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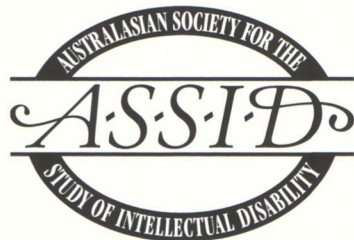
# IDA

Intellectual Disability Australasia

**review renew**



Magazine of the Australasian Society for the Study of Intellectual Disability



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**Front Cover:**

Pixelated ASSID Logo  
p3 Eddie Bartnik's photo  
c/- Greg Keating photography

# editorial



Regulation number 3 written for the Guidance of officers in charge of the Western Australian lunatic asylum' in 1858 states that 'They shall, on no account, use any means of restraint, such as strait waistcoat or handcuffs without the express sanction of the medical officer.'

In the same book, 'Eloquent Testimony' by SA Ellis the author describes a report written by a 'doctor in charge' in 1862 on the use of seclusion, which states that; 'it is never necessary.... to resort to seclusion for more than a few hours at a time and it has not been necessary during the whole year to use any mechanical restraint.'

ASSID members have for some time been concerned about the use of restrictive practices to manage people with intellectual disabilities who sometimes have behaviours that are considered challenging. 150 years ago professionals working in the disability field were expressing strong opinions about the use of such practices and the need to monitor such use. Of course, the views expressed in the quotes above are not in line with our current understanding of fundamental human rights and seem repressive in the light of modern thinking. Nevertheless it is of interest to note that the issues were very similar and the importance of good guidelines and policies remains the same.

ASSID has again led the field by developing a position paper to clearly articulate the beliefs of members on this important topic and the position paper and brief update on progress is included in this edition of IDA. Copies of the position paper can also be found on the ASSID webpage.

Also in this edition is a summary of the market research report provided by our Executive officer, Kerrie Akermans. The Board has found the report extremely valuable in setting strategic direction and the proposed actions are already in the process of implementation. Full copies of the report can be obtained from your local regional representative.

By the time you have finished reading IDA the 2010 annual conference will have drawn to a close, regional AGMs will have occurred and new councils and the Board will have commenced the new year.

As usual, your feedback is most welcome on any issues that are contained in the magazine. Happy reading!

**Cheers, Sue**

# Developing Personalised and Creative Community Living Options

## A West Australian Example of Influencing Systems Change

By **Eddie Bartnik**

*Director, Disability Services Commission, Western Australia*



Eddie is a Fellow of ASID and was recently appointed as Western Australia's first Mental Health Commissioner. This article follows on from Eddie's keynote address at the 2007 ASID national conference and his article published in Intellectual Disability Australia, June 2008.

It is a practical ongoing example of multi year significant systems change and the story will continue in the next edition of IDA with a follow up article by ASID member Kate Randall outlining her experiences as part of the Community Living Resource Team and some of the project outcomes.

**P**icture this: an evening workshop hosted by the Disability Services Commission's Local Area Coordinators at the local community bowls club, attended by some 50 family members and local service providers all gathered to hear more about the new West Australian state government Community Living Initiative. The first presentation covers the background and thinking behind this new initiative, including the first slide of what the research shows are the "building blocks" for creating a home and a good life for each person, one person at a time. The next slide shows a graphic picture of 5 key models or different ways in which support can be organised for each person and people can see and hear about examples that have been operating for many years with success. The presenter also outlines the new Community Living Support Funding Strategy and the resource materials and technical support available via the new Community Living Resource Team. The second presentation is made by a mother who shares her story of network building and planning, leading up to her son now moving out into his own home. The challenges of having faith, creative thinking and letting go are all part of this amazing journey. The third presentation is made by a man with a disability supported by his Local Area Coordinator who has moved out into his new Homeshare arrangement and is bursting with the happiness, optimism and security of having his own home in his local community and feeling secure.

The whole evening has a strong focus on people's strengths, relationships and contributions, as well as the need for effective partnerships and an action plan. At the end of the presentations, there is time for supper and

conversations...a time for each person and their family or network to chat with their Local Area Coordinator to assess where they are up to, what burning questions they might have and what some next practical steps might look like.

This workshop is one of dozens of regular events now happening across Western Australia which are planned on a local basis with individuals and families and are generating a new tide of optimism and positive momentum. It is still early days but already this has become a compelling story that I am delighted to share with you. It is a story of not only partnering with families, service providers and policy makers across the state to generate a big vision of possibility but also about then creating the policy framework and technical support on the grounds that can assist individuals and families to plan and achieve practical outcomes, on a step by step basis. The background, processes and outcomes so far of the Community Living Initiative will now be outlined as an example of a systemic change process.

### Background to the Community Living Plan for Western Australia

In 2006 the state Minister for Disability Services commissioned a Sector Health Check on Disability Services in Western Australia. Following a period of extensive investigation and consultation, the "Disability Services Sector Health Check 2007 Report" was published and included a clear direction to increase the range of community living options available to people with disabilities, with increased emphasis on no/low cost community support and more flexible and innovative options. Specific recommendations from the report included the development of a Community Living Plan, exploring and reporting on innovative options with demonstrated success in other states and countries, and building a second layer of expertise around innovative community living options.

As Project Director for the Community Living Plan, it was clear that a change of focus was needed:

- A focus outside of traditional models and providers and towards new pathways and partnerships.

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## ... Community Living Options

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- Enhancement of individualized planning, options exploration and technical support as well as a “big dose of vision building.”
- These new options would need to be “person centred” and emphasise key elements of a good life such as valued relationships, choice, contribution, security for the future, and challenge.
- Options would need to be sustainable, cost effective and demonstrate a strengths based, preventative approach.

The key deliverables for the project included:

- A Stage 1 Concept Plan - An information resource of innovative support options locally, nationally and internationally, a review of alternative planning pathways and partnership mechanisms and a new conceptual framework for community living that includes a vision statement, principles, strategies and broad measures of change.
- A Stage 2 Implementation Plan – a range of practical steps and measures for each of the 7 main strategy areas for the period 2008-11

The complete project methodology is outlined in the Community Living Concept Plan Stage 1 report (August 2008), however for the purpose of this article some key project processes are highlighted as follows:

- A Project Reference Group was established for both stages of the Project
- Stage 1 involved a series of statewide consultations that engaged people in a workshop type format where several innovative models and examples were presented to assist people to “imagine better” the possibilities and then participants completed an exercise in identifying barriers and opportunities for developing personalized community living options
- Public submissions were invited as well as commissioned presentations to the Reference group by international consultants Michael Kendrick (Key features of an individualized personal approach) and Heather Simmons (Person Centred Planning)
- A 2 day facilitated writing workshop where a statewide group of 30 participants (individuals, families, service providers, policy makers and funders, community and advocacy organizations) drafted the new Framework for Community Living (February 2008)
- Presentation of the Community Living Concept Plan Stage 1 Report (August 2008) and the web based Information Resource (with direct links to all primary sources)
- Two 1 day facilitated writing workshops with the Stage 2 reference group and key experts/decision makers to draft the new Policy and Funding

