



Inclusion Australia

Gathering the Evidence: Data on people with intellectual disability in Australia

A report for Inclusion Australia

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Executive summary

Inclusion Australia commissioned this report to collate recent data on people with intellectual disability living in Australia with a focus on prevalence, demographics, government support, restricted decision-making, schooling, employment, living situations, and access to technology. Compilation of the report involved systematic searches of relevant databases for peer-reviewed literature and an environmental scan of relevant websites.

Across Australia, numerous definitions of intellectual disability have been used for data collection and research, including those based on clinical diagnosis (of intellectual disability or IQ), support needs, and functioning. Data on intellectual disability tend to differ depending on which definition is applied. Estimates of the prevalence of intellectual disability range from 8.5 to 17.0 cases per 1,000 people based mainly on clinical and support needs data, and 63 per 1,000 people based on functioning (difficulties with learning or understanding).

Some areas lacked any accessible evidence. For example, we found limited or no publicly available information about the numbers and characteristics of people with intellectual disability accessing government services administered by the Department of Social Services, the Department of Education Skills and Employment or Aged Care.

The compilation of data for this report, highlighted the difficulties in accessing reliable and comparable information about people with intellectual disability in Australia. There is a need for agreement on definitions of intellectual disability to inform consistent data collection at Commonwealth and state and territory levels to enable comparison and accurate reporting to inform the provision of relevant supports and services including advocacy.

The proposed National Disability Data Set should go some way to filling these gaps but only if data are recorded and reported in ways that are meaningful to researchers, advocacy groups, policy makers, and others who seek to use it including using consistent definitions to assist with identifying those who have lifelong intellectual disability.

Introduction

The aim of this report is to provide an evidence-based overview of the Australian population of people with intellectual disability and identify data gaps¹. In commissioning this report, Inclusion Australia recognised their lack of access to a current, legitimate data set that accurately describes the size and status of the Australian population of people with intellectual disability. In seeking to provide input to the Disability Royal Commission, Inclusion Australia identified this data gap as hampering the Commission's understanding of the profile and context of Australians with intellectual disability. Inclusion Australia noted that the Disability Royal Commission has neither published a research agenda, nor indicated an intent to undertake any specific research about people with intellectual disability.

The term 'intellectual disability' encapsulates a broad and diverse array of experiences and characteristics. Intellectual disability can involve difficulties with communication, memory, understanding, problem solving, fine and gross motor skills, and self-care. Historically, the terms 'borderline', 'mild', 'moderate', 'severe' and 'profound' were applied as classifications of severity largely based on a person's IQ and daily skills as assessed by suitably qualified psychologists using standardised measures. Over the past 30-40 years, there has been a significant shift in the way disability, including intellectual disability, is described and conceptualised. Rather than reference to individual diagnostic measures and labels, the social model of disability highlights the disabling barriers presented by society that impact on a person's life. Under the social model, it is these social barriers, rather than a person's individual impairments, which create disability. The World Health Organization's International Classification system, revised in the 1980s, reflects this shift introducing measures of a person's functioning and participation <https://www.who.int/classifications/icf/en/>.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2011) enshrines universal rights for all people with disabilities. As important as the convention is, there is a danger as identified by Professor Tom Shakespeare (2013), that people with intellectual disability, who may be less able to represent their views and needs, may be overlooked within the rights movement as the voices and concerns of people with physical and sensory disability are foregrounded. Professors Jennifer Clegg and Chris Bigby (2017), used the term dedifferentiation to describe the shift away from a specific focus on intellectual disability to a position where broad commonalities of 'disability' predominate. Clegg and Bigby raised concerns that a focus on the rights and needs of people with disability as a broad group can obscure the diversity of those with intellectual disability and overshadow the additional support needs of this heterogeneous group. In particular, according to Clegg and Bigby, due to dedifferentiation the needs of people with the most severe and complex intellectual disabilities may be ignored and/or tokenistically represented by others.

In preparing this report, the difficulty of extracting data specific to people with intellectual disability was highlighted and it became evident that a major challenge in sourcing and accurately reporting on the population of people with intellectual disability was inconsistency in defining who and what this term refers to.

¹ The report does not cover data on medical and health outcomes for people with intellectual disability. Professor Julian Trollor from UNSW Sydney provided a statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disability, which comprehensively addresses these topics.

Definitional issues

Variations in the definition of *intellectual disability* introduces challenges when interpreting available statistics. Definitions used in compilations of statistics on intellectual disability include clinical diagnosis, self- or proxy-reported diagnosis, assessed or reported IQ, support needs, and functioning (self- or proxy-reported difficulty learning or understanding things). In the research reviewed, clinical diagnoses have been made using the criteria in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5; American Psychiatric Association, 2013) and, for older data, the 4th edition of this manual (DSM-IV; American Psychiatric Association, 2000). In some cases, an intellectual disability diagnosis may have been self- or proxy-reported, such as in the hospital medical records with comorbidity codes of *intellectual disability*, *mental retardation*, and *pervasive developmental disorder* (e.g., Lee, Heffernan, McDonnell, Short, & Naganathan, 2016). Some researchers (e.g., Haysom, Indig, Moore, & Gaskin, 2014) administered measures of IQ and defined intellectual disability as full scale IQ scores below 70.

