



# AADDM

Australian Association of  
Developmental Disability Medicine

April 2018

## Submission to Independent Hospital Pricing Authority Development of the Australian Non-Admitted Care Classification

### Introduction

The Australian Association of Developmental Disability Medicine (AADDM) is an organisation of medical practitioners who specialise or have an interest in the health of the over 300,000 Australian children, adolescents and adults with intellectual disability (ID). The key aim of the AADDM is to improve the health of children, adolescents and adults with intellectual and developmental disability.

We commend the Independent Hospital Pricing Authority (IHPA) for examining the evidence for adjustments to mental health care patients with concomitant ID. The ANACC system is a new classification being established by IHPA to classify non-admitted care in the future. The new classification is being established with the aim of replacing the current Tier 2 Non-Admitted Services Classification with a more patient centric model that will benefit data capture and also be useful beyond ABF for policy and other purposes. The development of the ANACC builds on a significant program of work to refine the ABF framework for non-admitted care.

There must be formal recognition in this new funding system that ID itself represents a risk for complexity of health care needs and poorer health outcomes. The health disadvantage for people with ID is stark. An analysis of NSW data highlights very high mortality rates in people with ID compared with the general population<sup>34</sup>, and that 38% of deaths are potentially avoidable in this group (over 2 x the proportion in the general population)<sup>35</sup>. Such stark differences in outcomes justified inclusion of this group as a specific focus in all healthcare initiatives, coding and outcomes analyses.

ID is a complexity factor which needs to be accommodated in every aspect of health care in including non-admitted patient care services. For example, complexity for people with ID was clearly evident in an analysis of ambulatory mental health data (which is a non-admitted patient care dataset). In a recent analysis it was shown that service use profiles revealed that people with an ID had 1.6 times more face-to-face contacts, and a total face-to-face contact time which was 2.5 times longer than people without an ID<sup>36</sup>.

An analysis of nationally representative GP data showed that people with ID had skewed demography, an over-representation of presentations for psychological, social and 'general and unspecified' reasons, and an under-representation of presentations for core physical health and preventive health measures. Administrative rather than medically related reasons dominated

---

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDMM

Australian Association of  
Developmental Disability Medicine

presentations to general practice at ID encounters, making it harder for GPs to get to preventative healthcare<sup>37</sup>.

In another analysis of nationally representative GP data it was shown that people with ID experienced significant differences in consultation types, consultation length, problem(s) managed during the consultation, medications, treatments provided, and referrals compared with people without ID. People with ID had longer consultations, more problems managed, but an under management of common health conditions in people with an ID. Administrative rather than medically related actions dominated clinical treatments for people with ID, and they received fewer procedural treatments, referrals to specialists, and medications compared with those at 'non-ID' encounters<sup>37</sup>.

Furthermore, an analysis of trajectory after first mental health admission showed that the presence of intellectual disability independently and strongly predicted subsequent likelihood of emergency department visits and readmission to hospital, suggesting both complexity and lack of cohesiveness of non-admitted patient care for this group<sup>39</sup>.

There are significant cost and resource implications for provision of health care services for people with ID. Consultations and other health care interventions typically take substantially longer and require the involvement of more than one health or other professional than standard models of care. People with ID often have many complex comorbidities that require a team of highly skilled clinicians to work in a collaborative approach to both diagnosis and treatment. Participation of the person with ID in their health care may also involve carers or other support people, and adjustments to the model of care, particularly in relation to the nature of communication between health professional, person with ID and their carer. Communication barriers have an impact on the capacity to accurately identify the diagnosis and associated comorbidities and develop an effective treatment plan.

Emerging evidence documents that for people with ID, there are an increased number and more complex health encounters and that some elements of the health system are disproportionately affected, such as inpatient services. This is particularly relevant for this IHPA review, as effective outpatients/community care services may lead to better health outcomes and reduced inpatient services and costs.

