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

About 1.8% of the Australian population have intellectual disability (ID), or approximately 450,000 individuals (1). These individuals:

- have extremely poor health status (2-3),
- have multiple barriers to timely, affordable and appropriately equipped health services (4-5),
- 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 (6-10).

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 has clearly demonstrated the substantial health needs of people with ID:

- in general practice on average, people with ID have 2.5 times the number of health problems than people without ID (3).
- young people with ID are more likely to experience poor health and are at an increased risk of mental health problems during their transition to adulthood than the general population (11).
- 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 (12-13), and higher rates of obesity (14).

- A review of published data from 2011-2015 showed that people with ID have higher unmet needs and lower use of preventative health services compared to people without ID (15).
- People with ID have 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% (16).

Australian research is congruent with international data and has shown:

- that people with ID have on average 5.4 medical disorders per person, half of which were previously undetected, and that compared to controls, people with ID had increased cardiovascular risks, medical consultation rates, hospitalisation and mortality (2).
- that in a representative sample of 582 young people with ID aged 4-19 years, about 40% of young people with ID had psychiatric disorders which persisted over 4 years. Clinically significant change in symptoms with either deterioration or improvement occurred in around 14% of the sample. Psychiatric disorder was 3-4 times more prevalent in young people with ID than in the general population. Less than 10% of these young people receive specialist services for a problem which is numerically as large as schizophrenia (17).
- that in Australian children followed longitudinally, significantly higher rates of obesity were observed among six to seven-year-old children with intellectual impairment when compared with their 'typically developing' peers (18)

Australian data shows that people with ID experience high mortality and a very high proportion of deaths from potentially avoidable causes.

NSW linkage data indicates:

- people with ID experience a median age at death of 54 years, that is 27 years earlier than the general population (6), and a comparative mortality figure (CMF) that is very high especially in young-mid adulthood (CMF for 20-45 years is 4.0 (95% CI 3.1-5.2)) (8).
- 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 (6, 8).

Western Australian linkage data shows that:

- people with ID aged 20 years and over were more likely to die prematurely than the general population. This study found high rates of potentially avoidable deaths, with people with ID being more likely to die from influenza/pneumonia, epilepsy, and cellulitis (10).
- children with an ID experience a 6-12 fold increased risk of mortality compared to children without ID (9). The most common underlying cause of death for children in this study were related to respiratory diseases. Potentially avoidable deaths, such as epilepsy and aspiration pneumonia accounted for one-quarter of deaths in the 11-25 years age group.



Primary care is the linchpin of accessible health care for people with ID, but Australian data suggests the current approach is suboptimal.

- Research by Lennox and others has highlighted a number of barriers that GPs experience in the delivery of care to people with ID (19-22).
- The effectiveness of comprehensive health checks for people with ID has been clearly demonstrated, with these checks being able to identify previously unrecognised disease and engaging GPs in health promotion in people with ID. (23)
- Carers of people with ID identify a range of barriers to primary care including a lack of knowledge and skills specific to ID, communication issues, negative attitudes towards ID, lack of flexibility and accommodation to an individuals need, and siloed approach to health care management (22),
- Data have been analysed from the Bettering the Evaluation and Care of Health (BEACH) program, regarding GP encounters relating to people with ID and compared 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 (24). 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 (25).

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

- After accounting for elevated prevalence of mental illness (26), psychotropic medication prescription and polypharmacy remain disproportionately high amongst people with ID (27-29).
- Antipsychotics are the most commonly prescribed psychotropic medication (30) and are frequently given in the absence of a psychiatric diagnosis (31). Antipsychotics are often given for challenging behaviour, a practice unsupported by evidence (32) 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 (33-34), 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

NSW Linked data has been used to examine health service use and costs for people with ID. This linkage work identifies 1.15% of the NSW population as having an ID and finds that people with ID:

- are over-represented in each major compartment of the health service system, including representing 6% of all mental health service users (35).
- have inpatient stays and admission costs which are twice that of the general population (36).
- have 1.6 times the rate of use of emergency departments compared to people without ID, and experience longer wait times, and higher likelihood of presentation via emergency

services (37).

- after their first ever admission for a mental health issue, are three times as likely to represent to emergency departments, and between 55-75 percent more likely to be readmitted at 1, 2-5 and 6-24 months after discharge than people without intellectual disability (38).
- require two and a half times the community mental health resources to meet their mental health needs compared with people without intellectual disability (39).

Linked data studies from Western Australia (40-41) also highlight the health needs of people with intellectual disability:

- children with ID were 1.6 times more likely to be admitted to hospital, had over twice the number of admissions, which were of a substantially longer duration than for those without ID, and were admitted for substantially longer than for children without ID. (40)
- the risk of hospitalisation for children with ID was up to 10 times that of children without ID, with the greatest risk being for those with severe ID (41).
- During the last year of life people with ID had higher rates of presentation and admission for ambulatory care sensitive conditions (that is, conditions for which hospitalisation is thought to be avoidable with the application of public health interventions or early management delivered in a primary care setting) than people without ID (10).

Australian findings are congruent with international data which shows that people with ID:

- were four times more likely to incur high annual health care cost compared to those without ID. The greatest health expenditure was due to hospitalisations, continuing care/rehabilitation, and medications (42).
- are more likely to be admitted to hospital for ambulatory care sensitive conditions than people without an ID (43-45).

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