For some datasets, the collection of data on clinical diagnoses has been replaced with obtaining data on support needs (e.g., levels of educational need (Bourke, de Klerk, Smith, & Leonard, 2016)). Level of support needs may be associated with severity of disability. (Bourke et al., 2016) In national surveys, functional, rather than diagnostic, definitions of intellectual disability have usually been applied (Lee et al., 2016). Since 1981, the Australian Bureau of Statistics (ABS) has conducted quinquennial surveys on disability - the *Survey of Disability, Ageing and Carers (SDAC)*. These surveys provide widely-used and detailed information on the extent of disability in Australia, its effect on daily living and participation in the usual activities of the community, and the need for, and receipt of, assistance.

In the 2001 (and subsequent) full population census seven questions were added to collect information on the prevalence of disability in the Australian population. These questions were designed to be used in conjunction with the more detailed *SDAC* data. In both the census and *SDAC*, disability is defined as "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months" and intellectual disability as "difficulty learning or understanding things" (Australian Bureau of Statistics, 2019b). The conditions grouped under the umbrella term 'intellectual disability' included attention deficit disorder, attention deficit hyperactivity disorder, autism (all forms - including Asperger's syndrome), dementia (all forms), Down syndrome, dyslexia/reading disorder, dyslalia, epilepsy (all forms), head injury, intellectual disability, and stroke (Australian Bureau of Statistics, 2018). For the purposes of compiling this report, which has a focus on people with lifelong intellectual disability, this broad grouping of conditions affecting cognitive functioning makes the task of extracting information specific to the defined group difficult.

National Disability Data

A further challenge in preparing this report was the lack of a national central database collecting, compiling, analysing and reporting on data related to people with disability generally and people with intellectual disability specifically. Longitudinal data is especially lacking. In recognition of this lack of data, the Commonwealth, states, and territories are jointly developing a cross-jurisdictional national disability data set.

An 18-month pilot phase commenced in early 2020 to identify the most effective ways (and potential barriers and solutions) to share, link and access the data. The pilot will also focus on privacy protections such as methods for de-identification and information security. The pilot is co-governed by nine partners representing the Commonwealth and all states and territories, the National Disability Insurance Agency (NDIA) and the Australian Institute of Health and Welfare (AIHW). A Disability Advisory Council guides the pilot. The Council members have expertise in disability policy, advocacy, social investment, research, service provision, business, economics and law. The Council includes those with experience working with a wide range of people with disability, including people with complex needs, people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds, and people living in regional and remote communities.

When completed, this linked and shared data should provide a better understanding of how people with disability are supported across multiple service systems including services, payments and programs. Without consistent and 'joined up' data capacity for identifying and reporting on disability, the ability to measure, report on, and improve outcomes for people with disability is limited as demonstrated in the compilation of this report. It will be important to ensure that data related to specific disabilities, such as intellectual disability, are collected and reported in ways that allow comparison within and across datasets.

Search Method

Within the allocated time and budget constraints and accommodating definitional caveats and, in the absence of a central database, a systematic search of peer-reviewed literature and an environmental scan of relevant websites were conducted for the preparation of this report. In addition, several academics with expertise in intellectual disability research were contacted to verify search strategies and ensure potential sources of data were included.

Systematic searches were run on 17 August, 2020 involving four electronic databases (CINAHL, MEDLINE, PsycINFO, and Web of Science Core Collection) using search terms for *intellectual disability* and *Australia* (full search terms are provided in Appendix A). Limiters were set for language (English) and article type (peer-reviewed papers), and the searches were restricted to the year 2010 onwards. The searches returned 1,928 database entries, of which 1,001 were duplicates. Screening the titles and abstracts of the remaining 927 entries resulted in the exclusion of 896 papers. Further screening of the full texts of the remaining 31 papers resulted in 16 of them being excluded. The remaining 15 papers (Abdullahi, Wong, Bebbington, et al., 2019; Abdullahi, Wong, Mutch, et al., 2019; Aitken et al., 2019; Bourke et al., 2016; Carroll, Townsend, Brown, & Nankervis, 2015; Foley et al., 2013; Giudice-Nairn et al., 2019; Graham, 2012; Gray et al., 2014; Haysom et al., 2014; Lee et al., 2016; Man, Wade, & Llewellyn, 2017; Nielssen et al., 2018; Webber et al., 2010; Webber, McVilly, & Chan, 2011) were included in the review. The environmental scan involved searching government and disability-related websites for data related to intellectual disability. Sites included: the ABS, AIHW, NDIA, Department of Social Services, Department of Education, Skills and Employment, and specific disability organisation websites.

