Volume 31, Issue 1, Mar 2010

IDA

Intellectual Disability Australasia

intellectual disability
ASSID research practice
australasia

power, passion, progress and change

Magazine of the Australasian Society for the Study of Intellectual Disability

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

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

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Printed by:
Bloxham & Chambers Printers

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photos from the 44th Conference

Editorial

Welcome to IDA 2010. This first edition for the year is packed full of interesting articles, news from the ASSID Board as well as the Conference report from Tasmania. Once again, the Tasmanians provided a great welcome to their overseas visitors and locals alike. Everything went according to plan, or it certainly seemed to, from the delegates' point of view. See how many Board members' faces you can spot from the conference photos!

Make sure you read the article on 'ASSID is changing" as each member will be asked to consider the future for ASSID in the next few months.

Everything is in full swing for the 2010 conference in Queensland this year, so watch out for more information both in IDA and on the ASSID website.

Our ASSID representative on the IASSID Board has once again managed to negotiate a great deal for ASSID members at the next IASSID Europe Regional Conference, on 20 to 22 October 2010 in Rome. The conference will have both pre and post conference workshops and is a fantastic opportunity to travel to one of the most beautiful cities in Europe. Full details of the conference can be obtained by visiting the IASSID webpage.

ASSID Members will be able to register at the IASSID Member registration rate but will need to include a code number in their registration.

Members wishing to avail themselves of the discounted registration rate should e-mail the ASSID Secretariat to get the registration code.

News from the Board.

The Board has been in negotiation for some months to arrange for all regions, to have insurance indemnity for their local events as well as for the annual Board conference. Not all regions currently hold public liability insurance, but following consultation, the Board has been advised that insurance cover is highly recommended for Board events as well as for any public events held at a local level by individual regions.

Regional representatives on the Board have given 'in principle' agreement to the proposal that each region will contribute 50% of their annual per capita membership fee towards with cost, with remainder being paid by the Board. This will ensure that all regions are protected and will not face excessive costs for public indemnity insurance when it is their turn to host the Board conference.

The Board recognises that the additional costs may impact on regional budgets and financial viability, therefore has requested each Board member to ensure that the issue has been raised at local regional councils prior to the matter being voted on at the next teleconference.

I hope you enjoy reading the first of this year's IDA.

Sue

From Community Access to Social Inclusion

Presentation at the 43rd ASSID Conference Melbourne November 2008

- an examination of the literature and practices relating to the inclusion of adults with an intellectual disability in the life of the community

by Anne Marie O'Brian

Throughout the western world, social policy has developed to address the long history of people with a disability being segregated and excluded from community life. Voices of people with disabilities have called for equal access to community spaces and for the opportunity to exercise their inherent rights to full participation as valued citizens. Whilst the community living movement has led to an increase presence of people with a disability in community spaces, active participation and belonging has eluded many despite the best efforts of community organisations that support people with a disability. This paper includes preliminary research as part of a larger research project on Inclusion of Adults with a disability within the Caboolture community, a regional centre in Queensland. This research is part of a research doctorate in Social Science. Research so far includes an exploration of existing literature on the concept and development of inclusion within disability research as well as Participatory Action Research that explores individual's experience of inclusion. It is hoped that by identifying what inclusion is through existing research and the lived experience of individuals, a clearer picture on how community organisations can assist will evolve. This preliminary research suggests that the time is right for community organisations supporting people with a disability, to explore new paradigms of inclusion and align themselves with asset based community development strategies. (Green, Moore, & O'Brien, 2006; John P. Kretzmann & Green, 1998; John P Kretzmann, McKnight, Dobrowolski, & Puntenney, 2005)

Every state of Australia has a Disability Service Standard entitled "Participation and Integration" outlining the obligation for service providers to assist people with a disability to integrate, participate and be involved in the life of the community. Inclusion is regularly mentioned as the outcome. Whilst integration is thought of as having a presence, with an understanding that this presence may lead to opportunities, the concept of inclusion is difficult to define. Most often used in educational setting, inclusion has come to mean the mainstreaming of children with a disability into regular classroom. Its use amongst community development projects is recent and interchanged often with the word participation.

As part of my research project, a reference group was established of community members within the Caboolture area to look at the lived experiences of people within this community regarding inclusion. Membership included residents of the areas, people who have a disability, allies of people with a disability, indigenous people and people from a multicultural background. This group met for 7 times – each meeting lasting 2 hours. The groups were facilitated by an external community development consultant. Notes were taken at each meeting.

The group looked at the following questions:

What do people believe is inclusion?

How do people experience inclusion?

How does inclusion happen?

What strategies would assist Caboolture to be a more inclusive community?

The 3 major statements that came from this process were:

- Inclusion is not a disability issue. Inclusion is a community issue. Other members of our community experience exclusion and wish to experience inclusion.
- Inclusion is increased within the community not by an education programme but by approaching the community from a perspective of possibility and invitation and enlisting people to participate in ways that make sense to them. That the more people participated in the process the more they would own the commitment.
- Inclusion has three components: Being there, feeling like you belong there and being missed if you were not there. (A.-M. O'Brien, 2007, p. 12)

The group saw **being there** is about physical access, getting there and getting home, having information about what is on and being taken into account or considered at an event or venue.

The groups saw that **feeling like you belong there** was about the first impression they got from others, the diversity they saw in a group the attitude of people around them, good communication that connects and respects difference, honesty, common courtesy.

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People getting to know your name and what you can contribute and feeling safe in the environment.

The group saw **being missed if you're not there** as the sense of belonging that an individual may experience. They felt that being missed developed from the first two components.

The group played a key role in shaping a strategy adopted by Homelife Association Inc. and funded through Disability Services Queensland under their Day Services programmes. *Better Together* is a community initiative designed to develop a more inclusive Caboolture and contribute to the overall strength and wellbeing of the community. More about *Better Together* later.

The information gained from the *Better Together* Reference group is consistent with existing literature examining inclusion within disability theory and the strategies that increase the likelihood of inclusion of adults with a disability.

The social theory of disability provides a construct in which society and its members are to take responsibility for the exclusion of people with disability.