***Funding of outpatients services that favours short, streamlined consultations, as currently occurs under Activity Based Funding models disadvantages people with ID as their health encounters are often longer, involve more services and professionals and address a range of health issues. Poorer health outcomes include shortened life expectancy of up to 30 years, with treatable health conditions contributing to at least 38% of this additional mortality.***

## Recommendations:

AADDMM recommends that the Independent Hospital Pricing Authority (IHPA):

---

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDM

Australian Association of  
Developmental Disability Medicine

1. Supports integrated care between health settings and also involving other related services such as education and schools and the disability sector.
  - a. A range of professionals, organisations and services may be involved in
    - i. health related interventions such as monitoring health, eg seizures, providing treatment, eg exercise programs, administering medication.
    - ii. Observing and reporting health related behaviours that contribute to diagnoses
    - iii. Providing reports or treatment plans that are inefficiently shared amongst providers due to limitations in technology and health records
    - iv. Specialist health care can be delivered in a variety of settings, and is best integrated with primary health care services.
    - v. Disability and education sector professionals may have highly relevant information about individual needs, communication impairments and lifestyle choices for persons with ID.
    - vi. Confidence and competence of different parts of the service sector can be extended by closer collaboration with specialists in ID health care
    - vii. Lower health literacy requires more extensive support and resources in order to deliver safe and effective care.
    - viii. Provision of high standard and comprehensive primary care services for people with disability is essentially unviable under current funding models due to complexities
  - b. The location of the service should be flexible, provide for the needs of the person with ID, and may involve a variety of settings such as schools, community clinics.
2. Involve newer technology
  - a. This could include technologies specifically to assist communication for people with ID
  - b. Diarised prompts for health care interventions, eg appointments
  - c. Anticipatory health guidance
  - d. Tools such as CHAP that could be completed online
  - e. Electronic records must accommodate access by person responsible or carers who support the health care of people with ID
  - f. Include valuable clinical interaction with persons and their carers via email or other social media in line with professional standards/practice
  - g. To upskill a range of professionals involved with health care delivery, eg specialised health care teams supporting primary health care or accommodation services
3. The classification principles
  - a. There must be inclusion of a measure of equity in recognition that a substantial component of the poorer health outcomes for people with ID are due to socioeconomic disadvantage
  - b. There ought to be recognition of the complexity of service offered, as important factors in the patient may not otherwise be identified
4. Proposed definition of presenting problem
  - a. Valuable clinical intervention can be provided to persons other than the patient, eg to care providers for a person living in supported accommodation
5. Proposed complexity variables
  - a. Intellectual disability and NDIS flag must be factored into the new funding system

---

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDM

Australian Association of  
Developmental Disability Medicine

- b. This has relevance for people with ID but would need to be carefully developed so that indicators actually identify those with added health complexity. Simple systems of diagnosis or severity of impairment may not adequately capture complexity.
- c. Must include involvement of multiple health care and other professionals in a transdisciplinary model of care
- d. A range of factors that contribute to disadvantage must be captured as people with ID can be multiply disadvantaged

## Why should adjustments be made for People with Intellectual Disability?

### Poorer health status of people with ID

People with intellectual disability have poor health status. Overall they have very high rates of physical and mental health problems which are often not diagnosed or appropriately treated. Furthermore, their life expectancy is reduced by up to 20 years.<sup>1,2</sup> They often have the added burden of socio-economic disadvantage and experience many barriers to receiving health services which directly impact their health and health care.

### Morbidity

Children, adolescents and adults with ID experience higher rates of many treatable health conditions compared to the mainstream population. Three Australian randomised controlled trials found high levels of unmet health needs in Australian adolescents and adults with intellectual disability.<sup>3-5</sup> These findings confirmed the community based population surveys of children and adolescents and adults with ID which demonstrates high levels of unrecognised and/or poorly managed physical and mental health conditions.<sup>6</sup> The most comprehensive study of this type finding 5.4 conditions per person; half of which were unrecognised or poorly treated.<sup>7</sup>

However, these findings underestimate the level of unmet health need in those with syndrome specific conditions. School age children with Down syndrome have high rates of ear (more than half) and of eye (more than three quarters) problems.<sup>8</sup> These conditions contribute to a significant burden on the families to meet increased need for health care services and management. Mental health conditions occur in as many as 40-60% of adolescents with ID<sup>9</sup> and 32% of adults with ID.<sup>10</sup> Young adults with Down syndrome continue to have high rates of health problems. Problems such as eye and vision (affecting 73%), ear and hearing (affecting 45%), cardiac (affecting 25%), respiratory (affecting 36%), musculoskeletal (affecting 61%), body weight (affecting 57%), skin (affecting 56%), mental health (affecting 32%) and menstrual conditions in young women (affecting 58%) significantly impact participation in employment and community leisure activities and contribute to safety concerns.<sup>11</sup>