Findings

Prevalence of intellectual disability in Australia

The most recent national prevalence data were sourced from the ABS (2019a). In interpreting these statistics, as noted earlier, the definition of intellectual disability used by the ABS is broad and includes people with other forms of cognitive impairment besides lifelong intellectual disability. In addition to the ABS data, two studies by Australian academics, one from Western Australia and the other from New South Wales, are provided as they indicate consistency in prevalence estimates.

Table 1 Prevalence of Intellectual Disability in Australia

Source	Datasets	Sample	Measure	Findings
Bourke et al. (2016)	IDEA (Intellectual Disability Exploring Answers) database	Births in Western Australia from 1983 to 2005 (with follow up to 2010, n=565,242)	Mix of measures (diagnosis of ID, recorded severity of ID, or education need level)	The prevalence of ID in was 17.0/1,000 live births (95% CI: 16.7, 17.4). This rate represents an increase from the prevalence rate calculated for births from 1983 to 1992 (with follow up to 1999) of 14.3/1,000 live births.
Lee et al. (2016)	Administrative data from the NSW Government departments of education, pensions, health, and disability	Approximately 57,000 with IDD receiving services in NSW in 2003	Mix of measures, including clinical/ medical assessment, IQ testing, comorbidity codes in hospital medical records, school information, and disability service assessments	The estimated prevalence of people with IDD receiving services in NSW was 85/10,000 people in 2003. By 2043, the researchers predicted that there will be 135,900 people with IDD in NSW, with a prevalence of 135/10,000 people.
ABS (2019a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^a	Of the estimated 4.4 million people with disability in Australia (17.7% of the population), 6.5% had intellectual or developmental disorders (similar to 6.3% in 2015).

Note. CI=confidence interval, ID=intellectual disability, IDD=intellectual developmental disorders, NSW=New South Wales. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.”

Prevalence of intellectual disability internationally

To contextualise the Australian data, international evidence is included which indicates that the prevalence of intellectual disability is 10.37 per 1,000 population (95% confidence interval [CI]: 9.55 to 11.18) (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). In the meta-analysis of 52 studies that produced this prevalence rate, differences between studies were apparent. Prevalence rates were:

- Lower in higher income countries (9.21 per 1,000 population; 95% CI: 8.46 to 9.96), such as Australia, than in middle income (15.94 per 1,000 population; 95% CI: 13.56 to 18.32) and low income countries (16.41 per 1,000 population; 95% CI: 11.14 to 21.68);
- Higher in child/adolescent samples (18.30 per 1,000 population; 95% CI: 15.17 to 21.43) than adult samples (15.94 per 1,000 population; 95% CI: 13.56 to 18.32);
- Higher in random household surveys (15.78 per 1,000 population; 95% CI: 13.73 to 17.86) than in data from hospitals or administrative registries (9.35 per 1,000 population; 95% CI: 8.60 to 10.10) and school-based studies (7.04 per 1,000 population; 95% CI: 6.35 to 7.73);
- Lower when the American Psychiatric Association's Diagnostic Statistical Manual (DSM) or the World Health Organization's International Classification of Disease (ICD) were used for diagnosis (8.68 per 1,000 population; 95% CI: 7.89 to 9.48) or disability schedules (American Association on Intellectual and Developmental Disabilities; International Classification of Functioning, Disability and Health; or some disability criteria) were used (6.41 per 1,000 population; 95% CI: 4.89 to 7.93), than when the administration of psychological instruments was used in conjunction with clinical judgement (14.30 per 1,000 population; 95% CI: 12.70 to 15.91).

What these statistics serve to show are that the prevalence rates in most studies fall within a fairly narrow range, but that variations seem to occur due to multiple factors, such as the population in focus and how intellectual disability is measured.

Severity of intellectual disability

The ABS (2019a) and Western Australian study by Bourke and colleagues (2016) referred to in Table 1, also reported on severity of intellectual disability. Again, definitional differences make comparison of these data problematic. It was not possible to find data which included a breakdown by conditions associated with intellectual disability (e.g., Down syndrome, Fragile X syndrome etc.) or which reported multiple disability diagnosis.

Table 2 Severity of intellectual disability

Source	Datasets	Sample	Measure	Findings
Bourke et al. (2016)	IDEA (Intellectual Disability Exploring Answers) database	Births in Western Australia from 1983 to 2005 (with follow up to 2010, n=565,242)	Mix of measures (diagnosis of ID, recorded severity of ID, or education need level)	Prevalence rates according to severity were: <ul style="list-style-type: none">• mild or moderate ID (IQ=40-69) was 15.0/1,000 live births (95% CI: 14.6, 15.3)• severe ID (IQ=<40) was 1.2/1,000 (95% CI: 1.1, 1.3)• unknown severity was 0.9/1,000 (95% CI: 0.8, 1.0).

