



Intellectual Disability Australasia



Optimise
Health
Care



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Front cover image
by Bruce Blaus



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

ISSN: 2206-4311

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

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Editorial



It is now over three years since we surveyed ASID members as to the format and content of the information we send out. Many thanks to the 50 of you who responded with your suggestions and views. It was pleasing to see that the electronic format of IDA is being read by 87.5% of the respondents and the electronic copy is preferred over the hard copy. Although 64% of respondents click on individual articles, over half of the respondents also printout the pdf version. You noted that your top four preferences to read are, specific articles of interest, information about ASID members, articles by/about people with an intellectual disability and books and video reviews. Over the next few editions the ASID directors will be discussing your comments on content and format and making some changes to IDA so please give us feedback. We are keen to experiment with new ideas so please keep the suggestions coming.

This edition focusses on health with articles by ASID fellow Dr Nick Lennox from Queensland and Dr Jane Tracy from Victoria. I also sourced some references and their abstracts of recent health articles from the ASID journals. The MOOCs also focus on health and we would be interested in any member feedback on these courses. Our president, Angus Buchanan, will sadly be stepping down at the next AGM and his report summarises some ASID highlights over the years. We have an article by Amanda Milliar a person with an intellectual disability and a link to where you can read more personal stories. Check out the Queensland divisional report as they are planning for the next national conference in 2018. Two of our Tasmanian conference keynotes are highlighted in this issue and indicate we have an exciting conference ahead in November 2017. I will be at the conference so do come and introduce yourself, share ideas or volunteer to write articles from your conference /poster presentations or about your experiences at the conference.

Contributions to IDA are welcome as are questions and comments. Please contact me at idaeditor@asid.asn.au

Hilary Johnson

How to promote good health & optimise the healthcare of people with an intellectual disability



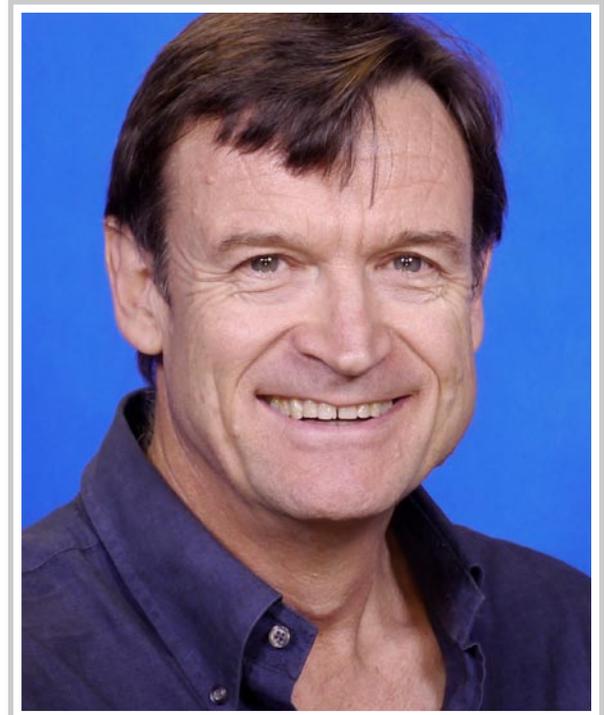
- Ideas,
Tips,
and
Strategies

by **Nick Lennox**

Director of the Queensland Centre
for Intellectual and
Developmental Disability.

n.lennox@uq.edu.au

<http://researchers.uq.edu.au/researcher/548>



Prof Nick Lennox

On July 4th, Dr Jane Tracy and I presented and drew on the expertise in the room to address how to promote good health and optimise the health of people with intellectual disability. Below I have tried to distil some of the day's presentations.

There is considerable evidence of suboptimal health and health care of people with intellectual disability in Australia both now and as long as such issues have been investigated (Beange, McElduff & Baker, 1995; Florio & Trollor 2015; Lennox et al., 2010) The barriers to good health care are many but include negative attitudes and devaluing, impediments to access healthy lifestyles and health care and the challenges of communication. The struggle to improve attitudes and value people with intellectual disability is a constant battle which goes to the core of why we as a society discriminate against people with disability. It is a battle which is ongoing. Likewise communication is fundamental to our being and especially as social animals, to our ability to live a good life including a good healthy life. To improve the health and health care of people with intellectual disability it is critical these three barriers are addressed.

I will now address specific strategies which may help if you are a person with intellectual disability or supporting someone.

- 1) **Maximise the person's value at every turn;** be it at home, the community or accessing healthcare. We need to be patient, persistent and respectful. Modelling such interactions may challenge negative behaviours by others toward the person you support. Access to mainstream healthy lifestyle activities and healthcare professionals may require negotiating some negative attitudes. Remember - Be patient, persistent and respectful.
- 2) **Optimal communication is crucial to the provision of healthcare.** As medical practitioners we are severely limited in our ability to provide high quality healthcare if we cannot understand what the person is feeling in their body and mind. I cannot emphasise this enough. Can you do the following?
 - a. Do everything you can to clarify what you as a person with a disability is experiencing or what the person

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... healthcare ...

- Ideas, Tips, and Strategies



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you support is experiencing. For example: What does the pain feel like? When did it start? How long does it last? What makes it worse? What makes it better? Have you had it before?

- b. What other major illness have you had? Write the answers to these question down or chart them. This is true of pain and psychological distress as well as other functions such as bowel habits, behaviours of concern or mood.
 - c. Get clarity and summarise the information and present it to your healthcare professionals. This information is critical to finding the underlying cause and directing what the health practitioner should do next. This may be gathering more information about what is happening for the person or doing investigations or an immediate intervention. At times waiting and following the changes in the person's wellbeing can act to clarify the diagnosis and what should be done. At other times action in the form of treatment/s or investigation is needed. This is the skill the health practitioner brings to the situation and should be respected but also understood and at times questioned.
 - d. Ask questions, for example you may ask, what else can we do as support person or as the person themselves, what further information do you need? If the practitioner recommends a treatment; how long do we wait to see if it works and if it does not, what next, or if they get worse what do we do?
- 3) There is considerable evidence that a **yearly health assessment will improve health care** provision and should be undertaken. Often health conditions do not reveal themselves early in their development or health promotion activities are not received by the person. The evidence suggests a health

check or health assessment can reveal unrecognised or poorly managed conditions. As support people you need to facilitate this process by gathering information and facilitating the process. One strategy is to access the nurse practitioner or practice nurse, who are often able to perform most of the assessment and decrease the time and administrative burden on the general practitioner. Negotiate a time for the assessment when the practice is not so busy and able to spend time with the person and send a support person who knows the person with a disability, their life and health story.

In short be vigilant to promote the value of the person with an intellectual disability, advocate respectfully, but firmly and maximise effective communication. Any communication must be in an accessible form – concise and accurate to the practitioner which will diminish some of the barriers to healthcare. Help the practitioner deliver information in a format that is understandable by the person with an intellectual disability, this will maximise the potential for a good outcome and good health and healthcare.

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Health Matters

by Jane Tracy

Centre for
Developmental Disability
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Dr Jane Tracy

Good health matters to us all. Feeling unwell or in discomfort or pain focuses us inwards and reduces our ability to engage with and enjoy the world around us. Achieving and maintaining optimal health and function is therefore an important foundation for a good life.

This paper highlights the role disability support practitioners and health professionals can play in monitoring the health of, and providing timely and appropriate healthcare to, people with intellectual disability. The paper follows a workshop run by ASID in July 2017 which Professor Nick Lennox and I had the privilege and pleasure of discussing how best to improve the health of people with intellectual disability with a room full of committed and thoughtful disability and health practitioners.

The focus of this particular paper focuses on the health of and healthcare for those who do not use speech or other formal systems to communicate.

Health inequity

People with intellectual disability have poor health when compared to the general population and have unique health vulnerabilities throughout their lives. Many of these health inequities are not directly related to the disability or its cause, but rather are the result of social and economic disadvantage (Kavanagh et al 2012, Emerson et al 2011). The consequent health outcomes are manifest in the increased morbidity and rates of premature death among people with intellectual and associated developmental disabilities (Troller et al 2017, Kavanagh et al 2012, Department of Health 2011, Lennox & Taylor 2008,).

Complex health needs

For children with disabilities the complexity of their health and social issues and the importance and interplay of health and disability are generally understood and addressed through the provision of multidisciplinary healthcare. The allied health team and general practitioner work with appropriate medical generalist physicians (paediatricians) and specialists according to the person's particular health issues and needs (cardiologists, gastroenterologists, neurologists etc),

When children become adults, the expectation is that their health needs can be met by mainstream health services. In Australia there is, however, no specialist generalist physician equivalent to the paediatrician (until people reach old age and a geriatrician is involved) and so the responsibility for monitoring, assessing and coordinating healthcare rests with the general practitioner. Many general practitioners feel ill equipped and resourced for this task. Similarly, specialized allied health teams support children and their families through childhood, but when people reach adulthood such teams are scarce and those in community health feel inadequately trained and resourced to meet the needs of people with complex disabilities.