---

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDMM

Australian Association of  
Developmental Disability Medicine

## Mortality

Life expectancy for people with ID is substantially reduced compared to the general population. A population based study showed that median life expectancies were 74.0, 67.6 and 58.6 years for people with mild, moderate and severe ID respectively.<sup>1</sup> Significant gain in life expectancy can be achieved with good medical care. People with Down syndrome now have a life expectancy of 50 years, whereas in the 1950s it was barely 30 years, and much of these gains can be attributed to better health care.<sup>12</sup>

## Socioeconomic disadvantage compounds poorer health outcomes

People with ID often have additional adverse determinants of health and wellbeing. Socioeconomic disadvantage has been demonstrated to affect not only the person with ID,<sup>13-16</sup> but also their family.<sup>17</sup> Further, children of mothers who are most disadvantaged are much more likely to experience ID.<sup>16</sup> There is clear evidence that socioeconomic adversity has a substantial impact on overall health and wellbeing.

## Barriers to healthcare

There are many causes of this situation; communication barriers between patients and health professionals, complexity of diagnosis, lack of general and specialised skills in the health workforce, passive or active discrimination within the health systems and absence of tailored health promotion campaigns and research not focusing on people with intellectual disability.<sup>18,19</sup>

People with ID encounter special challenges that are different to those of people with other types of disabilities in a number of important aspects; for example, they have difficulties in learning and applying knowledge and in decision making. They may also have difficulty in identifying and choosing options at key life transition points and difficulty adjusting to changed circumstances and unfamiliar environments and therefore need high support during times of change.<sup>20</sup>

People with intellectual disability are more likely to receive inappropriate and inadequate treatment, or be denied healthcare altogether. As identified in international reports and by the WHO people with intellectual disability and their families, face enormous obstacles in seeking the kind of basic healthcare many of us take for granted.<sup>21-23</sup>

## Impact on health care services

There is increased use of the health system by people with ID across the lifespan and is relevant for those with both physical and mental health conditions. For example children with an ID, Down syndrome or Autism Spectrum Disorder experience an increased risk of hospitalisation after the first year of life that varied from 2-10 times that of the rest of the population.<sup>24,25</sup> Adults with Down syndrome continue to experience increased rates and longer periods of hospitalisation than the general community<sup>26</sup>

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDM

Australian Association of  
Developmental Disability Medicine

The Royal Australian College of Physicians recommends that multidisciplinary models of care should be established at the time of diagnosis of intellectual disability. These should be characterised by effective and sustained collaboration across sectors, health, disability, education and family and community services, and professionals.<sup>27</sup> Furthermore the RACP suggests adults with ID need access to multidisciplinary teams of specialists who are funded to give them the time and expertise needed for diagnosis and treatment of complex problems.<sup>28</sup>

### People with ID incur increased health care costs.

People with ID and their families often experience increased costs compared to people without ID. A population based study of children and young people with Down syndrome found that mean annual direct health care costs were \$4209 and that these decreased with age. Respite costs tended to increase with age.<sup>30</sup> Data on all children, adolescents or adults with ID and hospital admission is not available because we do not identify if the patient has an ID during the admission process, unlike other at risk groups.

### Health problems in people with ID contribute to the overall health care burden of people with disability

Although people with ID differ in important aspects of their health care needs to those with disability due to other causes, they do form a significant but varying component of the overall population with disability across the lifespan.

There is a substantial gap in the health status of people with disability compared to those who do not. In 2007-8, almost half (46%) of Australian people aged 15-64 years with severe or profound ID reported poor or fair health compared to 5% of those without disability.<sup>31</sup> People aged under 65 years with severe or profound disability had a higher aged standardised prevalence rate of for all types of reported conditions than people without disability. The most commonly reported conditions were mental health problems, followed by back problems, arthritis, cardiovascular problems and asthma.