				These rates represent an increase in prevalence from births between 1983 to 1992 (with follow up to 1999) of 10.6/1000 for mild or moderate ID, 1.4/1,000 for severe ID, and 2.3/1,000 for unknown ID.
ABS (2019a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^a	As a percentage of the Australian population, 3.2% had profound limitations and 2.6% had severe limitations. ^b Of those with profound or severe limitations, 12.1% had intellectual or developmental disorders.

Note. CI=confidence interval, ID=intellectual disability. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.” ^b Profound limitation defined as “greatest need for help, that is, always needs help with at least one core activity.” Severe limitation defined as “needs help sometimes or has difficulty with a core activity.”

Demographics of people with intellectual disability

The following four tables provide demographic data related to age range, sex, and cultural diversity of people with intellectual disability in Australia. Data from the ABS (2019a) and the NSW study by Lee and colleagues (2016) reported in Table 3 shows that the majority of people with intellectual disability are aged under 40 years of age with the largest proportion aged between 5-14 years. With increased life expectancy due to better health care, lifestyle and environmental conditions, the Lee et al (2016) study projected an increase in the proportion of the population with intellectual disability in the 65+ age range from 10/10,000 (1.8%) in 2003 to 50/10,000 (6%) in 2023.

Age ranges

Table 3 Age ranges of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Lee et al. (2016)	Administrative data from the NSW Government departments of education, pensions, health, and disability	Approximately 57,000 with IDD receiving services in NSW in 2003	Mix of measures, including clinical/ medical assessment, IQ testing, comorbidity codes in hospital medical records, school information, and disability service assessments	<p>The estimated number (and prevalence, in brackets) of people with IDD receiving services in NSW in 2003 was:</p> <ul style="list-style-type: none"> • 32,000 aged 0-15y (240/10,000 people), representing 56.1% of people with IDD • 15,000 aged 16-39y (60/10,000 people), representing 26.3% of people with IDD • 9,000 aged 40-64y (40/10,000 people), representing 15.8% of people with IDD • 1,000 aged 65+y (10/10,000 people), representing 1.8% of people with IDD. <p>The researchers predicted that number (and prevalence, in brackets) of people with IDD in NSW in 2043 will be:</p> <ul style="list-style-type: none"> • 59,600 aged 0-15y (290/10,000 people), representing 43.9% of people with IDD • 42,500 aged 16-39y (110/10,000 people), representing 31.3% of people with IDD • 25,600 aged 40-64y (70/10,000 people),

				representing 18.8% of people with IDD <ul style="list-style-type: none"> 8,200 aged 65+y (50/10,000 people), representing 6.0% of people with IDD
ABS (2019a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^a	ID was the most common grouping of disabilities affecting children (aged 0-14y). Of the 4.7 million children in Australia, an estimated 208,800 (4.5%) had ID. Of those aged 0-14y, ID was almost twice as common in boys (5.8%, n=137,800) than girls (3.1%, n=70,600). ID was more likely to be reported for children aged 5-14y (6.1%, n=189,200) than those aged 0-4y (1.1%, n=17,800).

Note.ID=intellectual disability, IDD=intellectual developmental disorders, NSW=New South Wales. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.

Sex

Data from the ABS (2019a) and Western Australian study by Bourke and colleagues (2016), are consistent in reporting that intellectual disability is more common among males than females. The ABS (2014) notes that this difference between males and females may possibly be due to the fact that boys have higher rates of some conditions that are more commonly associated with intellectual disability (e.g., autism) or may be more likely to be diagnosed with intellectual disability due to behaviours of concern identified at school.

Table 4 Ratio of males to females with intellectual disability

Source	Datasets	Sample	Measure	Findings
Bourke et al. (2016)	IDEA (Intellectual Disability Exploring Answers) database	Births in Western Australia from 1983 to 2005 (with follow up to 2010, n=565,242)	Mix of measures (diagnosis of ID, recorded severity of ID, or education need level)	There were more males (65%) than females (35%) in the cohort. The prevalence rate was 21.7/1,000 for males and 12.2/1,000 for females. The prevalence ratio was 1.78 (95% CI: 1.71, 1.86).
ABS (2019a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from	Self- or proxy-reported difficulty learning or	Of the 4.7 million children in Australia aged 0-14y, ID was estimated to be almost twice as common in boys (5.8%,

		cared accommodation)	understanding things ^a	n=137,800) than girls (3.1%, n=70,600).
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Note. CI=confidence interval, ID=intellectual disability. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.

Cultural diversity

Estimates of intellectual disability among Aboriginal and Torres Strait Islander people consistently show higher levels than for the non-Indigenous population. These data indicate differences between Aboriginal and Torres Strait Islander people living in metropolitan, regional, and remote areas and associations between intellectual disability and social disadvantage.