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Health, communication and behaviour

When people become unwell or are in pain, their focus turns inward and they are less able to engage with the external world. For those not able to express their symptoms with words, or other formal communication systems, a change in behaviour may be the only way they express their illness or discomfort. Their behaviour may communicate important information about their symptoms. Refusing food, for example, may be a sign that the person is experiencing nausea; someone refusing to walk may have a broken toe, arthritic hip or pressure injury; someone not wanting to join in previously enjoyed group activities may be depressed.

A change in behaviour therefore becomes important information for disability support practitioners to notice, monitor, document and share with health professionals. Likewise, health professionals can ask targeted questions about behaviours that may indicate particular symptoms in order to make a diagnosis. Information about common medication side effects should be provided by health professionals to disability support practitioners so they can recognise the ways these may be demonstrated through behaviour change. For example, a medication may cause dizziness and if this information is given to the disability support practitioner it alerts them to watch for the person being unsteady on their feet; a medication likely to cause a dry mouth can explain a person's increased interest in asking for drinks.

Symptoms of illness may also lead to confusion or fear in those not able to understand what is happening to them. This is also the case in the general population when someone, for instance, develops psychosis or a delirium. For people with cognitive impairments, the onset of distressing symptoms may likewise provoke an emotive as well as a physical response. For instance, someone with pain may feel confused and fearful and, not understanding the

need for health professionals to examine them, may lash out when approached.

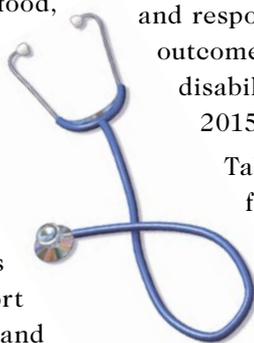
Healthcare is a partnership

The healthcare of many adults with intellectual disability depends on effective communication and collaboration between disability support practitioners, who have had little training in health, and medical practitioners who have had little training in disability. Gaps in knowledge, understanding and responsibility can contribute to the poor health outcomes currently experienced by people with disabilities (Troller 2017, Tracy & McDonald 2015).

Taking a proactive approach to healthcare is fundamentally important, particularly for people who have difficulty clearly describing their symptoms and concerns. A comprehensive annual health assessment by the GP, supported by a tool such as the CHAP (Lennox 2007) completed by someone who knows the person well, is an essential part of healthcare. The assessment is supported by Medicare and enables the GP to spend the time in the consultation ensuring a complete understanding of the person's health needs, including a focus on health promotion (including diet and exercise) and disease prevention (including immunisation and cancer screening). Hearing and vision assessment can also be undertaken in this appointment.

Working together, disability practitioners and health professionals can support people with intellectual disability to maintain good health. Just as disability practitioners learn about the person they support over time, so medical practitioners learn about the person's health needs and the way they look and behave when well and when unwell. The doctor builds the medical understanding and history over time, and learns how to best work meet the needs of the person. This is valuable knowledge and the benefit that comes with continuity

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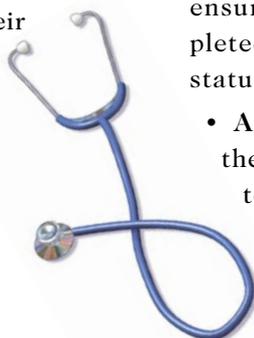


of care. It is therefore important to support and encourage the ongoing relationship between the person and their own individual GP whenever possible.

Better health means better lives

Disability support practitioners play a central role in ensuring people receive the healthcare they need to achieve and maintain optimal health and wellbeing.

Tips for support practitioners to improve healthcare for people with intellectual disability not able to describe their symptoms and manage their own healthcare. The tips below focus on the partnership between the disability support professional and the person's general practitioner (GP); most also apply to partnerships with other health professionals.



- **Be alert to change:** Changes in a person's behaviour, communication, sleeping or eating patterns, weight or mood could indicate physical or mental illness.
- **Record changes seen:** Charting behaviour, sleep, weight, mood, etc provides valuable clues to the person's health status.
- **If concerned act:** Don't be hesitant. If you think there is something wrong get it checked out. There is no harm done if there is nothing wrong – but there can be great harm done if physical or mental illness remains undetected.
- **Book a long appointment with the GP:** It usually takes more time for the doctor to work out what might be going on and making sure there is enough time reduces time pressure.
- **Support the person to tell their own story as much as is possible:** Be ready to model communication strategies and provide additional detail and information as required.

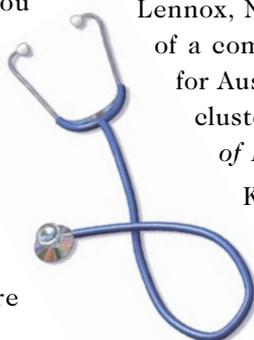
- **Accurate diagnosis depends on good information:** Ensure you have all the person's health information at the consultation, including the health file. Information about past physical or mental illness, the results of previous tests, health professionals involved (present and past), medications (both current and past), allergies and immunisations, previous surgery, family history may all be relevant. For the annual health assessment ensure the CHAP or a similar tool is completed to collect information about health status prior to the appointment.

- **Ask questions:** If you don't understand then you can't help the person concerned to understand or convey the information accurately to other staff - so ask questions until you do. Ask for written information - doctors use electronic record systems and will print out a copy of the outcomes of the consultation if asked.
- **Ensure management strategies are implemented:** Ensure the diagnosis and management strategies are recorded in the file and that all staff know the outcome of the appointment and what they need to do - new medication, tests/ referrals arranged.
- **Effective management strategies depend on accurate diagnosis:** The doctor depends on you to monitor whether the treatment or other interventions strategies are effective. If not, let the doctor know. Different treatments may be more effective, or perhaps the diagnosis needs to be reviewed.
- **Arrange follow up:** It is very important for the doctor to review the person to make sure the interventions have achieved the expected result and that medication side effects are detected. Medications may need to be changed, new tests ordered, progress of symptoms and signs

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monitored. Follow up provides a 'feedback safety loop' to check the original diagnosis was correct and the management strategies appropriate and effective.

- **If the person remains unwell act:** Sometimes things go wrong. The diagnosis may be incorrect. Medications can have side effects. A new problem may arise. If you feel the person has not responded as expected, then take the person back to the health professional again and again until the problem is resolved.
- **If not satisfied complain:** Don't give up! If you feel the person you are supporting is not receiving the care they need let your line manager know. The Disability Services Commissioner, the Health Services Commissioner and the Mental Health Complaints Commissioner all investigate complaints in their particular jurisdictions. Complaints are an important mechanism to drive service improvement.
- **Ensure the person has an annual comprehensive assessment by their GP supported by a tool such as the CHAP.**



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Kavanagh A., Krnjacki L. & Kelly M. (2012) Disability and Health Inequalities in Australia: Research Summary: Addressing the Social and Economic Determinants of Mental and Physical Health. Victorian Health Promotion Foundation, Carlton South, Vic. Available at: <https://www.vichealth.vic.gov.au/media-and-resources/publications/disability-and-health-inequalities-in-australia>

Tracy J, McDonald R. (2015) Health and disability: partnerships in health care. *Journal of Applied Research in Intellectual Disabilities*. 2015; 28(1):22–32.

Trollor J, Srasuebkul P, Xu H, et al. (2017) Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open* 2017;7:e013489. doi:10.1136/bmjopen-2016-013489 ●

In summary

The health and healthcare of people with intellectual disabilities can be greatly improved through an effective partnership between the disability practitioners and health professionals working with the person concerned. Respecting and valuing the contribution of all concerned establishes a solid foundation for this partnership.

References:

Department of Health (2011), Victorian population health survey of people with an intellectual disability 2009, Department of Health, Melbourne.

How to promote good health & optimise the healthcare of people with an intellectual disability

- Seminar report

by Hilary Johnson

ASIDVIC Member

This seminar was hosted by ASIDVIC in Melbourne on June 27th between 10-3pm. About 25 people attended from a range of areas including health professionals, students, family members and disability support workers. The speakers were experienced health professionals Professor Nick Lennox and Dr Jane Tracy. Professor Nick Lennox is the Director, University of Queensland's Centre for Intellectual & Developmental Disability based in the medical research institute at university of Queensland. He is also a fellow of ASID. He brought a range of skills to the seminar – those of researcher, educator, advocate and clinician. He has specialised in the health of adults with intellectual disability since 1992 and developed several interventions to improve the health of people with intellectual disability. They include the:

- CHAP (Comprehensive Health Assessment Program) health check
- Ask health diary
- First “whole of life” handbook on health for people with intellectual disability
- Online training for general practitioners & support workers
- 2016 Able X series of Massive Open Online Courses through Edx which focus on health and intellectual disability.

