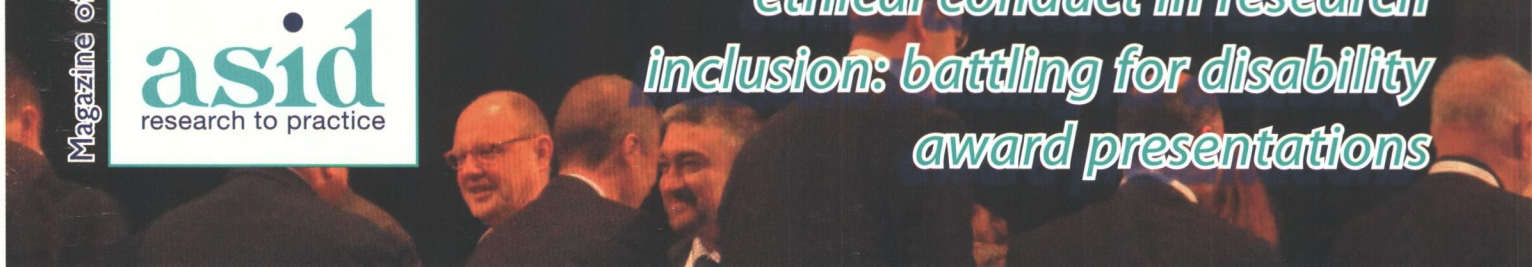


IDA

Intellectual Disability Australasia



*media bias in the trial
communications technologies trajectory
ethical conduct in research
inclusion: battling for disability
award presentations*



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front cover:

ASID Conference 2012

asid
research to practice

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editorial



Best wishes of the season to all ASID members.

This edition will be my last as editor of IDA, and the first for Kathy Ellem, as the articles have been gathered together as a joint effort this quarter.

Once again, IDA is packed with information that I hope is both of topical and practical interest to you, the reader. You will find details of the annual ASID awards. Both Kathy and I are pleased to congratulate all award winners, but most especially, Professor Nick Lennox, who was nominated by his colleagues in Queensland for the award of Fellow of ASID. The award of Fellow of ASID is only offered to ASID members who have demonstrated over many years that they actively support and promote the objectives and aims of ASID, in translating and applying research to practice that will improve the lives of people with an intellectual disability. An ASID Fellow will be both nationally and internationally renowned for their work in the field. Nick joins an impressive group of Fellows, including Professor Trevor Parmenter, Professor Emeritus in the Sydney School of Medicine, University of Sydney, Eddie Bartnik, Mental Health Commissioner, WA and Robert Martin, self advocate and recent keynote speaker at the 2012 ASID conference in New Zealand.

Within this edition of IDA you will find a paper that is a little out of the ordinary, as it is a review of a number of news articles regarding a man who was found guilty of arson which resulted in the deaths of several people in Victoria. After some deliberation I decided to publish the article as it demonstrates how language and imagery can be used to portray negative stereotypes of people with a disability. As always, the decision to publish an article does not endorse or support the conclusions or views of the author. The information contained within the article is already on the public record.

A full report of the ASID 2012 conference will be published in the March IDA, but in the meantime, we have included a few photos of participants and speakers for you to enjoy.

The ASID Board met for its final meeting of the year, just before the conference began. Further information can be obtained from your local regional representatives.

“A Former CFA Volunteer”

Media bias in the trial of Brendan Sokaluk

Ruth Wolverton*, PhD

*a pseudonym

On 20 March 2012, after four days of deliberation, Brendan Sokaluk was convicted of deliberately lighting a bushfire on February 7, 2009, by throwing burning paper near a eucalyptus plantation. This fire, known as the Churchill Fire, killed 10 people, destroyed over 156 homes and over 36,000 hectares and took 12 days to bring under control (R v Sokaluk). The Churchill fire was one of several fires in Victoria on that day which became known as Black Saturday. Mr Sokaluk was eventually sentenced on 27 April, 2012 to 17 years and 9 months with a non parole term of 14 years.

Understandably, the trial received a great deal of attention in the media. This paper looks at coverage of the trial from articles in two major Melbourne newspapers, *The Age* and *Herald Sun* (see references). All the information included in this paper is therefore in the public domain and all articles are readily available on the internet.

In examining these articles I was interested to find out how these newspapers portrayed Brendan Sokaluk, a 42 year-old man diagnosed with autism and mild intellectual disability. I looked for themes, imagery and logic in the newspaper articles of the trial using a framework of qualitative research (Taylor & Bogdan, 1998). My findings are presented below.

“A Former CFA Volunteer”

Nine articles mentioned that Mr Sokaluk was a former County Fire Authority volunteer in 1987-88 (Akerman, 2012; Petrie, 2012 a,b,c; Dunn, 2012a, b; Franklin, 2012; Ross, 2012a, b). Five of these articles presented this fact in their first or second sentence and three articles mentioned this fact twice in the same article. No further information or explanation is given as to why this fact is relevant to this case or why it is so important that it needs to be mentioned so early and so often especially given that Mr Sokaluk was a CFA volunteer for only one year 20 years ago.

continued page 4

editorial

continued

The issue of governance and accountability of the Board is of increasing concern to members. In the coming 12 months a small working group will be developing a paper for consideration by the Board on the options that are available to ASID for improved governance. The Board also aims to consider current publications and information to members, as part of its commitment to meet ASID's objectives of supporting members. A third publication has been proposed that will aim to provide useful practice based papers that will be of relevance to the Australasian disability sector and workforce.

In concluding my last editorial piece, I must thank all the IDA contributors over the years, in particular those regional representatives who have provided local news and updates regularly.

My biggest thank you, however, is reserved for Ross Tudman, IDA's assistant editor. Ross organizes the layouts, handles queries from advertisers, manages the publishing, printing and mail-outs every quarter and uses his amazing skills to ensure that IDA remains the professional and contemporary magazine that it is.

Thank you to you all,

Cheers, Sue and Kathy

One explanation may be that it raises in the reader's mind the stereotype that bushfires are often started by firefighters, so called "firefighter arson". However, the incidence of firefighter arson by currently enlisted firefighters is extremely rare, 11 out of 69,000 volunteer firefighters in NSW (Willis, 2004) and only six CFA members had been dismissed for lighting fires since 2003 in Victoria (Dunn, 2012c). This is an extremely small number considering there are approximately 60,000 CFA members in any one year in Victoria (CFA Corporate Plan).

