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IDA

Intellectual Disability Australasia

Magazine of the Australasian Society for Intellectual Disability

asid
research to practice

*creating safety
iassid in Halifax
my eRecord
DSW conference
ASID 2012 keynotes*

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front cover:

Victoria Gardens - Halifax IASSID
by Craig McIver

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editorial



Welcome to the third issue of IDA for 2012. We are already counting down for this year's conference; only the second time that ASID has held its Board Conference in New Zealand. As I write, the program has just been published on the conference website and it is looking to be an exciting and stimulating program indeed.

So, if you haven't yet organized your registration, it's not too late, and there are always some excellent offers around, for your flights over to Wellington, if you are travelling from Australia.

The ASID Board had its annual mid-year meeting in Melbourne in May when further work on the implementation of the strategic plan was undertaken. In addition, board members considered information on issues of governance and accountability of the Board. Members noted that there are occasional contradictions between local state law and some of the regional constitutions which need to be resolved. It was agreed that a small working group would commence the work of reviewing the issues and report to the Board with recommendations for a way forward.

The current federated ASID was created in May 1995. Each region has its own constitution and is incorporated according to local legislation. ASID members are members of their local regional association and as incorporated bodies, regional ASIDs hold separate annual general meetings and manage their own affairs. Each region is entitled to nominate up to three representatives to become members of the Australasian Board, which is incorporated in its own right in Western Australia. Members of the board, although representing their regional association, are in effect the only voting members of the Australasian Board of ASID. The AGM is always held on the first meeting after the Australasian conference, when the office bearers are elected. There are a number of ex-officio positions, with three year terms of office, such as the editor of IDA.

In 1995, the ASSID newsletter published an open letter from then President, Greg Lewis, explaining the need to restructure the Australasian Society for the Study of Intellectual Disability (ASSID) into its current structure. Briefly, prior to 1995, ASSID was registered as a company, because there was no suitable legislation that allowed for the Association to be incorporated. Each region operated as a branch of the national association. The Australian government of the time, through the Australian Securities Commission, ensured that companies complied with

Creating Safety: How Risk Management Leads to Aversive Decision

Bob Bowen

CEO, The Mandt System, Inc.

Tim Geels

Director of Organisational Sustainability, The Mandt System, Inc.

Vaughan Bowie

Australian Coordinator, The Mandt System, Inc.



Bob Bowen

Abstract: Managing risk in human service settings has become a major part of how we do the work of supporting people affected by all forms of disabilities. Quality assurance in most organisations means risk minimization, and has led to services that avoid risk and also minimise growth in individuals served. Creating safety provides an alternative approach to risk management that can manage liability whilst promoting self-determination and choice at the same time. In this approach, the focus is on moving towards safety which will move away from risk whilst increasing self-determination and choice for individuals served. A methodology to structure safety at an organisational level will be presented by the authors

Key words: risk management, person centred planning, opportunities, dignity of risk

When human service providers hear the term “risk management” they almost always have similar responses involving the flight or fight decision making process. There is often a low level of anxiety present during risk management meetings, and the process of risk management is seen as onerous and a necessary evil. (1) The official definition of risk management in the Australian human services context is:

“Risk management involves managing to achieve an appropriate balance between realising opportunities for gains while minimising losses. It is an integral part of good management practice an essential element of good corporate governance.” (2)

The problem at hand is that the focus within most organisations is on minimising losses, rather than on realizing opportunities. As an example, the steps outlined in Work Cover guidelines to do *continued page 4*

editorial

continued

relevant legislation and regulations. It was noted that ASSID was unable to comply with the regulations as it did not operate as a company, despite being registered as such. To avoid the very real threat of being ‘de-registered’ and having all assets seized, the current structure was approved and separate associations formed regionally.

Needs change, however, and it is becoming clear that more thought needs to be given to the issues that we face in 2012 and onwards. Governance, accountability

and risk management are important matters for us all to consider. Watch out for further debate at both local and Australasian levels.

IDA will endeavor to keep ASID members informed of all developments in the coming year.

For now, turn the page and enjoy some of the interesting news and articles in the September issue of IDA,

Cheers, Sue

Creating Safety: . . .

continued from page 3



Tim Geels

risk management in an occupational health and safety context involves:

1. **Think** - about what may effect employees and others health, safety or welfare. This step is to identify hazards and assess the risk they pose.
2. **Talk** - with employees. Consult about matters that may effect employees and others' health, safety or welfare.
3. **Do** - what is necessary to make the workplace safe. Implement risk controls.
4. **Review** - and monitor OHS measures (ensure risk controls are effective) (3)

Lost in translation between the theoretical level, the state regulatory and funding level, and then at the organisational level, is that the focus is on risks to be avoided and not on opportunities to be gained. As an example, the New South Wales Council of Social Service states that risk management:

- Is a procedure to avoid any negative consequences and reduce potential .legal liability
- Seeks to address potential problem areas before they occur and creates a safer environment
- Is a process to test the effectiveness of measures to prevent events happening that may result in negative outcomes. (4)

Risk in human services occurs primarily because of the actions or inactions of carers, or by a desire on the part of service users to engage in behaviour deemed "risky." The very first case one of the authors had to deal with was with a man who had gotten a job as a custodian. He was to be at work at 7am, and asked if he could ride his bicycle. The supervisors' first answer was "no" as the bus would get him there at 6:50am, plenty of time to make it to work. He persisted, and asked again to ride his bike, in pleading tones. The supervisor relented, and that morning he was hit and killed by a drunk driver.

