

Vol 34, Issue 1, Mar 2013

IDA

Intellectual Disability Australasia

Magazine of the Australasian Society for Intellectual Disability

asid
research to practice

*right relationships
wellington conference
inclusive research
eoi JIDD editor
note from the new president*

contents

editorial	2
<i>Right Relationships</i> <i>the Homes West experience</i>	3
ASID Conference NZ 2012	8
region update	10
A Note from ASID's President	13
<i>An Inclusive Research Approach</i> <i>to Exploring the Experiences of People</i> <i>with Intellectual Disabilities at Work</i> ..	14
Call for EOJ for JIDD Editor	18
upcoming events	19
Annual ASID Conference 2013	20

front cover:

Lifetime Photography - Bakari Chavanu



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

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

Editor: Kathy Ellem
Phone: (07) 3382 1453
Email: k.ellem@griffith.edu.au

Editorial Assistant:
Ross Tudman

Advertisers:
Rates are available, on inquiry,
from the editorial assistant at
krvt@optusnet.com.au

Editorial Address:
78A Cheltenham Rd,
Croydon, NSW, 2132

Membership and Subscription:
Sue Salisbury
ASID Secretariat
38 Surrey Road
KESWICK SA 5035
1800 644 741
secretariat@asid.asn.au

Artwork:
krvt DESIGN
krvt@optusnet.com.au

Printed by:
Bloxxham & Chambers Printers

editorial



Happy 2013
to all ASID members!

It is with some excitement and perhaps a bit of nervousness that I begin my new role as editor of IDA. It is a hard act to follow from the lovely Sue Peden, but I will do my best! I am very fortunate to have her continuing help with IDA, as well as the assistance of Ross Tudman, IDA's assistant editor.

Within this edition of IDA you will find a note from our new ASID President Angus Buchanan. Angus has taken over from Richard O'Loughlin's leadership and will be providing IDA readers with regular valuable updates on the latest news concerning ASID. Welcome Angus – we look forward to working with you over the next few years!

This IDA edition emphasises the importance of building meaningful relationships with people with an intellectual disability and their family members/significant others. I have included an accessible summary of each article in the magazine in Easy English so that anyone who may need support with language can read the contents. The first article in the magazine is a report on findings from the Centre for Disability Studies Inclusive Research Network on how people with intellectual disability experience work. At the end of the article, you will see the names of all the people who contributed to this collaborative piece of work.

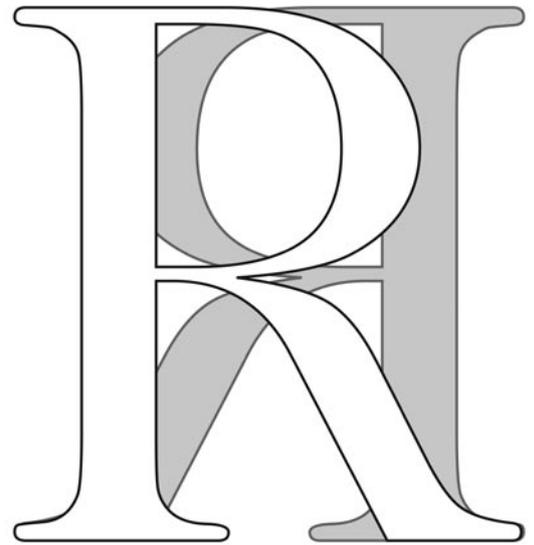
A brief summary of the 47th ASID Annual Conference in Wellington is also included in this edition. A big thank you goes to all of the people in New Zealand who organised this event in November last year. It was a great success and a wonderful opportunity for sharing knowledge, passion and camaraderie.

There are two articles devoted to direct practice in this month's IDA. The first is an outline of the practice framework "Liking People" developed by the Community Living Association in Nundah, Brisbane. Hopefully this will inspire and encourage those of us who work with people with intellectual disability about the importance of community presence. The second article is an articulation of the principles of "right relationship" – a concept developed by Michael Kendrick – and applied in this context, to the running of Homes West Association in Brisbane.

As per usual, regional updates from Australia and New Zealand are included here to keep us all in the loop. We also have an Expression of Interest request for a new editor for JIDD and a list of upcoming events you may be interested in.

Right Relationships: the Homes West experience

By Jan Dyke
and the Homes West Association



Accessible summary:

- Homes West is a small service in Brisbane Australia. It supports people with a disability to live in a home of their own with the support of their family.
- It is important for workers, people with a disability and families to work well together.
- Homes West calls this “working in right relationships”. This paper is about what right relationships might look like.

Homes West Association Incorporated (Homes West) is a service in Brisbane, Australia that works with a small number of families to support people with a disability to establish and to live in a home of their own and to be included as active and valued members in their local community. However for families, the Homes West experience is much more than having a service supporting the daily life of a

loved one. The experience has led to a way of life, one in which many aspects of authority and responsibility have been retained by family members or delegated by design, so that their choices and decisions give direction to their family member’s life and safeguard how life is played out, now and into the future. This paper shares families’ understanding and experience in grappling with the notion of right relationship and defining what authority and responsibility remains with whom, in their quest for a valued life with and for their family member with a disability.

Why this paper was written

Traditionally, many services that support the lives of people with disabilities have taken an all or nothing approach. People have either lived in their family home where they and their family took all responsibility for their care, or they lived in facilities run by services that took over this responsibility and with it, all authority over the person’s life, often to the great detriment of relationships, safety, and decent lives. Even when newer forms of service were established to support people with disabilities, many continued their same way of operating, moving into areas of life that, for other
continued page 4

editorial

continued

Please consider attending this year’s conference in Sydney in November. ASID relies on the participation of its members in such important events. Also, if you have any feedback or ideas for the IDA that you would like to share with me as new editor, please do not hesitate to contact me via email at k.ellem@griffith.edu.au

**All the best,
Kathy**

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

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

citizens, always remain the personal business of the people themselves and/or of their families and trusted friends.

The families who have formed Homes West have had experience of other services that have taken over this authority and responsibility in relation to their family member's life. Often the results have been devastating. Therefore in the development of the Homes West experience, family members have been keen to ensure that this service would not follow down the same path, but instead would be clear about who would hold authority and responsibility for what.

Families involved with Homes West believe that some very definite roles remain the province of the person, their family and enduring friends (family business), and that others remain the province of the service (service business). This may seem a rather

simple notion that is easy to define and to implement. However, there are many aspects that fall between these two poles because of life's complexities. This central part becomes a dynamic dance in support of the person's life where authority is negotiated and delegated, with responsibility shared between the people involved. Working in right relationship therefore can become quite variable and individualistic depending on the understanding, capacity, and efforts of all those involved.