> *People are disabled by society as well as their bodies. It is the social and environmental barriers, prejudiced attitudes and other exclusionary processes which often make living with an impairment so hard for disabled people and their families.* (Shakespeare, 2000)

This is not to deny an impairment but to acknowledge that the effect of an impairment is intrinsically linked to the social and historical context. (Abberley, 1987, p. 12) Society must address barriers to including people with a disability and attitudes that underpin the way it sees its members.(Abberley, 1987) Changing the attitudes of people through community education programmes has had limited success. (French, 1993) and the disability community is such a diverse population that environmental responses may benefit one individual and cause harm to another. The social theory, rather than being prescriptive is a framework from which discussions may start. (Tregaskis, 2002) It calls for the individualising of disability at a social, political, practical and personal level, (Oliver, 1996), the listening to lived experiences of disability, (Biklen, 2000) and moves emphasis away from a deficit or personal tragedy theory. (Coles, 2001; Oliver, 1986)

Recent extensions of the social theory of disability include a resistance or emancipation dimension. (Abberley, 1987; Branson & Miller, 1989; P. O'Brien & Sullivan, 2005) Important to the empowerment of people with a disability, this theory emphasises emancipation through the commitment of others who will stand alongside people with a disability and question their own normality and ableist beliefs. (McLean, 2005). This sees the person with a disability as a potential leader for societal change. It also makes quality interaction between people with a disability and other community member via family, friendships and workplaces, essential to dismantling ablest views and values. (McLean, 2005)

A common definition of inclusion is the addition of somebody or something to a group or mixture.(Microsoft) In social policy the meaning extends to an invitation to those who have been historically locked out to come in. This framework asks who has the power to include or exclude and what do people have to do to be invited in. If our community recognises equality amongst its members, then no-one has the right to do the inviting and inclusion becomes a right of all people no matter their diversity. Inclusion is the recognition that we are all in the community together – not the same, but equal in our difference. The act of inclusion is the fight against exclusion of any person and the embracing of "oneness". Inclusion is no longer a disability issue. (Asante; Pearpoint & Forest) Inclusion is a moral issue, that whilst difficult to impose is theoretically difficult to argue against. (Gallagher, 2001)

If inclusion is about being there, feeling like you belong and being missed, then integration (being there) is only one third of the story. Integration has its root in segregation. History witnessed the abnormal being segregated from the normal, often behind high institution walls on the outskirts of town, away from the community and normal life. Branson and Miller suggest that integration of "the other", the person with a disability, threatens the social –culture fabric of a society that relies on "the other" to define and maintain its own normalcy. (Branson & Miller, 1989) Integration limits people with a disability to being bystanders, observers waiting for a chance to "slot in' when allowed.(Batesa & Davis, 2004) Concepts of normality and abnormality need to be deconstructed. (Danforth & Rhodes, 1997) Without a new paradigm, the participation rate of people with a disability will continue to be limited to "community access" measured by the frequency of visiting community spaces. (Abberley, 1987; Branson & Miller, 1989; J. O'Brien & O'Brien, 1993; VandeVen, Post, Witte, & Heuvel, 2005)

This new paradigm is inclusion. Inclusion is a recognition of the interdependency and oneness of the members of a community. Inclusion does not mean that everyone in the community will be best friends and all individual concerns will disappear. (J. O'Brien, Marsha Forest, Pearpoint, Asante, & Snow) Inclusion does not mean that every community member with be satisfied. Inclusion implies that whilst working towards a more caring community, difference will be respected, individual gifts will be celebrated and members will make a commitment to live with each other as imperfect human beings.

> *"If the disabled are seen as normal, so much an accepted part of our world that we take their presence, their humanity their special qualities for granted then there can be no integrations for there is no segregation either conceptually in terms of categories, taxonomies, or actually in terms of institutional separation".* (Michael J. Kendrick, Bezanson, Petty, & Jones, 2006)

The degree to which people with a disability are included in the activities of a community is dependent on several factors: the attitude of the person with a disability and their desire to get involved., physical access, social justice programmes that address inequality and the attitudes and actions of other people within the community. Community member attitudes develop over time and depend on values, life experiences and social context. Three types of community member attitudes that affect the inclusion of people with a disability are: a preparedness to interact with a person with a disability as a consumers, neighbours and friends; awareness about people with a disability; and whether the member exhibits a wariness or hostility towards the concept of community inclusion. (Myers, Ager, Kerr, & Myles, 1998) Although studies of attitudes of Australians have shown that a majority of people feel uncomfortable when interacting with people with a disability (Yazbeck, McVilly, & Parmenter, 2004) and that attitudes differ between different age groups and educational standing, (Yazbeck et al., 2004) there is evidence to suggest that constructed meaningful contact between people with and without a disability can have a positive effect on attitudes towards disability.(Rees, Spreen, & Harnadek, 1991)

Inclusion for people with a disability will increase if the following factors are present:

1. a desire from the person with a disability to be involved and included,
2. a commitment from services to support inclusion and to do nothing that would further exclude a person,
3. an understanding of ablest views and values and the principles of inclusion amongst community members, and behaviour that reflects a commitment to inclusion.

Diversity is the cornerstone of a modern society. Diversity and inclusion turn to the "other" for enlightenment and gifts to strengthen the fabric of society for all people. Inclusion is measured by belonging rather than presence. (Amado, Conklin, & Wells, 1990; J. O'Brien et al.; J. O'Brien & O'Brien, 1993; Pearpoint, 1990)

Allies supporting people with a disability can be clustered in three main groups as to how they see inclusion developing. The most popular is what could be called will describe as the "one relationship at a time" theory. In this theory inclusion develops as contact with the person with a disability leads to ever increasing circles of support .Developed mostly through the telling of stories and supported by person-centred services approaches such as "Circles of Friends", this theory relies heavily on community members being drawn to the person with a disability. (Amado et al., 1990; O'Connell, 1988; Pearpoint, 1994; Perske, 1988) This contact with a person with a disability is expected to improve the attitude of community members,

Within this paradigm. community organisations that support people with a disability have a passive role confined to providing a system of " community access". Relationship facilitation and support are not within the job description and inclusion is seen as a magical entity within a circle of informal support or a dream outcome that may or may not lead from community access. Community organisations that provide service to people with a disability can reflect on the role they play in promoting models of support that continue to exclude people. The professionalisation of support skills within segregated services and programmes that allocate time each week to community access, have been found to separate people from their communities. (Rans & Green, 2005)

The second way inclusion may be achieved is to focus exclusively on members of the community to change the way they see people with a disability. Taking individuals through a process of disability deconstruction, often within a disability awareness programme, challenges beliefs and assumption and disestablish ableism. This created disability consciousness is expected then to flow over to any contact the individual may have with a person with a disability. (McLean, 2005)

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Within this paradigm, community organisations that support people with a disability are also off the hook as the lack of inclusion for people becomes the fault of the community. Perceiving the people that they support as too difficult or different to fit in and the community as an uncaring place, serves to elevate the role of paid staff in the person's life as skilled personnel, substitute friends and holders of the "right values". (Salzer & R.C.Baron, 2006)

The third way to view inclusion is as a community issue rather than a disability issue, focusing on community building aimed at increasing community capacity, connection possibilities and contribution. (McKnight, 2003) Focus is off the person with a disability or the ableist community member and directed not at a new programme or system but at a community where all people are required to participate.(Green, 2005; Green et al., 2006; John P Kretzmann et al., 2005; Rans & Green, 2005) Time is spent with people with a disability but not because of their disability but because of shared life-giving community values (Michael J Kendrick, 2001) or a common goal – a shared activity or project aimed to create a better community. (Biklen, 2000; Burls & Caan, 2004) This paradigm focuses on the assets of the community rather than the perceived needs of the person with a disability. Referred to as Asset Based Community Development (Green et al., 2006; John P. Kretzmann & Green, 1998; John P Kretzmann et al., 2005; McKnight, 2003; J. O'Brien et al.) this approach has the following characteristics:

- Capacity rather than deficient model,
- Focus is on strengths and potential of community rather than problem of people with a disability,
- Identifies desires of people with a disability as desires of many others,
- Long lasting change rather than personal relationships only.