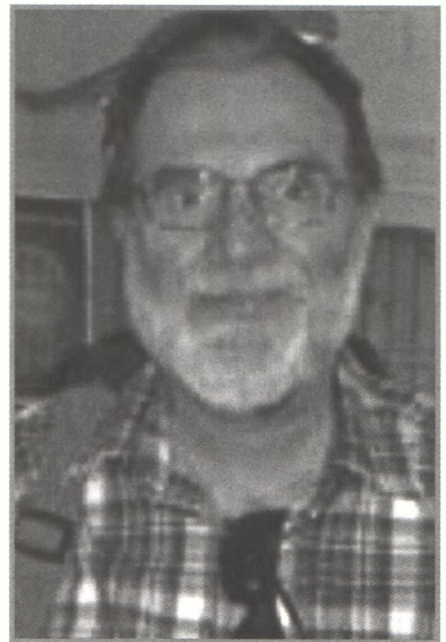
The driver's defense attorney questioned

why a man affected by an intellectual disability was riding his bicycle on a busy highway at 6:30 in the morning, why his carers and the supervisor were so reckless as to put this man in danger. There was an investigation by the state as to why this occurred, and the supervisor was grilled relentlessly in the newspaper and in the courts. The reason the organisation and the supervisor were not held to be negligent was that he had been through a bicycle safety course sponsored by the police department, was wearing a helmet, and was riding where he was taught to ride by the police.

In our zeal to avoid negative consequences in the process of managing risk, we often make or are tempted to make decisions that are aversive, although in a benign way. We just say "no" to requests from individuals as it is in their best interest, we tell ourselves. In managing risk, we ultimately avoid opportunities for growth.

One of the authors is the CEO of a consulting firm, and he states that "having been in executive positions in human service governmental and non-governmental organisations, I can tell you I never had my name in the paper or on a letter from a regulatory body for saying "no" to a service user. In the human service field, we do a great deal of training in person centred planning and the concept of dignity of risk, but the fact remains that our lawyers and insurance professionals tell us to focus not on the legal definition of risk management, but on the operational definition.

An operational definition is one which guides the operations of an organisation; in other words, how laws and regulations, ideas and ideals are translated into the policies and procedures which guide the day to day operations of an organisation. The NSW guidelines referenced above are similar in substance to guidelines



Vaughan Bowie

in America and Canada, and result in benign aversive interactions at best, and at worst, a denial of rights for service users. Whilst the legal definition and training given to organisational leaders focuses on the rights of service users and maximizing independence, the safety regulations governing safety for carers (Work Cover, Occupational Health and Safety) and safety for service users reward risk aversion and take support away from the phrase “supported employment and supported living.”

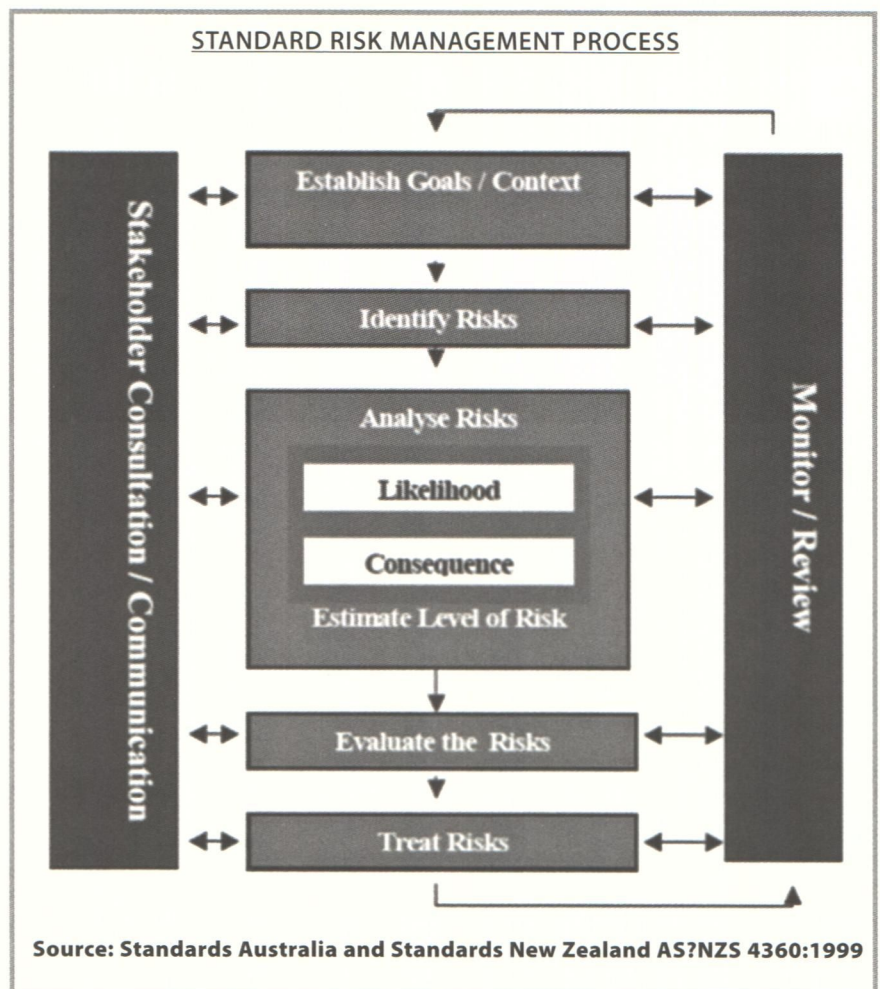
1. Establish the goals – he wanted to ride his bicycle to work on his first day to make a good impression. The supervisor wanted to ensure he got to work as safely as possible.
2. Identify the risks. Riding a bicycle on a busy street is inherently risky. So is driving a car. In a study of workplace violence in a *continued page 6*

A New Hope

In order to maintain the safety of all people and achieve the goal of maximizing independence for individuals served, a new approach to risk is needed. We need to use the definition in the Australian and New Zealand standards (1999) that risk and opportunity co-exist with each other. Most of the risk management guidelines and websites the authors reviewed for this article use the following steps in the diagram.

This model represents a standard of care in the industry of human services in New Zealand and Australia, and as such, is not subject to change. The authors would, however, make one clarification to the last point. Rather than “treat risks” we will prepare for them.