Dr Jane Tracy is the Director of the Centre for Developmental Disability Health, Monash Health and a medical practitioner who has worked for over 25 years with people with disabilities and their families. The CDDH works across the health and disability sectors to improve the healthcare of adults with intellectual disability through educational, clinical and service innovation activities. Jane brought her passion for health professional education, practical



Nick Lennox and Jane Tracy at the seminar

resources and her personal experience as a parent of adult son with intellectual and severe communication disability.

Nick opened the session by reminding us about the complexity of health and the many factors involved in being healthy. He cited a study with company directors that indicated they were healthier than their employees or managers, not simply due to economics but may also be due to having control. The issue of control is a taxing one in the health system as coordinated care for people with an intellectual disability often means involving a range of people and ensuring the person with an intellectual disability is as informed as possible and is supported to make decisions. Fortunately in Australia we have a good health care system, the third best system behind the UK and New Zealand. However people with a intellectual disability have a shorter life expectancy than the general population with people

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... Seminar report

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with severe intellectual disability dying twenty years earlier. Between 16-40% of with a intellectual disability also have mental health issues. Unfortunately health promotion and disease prevention is lacking for this population. One example of this is screening for breast cancer. Women are identified to attend screening from the electoral role, however many women with an intellectual disability will not be on the role and may miss routine screening. Also some samples are tricky to organise (collecting faeces for a bowel screen) and people with an intellectual disability may find the reason for the test difficult to understand and so may not cooperate.

There is increased identification of health risks related to specific syndromes and a specific diagnoses may be very helpful in identifying health risks (e.g Down syndrome). There is also a high level of sensory issues with 50% of people having difficulties hearing and/or seeing. The main message of the day was the importance of continuity of care (for instance keeping the same GP) and ensuring people have a complete health story (e.g. updated health passport). It is important to have health care enablers who know the person well in place. Medical appointments should allow extra time; to provide a diagnoses and treatment plan (particularly if the patient has communication difficulties) and, to help medical professionals understand the supports they need to put into place to provide the same level of care that they would provide to people without an intellectual disability.

Jane provided various case studies that reinforced this message about continuity of care and the need for the GP to work like a detective. People tend to miss out on good care for the following reasons:

- Families do not know about the health assessment and case conferences which can be funded through Medicare
- They don't know about asking for a double appointment with GP remuneration
- Doctors don't know about the health assessment for people with and intellectual disability
- There may be limited physical access for an examination
- The person may have had previous negative experiences so reluctant to go
- Need for regular reviews (at least annual). This also assists the doctor to know how the person presents when s/he is well.

What to do

- Book a long appointment
- Take any medications currently in use
- Prioritise the appointment to be the best time for the person (avoid Monday and Fridays in GP practices)
- Organise a person who knows them well to accompany them

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... Seminar report

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- Tell the GP in detail what observational changes you may have seen (if you nurture and inform your GP, you will get a better service)
- Provide communication information, for instance - how to ask yes/no questions and engage the person in the consultation. Model to the doctor how to communicate well
- Provide information if you have a rare syndrome
- Be prepared to ask questions of the GP
- Get health summary printed out from GP
- Use the Comprehensive Health Assessment Program (CHAP)

Additional reading

Newton, D. C., & McGillivray, J. A. (2017). Perspectives of carers of people with intellectual disability accessing general practice: "I'd travel to the ends of the earth for the right person". *Journal of Intellectual & Developmental Disability*, 1-9. doi:10.3109/13668250.2017.1310821. Access below: [Perspectives of carers of people with intellectual disability accessing general practice: "I'd travel to the ends of the earth for the right person"](#)

Ziviani, J., Lennox, N., Allison, H., Lyons, M., & Del Mar, C. (2004). Meeting in the middle: improving communication in primary health care consultations

with people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, 29(3), 211-225. doi:10.1080/13668250412331285163

Resources

www.cddh.monashhealth.org

<http://cddh-online.monash.org/> - online learning

- Free online resources for GPs, patients and carers
- Incl. Fact Sheets, booklets, Depression Checklist, online learning and much more information
- Telephone advice
- Clinical Assessments - reports with management recommendations.

Health Passport NZ:

www.hdc.org.nz/about-us/disability/health-passport/download-your-health-passport

Surrey Health Action:

<http://www.surreyhealthaction.org/a-to-z-of-health-information>

Easy Read Health Information:

www.easyhealth.org.uk

Nick's range of health resources and educational support

at <http://www.qcidd.com.au> ●

Recent Journal Articles related to Health

-you can access these through your ASID membership



Byrne, J. H. , Lennox, N. G. , & Ware, R. S. (2016). **Systematic review and meta-analysis of primary healthcare interventions on health actions in people with intellectual disability.**

Journal of Intellectual & Developmental Disability, 41(1), 66-74. doi:10. 3109/13668250. 2015. 1105939

Background: People with intellectual disability have substantially more unidentified health needs than the general population. We systematically reviewed the effectiveness of primary healthcare interventions intended to increase health actions for people with intellectual disability. **Methods:** Electronic databases were searched on 16 September 2014. Randomised and non-randomised studies with a concurrent control group were identified. Study quality was assessed and, where possible, meta-analysis was undertaken. **Results:** Five studies (3 randomised controlled trials, 1 matched cohort study, and 1 cohort study) with a total of 1,570 participants were included. General practitioner-led health checks were the most effective intervention and resulted in significantly more clinical activities, such as vision testing (risk ratio [RR]=3. 3, 95% CI [2. 3, 4. 7]) and hepatitis B vaccinations (RR=2. 4, 95% CI [1. 7, 3. 4]). **Conclusions:** Health checks were the only intervention to significantly increase short-term health promotion and disease prevention activity. The long-term effect of any intervention remains unknown.

Cocks, E. , Thomson, A. , Thoresen, S. , Parsons, R. , & Rosenwax, L. (2017).

Factors that affect the perceived health of adults with intellectual disability: A Western Australian study.

Journal of Intellectual & Developmental Disability, 1-12. doi:10. 3109/13668250. 2017. 1310816

Background: Adults with intellectual disability (ID) experience poorer overall health than the wider population. Identification of personal, support service and lifestyle factors affecting health status will provide opportunities to improve health outcomes. **Methods:** The study was a cross-sectional survey of adults with ID. Interviews were conducted between January and July 2013. Univariate and multivariate analyses were performed using self- or proxy-reported general health as the dependent variable. **Results:** Not good health was independently associated with increasing age, financial hardship, smoking, and living in a home of their own. Physical exercise was inversely associated with not good health. **Conclusions:** Subjective health may be improved by attention to the factors identified in this study. This could include closer monitoring of the health of people with ID as they age and if they live in a home of their own. Similarly, targeted programs promoting physical activity and smoking reduction could improve general health for adults with ID.

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... Articles related to Health

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Hemsley, B. , McCarthy, S. , Adams, N. , Georgiou, A. , Hill, S. , & Balandin, S. (2017).

Legal, ethical, and rights issues in the adoption and use of the “My Health Record” by people with communication disability in Australia.

Journal of Intellectual & Developmental Disability, 1-9. doi:10. 3109/13668250. 2017. 1294249

Background: The aim of this review was to explore the legal, ethical, and rights issues surrounding use of the Australian My Health Record (MyHR) by people with communication disability. **Method:** We undertook a narrative review of the legislation and research affecting the implementation of MyHR in populations with communication disability. **Results:** Use of MyHR by people with communication disability will require careful consideration in relation to (a) capacity and consent; (b) roles of nominated or authorised representatives in the system; and (c) the way decisions are made in relation to the use of MyHR, including supported decision-making for people with intellectual disability. **Conclusion:** Legal and ethical issues in the use of MyHR by people with communication disability centre on legal rights and equal access. These issues must be addressed if people with communication disability are to have full access to their legal rights and access in exercising personal choice and control in the use of MyHR.

Hussain, R. , Janicki, M. P. , Knox, M. , Wark, S. , & Parmenter, T. (2017).

Perspectives about support challenges facing health workers assisting older adults with and without intellectual disability in rural versus urban settings in Australia.

Journal of Intellectual & Developmental Disability, 1-10. doi:10. 3109/13668250. 2017. 1326589

Aims: Life expectancy for both sexes in Australia exceeds 80 years, with individuals with intellectual disability also increasingly living into older age. This research aimed to comparatively examine perceptions of staff supporting either older adults or age peers with lifelong intellectual disability. **Methods:** This project asked 420 medical, health, and support workers about training adequacy, health services access, and trigger points for premature institutionalisation. This paper is based on a subsample of 196 respondents who provided quantitative and qualitative responses. **Results:** There was considerable variation in confidence in supporting ageing individuals, while only 23. 7% of doctors reported their training was adequate to support adults ageing with intellectual disability. A lack of services and poor carer health were identified as triggers for premature institutionalisation. **Conclusions:** The study revealed key differences in staff perceptions of support provision and training adequacy when comparing ageing individuals with intellectual disability to the general ageing population.