It was this third view of inclusion that led to the formation of the *Better Together* initiative within the Caboolture community.

Homelife Association Inc. was established in 1993 as an accommodation services for adults with a disability. Since that time Homelife has developed other ways of supporting children and adults with a disability. Currently Homelife has 4 initiatives: *Homelife Lifestyle Service, Caboolture Family Network, Caboolture Community Work Cooperative,* and *Better Together.* The journey towards the establishment of *Better Together* came after many years of questioning what we as a community organisation could do to increase the inclusion of the people we supported in the life of the community. The leaders of the organisation had often observed how some workers "were good at the community connecting thing' and others failed to see possible links and connections. We had seen mixed results when a worker would support a person to attend a club or class. We wondered why after a few weeks it would fizzle out. I particularly recall one incidence where we had supported a young woman to join a water painting class. The first week went well but the second week the Art teacher approached the support worker to say that she didn't think the young lady should come any more. The worker left with the young lady thinking of all the reasons why people were uncaring and rude. She proceeded to find a new class. Another worker was surprised at this outcome and approached the art teacher. Her first response was pretty reasonable considering her age – aren't there special art classes for people with a disability. She had bought the myth that special teachers with special skills are needed to support an artist with a disability. Her second concern was that the young lady may not be able to do all of the things that the other artists were doing and that the young lady would be upset.

Better Together was created:

- to provide opportunities to have these conversations,
- to mobilize people to ct to create a more inclusive community,
- to support them in their commitment,
- to provide opportunities for committed people to connect with each other around this common goal.

If community organisations are to support the inclusion of individuals with a disability in the life of the community then they must discover new ways of working. – not solely in systems that require the unmet needs of clients but within communities that require the capacities, abilities and gifts of citizens. (McKnight, 1997) As well as being service providers, community organisations must rediscover their often neglected mandate to first and foremost create inclusive communities that welcome all people. The challenge for all community organisations is to see themselves as community developers as well as service providers and to use community building strategies to strengthen the inclusivity of the community.

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Rans, S. A., & Green, M. (2005). *Hidden treasurers: building community connections by engaging*

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Report on the 44th Annual ASSID Conference

held in Hobart, Tasmania, 4th – 6th November 2009.

by Craig Jones & Darryleen Wiggins

Conference Co-Convenors

PPPP9 POWER and PASSION: PROGRESS through PARTNERSHIPS
44th ASSID CONFERENCE, 4-6 NOVEMBER 2009
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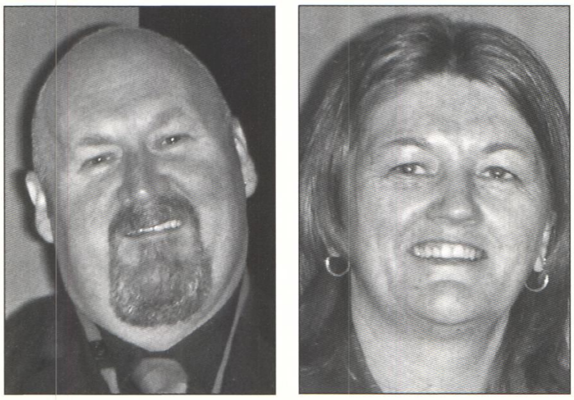

Well, what an amazing experience for a our committee to bring together a 3-day, action packed, fun filled, diverse program of events, speakers and papers, workshops and presentations to such a enthusiastic and friendly conference delegation.

The Committee members were:

Craig Jones - Co-convenor
Darryleen Wiggins - Co-convenor
Elizabeth Richardson
Barbara Olsen
Linda Glover
David Treanor
Geraldine Harwood
Andrea Goodwin - Conference Management.

The theme for the conference was "***Power and Passion: Progress through Partnerships***". We believe that the theme for this conference encompassed the mission and goals of ASSID by ensuring that the research undertaken in relation to progressing the understanding of disabilities, was partnered with contemporary practice to ensure people with an intellectual disability are provided with the most rewarding life experiences available.

As the disability sector undergoes major reforms, not just in Tasmania, but across Australasia and indeed internationally, partnerships have taken on a much greater focus. These partnerships should drive the current research agenda where progress can only be made by ensuring an inclusive focus. Across the three days of the conference, delegates were invited to attend various workshops, symposia, posters and concurrent sessions covering partnerships, positive supports, families, inclusion, health, service provision, ethics, advocacy, autism and behaviour. Feedback sought through the conference website at the conclusion was extremely positive with the conference reported to have good benefits to delegates' work skills and organisations.

All abstracts for this year's conference were peer reviewed to ensure that they were powerful and passionate, demonstrated links to progress and partnerships and most

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*the gifts * of people on welfare, people with disabilities, people with mental illness, older people and younger people*: the Asset Based Community Development Institute.

Rees, J., Spreen, O., & Harnadek, M. (1991). Do attitudes to persons with handicaps really shift over time? Comparison between 1975 and 1988. *Mental Retardation, 29*, 81-86.

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◆

importantly for ASSID, were evidence based. Thankyou to the peer review committee listed below:

Sharon Brandford
Rose Clark
Ian Dempsey
Sheridan Forster
Ken Hardaker
Geraldine Harwood
Craig Jones
Kevin Kriener
Mary Mallet
Keith McVilly
Sam Murray
David Pierce
Elizabeth Richardson
Brian Treanor
Olive Webb
Darryleen Wiggins.

At what has become a tradition for ASSID conferences in Tasmania, the Government House Reception on Tuesday 3rd November was an opportunity for delegates to enjoy the hospitality of His Excellency, the Honourable Peter Underwood AC, Governor of Tasmania and Mrs Underwood and experience the beauty of Government House. Delegates enjoyed a very powerful and passionate welcome to the reception thanks to the remarkable music students from The Friends School. From the post Conference Survey delegates enjoyed the experience with the majority rating the reception very good to excellent. Delegates commented:

- *"High school student musical presentation was fantastic."*
- *"First time I've been where the governor and his wife spoke and entertainment was provided. A great night."*
- *"This was one of the highlights for me - I thought it was great. As a Kiwi, it was really interesting, given our different political structure, and I found the whole evening very charming."*

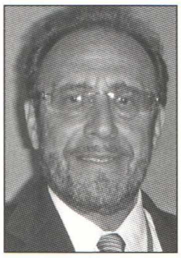
The following morning delegates were officially welcomed to the conference with a powerful performance by the Taiko Drummers followed by the inspiring words of Governor Peter Underwood.

Each day saw two keynote speakers who came from a diverse background of experience and knowledge and in their own right were extremely interesting and thought provoking. The Keynote speakers were:

Gary W LaVigna	(USA)
Beverley Funnell	(TAS)
Robert Martin	(NZ)
David Wareing	(TAS)
Denise Leembruggen	(VIC)
Teresa Iacono	(VIC).

Below are the comments from the post conference survey that relate to our international keynote speakers.