Table 5 Aboriginal and Torres Strait Islander people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Haysom et al. (2014)	Data collected as part of the NSW Young People in Custody Health Survey	295 young people, representing 65% of the NSW Juvenile Custodial Population from August to October 2009	Wechsler Adult Intelligence Scale – Fourth Edition (WAIS-IV) Australian and New Zealand Language Adaptation for young people aged 17 years and over	Results from the cognitive assessments (Full Scale IQ) were: <ul style="list-style-type: none"> • 13.6% (n=40) had extremely low IQ (<70) • 32.2% (n=95) had borderline IQ (70-79) • 31.5% (n=93) had low average IQ (80-89) • 21.4% (n=63) had average IQ (90-109) • 1.3% (n=4) had high average/superior IQ (≥110). Compared with non-Aboriginal young people (n=147), Aboriginal young people (n=148) had significantly lower Full Scale IQ scores (e.g., 20.3% vs 6.8% for Full Scale IQ<70). After adjusting for disparities in social disadvantage, however, Aboriginal origin was no longer a significant risk factor for ID (Full Scale IQ<70).
Carroll et al. (2015)	ABS's National Aboriginal and Torres Strait Islander Social Survey, 2008 and National Health Survey, 2007–2008	Indigenous and non-Indigenous adults within Australia aged 18-64y	Self- or proxy-reported difficulty learning or understanding things ^a	National prevalence estimates of ID were: <ul style="list-style-type: none"> • 7.6% for Indigenous adults • 2.5% for non-indigenous adults. Estimates of ID with profound or severe core activity limitation were: <ul style="list-style-type: none"> • 2.1% for Indigenous adults • 0.8% for non-indigenous adults. Prevalence estimates for Indigenous and non-Indigenous Australians with ID by geographical location were: <ul style="list-style-type: none"> • 9.1% vs 2.3% for major cities • 8.9% vs 2.8% for regional areas

				<ul style="list-style-type: none"> 3.4% vs 5.4%^b for remote areas.
ABS (2019c)	National Aboriginal and Torres Strait Islander Social Survey, 2014-15	Aboriginal and Torres Strait Islander people	Self- or proxy-reported difficulty learning or understanding things ^a	<p>For Aboriginal and Torres Strait Islander people aged 15+, an estimated 8% had intellectual impairments.</p> <p>Of the estimated 36,400 people with intellectual impairments, the distribution according to severity was as follows:</p> <ul style="list-style-type: none"> 30.7% profound/severe disability^c (n=11,200) 27.1% moderate/mild disability^c (n=9,900) 42.1% other disability^c (n=15,300).
Bourke et al. (2016)	IDEA (Intellectual Disability Exploring Answers) database	Births in Western Australia from 1983 to 2005 (with follow up to 2010, n=565,242)	Mix of measures (diagnosis of ID, recorded severity of ID, or education need level)	Aboriginal children had a higher prevalence rate (39.0/1,000 live births) than non-Aboriginal children (15.7/1,000).

Note. ABS=Australian Bureau of Statistics, CI=confidence interval, ID=intellectual disability. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.” ^b Estimate has a relative standard error of 25-50%, indicating it should be used with caution. ^c Profound=always needs help/supervision with core activities, severe=does not always need help with core activities, moderate=has difficulty with core activities, and mild=uses aids to assist with core activities.

The findings of two studies in Western Australia, are equivocal with respect to any possible association between intellectual disability and maternal country of birth (Abdullahi, Wong, Bebbington, et al., 2019; Abdullahi, Wong, Mutch, et al., 2019). Studies specifically reporting on the prevalence of intellectual disability among culturally and linguistically diverse groups are lacking.

Table 6 Maternal country of birth of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Abdullahi, Wong, Bebbington et al. (2019)	Western Australian Register for Autism Spectrum Disorders	4,776 cases notified to the Register between January 1999 and June 2017	DSM-IV and DSM-5 criteria	<p>Compared with children from Australian non-Indigenous mothers, risk of diagnosis with ID was higher among children with ASD whose mothers were foreign-born from:</p> <ul style="list-style-type: none"> Low-income countries (RR=2.16; 95% CI 1.63, 2.86) Lower-middle-income countries (RR=2.19; 95% CI 1.77, 2.70) Upper-middle-income countries (RR=2.16; 95% CI 1.66, 2.81)

				<ul style="list-style-type: none"> High-income countries (RR=1.76; 95% CI 1.33, 2.32).
Abdullahi, Wong, Mutch et al. (2019)	Western Australia (WA) Mid-wives Notification System (MNS), the WA Birth Register, the Intellectual Disability Exploring Answers (IDEA) database, and the WA Register of Developmental Anomalies (WARDA)	765,064 singleton livebirths in Western Australia from 1980 to 2010	Various criteria based on IQ and cognitive functioning	Adjusted analyses showed no associations between ASD with intellectual disability and mothers who were foreign born. In addition, the relative risk of intellectual disability only was lower for children of foreign-born mothers from lower-middle-income countries than for children of Australian-born mothers of non-indigenous backgrounds for children born from 1980 to 1996 (aRRR=0.67; 95% CI 0.56, 0.80) and those born from 1997 to 2010 (aRRR=0.73; 95% CI 0.57, 0.92).

