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IDA

Intellectual Disability Australasia

Magazine of the Australasian Society for Intellectual Disability

quality of life measurement
tweaking the future
ASID strategic plan
family inclusion
the autism experience

asid
research to practice



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Strawberry Icy Pole by krvt DESIGN

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editorial



Best wishes for the season and a Happy New Year to everyone.

This is the last IDA for 2011 and I hope you will find something of interest within its pages.

I have just returned from the 2011 ASID conference in Adelaide. It was as usual an exciting and informative event and ASID South Australia did a wonderful job of organising the three very full days. Highlights included the excellent keynote speakers and a range of papers including academic presentations, self-advocate discussions and workshops and well presented papers from practitioners in the field. The conference is ASID's premier event of the year, when the society truly demonstrates its focus of translating 'Research to Practice'. In March we hope to print some pictures from the conference proceedings and participants as well as the conference report from convener Denice Wharldall.

This quarter's IDA contains an article from last year's conference and news from the regions. With the holiday season fast approaching not every region has managed to submit their reports in time but we can expect bumper reports in the next March edition, I am sure.

2012 will be the last year that I shall edit IDA and the information on how to take advantage of the opportunity to nominate for this honorary role can be found in this month's IDA.

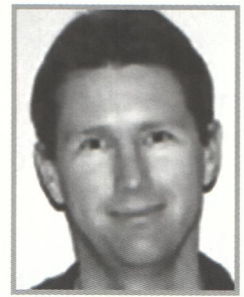
The Board held its last meeting of the year just prior to the conference and the new Board held its first meeting the day after the conference. Richard O'Loughlin was re-elected as President, Angus Buchanan as Vice President, Craig Jones as Treasurer and Denice Wharldall as Secretary. The Board thanked Darryleen Wiggins, who stepped down from the role this year, for her many years of hard work as ASID Secretary.

The new Board endorsed a new Strategic Plan for 2011-2020. The new plan is printed in IDA and will shortly be available on the ASID webpage. In addition, the new Board agreed to trial the appointment of a 'Web Editor'. It is anticipated that this role will be advertised as a three year honorary position pending an evaluation of the role in coming months. Sam Murray, from Victoria ASID has agreed to take on the task and is currently developing plans for the role statement.

Finally, you may notice a few changes at the ASID secretariat. The secretariat has moved to South Australia and is now run by 'NFP'. Email (secretariat@asid.asn.au) and phone contact (1800 644 741) remains the same, but our new address is NFP, ASID Secretariat, Suite 3, Level 1, 70 Wyatt Street, Adelaide SA 5000. Welcome to Suzanne Salisbury who will be the new contact with the secretariat. Our thanks go to Ross Parfett and Associates, in particular, Marg Wilson who managed the ASID Secretariat for many years.

Cheers, Sue

Implication of Quality of Life Measurement on Ageing with Intellectual Disability



by *Stuart Wark*

Introduction

The release of the 1983 Inquiry into Health Services for the Psychiatrically Ill and the Developmentally Disabled report, commonly known as the Richmond Report, provided an impetus to improve services to people with disabilities, to modify the way services were provided to people with disabilities, and to enhance the wider community's understanding of issues facing people with disabilities (NSW Audit Office, 1997). The Richmond Report was a catalyst in achieving a major change in service delivery for people with disabilities through the introduction of the Commonwealth Disability Services Act in 1986 and the NSW Disability Services Act in 1993. These Acts facilitated the development of clear policy directions that moved people away from institutionalised care and towards community integrated housing models. Some of the longer term implications of the Richmond Report are still taking place, in particular the issues of community placements for people ageing with a disability.

Demonstration projects were funded during the 1980s in an effort to prove that community based options were indeed viable within both metropolitan and rural Australia (Ward, 2006). Smaller hostel models that had been established during the 1960s and 70s, many of which still housed up to one hundred individuals, were reduced in size to form group home settings of just a handful of people, or even single individuals, living separately in their own dwelling (Edmundson et al, 2005). In the quarter of a century since these initiatives were first introduced, this group of people has naturally continued to age, and many are now experiencing difficulties in accessing appropriate care services. This situation has resulted in some people being prematurely 'reinstitutionalised' in congregate residential aged care facilities. The disability service providers have been unable to provide the specialist aged care required, but the supported person with the disability is often deemed ineligible for the in-home aged care assistance that other members of the community are able to receive. Sometimes, the only solution is for the disability provider to transfer the care of the person

to another organisation. The individual then enters a residential aged care facility far earlier than is typical in the mainstream (Webber et al, 2006), in a manner contrary to the concept of ageing in place (National Disability Services, 2007), with limited regard for maintaining their existing quality of life. Some reported problems with people with intellectual disabilities in residential aged care facilities include social isolation, boredom, an inability to participate in group activities and a shortage of resources to address their specific needs and requirements (Bigby et al, 2008).

Nearly two decades have passed since The Ascent Group (formerly known as Challenge Armidale) coordinated the first national conference in Australia on ageing and disability in May 1994. Titled the 'National Forum of Ageing and Disability', this conference was attended by parents, government officials, academics, service providers and other interested stakeholders from across Australasia. Janet Murphy from the Commonwealth Government Department of Human Services and Health made a presentation to this forum. In her paper, Murphy commented that there were a number of principles which should guide government and community with respect to the issues of ageing with a disability. These included:

- People should be able to access services appropriate to their need,
- Programs should be flexible enough to allow for special circumstances of individuals,
- People should be able to access packages of support, whether funded by both or one level of government, in line with their needs,
- Identified gaps in service delivery should be addressed as a matter of priority,
- People (young or old) should not be denied access to an appropriate service on the basis of age alone,
- Data collection and analysis should underpin major policy or program changes, and
- Cost shifting between levels of government should be minimised. (Murphy, 1994)

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Murphy concluded that these problems were not easily or quickly resolved when there were multiple levels of government involved. The fact that 17 years have passed since Murphy commented on these issues and yet they are still largely unresolved and as current as they were in 1994, indicates that the existing system is not working for ageing people with disabilities.

