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**People with ID: a minority group with significant health inequality, which requires action.**

About 1.8% of the Australian population, or approximately 400,000 individuals (1). These individuals:

- have extremely poor health status (2, 3),
- have multiple barriers to timely, affordable and appropriately equipped health services (4).
- experience a mismatch between health needs and accessible services, which has a major impact
- have substantially elevated mortality rates above the general population, including elevated deaths from potentially avoidable causes (5, 6, 7).

**Available data highlights much higher rates of ill health, greater service use, but lower rates of detection and poor access to preventative healthcare:**

- International research in general practice indicates that on average, people with ID have 2.5 times the number of health problems than people without ID (3).
- A small (n=202) landmark Australian study showed that people with ID averaged 5.4 medical disorders per person, half of which were previously undetected. Compared to controls, people with ID had increased cardiovascular risks, medical consultation rates, hospitalisation and mortality (2).

- International work indicates that people with ID have higher rates of potentially modifiable cardiometabolic risk factors than the general population. These include higher rates of psychotropic prescription and polypharmacy, lower rates of physical activity (9,10), and higher rates of obesity (11).
- In a longitudinal study of Australian children, significantly higher rates of obesity were observed among six to seven-year-old children with intellectual impairment when compared with their 'typically developing' peers (12)
- International evidence demonstrates under-diagnosis of chronic health conditions and lack of active management of risk factors. For example a landmark Dutch study demonstrated double the proportion of missed metabolic syndrome (MetS) diagnoses compared to the general population, and under detection of hypertension by 50% (8).
- Trollor/3DN's linkage between NSW disability and deaths data extends our understanding of deaths in people with ID by identifying multiple markers of premature mortality and a very high proportion of potentially avoidable deaths (38%), which was more than double that of the general population. Deaths are dominated by respiratory, circulatory, neoplasm and nervous system related causes (5, 7).

**Primary care is the linchpin of accessible health care for people with ID, providing the first point of contact with the health care system, and pathways to further services.**

- Lennox et al lead national developments in ID primary care. His and others' research has highlighted a number of barriers that GPs experience in the delivery of care to people with ID (13-15).
- Lennox has demonstrated the effectiveness of comprehensive health checks in identifying previously unrecognised disease (16) and in engaging GPs in health promotion in people with ID.
- Trollor/3DN has analysed data from the Bettering the Evaluation and Care of Health (BEACH) program, regarding GP encounters relating to people with ID and compared them to encounters representative of the general population. These data indicate that, compared to people without ID, those with ID had an over-representation of psychological, social and administrative reasons for presentation, and an under-representation of consultations addressing physical and preventative health issues. In an analysis of the prescribing data, people with ID were significantly less likely than the general population to be prescribed preventative health medications such as antihypertensives, and narcotic analgesics and modern antibiotics for infections (in favour of older style and less effective ones). They were more likely to be prescribed antipsychotic and anticonvulsant medication (17, 18).



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## Poor Prescribing practices in people with ID may drive adverse health outcomes.

- After accounting for elevated prevalence of mental illness (19), psychotropic medication prescription and polypharmacy remain disproportionately high amongst people with ID (20-22).
- Antipsychotics are the most commonly prescribed psychotropic medication (23), and are often given for challenging behaviour, a practice unsupported by evidence (24) and out of keeping with sector expectations.
- Psychotropic medication use in the general population has been associated with an elevated risk of cardiometabolic morbidity and mortality (25, 26), and may thus drive some of the poor health outcomes experienced by people with ID.

## People with ID use more hospital and ED services, and have higher associated costs

Trollor/3DN are examining health service use and costs of people with ID using a state-wide linkage and dataset of NSW Ministry of Health (MoH) and Ageing, Disability & Home Care (ADHC), and multiple other NSW agencies from 2005-2012:

- In emergency departments: Compared to people without ID, people with ID have:
  - significantly elevated rates of ED use (551 vs 283 per 1000 person years)
  - double the cost of ED use (\$235 vs \$123 per person year).
  - ED presentations that are *more likely* to occur via emergency services and end in admission, and *less likely* to be GP-type presentations or to be seen 'on time'.
- All hospital admissions: Compared to people without ID, people with ID experience:
  - rates of hospitalisations per 100,000 people which are 2.1 times higher
  - costs per episode that are double that of the general population
- Mental health admissions: Compared to people without ID, people with ID
  - are more than twice as likely to be admitted, stay twice as long and cost twice as much per admission.
  - Have different diagnoses, including much higher rates of "unknown" diagnoses.
  - are five times more likely to experience ultra-long stays (>365 days)
  - are twice as likely to be frequent users of mental health services (being admitted more than three times a year).
- Among people experiencing their first ever admission for a mental health issue, compared to people without ID, people with ID:
  - are between 25 and 50 percent more likely to be readmitted in the following 1, 2 and 24 month interval.
  - are about 3 times more likely to come back to ED in the following 1, 2 and 24 month interval.
- Ambulatory mental health care: compared to people without ID, people with ID have 1.6 times more, and 2.5 time longer, face-to-face contacts (27).
- NSW data is similar to linked data studies from Western Australia (28,29). Compared to children without ID, children with ID were more likely to be admitted to hospital (RR: 1.64; 95% CI 1.6 to 1.7), on more occasions (5.3 versus 2.2 admissions), for longer (29.6 versus 8.3 days), and for a larger range of clinical diagnoses. (28)