Analyzing the example of the man who wanted to ride his bicycle to work using this model results in the following:



psychiatric hospital in Finland, for instance, more people were injured driving their cars to work than were injured at work! (5)

3. Analyze the risk **and the opportunity**. Note the change here. Yes, there are risks, and they are fairly low. He has ridden his bicycle all over the city for 2 years with no accidents. There is a low risk and a high opportunity to make a good first impression with his boss and to feel worthwhile as a human being.
4. Evaluate the risks **and opportunities**. Again, note the change here. The opportunities in this example were deemed by the supervisor and the individual to as less important than the opportunities to be gained.
5. Prepare for the risk. Note the change here: instead of treating the risk, we are preparing for the risk. What skill sets do people need to have in order to maximize safety and minimize risk? What are the current skill levels relative to the planned activity? Are there any augmentative devices that can minimize risk in terms of communication, ambulation, manipulation, etc. In this example, the individual served had the skill level to ride a bicycle, and had successfully completed a bicycle safety class.

Had the supervisor in this example said “no” a death would have been averted in hindsight. But hindsight management is not possible, and by saying “no” to every opportunity we create aversive service delivery systems and aversive interactions between the stakeholders in the organisation. The legal question at hand here is this: when risk and opportunity are equally balanced, which is more important? In the present funding system, mitigating risk is seen as more important in our reading of Australian law and law in the constituent states. Under the NDIS it is possible that opportunity will be seen as more important than risk, given that individuals served will be seen as directing services and not just receiving them.

The last thing we need to do is change the name from Risk Management to Opportunity Enhancement. We want to enhance the quality of life for all people, regardless of their role in the human service system. Doing so will provide a framework for decision making that is based on the values we at ASID value for ourselves and most of all for those we serve.

Using this model to evaluate opportunities and risks jointly between service providers, service managers, risk managers, and most importantly the individuals we serve will provide a framework which can minimise risk, maximise safety and opportunity, and do so in a manner directed by the individuals we serve.

References

1. Rhode Island College, Digital Commons at RIC: Documentation in Social Work: Evolving Ethical and Risk Management Standards. Retrieved from <http://digitalcommons.ric.edu/cgi/viewcontent.cgi?article=1162&context=facultypublications> May 24, 2012
2. Paul Bullen Management Alternatives, retrieved from <http://www.mapl.com.au/risk/risk1.htm> 21 May, 2012
3. Ibid
4. New South Wales Family and Community Services, Department of Ageing, Disability, and Home Care: It's Your Business: Chapter 6, Risk Management, retrieved from http://www.adhc.nsw.gov.au/__data/assets/file/0009/228753/ItsYourBusinessChapter6RiskManagementWeb1.pdf 21 May, 2012
5. Pitkonen A, Kuivalainen S, Louheranta O, Repo-Tiihonen E, Kiviniemi V, Pekka O, Ryyananen JT (2011). A cluster randomized control study of seclusion and restraint in high security psychiatric care. Presented at the 7th International Congress on Violence in Clinical Psychiatry, Prague, CZ, October 2011. ●

IASSID World Congress, 2012 "A World of Potential"

9 to 14 July 2012
Halifax, Nova Scotia,
Canada

www.iassid.org

by *Keith McVilly*

photos by *Craig McIver*



**International Association
for the Scientific Study
of Intellectual Disabilities**

The four-yearly world congress of the International Association for the Scientific Study of Intellectual Disability (IASSID) was recently conducted at Halifax, in Canada. Nearly 1000 delegates were in attendance, including at least 70 from Australia and a further 10 from New Zealand.

There were numerous papers and posters by presenters from Australia and New Zealand, contributing to a rich and diverse programme. It was mentioned on more than a few occasions that the research output from Australia and New Zealand is incredible given our relatively small populations and limited resources compared to those available to many of our colleagues in the USA, UK and Europe.

Among the Key Note Speakers, representing the pride of Australasian research excellence, was **Professor Roger Stancliffe** from the University of Sydney, who reported on findings from research conducted in conjunction with colleagues from the USA on the topic of *Core Indicators and National Outcome Measures for Disability Services*. **Professor David McConnell**, formally of the University of Sydney and now at the University of Alberta, Canada, spoke on *the experience of marriage and family for people with intellectual disability*. Also, **Professor Roy Brown**, formally at Flinders University in South Australia and lately retired, spoke on the subject of *Family Quality of Life*.

Professor Christine Bigby from LaTrobe University at Melbourne was among a number *continued page 8*



Bird resting on the Titanic at Victoria Gardens

IASSID World Congress, 2012

continued from page 7

of people recognised with a Fellowship in IASSID. Fellowships are awarded on the basis of a person's *important contribution to the advancement of knowledge on intellectual disabilities, and their important contribution to the advancement of the work of the Association*. In addition to her prolific list of scientific publications, Chris has for many years been the Convenor of the IASSID Special Interest Research Group on Ageing.

Dr Kylie Gray of Monash University won the award for the Best Research Poster presented at the World Congress. There were a number of other members of the Australasian contingent whose contributions to research excellence were recognised with IASSID awards and travel grants. These included **Michelle Wiese** from the University of Sydney, and **Kitty Foley** of the University of Western Australia.

Australians and New Zealanders have continued to take a leading role in the work of IASSID, on the IASSID Council and as leading members of the various Special Interest Research Groups (SIRGs). Among these are: **Professor Gwynnyth Llewellyn** (University of Sydney), **A/Professor Robert Davis** (Monash University), **A/Professor Karen Nankervis** (University of Queensland), **Professor Monica Cuskelly** (University of Queensland), **Dr Rhonda Faragher** (Australian Catholic University), **Dr Jenny Torr** (Monash University), **Professor Susan Hayes** (University of Sydney), **Dr Chris Fyffe** (LaTrobe University), **Professor Nick Lennox** (University of Queensland), **Dr Sheridan Forster** (Monash University), **Mr Ian McLean** (Golden City Support Services), **Dr Fionna Rillotta** (Flinders University) and **A/Professor Keith McVilly** (Deakin University). Many thanks for flying the flags for Australia and New Zealand. Apologies to anyone missed off the list.