In recent years, the cohort of people with intellectual disabilities has seen a dramatic increase in their life expectancy. The trend whilst highly desirable, brings with it a number of challenges for both families and disability support staff. One of the main problems is that the mere extension of life does not necessarily equate to a high quality of life. There is an interesting ethical question about whether extending a person's life through interventions, without then also providing appropriate and necessary support structures, actually results in the overall betterment of life for the individual. For families and service providers, the difficult daily dilemma is how to meet the new and increasing individual support needs of people ageing with a disability, within a framework of no additional funding, while at the same time ensuring that the person maintains the same quality of life they have come to expect following the implementation of the Richmond Report recommendations.

Quality of Life scales have become one of the major measures of service provision by disability organisations in the past two decades (Kober & Eggleton, 2009). One of the problems being experienced by the disability and aged care sectors is that there is only partial data and information regarding the expectations and desires of people with an intellectual disability as they age. Prior to 1990, there was minimal research into the area of ageing with an intellectual disability, but recent years have seen much work that builds upon the efforts of pioneers in this field such as Matt Janicki and Chris Bigby. However, there remains only a limited understanding of how to accurately measure and assess the quality of life for individuals ageing with an intellectual disability.

Quality of Life measures for people ageing with an intellectual disability

One of the key concepts that has been strongly promoted in disability service provision is Quality of Life (e.g. Department of Ageing, Disability and Home Care, 2007). However, it would appear that many direct care

and support workers are not precisely sure what the term means and, in particular, how it applies to individuals with an intellectual disability who are ageing (Bigby, 2004). Part of the reason for this confusion relates to the fact that 'quality of life' is premised upon a generic concept that is not specific to intellectual disability and the term has been interpreted in disparate ways as a consequence of the difficulty in clearly defining its meaning (Felce & Perry, 1995).

The use of quality of life measures has gained considerable currency in the disability sector as a framework for evaluating the appropriateness of services. There is, however, only a limited amount of research data regarding quality of life measures suitability and appropriateness to the field of intellectual disability generically (Brown, Schalock & Brown, 2009) and specifically to those people who are also ageing. One of the central issues that quality of life researchers need to consider is whether there is inherently anything different between an individual with or without an intellectual disability. Does the person's disability mean that the mainstream measures of quality of life are not necessarily valid and, therefore, is there a need for a new set of specialised assessment items? Generic quality of life measures may not accurately capture the life experiences of a person with an intellectual disability but, conversely, one of the problems with using quality of life measures purposefully designed for people with intellectual disabilities is that they can be unduly focussed upon negatives and fail to accurately allow the person to express his/her actual level of happiness (Cummins, 1997).

The assessment and measurement of quality of life has become an increasingly important and crucial area of service provision for disability support organisations. It was argued that quality of life was the "pre-eminent issue of the 1990s" for intellectual disability services (McVilly & Rawlinson, 1998, p. 200). However, there is little agreement on a precise definition of quality of life for people with intellectual disabilities or what factors are most appropriate to assess and measure it. There have been in excess of two hundred different quality of life models developed to assess and measure aspects of an individual's life (Brown, 1998; Cummins, 1997), with one analysis reporting forty-four separate definitions of Quality of Life and 1243 difference measures (Hughes et al, 1995).

There remains confusion about how to best assess a person's quality of life when they are ageing with an

intellectual disability. An accurate assessment of quality of life is particularly important for this population group. With an increased incidence of ageing related health issues, it is very easy for the entire support time allocated to an individual to be subsumed with medical assessments, appointments and treatments, at the detriment of their previously established social life and community integration programs. It would be possible to complete an objective quality of life assessment and conclude that all is well, simply because the individual has met all the pre-determined medical targets that are considered important at that point in time. However, while this has happened, their social interactions with the local community may have almost completely stopped, and longstanding friendships may have been affected.

It is proposed that there needs to be a greater focus on outcome evaluation, in comparison to process evaluation, with respect to quality of life assessments. In process evaluations, the focus is upon examining the policies, practices and work procedures of the service and how these translate into day to day programs. Process evaluations are very good at determining the overall performance of a disability agency and generically how well the organisation supports people with intellectual disabilities. Outcome evaluations, however, are premised upon what the individual manages to achieve with the support of the service. Outcome evaluations are client focussed and, as such, are able to provide more accurate measures of a specific individual's quality of life, than process evaluations (McVilly & Rawlinson, 1998).

The majority of government conducted audits on disability services have a strong focus upon process evaluation. The auditors examine the systems and paperwork in great detail; however, the level of direct interaction with clients and their families is often limited to a brief meeting. Staff and disability organisations need to ensure that they do not simply rely on process evaluations to determine their performance in relation to services for individuals ageing with an intellectual disability, as many valuable personal experiences and information may be overlooked through a reliance upon this approach.

The issue of process versus outcome evaluations is particularly important with respect to supporting ageing people with an intellectual disability. At a time in which the individual's personal care needs are increasing but the funding is remaining constant, the individual's

quality of life can become secondary to the need to complete the requisite paperwork and documentation to satisfy external auditors. Both auditors and service providers need to be cognisant of the fact that the insistence on direct care staffing completing copious amounts of documentation associated with the meeting of regulations may actually become a significant barrier to the ongoing happiness of persons who live in these facilities (Borthwick-Duffy, 1990).

Issues to consider when conducting Quality of Life assessments

Eight key components, or life domains, have been described by Schalock and Verdugo-Alonso (2002) that need to be considered when assessing an individual with an intellectual disability's quality of life. These eight life domains are:

- physical well-being,
- emotional well-being,
- interpersonal relations,
- material well-being,
- personal development,
- self-determination,
- social inclusion, and
- rights.