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## References

1. Australian Institute of Health and Welfare. Disability Prevalence and Trends Canberra: AIHW; 2003.
2. Beange H, et al. Medical disorders of adults with mental retardation: a population study. *Am J Ment Retard*. 1995;99(6):595-604.
3. van Schrojenstein Lantman-De Valk HM, et al. Health problems in people with intellectual disability in general practice: a comparative study. *Fam Pract*. 2000;17(5):405-7.
4. Tuffrey-Wijne I, et al. The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a mixed-methods study. *BMJ Open*. 2014;4(4):e004606.
5. Florio T, Trollor J. Mortality among a Cohort of Persons with an Intellectual Disability in New South Wales, Australia. *J Appl Res Intellect Disabil*. 2015;28(5):383-93.
6. NSW Ombudsman. 2014-2015 Annual Report. Sydney: NSW Ombudsman; 2015.
7. Trollor J, Srasuebku P, Xu H, et al. 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
8. de Winter CF, et al. Overweight and obesity in older people with intellectual disability. *Res Dev Disabil*. 2012;33(2):398-405.
9. De S, Small J, Baur LA. Overweight and obesity among children with developmental disabilities. *J Intellect Dev Disabil*. 2008;33(1):43-7.
10. Dixon-Ibarra A, et al. Physical activity and sedentary behavior in older adults with intellectual disabilities: a comparative study. *Adapt Phys Activ Q*. 2013;30(1):1-19.
11. Yamaki K. Body weight status among adults with intellectual disability in the community. *Ment Retard*. 2005;43(1):1-10.
12. Emerson E, Robertson J. Obesity in young children with intellectual disabilities or borderline intellectual functioning. *International Journal of Pediatric Obesity*. 5(4):320-6, 2010.
13. Cook A, Lennox N. General practice registrars' care of people with intellectual disabilities. *J Intellect Dev Disabil* 2000;25:69-77.
14. Dovey S, Webb OJ. General practitioners' perception of their role in care for people with intellectual disability. *J Intellect Disabil Res*. 2000;44 ( Pt 5):553-61.
15. Lennox NG, et al. The general practice care of people with intellectual disability: barriers and solutions. *J Intellect Disabil Res*. 1997;41(Pt 5):380-90.
16. Lennox N, et al. Effects of health screening for adults with intellectual disability: a pooled analysis. *Br J Gen Pract*. 2011;61(584):193-6.
17. Weise J;Trollor JN;Pollack A;Britt H, 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*, <http://dx.doi.org/10.1111/jir.12301>
18. Weise J;Pollack AJ;Britt H;Trollor JN, 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 and Developmental Disability*, pp. 1-6, <http://dx.doi.org/10.3109/13668250.2016.1250252>
19. Tong B, Einfeld S. The trajectory of psychiatric disorders in young people with intellectual disabilities. *Aust N Z J Psychiatry*. 2000;34(1):80-4.
20. Deb S, et al. The effectiveness of aripiprazole in the management of problem behaviour in people with intellectual disabilities, developmental disabilities and/or autistic spectrum disorder--a systematic review. *Res Dev Disabil*. 2014;35(3):711-25.
21. Lott IT, et al. Longitudinal prescribing patterns for psychoactive medications in community-based individuals with developmental disabilities: utilization of pharmacy records. *J Intellect Disabil Res*. 2004;48(Pt 6):563-71.



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22. Sheehan R, et al. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *BMJ*. 2015;351:h4326.
23. Lunsy Y, Elserafi J. Antipsychotic medication prescription patterns in adults with developmental disabilities who have experienced psychiatric crisis. *Res Dev Disabil*. 2012;33:32-8
24. Tyrer P, et al. Drug treatments in people with intellectual disability and challenging behaviour. *BMJ*. 2014;349:g4323.
25. Oriot P, et al. Insulin sensitivity, adjusted  $\beta$ -cell function and adiponectinaemia among lean drug-naive schizophrenic patients treated with atypical antipsychotic drugs: A nine-month prospective study. *Diabetes Metab*. 2008;34(5):490-6.
26. Saari K, et al. Hyperlipidemia in persons using antipsychotic medication: a general population-based birth cohort study. *J Clin Psychiatry*. 2004 Apr;65(4):547-50.
27. Howlett S, Florio T, Xu H, Trollor J. 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. *Aust N Z J Psychiatry* 2015;49(2):137-44.
28. Williams, K; Leonard, H; et al. Hospitalisations from birth to 5 years in a population cohort of Western Australian children with intellectual disability. *Archives of Disease in Childhood*. 90(12):1243-8, 2005 Dec.
29. Bebbington A, Glasson E, Bourke J, et al Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983–1999: a population-based cohort study *BMJ Open* 2013;3:e002356. doi: 10.1136/bmjopen-2012-002356.