Willis (2004) cites no research on former firefighter arson let alone on arsonists who were firefighters 20 years prior to the arson. Thus, reporting Mr Sokaluk as a "former CFA firefighter" as somehow relevant to this case is a stretch and prejudicial in so far as it unnecessarily raises the very small probability of "firefighter arson".

Only one article by *The Age* (Franklin, 2012) presents some explanation as to why being a former CFA volunteer may be relevant. *The Age* article reports that Mr Sokaluk's application to the CFA was rejected because Brendan "had been involved in some things that were of concern," but no description of the concerns was given. The article goes on to state that "nothing was done by way of either punishment or treatment" despite Mr Sokaluk being spotted "near fresh grass fires and the like" over the next two decades strongly implying that Mr Sokaluk was responsible for the fires. Mr Sokaluk, it was reported, "had a thing for fire and lots of people knew it." (Franklin, 2012, p. 25). Thus, *The Age* presents a theory that Mr Sokaluk was a "firebug" (p. 24) which explains his application to the CFA, his proximity to small grass fires over a 20 year period and finally lighting the Churchill Fire.

To bolster the firebug theory *The Age* interviewed an expert on the psychology of arson. The arson expert

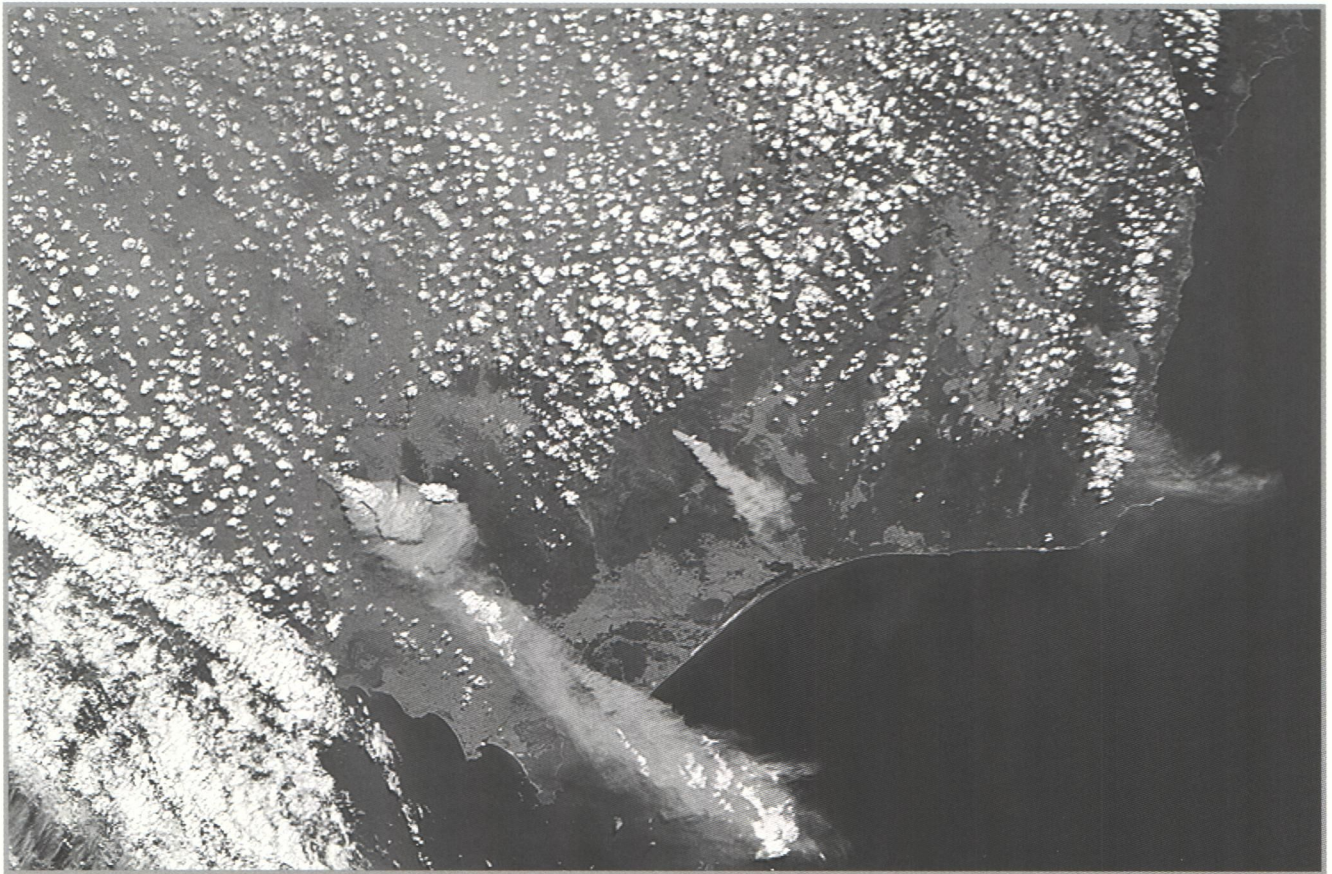
refused to discuss the specifics of Mr Sokaluk's case preferring instead to talk in generalities such as "the stock-standard arsonist is an outsider...pretty much helpless and hopeless", that fires confer a sense of power, demand attention to them and a chance to play the hero, and that the town usually knows who the arsonist is straight away (Franklin, 2012, p. 27). In a breathtaking stretch of logic Franklin nevertheless thought he could apply this directly to Mr Sokaluk and concluded that, "the court has now established," that the blaze was Brendan's "creation, a born loser's quest for omnipotence" (Franklin, 2012, p. 27).

"... it is not possible to present a fully comprehensive or empirically based classification scheme or typology of bushfire arsonists at this time"

However, this conclusion is not based on this expert's professional opinion in this particular case since she never met Mr Sokaluk. The article also omits any reference to a recent review of the literature on bushfire arson which states "Given the relative lack of literature specifically addressing arson in bushland settings, it is not possible to present a

fully comprehensive or empirically based classification scheme or typology of bushfire arsonists at this time" (Willis, 2012, p. 95). This is probably why the CFA "does not gather or hold information about whether or not our members have pyromania traits of histories, or suspected of having the capacity to deliberately light fires" (Dunn, 2012c). Thus, *The Age* is drawing a conclusion about Mr Sokaluk that even the CFA would not make.