It is proposed that these eight life domains cover most key factors that determine an individual ageing with an intellectual disability's quality of life. While some of these measures, such as physical well-being, can be determined objectively by considering their current health status, other life domains will require a subjective assessment by the person administering the tool. Any subjective judgement immediately raises the issue of whether it is accurately gauging the views of the individual with an intellectual disability.

One difficulty with establishing an individual's quality of life, particularly for a person ageing with an intellectual disability, is the potential communication barrier. If a person has a severe intellectual disability or has very limited receptive or expressive communication skills it can be hard to clearly establish the individual's understanding of the issue, let alone his/her personal views. This problem can be partially addressed through family, friends and carers responding on behalf of the person with the intellectual disability; however, it is impossible to confirm whether these proxy answers

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accurately reflect the individual's feelings (Cummins, 1997). Direct care staff need to carefully consider the relevance of the information from families, staff and other stakeholders for any subjective measure in a quality of life assessment. It is very easy for other agendas and issues to become enmeshed into the process.

Another major difficulty associated with personal interviews and quality of life assessments for people with an intellectual disability is the known phenomenon of 'acquiescence bias', in which participants are increasingly likely to agree with a question without necessarily either understanding or comprehending the meaning of the question (Rapley & Antaki, 1996). The problem of acquiescence bias is an important issue for staff to consider as it is naturally desirable to have the direct input, whenever possible and practical, of the individual ageing with an intellectual disability with regard to the services they receive. Respondent acquiescence can be overcome, at least partially, through ensuring that the questionnaires utilised in the Quality of Life are grammatically simple (Finlay & Lyons, 2002), do not follow a simple 'yes/no' dichotomy, and provide the respondent with ample opportunity to elaborate and express their feelings on the issue (Burnett, 1989). Staff need to ensure that the person is given enough information to clearly understand what the question is asking, and then sufficient time to then answer the question in their own words.

Conclusions

Assessing and determining quality of life for people with intellectual disabilities is an ongoing process for most disability organisations. However, the lack of clear definitions and the difficulties associated with the application of quality of life measurements to people with intellectual disabilities remain problematic within the sector. These problems are highlighted by the fact that there is currently no standardised measurement tool for quality of life developed for ageing people with an intellectual disability.

Regardless of which quality of life tool is used, the assessment process must be considered in light of the desired outcomes and what specific information is sought. While objective and process indicators are valuable in providing an over-arching methodology for determining service achievements, it is important to ensure that adequate inclusion of appropriate subjective and outcome indicators also occur. These mechanisms are vital, as they facilitate the direct involvement of people with disabilities in the assessment process. A quality of

life tool can be an invaluable aid in assessing whether an individual is receiving an appropriate service. However, if the actual assessment is inappropriately applied or not specific to the individual, the results can be potentially misleading and not accurately identify when a change in service delivery options is desirable. Disability organisations and their direct care staff need to carefully consider what tools they are using to assess Quality of Life in people ageing with an intellectual disability, how they are administering the tool, and whether it is actually giving all the information needed to plan both current and future service delivery.

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Tweaking the Future

“Small Changes »» Big Outcomes”

by Tina Purdon



The NSW annual conference program aimed to provide a variety of topics designed to challenge attendees to review their practice and adopt a ‘research to practice’ attitude in all that they do.

The theme of Tweaking the Future recognised that it is the often small things that we do on a daily basis, when based on sound research, can make substantial contributions to the lives of people with disabilities and the professional satisfaction of support staff.

The Conference got off to a lively start with an engaging presentation by Bob Bowen CEO The Mandt System®. Bob explained his theories around the impact of trauma and practice designed to prevent, de-escalate and, if necessary, intervene in the prevention of aggression.

“Bob’s session blew me away, it was a great start to a great day – what an eye opener”

A deliberate focus for all activities of ASID NSW / ACT is the involvement of people with disabilities.

This includes as regular presenters at our Conferences and support for people with disabilities as researchers. Again this year, these sessions were well received and enlightening. ASID NSW / ACT will continue to support involvement of people with disabilities as researchers and presenters of their research and information.

The program covered a broad range of topics and this was well received by attendees -

“Great variety of presentations”

“Excellent day (to be able) to get involved and share info with other people and organisations”

“Great to see the involvement of people with disabilities”

“Thank you for a diverse range of speakers and topics. Well considered and well received”

Tom Tutton challenged the work practice of all in attendance when his bio introduced

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... Quality of Life Measurement ...

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The 2010 ASID NSW / ACT Disability Support Professional – Lynanne Leahy with the 2011 Award recipients, Hayley Purdon and Samantha Nelson.

him relating to his challenging behaviours and support needs. His presentation then discussed addressing behaviour support plans within a ‘person-centred’ context.

Evaluations also presented us with a number of challenges for improvements for next year including ensuring that we provide more detail in information about the program prior to the event, how to balance the provision of paper handouts / access to electronic versions and meet everyone’s needs around information and environmental sustainability, and as with all events, how to give sufficient time to all presenters and still present a variety of topics within the time frame available – maybe next year we will need to extend the one day format or offer concurrent sessions!?

On behalf of the NSW / ACT Committee and all conference attendees, we thank all presenters for their efforts and acknowledge their contribution to the success of this event.

A highlight of the day was the announcement of the ASID NSW / ACT Disability Support Professional Recognition Awards. The Award ceremony was preceded with a presentation by Lynanne Leahy – our 2010 Award recipient and Warwick Brown as they spoke about the work that they do together.

ASID NSW / ACT introduced the Disability Support Professional Recognition Award in 2010 and this year expanded to include a category for a Disability Support Professional new to the role. The calibre of entries in the main Award was outstanding and selection of the

Award recipient was difficult. To ensure transparency the Award recipients were selected by a panel from CDS and the University of Sydney.

All entries were judged against the rigorous selection criteria and the content of their Nominations. The Panel reported that due to the high standard of entries it was a very difficult decision and we are very pleased to announce the 2011 Award recipients;

1. An outstanding Disability Support Professional who has been working in the sector for at least 3 years – Awarded to Hayley Purdon.