Note. ASD= autism spectrum disorders. CI=confidence interval, ID=intellectual disability. ^a Estimate has a relative standard error of 25-50%, indicating it should be used with caution.

Government support of people with intellectual disability

Access to government data reporting on the support provided to people with intellectual disability was difficult to source within the time-period and resources available. The Department of Social Services website <https://www.dss.gov.au/disability-and-carers/publications-articles> provides information about available financial support for people with disability and carers but there is a lack of readily available data on the numbers and breakdown of people with disability accessing this support. In collecting data on people with people with intellectual disability, DSS uses the following definition “[Intellectual disability] applies to medical conditions appearing in the developmental period (age 0-18) associated with impairment of mental functions, difficulties in learning and performing certain daily life skills and limitation of adaptive skills in the context of community environments compared to others of the same age. Intellectual disability may be associated with Down syndrome, autism, etc.” (Australian Government Disability Services Census, 2008, p. 148). In the absence of access to data, some sections below only report eligibility criteria.

Disability Support Pension

The Department of Social Services administers the Disability Support Pension (DSP). According to the DSP demographic data tables (June, 2020) “DSP is an income support payment for people who are unable to work for 15 hours or more per week at or above the relevant minimum wage, independent of a Program of Support due to permanent physical, intellectual or psychiatric impairment. A DSP claimant must be aged 16 years or over and under Age Pension age at date of claim, however once in receipt of DSP, a person can continue to receive DSP beyond Age Pension age”. Eligibility for DSP is assessed based on Work-related Impairment Tables (updated in 2011). Table 9 defines intellectual disability eligibility as “low intellectual function (IQ scores of 70 to 85) resulting in functional impairment, which originated before the person turned 18 years old.” Assessment is conducted, after the person turns 16 years of age, by a qualified clinical psychologist using Wechsler Adult Intelligence Scale IV (WAIS IV) or equivalent contemporary assessment. An assessment of adaptive behaviour is also required in the form of either the Adaptive Behaviour Assessment System (ABAS-II), the Scales for Independent Behaviour – Revised (SIB-R), the Vineland Adaptive Behaviour Scales (Vineland-II) or any other standardised assessment of adaptive behaviour. Assessors use the Assessment Tables to report on the impact of intellectual disability on intellectual function according to: “no (impact), mild, moderate, severe and extreme”.

The June 2020 DSP demographic data tables report people with “intellectual/learning” disability as the third largest group of the total 754,181 DSP recipients (after “psychological/psychiatric” and “musculo-skeletal and connective tissue”). In the 12 months to June 2020, a total of 113,410 people with “intellectual/learning” disability received the DSP with the majority (66,589) male and aged 25-54 years (71,239). <https://data.gov.au/search?q=DSS>

Disability Services Data Collection

The Disability Services Data Collection (formerly known as the Disability Services Census), collects information each year from disability services funded by the Department of Social Services including: supported employment services (also known as Australian Disability Enterprises), advocacy services, respite services for carers of young people with severe or profound disabilities, information/referral services, and alternative formats of communication (including print disability services).

Disability Employment Services – are funded through The Department of Social Services to assist people with disability to find and keep employment. Disability Employment Services (DES) providers include for-profit and not-for-profit organisations. DES providers have experience supporting people with disability and working with employers to ensure their practices support the employee in the workplace. Disability Employment Services are divided according to:

- Disability Management Services (DMS) for “job seekers with disability, injury or health condition who need assistance to find a job and occasional support in the workplace to keep a job”.
- Employment Support Service (ESS) “provides assistance to job seekers with permanent disability to find a job and who need regular, ongoing support in the workplace to keep a job.”

The Disability Employment Services summary report for the month of August 2020 indicated that 3.4% (10,028) of those using DES had intellectual disability. Of these, 357 were receiving DMS support and 9,671 ESS support. Caseload characteristics are not cross-tabulated by disability type so further interrogation of the data specific to those with intellectual disability was not possible.

<https://lmip.gov.au/default.aspx?LMIP/Downloads/DisabilityEmploymentServicesData/MonthlyData>

Department of Education Skills and Employment

The annual Nationally Consistent Collection of Data on School Students with Disability (NCCD) collects information about Australian school students who receive an adjustment to address disability <https://www.education.gov.au/what-nationally-consistent-collection-data-school-students-disability> The term ‘cognitive disability’ is used to describe “total or partial loss of a person’s bodily or mental functions and a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction”.