At the 2012 General Assembly of IASSID, conducted during the conference, there were a number of signifi-



Guard at Halifax Citadel



Sheridan and Curtis

cant amendments to the IASSID Constitution. Among these were a change in the name of the association, to now include reference to a further “D” recognising the association’s long-standing interest in and commitment to research in the broader field of ‘developmental disability’. Recognising the changing nature of IASSID’s membership, the former category of “Association Member” – of which ASID was one such association – has now been replaced with a more flexible provision for “Affiliation Agreements” with like-minded associations. This will provide an opportunity for ASID to negotiate with IASSID for a more individualised arrangement, better reflecting the interests of our membership.

Also during the Congress, **Professor Ian Dempsey** (University of Newcastle) and **Professor Susan Balandin** (Molde University College, Norway), as Co-Editors of our own ASID journal, the *Journal of Intellectual & Developmental Disabilities*, convened an international meeting of the JIDD Editorial Board. This was an important opportunity to bring together the interna-

tional expertise on the Editorial Board that marks our journal out as a world-leader in scientific publication in our field.

On a less serious note, the highlight of the social calendar was the “kitchen party” (conference dinner) which was a lobster banquet and bagpipe feast! Also those who did not do a harbour tour on “Toot the Tugboat” can’t claim to have experienced the best of what Halifax had to offer.

An important announcement that was made during the closing ceremony was the official declaration that the next IASSID World Congress is to be held at Melbourne, in August 2016.

Up-coming IASSID Conferences for your diary:

IASSID Asia Pacific Conference @ Tokyo, Japan, 22 - 24 August 2013

IASSID Europe @ Vienna, Austria, August 2014

IASSID World Congress @ Melbourne, Victoria, Australia, August 2016 ●

Queensland

by Morrie O'Connor

The Qld Branch of ASID has been busy organizing a number of interesting and relevant events, and has been especially dedicated to explore ways to engage with and provide services to members located outside of the greater Brisbane area. More information on these initiatives will be provided later in the update.

In August, ASID Qld partnered with QCIDD to present its first learning and development event for 2012. The well attended event featured a stimulating presentation by Dr Janet Hammill (Senior Research Fellow, FASD Scientific Research Centre, University of Queensland Centre for Clinical Research) who spoke about 'Fetal Alcohol Spectrum Disorders, Intellectual Disability and the Justice System: Is Alcohol our new thalidomide?'.

Plans are currently underway for the State Conference "Rights, Risks and Leadership", which will be held on 15 September at the Ipswich campus of the University of Queensland. We are pleased to announce Mr David Green (Co-author of 'Managing Risk in Community Services: A preliminary study of the impacts of Risk Management on Victorian Services and Clients') will be presenting one of the key note addresses. Expressions of interest for papers have been sought and the program for the day is taking shape. Updates and registration details will be posted on our website as they become available.

ASID Qld has also set the date for and is finalising plans for its Annual General Meeting, which will be held in the early evening, Thursday 4 October 2012. At this stage, we are looking to host a combined event of the AGM, guest speaker and light refreshments. More details about this event will be sent to members in September.

Michael Keates (President, ASID Qld) and Louise Young (ASID Qld Committee member) are planning an event in Townsville, North Queensland later this year to provide the opportunity for member networking and

to explore ways ASID can support rural and remote members and services providers.

The Committee has also had preliminary discussions about establishing a bursaries program for University post graduate students. We plan to explore this possibility later in the year and will provide more details as plans are confirmed.

Finally, ASID Qld is pleased to announce the appointment of Fiona Davis as a new member to the Committee. Fiona works at the Centre of Excellence for Behaviour Support at the University of Queensland, as the Principal Learning and Development Officer. We warmly welcome her to the Committee of ASID Qld.

South Australia

by Denice Wharldall

Our latest local event was two Workshops related to Individualised/Self-Managed Funding held on 19th July. We were presently surprised by the number of people who attended with over 160 during the day and over 50 people at the evening session. This is an indication of the intense interest in the topic. As South Australia has only formally had Individualised Funding for less than two years it was decided it was important to have a speaker from interstate were Individualised Funding was more established and as a result Maureen McLeish presented the Victorian experience from the perspective of a parent of an adult with a disability. For many in the audience Maureen's presentation was very reassuring as she demystified individualised funding and focused on how simply it can be from a family perspective. Many families reported feeling inspired by Maureen's presentation and a presentation by a local parent Ronni Wood and feel they now want to "give it a go".

There were also presentations related to the evaluations of two South Australian Projects and a demonstration of some simple tools and spread sheets to assist with the practical implementation of Individualised Funding

such as a budget plan that does the adding and subtracting for you. If you would like a copy of these tools please email Frauke Husner at Cara fhusner@cara.org.au and she will be happy to send you a copy of the tools and the evaluation report.

Our next event will be our Annual General Meeting on the 25th October at which we hope to have a lively debate on the protection of vulnerable adults from abuse.

Western Australia

by Chris Yates

ASID WA continues to provide a range of research to practice opportunities for members and people with an interest in intellectual disability.

On August 8 we held our Research Forum at Curtin University. The forum was a panel format with four presenters drawn from a range of areas putting forward ideas pertaining to research with a follow up discussion to see what might emerge.

Jackie Softly, a parent and advocate, spoke of the challenges and advantages of involving people with intellectual disability in research and engendering respect for the expertise of people with ID and their families

Jenny Bourke, from the Institute for Child Health Research provided information about some of the areas being researched at the Institute including qualitative studies asking young people with ID and their families about the transition to post-school options.

Errol Cocks, from Curtin University, described four of the current studies in the Centre for Research into Disability and Society including the study of individual supported living and the health disparities for people with ID, and access to health promotion and prevention programs.