Hayley was nominated by Civic Disability Services in Sydney, in recognition of her dedication to the people she supports. Her nomination begins “Hayley is a front-line champion because she brings to all her work a positive, can-do attitude. This is portrayed in all aspects of her work, both in relation to the people she supports and also to her colleagues. Hayley is an excellent role model, demonstrating a calm enthusiasm towards all aspects of her work and has also dedication and determination to attempt to bring out the best in both people with disabilities and other team members”.

2. A Disability Support Professional who has been employed in the sector for less than 3 years and who has made a significant contribution during this time – Awarded to Samantha Nelson.

Samantha’s was nominated by her Supervisor at The Ascent Group in Armidale “due to her willingness to contribute 200% to the work that she does”. ●

Australasian Society for Intellectual Disability



2011- 2020

STRATEGIC PLAN

ASID's VISION

ASID's vision is an inclusive society.

ASID's MISSION

To improve the quality of life for people with an intellectual disability.

ASID's STRATEGIC GOALS

1. To be an independent authority on intellectual disability issues across Australasia,
2. To forge interaction between intellectual disability research, policy and practice,
3. To lead the development of strategic partnerships,
4. To engage and strengthen membership,
5. To ensure sound governance.

To be an independent authority on intellectual disability issues across Australasia ASID will:

- identify issues of critical importance across the sector about which ASID will provide independent evidence based position statements, articulating the views of the Board and enabling ASID to lead the debate,
- establish ASID's credibility as an independent authority and body of influence.

To forge interaction between intellectual disability research, policy and practice ASID will:

- promote and support successful high quality research based, peer reviewed annual Australasian Board conferences,
- facilitate the dissemination of good quality research that provides the theoretical basis for evidence based practice,
- produce publications that provide evidence and practical solutions to commission, manage and deliver better services that support people with intellectual disability,
- prepare and deliver and/or facilitate high quality training and professional development in the provision of services to people with an intellectual disability,
- contribute written submissions to inform policy makers and government based on strong research

evidence on matters of importance to the field of intellectual disability.

To lead the development of strategic partnerships the ASID Board will:

- ensure ASID is well positioned to develop and enhance relationships of influence within and across the sector,
- Develop and maintain regular interaction and propose partnership opportunities with relevant stakeholders.

To engage and strengthen membership ASID will:

- develop and implement strategies that;
 - o support membership retention,
 - o increase membership,
 - o maintain and strengthen membership diversity,
 - o better engages and communicate with ASID members,
- Develop, identify and promote the benefits of ASID membership to existing and potential members.

To ensure sound governance members of the ASID Board will.

- develop sound governance strategies to ensure an effective and functional Board,
- maintain a paid secretariat and executive function that provides effective and functional executive and operational support,
- develop, implement and regularly review the Board's operational plan,
- develop strong policy and operational frameworks that ensure sound financial governance,
- develop and maintain operational guidelines that ensure effective Information management,
- regularly review the Board's decision making and related governance strategies regarding;
 - o effective Board management,
 - o media statements and submissions to government on behalf of the ASID membership,
 - o the establishment and maintenance of external relationships with significant networks and people of influence.

Queensland

by Cecily Harker

At the ASID Queensland branch's Annual General Meeting held on 3 November, all current committee members were voted in for another year. Michael Keates accepted nomination for the president's position, with Hamish Millard as secretary and Julie Kelly as treasurer. Australasian Board Members will be Lisa Fraser, Madonna Tucker and Michael Keates.

At the AGM, we also welcomed an injection of additional enthusiasm and expertise onto the committee with the appointment of four new committee members, Nagedeva Higgins, Senior Advisor for Challenging Behaviours and Complex Needs with Endeavour Foundation, Hillary Maloney, manager of "Clear Horizons," a post school day service, Maurie O'Connor, Co-ordinator of CLA Inc. (Community Living Association), and Louise Young, Associate Professor in Rural Medicine at the School of Medicine and Dentistry at James Cook University and previous ASID Qld committee member.

We have made a concerted effort to have representation on the committee from regional Queensland in the hope that ASID membership can be increased throughout Queensland. Now that we have two committee members based in the State's north, along with two on the Sunshine Coast, we hope we will be able to better address the constant challenge of providing for ASID membership in regional and rural Queensland.

The ASID Qld committee is continuing to trial its blog site at <http://asidqueenslandnews.wordpress.com>. We recently posted pdf versions of our state conference presentations on the site. The blog has also highlighted some other community events and news items. Our busiest period of activity resulted in over 30 views in one day, which is a great start. However, we need more content! If you have some news you would like us to put on the blog, you can use the "contact ASIDQueenslandNews" link on the blog webpage. You also have the ability to leave comments about any posts on the blog site. This could be a great way to stimulate discussion about important issues or events. You can also subscribe to the blog if you want to receive an email alert when we post new information.

On a more personal note, the committee has shared in the joy of Hamish Millard's becoming a Dad.

Congratulations to Hamish and his wife Sam on the arrival of Madeline Narissa, born 23 September.

As this issue goes to print, we would like to send season's greetings to all our ASID colleagues and wish you a refreshing break over the year end and hope we all feel revitalized for a productive and innovative year ahead.

Victoria

by Sam Murray

We took a punt and it paid off.

As I sit here at the 46th Annual ASID Board Conference in Glenelg SA, I reflect back to last week and the 11th Annual Disability Support Workers' Conference back home in Melbourne. After a decade of the DSW Conference being at the University of Melbourne, ASID (Vic) made the move to a bigger, and indeed better, venue – the hallowed grounds of the MCG. The lame 'punt' reference may now make sense.

Over 600 delegates, representing over 260 organisations, from all over Australia, New Zealand, England, Scotland, and Canada attended DSW11. This was our biggest conference to date. So despite our own trepidation at the start of the year, the decision to move was well worth it. One delegate, an attendee of many years of conference, commented that the DSW conference "has grown up...it's come of age...". And as we approach our 'teenage years', we thought it was a great metaphor for the growth and success of this annual event.

