# Health Status of People with Intellectual Disability Evidence Summary 22nd June, 2021

**Prepared by**

**Professor Julian Trollor**, Chair, Intellectual Disability Mental Health & Head, Department of Developmental Disability Neuropsychiatry, UNSW Medicine & Health
M: 0411406770; E: J.Trollor@unsw.edu.au; W: https://www.3dn.unsw.edu.au

## About

The Department of Developmental Disability Neuropsychiatry (known as 3DN) sits within the UNSW Sydney's Faculty of Medicine and Health. **Julian Trollor** is a Neuropsychiatrist and head of 3DN. **Julian leads an internationally recognised translational research program which aims to reduce the health inequalities experienced by people with intellectual and developmental disorders**. He has published over 450 research outputs (see https://research.unsw.edu.au/people/professor-julian-norman-trollor/publications?type=reports for details). **Julian sits on multiple Commonwealth and State Government Advisory Committees and is the President of the Australian Association of Developmental Disability Medicine**.

## Context

People with intellectual disability (ID) represent about 1.8% of the Australian population. They experience one of the most substantial health gaps of any sub-population in Australia. The health inequalities experienced by this group are stark and include **high rates of multi-morbidity, early onset of frailty, premature deaths, and double the proportion of potentially avoidable deaths compared to the general population** [1-4]. Based mainly on the lived experience testimonies and research related to people with ID, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC) made its only substantive finding to date: "***the evidence justifies the Royal Commission finding that people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system. We make that finding.***" [5].

## Deaths

Mortality, a sentinel health indicator [6], is very high in this group. Its drivers are largely unrelated to the aetiology of the disability and are the culmination of a lifetime of health disadvantage. **Our research documents premature mortality in people with ID: median age at death is just 54 years, and deaths from potentially avoidable causes comprise 38% of all deaths, more than double that of the general population** [3]. Leading underlying causes of death in this population are respiratory, circulatory, cancer and neurological. Our work identifies key predictors of death including epilepsy, chronic diseases such as kidney disease, serious mental illness and cancers [7]. Thus, **many deaths could be prevented with appropriate and timely access to health and preventative health care** [3, 5].

## Drivers of Poor Outcomes

Preventative health care is a key pillar of Australia's long-term national health plan [8], yet equity in preventative health care eludes many with ID [9]. For this group, disease endpoints have their genesis earlier in life with poor

access to health care, including preventative health care [5]. International research indicates that people with ID have poor engagement in preventative health care compared to the general population [10] including lower rates of vaccination, participation in health lifestyle interventions, and preventative health screening measures such as cancer, cholesterol, and oral health screening [11-16].

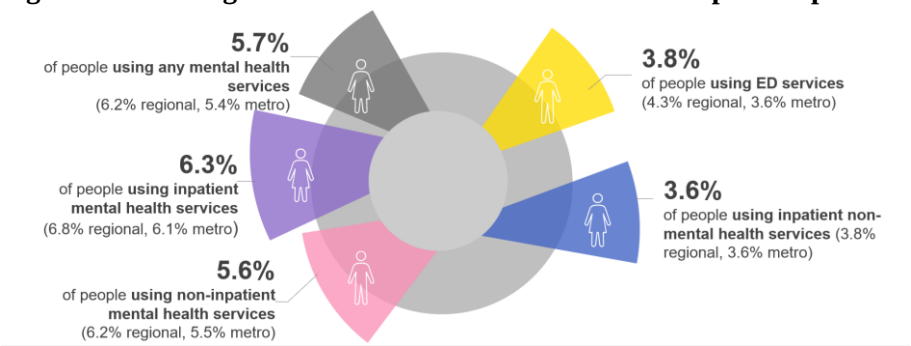
**Our research shows that people with ID are less likely to access primary care to have their preventative health care needs met compared to the general population** [17, 18]. Our population-based linkage from NSW indicates a flow on effect of high acute care service use [19].

## Acute Care

**Our work shows that compared to the general population, people with ID are over-represented in every compartment of the acute health care system**, experiencing very high rates of emergency department presentation and admissions, with substantially higher associated costs. Our data linkage reveals that despite only representing 1.1% of the NSW population, people with intellectual disability comprise 4% of people using ED services, 4% of people using inpatient non-mental health services, and over 6% of inpatient mental health services (figure 1). Furthermore, despite this over-representation, **people with intellectual disability receive ineffective care characterized by repeat presentation to acute care after mental health inpatient stays** [20].

Potentially preventable hospitalisations (PPHs) are a routinely reported performance indicator of accessibility and effectiveness of health in Australia. **Our research demonstrates that PPHs for people with ID are up to 4.5 times higher than for the general population**, with PPHs for acute conditions being up to 8 times higher and PPHs for vaccine preventable conditions up to 3 times higher [21]**.**

**Figure 1. Percentage of NSW Health Service Users with ID per compartment, FY 2014/15**




## Mental Health

Mental health disorders account for 24% of the non-fatal burden of disease in Australia [22], and are leading causes of disability and morbidity. ID is associated with substantial over-representation of mental illness. Available data suggests overrepresentation for most mental health disorders including schizophrenia, affective disorders, anxiety disorders and dementia of 2-3 times that of the general population [23-25].

3DN's research demonstrates lack of capacity of professionals and systems to respond to this issue. **Our research shows that people with ID are very high users of acute mental health services at greatly inflated cost [20, 26, 27]; experience multiple barriers to mental health services [28]; receive ineffective care characterized by repeat presentation to acute care after a mental health inpatient stay [20]; encounter professionals and services that are ill-equipped to meet their basic rights to access mental health care [29-31]; and are usually excluded from mental health policy [32, 33].**

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