About working in Right Relationship

People involved with Homes West talk about the need to work in right relationship with one another so that proper authority and responsibility are understood and respected, as well as their delegation. In other words the dance of life is choreographed in partnership with one another with a clear understanding of who leads which parts of the dance and how parts are negotiated and created together.

Michael Kendrick (2005) sees this right relationship as having a shared commitment and ideal, and being achieved only when the following are in place:

- a genuine desire to work together
- an appreciation of each other's strengths and capacity to contribute
- a willingness to have an ethical relationship, both at the level of personal daily interactions, as well as in regards to structures and formal roles.

Families involved with Homes West agree with these ideals.

What families can expect from the service

Families can expect that the service works in right relationship with them. For right relationship to work they are clear about what they want and do not want from workers: (see table page 5)

What workers can expect from families

In the collaboration process, workers can also expect families to work in right relationship with them. Families therefore are also clear about what workers want and do not want from them: (see table page 6)

These examples of what the people involved with Homes West want and do not want relate to the principles that Michael Kendrick (2000) sets forth about right relationship:

- Relating with people, not at, on or down to them
By relating with people, both parties are generally viewed as reinforcing the sense of each other as being respected, equal, important, credible and resourceful, and not being involved in an unequal power play.
- Negotiating with people rather than imposing answers upon them
By negotiating, the person and their family have the chance to respond to and counter the views of others, as well as remind any potential controller of the need to respect their will, personhood and entitlement to determine their own sense of what should be happening with their life.
- Creating mutual and shared ideals of what constitutes right relationship
The ethos of mutuality sets the expectation that values, goals and priorities are to be developed together. As much of this dance of life with the service is dynamic, expectations can change and need to be worked through and agreed upon.
- Rejecting the theory of ultimate professional or managerial authority over service

If the service side of the relationship has the final say on important matters affecting life, then it is predictable that the less favoured party, who is the person being assisted, will be subject to domination with the outcome not likely to be in their best interest.



- Relating to each person as unique in how services are designed and operated

This principle relies on an ethic of supporting one person at a time and permitting ways that give high degrees of flexibility and individualisation at the personal level.

- Leaving the core decisions of a personal nature to the person served or as close as possible to them with people who know them most

This relates back to the question of personal authority and to matters that are generally recognised as personal and private by most of society. By returning the greatest degree of control of life

that may be possible, back to the person and/or those closest to them, this stops the taking over of the business of families which is private or at least very personal.

About the service as a buffer against bureaucracy

As government has moved towards taking greater authority and responsibility for setting and monitoring the quality of community life, its interests and preferences have taken over many matters that have been largely under the control of commu- *continued page 6*

Table: What families can expect from the service:

Wrong relationship is:	Right relationship is:
<p>Absence of ethical relationships:</p> <ul style="list-style-type: none"> • workers not valuing the person or their family • being neglectful, abusive, or harmful • not ensuring safeguards are in place • divulging private information and breaching confidentiality • being unavailable when needed, not turning up, being inefficient • not doing the work expected of them 	<p>Presence of ethical relationships:</p> <ul style="list-style-type: none"> • workers knowing people well • valuing their contribution and remaining loyal to them • taking a genuine interest in the person and understanding their uniqueness • using common sense, being honest and open • applying good work ethics and being reliable and trustworthy
<p>Lack of genuine desire to work together:</p> <ul style="list-style-type: none"> • workers making decisions alone • making decisions about which they have no authority • using emotional blackmail • promoting self-interest or manipulating to get what they want 	<p>A genuine desire to work together:</p> <ul style="list-style-type: none"> • workers working respectfully alongside people involved in the person's life • building on the supports, strengths and capacities that are naturally there • having ability to create respectful responses together to meet needs • being willing to work in a team
<p>A lack of appreciation of each other's strengths and capacity to contribute:</p> <ul style="list-style-type: none"> • workers overstepping their role and going into areas that are not expected of paid service • being disrespectful, condescending or patronising about the person, their family or their way of life • not listening and ignoring the wishes and concerns of the person and their family • treating people in standardised ways. 	<p>An appreciation of each other's strengths and capacity to contribute:</p> <ul style="list-style-type: none"> • workers supporting no more than the paid service element of a person's life • knowing people well enough to know when to step forward and when to step back • managing service business and protecting people from intrusive bureaucratic processes • supporting and encouraging family members and trusted friends to do their best now and into the future.

Right Relationships . . .

continued from page 5

nity, families or citizens (Kendrick, 2002, 2005). Yet, as described earlier, disability services are called into people's lives to meet people's needs, and not to do service business. The core business of supporting life therefore is not about meeting the need of the bureaucracies that organise, govern, regulate and perpetuate the formal service.

The Homes West experience has shown that when the service acts as a buffer between family business and service business, life is focussed on what is needed to live a good life and is much less complicated for all involved. The role of the service as buffer is an integral part of the understanding of right relationship, as it does not allow bureaucratic expectations to regulate how ordinary life is played out, yet the service still

Table: What workers can expect from families:

Wrong relationship is:	Right relationship is:
<p>Absence of ethical relationships:</p> <ul style="list-style-type: none"> • family treating their family member with a disability disrespectfully • putting personal interests first and overriding the welfare of others and the sense of the common good • doing things that could be interpreted as abuse or neglect, eg: using the person's finances to serve personal interests, cruelty to the person etc. 	<p>Presence of ethical relationships:</p> <ul style="list-style-type: none"> • family using common sense, being honest, reliable and trustworthy, and applying good ethics • making the hard decisions about what is non-negotiable, when to compromise, what is possible and what just can't be done • setting negotiated boundaries for authority and its delegation, with a written agreement
<p>Lack of genuine desire to work together:</p> <ul style="list-style-type: none"> • family imposing personal will without explanation or through intimidation • not being available when greatly needed • giving mixed messages to workers based on family disagreements about what should or shouldn't happen in the person's life • expecting workers to do it all and not be willing to partner in the arrangement • being disrespectful of the worker, not recognising the worker's rights 	<p>A genuine desire to work together:</p> <ul style="list-style-type: none"> • family being reasonable in requests and understanding the consequences of their directions for workers • holding regular meetings with workers and spending time sharing information with them • setting the overall values and policy direction of the service to ensure the organisation does the best for people • nurturing organisational spirit and taking a stewardship role, maintaining a willingness to come together to work for the common good of the people and their families • reflecting on how the service is going • reaching out to the broader community to find the next generation of leadership to take over family business and to continue and renew the organisation. • respecting workers' rights
<p>A lack of appreciation of each other's strengths and capacity to contribute:</p> <ul style="list-style-type: none"> • family not giving workers clear information and guidelines about family values, traditions, relationships that are to be preserved • not negotiating about who does what parts of the dance. 	<p>An appreciation of each other's strengths and capacity to contribute:</p> <ul style="list-style-type: none"> • family being clear about what is family business and what is service business.



fulfils its obligations as a funded, quality assured disability service.