Delegates were offered paper presentations and workshops on a wide range of topics, presented by researchers, service providers, people with a disability, support workers, family and carers, allied health, therapists and government.

We were privileged to have had **The Hon Mary Wooldridge MP**, Minister for Mental Health, Women's Affairs and Community Services open DSW11, along with keynote papers presented by:

- **John Della Bosca** from the Every Australian Counts campaign (National Disability Insurance Scheme)
- **Dr Pat Mirenda** from University of British Columbia (Supporting Individuals with Complex

Communication Needs:
From Research to
Practice);

- **Prof Eric Emerson** from
Lancaster University
(Tackling the health

inequalities faced by people with intellectual disabilities) and

- **Dr Wendy Lawson** (Advances in brain imaging technology will significantly enhance the lives of people with autism).

All of the papers from DSW11 (where presenters gave consent), will be loaded onto the Victoria Region page of the ASID website by the end of November. Take some time to visit <http://asid.asn.au/Regions/Victoria.aspx> for more details.

The ongoing interest and support for the DSW Conference hosted by ASID (Vic) conveys to us a strong message of the need for such an event for the direct support workforce. This event provides a forum to engage not only with the research and practice innovations, but to build networks with other likeminded support staff from their local area and further abroad.

This conference takes a lot of work and would not happen without the support of our major financial sponsors: **Victorian Department of Human Services, Disability Services; the Office of the Senior Practitioner, the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and VicHealth.** A full list of sponsors and supporters can be found on the website.

NSW & ACT

By Tina Purdon

As the year draws to a close, we look to our activities throughout the last 12 months and measure our success against what we set out to achieve.

Almost 150 people attended the 2011 NSW / ACT Conference on the 12th September to hear from a range of very interesting speakers, witness the announcement of the ASID Disability Support Professional Award recipients and have the opportunity to participate in the AGM. We are happy to share some of the highlights from the Conference in this edition of IDA.

Since the Special General Meeting in January 2008, ASID has continued to grow and strengthen in NSW / ACT. Throughout this time, Tony Harman has been the Committee President, supported by active and dedicated Executive and General Committee Members. On behalf of all ASID members, the Committee extends sincere thanks to Tony for his leadership and guidance throughout this period of growth and change. Much has been achieved during this period with Tony at the helm and the efforts of all are acknowledged.

At the 2011 AGM, we welcomed a new Executive with Vivienne Riches as President, Dennis Robson as Vice President, Sam Arnold as Treasurer and we thank Linda Ward for continuing in the role of Secretary.

In addition we welcome new Committee Members Gail Jelts, Edward Birt, Laura Hogan and Michelle Weise (it is great to see Michelle and Laura back after a short absence) as well as all those who were re-elected. It is pleasing to again note that regional representation grows each year. With the inclusion of Edward we now have Committee Members from the Hunter, Western and New England regions as well as across the Sydney metropolitan area.

We would however welcome representation from ACT and encourage ACT members to please contact the Secretary to discuss their interest in joining the Committee. Linda Ward lward4444@hotmail.com

We start the year with a large, strong and enthusiastic Committee and look forward to our annual Strategic Planning workshop this year set for 12th December.

The ASID NSW / ACT Committee acknowledges the efforts of our South Australian colleagues with the Australasian Conference and thanks all for a terrific, well run and informative event.

We wish all ASID members a safe and happy Christmas and we look forward to sharing the journey with you again in 2012.

New Zealand

By Adrian Higgins

The New Zealand Regional conference and AGM was held in Rotorua in late August. The conference theme was Foundations for the Future and the keynote speakers were Mark Benjamin, Ass Professor Kate Diesfeld and Dr Mhairi Duff. Around 170 delegates attended

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and the conference is now well established as major event within the NZ intellectual disability sector. A particularly pleasing aspect of the conference was the emergence of papers from a number of younger presenters. Four of these presenters have been invited to re-present these papers at a seminar to be held in Dunedin under the auspices ASID-NZ. Our plan is to extend this to hosting similar seminars in both the North and South Islands.

All of the former ASID-NZ Council were re-elected at the AGM. Our hard-working secretary Gary Wyatt has stood down from this office at the AGM but has remained on as a member of the council. His work as secretary has been greatly appreciated and we welcome his ongoing contributions.

Preparations are well in hand for hosting the 47th Annual Conference of the Australasian Society for Intellectual Disability in Wellington, New Zealand. The conference theme is University in Diversity: Kotahitanga ki ro Kanorau and the confirmed keynote speakers are Bill Lindsay, Shoumitro Deb, Jayne Clapton, Teresa Iacono, Robyn Mundford, Averil Herbert and Susan Balandin

Western Australia

by Chris Yates

After a relatively quiet year ASID WA has had a flurry of activity over the last few months. This commenced with a Strategic Planning breakfast in August where we had 20 members present and a very lively discussion ensued. The outcomes of that meeting have been collated and worked on by a smaller sub-committee from Regional Council in preparation for distribution as part of the process for developing a three year vision and plan for ASID in WA. Key issues arising from that session include health and mental health issues for people with intellectual disability.

It would be expected that many other important areas will be put forward. I hope that all ASID members will also want to contribute to the work of the organisation when the plan is finalised.

On September 26th the WA Regional Conference was held at Technology Park and attended by some 80 people. The theme was Transformations with a focus on the influence of person centred approaches. Speakers were drawn from the ranks of academic researchers,

family members, service providers and people with an intellectual disability. Those attending also had the opportunity to hear a presentation on the honours research undertaken by Carmel McDougall with assistance from the inaugural Guy Hamilton Scholarship and to meet Naomi Isaacson winner of this year's award. The day concluded with a 'speed forum' which was a series of rapid fire discussions designed to generate further ideas and areas of exploration as part of the strategic plan.