Framework for Community Living and the Community Living Implementation Plan (August 2008)

- Establishment of a new Community Living Resource Team and a new Community Living Support funding Strategy (September 2008)
- Recruitment of Project Reference Group community members to the new independent Community Support Funding Panel (November 2008)
- Production of a new planning booklet for families and service providers “Looking forward to Community Living” (October 2008)
- A statewide series of Information Seminars to present the new Community living Support Funding strategy (from September 2008). Note that some of these sessions attracted up to 100 people.
- Ongoing series of Local Community Living (vision building) workshops plus a Metropolitan Community Living Innovations Forum in November 2009 and a Statewide Community Living Innovations Forum in Bunbury in February 2010

### Thinking about new pathways and partnerships

A useful way to think about some of the changes required to create more community living options is to consider the concept of a change in pathway and partnerships. From many discussions with families as part of this project, planning in the area of community living has often been equated to planning for Accommodation Support Funding through the Combined Applications Process. Individuals and families can then be caught ‘waiting’ in a system that places focus on critical needs (usually defined negatively) and families often say that after a time of writing these critical needs type of funding applications, they are simply left ‘waiting in negativity’. Some people get funding but still can’t find what they want and others may have paid support but few friends. The Sector Health Check report (p93) also identified a range of other risks that may be unintended consequences of the current system. These include:

- some people believing that a successful CAP funding application is the only way of moving from the family home to a more independent option;
- a reluctance to plan for or trial alternative arrangements without having first secured funding; and
- also a more generalised reduction in community capacity, with consequent isolation of people with disabilities, if the community comes to rely too heavily on funded supports rather than inclusive

practices and informal supports particularly for people with mild to moderate disabilities.

There is clearly a need for new planning pathways that build on people's strengths, relationships and resources so that they can start to create the life that they want. When asked about what makes a good life, valued relationships, security for the future and making a contribution are high on everyone's list.

However, it is also important to note that even very good human services have limitations when it comes to delivering these reciprocal personal relationships and sense of security, and that renewed importance must be placed on the contributions of family and friends, ordinary people and local communities. Al Etmanski, co founder of PLAN Canada, describes this as moving from 'a scarcity framework', where the main aim is the allocation and acquisition of scarce disability resources and funding, to 'an abundance framework', where each person's fundamental need for opportunities for reciprocal relationships and contribution are paramount and where there is an abundant supply through ordinary people in local communities. These new planning pathways require a change from seeing people with disabilities as 'service users' to 'active citizens', with themes of being included, making a contribution and being recognised, and directing your own life (see Bartnik 2008).

Marg Rogers in her 2004 article 'Not waiting: creating' puts this argument succinctly:

"The important word is go - start now, do not wait; it is never too early and never too late to begin dreaming and scheming with this person about how they can live their own life or perhaps a fuller life. If you have been waiting then work out what you have been waiting for.

Many people wait for funding. Paid support will continue to be an important component of life for many people, but funding will never buy friendship, belonging, intimacy or commitment. These are things that money cannot buy which means they can be worked on at any time" (p4).

Fyffe, McCubbery and Bigby (2008) in their recent evaluation of the Victorian innovations in accommodation funding strategy, also highlight the importance of natural and community supports and note that these informal supports usually required more time to develop than the formal supports.

In addition to the new planning pathways, it is important to also focus on the broader range of partnerships required. The range of innovative examples included as part of this project highlight a strong sense of shared contribution and responsibility involving the person, their family and friends, community, business, govern-

ment and services. It is clearly not just a case of one party having all the answers or all of the responsibility, but of each party adding value to the overall situation.

In Australia, this sense of new partnerships is often covered under policy headings such as 'social inclusion' and 'corporate social responsibility', whereas in the United Kingdom for example, some current policy descriptors in social care include 'personalisation' and 'co-production' where people who receive social care services are being seen to be 'co-designers' and 'co-producers' of individual and community wellbeing (see Hunter and Ritchie 2007; Bartlett, Gallagher and Leadbetter 2008).

## Vision, Principles and Outcomes for Community Living

There are two main components of the vision for the Community Living Plan: firstly, the Commission's overarching vision statement that applies to all areas of the Commission; and secondly, the specific wording for the Community Living Plan vision statement.

The Disability Services Commission vision is that "All people live in welcoming communities which facilitate citizenship, friendship, mutual support and a fair go for everyone." The vision for Community Living is for "All Western Australians to have the same opportunity: my own life, my own home, in communities where we all belong."

The key principles are grouped in a number of major theme areas as follows:

### Core values

Some fundamental beliefs underpinning community living are that each person:

- is valued and respected for their uniqueness and capacity to make decisions
- has a right to real choices and ongoing opportunities for challenge and growth

### Person centred approach

Community living must focus on:

- getting to know the person well, honoring their life so far, their strengths, gifts, goals, fears and dreams; and
- understanding the person in the context of their family, friends, culture, beliefs and community networks, and the primary importance of valued relationships in each person's life.

### Information and high quality planning processes

In planning for a life in the community, people should have access to:

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## ... Community Living Options

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- timely, accurate and culturally relevant and accessible information from a variety of sources to enable people to consider alternatives and to make decisions about how and where to live;
- other individuals and families who can speak with authority and relevant experience about community living; and
- a range of planning processes that draw family, friends and supporters together to support the person to explore their vision and create practical strategies.

### Partnerships for action

Transforming plans into action will require:

- shared responsibility from the person, family, friends, community, business, government and services; and
- practical and technical support in areas such as communication, planning facilitation and network development.

### Systems to support each person

To establish a good life in the community each person should have access to:

- flexible support and resources as needed to strengthen and complement personal and community networks; and
- a range of measures to keep people safe and secure.

### Reflection and review

To sustain a good life over time each person should be able to:

- have confidence that their home and supports are secure; and
- have control over the review and change of their living and support arrangements.

The Commission, in collaboration with the disability sector, has developed a set of outcome statements for Accommodation Support Services. These sector wide outcome statements have therefore been used for the Community Living Plan, with modifications and enhancements over time as the Community Living Plan is further developed.