About areas of shared responsibility

The Homes West experience has also mirrored Michael Kendrick's belief (2006) that people who use services to support life can contribute to areas that have often been seen as the realm of service authority in traditional service provision.

These areas have become shared responsibility with Homes West because people and their families:

- are aware of what makes a good workforce
- know whether the service is working well or not
- have a stake in service quality
- can guide the service to what it is or could be
- are able to provide leadership and purpose.

Family members also help to:

- select, supervise and release staff
- induct, train and mentor staff
- clarify what it is that they most need from the service
- build a vision about what is possible and can inspire staff and others to share and implement it
- develop needed innovations.

They also:

- play a key role in evaluating services
- safeguard quality through active advocacy, monitoring and raising awareness
- help to mobilize support for quality service
- are reflective sounding boards for crucial developments
- contribute to family and organisational renewal.

About Right Relationship and integrity

For right relationship to work, all those involved with the Homes West experience are expected to own the shared responsibility of acting with integrity. This is perhaps the hardest part in working in right relationship, as it involves acting towards one another in ways that demonstrate respect, decency and actual useful service and not be involved in the quest of selfish or narrow self-interest. Such behaviour involves (Kendrick, 2003):

Respect:

- withdrawing from carrying out or supporting any devaluing or degrading practices

- recognising personal shortcomings, ethical lapses, or being a role model for poor or improper practices
- supporting others who are attempting to be good and ethical.

Decency:

- deciding to uphold openness and truthfulness
- remaining loyal to the people being served
- acting as advocates, protectors and champions of the people being served.

Useful service:

- remaining consistently principled
- challenging the organisation to be more faithful to people
- persevering to make a real difference over time.

Maintaining integrity is always complex. As people are people, human frailty will be a constant struggle in the development and provision of personalised service responses.

Such commitment and responsibility may seem quite unattractive to other families who are in search of services that do it all, yet take away all authority and responsibility, often with very detrimental outcomes. For the people involved with Homes West, these principled struggles are worth the effort:

- People with disabilities are entitled to a lifestyle which is based on the same rights and opportunities as other citizens, regardless of type or degree of disability
- Regardless of capacity or skill, family members and their trusted, enduring friends have a natural authority and are entitled to influence the direction of a family member's life, if they have remained faithful and committed to that person's development and wellbeing
- A home is much more than bricks and mortar. It should enhance a person's personal privacy and security, the development of relationships and intimacy, and expression of individuality through flexibility and choice
- Community inclusion is more than just living in a house in the suburbs. It gives rise to active and meaningful participation in community life and to the development of broader networks.
- Families, community and paid support staff can work together in a respectful right relationship to support a person with a disability to live his or her life well

continued page 8

ASID Conference NZ 2012

Prepared by Paardekooper
and Associates



Accessible summary:

- The conference for ASID in 2012 was held in Wellington, New Zealand on Wednesday 7th to Friday 9th November.
- The conference was about Unity in Diversity – in Maori Kotahitanga ki rō Kanorau – it was about sharing different ideas from different people.
- The people who helped in the conference are listed below.

The 47th Annual Conference for Australasian Society for Intellectual Disability was held on Wednesday 7 to Friday 9 November 2012 at the Wellington Town Hall, Wellington, New Zealand.

The Theme

The theme of the conference was Unity in Diversity Kotahitanga ki rō Kanorau – Different Perspectives : Common Purpose.

The theme acknowledged:

- The rich diversity of perspectives that contribute to our shared knowledge base – philosophies and

values, cultural diversity related to ethnicity, place in the lifespan, gender, as well as different consumer perspectives.

- A desire across Australasia to move from splintered and uncoordinated support frameworks to a more integrated approach to individuals, family and social groups, and communities.

Purpose of the Conference

The ASID conference is held annually, by one of the 7 regional branches of ASID. This is the second year that it has been held in New Zealand.

The conference is a forum to exchange ideas, best practices and expertise. It is the premier platform across Australasia for academics, researchers, policy makers, providers and people with intellectual disability to hear about and share current evidence-based research, about ways to best support people with disabilities and their families to have great lives within their communities.

Conference Structure

The 2012 conference was held over three days, with a pre-conference workshop held the day prior to the conference commencing. The main conference was a mixture of keynote speakers in plenary sessions and break out parallel sessions. There were social functions at the end of each conference day.

Right Relationships . . .

continued from page 7

- Families do best when they work together, sharing their skills, experiences and capacities. With collaboration comes a synergy. The whole is greater than the sum of the parts.

To sum up the feeling of the Homes West experience:

We feel the costs are more than offset by the satisfaction of putting our efforts into making a real and significant difference to life, rather than having to deal

with fighting systems and services that take over and do not come up with the goods.

References:

People involved with Homes West are indebted to Michael Kendrick who has shared his wisdom with us and many other Queenslanders over many decades.

(references available upon request - please contact the editor) ●



Conference Committee

Sharon Brandford	IDEA Services	Convenor
Debbie Espiner	University of Auckland	Programme chair
Brigit Mirfin-Veitch	Donald Beasley Institute	Programme
Louise Mitchel	Explore	Promotion
Martyn Matthews	IDEA Services	Finance, social programme
Olive Webb	Institute of Applied Human Services	Sponsorship
Anne Mathieson	CCDHB	Social programme

The following people from the ASID NZ Council also helped:

Adrian Higgins	Council Chair
Marlene Verhoeven	Proof reading
Hamish Taverner	Accessibility
Fran Hartnett	
Bev Kohleis	
Christine Wilson	
Gary Wyatt	Social media

An external PCO was engaged through a tender process, to help with the conference organising. This was: Paardekooper and Associates, PO Box 41002, Eastbourne, Lower Hutt 5047, New Zealand.