The Conference was followed by the AGM where we had one of the largest roll-ups in recent times and a good level of comment and discussion and the early work on the strategic plan was presented. At the AGM Angus Buchanan stood down from the role of President after three very busy years and was warmly thanked for his strong leadership and strategic direction setting. Chris Yates has taken over the President's role and all other executive roles remain the same. The council now looks forward to finalising the strategic plan and ensuring that the membership is engaged in achieving the goals set out in it.

Tasmania & South Australia

No reports ●

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Family inclusion and people with profound intellectual disabilities:

An exploration of the policy-practice interface and the experiences of adult siblings

by Davina Taylor

School of Health and Human Services CQUniversity



Introduction

This research focused on neglected, but important, issues within the disability field that appeared to not have been previously explored in an adequate way within an Australian context. The research explored the policy practice interface with particular emphasis on the experiences of siblings of people with profound intellectual disability. There were two components. First, the research investigated government documents related to family inclusion and disability service provision, using content analysis. Second, the research explored the experiences of adult siblings of people with profound intellectual disability living in group home supported accommodation. The overall aim was to critically evaluate what should be reasonably expected from service providers, in regards to family inclusion, and how this relates to the experiences of adult siblings of people with profound intellectual disability living in group home supported accommodation.

Policy Analysis

A content analysis was conducted on three key government documents that govern services provided to people with a disability in Queensland. These were:

- Disability Services Act 2006 (Qld)
- Disability Services Queensland Strategic Plan 2007-2011
- Disability Sector Quality System (with particular attention to the 10 Queensland Disability Service Standards)

The aim of the content analysis was to determine exactly what was contained within these documents about families of people with disabilities, particularly when the family member was receiving support from a disability service provider.

The research found that while the first two documents contained multiple references to family related terms, the Disability Sector Quality System document contained only a single reference to families. Within Queensland Disability Service Standards no information was found that related to families or included a focus on families. This is very significant as all services that receive recurrent funding from Disability Services Queensland (including both government and non-government agencies) are required to implement the Disability Sector Quality System and undertake an external and independent audit process to demonstrate that all organisational policies and practices comply with the Queensland Disability Service Standards (Queensland Government 2004).

Therefore, it would seem that there is a discrepancy between the Disability Services Act 2006 (Qld) and the Disability Services Queensland Strategic Plan 2007-2011; and the standards contained in the Disability Sector Quality System. As the policies and practices of service providers in Queensland need to adhere to the Queensland Disability Services Standards, these standards would, therefore, reflect what is required from service providers in practice. Thus, it is evident that where family inclusion is concerned, there is a 'gap' between 'law' and 'policy' and what is required in 'practice' (as per Illustration 1).

So, while in principle it would appear that the needs of families are intended to be met, it is evident that there may be gaps in what is required in practice. Therefore, it is plausible for a service provider to be audited against the ten Disability Service Standards and show no acknowledgement of the members of the client's family, the importance of the family unit or the needs of the family, and still be successful at the conclusion of the audit.

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Siblings' Experiences

The second aspect of this research was explored through face to face interviews and presented in case studies. The case study participants, Gina and Elizabeth, are both living in Queensland. They each have a brother with a profound intellectual disability living in group home supported accommodation whom they each have regular contact with. Gina and Elizabeth spoke of many different aspects relating to their sibling relationship. This paper will explore their interactions with and perceptions of the group home and its staff.

The 'atmosphere' of group homes and Gina and Elizabeth's own interactions with staff when visiting was raised and discussed at length by both.

Elizabeth: *It's always got a good atmosphere...They are all really welcoming and it's a good environment... I can pop in there at any time..it's good that I can do that.*

Meanwhile, Gina has a very different experience with the atmosphere of her brother's group home and her own interactions with staff.

Gina: *... I do not feel comfortable ... I can not just rock up, walk through the door ...and go and sit on the couch with him or something. It's not the same.*

A criticism of group home supported accommodation has been there has not been enough attention given to social networks and relationship building for people with disabilities (Parmenter 1999). Elizabeth's experience has been very positive in that she is always made to feel welcome at the group home and staff have always been welcoming and approachable. However, Gina's experiences indicate that she did not feel comfortable visiting the group home and, as a result did not feel that she could just arrive at the group home to spend time with her brother. This could be seen as an indication that social networks and relationship building for Ross (her brother) may not have been given enough attention in the group home. Gina's experiences support the view taken by Meyer and Vadasy (1994); that the siblings of people with intellectual disability receive little attention from disability service providers. Gina's experience also highlights the importance of staff being appropriately trained. Goggin and Newell (2005) have questioned the "...significant degree of support by untrained support workers" (p.129) while other researchers have deemed staffing to be a critical aspect of the quality of service for people with disabilities in supported accommodation (Institute for Family

Advocacy and Leadership Development 2006; Young et al 1998; Gianatti & Copes 2006; Borbasi et al. 2008; Bigby & Fyffe 2006).

Gina's experience of not feeling comfortable when visiting her brother is supported by Mansell et al. (2003) who has previously expressed concern regarding the inactivity and isolation of clients who are living in a community setting. Clients with higher support needs reported lower activity levels than for other clients. Staff play such an important role in the client's involvement in an activity (Mansell et al. 2002, cited in Mansell et al. 2003).

It is worthy to note that, while both group homes are governed by the same legislation, the experiences of Gina and Elizabeth are considerably different. As mentioned in the policy analysis, the *Disability Services Act (2006)* states that families have the right to receive a service from service providers that encourage and support the family. While Elizabeth's experiences suggested that legislation is being adhered to, Gina's experiences differed.

Both participants independently commented on the policies and practices of service providers and demonstrated their awareness of the importance of this aspect of service provision. Elizabeth spoke of her experience with policy as follows: [Service provider] *does seem to have a lot of policies and procedures for everything. But, I suppose that the policies and procedures are only as good as the people following them.* Gina reported similar views: *...they don't follow through with them [policies]. They're just there to cover them [service provider]; they're not a major thing... It's all too perfect. When they write about them [the policies] or you read it, they make it sound so perfect.*

The above mentioned comments indicate that while both participants acknowledge there were policies in place guiding service providers, both participants questioned the effectiveness of the policies and service providers putting policy into practice.