Furthermore, it is a stretch to argue that Mr Sokaluk committed arson in 2009 because of something that happened some 20 years earlier. However, *The Age* suggests just that in stating that Mr Sokaluk's email to Crime Stoppers alleging the fire was lit by a rogue member of the local CFA unit was "Payback, perhaps, for the brigade's rejection all those years before" (Franklin, 2012, p. 27).



**7 February 2009 MODIS Aqua satellite image of smoke plumes from bushfires burning in Victoria
National Aeronautics and Space Administration (NASA)**

Mr Sokaluk as “Mass Killer”

Mr Sokaluk is described as “Victoria’s worst convicted mass killer” (Carlyon, 2012) and as Victoria’s “worst killer” (AAP, 2012c). Judge Coghlan however, stated he did not believe Mr Sokaluk intended to kill anyone (R v Sokaluk).

While *The Age* ascribed the deaths from another Black Saturday fire at Maryville to the “dumb malevolence of fickle winds, which wheeled the fire’s main body on its flank” (Franklin, 2012, p. 24) there was no mention of a similar wind change in the Churchill Fire. Initially the wind was in a SE direction but “at 6pm there was a wind change which led to truly catastrophic consequences. Prior to that time, nobody had been killed by the fire” (R v Sokaluk, p. 5). When the wind changed to a SW direction it also increased its speed with gusts up to 70kph. A few kilometres of fire rapidly became a 15 km fire front moving towards five townships in which 10 people lost their lives (R v Sokaluk, 2012). Thus, it is more accurate to talk about a “killer wind” than to call Mr Sokaluk a “mass killer.”

Another article presented a map of the fire area with the caption “Sokaluk’s path of destruction” (Carlyon,

2012). The caption therefore, blames the fire’s destruction on Mr Sokaluk as if Sokaluk actually controlled the wind.

Admittedly this is a somewhat academic distinction for someone who has lost a loved one to the fire and believes the fire to have been deliberately lit, but it is a distinction that a journalist should be able to draw and not doing so is prejudicial to Mr Sokaluk.

Character Assassination

Following Mr Sokaluk’s conviction these two newspapers unleashed a torrent of extremely negative opinion of Mr Sokaluk taken from interviews with local Churchill residents. The *Herald Sun* (Carlyon, 2012) said Mr Sokaluk was a suspect within minutes; that the crime had an instant face, “that weirdo with that car”; that death threats still whistle across the charred hills; that Mr Sokaluk sometimes pretended to be more impaired than he was; that he is as cunning as a fox; that he has “weird” conversations with his neighbour; and that Mr Sokaluk would listen to tapes of Bob the Builder or Thomas the Tank Engine.

Franklin, (2012) added further comments from people interviewed that referred to Mr *continued page 6*

Sokaluk as “sly” and a “devious, lying, evil prick” and referred to his sentencing as cleaning up, sorting out and sweeping away the “last of Black Saturday’s rubbish” (p.25). Carlyon (2012) used very negative image when he wrote “The undergrowth is again thick and twitching with unseen life. One thinks of snakes.” Franklin (2012) concluded that Mr Sokaluk has an “underlying toxic personality” and one day after Mr Sokaluk’s conviction, the *Herald Sun* headlined “Brendan Sokaluk—the boy who played with fire” (Carlyon, 2012). Mr Sokaluk was 42 years old at the time.

Mr Sokaluk’s courtroom behaviour was also used against him as it is reported “everyone agreed that Sokaluk looked decidedly odd”

(Carlyon, 2012) and “He applied himself to a notepad. Red pen, then blue, then red pen. His link to the dramas playing out around him, about him, seemed remote” (Carlyon, 2012). Furthermore, Mr Sokaluk “appeared oblivious to what was going on” (Petrie, 2012c) and “looked impassively at the ceiling” (Dunn, 2012a) during sentencing. There is little recognition that courtroom procedure may be hard to follow when you have autism and an intellectual disability.

One day after his sentencing, the *Herald Sun* printed Brendan’s full name in its headline “Brendan James Sokaluk jailed for Black Saturday fire that killed 10 people” (Dunn, 2012a) and even framed a head and shoulder shot of Mr Sokaluk inside a charred hole in a sheet of paper. *The Age* added Mr Sokaluk’s home street name (Franklin, 2012). Publishing a person’s full name, street name and stating that Mr Sokaluk “will be among us in the years to come” (Bezzina, 2012) has a very ominous undertone and could be seen as tacit approval for vigilante justice.

Noticeably absent from these descriptions is any positive information relating to Mr Sokaluk. For example,

“learning to ignore Brendan Sokaluk was a life skill an entire town believed it had mastered”

that Mr Sokaluk has a strong interest in gardening and worked as an assistant landscape gardener for 15 years at the Churchill Campus of Monash University. This is inconsistent with a description of a person who would deliberately start a bushfire that destroyed the very plants he worked with for many years. While Mr Sokaluk’s scavenging of scrap metal may fall short of being called a recycling business it nevertheless shows some enterprise, and keeping a 35 year-old car in work-

ing condition is not an insignificant achievement. It would also have been relevant to point out that Mr Sokaluk had no prior criminal history.

When *The Age* states that “learning to ignore Brendan Sokaluk was a life skill an entire town believed it

had mastered” (Franklin, 2012) it does not go on to discuss how and why such a situation could arise. Does this say something about the town of Churchill or Mr Sokaluk or both?

Autism and the “Comfort of Fire”

The Age (Franklin, 2012) consulted the Executive Director of Autism Victoria for an opinion on the case. The Director refused to address specifics of this case but he believed that from what he had read in the papers that Mr Sokaluk “would seem to fit the case [of autism] like a glove” (p. 26). Thus, Mr Sokaluk’s imitation of his neighbours, his inept conversations, and drawing comfort from “activities that can only mystify the rest of us” (p. 26) are highly consistent with a diagnosis of autism. Remarkably, Franklin (2012) concluded on the basis of this opinion that “Sokaluk’s comfort appears to have been fire” (p. 26). This conclusion is highly speculative and lacks evidence that directly points to Mr Sokaluk drawing comfort from fire and is made despite the expert specifically avoiding any comments connecting lighting fires and autism.