Keynote Speakers

1. Jayne Clapton, Associate Professor, School of Human Services and Social Work, Griffith University, Australia
2. Bill Lindsay, Chair of Learning Disabilities and Forensic Psychology, University of Abertay, Dundee
3. Averil Herbert, Clinical psychologist, University of Waikato, New Zealand
4. Teresa Iacono, Professor of Regional and Rural Allied Health, La Trobe University, Australia
5. Susan Balandin, Director, Jessie Hetherington Education Research Centre, Victoria University of Wellington, New Zealand
6. Robyn Munford, Professor of Social Work and Director of Practice Research and Professional Development Hub, School of Health and Social Services, Massey University, New Zealand

Pre-conference Workshop

A full day pre-conference workshop was held on Tuesday 6 November in Civic Suites, Wellington Town Hall, and presented by Prof. Bill Lindsay. The topic was “Assessment and treatment of sex offenders with developmental disabilities” and attracted 65 attendees.

Opening / Mihi

The conference was opened with a traditional mihi whakatau (Maori welcome), followed by speeches from the Sharon Brandford, Conference convenor; Robert Martin, Fellow of ASID and Richard O’Loughlin, President ASID.

Hypothetical Panel

A hypothetical panel was held at the conclusion of Day 1 of the conference.

The statement was: 2032: What will life be like for people with intellectual disability? This was chaired by Mark Henaghan, University of Otago.

Poster Sessions

A total of 14 posters were timetabled during the lunch breaks of the three days. These were located in the trade and exhibition area alongside the catering.

Workshops

Two in-conference workshops were held on Thursday.

- Stepping Stones – a group therapy programme for the treatment of emotion regulation difficulties in people with an intellectual disability. This workshop had a limit of 50 attendees, and delegates advised their attendance via the online registration system. This workshop ran from 10.15am – 4.05pm
- Let’s Talk – Self Advocacy Forum This workshop was hosted by People First New Zealand Inc. Nga Tangata Tuatahi, and sponsored by Frozen Funds Charitable Trust. The workshop was closed to self advocates only, who worked through a programme and reported back to the full conference delegation during the closing of Day 2. Approximately 24 people attended this workshop. *continued page 10*

New Zealand

By Adrian Higgins

The NZ Region has taken a well earned break following the successful hosting of the very successful Australasian Conference. The conference convener, Sharon Brandford has presented the Board with a full conference report a financial statement, The conference ran at profit and 403 delegates registered and 382 attended. A full database of attendees and email addresses has been established to enable wider publicity for future conferences. Sharon and her team are to be congratulated on their superb job and their choice of Paardekoooper and Associates as conference convenors. ASID-NZ would like to acknowledge the major sponsors for the conference:

- IHC
- Frozen Funds Charitable Trust
- Nova Employment
- Te Pou
- Standards Monitoring Services

Prior to the conference a keynote speaker Professor. Bill Lindsay ran a sold out, one day workshop on

“Assessment and treatment of sex offenders with developmental disabilities” attended by 65 participants.

ASID - NZ will hold its annual face-to-face meeting in Wellington on 23 February.

Tasmania

by Ben Crothers

Once again the fast-approaching launch of the NDIS in Tasmania is dominating professional activities though still so little detail regarding the scheme is known. The NDIS Launch Transition Agency's public information sessions through late-February will provide detail on which I can report in the next edition of IDA.

The Speakout Association of Tasmania was successful in securing a piece of the Practical Design Fund to be used to develop a toolkit for young people with intellectual disability to assist them in making choices especially relation to funding related to the NDIS.

ASID Tasmania will be present at the upcoming Gearing Up Expo in Hobart on Thursday 23 May at

ASID Conference . . .

continued from page 9

Welcome Function and Wine Tasting

A Welcome Function and Wine Tasting took place on Wednesday 7 November at the conference venue from 5.30-7.00pm. This was also a chance for delegates to meet with other delegates and discuss and share their experiences and reflect on day one of the conference. Networking is an important aspect of a conference and this function provided for a casual atmosphere to do so. Approx 260 people attended the function of which 130 attended the wine tasting.

Conference Dinner

The conference dinner took place at Pencarrow Lodge on Thursday 8 November. The cost to the delegates was \$95 inc GST.

Pencarrow Lodge is located at the heads of Wellington harbour, and delegates either had to bus, or bus and ferry to the venue. Delegates were taken by bus, with

65 on a first come first served basis going on the ferry, to meet the buses at Days Bay. The journey continued around the harbour to the stunning setting of Pencarrow Lodge. Guests were invited to enjoy drinks and nibbles on the veranda overlooking the Cook Strait and then enjoyed a two course buffet in the cellar room.

During dinner, Tim Launder, the general manager of Weta Ltd spoke for 40 minutes about the history of Weta and showed some short clips.

There were some reservations initially with regards to the distance to the venue and the accessibility of the venue.

The journey was an hour from Wellington, however, the venue was considered well worth the drive with the journey being part of the experience and the opportunity of delegates taking in the views of the rugged Wellington coastline. ●

PW1. The Gearing Up Expos – held throughout the state – are a great opportunity for individuals and their families to collect information about supports, services, and programs that are available to them now and into the future. Come and visit our table to have a chat and grab a free pen!

Western Australia

by Chris Yates

2012 ended with a flurry of activity as ASID auspiced a series of workshops delivered by ASID's own Professor Christine Bigby. The topics were:

- Supporting People with Intellectual Disability to Live Good Lives in the Community - the Role of Group Homes Past and Future
- Beyond Person Centered Planning to Person Centered Action in Group Homes –Achieving Optimal Outcomes for Residents in Group Homes.
- Aging of people with lifelong disabilities - planning for the future

These workshops were well attended and very well received and a good indication that people are hungry for good research based information which is relevant and skillfully presented.

ASID WA is gearing up for two big years as we head towards the Australasian Conference in 2014 and planning has commenced for this important event with a meeting in November and another in January. We have chosen joint convenors and started to set up a sub-committee structure and are now looking forward to engaging with the Board Sub-committee to plan ahead.

Meanwhile, we want to engage strongly with our members and offer a vibrant program of events this year also. On the drawing board we have a joint intellectual disability and mental health symposium, possible event around the visit of Professor Tamar Heller later in the year and we are also looking to take advantage of any other opportunities which come our way.

It is looking like another exciting year.

South Australia

by Ian Pearce

Our last AGM saw some new faces join the SA Committee and those present were entertained by “The Great Debate” about whether mandated notification should have been included in the re-drafting of SA's Disability Services Act as a means to keep vulnerable adults with a disability safe from abuse.