The current outcomes are as follows:

- Wellbeing : Maintenance and/or improvement of the social, mental, physical, emotional, spiritual, sexual and cultural aspects of the individual
- Relationships and Social Connection: Relationships are diverse and contribute to the individual's life and social connections
- Lifestyle : Participation in a lifestyle of the individual's choice

- Home : The place where a person lives is safe, secure and comfortable, and where they can be themselves

### The Power of a Good Graphic: "The Community Living Placemat"

An important learning experience early in the project implementation was that people generally found it hard to tune into notions of "Framework" and "Building community living options one person at a time". Many people found the concepts to be not easily understood and intangible. While the project documentation was helpful, what really engaged people were the two community living graphics: "Building Blocks for Community living" and "Models of Community Living Support." We soon learned to make these the main means of communication and developed a laminated version with one graphic on each side, that we affectionately titled the "Community living Placemat." These are handed out at every community living presentation and have assisted in making the concepts more practical and easily understood. People also understand the concept that all the building blocks are needed if a plan is to be successful (and therefore able to be funded). Sitting alongside families, they literally go through the building blocks and identify where they are strong and where they need more work. Crucially, the focus is on the person and starts with the primary importance of building relationships and a network of family, friends and supporters

The booklet "Looking Forward to Community Living" is used in conjunction with the graphics, and includes a detailed description plus practical examples of each of the main components. The Information Resource provides direct electronic links to primary sources and research.

A diagrams of the combined graphic is presented page right, illustrating the person at the centre of the foundation building blocks and then the various support options.

### Community Living Support Funding Strategy

An immediate implementation action arising from the Stage 1 Concept plan was the development of a new funding strategy to build on the energy and momentum that had been created. Many individuals and families were saying that they had been planning for years, were ready to go and often only required modest amount of resources but had no funding source unless they were assessed to be in critical need.

Some key features of the new funding included:

- Budget funds of \$650,000 recurrent for approximately 40 people
- A new pathway established as a separate strategy commencing September 2008
- A new policy framework and funding process, with funds individually allocated and able to be used flexibly and with various options for self management
- Some capital funding for housing
- A Community Living Resource Team established to assist people and their Local Area coordinators or service providers with technical support to develop, submit and implement plans.

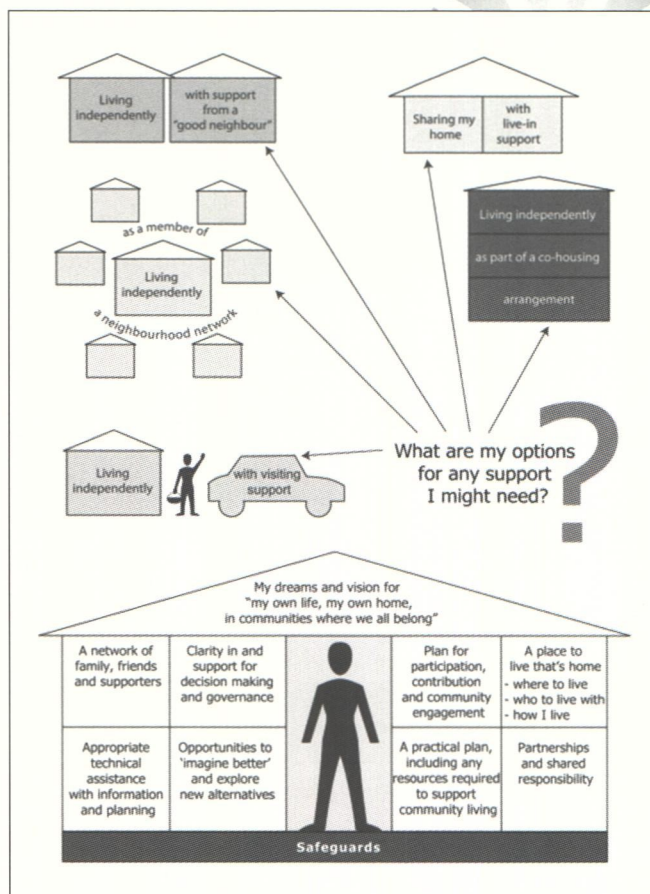
The policy framework had four key objectives:

- Support people with a disability to have their own home and life in the community;
- Enable the person with a disability to have a choice in who provides the support and how the support is provided;
- Build on the strengths and capacities of people with disabilities, their families/ networks and local community partnerships
- Increase and evaluate the range of innovative and flexible community support options, on a statewide basis and with regard to cultural background.

Adults (or their families on their behalf) could submit a plan, provided they were eligible for specialist disability services and not already receiving compensation for this purpose. It didn't matter whether the person was still at home, living independently or in some form of supported accommodation, provided their needs could be met with the maximum allocation of \$20,000 per annum recurrent community living support funding (they could however have post school options or alternatives to employment funding in addition to this amount). The criteria for funding were not the usual ones related to critical need: instead, they related to the personal outcomes for community living and the various "Building Blocks" related to planning and support. Individuals could submit a concept plan to develop their option or a well developed plan for approval. Individuals could also specify that their individual plan was part of a collective project such as a "Keyring Network."

The Community Living Bulletin (August 2009) provides a snapshot of progress so far:

- 54 plans were funded during the 2008/9 year from a total of \$650,000 recurrent funding, including a number of plans that were supported following feedback and further development. There have been a good mix of country and metropolitan plans, with



creative options where funds are being used in ways to build relationships and increase community inclusion with a shift away from the traditional fee for service approach.

- As part of the 2009/10 State Budget, Disability Services Minister Simon O'Brien announced an additional amount of \$1.2m has been made available for an estimated additional 60 people under the Community Living initiative, making use of an expanded range of community based accommodation options as an alternative to more traditional forms of accommodation support.
- Rather than having funding rounds, there will now be an ongoing process where small groups of plans can be considered as they are received.
- Country and metropolitan Local Area Coordinators and service providers are have hosted an ongoing series of local events to introduce community living to families, community groups and service providers and also to assist families to build the "building blocks" through targeted strategies. Many hundreds of people are now actively engaged in planning and development across the state including the involvement of new local community groups and the development of infrastructure for new service models.
- An initial formative evaluation has been completed of the funding process and planning for an external longitudinal evaluation is underway.

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## ... Community Living Options

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### Summary and Reflection

From the perspective of individuals, families and staff on the ground in local communities, a key observation is that the initiative is growing from strength to strength due to the engagement with individuals and families as key partners in this whole process and the powerful impact of good local examples and inspiring local speakers who can speak with great personal authority about the planning journey and also the practical outcomes of their efforts so far. The statewide network of Local Area Coordinators and the Community Living Resource Team provide on the ground assistance to engage local people and map out next steps. Training initiatives such as Michael Kendrick's Optimal Individual Service Design Course are a critical capacity building strategy across all sectors and investments in person centred planning approaches and personal network development are key building blocks for families in particular. The evidence base is also growing and starting to demonstrate a high level of value for money where relatively modest levels of funding are being used to generate substantial amounts of informal and community supports. Attention to quality, flexibility, safeguards and sustainability is crucial as part of the longitudinal evaluation. Most of all, the focus must remain clearly on each person and the sort of life and home that they wish to choose, in a community where they belong and are surrounded by people who value and care about them.

