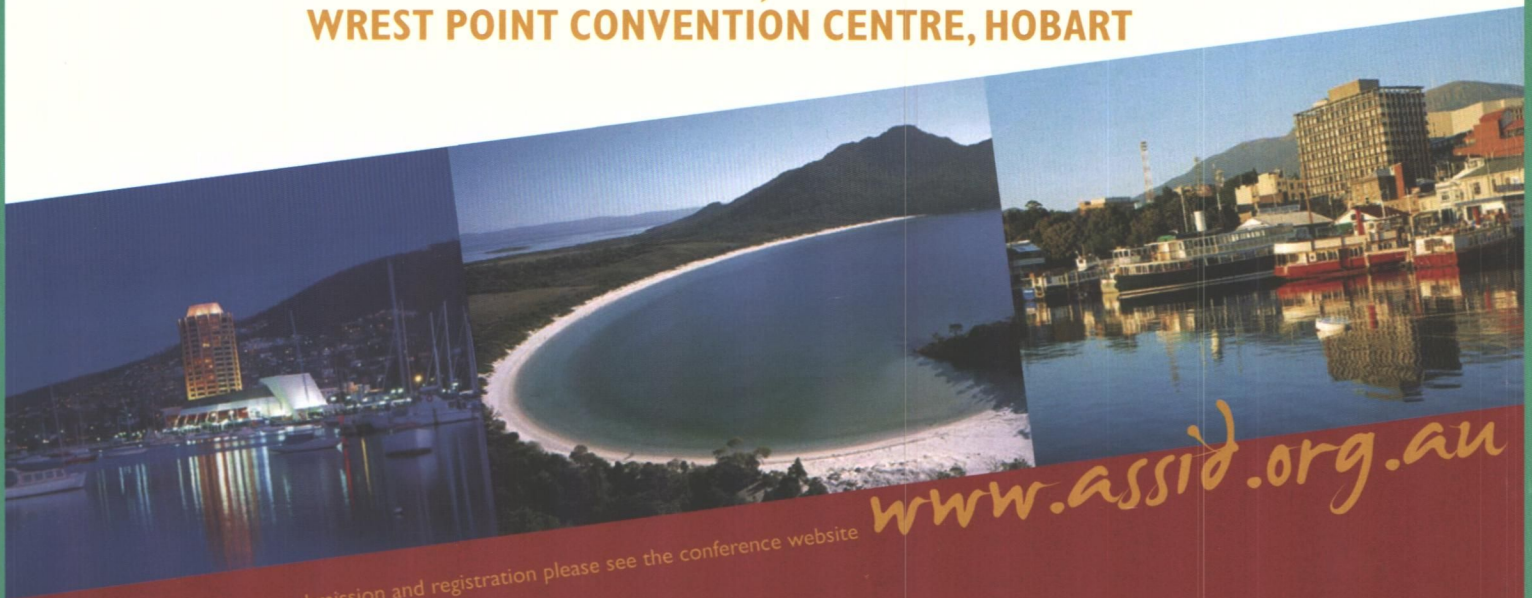


PPPP09



POWER *and* **PASSION:** **PROGRESS** *through* **PARTNERSHIPS**

44th ASSID CONFERENCE, 4-6 NOVEMBER 2009
WREST POINT CONVENTION CENTRE, HOBART



www.assid.org.au

For information on abstract submission and registration please see the conference website

The theme for the 44th ASSID Conference, Power and Passion: Progress through Partnerships has been chosen because it encompasses the mission and goals of ASSID by ensuring that the research undertaken in relation to progressing the understanding of disabilities is properly partnered with the practices put in place to ensure people with an intellectual disability are provided with the most rewarding life experiences available.

CALL FOR ABSTRACTS:

REGISTRATION:

ABSTRACTS SUBMISSION CLOSES:

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13 APRIL 2009

30 JULY 2009

30 SEPTEMBER 2009

1 OCTOBER 2009