Two events are already on the drawing board for this year. The first promises to be a workshop aimed at direct care staff on improving the quality of their interactions with those they support. Later in the year we hope to offer a workshop by the well known author and speaker John O'Brien. A further task for 2013 is to look at ways we can better support our members in the Northern Territory. While airfares and other means of travel between Adelaide and Darwin are still expensive in money or time, this can be overcome now thanks to the advent of affordable technology. NT members can expect to hear from ASID down south in the not too distant future.

Victoria

by Trevor Skerry

Greetings from the ASID Vic committee members.

ASID Vic have hit the ground running in 2013.

Following on from the successful November workshop facilitated by Grafton ASID VIC's planning for our next event is well underway.

The day seminar and workshop will be held in Ballarat and has a working title of Choices, challenges and changes: moving into adult life.

The seminar and workshop will act as a forum for young people with an intellectual disability, their family/carers, service providers and person centred planners focussing on transition to adult life.

The aim of the day is to bring a range of people together to hear about the way young people can make choices, face challenges and plan for adult life as and to share and learn from current practice and people's experiences

Please keep an eye out for further information over the next few months.

As well as planning for this event Board Members, in particular Christine Bigby (as the lead researcher) have been very productive in publish- *continued page 12*



ing their research. A full list of her four pieces can be found on the ASID Vic page. Congratulations should also go to Hilary Johnson (another productive and busy board member) with her work in the area of models of processes that underpin positive relationships for adults with severe intellectual disability which has also been published. Hilary's work is also worth noting for the cooperation received and the interest shown from other disability researchers in this very important area.

Board member Mark Heeney recently represented ASID Vic at the recent forum at the Olga Tennison Autism Research Centre (OTARC). The forum's aim was to highlight and discuss the proposed changes that will occur for the diagnosis of an Autism Spectrum Disorder in the Diagnostic and Statistical Manual of Mental Disorders, Volume 5 (DSM-5).

Mark feedback to members at the monthly ASID Vic meeting and highlighted the fifth edition will do away with the discrete categories of Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) and will instead use an umbrella term of Autism Spectrum Disorder to describe conditions along the spectrum with an additional dimension describing severity.

Mark reported the forum continued with short presentations from a panel that included Dr Nicole Rinehart, Dr David Trembath, Dr Janine Manjiviona, and parent Lisbeth Wilks, who each discussed the proposed changes and how they felt they would impact on research and practice. Most felt the changes were a positive step and a reflection of current thinking and practice around autism.

As we all know the NDIS continues to be a source of questioning and discussion as many people try to work out what it will mean to them. Many projects have been funded to determine or plan for the impact of this important scheme.

I have recently joined a steering committee on one such project and will ensure the outcomes of this project will be feedback to all ASID Vic members.

The project is titled "NDIS Workforce Ready" and is a research project funded by the Practical Design Fund. The purpose of this initiative is to identify practical ways to support the transition to a National Disability Insurance Scheme (NDIS).

The NDIS Workforce Ready Project will also research options for professional certification of disability sup-

port workers, and present draft models and recommendations for professional certification to support the objectives and principles of a NDIS.

Looking forward to a positive 2013

Queensland

by Michael Keates

ASID Queensland begins the New Year with a strong and vibrant regional council and executive. We would like to thank Cecily Harker for her valuable input over the past several years and welcome new members Cheryl Walker, Sharon Paley and Mark Wakefield. Special note should also be made of the valuable role that Madonna Tucker has played in her role as a state representative on the Australasian council. Madonna steps down from this role after several years of valuable contribution. Fiona Davis will take up this challenge in 2013.

In early January ASID Queensland conducted a planning day and undertook a review of our strategic plan. The regional council will be presenting this plan to the broader regional members to seek their feedback and set some future directions.

ASID Queensland will continue with an over arching focus on encouraging and supporting local research and practice initiatives to enhance the lives of people with an intellectual disability. Some initial work has been undertaken to establish a series of grants for local tertiary students and academics to support research. A forum is also being proposed to bring together researchers and service providers from across the state to share ideas about current and future research opportunities.

We will be presenting a series of bi-monthly seminars across the course of the year. Our first event will be held in March and will be presented by Professor Nick Lennox who will address the issue of "Working with the Healthcare system - Now & into the future. The presentation will move from what is health and healthcare to the enablers and barriers to healthcare relevant to people with intellectual disability in Australia. He will discuss what has been tested and found demonstrably useful and what seems promising or even possible. The innovations, ideas and ways forward will be discussed with highlights of current work in Australia and overseas.

The regional council and executive will also continue to focus on improving communication with our regional members and providing greater benefits for members through access to information, support. The establishment of a Face Book page has been a useful step in this

A Note from ASID's President

Dr Angus Buchanan



I would like to thank Richard O'Loughlin for his strong leadership as President of ASID for the past three years. Richard leaves the role of President with ASID having a membership of over 700 individuals and organisations. As an organisation ASID is a strong voice "to improve the quality of life for people with an intellectual disability" through research to practice. The goals of the Australasian Society for Intellectual Disability are:

- to be an independent authority on intellectual disability issues across Australasia;
- to forge interaction between intellectual disability research, policy and practice;

- to lead the development of strategic partnerships;
- to engage and strengthen membership; and
- to ensure sound governance.

ASID is as effective as its membership – us! As President I am in the privileged position to hear and see the scope of work undertaken by regions around Australia and New Zealand including professional development, Conferences, research scholarships, and advocacy. I encourage you to keep in touch and

continued page 14

direction and has already proven to be a highly efficient means of connecting with people and promoting ASID. An exploration of the use of Twitter is to follow.

In all 2013 is promising to be a dynamic and exciting year for ASID QLD.

NSW & ACT

By Tina Purdon

The big news for NSW / ACT is the 2013 ASID Australasian Conference!

'OUR TIME'

The venue will be the lovely Sheraton on the Park, located in the middle of the Sydney CBD. Close to transport and everything beautiful Sydney has to offer – great location for a weekend in this spectacular city after the conference!

What you need to know now:

- **Registrations** are NOW OPEN!
- **Early Bird** discounts apply NOW (until 9.8.13)
- **Call for Papers** OPEN NOW, closes 4.5.13
- **Pre-Conference Workshops** commence on **Monday 4th November**
- **The Conference** will run **Wednesday 6th November to Friday 8th November**
- We will have something for everyone, with all presentations around the theme of 'OUR TIME' celebrating the fabulous achievements of partnerships across the sector – in metro areas as well as rural and remote locations, with the people we support, local communities, service providers, education and health services!