Lightness of Sentence

The *Herald Sun* strongly disagreed with Judge Coghlan's sentencing of Mr Sokaluk stating that the sentence "is so manifestly inadequate it beggars belief" (Bezzina, 2012). Once again, the paper is siding with the prosecution who have appealed the sentence as being "manifestly inadequate" (Dunn, 2012b).

Conclusion

I conclude from this analysis that *The Age* and *Herald Sun*, two major Melbourne newspapers, were aligned with the prosecution in their extremely one-sided and negative portrayal of Mr Sokaluk. This may be seen in the repeated use of the prejudicial phrase "Former CFA volunteer", referring to Mr Sokaluk as a "Mass killer", and agreeing with the prosecutor that the sentence was much too light.

Moreover, theories provided to explain Mr Sokaluk's arson conviction, namely that Mr Sokaluk deliberately lit two fires because he was a disgruntled former CFA volunteer; because he had a "thing for fire"; and because fire provides comfort and security for him, lack direct evidence and are speculative at best. In addition, the lack of a fair and balanced portrayal of the nature of autism and intellectual disability and of Mr Sokaluk's life experience goes against a fair and reasonable appreciation of Mr Sokaluk.

The Age and *Herald Sun* have done a disservice to people with disabilities in this case.

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From inclusive accessibility to exclusionary complexity:

The communications technologies trajectory



Fran Vicary

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Brisbane, Australia



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Technology has moved from an enabler of people with disability (when simple devices such as television remotes and press button telephones facilitated independence for many) to having a focus on complex devices, modes of access and multi-media interfaces that set up an exclusionary paradigm where only the most able benefit.

The World Wide Web Consortium (W3C) developed web page standards for internet and mobile accessibility which promotes the web as an enable of human communication for all, regardless of intellectual or physical capacity, hardware and software, specific infrastructures, languages and cultures, and where people live in the world. Website design to include easy access for people with disabilities is possible and not necessarily costly (Lennox, Edie, Taylor, Rey-Conde, & McPhee, 2009).

Exclusionary technology showcases ablest design. Inclusionary communications technologies adopt universal design principles (Wong, Chan, Li-Tsang, & Lam, 2009).

Newer digital communications technologies are often marketed as revolutionizing the lives of people, but current design distinguishes more profoundly between abled and dis-abled (Moser, 2006).

New communications technologies are about the economy of profit rather than the economy of need, meaning that those who have more resources are able to access new communications technologies more readily. (Lupton & Seymour, 2000) Upgrading from old to new can be costly. Technology is increasingly more complex and costly, and as such it becomes more exclusionary.

Disability funding can constrain access to communications technologies for people with disability who are economically marginalised. Because of the limited scope and availability of funding, consumers do not have access to the communications technologies they require when they require it. Many consumers are forced to purchase their own devices which are not only costly but in fact, due to their design for the general market, may not suit the person's needs.

Laptop computers and smartphones are developing rapidly. However, many do not have stylus support for those who cannot use their hands, or sophisticated hot finger support for those who cannot use more than one hot-finger at a time. Many devices are not robust and if dropped they scratch or break easily. Many devices require high levels of dexterity to hold, grip and manipulate.

Monitors and visual representation devices classically have limited depth which excludes people with depth-perception difficulties including people with cognitive impairment, people with Parkinson's and other neurological disorders. The text-based nature of both keyboard or mouse driven devices and touchscreens exclude people with limited literacy due to the impact of their impairment, e.g. people with acquired brain injury, or intellectual disability and low levels of education.

The intrusion of these technologies into things as basic as buying groceries and having to process your own purchases raises huge barriers and prove that the design guidelines for technology are failing a significant portion of the population.

Early communications technologies have enabled people with disabilities whilst touchscreen technologies potentially exclude. We strongly advocate for access standards or at least design guidelines to be implemented so that future technological developments are accessible to all and can benefit those who are most often excluded from social and virtual interactions.

Rather than assisting people and augmenting community interaction, current communications technologies are moving away from being easily accessible to exclusive use by those with the skills, dexterity and money to navigate these devices and to upgrade them on a frequent basis (Li-Tsang, Yeung, Chan, & Hui-Chan, 2005). We urge designers to remember those with limited means and those who require innovative design. We look forward to a new age where aesthetics and access collide and result in a beautiful explosion of new communications technologies that meet the needs of all of the population.

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The screenshot shows the homepage of the Australasian Society for Intellectual Disability (ASID). The header features the website URL 'www.asid.asn.au' and the ASID logo with the tagline 'research to practice'. A navigation menu includes links for Home, Publications, Regions, About, News, Conferences, Events, and Pay Invoice. A search bar is located in the top right corner. The main content area is divided into three columns: 'Upcoming Events' (announcing office closure for the festive season), 'Welcome to ASID' (providing contact information and a list of benefits for members), and 'Latest News' (highlighting NDIS feedback and support, and the 2012 NSW/ACT Disability Support Professional Recognition Awards).

New Zealand Well Done New Zealand!!!



Western Australia

by Chris Yates

ASID WA is finishing the year strongly and continues to provide and build a range of opportunities for those with an interest in intellectual disability.

Our Regional Conference was held on September 7 and it was a resounding success both in terms of the range of important presentations, the level of interest and the feedback received. Many people commented on the welcome to country, the Minister's opening and the quality of the keynote and concurrent presentations. There was an overwhelmingly positive tone to the feedback and a strong endorsement of both the Health for Living theme and the focus on the particular needs of people with an intellectual disability.

Our keynote speakers were Professor Nick Lennox from the University of Queensland and Dr Linda Goddard from Charles Sturt University and there was also a really wide representation of local researchers and practitioners. One of the most interesting presentations related to a 'study in waiting' which is the WA Study of Health and Intellectual Disability (WASHID) which will be led by Errol Cocks and be a broad based study – ASID WA will watch and support this project with interest.