Gary LaVigna



- *"The speaker re-focused my thinking about work practice and provided the scaffolding for improving my efforts. It was an inspiration to hear Gary talk in person."*
- *"Fantastic presentation!!!"*
- *"Gary's address made me think about positive behaviour support as more than just plans and restrictive practices and has given me the knowledge to question some of the practices that we employ in this field. Fantastic speaker."*

Robert Martin

- *"Great to hear from very personal experience and to see the hope for others."*
- *"Well done Robert, well said with the visual presentation and the screen to read as well. It inspires to see how changes to a person's life can be made."*
- *"Inspiring and cautionary for professionals."*
- *"Such an inspirational story - really enjoyed this one and would love to see more presenters like this at future conferences."*

The program saw a very full three days of activity with the keynote presentations, 58 concurrent sessions, six workshops and three symposia. Each day four streams ran at the same time to provide delegates with a wide range of presentations.

Finally, we would like to thank the sponsors and exhibitors of the 2009 Conference including the Tasmanian Government. Thank you to all the organisations and businesses who took the time to exhibit at the conference and to assist in expanding the knowledge of products and services available within the disability sector.

On behalf of the ASSID Board, the Organising Committee and Leishman Associates, we would like to say thanks again for attending the 44th ASSID Conference and making it such a great success.

The ASSID Board hopes to see all of you again in Brisbane, 2010 (29 September - 1October) at the 45th ASSID Conference. Make a note of these dates in your diary! ◆

(See front cover for more conference photos)

Queensland

by Hamish Millard

The state committee participated in the annual planning day on 05 February. The committee discussed a range of options to promote ASSID membership and provide learning and development opportunities during 2010. Of course, with Queensland hosting the National Conference in late September, a large part of the committee's work will involve preparation for this major event. This year is a great one for encouraging our colleagues in Queensland to consider joining ASSID and enjoying the discounted member's conference rate!

Details regarding the next ASSID Qld Site Visit will be circulated soon. We are looking to host the next of these networking events in April, involving an information sharing. Keep an eye out for the invitation in your inbox, and please circulate our invitations to people outside of ASSID who you know might be interested in attending.

ASSID Qld aims to be represented at the National Disability Services Conference at the Gold Coast in May. We will use this event to promote our own National Conference. We will also have links with the Centre of Excellence's Positive Behaviour Support conference in July.

Of course, the highlight of the year will be our National Conference, in Brisbane from 29 September to 01 October. We hope you received a copy of the Call for Abstracts via mail. This will be a great opportunity to promote the diverse research and practice being undertaken by ASSID members in Queensland, so please consider submitting an abstract and enjoying the cheap travel costs of a attending a local conference!

Our AGM has been tentatively scheduled to occur on Wednesday 15 September. On behalf of the committee, we look forward to seeing you at one or more of our events during 2010.

New Zealand

by Gary Wyatt

Since the last update in IDA, the New Zealand Council has met in Wellington for our annual face to face meeting to discuss plans for 2010. We hold a face to face meeting once a year to plan our pathway for the next 12 months and discuss areas to advance the role of ASSID in New Zealand.

NZASID wishes to congratulate the organizers of the 2009 ASSID conference which was held in Hobart. This was a very interesting and stimulating conference and it was great to also see a large number of New Zealanders in attendance.

NZASID would like to acknowledge the tireless work by Dr Olive Webb who stepped down as ASSID President last year. Her work within the intellectual disability sector in New Zealand is wide spread and we are pleased that she is remaining on the NZASID council.

After a very successful conference in Hamilton 2009, it was decided to take the annual NZASID Conference and AGM to another region within New Zealand. We are pleased to announce that Dunedin will be the venue for the 2010 NZASID Conference. With final dates being confirmed at this stage, the intellectual disability sector in New Zealand and Australia are invited to join us in Dunedin in late August 2010. The dates for the conference will be announced to our mailing list and on the ASSID website once confirmed within the next few weeks.

Dunedin offers a wide range of Accommodation, Restaurants, Arts & Crafts, Attractions and Eco Tours & Cruises to the Wildlife situated on the Otago Peninsula that is unique in the world. As New Zealand's oldest city, a university city of Scottish heritage, Dunedin possesses a unique combination of cultural riches, fine architecture, and world-famous wildlife reserves on the Otago Peninsula as well as a gateway to the Southern Alps and some amazing coastal sights.

Our theme this year is "*Life Transitions: Perspectives and Practices*" and we are pleased to announce that our key note speakers will be:

- Dr Brigit Mirfin-Veitch from the Donald Beasley Institute
- Dr Jennifer Torr of Monash University
- Professor Patricia O'Brien from Centre for Disability Studies, Sydney University.

Further details about the 2010 Conference, information for the submission of abstracts and registration details will be available on the ASSID website (www.assid.org.au) from the 1st April 2010.

ASSID initiatives that we are currently working on include a New Zealand joint working group looking at using the ASSID Code of Ethics for Disability Support Workers as the basis for developing New Zealand wide discussion around ethical practice with both agencies and direct support staff in the ID sector.

The working group consists of the President of NRID and representatives from two significant unions (Public Service Association (PSA) and the Service and Food Workers Union (SWFU). We are also pleased to have Brigit Mirfin-Veitch of the Donald Beasley Institute (DBI) involved.

The current proposal is to host a series of regional events to discuss ethical issues using ASSID Code of Ethics as the basis for this.

For more information about NZASID and its events/conferences, look under the New Zealand branch on the ASSID website (www.assid.org.au) or by emailing gary@accessability.org.nz

Western Australia

by Angus Buchanan

2010 is looking to be a busy and interesting year for ASSID WA. The Committee has been working hard to develop an interesting and varied program of events for the year.

The year commenced with a workshop conducted by Sheridan Forster exploring the "*Hanging Out Program*" for people working with adults and young people in residential, school or Post School Options environments. This event was in high demand and sold out well in advance. Sheridan's years of clinical experience together with her research was well received by all who attended.

The second event of the year will be a workshop on *A Practical Guide to Ethical Decision Making in Mealtime Management* presented by Jodie Ellis. Jodie is an experienced accredited practicing dietician specialising in the areas of palliative care and developmental disabilities. Jodie is current undertaking her PHD investigating the psychosocial impact of food and nutrition on palliative care patients and their families. Based on early demand for workshop places, the topic is of significant interest and it is expected that this workshop will also be sold out.

Planning has commenced to run a research forum mid year. The intention will be to bring together researchers and interested people who would like to discuss share and explore the latest research being conducted in Western Australia. This one day event will be in partnership with a University. Associated with this initiative will be the implementation of a student research scholarship and ASSID conference scholarship.

The State ASSID Conference will be held in August. Planning is well under way for what should be an excellent event which has become a highlight of the annual calendar.

The Committee continues to work on membership and is pleased to see a growing interest in the work of ASSID in Western Australia from both individuals and organisations.

ASSID WA is pleased to have established an Honours Student Scholarship and a Travel Bursary, each to be awarded annually. The ASSID WA Honours Student Scholarship is an award of up to $2000 to assist with the costs of completing an Honours project. The first Scholarship will be awarded for a project undertaken in 2011.

The ASSID WA Travel Bursary is an award of $1000 to assist with the costs associated with attendance at the Annual Australasian ASSID Conference. The first of these bursaries will be made available for the Australasian ASSID Conference in Brisbane on 29th Sept.-1st Oct. 2010.