From a policy and systems change perspective, some key features of the process that I believe have contributed to success so far include:

- Clear problem formulation in the Sector Health Check Report (2007), a clear policy mandate and high level project leadership and support
- An emphasis on engagement and joint vision building, rather than the traditional form of consultation, leading to a strong sense of "co-production" and a "community of shared interest". Eliciting and listening to critical feedback and taking this on board, for example with the need for graphics and practical resources for families.
- A national and international perspective on best practice, with strong analysis and external critique, leading to a broad range of strategies to effect systems change
- Engagement of key decision makers in policy development and implementation planning, leading to a creative and timely implementation plan with a commitment to action and practical results; and
- Commitment to safeguards including evaluation and policy review so that the focus on outcomes and quality is sustained.

Extensive information about the West Australian Community living Initiative can be found on the Disability Western Australia website [www.disability.wa.gov.au](http://www.disability.wa.gov.au) by clicking on the Community Living icon on the right hand side of the home page. A short version of this paper with an emphasis on leadership aspects has also been published by the Community Resource Unit in Queensland in CRUcial Times, September 2010.

The author would like to acknowledge Rosemary Woodward (Senior Project Officer), members of the Project Reference group (see Community Living Concept Plan report for details) and the Community Living Resource team for their contributions to the development and implementation of this project. The leadership and support of Dr Ron Chalmers, Director General of the Disability Services Commission is also acknowledged.

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# Restrictive Interventions

## Position Statement

ASSID's membership has spoken. We must find better ways to support people with intellectual disability who, as a result of their severe challenging behaviours, are subject to restrictive interventions. In particular, ASSID is concerned about the wide-spread use of *chemical restraint* (i.e., medication used to modify behaviour in the absence of any diagnosed mental illness), *mechanical restraint* (i.e. the use of devices and clothing etc to impede peoples movement), *seclusion* (the isolation and confinement of people to places from which they cannot themselves leave when they choose) and *physical restraint* (i.e., where physical force is used in excess of what might be reasonable to provide support or guidance).

The views expressed by ASSID's membership in a series of conference forums over the past 2 years, consistent with the international literature, are twofold. First the continued use of restrictive interventions, especially where they are unregulated and unmonitored, place people with disability at unacceptable risk of psychological and physical harm, and can result in death. Furthermore, the continued use of these practices represents a serious breach of people's human rights and can also breach their civil rights. Secondly, the continued use of restrictive interventions place staff (and family members) using these interventions at serious risk of psychological and physical injury. For these reasons, the continued use of restrictive interventions in disability services constitutes a major occupational health and safety concern.

ASSID's position on the use of restrictive interventions is consistent with its long standing concern with the support of people with disability who exhibit challenging behaviour. In the past, ASSID has provided guidance on evidence-based practice through the publication of resources such as "*Challenging behaviour – an approach for the 90s*", and in more recent years, "*Positive behaviour support – evidence-based practice promoting quality of life*". For further details, refer to our publications at [www.assid.org.au](http://www.assid.org.au).

More recently, during the 2008 ASSID conference at Melbourne, a forum was conducted in collaboration with the Victorian Office of the Senior Practitioner. Brief reports on current legislation, policy and practices were

provided from all states of Australia and New Zealand. As a consequence of the concerns expressed at the meeting by the ASSID membership, a working party was established. The proceeding of the working party were presented to the 2009 ASSID conference at Hobart. At the Hobart conference, the membership endorsed ASSID formulating a formal position statement on the issue and progressing action in consultation with government, across Australia and New Zealand.

- ASSID has now published a position statement; *Against the Use of Restrictive Practices in the Support of People who Have an Intellectual Disability*. This position statement is available on the ASSID website.
- ASSID has written to the Australian Federal Parliamentary Secretary for Disability, the Honourable Bill Shorten, and the New Zealand Minister for Disability Issues, the Honourable Tariana Turia.
- ASSID has requested, on behalf of the membership, that our respective national governments take immediate action to address serious policy deficits that allow for the continued and, in some states, the unregulated and unmonitored use of restrictive interventions in disability services.
- ASSID has proposed that in both Australia and New Zealand, a national strategy be instigated, similar to that which has already been established in Australia to reduce the use of restraint in public mental health services.
- ASSID is co-ordinating its activities with those of the Australian Psychological Society, which has developed a position statement to guide psychologists and a set of guidelines to assist clinicians working in disability services.
- ASSID and the Australian Psychological Society will be seeking to work with other professional associations to progress practice standards and guidelines to promote better ways to support people with intellectual disability who, as a result of their severe challenging behaviours, are subject to restrictive interventions. ♦

## **Victoria**

by Sam Murray

The years seem to whiz past at the best of times, however with our AGM a little earlier this year it made things feel even more 'fast-paced' than usual.

With the success of last year's 'dinner conversation' style AGM, with guest speaker Bruce Bonhady AM, we decided to give that approach another run this year. Our guest speaker this year was Rhonda Lawson-Street from National Disability Services (NDS). Rhonda gave a very informative account of the work done to date with NDS, particularly with the National Disability Insurance Scheme (NDIS) and in the campaign work they are running leading into both state and federal elections.

Attendance at this year's AGM was an impressive 21 members, and we head into 2010/2011 with a generous sized committee to lead the way. We welcome back old member to the committee and also welcome the new members that have joined committee for the first time this year.

ASSID (Vic) has for many years had the aim of bringing about as much diversity to the Regional Council as is reflected within the sector. And I believe we have captured a diverse and impressive array of experiences and knowledge to the 2010/2011 council.

As always, the ASSID (Vic) DSW Conference consume a large proportion of time for members, and we are again looking at hosting yet another successful conference in November. The Hon Bill Shorten's office contacted us and asked if Mr Shorten would be able to be involved again this year, and we warmly welcome him back to open our event. Call for papers has now closed, and we have been inundated with papers. Committee will over the next month refine this collection down to a manageable and robust program of informative and practical session to further strengthen our DSW workforce. With a growing number of interstate (and indeed NZ) delegates each year, we are exploring ways to further expand the reach of this conference.

With a large amount of committee time used to present this conference each year, we are excited to have a larger committee going into the next twelve months so that we can explore ways that our Victorian members can interact with ASSID throughout the year with a number

of smaller activities and events. Also we aim to review how we are serving our members and ensuring they are getting value and benefit for their membership.