The final panellist, Monique Williamson from DSC, stressed the importance of questioning assumptions and paradigms. She identified a range of current questions including

- How do we get services right for people who are difficult to support well?
- How do we get more people with intellectual disability, especially those with greater difficulties, into employment?
- Why are services disconnected from the needs and desires of consumers?

The first of the ASID WA research forums was well supported and raised many interesting issues for consideration. The committee is planning another forum early in 2013, which will cover a range of ethical issues which arise when researching with people with ID. This will be followed by a session in mid-2013 around recruitment strategies.

Looking further ahead this year's conference to be held on September 7 is almost upon us. The theme is 'Health for Living' and we look forward to welcoming Professor Nick Lennox and Dr Linda Goddard along with a host of local researchers to present keynotes, plenary sessions and concurrent sessions on the topic.

The day will conclude with drinks and nibbles followed by our AGM.

Tasmania

by Ben Crothers

The Tasmanian regional council welcomes the announcement of the state as a launch site for the National Disability Insurance Scheme (NDIS). The focus of the launch will be on services for people (many who would identify as living with intellectual disability) aged 15-24 – covering the key period of transition from school to employment, further education and training, and community participation, and the transition from childhood to adulthood, when typically many financial supports fall away.

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In response to this announcement, the Tasmanian council has qualified our strategic objective - to forge the interaction between intellectual disability research, policy and practice - by making explicit the focus on research relating to the NDIS trial's identified age range. The effective implementation of the NDIS trial in Tasmania, as well as the future implementation of the full scheme nation-wide will require quality research in relevant areas and ASID Tasmania is planning to be extensively involved in this.

Finally, This month we say goodbye to our long-standing treasurer, Craig Jones, who has contributed vastly to ASID Tasmania over the previous six years, including extensive work on the successful Annual ASID conference in 2009, and as a representative on the Australasian Board. We thank Craig for his contribution and wish him well in the future.

Victoria

by: Trevor Skerry

The start of 2012 has seen a number of dramatic changes to ASID Vic, Regrettably we say goodbye to a number of Regional Councillors this year. Firstly, Sam Murray resigned as President, member of the committee, DSW Conference Chair, and as a representative on the Australasian Board; his energy and commitment will be greatly missed. We also farewell Keith McVilly who has served both the Region and the Board for many years; Ralph Kober (Treasurer), Louise Mountford (Vice President), Erin Lindley and Jon Slingsby. The remaining ASID Vic Regional Councillors thank all outgoing councillors and staff for their involvement in ASID Vic.

2011-2012 has however been a productive time for the Region. ASID Vic continues to take up the challenge to reflect the strategic direction of the Board and the Region by honouring the goals set out in both the Region's Strategic Plan and subsequent Action Plan, particularly around diversity of activity.

A refocusing on activities in accordance with the goals stated in the Strategic Plan in terms of increasing the focus on the evidence base for work which honours the rights and needs of people with an intellectual disability; and correspondingly there will be a greater emphasis on workshops and events which reflect this aim.

The first of these events was a workshop presented by Associate Professor Douglas P. Boer from The University of Waikato. The workshop - "Risk assessment in disability services" occurred in May 2012. Dr Keith McVilly took the lead on this workshop which had a small but interested attendance.

The ASID VIC AGM was held on the 7th August 2012 and ASID VIC was fortunate enough to have Mr Bruce Bonyhady AM present on the NDIS. A really informative and interesting session and a great led into the AGM.

The reminder of 2012 will be an opportunity for experimenting, trying new things, evaluating and reviewing. The committee is very positive and excited about the new way forward and looks forward to seeing members new and old at the regional events.

NSW & ACT

New Zealand

No reports ●

My eRecord

How unique collaboration is creating consumer centred support for Queenslanders with a disability

from Jacqui Hawgood

Project Officer (National Disability Services)

**with input from members of the G8:
Centacare, Cerebral Palsy League, Endeavour Foundation,
FSG Australia, Life Without Barriers, Multicap,
Spinal Injuries Association, UnitingCare Community.**

Introduction

The fragmentation of health and personal records across providers is problematic for people with a disability, who typically engage with multiple service and health providers. Each provider may hold key information about a person's history, health status, support and funding arrangements, key relationships, and decision-making capacity. Barriers to accessing this information in a timely manner makes it difficult for individual organisations to efficiently and effectively meet the needs of service users as they live and engage with their community. This can result in delays in decision-making, duplication and inaccuracy in information management, and may cause unnecessary and repetitive consultations to obtain relevant information required for quality health care and support.

These issues are particularly concerning in the context of intellectual disability (ID), given that "individuals with an ID are often unable to fully articulate their needs or to comment on the adequacy of services" (Glasson & Hussain, 2008, pg. 285). In addition, service users and substitute decision makers (if required) generally do not have easy access to their own records and are dependent on service providers to supply them with personally relevant health and support information.

Concerns about the fragmentation of health information are reflected in a broader shift within the healthcare sector, in which electronic and Web-based health record systems are increasingly in use. These information technologies are driving improvements in quality, safety and access to health care, and include models that are consumer focused and controlled. The National Personally

Controlled Electronic Health Record (PCEHR) is one example that went live this year as part of the National Health Reform.

The logo for 'My eRecord' is displayed in a large, stylized, outlined font. The letters 'M' and 'V' are stacked vertically, with 'M' on top and 'V' below it. Below 'V' are the letters 'e', 'R', and 'e', which are also stacked vertically. The 'e' is on the left, 'R' is in the middle, and 'e' is on the right. The entire logo is enclosed within a thin circular border.

The Shared Electronic Record (Shared Record) project was initiated in Queensland to streamline current systems for gathering and sharing health and other personal information for Queenslanders with a disability. This project envisages the implementation of a shared record to enable privacy compliant sharing of personal data when and where it is needed. The Shared Record developed by Extensia, "My eRecord", aims to reduce duplication and improve service quality and continuity of care, so that each person has better health and lifestyle outcomes. My eRecord will also ensure consistency amongst service provider's systems and documentation, enable access to accurate information to provide better and more timely support, and provide a user-friendly record that interfaces with a broad range of structures across multiple sectors.