Milne, J. , Johnson, J. K. , Lord, B. , Ong, N. , Tomsic, G. , & Silove, N. (2016).

Assessing health needs of children with intellectual disabilities: a formative evaluation of a pilot service.

Research and Practice in Intellectual and Developmental Disabilities, 1-11. doi:10. 1080/23297018. 2016. 1168712

Background: Children and adolescents with intellectual disabilities commonly have unmet complex health needs. Their parents often experience barriers in locating and accessing services to assist in diagnosing and managing those needs. **Method:** In response to this service gap, a pilot Paediatric Assessment Clinic was established under the auspices of a large paediatric hospital, to offer a comprehensive disability health service for children aged 6 to 18 years with intellectual

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... Articles related to Health

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disabilities and complex health needs. A formative evaluation used observations and a survey of key stakeholders, including 13 parents of children with intellectual disabilities, 6 referring clinicians, and 6 specialists to whom cases were referred post-assessment to understand early outcomes of the pilot service. **Results:** Findings highlighted the benefits of a multidisciplinary, staged approach to health assessment, coupled with a thorough understanding of family, cultural, and psycho-social issues, in providing interdisciplinary and inter-agency service for children with intellectual disabilities. Coordinated management plans between the clinic and disability and specialist health service providers supported parents access to services. **Conclusion:** The evaluation demonstrated the importance of clinical pathways between primary and tertiary health services providers. While demonstrating the intensive resources and engagement processes required to provide an effective multidisciplinary assessment model of care, the evaluation identified limits of the assessment and referral model in ensuring access to needed services.

Newton, D. C. , & McGillivray, J. A. (2017).

Perspectives of carers of people with intellectual disability accessing general practice: “I’d travel to the ends of the earth for the right person”.

Journal of Intellectual & Developmental Disability, 1-9. doi:10. 3109/13668250. 2017. 1310821

Background: Informal carers often play an integral role in the lives of people with intellectual disability (ID) residing in the community. In this study, we explored the extent to which carers of people with ID believe that the health care needs of the person they care for are being accommodated by general practice. **Method:** Semi-structured interviews were conducted with 25 informal carers to people with ID living in Australia. **Results:** Carers of people with

ID report that they experience considerable barriers to accessing general practice care on behalf of the people they care for. **Conclusions:** Given the ever-increasing number of people with ID now living in the community and their vulnerability to health problems, it is imperative that future research focuses on the development of strategies to overcome the barriers identified in this study

Ong, N. , McCleod, E. , Nicholls, L. E. , Fairbairn, N. , Tomsic, G. , Lord, B. , & Eapen, V. (2017).

Attitudes of healthcare staff in the treatment of children and adolescents with intellectual disability: A brief report.

Journal of Intellectual & Developmental Disability, 42(3), 295-300. doi:10. 3109/13668250. 2016. 1236368

Background: Children with an intellectual disability (ID) have complex health needs that extend beyond the expected cognitive deficits, affecting a myriad of developmental domains. These children frequently receive inadequate health care such that their needs remain poorly managed. **Methods:** Staff from the Sydney Children’s Hospital Network (N=160) completed a survey on attitudes, experiences, and training satisfaction when working with patients with ID. The 48 question needs analysis survey was distributed electronically to staff from a variety of disciplines and experience levels. **Results:** Although staff considered themselves broadly competent in caring for children with ID, they were less confident in specific skills, such as managing associated challenging behaviours in the clinic. As confidence in skills such as these decreased, the desire for further training increased. **Conclusion:** This study emphasises the importance of providing accessible, high-quality professional development resources to further develop these skills.

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... Articles related to Health

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Webber, R. , Bowers, B. , & Bigby, C. (2016).
Confidence of group home staff in supporting the health needs of older residents with intellectual disability.

Journal of Intellectual & Developmental Disability, 41(2), 107-114. doi:10.3109/13668250.2015.1130218

Background: Increased life expectancy for people with intellectual disability is accompanied by increased age-related health concerns. People ageing with intellectual disability experience more health conditions and are relocated to aged care earlier than their age peers. **Method:** Group home staff were surveyed about their (a) training and confidence in 11 health conditions and 7 health procedures, and (b) attitude to relocating residents with health needs to aged care. **Results:** Staff training in each of 10 health conditions and 7 health procedures was positively associated with increased confidence in supporting residents with those health issues. Higher staff confidence in caring for residents with 9 conditions and requiring 4 procedures was negatively associated with a likelihood of recommending that a person with those health needs should relocate to aged care. **Conclusions:** Targeted training of staff in age-related health issues may contribute to better health care and delay residents relocating to aged care.

Weise, J. , Pollack, A. J. , Britt, H. , & Trollor, J. N. (2016).

Who provides primary health care for people with an intellectual disability: General practitioner and general practice characteristics from the BEACH dataset.

Journal of Intellectual & Developmental Disability, 1-6. doi:10.3109/13668250.2016.1250252

Background: People with an intellectual disability (ID) have complex healthcare needs yet experience barriers to participation in primary care. Further

research is required to examine if the characteristics of general practitioners (GPs) and their practices influence their delivery of care to people with ID. **Methods:** Data from the Bettering the Evaluation and Care of Health program was used to determine if there are significant differences in the ID-GP and Non ID-GP group. Analysis included characteristic-specific rates, chi-square, and odds ratios. **Results:** This study found that GPs who were Australian medical graduates, practising in rural areas, in accredited practices, and in some states of Australia were significantly more likely to be classified to the ID-GP than the Non ID-GP group. **Conclusions:** This research suggests that certain GP and practice characteristics may present barriers to primary care participation for people with ID and supports the need for a comprehensive national action framework. ●



Centre of Research Excellence in Disability and Health (CRE-DH)



The Centre of Research Excellence in Disability and Health (CRE-DH) was launched on the 27/06/17. The centre was launched by the Disability Discrimination Commissioner, Alistair McEwin, with a panel event featuring the Commissioner, media personality Julie McCrossin, writer and performer Emily Dash, and journalist and appearance activist Carly Findlay. See photos or read the transcript at <http://credh.org.au/launch-event/> of the event.

The centre aims to identify cost-effective policies that improve the health of people with disabilities in Australia. The centre involves an impressive range of local national and international researchers, practitioner and people with a lived experience of disability <http://credh.org.au/>

The centre's webpage states the following:

While 15% of the world's population have a disability, they have largely been ignored by public health research, practice and policy. Research clearly shows that on traditional indicators of health, Australians with disabilities fare particularly badly in global terms – they have the lowest relative income and one of the lowest levels of labour force participation of all the OECD countries. An Australian with a disability is more likely to be unemployed, live in inadequate and unaffordable housing, have not completed school, and live in financial stress. They may face discrimination in all aspects of their lives including their experience at school, with the health system, getting a job, and their family situation. All of these aspects contribute to their poorer

health. Reducing these inequities would substantially improve the health of Australians with disability. Improving their health will also increase the overall health of the population, and significantly reduce health and welfare expenditure.

Solving the problem of disadvantage

Solving the problem of disadvantage and the consequent poor health of people with disabilities requires a robust knowledge base to inform policy reform. This is why the CRE-DH is important. The Centre of Research Excellence in Disability and Health is a world first; it aims to gather the evidence needed to guide social and health policy reform for people with disabilities in Australia. We bring together an interdisciplinary group of researchers with stakeholders from the health and disability sectors, state and federal governments, and disability consumer representative groups – who are embedded in the research design and development. In collaboration with people with disabilities, service providers, non-government organisations and other stakeholders, we will identify the key and emerging issues affecting Australians with disabilities. Based on these ongoing consultations we will document how these vary between people with and without disabilities over time, across different geographical areas and between subgroups of the population. Our team is characterised by diversity – from public health academics to disability advocates, health economists and policy analysts – all of whom are focused on reducing disadvantage for people with disabilities.

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Mental Health Core Competency Framework

The Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals describes the specific skills and attributes required by mental health professionals for the provision of quality services to people with an intellectual disability. It outlines the necessary approaches to clinical practice when working with people with an intellectual disability and identifies the core competencies that mental health professionals require to work in this area.

The Framework also includes a self-assessment tool to help professionals determine their current skill set and guides readers to resources



that support professional development in intellectual disability mental health.