NSW & ACT

By Tina Purdon

The NSW and ACT State Committee welcomed in the New Year with a Strategic Planning day held in early January. The enthusiasm of our new Committee members combined with the energy of those returning for another year, contributed to a very productive day.

With a stable Committee since 2008, when ASSID NSW and ACT was reformed, we were able to benefit from knowledge acquired over the last few years in order to create a Plan which we hope will steer the Association to greater strength and increased activity and profile over the next 12 - 18 months.

Feedback collected from participants and presenters at Hot Topics Workshops and State Conferences since 2008, was also considered when creating our Strategic Plan.

The State Plan is based on the Goals and Objectives outlined in the ASSID Strategic Plan, Operational Plan and Budget. The NSW ACT State Committee customised the aims outlined in the Australasian Plan to develop a series of Strategies which we felt reflected the needs of NSW and the ACT as well as taking advantage of skills, expertise and networks of the Committee Members.

Focus areas for 2010 – 2011 include;

- greater exposure for ASSID through expanding the current sponsorship program from Sydney University to consider graduate programs in Disability in other Universities across the State and ACT,
- establishing a NSW / ACT Awards process in recognition of service or achievement,
- increased opportunities to promote local research projects and actively assisting with the dissemination of research outcomes,
- active liaison with, and the establishment of, mutually beneficial relationships with other suitable Organisations or Associations,
- increasing the involvement of people with disabilities in all activities of the Association,
- continuing to build the networking, research and professional development opportunities for members.

The NSW and ACT Committee send our best wishes to all other States for success with their activities over the coming year. A review of the Region Updates in the IDA December 2009 issue, indicates that 2009 was indeed a very busy year for all and that 2010 promises to be just as action packed!

Tasmania

by Craig Jones

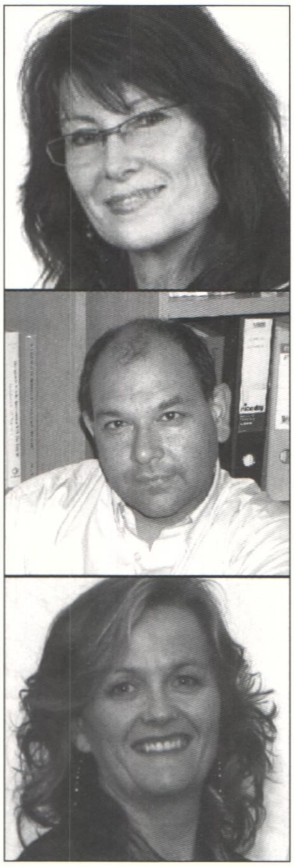
See full conference report.

South Australia & Victoria

No reports ◆

Minimising Restraint

a case study



from ***Lynne S. Webber***
Office of the Senior Practitioner, Department of Human Services Victoria
& Paul Ramcharan
RMIT University, Melbourne, Victoria
& Dariane McLean
Individual Advocate with VALID, Melbourne, Victoria
& Parent of a young man with autism

What Josh needs: Reducing restrictive interventions and improving quality of life

Josh is an active 16 year old with a diagnosis of moderate intellectual disability and autism, he has a few words and has difficulty communicating his needs to his support workers. He has recently been relinquished by his family into care because his mother passed away and his father and grandmother were no longer able to support him. Since leaving the family home he has shown several behaviours of concern that his support workers find difficult to manage. He has torn, bitten, and ripped fabrics and materials including his own clothing and furnishings. Many of his behaviours of concern occur when he is told he can't go home to see his relatives, and to cope with this fact, the support workers have removed "Wednesday" from the weekly activities because each Wednesday, if his family do not visit, he becomes extremely upset. Over time the support workers have removed all furnishings and equipment from his house, including taps. Josh has a trampoline in the garden which he enjoys for short periods of time. He recently jumped up and grabbed a light fitting attached to the roof which smashed on the floor. As a result, he was given PRN chemical restraint (sedative medication).

No functional behaviour assessment had been completed on his behaviours of concern, the main treatment for his behaviours of concern was the use of chemical restraint and efforts at keeping him safe by adapting the environment. While the chemical restraint appeared to slow him down for a short time, the routine use of anti-psychotics appeared to have little if any effect and his support workers were not sure what they could do. Both of the support workers were quite fearful of him, viewing him as unpredictable and potentially dangerous. As a result they are distanced and disengaged from Josh and Josh has little to do in the barren environment the support workers had created to 'keep him safe'.

The use of restraint and seclusion in disability has come under greater scrutiny by governments world wide recently, especially in those countries who are signatory to the United Nations Convention of the Persons with a Disability (UNCRPD). A number of countries are now engaged in work designed to minimise such restraints and academics are gradually developing evidence and theory to support the new values and principles involved in restraint reduction (Department of Public Welfare, 2006; McDonnell, 2007; Ramcharan et al., 2009). This represents a radical change and is taking place because, like institutionalisation, the effects of at least some restraints are coming to be seen as unethical. Such change is never easy and requires careful thought and a significant period of research and evaluation before better ways of working are found.

The use of chemical, mechanical, and physical restraint and seclusion are still used in Disability services in Victoria and other States and Territories in Australia. However, the Office of the Senior Practitioner based in the Department of Human Services in Melbourne has set a goal under the Victorian Disability Act 2006 to 'support people to achieve dignity without restraints' and in doing so is seeking to establish new value positions, principles and approaches to minimise restraint. As three people variously involved with the work of the Office of the Senior Practitioner in Melbourne as a family carer, researcher and practice leader we argue that the use of restrictive interventions only provides temporary prevention of behaviours of concern with potentially damaging physical and or psychological side effects for both the people who are restrained as well as the people who do the restraining and that there are good moral, ethical and economic reasons to minimize the use of restrictive interventions now. We also suggest some practical ways forward exemplifying these by using the case study of Josh presented above.

Focussing on Josh's needs

Understanding how Josh feels and what Josh needs are important in helping Josh to reduce his behaviours of concern and, in turn, to decide how best to provide support which minimizes the use of restrictive interventions presently being used. It is well accepted that a functional behaviour assessment is critical as a first step to achieve this understanding (Carr, Innis, Blakeley-Smith, & Vasdev, 2004; Deb, et al., 2009) and in what follows it is argued that as a prior step, or in making this assessment, a significant number of causative factors should be taken into account.

In the vignette it is possible to view Josh's latest behaviours of concern as: behaviours of protest at the restraints placed upon him by staff (see Ramcharan et al., 2009; p.44); behaviours of grief at the loss of his family and loved ones (particularly loss of his mother); frustration at having nothing to do; and, or having a lack of control in his life and having to live in a house so different to his own family home. And if these are the causative factors it is no use trying to dispel the behaviours (the symptoms) without treating the underlying causes. Once the reasons for the behaviours are understood, interventions can be put in place to help to address his needs.