My eRecord was devised as two stages. Stage One is the development and customisation of My eRecord and this article covers the collaboration and reflections to date.

Conceptualising My eRecord for Queensland

My eRecord is a project of the “G8”, a unique collaboration of the eight largest non-government disability service providers in Queensland. The G8 was formed in order to share information and resources, work together to resolve common concerns, and present a unified voice on issues affecting people with a disability. Membership includes Cerebral Palsy League of Queensland, UnitingCare Community, Centacare, Spinal Injuries Association, FSG Australia, Multicap, Life Without Barriers, and Endeavour Foundation.

Consultation between the members of the G8 revealed a lack of capacity to share information about individual service users across organisations. Organisational processes and information systems were fractured and inconsistent, and a wide variety of disparate information forms were in use. Early on, a key objective was agreed: the individual (together with any required decision-making support) would be at the centre and control his/her healthcare and lifestyle support records. My eRecord aims to be person-centred and controlled, empowering the person to access their record and make informed decisions about which service and health providers can access and contribute to their record.

Setting up the Pilot

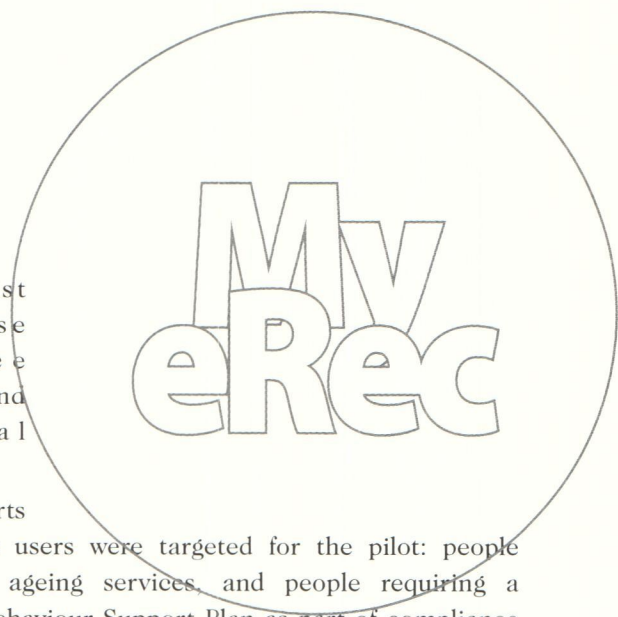
The G8 established a limited liability Company and the members contributed funds for licensing costs for the record, and the Queensland Department of Communities, Child Safety and Disability Services provided funding to employ a full-time Project Officer. The National Disability Service (NDS) was auspiced to hold these funds, and to provide office space and equipment for the Project Officer. An Advisory Group was set up for the project, consisting of selected G8 members and Chaired by the NDS. Three of the G8 organisations agreed to participate as pilot sites. Other stakeholder groups were engaged in planning, including the Office of the Adult Guardian, the Queensland Government

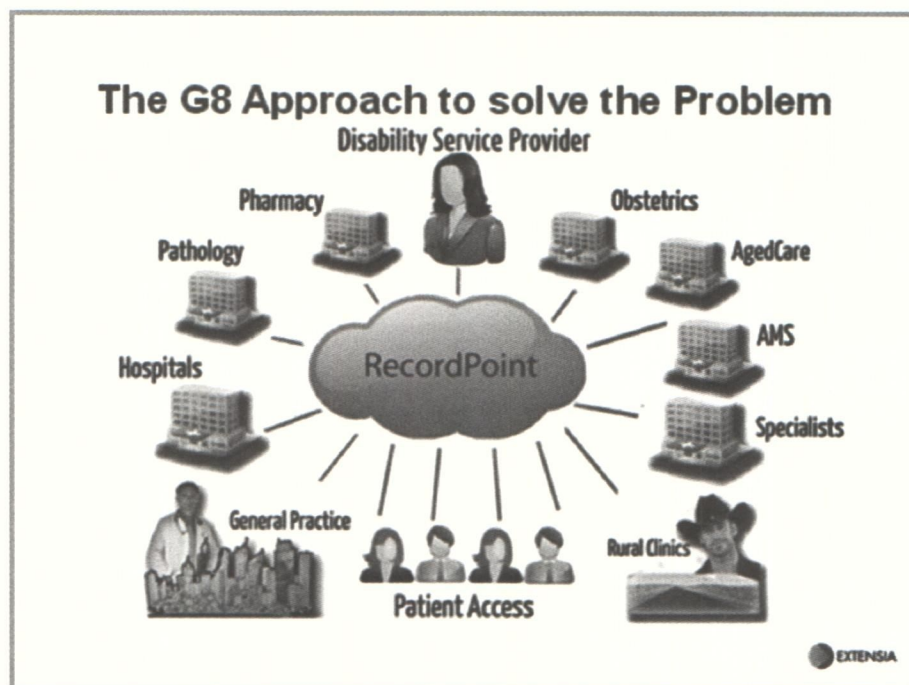
Specialist Response Service Team, and General Practices.

Two cohorts of service users were targeted for the pilot: people accessing ageing services, and people requiring a Positive Behaviour Support Plan as part of compliance with the Disability Services Act 2006 restrictive practices (RP) provisions. A major impediment for ageing service users transitioning from disability into aged care services is the lack of available clinical and general data in a form that assists Aged Care Assessment Team (ACAT) assessments and referrals. My eRecord would function as a central repository for information relating to health history, medications, allergies, diagnosis, assessments and care plans, and be able to be accessed by healthcare and disability service providers. For service users under RP, My eRecord could store Positive Behaviour Support Plans, avoiding the need to duplicate documents across organisations or to create multiple plans.