National Disability Insurance Scheme (NDIS)

In early 2020, the NDIA released the report *People with Intellectual Disability in the NDIS* (NDIA, 2020). According to the report, as of 31 December 2019, people with intellectual disability represented almost 40% (109,138 people) of all participants with an approved plan. Of these, 78,992 participants reported intellectual disability as their primary disability, making up 23.3% of all Scheme participants with an approved plan. The majority of participants reporting intellectual disability as their primary disability were previously receiving Commonwealth or state and territory support. The proportion of participants with a primary intellectual disability who met the access requirements were reasonably consistent across all states and territories. In contrast with the ABS (2019a) data on age distribution of people with intellectual disability, the NDIS reported that, compared to all Scheme participants, a considerably lower proportion of participants with an intellectual disability were aged 0-14 years. Most Scheme users with intellectual disability as a primary or secondary disability were aged 15-44 years. The proportion of NDIS participants with an intellectual disability who identified as Aboriginal and Torres Strait Islander (6.9%) was slightly higher than that of all participants of the Scheme (6.1%), with the greatest difference reported in the Northern Territory. There was a lower proportion of participants with a primary intellectual disability who identified as Culturally and Linguistically Diverse (6.8%) compared to all participants within the Scheme (8.9%).

Restricted Decision-Making

Guardianship

Guardianship is the term given to “the regime of control, management and substitute decision-making exercised by another person on behalf of a person with decision-making disability who does not have capacity and is in need of such support”. Guardianship can be informal through adult family members, and/or formal through a publicly appointed guardian or advocate. Guardianship includes decisions about welfare and health but does not cover decisions about financial affairs as these are matters for a financial manager (may also be called an administrator).

http://www.idrs.org.au/pdf/Guardianship_and_administration_laws_across_Australia_by_Ben_Fogarty.pdf

Restrictive practices

Some people with intellectual disability may display behaviours of concern resulting in development of behaviour support strategies. Behaviours of concern (also known as challenging behaviours) include aggression toward others, self-injury including unintentional or deliberate self-harm, or destruction of property. Behaviour support strategies to address behaviours of concern may include a set of practices identified as restrictive practices. These practices effectively restrict a person’s rights or freedom and may include environmental restraint, physical restraint, mechanical restraint, chemical restraint and seclusion. Behaviour support plans that include a restrictive practice, must be developed by a registered behaviour support practitioner and approved by a mechanism for restrictive practice authorisation. The use and effectiveness of restrictive practices, which were inconsistently regulated across Australia, may be considered a contravention of an individual’s human rights as articulated in the UNCPRD. The Australian Law Reform Commission (2014) identified the need for a nationally consistent approach to the regulation of restrictive practices. Consequently, in 2016, the NDIS Quality and Safeguarding Framework was agreed to by all states and territories at the Council of Australian Governments to work towards the reduction and elimination of restrictive practices.

Two studies by Webber and colleagues (2010; 2011) reported on Victorian data for people with intellectual disabilities receiving restrictive practices. The restrictive practices included chemical and mechanical restraint and seclusion.

Table 7 Chemical and mechanical restraint and seclusion of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Webber et al. (2010)	Database of cases of chemical or mechanical restraint or seclusion reported to the Senior Practitioner of Victoria’s Department of Human Services	27 people with ID who were in receipt of compulsory treatment orders (CTOs) during the year from July 2008 to June 2009 and a sample matched for age and	Measure of ID not reported	Comparing people with ID on CTOs with the matched sample, people with ID on CTOs: <ul style="list-style-type: none">• Were subjected to chemical restraint (96% vs 98%) and mechanical restraint (4% to 11%) in similar proportions as the matched sample, but were more likely to be subjected to seclusion (44% vs 5%)• Received more administrations of four types of medications: (1) anti-androgens (47% more), (2)

		gender in receipt of restrictive practices (n=498)		anticholinergic (45% more), (3) mood stabilizers (38% more), and (4) antidepressants (33% more) • Received fewer administrations of two types of medications: (1) benzodiazepines (68% less) and (2) sedatives (87% less).
Webber et al. (2011)	Database of cases of chemical or mechanical restraint or seclusion reported to the Senior Practitioner of Victoria's Department of Human Services	30,932 episodes of restrictive interventions relating to behaviour interventions involving 2,102 people during the year June 2007–July 2008	Measure of ID not reported	<ul style="list-style-type: none"> • The 2,012 people subjected to restrictive interventions represent approximately 9% of people with ID in Victoria who were in receipt of government-funded disability support services • Restraints were either routine (65.5% of episodes involving 94% of people), PRN (27.0% of episodes involving 27% of people), emergency (7.5% of episodes involving 23% of people). • Restrictive practices were either chemical restraints (82.7% of episodes involving 96.2% of people), mechanical restraints (11.2% of episodes involving 9.0% of people), or seclusion (7.6% of episodes involving 7.0% of people) • 10.7% of people received more than one type of restrictive practice.

Note. ID=intellectual disability, PRN=pro re nata (as required).

Schooling

As previously reported, within the available time and resources, no publicly available information was found on the Department of Education, Skills and Employment website that provided data on the number or characteristics of people with intellectual disability in mainstream education (public, independent or Catholic), segregated settings, or being home schooled. One peer-reviewed article by Graham (2012) provided information comparing enrolment of Indigenous children in NSW Schools for Specific Purposes. Graham noted the difficulties of accessing education data.