Lastly, ASSID (Vic) wishes to acknowledge Glen Jose (ASSID Vic Secretary) in receiving a Public Service Medal in the Queen's Birthday Honours List. Glen was recognised for "outstanding public service to persons with a disability and to those who are disadvantaged within the community". A well deserved accolade Glen, and one that recognises your significant contributions to the sector.

## **NSW & ACT**

By Tina Purdon

**By the time this edition of IDA reaches readers, ASSID NSW and ACT will have conducted our 2010 Conference.**

With the reforming of an active committee across NSW and ACT at the start of 2008, we are excited to note the growth of these events. In 2008 ASSID NSW combined with Disability Professionals Australasia and facilitated an event attended by approximately 85 people. In 2009, the ASSID NSW and ACT Conference was attended by close to 100 people. Registrations for the 2010 event have reached 160. The Committee feels that this reflects increased local recognition of ASSID as well as the relevance of the content of each of the events.

It is with great anticipation that we prepare for the presentation of the inaugural ASSID NSW and ACT, Disability Support Professional Recognition Award. The Committee has received many outstanding nominations for this Award and the worthy recipient will be announced at the 2010 Conference on 20th August. We gratefully acknowledge the sponsors of this Award – The NSW Department of Human Services, Ageing Disability and Home Care, Edmen Community Staffing Solutions and Disability Professionals Australasia. It is additionally pleasing to note that Nominations for the Award were received from across the State, including from both metropolitan and regional areas. It has been a focus of the Committee to promote the activities of ASSID across the whole of the State and ACT, and it is encouraging to see the broad focus developing.

ASSID NSW and ACT has also taken steps towards the achievement of another of our Strategic Goals in the provision of financial support to The University of Sydney, Centre for Disability Studies for an inclusive research project. The funds will be used to provide training workshops to people with intellectual disability and their associates or family members, to become co-researchers and will aim to culminate in the conduct of a research project of interest to those involved. Findings will be disseminated through a variety of avenues, including Conference presentations, workshops and journal articles. As this project progresses we will keep IDA readers updated with developments.

ASSID Members from NSW and ACT should also be receiving a survey before the end of 2010, to provide them with the opportunity of directing the activities of the Committee into 2011. The survey will be looking at what Members are interested in, what they would like to be involved in and how they see the future of ASSID in NSW and ACT. We will also look at how to most successfully communicate with our Members. Please take this as advance notice and we encourage you to complete the Survey when you receive it so that we can continue to build ASSID in NSW and ACT to best meet the needs of local members.

Advance Notice is also given for the NSW and ACT Annual General Meeting on Friday 17th September, 2010. Please note this date in your diary. We wish to encourage as many people as possible to attend and encourage involvement on the Committee from new faces. This will also be a chance for Members to meet their Committee and speak to them personally about any issues, concerns or feedback and we would be pleased to see as many people as possible attend. The AGM will be preceded by a presentation by Rachel Dickson from CDS – “Person Centredness : Fad or Phenomenon?” Rachel has had extensive involvement in the move to Person Centred Planning in NSW and this presentation promises to be interesting and enlightening for those involved in all aspects of service provision.

Finally we wish our Queensland colleagues all the best for the Australasian Conference, this month and acknowledge the planning and preparation that goes into such an event.

## New Zealand

by Gary Wyatt

The NZASID Council has been very busy in the last few weeks organizing the 2010 New Zealand conference. This report will be a brief one with our conference only a week away.

Whilst this report is written one week prior to the conference occurring, I am pleased to report that we have again exceeded expectations this year and we have been forced to turn down late registrations. We hope that the conference will be a success, we certainly have a large number of disability sector professionals, educators, academics and self advocates attending this year.

With this report going to press, we are also pleased to be hosting a pre-conference workshop in Christchurch with Dr Jennifer Torr, one of our keynote speakers for the conference this year. Interest has been growing for this workshop and it is hoped that this workshop will kick off a busy week for the NZASID council.

We will also be holding our Annual General Meeting on the 25th August at the conference as well as holding a book launch titled “Parents with intellectual disabilities: Past, Present and Futures” to which Dr Brigit Mirfin-Veitch, one of our keynote speakers, contributed to. I hope to have more details of this publication on the NZ website page in due course

The Dr Torr workshop is being held on the 23rd August in Christchurch with the NZ conference being held for the following three days in the Southern City of Dunedin.

Another workshop creating great interest is the afternoon with Dr Matthew Janicki, being held in Auckland on the 20th September 2010. More details can be found on the NZ page of the ASSID website.

For further information on the NZASID branch, conference information or networking, please contact me at [gary@accessability.org.nz](mailto:gary@accessability.org.nz) – other contact details are available on the New Zealand branch page of the ASSID website – [www.assid.org.au](http://www.assid.org.au)

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## Western Australia

by Angus Buchanan

The Western Australian Region is proud to announce the launch of the Guy Hamilton Honours Research Scholarship to be awarded annually to an honours student from a Western Australian University completing researching the area of intellectual disability. This Scholarship honours Dr Guy Hamilton and recognises his outstanding work for people with disabilities and their families and his contribution to ASSID. The Award will be launched on September 1 at the State Conference and the first winner will be announced at this time. ASSID received a significant number of applications for this award highlighting that research in the area is strong and it is hoped that scholarships such as these will further promote interest at the undergraduate student level.

Planning for the State conference is well underway and has the theme "seeking Excellence". The theme this year is "Seeking Excellence". This year's conference will focus on what excellence means in the lives of people with intellectual disability. There will be a focus on how research can lead to excellence and also on programs and experiences which promote and provide excellence.

The key note speaker is Professor Tricia O'Brien. The Annual General meeting will be held on following the Conference

The Western Australian Council would like to acknowledge the recent appointment of Eddie Bartnik to the position of the Western Australian Commissioner, Mental Health Commission. Eddie is a member and Fellow of ASSID and is internationally and nationally recognised for his leadership, vision, and contemporary program and service developments for people with disabilities. We congratulate Eddie on this achievement. ♦

*Editor's note- Look out for this quarter's article by Eddie*

## Queensland

## Tasmania

## South Australia

No report this issue

# ASSID

# membership

# details

### 4 membership types:

Organisation / Individual / Student / Associate

### to join:

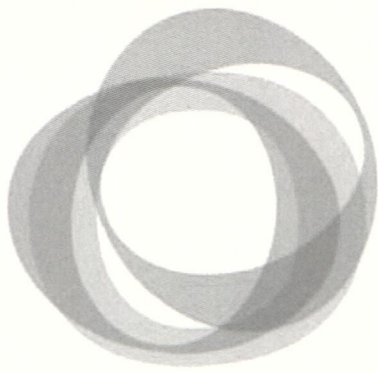
download a form from [www.assid.org.au](http://www.assid.org.au), or, contact the registrar at the address below