How to get involved:

1. Check the website for up to date program information www.asid.asn.au
2. Submit an Abstract through the Call for Papers – we welcome submissions from first time and seasoned presenters alike!
3. Take advantage of the Early Bird Registrations and BOOK NOW!
4. Book your accommodation at the Sheraton for the conference rate (limited rooms available at this rate), just let the Hotel know you are attending the ASID Conference and request the special rate – EASY!
5. Check out the pre-conference workshops on the website and make the most of your trip to Sydney by attending one or more workshops as well!

Sponsorship

The 2013 ASID Conference Prospectus is available for distribution. If you would like to see how we can assist to promote your company, please request a Prospectus using the email address below. We have a huge variety of sponsorship packages available – and can also look at tailoring something just for your business. This is a great promotion opportunity!

If you have any questions, or would like to help in anyway, please contact Tina Purdon – Conference Convenor, tpurdon@hwns.com.au

This will be an event not to be missed, we would love to meet as many of our ASID colleagues as possible in Sydney this November! ●

An Inclusive Research Approach to Exploring the Experiences of People with Intellectual Disabilities at Work

We Do Research Together

Authors

Susan Adrian, Jodie Airey, Julie Bannerman, Sarah Butler, Alex Butters, Julie Deane, Friederike Gadow, Robert Griffiths, Lisa Hamilton, Suzy Jessep, Julian Kim, Marie Knox, Lesley Lewis, Annie Mills, Patricia O'Brien, Alex Papas, Glen Pudney, Peter Rondo, Mark Walters, Elizabeth Young

Accessible summary:

- Inclusive Research is about people with intellectual disabilities doing research with other researchers. Each person in the research team is important and is seen as an expert.
- The Centre for Disability Studies (CDS) Inclusive Research Network is a group of people with intellectual disability doing research with other researchers. The research is not done to the people with

intellectual disability. They work alongside the other researchers.

- The research question in this paper is: “What are the experiences of people with an intellectual disability around their right as workers?”
- While some people were happy with their work and felt their rights were being met, there were other people who were not happy with their workplace. Some people were bullied and treated unfairly.

A Note from ASID's President

continued from page 13

participate in your local regional activities.

The ASID Voice at time is not always overt. At present I am sure many of you have been involved in and contributing to the development of the NDIS. It is in such areas that ASID can be a strong voice to ensure that the needs and aspirations of people with intellectual disabilities and their families are well understood. Often while ASID may not be necessarily named as “the voice” many of the organisation’s members are participating in a wide variety of consultations, committees and providing valuable critique and commentary on policy and legislation.

ASID’s role is to ensure that research drives quality practice. A strength of the organisation is the diversity of its membership including practitioners, clinicians, academics, researchers, and people with disabilities and their families. ASID is working towards strengthening the interaction between disability research, policy and practice by the launching of a new publication in 2014 called Research and Practice in Intellectual

and Developmental Disabilities (RAPIDD). RAPIDD’s purpose is to disseminate research, encourage its translation and relevance to practice and policy, and generates informed debate on contemporary issues that matter to the quality of life of people with intellectual disability and their families. RAPIDD will inform the design and delivery of support important for people with intellectual disability and their families and identify pressing research questions. The Australian context and the pursuit of a more inclusive society for people with intellectual and developmental disabilities are the core focus of the journal. All members will receive a copy of the Journal as part of the membership package along with the current Journal for intellectual and developmental Disability (JIDD).

ASID in 2013 is a strong organisation, working towards developing increased agility to be responsive in a dynamic environment, and committed to its mission “to improve the quality of life for people with an intellectual disability.” ●



Introduction

Inclusive research is about people with intellectual disabilities doing research with other researchers without disabilities (Ham et al 2004, McClimens 2007). Walmsley (2004) described this type of research as research where people with intellectual disabilities are involved as active and not passive participants. It is underpinned by the principles inherent in the self advocacy maxim 'Nothing About Us Without Us' (Charlton, 1998).

It is, in effect, about equalising the power or control in research and shared decision making around research, what research we will do and how we will do it.

However, it is also important to consider not just who is involved in inclusive research but also about how we do inclusive research. Walmsley (2005, p56) argued that people with intellectual disabilities can do research tasks if the circumstances are right and if they get the right type of support. Additionally, Grant and Ramcharan (2007) pointed out that people with intellectual disabilities have the expertise of the lived experience to bring to our research projects.

Our Group

The Centre for Disability Studies (CDS) Inclusive Research Network is about people with intellectual disabilities doing research rather than having research done to them (Barnes, 2003). The network has a core membership of co-researchers with intellectual disabilities, university co-researcher and agency co-researchers who support those researchers with intellectual disabilities

In the network, each researcher's skills, experience and expertise are valued as equally important to the project, whether the researcher has an intellectual disability or whether they are a researcher without an intellectual disability (Johnson, 2009; Williams et al., 2005).

Purpose of the Study

We learned that not a lot of research has been done around the everyday experiences of people with intellectual disabilities and the rights covered in the UN Convention on the Rights of Persons with Disability. We

decided to explore peoples' experiences around their rights in the areas of health, housing, education and employment; this paper is about one of these rights, that of employment. This right is affirmed in Article 27 of the Convention that says people with disabilities have the same chances and rights at work as other people.

Our Research Question

"What are the experiences of people with intellectual disability around their rights as workers?"

What We Did

We developed a series of questions about rights around work and held individual interviews in the Sydney metropolitan area with 24 participants; 17 participants were male and 7 participants were female. A co-researcher with an intellectual disability and a co-researcher without an intellectual disability worked together and conducted interviews. We used an interview guide, with six questions, to ask participants about their employment experiences.

Our study was approved by the University of Sydney's Human Research Ethic Committee.

What We Found

Question 1: "Do you think you have equal opportunity to do the work you want to do?"

In response to this question, 17 participants answered 'yes', 5 participants answered 'no', and 2 participants did not provide a response.

- Happy about their job opportunities

One person told us that he is working with dedicated staff and working in a team. He has the opportunity to teach others and learn from others.

- Unhappy about their opportunities because of bullying or not getting a fair go

One person told us that there are people out there who do not give people with disabilities a fair go. He felt people should give them more of a go because it is hard for them.

continued page 16

An Inclusive Research Approach ...

continued from page 15

Figure 1 provides more qualitative data about the responses.