The Framework was developed in consultation with key stakeholders, and was funded by Mental Health-Children and Young People, NSW Ministry of Health

<https://3dn.unsw.edu.au/IDMH-CORE-COMPETENCY-FRAMEWORK>

CRE-DH

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Our research

We will map the spatial distribution of social, economic and health inequities between people with and without disabilities; apply cutting-edge epidemiological methods to establish the main social determinants of health of people with disability; build the first ever cost-effectiveness model to estimate the health impacts and value for money of policy interventions for people with disabilities, and embed stakeholders in the research process so that they are involved in the co-production of knowledge.

Capacity building

A major focus of the CRE-DH is to produce a skilled research workforce in disability and health. This

means we will train early-career researchers and PhD students and build the research capacity of academics and policy-makers across sectors to respond to the pressing problem of people with disabilities' poor health.

Note from the editor:

We look forward to the results of research from this Centre. How their work will assist people with an intellectual disability is still an unknown. ●

President's report

Dr Angus Buchanan



I have had the privilege to be the President of ASID for nearly five years with my term coming to completion in November 2017. In preparing my final President's Column I have reviewed all of my previous inclusions in to IDA. What I was struck by is how much has happened over the past five years, both within and external to the organisation. There is little doubt since 2013 the disability sector has been turned on its head with the 'once in a generation' change of the NDIS. The expectation of what it can deliver for people with intellectual disability continues to be challenging with both many positive outcomes and significant issues for individuals and families. Over the same time ASID has been an organisation going through change and development to ensure it is best positioned in a contemporary world to meets its strategic goals.

In my first column five years ago I asked the question "do you have moments and happenings in your life where you have had an encounter that leaves you challenged for the better? I shared my experience from the ASID Conference Dinner in 2012, where the guest speaker from Weta Studios (Lord of the Rings fame) explained that when they made props for movies they were real and built with complete authenticity. An example was that all the swords used in the films were made by master craftsmen. It has been something that has stuck with me. When something is important you should built authentic approaches to ensure the outcomes you desire. I would like to think that this is what ASID has been doing over the past five years.

One of the roles of ASID is to be a voice for people with intellectual disabilities through the use of research and evidence to support effective practice. ASID continues to achieve this outcome

through the publication of two excellent journals – The Journal of Intellectual and Developmental Disability (JIDD), and Research and Practice in Developmental Intellectual Disability (RAPIDD). RAPIDD was launched in 2014 and is growing into a respected and successful publication. ASID also has continue to run the successful Annual Conferences that provides an excellent platform for the sharing of research between families, service providers and people with disabilities.

To position itself for the future, the last five years have seen a major development of a contemporary governance model for ASID. In 2014 the decision was made to form one Australasian organisation moving from seven independent regional based incorporated bodies. This was major decision which has seen the formation of a strong, focussed and financially sustainable organisation with seven divisions. Recently the decision was made to reduce the number of Board directors from 21 to 14. It is positive that ASID has had the willingness and the ability to navigate such major governance changes. The building of the new entity has seen a range of major activities that would previously have been impossible. One example is the employment of a new executive officer. Having an EO has enabled the organisation to be more effective and responsive. The benefits of the additional capacity are already being seen in member communication, website development and other improved procedures.

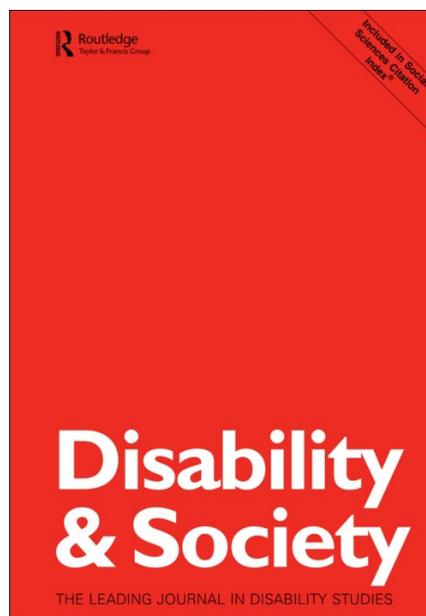
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ASID are excited to announce that individual members can now access two more leading journals on our website: **Disability & Society** and the **Journal of Mental Health Research in Intellectual Disabilities**.



The Journal of Mental Health Research in Intellectual Disabilities (JMHRID) is the official research journal of NADD and is published quarterly by Taylor and Francis. It is an international, peer-reviewed interdisciplinary journal with the purpose of reporting original scientific and scholarly contributions to advance knowledge about mental health issues among persons with intellectual and developmental disabilities.

See more at
<http://tandfonline.com/toc/umid20/current>



Disability & Society is an international journal published 10 times a year by Taylor & Francis. It provides a focus for debate about such issues as human rights, discrimination, definitions, policy and practices.

It appears against a background of change in the ways in which disability is viewed and responded to.

See more at
<http://tandfonline.com/toc/cdso20/current>

President's report

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As I have said many times before ASID is still primarily a volunteer based membership organisation. ASID's success is directly related to the many hours that are freely given each year by the many individuals to run local Divisions, plan conferences and events, edit journals, produce newsletters, attend board meetings and committees and run various portfolios. As President I have been well supported in my role by a strong and able team of volunteers who I sincerely thank for their dedication and commitment.

As we look to the next five years, ASID has an important role to play in the dynamic and changing environment for people with intellectual disabilities ensuring the link of research to practice is at the forefront of developments. ASID's voice will remain relevant, strong and authentic through current and new activities. ASID is as strong as its membership and I encourage you not only to continue to support this organisation but promote it widely.



Division Update

Aotearoa NZ

by Fran Hartnett

On August 10 & 11 2017, the Australasian Society for Intellectual Disability held its first New Zealand conference solely for support workers entitled “Support Workers Talking”. Fifty-seven support workers talked for a day and a half and went away informed, invigorated, and re-inspired. The event was a great success

and the New Zealand Division hopes to replicate this success with a similar event in Auckland late in 2017. Olive Webb and John Grant played leadership roles in getting this event off the ground.

The powhiri supported by the Hillmorton High School kapahaka group was spine chilling and the poroporoaki, with a closing hymn, launched and closed the event perfectly. Richard Buchanan gave a warm, entertaining and heartfelt talk about how

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support workers impacted on his life. John Grant took participants through a series of questions in the format of a “World Café” providing participants with an opportunity to reflect, share and discuss key aspects of support work. The World Café stimulated vibrant conversation and debate which reached new heights as participants confronted difficult and contentious issues in a session facilitated by Adrian Higgins. Adrian acknowledged and shared examples of the many complex and challenging situations that may confront support workers. The Learning Market Place complemented the talking by showing participants new ways to engage and teach the people. New technologies and new uses of old technologies were fascinating. Presenters and topics included: Trisha Ventom Emergency Planning : Jacinta Grice – Tac Pac; Laurence Walker - Video Self-modelling; Lynley Kerr – Communication and Apps; Hannah Perry – Enabling Good Livesp; Rachel Sadgrove - Visual communication strategies.

Issues discussed at the conference were drawn together by Rebekah McCullough and summarised in a form that will be sent back to participants and the organisations that sponsored their attendance. The venue was perfect, made available to ASID at no cost and ideally suited for an event like this.

NSW & ACT

no report

South Australia

no report

Queensland

by Paul O’Dea & Morrie O’Connor

Significant activities have included a consultation with self-advocates to brainstorm potential titles and themes for ASID National Conference at Gold Coast in November 2018.

Paul O’Dea, QLD National Board Member and Michelle Moss, QLD Divisional Committee led the consultation.

The group recommended two potential titles:

- ‘Let’s Shake It Up: Human Rights for Everyone’
- ‘Stop Talking; Let’s Just Do It: Human Rights for Everyone’

We will be taking these to the National Board for discussion and decision.

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The group also discussed potential conference themes and votes on their preferences; these are as documented below. These suggested themes will also be taken to the National Board for discussion and decision.

Themes & voting

- Human rights - 6
- Bullying and abuse - 5
- Living independently - 5
- Mental illness - 4
- NDIS - 4
- Health and hospital - 3
- Scammers and safety - 3
- Access for people in wheelchairs .. - 2
- Housing - 2
- Transport - 2
- Jobs - 0
- Budgeting - 0

QLD Division is also hosting two local workshops this year. First one ‘What Makes a Good Worker’, second one ‘Trauma and Intellectual Disability’.

Paul O’Dea also continues in his work in the Peer Leadership program which is a project aimed at informing people with intellectual disabilities who are on society’s fringe about the NDIS.

Victoria

by Mark Di Marco

The Victorian ASID continues to meet monthly at Haskins pub in north Fitzroy, Melbourne. The committee continues to focus on providing a range of seminars that are of interest to our members.