Another issue raised by both Gina and Elizabeth was in relation to the importance of open communication with each particular services provider.

Elizabeth spoke of situations where there were breakdowns in communication: *Between staff, sometimes there are breakdowns of communication. I have been phoned and asked was I taking Peter to his doctor's appointment and I am thinking - I didn't even know that Peter had a doctor's appointment... sometimes*

Disability Services Act 2006 & Disability Services Queensland Strategic Plan 2007-2011 (Law)

- Family unit will be encouraged
- Needs of the family will be taken into account
- Families can make complaints and these complaints will be taken seriously
- There is a need to empower families
- Continuous improvement for families
- Families will be supported



Disability Sector Quality System (Policy)

- Families need confidence in the quality of the services their family member with a disability is receiving



Queensland Disability Service Standards (What is required in practice)

- No reference at all to families

Illustration 1: The 'gap' between 'law and policy' and what is required in 'practice'

there can just be a bit of a breakdown of communication between staff and sometimes you are just not quite sure what is going on.

Gina has also had experiences of breakdowns in communication, and voiced apprehension that raising such issues would make communication more difficult. This reflects underlying powerlessness that family members may feel even though they theoretically have the right to raise issues or concerns with service providers.

Gina: ...if you rock the boat it just makes things harder for Ross. It doesn't make the communication any easier ...

While in the Disability Services Strategic Plan (2007-2010) (Queensland Government 2007) the, then Minister, Warren Pitt, referred to the empowerment of the families of people with disabilities; it would be expected that Gina and Elizabeth would have shared experiences of empowerment. However, the communication breakdowns experienced by Elizabeth and Gina do not appear to be empowering.

Gina's fears about 'rocking the boat' would also seem to be at variance with the intentions of the *Disability Services Act 2006* and the *Queensland Disability Services Standards*. The *Disability Services Act 2006* states; a family member can make a complaint to the chief executive about the delivery of service by a funded service provider. Despite this, through Gina's past experiences, she feels that making a complaint would

have problematic ramifications for her family and her brother. This situation reinforces the complexity and difficulty that may be experienced by family members who may wish to raise issues and concerns with their siblings' service provider.

Furthermore, the *Queensland Disability Service Standards* state that service providers are required to demonstrate "[A] proactive approach to complaints and disputes management that safeguards service users/supports from retributive action when raising complaints" (Queensland Government 2004). From Gina's experience however, this did not seem to be happening in Ross' group home. Following written policy, Gina should feel free to advocate for her brother and for herself without fear of retribution from service provider staff.

Another aspect of their interactions with the service provider that was raised by both participants is related to reports of critical incidents that had occurred in relation to their brothers in the past. Both Gina and Elizabeth reported distressing events that appeared to indicate a lack of communication in the interactions between service provider management and families. Due to confidentiality and the sensitive nature of the critical incidents, the details of these incidents will not be included.

Following an incident, Elizabeth experienced feelings of disappointed with the level of communication from the

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service provider and also questioned the practices of the service provider and the level of support provided to the family. Elizabeth's experience would appear to be at odds with the Disability Services Act 2006, which states that the needs of the family would be recognised and that there would be an acknowledgement of the demands on the family. This was not the case, from Elizabeth's experience, as there was no attempt made to contact the family or provide any support to them throughout the difficult time and thus, it would appear that their expectations were unmet.

Gina also spoke of a critical incident that involved her brother and highlighted her concern about the lack of communication between service providers and families. Following on from this incident, Gina spoke of an experience when she and her family felt that the service provider was withholding information. While this was dealt with at the time of the incident, Gina felt that the resolution to this problem was not appropriate and Gina believes that the service provider's practice does not encourage or support open communication.

This experience appears to contradict legislation. While the Disability Services Act 2006 legislates for the family unit to be encouraged and families to be encouraged and supported and for the needs of the family to be considered from Gina's experience this did not seem to be occurring. Furthermore, while on paper it would seem that the family would expect to be able to make a complaint (as per the Disability Services Act 2006 and Queensland Disability Service Standard 7), Gina's experience indicates that the process and the resolution of the complaint was inadequate.

Gina still upheld the belief that her family were not told everything that they would expect to know, further calling into question the complaints process. Withholding information from the family may have indicated a lack of appreciation of the importance of relationship building and connecting to social networks. Without this relationship, service providers are granted decision making that is less accountable than it should be.

Conclusion and Recommendations

This research was explored through a content analysis of key government written documents and two case studies that were conducted.

The content analysis found that the Disability Services Act 2006 and the Disability Services Queensland Strategic Plan 2007-2011 both made references to

family inclusion. Despite this, the Queensland Sector Quality System made very little reference to families and the Queensland Disability Service Standards made no reference to families whatsoever. Therefore, while legislation advocated for families, there was no mechanism in place to ensure that this legislation was implemented through relevant or appropriate standards; for example, a service provider did not need to provide any evidence of family involvement in order to meet the standards required to receive government funding.

The analysis of the case studies resulted in two important points. First, when the reported practices of service providers coincided with the aims of policy and legislation, the experiences of siblings were generally positive. Second, when the reported group home practices appeared to contradict policies and legislation and families were not included, the siblings tended to have negative experiences.

Therefore, the researcher recommends an additional Queensland Disability Service Standard. This service standard is 'Queensland Disability Service Standard 11: Family Inclusion'.

Queensland Disability Service Standard 11: Family Inclusion

Encouraging and nurturing family inclusion when a person is receiving services from a disability service provider. This standard is intended to ensure the service provider implements policies and practices that:

- Provide opportunities for family members to become involved in the daily life of their family member with a disability.
- Recognise the importance of the family unit.
- Assist in supporting the family, when appropriate.