The 2007 National Survey of Mental Health and Wellbeing reveals that people with disability aged 16-64 years consult both mental health and non-mental health professionals 2-3 times those without disability.<sup>29</sup> The high use of health services among people with severe or profound disability was associated with a high prevalence of multiple conditions, and comorbidity of mental and physical conditions.

### Comparison with a population acknowledged to be at high risk of adverse health outcomes

Persons who identify as being of Aboriginal or Torres Strait Islander origin are able to receive evidence based price adjustments in NEP14 (IHPA, 2014).<sup>32</sup>

---

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDM

Australian Association of  
Developmental Disability Medicine

In comparison to Indigenous Australians, a population justifiably and widely recognised for its poorer health outcomes and lower life expectancy, people with ID may have even poorer health and lower life expectancy. While we acknowledge difficulties arise with direct comparison due to different methods of determining prevalence of health conditions and the health outcomes chosen for measurement. Nonetheless, the available data does lend strong support to affording people with ID a similar level of targeted health service support and adjustments within health care funding in order to address inequities of health outcomes.

## Responding to the special needs of people with ID in the health system

Provision of health services for people with ID typically take substantially longer and require the involvement of more than one health professional than standard models of care. The presence of comorbid health conditions only partially explains the difference in health service usage, suggesting that other characteristics of this group of people influence the nature and frequency of health services access. Potentially, health system characteristics may also contribute to this difference.

Person characteristics that may impact health service usage include;

- difficulties with verbal communication
- reliance on formal and informal carers for meeting health care needs
- need for others to support decision making and provision of consent
- needs for assistance to participate in community access and leisure activities that might restrict healthy lifestyles, e.g. adequate activity
- limited literacy skills
- inability to recall personal health information such as past major disease, operations or health interventions

Health system characteristics that may impact health service usage include;

- attitudes towards people with ID
- limited skills with adapting communication styles or use of augmented communication strategies
- short consultation times that don't allow for adequate time for explanation
- fragmentation of within health services and with other services
- minimal availability of easy to read health literature

---

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDM

Australian Association of  
Developmental Disability Medicine

## Case Study highlighting clinical complexity

Specialist health services for children, adolescents and adults with ID tend to take more time and involve more clinicians than the general population.<sup>33</sup>

### *An adult with ID and complex healthcare*

Andrew was born with cerebral palsy of unknown cause. He has a good quality of life as his family have supported him to be as independent as possible. The health challenges he faces means he is wheelchair bound, unable to communicate verbally and has frequent seizures which are proving difficult to control. He receives feeding through a tube into his stomach. In addition, he experiences recurrent constipation, pressure areas/ulcers and dependant oedema and recurrent migraines. It is difficult for him to indicate where he has pain. Recently, Andrew become very agitated, irritable and anorexic. It was only after multiple consultations requiring Andrew to be transported to various locations that included assessments by his GP and the local Emergency Department, then a gastroenterologist, neurologist and a dietician, and extensive investigation, that a diagnosis of a relapse of his reflux oesophagitis was made and adequately treated. Patients with such complexity require extra time with multiple clinicians as assessment can be very difficult and time consuming.

### The need to identify people with ID when they access health services

Provision of appropriate funding for the complex health care requirements of people with ID would require health systems to routinely identify ID. This is done either inconsistently or not at all across Australia. The benefits that have ensued from identification of people with disability within national surveys, eg ABS, have enormous implications for both improved understanding of their health care needs and capacity to plan a system around those needs.

An ABF system of funding health care is appealing for its simplicity and ease of cross jurisdictional comparison. However, implementation without adjustments, risks distortion of health care services towards more straight forward clinical care and those with fewer comorbidities providing a further barrier to healthcare for children, adolescents and adult with an intellectual disability.

### In conclusion

AADDM would encourage the Independent Hospital Pricing Authority (IPHA) to specifically consider and fund people with Intellectual Disability, a vulnerable population with complex mental and physical health care problems. People with ID must be specifically considered due to unique aspects of their health care needs that must be adequately accommodated within outpatients and community health care settings. This population not only has complex health care needs, but aspects of their disability have significant impact on the way health care services are provided. Unless action is taken, people with ID will continue to experience substantial and preventable health inequality and poorer health outcomes.