A very successful ASID workshop was held recently at the Multicultural Hub in Melbourne. The workshop focused on the health needs of people with an intellectual disability and explored how to promote good healthcare. The workshop provided participants with a range of ideas, tips and strategies. We

were fortunate to have Prof Nick Lennox and Dr Jane Tracey facilitate this workshop. The event was well attended and feedback from the participants was positive as reflected in the following feedback, ‘I think the entire seminar was both useful and interesting. I have certainly taken many things away with me. All information was relevant and solid and I will use it when I can’. Following up on this event we have released a podcast, available on the ASID website, with Jane and Nick talking about how to optimise health care.

Hilary Johnson, on behalf of the ASID board was asked to participate in a forum held by Speech Pathology Australia on August 24th. This forum was held as part of Speech Pathology Australia’s awareness week. The forum brought together a diverse group of stakeholders to look at Communication Access and how to ensure all people with a communication difficulty can participate in the community and be treated with dignity and respect. For more information on the initiative see <http://bit.ly/20RZOAr>

Our next event will occur on the 5th October on the topic of ‘supported decision making’.

Western Australia

no report

Tasmania

by Darryleen Wiggins

The Tasmanian region is well into to the throws of ensuring that this year’s Australasian conference is a great success. We have been heavily supported this year by the whole Australasian board of directors. You will find the preliminary program on the ASID website here <http://www.asid2017.com.au/wp-content/uploads/2017/08/2017-ASID-Conference-program-10.08.17.pdf>

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The theme of the conference is “Pushing the Boundaries”. It reflects the major challenges facing all communities who desire to realise the goals of the UN Convention on the Rights of Persons with Disabilities. In Australasia, it encompasses the issues arising from new approaches to service provision such as increased self-direction, choice and control.

The program highlights the theme of the conference across many of the abstracts and certainly assures that the 2017 conference will be pushing the boundaries in November and beyond.

Although early bird registration has now closed you still have time to register and be part of the conference.

Aside from the conference the Tasmanian region has not been functioning as a committee for the past 12 months. I would like to hear from people who might be interested in coming together and forming a functioning committee so that ASID Tasmania can support ASID’s focus on research to practice. Contact me on darryleen.wiggins@lifestylesolutions.org.au for further information on becoming a committee member. ●



keynote speaker profile:

Rob Greig

Chief Executive
National Development Team for Inclusion
Rob.Greig@ndti.org.uk



My involvement in the world of learning disabilities (the terms used in the UK for intellectual disabilities) came about more by luck than judgement. Through circuitous routes, I found myself working for a London Health Authority, planning the closure of large mental illness institutions. After a couple of years, the Health Authority Chief Executive ‘press-ganged’ me into applying to be Director of Learning Disabilities. Thinking this could be an interesting diversion, I had no idea that this job-change was to prove life changing. My direct engagement with people with learning disabilities up until then had been limited to a cousin with Down Syndrome who had died several years previously. Just a few weeks in, it was blindingly obvious (to me, if not to services at the time) that the real issue was how society viewed and treated people with learning disabilities. Yes, efficient and effective services are important, but only to the extent that they are helping people lead good lives as equal citizens and community members. Given that politics had been my passion up to that point – work became the vehicle through which societal change could be achieved – as we (for example) developed one of the UKs first supported employment services and replaced the institutions with ordinary housing and support and real tenancies. With hindsight though, we were still operating a paternalistic service model. The voice of people with learning disabilities was largely absent. Two jobs on and a few years later, another of those life-changing moments. A call from the Department of Health invited me to be the external advisor on

the development of a new English learning disability policy – what eventually became the Valuing People White Paper. Valuing People fundamentally shifted English policy. Previously, policy was about how services could best care for people. Valuing People sought to ensure that people lived a full life as equal citizens – with the role of services being to support that. People with learning disabilities (and family carers) were central to developing that policy – the first time that had ever happened with any Department of Health policy. Voice became a national policy priority – “Nothing About Us Without Us”.

The Government created a role to head up the delivery of Valuing People, reporting directly to the Minister. I applied and one of my proudest moments was when the panel of people with learning disabilities (who were part of the process) unanimously plumped for me! There followed exciting years where, with a brilliant team and a small budget, we set about trying to change the culture and attitude that underpinned services. We had some success but our no doubt overly ambitious aspirations were far from fully met. After six years, it was time to move on as Government priority for the policy waned. Since then, I’ve headed up the independent National Development Team for Inclusion (NDTi) where we work on similar issues of rights, choice and inclu-

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Doctors told to offer mums a screen for intellectual disabilities

(*Gatton Star* – 31/07/2017)

Drs have been told to offer screening for a syndrome causing intellectual disabilities - including autism - to all women who are pregnant or planning to have children.

The genetic test for fragile X syndrome - the leading cause of

inherited intellectual disability - costs as little as \$100, the Daily Telegraph reports.

<https://www.gattonstar.com.au/news/drs-told-offer-mums-screen-intellectual-disabiliti/3206824/>



Rob Greig

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sion, but across all aspects of disability and ageing.

I have learnt so much from this (and other) work – too much to share in this short piece. Some brief headings though – with an underpinning theme that for every positive there’s usually a negative, and the challenge is often to manage that balance:

- There is no substitute for sound values and principles – but don’t be conned by people who spout the right words. Check out what people do in reality.
- Evidence of what works is really important, but many people (including politicians), are only really interested in evidence that supports their case.
- Government policy support is important, but on its own is not enough – local leaders are those who really make change happen. The absence of Government support can be equally important and the interest of politicians in disabled people has to be con-

tinually nurtured and campaigned for.

- Building teams of like-minded people is an essential building block of positive change. Look for allies, build connections, but also make sure you avoid ‘group-think’.
- The most important alliance of all is that with people with learning disabilities and families. They have a life-long investment in policy leading to better lives.

Which leads me to three crucial headlines for how I would urge everyone to operate:

- (1) Stick to your values,
- (2) Make sure you can evidence what you claim, and,
- (3) Always work to move more power to people and families.

For those interested in hearing more, I hope to meet you at the ASID Conference in Hobart. ●

keynote speaker profile:

Judy Huett

Self-Advocate with Speak Out
burnie@speakoutadvocacy.org



My Name is Judy Huett,

I was born and raised on the west coast of Tasmania in a small town called Strahan. My father was the Harbour Master and my mother a teacher's aide at the local primary school. My parents always wanted me to be included in my community. This is easier in small towns than larger cities where people are strangers.

I am happily married to Peter and we live in Burnie on the north west coast.

I have been with Speak Out for around 15 years. Speak Out is an advocacy service for people with disability, but also a member organisation for people with intellectual disability. We have around 200 members state-wide. Speak Out's governance structure includes people with intellectual disability. We have 6 regional representatives and a Members President who are voted by the members from our three regions. The President sits on the Speak Out Board. All our work around intellectual disability is done by getting the advice and experience of our members.

Speak Out has been a good pathway for me to become a strong self advocate. I first started as a member, then was elected as a regional representative and President. I have been employed by Speak Out part time for around 5 years, I really love my job. I am the Self-advocacy support. I support the Members Executive and mentor new and upcoming leaders within the organisation. I also do some work where I help consumers of organisations talk about the quality of their services and how to improve it.

I have been a member of the NDIA's Intellectual

Disability Reference Group for two years, we give advice around intellectual disability and the NDIS. I have also just been appointed as a Member of the NDIA's Independent Advisory Council. The Council gives advice to the NDIA Board around the NDIS. I think it is really important to have someone with an intellectual disability on these. We get to have a say, I take the experiences of not only myself, but from Speak Out members.

Good support is really important for people with intellectual disability to help them grow into strong self advocates. The support I have gotten from Speak Out over many years means I have someone with me at meetings to help explain information if I don't understand and to read board papers. I have had many opportunities to contribute to my community, to grow and help others grow as well. I've travelled overseas to conferences, I've spoken in parliament and I've been on many boards. Without good support and mentorship I wouldn't be the self advocate I am today. ●



UQ MOOCs

The Able X Series - Intellectual Disability Healthcare around the world - Online learning

Miriam Taylor

Education Coordinator
 m.taylor3@uq.edu.au;
 Queensland Centre for Intellectual and
 Developmental Disability QCIDD

The Able X series has been developed through The Queensland Centre for Intellectual and Developmental Disability or QCIDD. The centre commenced in 1997 and is located in the Mater Hospital in Brisbane Australia, as part of the Mater Research Institute, the University of Queensland, and it aims to improve the health and wellbeing of adults with intellectual and developmental disability who live in Queensland through clinical practice, education, research and advocacy.

The ABLE X Series

In the first round of this popular Massive Open Online Course (MOOC) series, we had 7000 enrolled students. Now in the second round, we have nearly 5000 students. 120 contributors from 22 countries



Miriam Taylor

have made this course series dynamic and highly interactive. Our students come from 135 countries! The courses are self-paced and free.