Indicators:

- 11.1 The service provider encourages open communication with family members.
- 11.2 The service provider promotes a belief in the importance of family inclusion and the family unit.
- 11.3 The service provider promotes opportunities for service users to interact with their family.
- 11.4 The service provider encourages discussion and the raising of complaints by family members regarding any areas of dissatisfaction with service delivery.

11.5 The service provider has current policies and practices protecting the rights of families that are consistent with Commonwealth and State Legislation.

By implementing the additional standard, all disability service providers who receive recurrent funding from Disability Services Queensland would be audited on the services, policies and practices pertaining to family inclusion. Therefore, there would be an obligation for service providers to adhere to current law and policy and advocate and encourage family inclusion. The benefit of family inclusion would then flow to people with intellectual disabilities, families and service providers.

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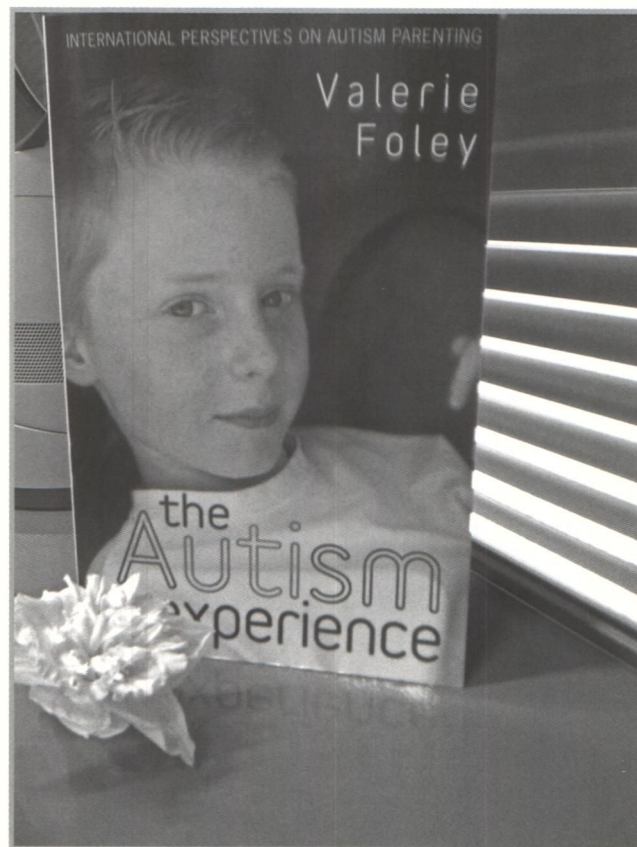
book review

The Autism Experience: International Perspectives on Autism Parenting

by Valerie Foley

Published by Jane Curry Publishing 2011

review by Jo Bristow



In this eminently readable book, Valerie Foley brings together a vast array of unique stories from 29 families who are living with children and young adults who have a diagnosis on the autism spectrum.

Valerie describes how these parents from across the globe “met” on the internet and began to share their stories; recognizing similarities in their journeys and providing support to each other across the miles.

The families in the book come mainly from North America but there are 4 from Australia, some from New Zealand, the UK and Vietnam.

Consequently the experiences the parents relay vary considerably but one overwhelming theme persists – that of the need and gratitude for the support this group has shared.

The book is divided into 4 main sections that cover significant events and milestones in any parent and child’s life. These include pregnancy and birth, getting a diagnosis, school, growing up, money, relationships and marriage.

In each section parents discuss their own experiences and insights as well as providing helpful hints (some of which are captured in easy-to-find information text boxes adjacent to the main text)

The Australian parents all detail the emotional roller-coaster of diagnosis. Livian in Sydney sums up several parents’ reactions when the diagnosis is finally made. “Thank God!!! Someone was finally getting it!!!”

The book goes on to describe parents’ experiences of therapies and navigating day-to-day activities such as hair-cuts, toilet training and food.

There are some useful insights to choosing a school and supporting a child with autism in the education system. No clear “winner” emerges with mainstream, private and autism-specific schools all having their advantages and drawbacks.

Some of the most touching stories emerge as the families share more intimate moments of their lives including the reactions of siblings, other family member and friends and as these children with autism grow into young adults.

Ro from Melbourne describe how friends have been lost along the way as they “don’t believe autism/Aspergers exists”. In contrast Livian maintains she has “gained some beautiful relationships with people” because of their association with her son who has autism.

This book gives a clear message that there is no “one way” to parent a child with autism.

This may not be a book that you would read from start to finish but it’s one that could sit on the bookshelf and provide advice and encouragement to parents at different stages of their child’s life. ●

upcoming events

18 - 20 Jan 2012	DADD's 13th International Conference <i>on Autism, Intellectual Disabilities, and other Developmental Disabilities</i> Miami Beach, FL
8 - 10 Mar 2012	Australasian Association of Developmental Disability Medicine Sydney NSW www.aaddm2012.com
3 - 4 May 2012	National Disability Services Conference Adelaide South Australia www.nds.org.au/events/ 1317948204
9 - 14 July 2012	2012 IASSID World Congress Halifax Canada
8 - 10 Aug 2012	10th Biennial Early Childhood Intervention Australia Conference Perth, Western Australia
11 - 13 Sept 2012	Disability Studies Conference Lancaster University www.lancs.ac.uk/disabilityconference/
7 - 9 Nov 2012	47th ASID annual conference Wellington New Zealand www.asid-2012.org.nz

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expression of interest

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

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

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

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Your expression of interest should include: a brief summary of the reasons for your interest, previous experience within the field of intellectual disability, and previous experience in publication and/or journalism in a volunteer or professional capacity.

Demonstrated proficiency in written communication is essential.

Enthusiasm, a commitment to team work, an ability to set and meet goals, and an interest in ASID and its objectives are considered essential.

Previous experience in publishing/journalism is an advantage but not a requirement.

On taking up the position of IDA Editor, membership of ASID is a requirement.

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

asid

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

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

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Jayne Clapton, Griffith University, Queensland, Australia

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