Extensia licensed their Shared Record “RecordPoint” and EPRX, as fully hosted and managed services. The G8 collaborated with Extensia to modify the record to suit the sector’s needs, and streamlined processes with some standardised forms and templates developed. Extensia delivered train-the-trainer workshops to familiarise service staff with record installation and updates, and the G8 developed unique branding. The service providers involved in the pilot applied for Medicare Site Certification, which was approved and installed before the record could be accessed.

As of 1st August 2012, 21 service providers have been trained in use of the record system, and 7 organisations have registered as Medicare Sites. Around 20 service users have been identified for the pilot, and to date, 7 have provided written consent. Of these, 4 have been





registered with My eRecord. Recruitment of service users, their GPs and other providers is ongoing, and service user information is uploaded as it becomes available.

Barriers Overcome

Developing a system that meets all the aspirations of the G8 is challenging. One critical task has been to construct and trial robust consent processes. In the international literature on electronic health records, security and privacy of information is one of the biggest concerns for consumers and providers (Horan et al., 2010; Kim et al., 2011). The My eRecord project aimed to build levels of access within the system to guard against unauthorised access and potential misuse of information. This depended on developing an understanding of different staff roles and the access privileges they would require.

Meaningful consent requires service users and their decision making supporters to understand the repercussions of allowing or blocking provider access to their record. This requires a certain level of "health literacy" and medical records are not always presented in a language that is easily understood, even by the highly educated (Horan et al., 2010; Keselman et al. 2007). This is compounded when information is managed by a system with which people are inexperienced (Horan et al., 2010). Future evaluations will need to assess the extent to which the My eRecord overcame these barriers.

Receiving support from medical providers is another challenge, given concerns about the functionality and risks of the recently launched national PCEHR (The Weekend Australian, June 30-July 1, 2012). Within My eRecord, efforts have been made to ensure that the service user's GPs understand its value, and that it will align with the National Health Reform. Ensuring the system is equipped with sufficient security to pro-

tect privacy is paramount. Once on board, GPs must install the software within their local clinical system, enabling My eRecord to be populated with client data. Ensuring a smooth interface between the two systems and reducing information duplication is critical for time poor GPs.

Design issues were inevitably encountered. Different providers have different information requirements collected using specially designed templates. Some of these templates have been retained within the current pilot, but it is hoped that these will be streamlined in Stage Two. Design also needs to consider the needs of service users. Specific functionalities to support accessibility for people with disabilities can include zoom text and audio features (Archer et al, 2011). For the pilot cohorts, plain-English explanations in addition to visual aids and images could be valuable. Finally, access to computers has proven to be an issue, impacting particularly on service users, but also some support staff.

Looking Ahead: Stage Two and Beyond

The pilot is scheduled for completion in October 2012, and further results will be available at a later point. With funding now approved, Stage Two will expand My eRecord to include additional service users' requirements, including aids and equipment, provision of housing and support for living arrangements, people with allocated self-managed funding, and those who want or require a Shared Record. It is hoped that the system can be expanded beyond the 8 original organisations. An independent evaluation will be undertaken to assess the impact for multiple stakeholders,

continued page 16

My eRecord . . .

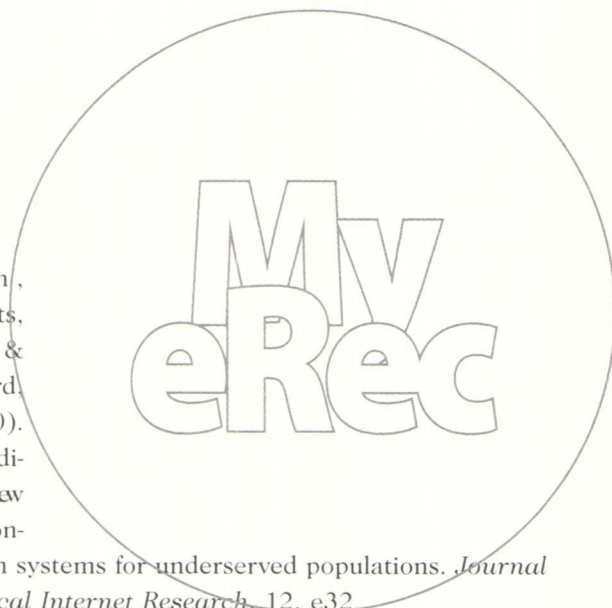
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and whether improved outcomes for service users have been achieved. Looking forward, the ultimate vision for My eRecord is that it includes all data relevant to a person's life. A comprehensive record of this type has clear potential to function as an interface between service systems, to "assist all stakeholders in the disability process through the coordination of services and supporting the disability community in obtaining customized services" (Tulu & Horan, 2009, pg. 9).

For more information, contact: Jacqui Hawgood (Project Officer – National Disability Services) at jacqui.hawgood@nds.org.au

References

- Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K. & Straus, S. (2011). Personal health records: A scoping review. *Journal of the American Informatics Association*, 18, 515-522.
- The Weekend Australian (June 30-July 1, 2012) *Sceptic's wary of risks and inadequacies*.
- Glasson, E. & Hussain, R. (2008). Linked data: Opportunities and challenges in disability research. *Journal of Intellectual & Developmental Disability*, 33(4), 285-291.
- Horan, T., Botts, N. & Burkhardt, R. (2010). A multidimensional view of personal health systems for underserved populations. *Journal of Medical Internet Research*, 12, e32.
- Keselman, A., Slaughter, L., Arnett Smith, C., Kim, H., Divita, G., Browne, A., Tsai, C. & Zeng-Treitler, Q. (2007). Towards consumer-friendly PHRs: Patients' experience with reviewing their health records. *AMIA Symposium Proceedings*, 399-403.
- Kim, J., Jung, H. & Bates, D. (2011). History and trends of "Personal Health Record" research in PubMed. *Healthcare Informatics Research*, 17(1), 3-17.
- Tulu, B. & Horan, T. (2009). The Electronic Disability Record: Purpose, parameters, and model use case. *Journal of the American Informatics Association*, 16(1), 7-13. ●



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Victorian disabilitySUPPORTworkers CONFERENCE announcement

The recent ASID Vic strategic planning day identified a number of issues and concerns in relation to the focus of ASID Vic, in particular in relation to the question.