---

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522







# AADDMM

Australian Association of  
Developmental Disability Medicine

Key Contact:

**Dr Jacqueline Small MBBS, MPH (Hons), FRACP.**

President, AADDMM

**Prof Julian Trollor MBBS, MD, FRANZCP**

Vice President, AADDMM

## References

1. Bittles AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ, Montgomery PD. The influence of intellectual disability on life expectancy. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*. 07 2002;57(7):M470-M472.
2. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet*. Mar 8 2014;383(9920):889-895.
3. Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *International Journal of Epidemiology*. 2007;36(1):139-146.
4. Lennox N, Bain C, Rey-Conde T, et al. Cluster Randomized-Controlled Trial of Interventions to Improve Health for Adults with Intellectual Disability Who Live in Private Dwellings. *Journal of Applied Research in Intellectual Disabilities*. Jul 2010;23(4):303-311.
5. Lennox N, Ware R, Carrington S, et al. Ask: a health advocacy program for adolescents with an intellectual disability: a cluster randomised controlled trial. *Bmc Public Health*. Sep 7 2012;12.
6. Ackland MJ, Wade RW. Health status of Victorian special school children. *Journal of Paediatrics And Child Health*. 1995;31(5):571-575.
7. Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: a population study. *Am J Ment Retard*. May 1995;99(6):595-604.
8. Leonard S, Bower C, Petterson B, Leonard H. Medical aspects of school-aged children with Down syndrome. *Dev Med Child Neurol*. Oct 1999;41(10):683-688.
9. Einfeld SL, Piccinin AM, Mackinnon A, et al. Psychopathology in young people with intellectual disability. *Jama*. Oct 25 2006;296(16):1981-1989.
10. Morgan VA, Leonard H, Bourke J, Jablensky A. Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. *Brit J Psychiat*. Nov 2008;193(5):364-372.
11. Pikora TJ, Bourke J, Bathgate K, Foley KR, Lennox N, Leonard H. Health Conditions and Their Impact among Adolescents and Young Adults with Down Syndrome. *Plos One*. May 12 2014;9(5).
12. Megarbane A, Ravel A, Mircher C, et al. The 50th anniversary of the discovery of trisomy 21: the past, present, and future of research and treatment of Down syndrome. *Genet Med*. Sep 2009;11(9):611-616.
13. Emerson E. Commentary: Childhood exposure to environmental adversity and the well-being of people with intellectual disabilities. *J Intell Disabil Res*. Jul 2013;57(7):589-600.

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDMM

Australian Association of  
Developmental Disability Medicine

14. Emerson E, Hatton C. Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication. *J Intell Disabil Res.* Nov 2007;51:866-874.
15. Leonard H, Glasson E, Nassar N, et al. Autism and intellectual disability are differentially related to sociodemographic background at birth. *PLoS ONE [Electronic Resource]*. 2011;6(3):e17875.
16. Leonard H, Petterson B, De Klerk N, et al. Association of sociodemographic characteristics of children with intellectual disability in Western Australia. *Soc Sci Med.* Apr 2005;60(7):1499-1513.
17. Emerson E, Hatton C, Llewellyn G, Blacker J, Graham H. Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *J Intell Disabil Res.* Dec 2006;50:862-873.
18. Lennox NG, Diggins JN, Ugoni AM. The general practice care of people with intellectual disability: barriers and solutions. *J Intell Disabil Res.* Oct 1997;41(Pt 5):380-390.
19. National and NSW Councils for Intellectual Disability, Australian Association of Developmental Disability Medicine. Position Statement on the Health of People with Intellectual Disability. 2011; <http://ausaddm.files.wordpress.com/2010/08/posn-with-endorsements-311.pdf>. Accessed 24 July, 2014.
20. Australian Institute of Health and Welfare. *Disability in Australia: Intellectual disability. Bulletin no. 67. Cat no. AUS 110.* Canberra: AIHW; 2008.
21. U.K. Department of Health. *Valuing people: a new strategy for learning disability for the 21st Century.* London: The Stationery Office; 2001.
22. U.S. Department of Health and Human Services. *The Surgeon General's Call To Action To Improve the Health and Wellness of Persons with Disabilities.* Rockville, MD: Office of the Surgeon General; 2005.
23. World Health Organization, The World Bank. *World Report on Disability.* Geneva: WHO; 2011.
24. Bebbington A, Glasson E, Bourke J, de Klerk N, Leonard H. Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983-1999: a population-based cohort study. *BMJ Open.* 2013;3(2).
25. Fitzgerald P, Leonard H, Pikora TJ, Bourke J, Hammond G. Hospital Admissions in Children with Down Syndrome: Experience of a Population-Based Cohort Followed from Birth. *Plos One.* Aug 13 2013;8(8).
26. Tenenbaum A, Chavkin M, Wexler ID, Korem M, Merrick J. Morbidity and hospitalizations of adults with Down syndrome. *Research in developmental disabilities.* Mar-Apr 2012;33(2):435-441.
27. Royal College of General Practitioners. The Royal College of General Practitioners Curriculum 2010: 3.11 The Clinical Example on Care of People with Intellectual Disability. 2013; [http://www.gmc-uk.org/3\\_11\\_Intellectual\\_disability\\_April\\_2013.pdf](http://www.gmc-uk.org/3_11_Intellectual_disability_April_2013.pdf) 52885340.pdf. Accessed Feb 12, 2014.
28. Beange H, Bones C, Cameron I, et al. *Policy Statement on Disability.* Sydney: Royal Australian College of General Practitioners; 2012.
29. Australian Institute of Health and Welfare. *The use of health services among Australians with disability. AIHW bulletin no. 91. Cat. no. AUS 140.* Canberra: AIHW; 2011.
30. Geelhoed EA, Bebbington A, Bower C, Deshpande A, Leonard H. Direct health care costs of children and adolescents with Down syndrome. *J Pediatr.* Oct 2011;159(4):541-545.