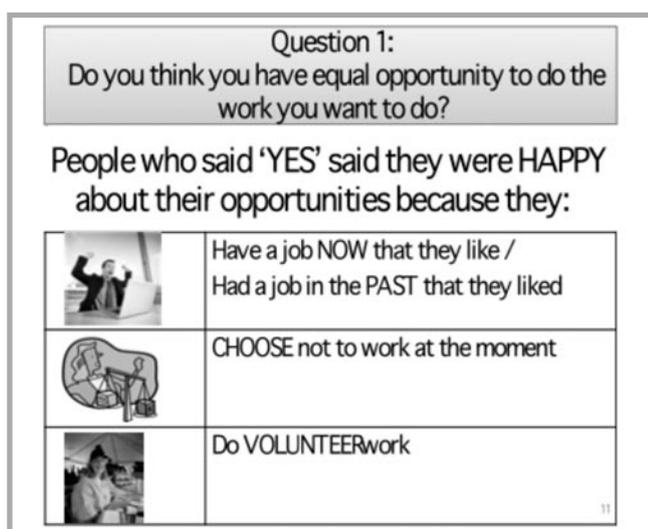


Figure 1

Question 2: "Do you have security and safety at work?"

18 people said yes and some participants said that people at their workplace are helpful and have good workplace health and safety.

- One person said, "Yes, people are nice and helpful. When I ask for help they come."

3 people said no and noted that there was no job security, that they had experienced bullying and there was poor workplace health and safety in their workplace.

- One person said that the room at their previous work was too tiny and not ventilated. He got a sinus infection because of this, which is the main reason why he left the job. He also experienced high blood pressure while there because he was anxious about the small room.

3 people did not provide a response.

Question 3: "Is it easy for you to find the job that you want to do?"

8 people said yes, 12 people said no, 1 person had never looked and 3 people had no answer to this question.

- People talked about finding a job on their own, getting help to find a job and the difficulty of finding a job. One person who found her own job told us that she found an ad in the paper run in the local newspaper, rang up about it and got the job. A per-

son who found it difficult to find a job said, "With the employment situation at the moment, it's hard to find a job anywhere."

Question 4: "Is it important that you can get to and from work and that you can get around your workplace easily?"

16 people answered yes, 4 people said no and 4 people gave no answer.

The topics people spoke about were public transport, coping, wheelchair access and having no issues.

- One person said about having no issues: "I can walk really well. Never been in a wheelchair."
- Another person said that he has anxiety catching buses.

Question 5: "How important is training for you to get a job and keep a job?"

20 people said it was important, 1 person said it was not important, 3 people did not answer this question. Figure 2 emphasises the importance of training, as identified by the participants.

- One person said "Very important – but are they willing to do that for me? Can't take pressure when employers are in your face. I would struggle."

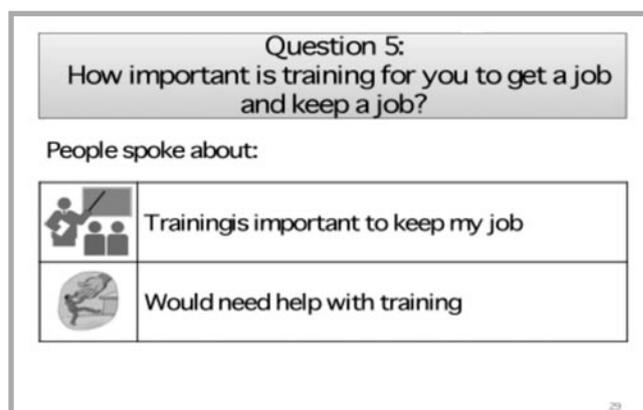


Figure 2

Question 6: "Is there anything else about employment that you would like to mention?"

- It's a good job and I'm very happy with my manager.
- Not getting paid enough, I'm a hard worker.
- I just want to get a job and earn my own money. I have hope for the future.

People also said that safety is important. Maybe I can

talk for other people – very important to their workplace and inside their workplace and they must have a safe workplace.

People also made comments about having the same rights as others. We can be just as productive as non-disabled workers.

Hopefully future employers will accept people with intellectual and learning disabilities. Want to be treated like any other normal human being. Have to accept and be patient.

How do Our Findings Relate to the Convention?

Article 27 of the Convention says that people with disabilities have the same chances and rights at work as other people. While several of the study participants were satisfied with their work and considered their rights were being upheld, we also found that many had difficulties finding a job to their liking and one in which they were adequately paid. Their right to a safe and accessible work environment was compromised and there were instances of bullying and of being treated less favourably than workers without disabilities. It appears for these participants, at least, there is some way to go before they experience the rights at work articulated in the UN Convention.

While embarking on an inclusive research initiative was a new experience for all, this is what we learned:

An important lesson we learned from doing our research is how doing inclusive research builds us as a team. We were, as Walmsley (2001) says, working as a team rather than with any one group of co-researchers being “in charge”. This is rather different from inclusive research with co-researchers with non-intellectual disabilities where the people with disabilities are definitely “in charge” (Shakespeare, 2006). However, just as in much other research, the research team’s dilemmas and issues were very similar to those of non-disabled researchers, who also have to find a method of planning and implementation that suits them as a team and suits individual members of the team.

We have also identified from our research, the important role of both University staff co-researchers for their skill in research, and agency staff co-researchers for their skill in supporting individual co-researchers with

intellectual disability. Walmsley (2001) points out that we often don’t describe what the supporters do or pay enough attention to how important they are in making sure the research is done properly. Walmsley (2001) and Sinason (1996) both argue that this is an attempt to deny or erase difference. We have tried to show that as a team we are indeed different in terms of our skills and experience and so often we have different roles to carry out. But we are all equal in what we contribute.

The agency staff co-researchers were critical in supporting individual co-researchers with intellectual disability whom they knew well and who the co-researcher trusted. These were critical players in the team. We do not think that others interested in inclusive research studies have examined this role.

We look forward to sharing more of our research in the future – especially with people and organisations who can use our research to help bring about change and improvements in the lives of people with intellectual disability.

References

(references available upon request - please contact the editor) ●

ASID membership details

4 membership types:

Organisation / Individual / Student / Associate
to join:

download a form from www.asid.asn.au, or
contact the registrar at the address below

to current members:

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

registrar:

1800 644 741
38 Surrey Road
KESWICK SA 5035 Australia
secretariat@asid.asn.au

Call for expressions of interest: Editor(s) Journal of Intellectual & Developmental Disability

Susan Balandin & Ian Dempsey



The Journal of Intellectual & Developmental Disability is the official journal of the Australasian Society for Intellectual Disability (ASID), whose members are interested in social, psychological, educational, and medical aspects of intellectual and developmental disability across the lifespan. Four issues of the Journal are published each year.