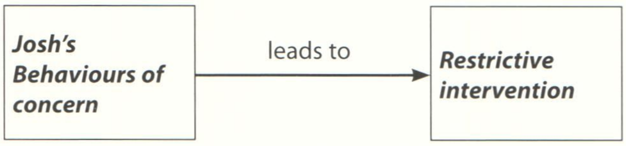
To see Josh's behaviour as 'a behaviour of concern' may be an understandable and a natural reaction by staff, but the approach is not one that will address the issues in Josh's life. In addition, lack of resolution to his traumas will leave additional unresolved issues that Josh will carry with him throughout his life adding to those with which he is already grappling. It is generally well accepted that prolonged trauma of an interpersonal nature that occurs at an early age can have significant effects on psychological functioning into adulthood (Van der Kolk, Roth, Pelcovitz, Sunday & Spinazzola, 2005). Like many examples of post-traumatic stress small, subtle and unseen cues and reminders can in the future continue to prompt particular behavioural responses as the person struggles with damaging memories. We do not know the extent of these damaging memories for many people with disabilities, especially those who cannot communicate their feelings clearly or relate their life history openly. However given the high levels of abuse reported (Fyson & Kitson, 2007; Mitchell & Buchele-Ash, 2000), the revolving door of residential options, many of which have not been chosen by the person themselves and the number of people passing through their lives that trauma and stress may be disproportionately large among this population.

These unresolved issues are represented in Diagram 2 as potential causes of behaviour and they may over time establish a complex of patterned behaviour that is extraordinarily hard to disentangle and explain. In the case study knowing as much as possible about Josh's history is therefore important. His lifelong social and living relationship with his parents clearly provides an immediate breach to well known and well rehearsed patterns of everyday life and the fundamental changes in his circumstances may lead to grief and resettlement trauma (Salovita, 1996; Macloed et al, 2002). But little else is known in the case study that may contribute further to our understanding of Josh's history. Knowing the person and their history (another of the causative agents in Diagram 2) is therefore a potentially important factor in developing a response. It is hugely important therefore to know as much as possible about a client and their history as a basis for understanding them and, indeed, being understanding of their behaviour.

The second major factor in the case study is that if 'behaviour' is the sole or primary basis upon which to formulate responses rather than causative agents, a downward spiral of intervention takes place in which the attempts to block the 'behaviours of concern' increase in intensity over time as Josh's own response to the controls increases (Ramcharan et al., 2009: 43). Josh is already experiencing huge trauma at the very least from his recent experiences alone, so using the environment as a further negative reinforcement simply accentuates his experiences of stress, frustration, anger and sadness. Josh's support workers have: turned his environment from a home to the sparseness of a prison; withdrawn his free access to food and to those things which provide him comfort and warmth; put him outside of the main home. And as outlined by Ramcharan et al., (2009) it is often not clear that such changes to environment and experience are recorded as restrictive interventions.

Finally when working at the personal, environmental and interactional levels have not worked to change Josh's behaviour all that is left is to change is his biology, that is, to change the person by using chemical restraint. That way it is never necessary to address the deep emotional discomfort and angst that Josh feels and it is possible to say that 'all is well'!

The case study therefore leads to two contrasting approaches. The first is based upon the simple equation that:



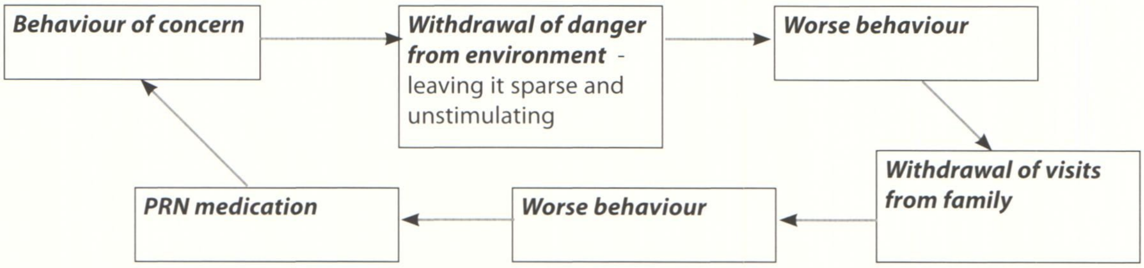
In contrast, the second approach puts in place a functional behavioural assessment but also places the onus on services to understand and

continued page 14

Minimising Restraint ...

continued from pg 13

Diagram 1a. A downward spiral of control and behaviour



address the root causes of Josh's behaviours by taking into account and addressing a number of causative factors. The two approaches lead to two entirely different outcomes (See Ramcharan et al, 2009: p. 44) represented in Diagrams 1a and 1b:

The second approach is one in which the assessment is likely to lead to increased levels of support to address the underlying causes of the behaviour and to build trust into the new relationships. An example of one aspect of the approach is shown below and others might equally be applied around changing homes, around supporting engagement with a stimulating environment (using treasured items for example) and so forth.

Ramcharan et al (2009) argue that where staff are the agents of control, trust is broken between the support worker and the person on the receiving end of their controlling measures and that

> '...the controlling environment created more of the very behaviours it was supposed to resolve' (ibid: 44).

Such adaptive behaviours to maladaptive environments should not be seen as behaviours of concern but rather as legitimate and understandable reactions, i.e. as behaviours of protest.

In the worst case scenario the loss of trust with support workers makes the support relationship difficult to sustain as a positive relationship and one upon which the person can thrive and feel comfortable. So the person may come to a new setting with a hidden history, with a loss of family, change of home and environment, the replacement of loving family relationships with support staff who are seen to be cold, threatening and controlling. In light of these Josh's identity and concept of self are likely to be significantly challenged (see Diagram 2 'Causative factors).

The issues around identity also works two ways since staff seeing only the behaviour will note in their files that there are problem behaviours. The signs left for future generations of support workers that ask them to view Josh in this negative light, as a trouble-maker or as being violent. The reaction of later staff is therefore likely to become a self-fulfilling prophecy as they use it to structure their view of Josh and the right ways to control his behaviour. It is therefore not only vital to help Josh to feel positive about himself and his relationships but, further, to ensure that the identity constructed in Josh's files is positive and places the responsibility on staff to say that their ability to locate the cause of the behaviours is the failing and not the behaviours themselves.