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522





# AADDM

Australian Association of  
Developmental Disability Medicine

31. Australian Institute of Health and Welfare. *Health of Australians with disability: health status and risk factors. AIHW bulletin no. 83. Cat. no. AUS 132.* Canberra: AIHW; 2010.
32. Independent Hospital Pricing Authority. National Efficient Price Determination 2014-15. 2014. Accessed 25 July, 2014.
33. Edwards N, Lennox N, White P. Queensland psychiatrists' attitudes and perceptions of adults with intellectual disability. *J Intell Disabil Res.* Jan 2007;51(Pt 1):75-81.
34. Florio, T., & Trollor, J. (2015). Mortality among a Cohort of Persons with an Intellectual Disability in New South Wales, Australia. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 383-393. doi:10.1111/jar.12190
35. Trollor, J., Srasuebkul, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open*, 7(2). doi:10.1136/bmjopen-2016-013489
36. Howlett, S., Florio, T., Xu, H., & Trollor, J. (2015). Ambulatory mental health data demonstrates the high needs of people with an intellectual disability: Results from the New South Wales intellectual disability and mental health data linkage project. *Australian and New Zealand Journal of Psychiatry*, 49(2), 137-144. doi:10.1177/0004867414536933
37. Weise, J., Pollack, A., Britt, H., & Trollor, J. N. (2016). Primary health care for people with an intellectual disability: an exploration of demographic characteristics and reasons for encounters from the BEACH programme. *Journal of Intellectual Disability Research*, 60(11), 1119-1127. doi:10.1111/jir.12301
38. Weise, J., Pollack, A. J., Britt, H., & Trollor, J. N. (2017). Who provides primary health care for people with an intellectual disability: General practitioner and general practice characteristics from the BEACH dataset. *Journal of Intellectual and Developmental Disability*, 42(4), 416-421. doi:10.3109/13668250.2016.1250252
39. Li, X., Srasuebkul, P., Reppermund, S., & Trollor, J. (n.d.). Emergency department presentation and readmission after index psychiatric admission: a data linkage study.. *BMJ Open*, 8(2), e018613. doi:10.1136/bmjopen-2017-018613

---

**President: Dr Jacqueline Small**  
**Vice-President: Prof Julian Trollor**

C/- QCIDD, Level 2, Aubigny Place, Mater Hospitals, South Brisbane Qld 4101  
T: +61 (7) 3163 1589 | F: +61 (7) 3163 2445  
E: AADDMsecretariat@gmail.com | W: <http://aaddm.com.au>  
ABN: 61 039 294 522