### 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.nat@bigpond.com](mailto:assid.nat@bigpond.com)



## People with Intellectual Disabilities: Achieving Full Participation in Training and Employment

# Lusaka Declaration

We, the participants at the sub-regional conference on People with Intellectual Disabilities – Opening Pathways to Training and Employment, Lusaka, 9–11 March 2010, involving representatives of governments, employers' and workers' organizations and civil society groups from six countries of East and Southern Africa and the United Kingdom, expressing the need to bring about meaningful improvement in the lives of people with intellectual disabilities and their families, who are inordinately affected by poverty and social and economic exclusion, hereby adopt the following Declaration

### We recognize:

That a fundamental shift has taken place at international policy level with the adoption and entry into force of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), signalling a move away from practices that segregate people with disabilities to an approach that seeks to promote their inclusion in all sectors of society in respect of human rights;

That many African countries have ratified the CRPD, and ILO Convention concerning Vocational Rehabilitation and Employment (Disabled Persons) 1983 (No. 159) although there is as yet little evidence of their practical application on the continent;

That, whilst people with intellectual disabilities are entitled to gain from the provisions of the CRPD as well as people with other types of disability, they are frequently not well placed to benefit from this changed emphasis on full inclusion because they are often deprived of the opportunity to attend school or to acquire relevant vocational skills leaving them at a disadvantage when it comes to seeking jobs;

That people with intellectual disabilities are frequently excluded from educational, vocational training and employment opportunities by widespread stereotypes, mistaken assumptions and negative attitudes that focus on their disabilities rather than their abilities;

That the voices of people with intellectual disabilities are frequently unheard in policy decisions or in decisions about themselves and their own future;

That parents groups and non-governmental organizations have played and continue to play a central role in providing for and drawing attention to the rights and requirements of people with intellectual disabilities;

That competing demands on scarce government and donor resources have led to minimal allocation of funding for services to people with intellectual disabilities and their families.

### We affirm:

That people with intellectual disabilities who have access to jobs suited to their interests, skills and abilities make valued contributions to the workforce and the broader society;

That the capacity of people with intellectual disabilities to contribute to society is enhanced through the development of self-advocacy and specific support measures that empower the individual, so that they have increased control of their own lives and that their voices are heard by legislators policy shapers and makers, programme and service providers;

That the capacity of parents' organizations to advocate for training and employment opportunities for people with intellectual disabilities needs to be strengthened;

That the current allocation of resources by governments to appropriate training and supports to people with intellectual disabilities needs to be increased;

That the collaboration and support of employers and employers' organizations are central to achieving progress in promoting opportunities for people with intellectual disabilities to take part in the workforce;

That the active involvement of trade unions and civil society groups will contribute to progress in achieving the goal of full participation of people with intellectual disabilities in the workforce, in their communities and society.

### We consider:

That the main aim for the immediate future is to improve the quality of life of people with intellectual disabilities and their families through training and employment strategies which will in turn benefit their communities and society as a whole;

That improvement will be achieved through evidence-based measures that focus upon the potential and needs of the individual;

That creative and innovative approaches to training and employment-related services should be introduced taking account of the individuals' preferences, entitlements and circumstances;

That supported employment pilot projects in countries of Africa have indicated the potential of this approach for Africa;

That a comprehensive, community-based approach to service provision, reflecting the ILO/WHO/UNESCO Joint Position on Community-based Rehabilitation (CBR), is in line with the provisions of the UN CRPD;

That appropriate strategies to reach this aim should be expressed in a national action plan to be adopted by respective governments, focusing on promoting training and employment as well as other opportunities for persons with disabilities, with an explicit focus on people with intellectual disabilities;

That emphasis should be placed on promoting access to mainstream education at every level and on access to lifelong learning, to work experience opportunities from an early stage, to skills development in a variety of forms, including on-job training through supported employment;

That the development of self-advocacy among people with intellectual disabilities is central to raising awareness, overcoming stereotypes and identifying resource requirements;

That, for the foreseeable future, parents will continue to play a central role in advocating the full participation of people with intellectual disabilities in the workplace, in their communities and society; That explicit attention is required to the training and employment-related requirements of women and girls with intellectual disabilities;

That international collaboration is necessary and will be of great benefit in moving the agenda forward.

## We undertake:

To explore the linkages with existing international networks on supported employment;

To develop linkages between civil society groups and service providers in other countries of the region;

To support the development of self advocacy amongst people with intellectual disabilities;

To collaborate with the media to promote positive images of people with intellectual disabilities;

To sensitize employers to business case of employing people with intellectual disabilities and to build the capacity for support workers to provide the necessary job-coaching and other support services;

To provide further supports to employers as they move to providing opportunities for on-job training and supported employment;

To champion the inclusion of people with intellectual disabilities in training, employment and other walks of life through sensitization campaigns and by making a commitment to people with intellectual disabilities as citizens with control over their own life.

## Recommend:

### That governments:

- Ratify the Convention on the Rights of Persons with Disabilities (CRPD) and ILO Convention No. 159, and implement these at national level, paying explicit attention to the requirements of persons with intellectual disabilities as well as other disability groups, including in the framework of the ILO/WHO/UNESCO CBR model;
- Establish mechanisms to monitor and enforce the implementation of the CRPD;
- Sensitize government officials and the broader community, including families, on the rights of persons with disabilities, including those with intellectual disabilities, and the issues faced in accessing these rights;
- Ensure early identification of intellectual disability, including through providing additional training for health and other relevant professionals and by enabling parents to access information and support;
- Establish a comprehensive system of data collection on persons with intellectual disabilities;
- Develop a clear social model of service provision relating to the health, education, training, employment and career development of people with intellectual disabilities, as well as people with other types of disability, ensuring that those involved in implementing it are adequately trained;
- Work closely with key stakeholders to implement existing policies;
- Allocate resources to develop and sustain innovative approaches to training and employment-related programmes and services for people with intellectual disabilities, including supported employment;
- Make provisions for reasonable accommodation in training and in the workplace to facilitate the inclusion of persons with disabilities in general and persons with intellectual disabilities in particular;
- Provide for employer incentives to promote the employment of people with intellectual disabilities; Encourage national and regional networking and collaboration, in particular on supported employment, to ensure that relevant expertise is shared and good practice is disseminated;
- Pilot test innovative models, including in the informal economy, accessing international funding where possible;

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- Play a leading role in employing people with intellectual disabilities.