After the conference our AGM was held and we continue with a strong and stable Regional Council and executive. One notable change was that Sue Peden stepped down from the role of treasurer after many years of service in a variety of roles at both Regional

and Australasian level. Sue's contribution has been truly amazing and will be duly recognised at an Australasian level at an appropriate time.

As part of the AGM and our regular council meetings we are reviewing our strategic plan and we will be going to our broader membership to provide an update and set some future directions early in the new year.

Our final event for this year is a series of three half day workshops which we are presenting in partnership with the Disability Services Commission. They will feature ASID's own Professor Christine Bigby and have been scheduled for late November. The topics are:

- **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**

Just so that we don't rest on our laurels we have also recently had our 'kick-off' meeting to begin planning for the ASID Australasian conference to be held in Perth in 2014.

Tasmania

by Ben Crothers

The last few months have seen a lot of activity focussed on the National Disability Insurance Scheme in Tasmania including DisabiliTEAs being held around the state on October 26th, regular networking meetings focusing on NDIS related topics, the visit of Prime Minister Gillard to Cosmos Recreation Services to speak with service users, and the commencement of a user consultation process by the NDIS Launch Transition Agency.

Autism Tasmania capped-off an excellent year of professional development events with a visit from Professor Tony Attwood who presented alongside Dr Michelle Garnett on Cognitive Behaviour Therapy as a strategy for self-regulation of feelings and behaviour in people with Autism Spectrum Disorder.



update

Finally, ASID Tasmania welcomes the recent appointment of Kirsten Foss as the Disability Services Senior Practitioner for the state. The role of Senior Practitioner replaces the department's Disability Services Ethics Committee, one of many changes heralded by

the Tasmanian Disability Services Act 2011. While the role broadly covers the promotion of quality disability services provision, it has the specific brief of monitoring and investigating restrictive practices and interventions.

Victoria

by Trevor Skerry

Greetings from the ASID Vic committee members.

The last few months have been a very busy time for the ASID Vic committee members. We have had an injection of new members and with this comes new energy, experiences and outlooks. As a group we have formally responded to the NDIS and raised a number of concerns with the current document in relation to access and equality for not just people with disabilities but in particular people with an intellectual disability. This was led by Christine Bigby from La Trobe University and her work in pulling together the ideas of the committee was fantastic, as you could imagine undertaking this task not only required skills in diplomacy but also skills in juggling and other balancing feats!

We are well on the way to achieving the first of our many goals for ASID Vic for 2012. The goal of becoming a 'meeting place of ideas' for the coming together, expression and contribution of all perspectives interested in people with an intellectual disability has seen ASID Vic support the Office of the Senior Practitioner in running the first in hopefully a series of "emerging practice seminars". The first in the series is titled "Fostering Quality of Life and Goal Mastery for Individuals with Significant Disabilities" and will be held in Melbourne on the 12 and 13th of November 2012. Please refer to the ASID Vic web page for more information on this.

The work undertaken with the OSP will hopefully be a strategic and ongoing relationship.

The notion of strengthening strategic alliances and raising the profile of ASID Vic is also reflected in the backgrounds of the new board members. We are fortunate enough to have representation from RMIT University, La Trobe University and Ballarat University on the current board. This academic and research perspective I believe will work well with the strong representation from those currently working in the field of disabilities who also make up the board. Currently we have representation from the Department of Human Services, Wesley Mission Victoria, SCOPE and the Mental Illness Fellowship of Victoria. This diversity of experience brings a new level of excitement to monthly meetings as we share our views and individual perspectives on our work and how we can best place ourselves to be active commentators on the issues related to working within the human service sector. Over the next few months we aim to also include profiles of the board members so you can see the interests and background of those on the committee.

So in closing while the last few months have been a time of change the future looks exciting and I am glad to be part of a wonderful team made up by very passionate and committed people.

NSW & ACT

By Tina Purdon

Despite the year drawing to a close, the NSW / ACT Regional Committee is continuing with a busy schedule supporting local research, recognising the efforts of those working in partnership with people with disabilities and planning for the Australasian 2013 Conference.

This year's Regional Conference – *Through the Looking Glass* was held in August and attended by 150 people. We were pleased to hear from John Della Bosca, Campaign Director for Every Australian Counts, in preparation for the NDIS, and Professor Roger Stancliffe with the keynote address around 'Outcomes Measurement'.

Attendees were also informed of local research to practice initiatives including a number of projects where people with disabilities, academics, researchers and service providers are working in partnership and achieving great things. We also heard *continued page 12*



some engaging presentations on support for staff and carers including mindfulness training for staff and working across disciplines. A focus we will continue into the future commenced as we looked at support in regional and remote communities and how we can ensure the same high standard for people outside of metropolitan areas.

As in previous years, a highlight of the event was the presentation of the NSW / ACT Disability Support Professional Award 2012. We are pleased to announce the following Award recipients;

John Corradin of Nepean Area Disabilities Organisation (NADO) is the Award recipient for a “professional working in the sector for 3 years or more”. John was an outstanding nomination - “it is not an exaggeration to say that the co-ordinators wish they could clone him!”

Paula Schramm of Lorna Hodgkinson Sunshine Home is the Award recipient for a “professional working in the sector for less than 3 years”. Paula was nominated as a professional who “encourages people to be more involved and assertive in all aspects of their lives,... is enthusiastic about her key-worker role and is a great communicator”.

This year the Selection Committee decided to also issue a third Award of ‘Highly Commended’.

Casey Gray of House with No Steps was recognised for her “very strong sense of social justice...Casey has developed a pen pal program targeting people living in isolation and there are now 50 people in this program”.

Do you know anyone who would like a penpal?
- Casey is keen to expand the penpal program – currently reaching people with disabilities from the coast to the outback, and invites contact from anyone interested in finding out how they can get involved. Please email Linda Ward, the NSW / ACT Secretary lindaward@sunshinehome.net.au Linda will pass your contact details on to Casey.

These Awards are only possible with the financial support of our sponsors for the past 3 years – Edmen Community Staffing Solutions and FACS – ADHC Met-South Region. We gratefully acknowledge this support and thank our sponsors.