ABLE101x – Through my Eyes focuses on the stories of people with intellectual disability around the world, and their families and supporters. Over four parts, students will look at the barriers and enablers to healthcare for people with intellectual disability, their experience of specific syndromes and communication difficulties, and how they *continued page 28*

stay healthy. Students will listen to family members speaking about complex care, rare syndromes, early death, and planning for independence. The final component focuses on the history of treatment, the impact of rights' movements on healthcare delivery, common health conditions, and health promotion.

<https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x-0>

ABLE201x – Well and Able examines the specific physical health issues that affect people with an intellectual disability including, oral health, syndrome specific health issues, health communication, especially for non-verbal patients, sexual health, and interactions between tertiary and primary healthcare systems. There is a special section on complex care including issues associated with aging and spasticity, and the health impacts of epilepsy.

<https://www.edx.org/course/well-able-improving-physical-health-uqx-able201x-0>

ABLE301x – Able-Minded focuses on the mental health issues of people with intellectual disability. Students learn about the complexities of diagnosing mental health issues in people with intellectual disabilities and the types of disorders, assessments, screenings, and treatments used. There is a special focus on the legal and ethical complexities in health practice with patients who often require substituted consent.

<https://www.edx.org/course/able-minded-mental-health-people-uqx-able301x-0>

Here are some of the interesting comments and insights from the most recent students of the courses:

USA

I know personally, raising my son, how hard it is for people with disabilities to be accepted. We live in the Tennessee, USA, the options are getting much better for help but it's people in general who are cruel. Adults need to teach their children to be more accepting & teach them to treat everyone the same, to offer friendship & help against others who are being mistreated. As quality of life is probably the most important aspect of caring for an individual with I/DD, quality of death should also be consid-

ered. I would try to communicate with Ray about how he feels, both physically and emotionally, have pain medication administered, and mostly just be there with him. I was with my father as he was dying of cancer, and when he could no longer speak it was difficult to determine his needs. But I think what he appreciated most was that I was there by his side through to the end.

NIGERIA

In my country there is no mainstream support in place for aging people with or without disabilities. Children generally house their aging parents disabled or able, and cater for them by themselves. Such responsibilities usually fall on the wives and can be very stressful at times but that is our norm.

LEBANON

In a third world country like mine, mental health is taboo. Poor people are treated in very large hospital type institutions. Private consumers usually stay at a wing of a regular hospital specialized in mental health.

NEPAL

I have seen some who are having mental issue, they are not getting proper counseling from their family, relatives, society and even from governmental support.

Other Courses

- ASK Diary (Advocacy Skills Kit Diary)
<https://appsto.re/au/pkVubb.i>
- What about our YouTube channel?
https://www.youtube.com/channel/UChCUpCHdvnHqAf8SSBOuV_tA
- Dive into our free course for support workers about being a great health advocate for people with disability.
Email m.taylor3@uq.edu.au to get the pdfs.
- Having a yearly health check keeps you well, and here's why
<http://eshop.uniquet.com.au/chap/>
- Girls, are your periods hard to handle?
Plenty of tips here for you:
 - <http://www.qcidd.com.au/me/health/women-s-health>
 - <https://qcidd.centre.uq> ●

extract from

A Day in My Shoes

by Amanda Millear



Amanda Millear

Amanda has agreed to some of her story being republished in IDA. The story is about her early life growing up at school in Melbourne and home on the farm. The long story can be found by clicking on this link <http://arrow.latrobe.edu.au:8080/vital/access/manager/Repository/latrobe:37717>

The story was started in 2011 by Amanda Hiscoe and David Henderson and finished in 2014. Amanda got divorced since writing her story and now prefers to be known as Amanda Millear.

When Amanda was six years old her parents decided to send her to Melbourne to attend a special school.

‘So then I’ve been down in Melbourne since six years of age’, Amanda explained. She told David how she had lived in hostels and boarding houses and all kinds of different accommodation. ‘I shared a flat and I also lived in one by myself and all this was done while I was going to school. I went to a special school for slow learners. It was from 1965 or 1966 until the end of 1972 and that was my school life’.

The school was an old two-storey brick homestead on Power Street in Hawthorn. By Amanda’s own account, her first days at school were scary.

‘I still remember even now going into the mistress’s house. I remember sitting at this big table and I was one of the first students. I guess I must have been very alone because I’d never been down to the big smoke before and at six years of age it must have

been very scary stuff. Like walking into a big room as if I was a little mouse. In terms of what it (school) was like, it gave me the skills I need today. They went at a slower pace. I learned to read and write and also did swimming lessons. We used to have sports days and everything else.’

Amanda went home for the school holidays and she has vivid memories of this precious time she got to spend with her brothers and sisters on the farm. Each year, the family would pile into the car for their annual holiday to Narooma. Amanda’s grandmother owned a house outside the town that looked out over the ocean.

‘We would often go fishing in Dad’s boat and I will always remember this. Dad held up a trumpet fish up to my left ear and I couldn’t hear it because that was my deaf ear.’

‘I was the only one that didn’t have home schooling’, said Amanda, ‘the others did. Ruth, Pete, and my younger sister had home schooling.’

‘My youngest sister works in the country area in Victoria with her family.’

continued page 30

A Day in My Shoes

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‘Peter, my brother is in Queensland and he’s got two grown up children who are now are legally adults.’

‘Mum’s still living where she’s living and Ruth has got three grown up children as well. And most of them have got cars!’ Amanda laughed. ‘Look out on the road!’ she exclaimed, ‘Gee! Oh gee wiz’.

‘We had that property’, she said, referring to the family farm 56 miles from Deniliquin. ‘And we had a dog called Penny and Dad also had cattle and sheep as well. If the cattle came in the house yard, you know, Penny would bite their heels. Snap, snap, snap, snap, snap. She was a corgi and she would nip the heels of the cattle to get away’.

‘We’ve had fires, floods, a grasshopper plague and a mouse plague and droughts as well!’

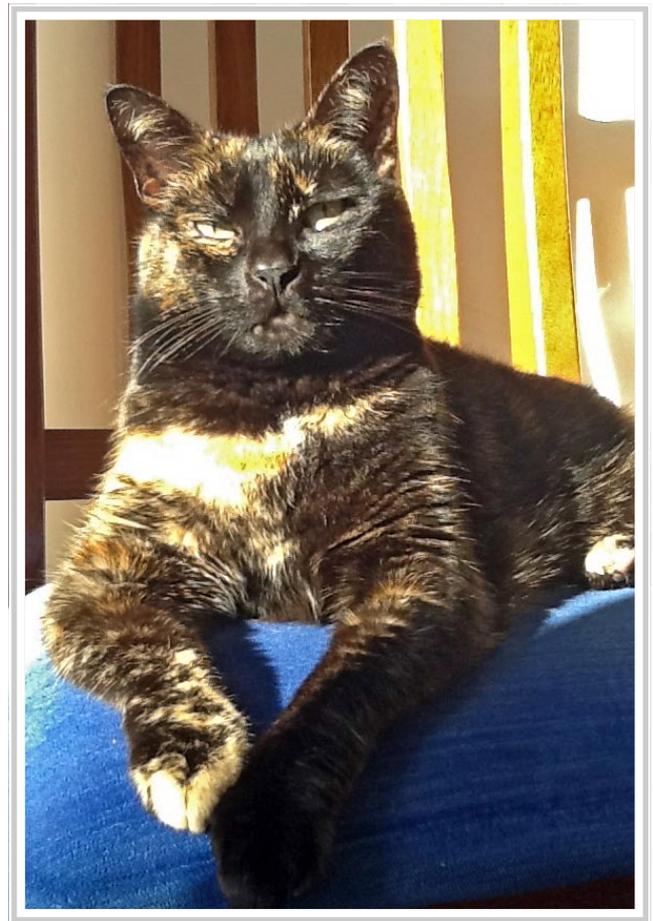
‘The poor cats’, she cried, before launching into story about a time when the house had been overrun by hundreds of mice.