#### That employers and their organizations should:

- Raise awareness of the working capacity of persons with intellectual disabilities including through having people specialized in dealing with persons with intellectual disability in the workplace;
- Be involved in the formation of a company human resources policy manual which includes provision for people with intellectual disabilities;
- Adopt Corporate Social Responsibility policies that include a commitment by employers to promoting training and employment opportunities for persons with intellectual disabilities;
- Form a consultative forum with workers' organizations and relevant civil society organizations regarding the employment of persons with disabilities, including those with intellectual disabilities.

#### That trade unions should:

- Sensitize their members on the rights of persons with intellectual disabilities and issues involved in accessing these rights;
- Develop a policy on how to protect the rights of persons with intellectual disabilities in the workplace;
- Form a consultative forum with employer organizations and relevant civil society organizations regarding the employment of persons with disabilities, including those with intellectual disabilities;
- Develop a data base on persons with intellectual disabilities in employment, including success stories of employees with intellectual disabilities;
- Use collective bargaining agreements to promote the rights of workers with intellectual disabilities.

#### That non-governmental organizations and parent's groups in the disability field should:

- Continue as service providers, adjusting their approach in line with the provisions of the UN CRPD, including the increased emphasis on inclusion and the need to sensitize and advise personnel in mainstream institutions;
- Advocate training and employment opportunities for people with intellectual disabilities, drawing on

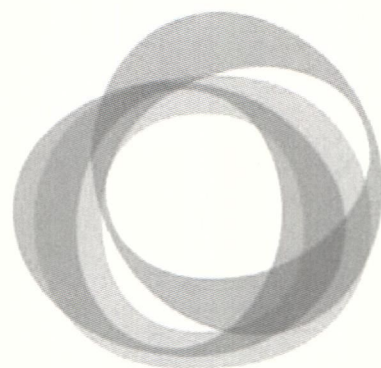
national and international research findings to provide the evidence base for their efforts;

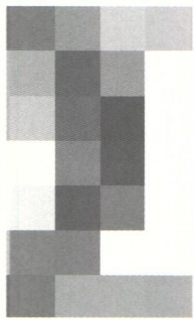
- Create awareness of the capacity, abilities and potential of people with intellectual disabilities in training and employment, by highlighting success cases;
- Build networks, coalitions and alliances in civil society to increase cohesion and coordination of efforts to promote inclusion of people with intellectual disabilities in training and employment.

#### That international organizations and networks should:

- Advocate equal opportunities for people with intellectual disabilities through policy development, laws, and evidence-based implementation measures;
- Support capacity building through training programmes for government officials, employers' and workers' organizations, non-governmental organizations and organizations of parents, as well as providing financial and logistical support at national level;
- Foster networking opportunities, including information sharing through the organization of study visits and regional conferences;
- Ensure that disability issues are taken into account in all their programmes and activities.

### Will you join us in making this Declaration a reality?





# Summary of the ASSID Market Research Report 2010

Prepared by Executive Officer, Kerrie Akkermans; Editor, Susan Peden

The following information was derived from interviews with ASSID members to determine the critical strategic factors for ASSID to consider, as it moves forward as a sustainable, contemporary and relevant professional organization.

## Survey methodology

The survey was conducted over a two month period, in May and June 2010.

Members were contacted from all regions, from a range of membership categories and different professional backgrounds in order to gain a broad perspective. The aim was to contact a minimum of 15% of the membership.

Members were informed of the pending telephone interviews via a notification letter, from the ASSID secretariat. Follow up emails were forwarded to members who could not be contacted by telephone.

The following questions were posed to members:

- The value of your membership with ASSID,
- The website as a resource tool,
- The research journal and publications,
- ASSID follow up and ongoing membership services, including communication, Executive Officer role and the Board,
- Feedback on the annual conference,
- Feedback on local events,
- The name and branding of ASSID, including what ASSID should stand for,
- What services members would like to see in the future.

This summary provides an overview of the range and perspectives from members that will assist in shaping the future strategic direction of the organization.

## The value of your membership with ASSID:

For those who believed they did receive value:

- The majority of members believed they received value for their membership,
- The journal was seen as the most valuable reason for membership,
- Networking was a key feature of many of the discussions and a key reason for remaining a member,
- The conferences were also seen as a reason for joining,

- Some stayed from loyalty,
- Some didn't know why they were still a member.

For those who did not believe it offered value for money

- Change of role,
- Lack of resources,
- Pressure of time,
- Distance from events,
- Other professional organizations fulfilling the need,
- Lack of contact if an organizational member particularly.

Comments included:

'Definitely been a positive benefit'

'Very much support research into intellectual disability'

'ASSID value is the networking at conferences'

'Been a member for 30 years'

'The value is in the networking and research'

'Central to my work-provides route to collegial network and support'

'Don't value the organization very much'

'Enjoy it being called ASSID. Everyone thinks I am an old hippy on drugs'

## The website as a resource tool:

- The website was rarely visited,
- Members opinions included;
- Too busy,
- Don't know when there is new information,
- It needs updating,
- Can't use it to register for local events,
- Can't access members' lists.

Comments included:

'The website is OK'

'The website is a point of reference''

'The website needs to be on a par with the publications in quality'

'Haven't seen much on the website that I would use'

'Never been on the website'

'Nothing on the ASSID website''



## The research journal and publications:

- The research journal is the main reason why people join and stay,
- The magazines are perceived as valuable, as are specific publications,
- It is seen by the majority as a valuable resource and provides excellent access to the latest information,
- The research is seen as most valuable for its practice based application,
- Some see the journal as inferior to what can be accessed on-line from overseas.

## Comments included:

'Love the magazine'

'The research journal and publications - of a high standard. It would be great to see publications of more books on specific topics'

'The journal is the value I get from ASSID'

'Haven't seen the journal'

'The journal is a critical part of ASSID'

'Use the Code of Ethics a lot and appreciate its availability'

'They are very high standard journals and I appreciate the Australasian focus'

## ASSID follow up and ongoing membership services, including communication, Executive Officer role and the Board:

- Virtually non-existent as far as follow services from ASSID,
- A common response from members was 'what follow up.'

## Comments were across a range of topics:

'Governance is long overdue for the board to look at'

'Need to make decisions at board level'

'Don't get any follow up from ASSID'

'Really appreciate being called and asked about ASSID'

'Everyone on the Board is nice'

'What follow up?'

'Face to face is always a better way to communicate'

'Everything happens adhoc because it is a volunteer basis'

'Not sure whether the member updates we send are

being put into the system'

'A newsletter would be good in both hard and soft copy so people can choose'

'Have to provide responses to issues far quicker than we have'

'It will be valuable having a central person (executive officer) for the conferences'

## Feedback on the annual conference:

### Negative comments were around:

- The quality of papers presented,
- The quality of the speakers,
- The need for more local keynotes,
- The promotion of clients being able to attend and the experience not being a positive one,
- Should be more outcome/practice based,
- Other conferences are better,
- There are many other conferences that they have to go to,
- The cost,
- The distance to travel.