We are currently seeking sponsors for the Awards for the next three years. If you would like to find out how you can support this worthwhile Award – recognising

the outstanding efforts of our fabulous frontline support staff, please contact Tina Purdon to discuss – tpurdon@hwms.com.au

We also held our AGM in August and are pleased to welcome Angela Dew and Hayley Purdon - newcomers to our Regional Committee. Angela has a particular focus on working with people in regional and remote locations. Hayley is our 2011 Award recipient and brings to the Committee the voice of the next generation of disability professionals. Your NSW / ACT Regional Committee has Dr. Vivienne Riches as President, Dennis Robson as Vice President, Linda Ward as Secretary and Sharon Duffin will be our Treasurer.

We are very excited to be the hosting next year’s ASID Australasian Conference in Sydney. The venue will be the Sheraton on the Park. Please set aside the dates of 6th to 8th November, 2013 as this is sure to be an informative, interesting and exciting event. Please check out the ASID website to keep an eye on progress. We thank the ASID Board for their support of this event.

ASID Conferences are organised by Regional Committees consisting of small groups of volunteers. It is a substantial task to bring together everything involved in an event for around 350 people. The NSW / ACT Regional Committee congratulates the New Zealand Conference Committee for hosting such a fabulous and genuinely inclusive event this year. The bar for ASID conferences has indeed been set very high and we are honoured to have received the ‘banner’ from NZ. We look forward to welcoming our New Zealand friends to Sydney next year.

Please contact Linda Ward (email address above) if you would like to be involved with the 2013 Conference in any capacity. We would welcome contact from sponsors, ideas people – anyone who thinks they may be able to assist.

Thank you to all who have supported our events this year, from our regional Conference to the Ethics Roundtable and other workshops. In the next issue we will announce the outcome of our new Research Seeding Grant program.

We wish all our colleagues across Australasia, a peaceful Christmas and a fabulous new year in 2013.

Queensland & South Australia

No reports ●

The sector makes steps towards ensuring the ethical conduct of research in service delivery agencies

Michele Wiese

(Northcott Disability Services & ASID NSW/ ACT)

Bronwyn Newman

(Northcott Disability Services)

Anna Green

(ANGLICARE, Sydney Diocese)

Adrian Lee

(Emeritus Professor, University of New South Wales)

Linda Ward

(Lorna Hodgkinson Sunshine Home & ASID NSW/ ACT)

Laura Hogan

(NSW Department of Family & Community Services & ASID NSW/ ACT)

Jack Dikian

(NSW Department of Family & Community Services)

For a while now, some of us in the disability sector have struggled with understanding the “rules of the game” for the ethical conduct of research. A hypothetical scenario highlights the range of potential challenges:

Phoebe works part time at a respite service, and is studying for a Masters degree in disability. Most of the children accessing the respite are young children and teenagers. Phoebe wishes to interview a couple of the teens for a university assignment. She indicated to you, her manager, that she would perhaps include some background information from their files and because she has “known these people for ages” might include some other information but isn’t sure yet. Phoebe has asked you if this would be okay.

This scenario raises a lot of questions: “Is it research?”, “If it is research, what approvals might be necessary?”, “If it isn’t research, what responsibilities still apply?”, “Consent issues?”, “Confidentiality issues?”...and many more.

We also have a variable understanding of the National Health and Medical Research Council Act 1992

(NHMRC Act). Some think it just applies to university researchers. However, the legislation requires that if we do research, or participate in it, our service delivery agencies must have proper policies and procedures in place.

As a first step to ensuring that we all understand the rules of the game, on 4th June 2012, ASID NSW/ ACT and Northcott Disability Services co-convened a forum, “*Research Ethics in to Practice: A Roundtable Discussion for Disability Service Providers*”. Forty five participants attended, representing government, not-for-profit agencies, and universities. The purpose of the forum was to discuss our collective understanding (and misunderstanding) of the legislative requirements, and plan a way forward so that the disability sector ensures that all its people, including clients, families, and staff, are respected and protected when they participate in, or, do research.

The Roundtable was chaired by Dr. Fabian Sack, an ethicist, and the keynote was offered by Professor Peter Sainsbury, current member of the Australian Health Ethics Committee and National Health and Medical Research Council. Both Fabian and Peter facilitated a wonderful day of learning, with participants quickly coming to the realisation that there is much to learn and do, to ensure consistency in the ethical conduct of research across the disability sector. Arising from the day, a working party was formed, and one of its tasks was to develop a set of easy-to-use guidelines that service delivery agencies could use to identify when the NHRMC Act applies, and then what to do.

The working party has so far met three times, and a document is fast developing. We aim to have the draft guidelines available to all participants of the Roundtable before Christmas, with feedback due in late February. When the feedback is included, we hope that ASID NSW/ ACT and Northcott Disability Services will again be able to host a forum, this time to launch the new guidelines. Watch this space, we’ll keep you posted!

Groups have Fun with Healthy Relationships Programme

by Dr Christine Wilson

How can you teach personal safety and violence prevention to people with learning disabilities and make it fun? After years of experience Kidpower™ NZ have devised an interactive programme called 'Healthy Relationships', that allows people to choose a preferred character and then work through one or more of 40 different scenarios. However, the interactive features of the programme are only the beginning. After gaining some familiarity with a scenario or two, individuals and groups are then encouraged to act out the situations with the help of a supporter (coach) who typically takes on the role of the protagonist ("the bad guy/girl"). Dramatic licence is a great thing! After a bit of practice the scenarios can be acted out using props and costumes, and for one enterprising group in Tasman (near Nelson), the dramas have been filmed.

each player (learner) having parts to play. As the videos progress, you can see the supporters gradually giving up their role as coach (in this case, to remind people of responses or lines) to the players (learners). The beauty of this series of videos is the clear progression of learning that is taking place. The most important thing of all, however, is the amount of laughter and fun that is occurring along the way.

The Health Relationships programme is perfect for small groups or individuals who have a high degree of interaction with other members of the public: for example at work, on the buses, at school, at the mall, in the park etc. It teaches people to recognise risky situations or situations that can create a high degree of anxiety both in one-self and in others as a result of one's own actions. Naturally, many of the scenarios refer to how to act appropriately in relationships with other people

"Marama" sets a clear boundary

The comic panels include the following text:

- Panel 1:** Adam wants to Hold Hands. Hi Marama! Adam tries to touch Marama's arm and hold her hand. Marama likes Adam but doesn't want to hold hands.
- Panel 2:** Please stop! Marama looks at him. She gives him back his hand. She uses her words to tell him to stop.
- Panel 3:** I just want to hold your hand. I said stop! Adam does not listen. Marama makes a fence with her hands. She makes sure that her voice says "Stop!", her words say "Stop!", and her body says "Stop!"