"Are we meeting the needs of our membership?"

ASID Vic identified a priority goal to be a 'meeting place of ideas' for the coming together, expression and contribution of all perspectives interested in people with an intellectual disability.

It was felt that it was time to set in motion new activities and ways of doing things consistent with this goal. The committee decided that when there is opportunity to, 2012 is to be a year for experimenting, trying new things, evaluating and reviewing.

It was recognised that this is a significant change but it was necessary to meet the goals of the ASID Vic strategic plan and to also ensure all members have access to opportunities to share ideas and be part of the discussion about the importance of research and practice in intellectual disability.

The Victorian Disability Support Workers Conference has in the past been a fantastic meeting place for direct support workers to come together and share ideas; however in the past due to the resources and time commitments needed to run the conference, it has been the primary activity of ASID Vic leaving few resources to run other events.

Members have identified that while there were benefits in running the annual conference there is a stronger need for a range of events including regionally based smaller events targeted towards the needs of the region, the local community and the broader membership.



As such the ASID Vic committee has decided to cancel the 2012 Victorian Disability Support Workers Conference and focus on the smaller events that the membership has been asking for.

This will mean that more events and opportunities will be provided (not less) aimed at meeting the needs of our membership.

The cancelling of the Direct Support Workers Conference for 2012 will not mean that members will not have a voice in a larger conference. This opportunity will continue to be provided by the annual Australasian ASID Board conference.

The committee is very positive and excited about the future of ASID Victoria and looks forward to seeing members new and old at upcoming events.

To have your say about ASID Vic please come along to the AGM on August 7 or send in your proxy vote. ●

ASID 2012 Keynote Speakers

www.asid-2012.org.nz



Bill Lindsay

Bill Lindsay is Consultant Psychologist, Clinical Director in Scotland and Head of Research for Castlebeck Care. He has held over £1 million in research funds studying cognitive therapy and offenders with Intellectual Disabilities and is currently conducting research on the assessment of offenders and on cognitive therapy. Bill's presentation is titled, 'Factors influencing referral pathways into and through forensic ID services'.



Jayne Clapton

Jayne Clapton is a Professor in the School of Human Services and Social Work at Griffith University in Queensland, Australia. Her research explores how different philosophies and values have underpinned historical and contemporary practices, and also impacted the exclusion- inclusion dualism. She will present a session titled, 'Ethics and Intellectual Disability: Perspectives for a common purpose.'



Teresa Iacono

Teresa Iacono is the Professor of Rural and Regional Allied Health, La Trobe University. In this role, she is overseeing the delivery of allied health degree programs across campuses in northern Victoria. With a background in Speech Pathology, Teresa's clinical, teaching and research interests have been in severe communication impairment in people with developmental disabilities. The title of her session is, 'Understanding the complexity of communication in people with intellectual disabilities'.



Susan Balandin

Susan Balandin trained as speech pathologist in the UK and worked as a clinician focusing particularly on people with disability and little or no functional speech in Australia for many years. After completing her doctorate she worked at the University of Sydney and then at Molde University College Norway. Her presentation is titled 'Virtual Worlds: A new tool for people with intellectual or developmental disability and those who support them'.



Averil Herbert

(Ngāti Maniapoto, Ngāti Paretekawa, Kaputuhi)

Dr Averil Herbert has worked for over 30 years as a clinical psychologist in community and Māori settings. She has been active in promoting Māori-centred research and cultural competencies in research, training and practice. Dr Herbert will talk about 'Unity in Diversity: Cultural Imperatives in Disability Research and Practice'.



Robyn Munford

Robyn is Professor of Social Work and Director of the Practice Research and Professional Development Hub, School of Health and Social Services, Massey University, New Zealand. Her plenary session is titled 'Supporting families: Building strengths and resilience.'



upcoming events

11 - 13 Sept 2012	Disability Studies Conference Lancaster University www.lancs.ac.uk/disabilityconference/
1 - 2 Nov 2012	23rd PANDDA 2012 Conference venue to be confirmed Professional Association of Nurses in Developmental Disability Australia. www.pandda.com
7 - 9 Nov 2012	47th ASID annual conference Wellington New Zealand www.asid-2012.org.nz
29 - 30 April 2013	Pacific Rim International Conference on Disability and Diversity Hawaii www.pacrim.hawaii.edu
22 - 24 Aug 2013	IASSID Asia Pacific Conference Tokyo, Japan
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: susan.peden@dsc.wa.gov.au

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4 membership types: Organisation / Individual / Student / Associate
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to current members: please make sure you don't miss out and keep your contact details up to date
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research to practice

Conference 2012

Wellington, New Zealand



UNITY IN DIVERSITY
Kotahitanga ki rō Kanorau
Different Perspectives : Common Purpose

Australasian Society for Intellectual Disability (ASID) 47th Annual Conference 2012

**Wellington Convention Centre, New Zealand
Wednesday 7 to Friday 9 November 2012**

Keynote speakers:

- Bill Lindsay, University of Abertay, Scotland
- Professor Susan Balandin, Høgskolen i Molde, Norway
- Jayne Clapton, Griffith University, Queensland, Australia
- Teresa Iacono, La Trobe University, Victoria, Australia
- Robyn Munford, Massey University, New Zealand
- Averil Herbert, University of Waikato, New Zealand

Workshops – limited spaces REGISTER NOW

Pre-conference workshop – Tuesday 6 November

- Assessment and treatment of sex offenders with developmental disabilities

In-conference workshops – Thursday 8 November

- Stepping Stones – A group therapy programme for the treatment of emotion regulation difficulties in people with an intellectual disability
 - Let's Talk – forum for people with disabilities

The full conference programme is available on the conference website

Early Bird registrations close on Friday 7 September 2012

www.asid-2012.org.nz