The current Editors of JIDD, Professor Susan Balandin and Associate Professor Ian Dempsey, intend to step down in 2014.

ASID is therefore now calling for expressions of interest in the honorary position of Editor or joint Editors, Journal of Intellectual & Developmental Disability.

The new Editor(s) will be appointed for a period of 3 years and must be a member of ASID throughout their tenure.

To ensure a smooth handover, a period of transition is envisaged during which the new Editor(s) will work alongside the outgoing Editors (subject to negotiation). Most likely, the incoming Editor(s) will take up responsibility for newly submitted manuscripts in the latter part of 2013, with the outgoing Editors retaining responsibility for the remaining issues for 2013, and continuing to deal with manuscripts already under their review.

The Editor's main responsibilities are:

- to ensure that the scholarly standards of the Journal are maintained;
- to appoint an international team of Associate Editors and Editorial Consultants; to ensure the prompt processing of manuscripts submitted to the Journal;
- to make editorial decisions regarding the publication of manuscripts; to consider proposals for special issues;
- to review editorial policy as required; and to promote the overall development of the Journal.

In conjunction with a subcommittee of the ASID Australasian Board, the Editor will from time to time be required to negotiate a publishing contract with commercial publishers.

The Editor also selects the winners of the annual ASID Australasian Research Prize and JIDD Editor's Prize from among the articles published (or to be published) in JIDD during the calendar year for which the prizes are awarded, and presents these prizes at the ASID annual conference.

Other duties of the Editor include preparing a written report to the ASID Australasian Board twice annually, attending the ASID annual conference (and where possible attending a mid-year ASID meeting), and presenting a JIDD Editor's Workshop at the ASID conference.

The Editor's position is supported by a paid Editorial Assistant. The current Editorial Assistant is Genevieve Farrell. The Editor has access to a modest budget for travel and accommodation expenses directly related to JIDD business.

All articles submitted to the Journal of Intellectual & Developmental Disability are subject to anonymous peer review. The Journal uses a web-based manuscript submission and review system hosted by Manuscript Central at <http://mc.manuscriptcentral.com/ejid>. This system affords flexible working arrangements for the Editors and Editorial Assistant, in that the Journal's online manuscript management system can be accessed via the web throughout the world.

Expressions of interest will be evaluated by a subcommittee of the ASID Australasian Board. It is expected that the subcommittee will convene initially in September 2013 to consider the expressions of interest. The subcommittee may choose to interview applicants via teleconference, and an appointment is likely to be made later in 2013.

upcoming events

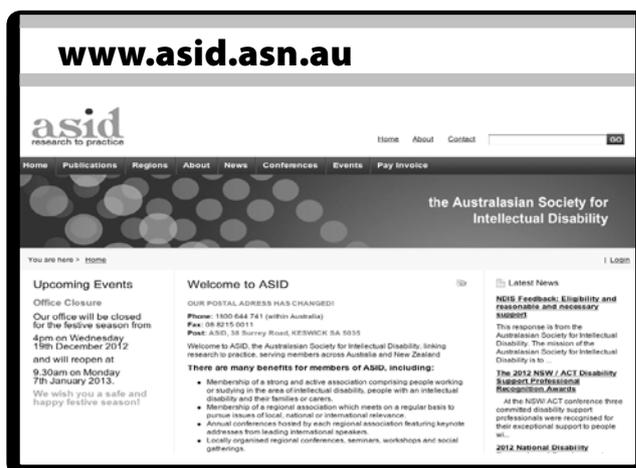
10 - 11 Apr 2013	Pacific Regional Conference on Disability 2013 <i>"Promoting Disability Perspective in the post 2015 Development Agenda"</i> Ramada Plaza, New Caledonia www.daru.org.au/event/pacific-regional-conference-2013
29 - 30 Apr 2013	Pacific Rim International Conference on Disability and Diversity Hawaii www.pacrim.hawaii.edu
8 - 10 Aug 2013	Asia Pacific Autism Conference APAC 2013 Adelaide, South Australia www.apac13.org.au
22 - 24 Aug 2013	IASSID Asia Pacific Conference Tokyo, Japan
11 - 12 Sep 2013	Centre for Culture and Disability Studies <i>"Avoidance and the Academy: The International Conference on Disability, Culture, and Education"</i> Liverpool Hope University, UK www.disabilitystudiesnetwork.gla.ac.uk/2013/01/04/avoidance-and-the-academy-international-conference-on-disability-culture-and-education
16 Sep; 23 Sep; 25 Sep; 2013	Fragile X Workshops Adelaide 16 September, Brisbane 23 September, and Sydney 25 September Event venues TBC www.fragilex.org.au
6 - 8 Nov 2013	48th ASID Annual Conference <i>"Our Time" to celebrate the future of person centred disability services</i> Sheraton on the Park, Sydney, NSW www.asid.asn.au
Aug 2014	IASSID Europe Vienna Austria
Aug 2016	IASSID World Congress Melbourne Victoria Australia

If you want to advertise your conference in IDA's upcoming events section, please e-mail: k.ellem@griffith.edu.au

Applicants should send a statement on their suitability for the position and a copy of their curriculum vitae to the ASID Secretariat (secretariat@asid.asn.au). The application should indicate whether the applicant prefers to act as sole Editor or is willing to share the role with another.

Enquiries can be directed to the current Editors, Susan Balandin (sue.balandin@vuw.ac.nz) and Ian Dempsey (ian.dempsey@newcastle.edu.au).

Expressions of Interest close July 31, 2013. ●



"Our Time"

- Registrations - NOW OPEN!
- Early Bird Discounts - until 9.8.13
- Call for Papers - closes 4.5.13



ASID
CONFERENCE 2013



asid
research to practice

Dear Colleague,

You're invited to the 48th Annual Conference "Our Time" presented by ASID from the 6th - 8th November at Sheraton on the Park, Sydney.

"Our Time" celebrates the future of person centred disability services with keynote addresses from Profs Eric Emerson, Trevor Parmenter, Sue Read, Keith McVilly & Barry Carpenter.

Check out: www.asid.asn.au

Hope to see you there,

Tina Purdon

Conference Convenor



asid
research to practice

Australasian Society for
Intellectual Disability (ASID)

P. 1800 644 741 (within Australia)

w. www.asid.asn.au/

Check the website for up to date program information www.asid.asn.au