The Tasman group have given permission to talk about their experience of using the Healthy Relationships programme and can be seen pictured here with their group of supporters (who in this case are mostly Mums and Dads). They filmed several scenarios in action with

and how to turn down advances from others when they are not wanted; politely at first and then with some firmness. The programme also teaches how to get help and how to persist when help is needed.



The programme has been funded by the Ministries of Justice and Social Development. It has been used in New Zealand by a number of groups and individuals, particularly in schools, in vocational settings and in private situations.

As part of an independent evaluation, SAMS (an independent New Zealand based evaluation service in the disability sector) will revisit the Tasman group to talk about situations people in the group may have encountered and how they dealt with each situation. It is hoped that such discussions will allow us to continue to gather evidence of how useful the programme has

been, but also to allow the group to revisit the skills and discuss the real purpose behind the programme: keeping them and others safe.

Kidpower™ NZ is part of an international organisation dedicated to violence prevention. It traditionally provides workshops for children (“Kidpower”), teens (“Teenpower”) and adults (“Fullpower”) of the main stream population as well as with people who have disabilities.

Healthy Relationships can be found on the Kidpower website: www.kidpower.org.nz. ●

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

book review

INCLUSION: Battling for Disability

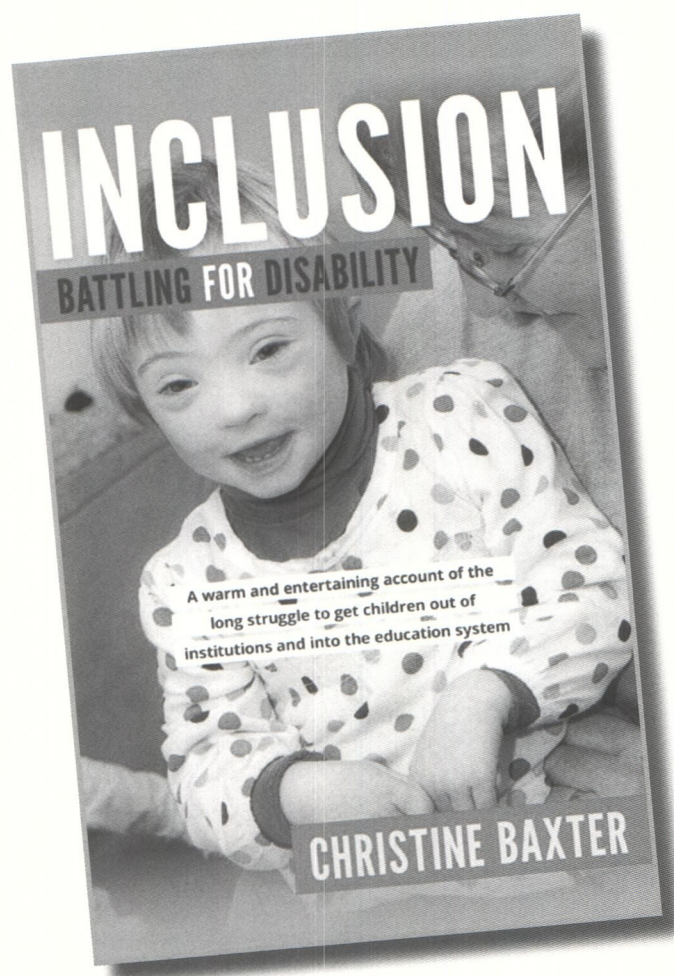
by *Christine Baxter*

review by *Keith McVilly*

This book documents the reflections of the author concerning her first hand experiences of working in disability services in Australia, over a period of 40+ years. The author writes with authority and authenticity. The book is written in a very accessible style for a lay readership, but is also suitable for a professional and academic audience.

The book will be of great interest to families, teachers and service personnel, as well as to those with an interest in the history of social policy and social reform in Australia. The subject matter, concerning the social inclusion of people with disability, is very topical in Australia, given on-going social policy developments at both a state and commonwealth level, including the recently announced plans for a National Disability Insurance Scheme (NDIS) designed to address many of the issues raised in the manuscript. Furthermore, the issue of social inclusion for people with disability is a matter of international concern, as exemplified in the recent proclamation of the United Nations Convention on the Rights of Persons with Disability. This book will make a very valuable contribution to the international literature on this topic – a literature which is dominated by accounts based largely on perspectives and events in the UK and USA.

Those already familiar with developments in the disability sector in Australia will recognise many of the places and people referred to in the manuscript. The controversies surrounding events at Kew Cottages and the St Nicholas Hospital were landmark events which brought to public attention the appalling treatment of children and adults with disability, and consequently sparked the political impetus for legislative and policy



reform across Australia. The subsequent development of community based accommodation alternatives to institutional living were a key social development in Australia, improving the health, wellbeing and quality of life of people with disability.

The author accounts her personal experiences with key figures in the disability reform agenda, such as Anne McDonald and Rosemary Crossley (author of the classic Australian novel, and later film, *Annie's Coming Out*), Ethel Temby (who gifted in perpetuity the Ethel Temby Scholarship Programme) and her son Rowan, as well as people such as Dr Cunningham Dax whose reforms of mental health services in Victoria provided a model for the rest of Australia to follow. The author recalls the controversies surrounding Facilitated Communication, which is again the topic of recent public debate in the disability sector, as well as therapeutic techniques such as the Doman Delacato patterning therapies. The important place of education in the lives of children with disabilities is strongly addressed. At a time when inclusive education is again being debated on the public agenda, it is sobering to be reminded that only a generation ago people with intellectual disability had no access to the school system.

The overarching theme that runs through this manuscript is the persistent search by parents and people

with disability over many decades for inclusion and a normal life. The author has captured the facts and the emotions, and presents these in a way that causes the reader to reflect on both history and humanity. As Australia debates what it means to be an inclusive society, as it questions the processes of deinstitutionalisation, and contemplates the radical reform agenda of the NDIS, 'INCLUSION: Battling for Disability' arises as a timely reminder of where we have come from and why we must continue the revolution in the interests of people with disability, their families and the integrity of our community.