There were many positive comments on the value and usefulness of the annual conference. The following comments were noted:

'People have wonderful ideas, but want to see the practical application'

'Conferences are good'

'The assessment of papers needs to be quality driven'

'Found a huge number of colleagues at the conference which was fantastic'

'Staff didn't want to go back as it went over their head'

'The majority of people who attend the conference are not members of ASSID'

'Its great having the papers and feedback from the latest conference on the website'

## Feedback on local events:

- The number of attendances at local events was far less than the number at Australasian conferences,
- Many members do not interact locally at all,
- Many members were not aware of any local events,
- Lack of time was given as the reason for lack of involvement,

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# ASSID Market Research Report

continued from page 17



- Lack of use of technology to keep informed or have access to events they couldn't go to physically,
- History of the region- members leave and the activity ebbs and flows depending on who is involved,
- There were less comments on a local level than from a total organizational perspective.

## Comments included:

- 'Haven't been to any local events'
- 'Nothing offered at local level that I want to go to'
- 'The disability support workers' conference is fabulous'
- 'Can't just sit back-have to participate as a leader'
- 'Contribute at a local level, but it is the broader association with ASSID that is valuable'
- 'Local committees are too few doing too much'

## The name and branding of ASSID, including what ASSID should stand for:

- There were varying responses to the naming issue,
- By a small margin, the vote for a name change was positive, however there were also many 'don't care' 'unsure' 'haven't thought about it' used to it' comments from members,
- Overwhelmingly, the response was to how ASSID is branded was a mix of research and practice based foci,
- Only a few opted for research alone,
- There was minimal interest in advocacy but only as it is already being done better by others,
- Lobbying is seen as the role of everyone in the industry and that ASSID should use research outcomes to influence policy,
- ASSID isn't seen as relevant anymore except for 'cutting edge research' other organizations fulfilling other needs.

## Comments to note:

- 'Don't know who ASSID is, or should be – who are ASSID actually there for?'
- 'The name should be simpler'
- 'It's the link between research and practice that's needed'
- 'ASSID should be research and practice. More interested in the practice side'
- 'I have no interest in the name or brand other than to question if the scientific study of ID is all that the organization does or what its seen to be doing'

- 'Do the research, but need to go the next step'
- 'Research is vital to good practice'
- 'Need to remain academic and practice focused'
- 'ASSID should stay research based'

## What services members would like to see in the future:

- Most members were unsure, their comments about this were interwoven into the responses to the other questions,
- The majority expressed their dissatisfaction about what isn't being done well rather than what ASSID could be doing as a new service,
- The key factors affecting this is the fact that everyone is busy anyway, they need to have an electronic communication and access along with the use of technology to interact ie. Webinars and recording live events.

## The recommendations drawn from the market research and supported by the Board were as follows:

- Promote ASSID as an organization that provides information and support for cutting edge research with practice based outcomes,
- Modernise the website and use it for content management to keep in touch with members (eg, email alerts) and as a valuable resource for networking and accessing latest best practice,
- Take a prominent role in the industry by having a media presence,
- Consider delivery of services so that they are time efficient, relevant and value added.

## Where to from here:

- Further investigation as required on specific feedback,
- Set up subcommittees to address individual issues/opportunities,
- Allocate tasks as required to consider the above recommendations.

## Actions to date:

- The Board has approved a change of name, and development of a new logo and tag-line,
- Work has commenced on redevelopment of the webpage to better meet member requirements. ♦

## upcoming events

29 Sept - 1 Oct 2010	<b>45th ASSID Conference</b> <b>Seeking Excellence</b> Brisbane, Queensland For more information contact <a href="mailto:assid2010@optusnet.com.au">assid2010@optusnet.com.au</a>
20 - 23 Oct 2010	<b>3th IASSID-Europe Conference</b> Rome, Italy For information, correspond with the IASSID-Europe 2010 Conference Secretariat, Ms. Isabelle Biondi: <a href="mailto:the.biondis@alice.it">the.biondis@alice.it</a> .
17 - 18 Nov 2010	<b>10th ASSID VICTORIA Disability Support Worker Conference</b> Melbourne check <a href="http://www.assid.org.au">www.assid.org.au</a> or email <a href="mailto:dswconference@rmit.edu.au">dswconference@rmit.edu.au</a> or telephone 61 (0)3 9925 7899
24 - 26 Nov 2010	<b>4th Australasian Orientation and Mobility Conference</b> Woemen's College University of Sydney <a href="http://www.guidedogs.com.au/amc2010">www.guidedogs.com.au/amc2010</a>
5 - 6 Sept 2011	<b>NDS Employment Forum</b> venue to be announced
8 - 10 Sept 2011	<b>Asia Pacific Autism Conference 2011 (APAC 2011)</b> Perth, Western Australia ph + 618 9389 1488 e-mail <a href="mailto:info@eecw.com.au">info@eecw.com.au</a>
8 - 10 Aug 2012	<b>10th Biennial Early Childhood Intervention Australia Conference</b> Perth, Western Australia

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

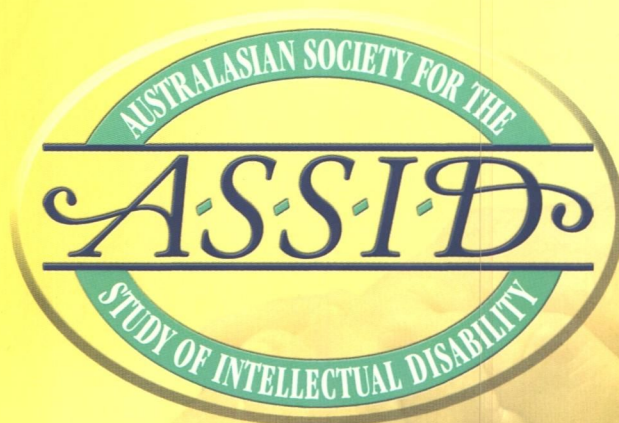
## IDA Advertising

- Display advertisement: \$176 (incl. GST) for quarter page (artwork supplied).
- Pre-printed inserts: \$242 (incl. GST). Weight restrictions apply.

Please contact:

The Editorial Assistant, Intellectual Disability Australasia  
 email: [krvt@optusnet.com.au](mailto: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.*



# SEEKING EXCELLENCE

**45th ASSID AUSTRALASIAN CONFERENCE**

**29 September - 1 October 2010**

**Hilton Hotel, Brisbane**

Co-Sponsored by AADDM and CEBS

**Standard Registration closes 31st August 2010**

For more information contact:

[assid2010@optusnet.com.au](mailto:assid2010@optusnet.com.au)

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