Josh's problems are those problems of life which will at times confront us all. We all expect those around us to respond with some compassion, to be understand-

Diagram 1b: A positive cycle for positive change

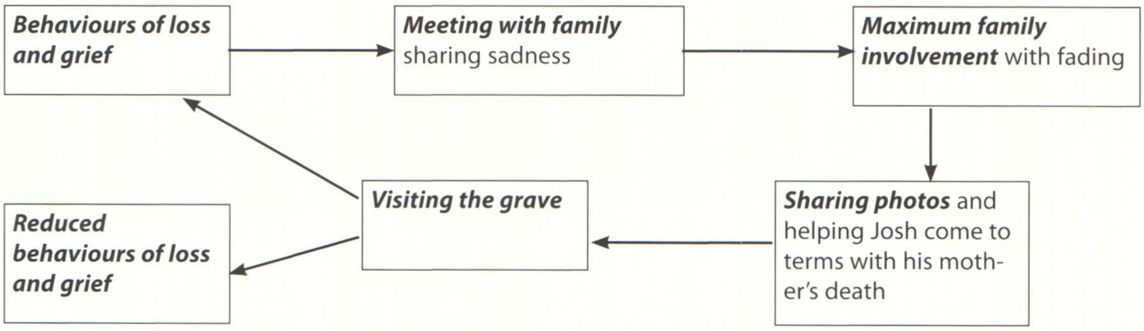
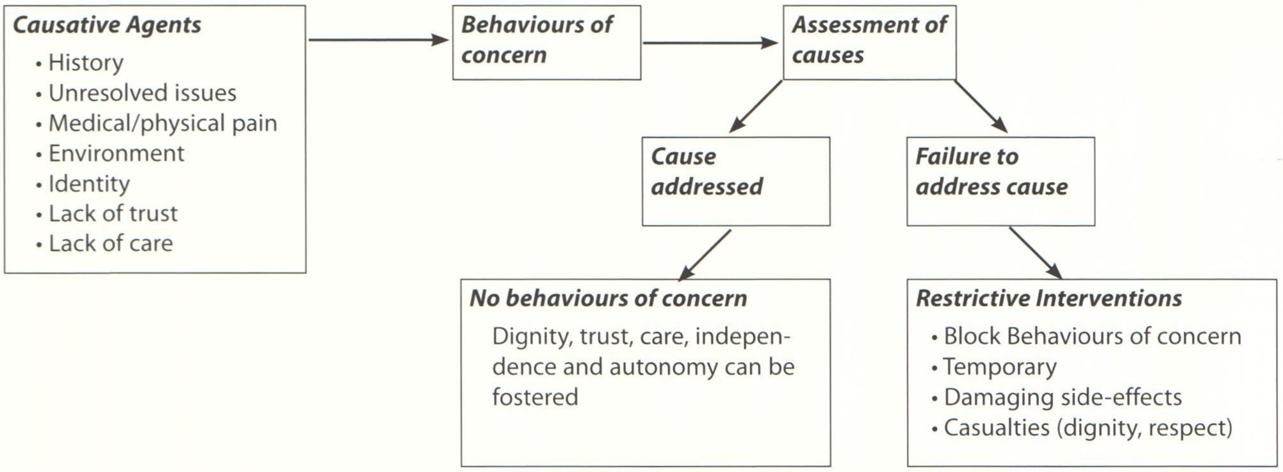


Diagram 2: A model for thinking about restrictive interventions



ing about our moods and to accept our apologies about behaviours we later regret. But in the face of such challenges we would want to know that those around understood and supported and did not ignore our behaviour.The resolution to Josh's issues will not occur overnight and will take time, energy and understanding from his support workers, especially where he displays behaviours of grief and loss. But to live with those and maintaining a loving and caring environment will make his world and our own a more comfortable place in which to share each others' lives.

When discussing the above case study many of those who provide support to people may say that what is being said is nothing new. However, if this is so, it does not explain why so many stories similar to Josh's come to the attention of the Office of the Senior Practitioner on a regular basis. To support people to think about their practice consistently in this way we provide in Diagram 2 below a model that may help practitioners to move towards minimising restraints and increasing quality of life for the people they support.

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ASSID is changing ...

The Australasian Society for the Study of Intellectual Disability was formed in 1965. Originally called the 'Australian Group for the Scientific Study of Mental Deficiency' it became known as the 'Australian Society for the Study of Intellectual Disability' in 1986 and changed its name again in 2000 to reflect a broader Australasian membership.

Ten years later, the ASSID Board has recognised that the Australasian Society for the Study of Intellectual Disability must again consider its name, aims and objectives to ensure it remains contemporary and meaningful to current and future members, as well as the disability sector in general.

The Board has proposed a way forward and is seeking the endorsement of all regional associations in considering a contemporary name and new logo for ASSID.

The Board members, as representatives of the regional associations all agree that continuity with ASSID's long history cannot be lost.

Any change must ensure that ASSID's traditions and reputation, aims and objectives are carried over.

ASSID is the only Australasian professional association dedicated to people working and researching in the intellectual and developmental disability field.

It is worth noting ASSID's many achievements:

- ASSID has always had an important national and international role in promoting the importance of research to inform practice.
- ASSID has led the way in the Australasian context when it came to new and innovative ways of supporting people with intellectual and developmental disabilities.
- The annual ASSID conference continues to attract a wide variety of people with an interest in intellectual disability.
- ASSID was one of the first organisations to promote the concept of inclusion, self advocacy and citizenship in Australasia,
- ASSID introduced the first media awards to recognise good practice in journalism and positive reporting of people with disabilities,
- ASSID provided pamphlets to inform and advise families who had a child with a disability,
- ASSID has published practical books on behaviour management to support disability support workers,
- Most recently, ASSID developed and published a code of ethics for disability support workers.

ASSID's aims and objectives continue to be relevant in today's context. They are:

- to promote the rights, development and well being of people with intellectual disability,
- to promote the research and understanding of intellectual disability,
- to bring together people who have an interest in the field of intellectual disability,
- to promote high ethical standards of practice in the field of intellectual disability,
- to promote communication via conferences, special interest groups, symposia, workshops and other professional development activities,
- to promote research, scholarship and the dissemination of information about intellectual disability through appropriate publications and networks.

The Board believes that its members and others in the field respect and support the work of ASSID, its focus on research and evidence based practice, and its commitment to the Society's objectives.

As the process to change the name and logo proceeds, members should be aware of some of the important milestones in the Society's history:

1964: The first conference of the International Group for the Scientific Study of Mental Deficiency in Copenhagen

The Australian Group for the Scientific Study of Mental Deficiency (AGSOMD) established with 41 founding members.

1965: The first AGSOMD conference and general meeting in Melbourne.

1969: AGSOMD Bulletin first published.

1970: 278 members in every state of Australia as well as in New Zealand.

Bulletin replaced by the Australian Journal of Mental Retardation.

intellectual disability
ASSID research ▸ practice ▸▸▸
australasia

1980: Membership approximately 800. Mainly people 'working in the field of Intellectual Disability, with a tertiary qualification'.

Members newsletter regularly published.

1985/86: A small 'Secretariat' established.

AGSOMD changed it name to 'the Australian Society for the Study of Intellectual Disability'.

The 'Journal of Intellectual and Developmental Disability' was becoming recognised as one of the leading journals in the field.

1990: Membership approximately 500. Membership categories broadened to encourage family memberships and people with a disability.

2000: ASSID welcomed the New Zealand association and changed its name to the 'Australasian Society for the Study of Intellectual Disability'.

In 2004 and 2008 IDA published short articles: 'It's time to change our name' and 'Opening the debate' which proposed that ASSID should consider a change of name. Several members of the Society responded to these articles, many affirming the belief that the time has come to change:

Extracts from letters to the editor, IDA June 2008.

'I would like to take up Sue's challenge to progress the debate over the name of our Society.'

Dr V Ruth Davey.

'Furthermore, our current acronym-based name does not capture the scope of our mission and goals. We are far more complex than A S S I D. So, I am going to put a bid on the table for a new name right now – Intellectual Disability Australasia. (And if we must have an acronym, we could do a lot worse than IDA!)'