The Reviewer:

Assoc. Prof. Keith R. McVilly PhD.
Principal Research Fellow – School of Psychology,
Faculty of Health, Deakin University
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Tel: 61 -3 97629100 Fax 61- 3 97629200

The Author:

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The author is a sociologist and former teacher, disability service advisor, UNESCO consultant in special education and senior lecturer in the Institute of Special Education and Disability Studies at Deakin University. Following retirement, she continues her advocacy work for people with disability and their parents and as a writer. Feedback is very welcome. ●

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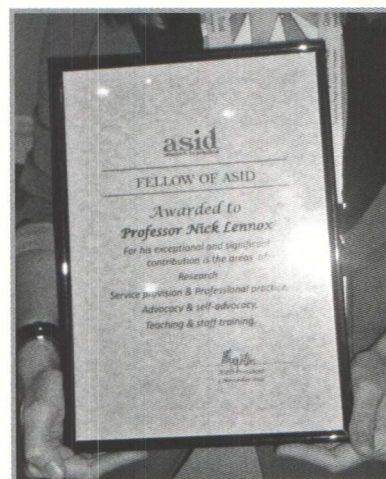
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ASID Annual Award Presentations

2012



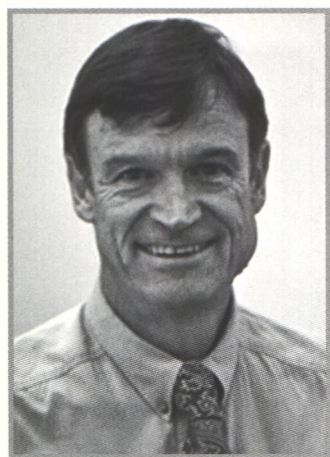
Fellow of the Australasian Society for Intellectual Disability.

Professor Nick Lennox was awarded the honorary title of 'ASID Fellow' in recognition of his significant achievements working on behalf of people with intellectual and developmental disability. Prof Lennox is a researcher, educator, advocate and clinician. He has specialised in the health of adults with intellectual disability since 1992. He trained in general practice and also for a time in psychiatry.

He has developed several interventions to improve the health of people with intellectual disability. They include:

- the CHAP (Comprehensive Health Assessment Program) review
- the Ask health diary
- the first "whole of life" handbook on health people with intellectual disability
- a dual diagnosis educational kit.

He has been instrumental in the IASSID (International Association for the Scientific Study of Intellectual Disability) ratification of health guidelines and has successfully advocated for systemic change at local, state, national and international level. This includes the adoption of the CHAP health review process by most state governments and many NGOs across Australia and overseas.



He has also been instrumental with others in the successfully advocating for a health assessment Medicare payment system to support GPs to perform these assessments on people with intellectual disability.

Journal of Intellectual and Developmental Disability Awards

The official journal of the Australasian Society for Intellectual Disability (ASSID) is the Journal of

Intellectual and Developmental Disability, co-edited by Dr Ian Dempsey and Professor Susan Balandin.

JIDD is a peer reviewed journal which is published quarterly and is listed on both Medline & Web of Science.

The journal is also available on-line from Vol. 1, 1970

An added benefit of ASID membership for both full and student members is electronic access to both current and back copies of the journal.

On behalf of the ASID Board, the Journal Editors award an annual "Australasian Research Prize" at the Conference for the paper by an Australian author(s), that is published in the Journal of Intellectual and Developmental Disability in the current volume and which best meets the following criteria:

- i. a report of high quality innovative and/or practical research;
- ii. has potential for positive changes to the quality of life of people with intellectual disability

Additionally, the Editors award an annual "International Research Prize" for the paper by an author(s) of any nationality, that is published in the Journal of Intellectual and Developmental Disability in the current volume and which best meets the following criteria:

- iii. a report of high quality innovative and/or practical research;
- iv. has potential for positive changes to the quality of life of people with intellectual disability.

The International Research Prize 2012

was awarded to **Professors Yueh-Ching Chou** and **Zxy Yann Jane Lu**. Yueh-Ching Chou is Professor with the Institute of Health and Welfare Policy, National Yang-Ming University, Taipei, Taiwan. She has been working with people with ID and their families for almost 30 years since having worked as a care worker in an institution for people with ID. Zxy Yann Jane Lu is a professor of the Institute of Clinical & Community Health Nursing at the National Yang-Ming University in Taipei, Taiwan. She obtained her PhD in nursing from the University of Michigan in 1990.

upcoming events

29 - 30 April 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
6 - 8 Nov 2013	48th ASID Annual Conference <i>"Our Time" to celebrate the future of person centred disability services</i> 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

The Australasian Research Prize 2012

was awarded to Professors Stuart Einfeld and Christopher Doran.



Professor Einfeld is the Chair of Mental Health, Faculty of Health Sciences, University of Sydney, and Senior Scientist at the Brain & Mind Research Institute, University of Sydney.

His research interests are in the area of child and adolescent psychiatry and developmental

disabilities, particularly "behaviour phenotypes", or the behavioural concomitants of genetic syndromes associated with developmental disabilities.

Professor Christopher Doran is currently affiliated with the Hunter Medical Research Institute, the University of Newcastle and the Hunter Valley Research Foundation.

Professor Doran holds the qualifications of Bachelor of Economics (Hons, majoring in econometrics) and Doctor of Philosophy (PhD, Newcastle, in health economics).

Professor Doran is a Health Economist with extensive experience in collating data used to evaluate health



interventions and guide policy. He specialises in econometric analysis; economic evaluation including cost benefit analysis, cost effectiveness analysis and cost utility analysis; cost of illness studies; pharmacoeconomics; and assessment of health technology.

ASID Research Award

was awarded to Nathan Wilson and Patsie Frawley from La Trobe university and the University of Sydney to support their research into issues regarding sexuality during the transition to adulthood for young people with an intellectual disability, framing the tension between unwanted risk and promoting a healthy lifestyle. ●

Congratulations and Best Wishes to all Award Winners.

"Our Time"



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



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