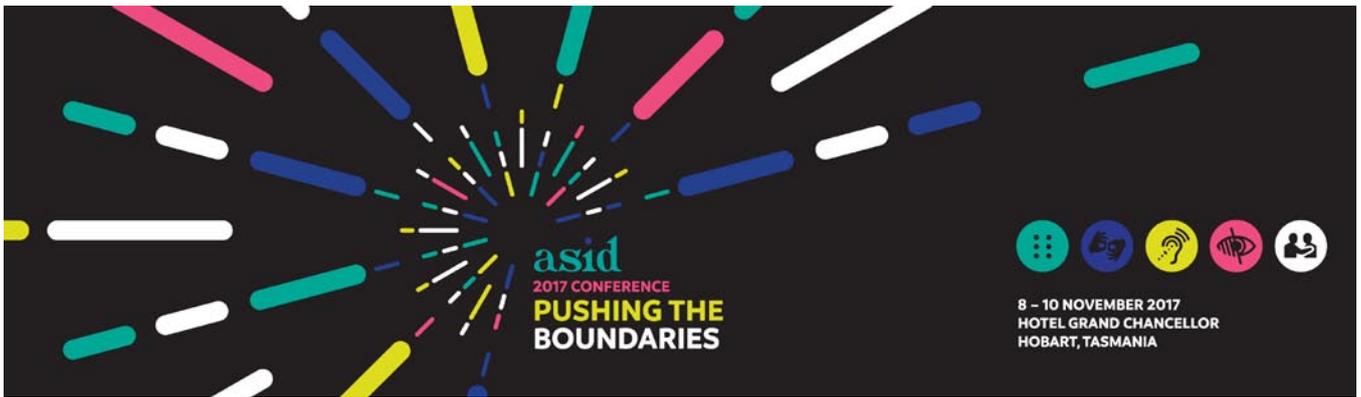
‘They didn’t know what to do with the mice because they were everywhere. In Mum’s drawers! Yuck! The poor cats’, Amanda said again. ‘They didn’t know what to do. Oh they were in the hay bags and everything. Yuck! Then, outside the kitchen door there was this old Agar stove that sat this way and a hot-water tap was on there’, Amanda said as she was painting a picture with her hands.

‘Muff and Two Butter cats and a whole lot of other cats used to sit there. As soon as the back door opened: “Meow, meow! Rar, rar, rar, rar!” Now when it come feeding time, watch out, watch out! “Ree-ow!” They would even jump up this high to get the plate’, said Amanda. She held her hand about a meter and a half above the ground to indicate the height of the stove.

‘At one stage, 24 cats at once, whoa! Each of us four kids had our own little pet cat. Mine was Two Butter

Cats. And there was this cat named Muff, and she was the mother of all cats. There was Santa Claus and so on and so on. I think I’ve got thousands of cat photos’, she said, ‘don’t ask me where they are, but they’re somewhere at home’. ●





The Australian Society for Intellectual Disability (ASiD) National Conference is being held in Hobart from November 8 until 10, 2017

The conference theme, *Pushing The Boundaries*, is highly pertinent and reflects the critical challenges facing all communities in Australia and New Zealand who desire to realize the goals of the UN Convention on the Rights of Persons with Disabilities.

In Australasia, it encompasses the issues arising from new approaches to service provision such as increased self-direction, choice and control.

The conference program is available on the website and it is an inclusive and exciting program with many opportunities for discussion and debate and networking with peers and key people in Australasia.

<http://www.asid2017.com.au/program-2/>

ASiD's focus is research to practice – the dialogue between researchers, practitioners, service providers, governments, families and people with intellectual disability which has the goal of finding better ways to support inclusion for individuals and to change systems.

The 2017 Conference follows on from the success of the 2015 ASiD National Conference in Melbourne to host the conference dinner over several different restaurants in Hobart.

Each restaurant will be attended by one of the Keynote speakers and there will be an opportunity to have more informal conversation and explore in more detail those issues that are pertinent to your practice.

For people who know or have been to Hobart previously the restaurants will be:

Mures Upper Deck

<http://mures.com.au/upper-deck/>

The Drunken Admiral

<http://drunkenadmiral.com.au/>

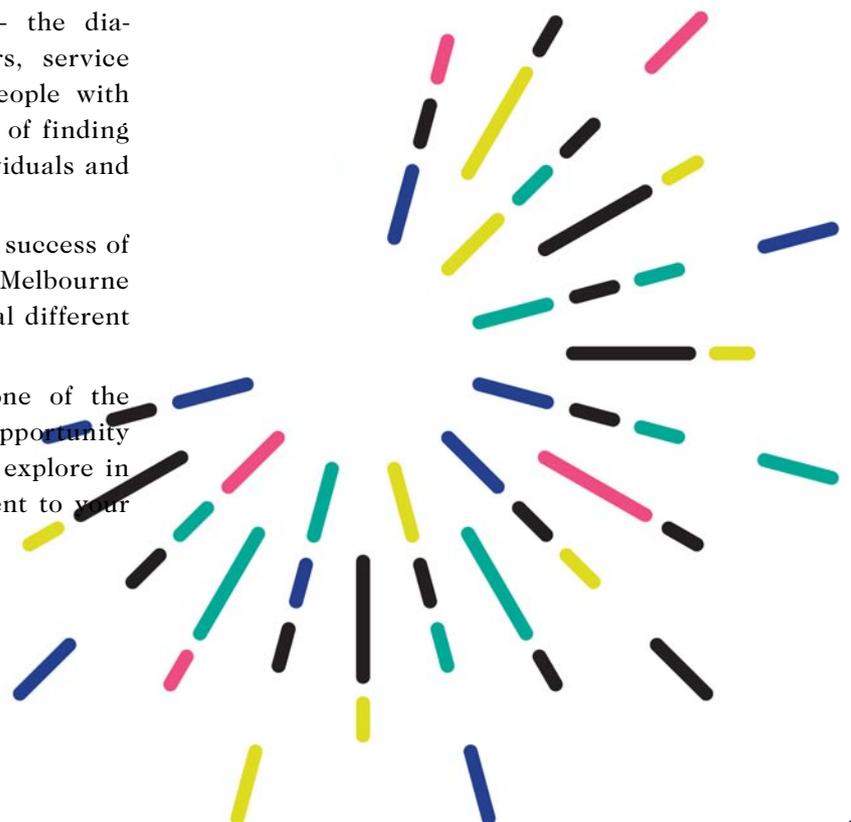
The Astor Grill

astorgrill.com.au

Awu Delicious Food Chinese

<http://www.awums.com.au/picview/about.html>

The Keynote speakers are leaders in their field of expertise and we anticipate that in sharing a meal together you will develop critical insights into their knowledge and learning from practices. So stay tuned to your email for which speaker will be dining where!



Upcoming Events

5 Oct 2017	Supported Decision Making Multi cultural hub, Melbourne http://www.asid.asn.au/events
16 - 17 Oct 2017	Person-Centred Planning and Practice Workshop Darwin https://cde.org.au/
17 Oct 2017	Easy English – an introduction Melbourne http://www.scopeaust.org.au/service/education-training/
24 Oct - 3 Nov 2017	A series of New Perspectives master classes and seminars La Trobe University, Melbourne http://www.latrobe.edu.au/lids/events-and-seminars
8 - 10 Nov 2017	Australasian Society for Intellectual Disability Annual Board Conference Pushing The Boundaries The Grand Chancellor Hotel, Hobart https://www.asid.asn.au/events/53_2017_asid_conference__pushing_the_boundaries
13 - 16 Nov 2017	2017 IASSIDD 4th Asia-Pacific Regional Congress Inclusiveness and Sustainable Development The Ambassador Hotel, Bangkok, Thailand https://www.iasidd.org/conference/index.php/2017APRC/2017APRC/schedConf/overview

If you want to advertise in IDA's upcoming events section,
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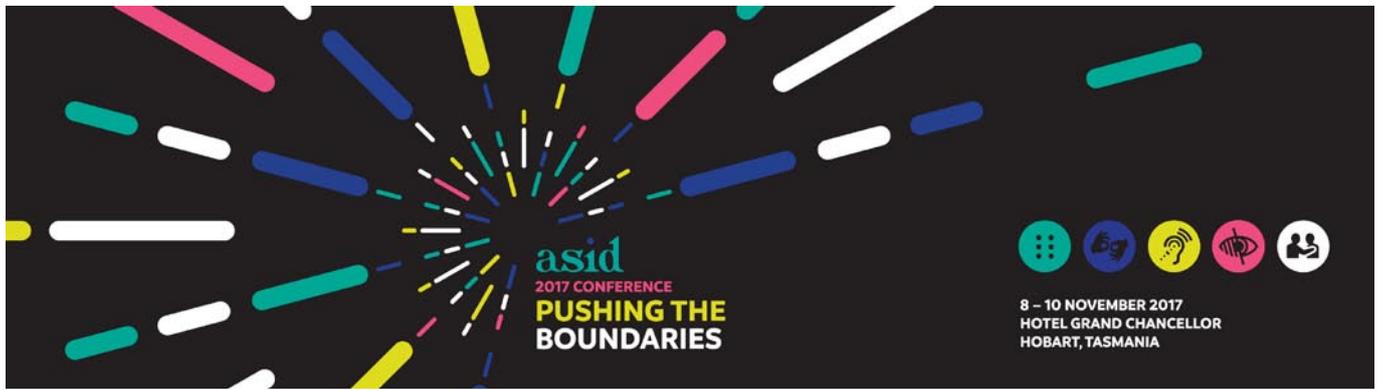
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Hobart on 8 - 10 November 2017**

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Leanne Dowse



Rob Greig

Further information available on the [ASID 2017 website](#)