Professor Anthony Shaddock

'A good product (which we have) should be recognisable by it name and not require in-depth explanation for a person to achieve that initial sense of recognition or interest.

... it is essential that we market ourselves in a way which is both contemporary and easily accessible.'

Associate Professor Angus Buchanan.

During 2010 the ASSID Board will be writing to all the regional associations to invite them to consider the proposal to change the name of ASSID from 'the Australasian Society for the Study of Intellectual Disability' to 'Intellectual Disability Australasia' and to move to a new, more contemporary logo, which will incorporate both the new name, the original acronym and the core purpose of ASSID- 'research to practice'.

The new logo encompasses all that ASSID currently stands for:

- 'Intellectual Disability Australasia' is instantly recognisable as the focus and intent of the association.
- 'ASSID' incorporated into the logo ensures connection with the past and continuity into the future.
- 'Research into practice' highlights the partnerships between the academic and professional interests in the field, and commitment to evidence-based practice.

Regional representatives/ASSID Board members are asked to canvass opinion for the new name and logo through members' and council meetings.

At the mid year meeting in May, the Board will hold an extraordinary general meeting to address the proposal that 'the Australasian Society for the Study of Intellectual Disability' will amend the constitution in order to change its name to 'Intellectual Disability Australasia' and adopt a new logo, incorporating the ASSID acronym'. Board members will be expected to be in a position to represent the views of their local associations.

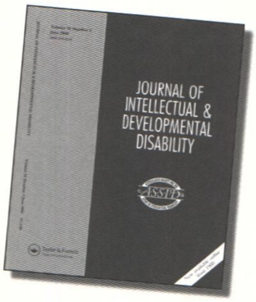
If the motion is carried, regional associations will be asked to hold similar general meetings to make the same constitutional amendment to change the name of their regional association. Each regional annual general meeting would be the appropriate venue for the amendments to be tabled, thus effecting the changes in time for announcements to be made at the annual conference in Brisbane in September.

IDA hopes that all readers will take the time to contact their regional representative to express their view on the proposed change in time for the next face to face Board meeting in May. ◆

People in Trouble with the Law Living in a Hospital

What Did They Say About Staff?

from Clarkson, R., Murphy, G. H., Coldwell, J. B., & Dawson, D. L. (2009)



Plain English Translation of - **What characteristics do service users with intellectual disability value in direct support staff within residential forensic services?**

Journal of Intellectual and Developmental Disabilities, 34(4), 283-289.

By Sheridan Forster

Some people with intellectual disability have been in trouble with the law. Some have been locked in hospitals called forensic units. This research is about people living in these locked hospitals.

There is lots of research about direct support staff. But not many researchers have asked people with intellectual disability about what they think about their staff.

Nobody has asked people in locked hospitals what they think. We wanted to know what people living in locked hospitals thought about their staff.

What did the researchers do?

We asked special permission to do the research. This is called an *ethics approval*. We said that we would make sure everyone would be safe and have privacy protected.

We asked people living in locked hospitals to be in our study. We told them lots about the research so they could make a choice. They could choose if they wanted to be in our research or not.

We talked to two small groups of people living in locked hospitals. They told us about their staff. What they said was very helpful. This helped us decide on what questions to ask other people.

Then we talked to 11 different people. We asked them lots of questions about their direct support staff.

We tape-recorded what everybody said. Later on we wrote down what they said, but we didn't write down anyone's names. People's names were made private.

Then we read what people said. We read what they said lots of times. We thought about what they said. Then we wrote down lots of points. We talked to each other to make sure we got the right ideas.

What did the researchers find out?

We found out lots of things. The people talked about their relationships with the staff. They also talked about things to do with the staff.

Relationships with the staff

Relationships with staff were very important to the people.

The people we talked to said it was important to be able to trust staff. Some people trusted some staff. One person said, "*They are patient with you and that, they are there to understand you when you have got things on your mind and you can talk to them about it.*" Some staff weren't trusted. One person said, "*Because they are just not bothered, and you can tell by their body language.*"

People also said it was important that staff were sensitive. One person said, "*They can tell when I'm a bit down, because they've got used to it by now.*"

Getting help was important to people. Staff could help organising going out. Staff could explain things when somebody didn't understand by themself.

Some people said that staff were like family to them.

People talked about feeling protected by staff. Staff could help them feel safe if other people were getting angry. Some people also said they could help staff be safe. One person said, "*It is normally the case that I can help staff if they are in trouble. Because I have a lot of time for them. Because they have done a lot for me and if I can stop them getting hurt then I will do.*"

Things about the staff

The people with disabilities talked about good things and bad things about staff.

They said good staff were helpful, honest, and could have a laugh. One person said, "*Even though they are just doing their job [staff] can have a laugh, you can still have a laugh, you can have a joke. You can have a good time with staff.*"

People also liked it when staff knew what they were doing. Some people didn't really like the young staff who didn't have much experience. Another person didn't really like the older staff; they said, "*They've been here so long that they've had enough of the job.*"

The people didn't like it when staff weren't helpful. One person said that some staff could be lazy. Some people said that some staff make trouble, they wind people up and could be nasty.

What did the researchers say in the end?

We learnt lots about what people in locked hospitals think about direct support staff. A good relationship with the staff was very important to people.

We think that it would be good to do more research like this. ◆

upcoming events

10 - 11 April 2010	**The Third Pacific Rim International Forum on the Rights of Persons with Disabilities** Honolulu, Hawaii www.pacrim.hawaii.edu
28 - 30 April 2010	**8th National Deafblind Conference** Venue: Jasper Hotel, Melbourne Enquiries: Able Australia Services, 1300 225 369, patricia.karagiorgos@ableaustralia.org.au
11 - 13 August 2010	**ARATA Conference** ***The tip of the iceberg*** Hobart, Tasmania www.ebility.com/arata/conf.php
29 Sept - 1 Oct 2010	**45th ASSID Conference** ***Seeking Excellence*** Brisbane, Queensland For more information contact assid2010@optusnet.com.au
20 - 23 Oct 2010	**3th IASSID-Europe Conference** Rome, Italy For information, correspond with the IASSID-Europe 2010 Conference Secretariat, Ms. Isabelle Biondi: the.biondis@alice.it.

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

expressions of interest Editor *IDA*

3 Year Term 2011

Expressions of interest are invited for the honorary position of Editor for the official magazine of the Australasian Society for the Study of Intellectual Disability (ASSID) – IDA

The Editor is an ex-officio member of the ASSID National Council and, in addition to participation in teleconferences and the annual mid-year meeting, attends the ASSID Annual National Conference.

National Council provides financial support to cover out of pocket expenses including conference registration, air fares, and some incidental expenses.

The Editor, in conjunction with other ASSID members, is responsible for attracting and editing articles, book reviews, conference reports, advertising, and regional reports, as well as writing quarterly editorials.

An editorial assistant provides administrative support, and the publications sub-committee of ASSID National Council provides advice and support as required.

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For further information contact Angus Buchanan at a.buchanan@curtin.edu.au

Expressions of Interest are sought immediately via -

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