Table 8 NSW Indigenous children in schools for specific purposes

Source	Datasets	Sample	Measure	Findings
Graham (2012)	NSW DET <i>Schools Locator</i> database, <i>My School</i> website, school websites and annual reports, plus other sources	4,466 students enrolled in 113 Schools for Specific Purposes in 2009	Inferred from enrolment at traditional Schools for Specific Purposes	Indigenous Australian children have equal chances of being enrolled at traditional Schools for Specific Purposes (serving children with autism or intellectual, physical, and sensory disabilities) as non-Indigenous children.

Note. ID=intellectual disability, NSW DET=New South Wales Department of Education and Training

Employment

According to the ABS (2012), of the estimated 4 million Australians with disability, 2.2 million were of 'prime working age' between 15-64 years. Levels of employment for people with disability are declining with workforce participation for this group dropping from 54.9% in 1993 to 52.8% in 2012 (Australian Bureau of Statistics, 2012). The UNCRPD (United Nations, 2011) recognises persons with disabilities have the right to work on an equal basis with others. The Australian government's National Disability Strategy 2010-2020 (Council of Australian Governments, 2011) similarly identifies the importance of paid employment to economic security, social inclusion, physical and mental health and wellbeing, and sense of identity. Hence, increasing access to employment opportunities for people with disability is crucial to increasing economic security and personal wellbeing. People with disability, including many with intellectual disability, want to work (Department of Education Employment and Workplace Relations, 2009). Barriers to their employment exist both at the systemic policy level and at the employer level. At the systemic policy level, despite government recognition of the importance and value of employment for people with disability, translating this into practice remains a challenge with Australia ranked 21 of 29 OECD countries in employment of people with disability (PWC, 2011).

The NDIA (2020) report on people with intellectual disability notes that for Scheme participants over the previous two years, the percentage with a primary intellectual disability in paid work increased from a baseline of 18% to 25% in year two for those aged 15 to 24, and decreased from a baseline of 38% to 36% for those aged 25 and over. Overall, the percentage of participants with a primary intellectual disability in employment remained stable and higher than the full Scheme at 33%. The ABS (2019a, 2020a) data reported in Table 9, indicated 14 – 18% of people with intellectual disability aged 15 – 64 years were in full or part time employment and 60% were not in the labour market.

Table 9 Employment of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Foley et al. (2013)	Survey sent to families identified through the population-based Down Syndrome Needs Opinions Wishes study in Western Australia	203 families of people with Down syndrome aged 15-30y in 2009, 164 of whom had left school	Diagnosis	Post-school, the young people with Down syndrome were engaged in: <ul style="list-style-type: none"> • Sheltered employment (39.0%) • Open employment (25.6%) • Alternatives to employment (25.0%) • Training (10.4%).
Gray et al. (2014)	Australian Child to Adult Development Study in NSW and Victoria	354 people with ID aged 20.5-37.6y when followed up at Wave 5 in 2008-2009 (Wave 1: 1991-1992)	Diagnosis, with severity based on the results of existing cognitive assessments and DSM-IV ranges	Living circumstances at Wave 5: <ul style="list-style-type: none"> • Mild impairment (IQ=50-69) <ul style="list-style-type: none"> - Mainstream ^a (21.6%, n=24; Wave 1: 29.5%) - Non-mainstream ^b (65.8%, n=73; Wave 1: 70.5%) - No organised activity (12.6%, n=14; Wave 1: 0%)

				<ul style="list-style-type: none"> • Moderate impairment (IQ=36-49) <ul style="list-style-type: none"> - Mainstream ^a (16.0%, n=25; Wave 1: 17.5%) - Non-mainstream ^b (79.5%, n=124; Wave 1: 81.9%) - No organised activity (4.5%, n=7; Wave 1: 0.6%) • Severe impairment (IQ=20-35) <ul style="list-style-type: none"> - Mainstream ^a (0%, n=0; Wave 1: 4.3%) - Non-mainstream ^b (96.0%, n=72; Wave 1: 95.7%) - No organised activity (4.0%, n=3; Wave 1: 0%) • Profound impairment (IQ<20) <ul style="list-style-type: none"> - Non-mainstream ^b (100%, n=8; Wave 1: 100%).
ABS (2019a, 2020a)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^c	<p>The labour force statuses of the estimated 327,600 people with ID aged 15-64y living in households were (percentages for people with disability provided in parentheses for comparison):</p> <ul style="list-style-type: none"> • 13.8% employed full-time (28.3%) • 18.2% employed part-time (19.6%) • 5.5% underemployed (4.8%) • 6.9% unemployed (5.5%) • 61.2% not in the labour force (46.6%)

Note. DSM= Diagnostic and Statistical Manual of Mental Disorders, ID=intellectual disability, NSW=New South Wales. ^a Mainstream=mainstream daytime activity (e.g. mainstream school, technical and vocational training, or a paid job), ^b Non-mainstream= activities specifically for people with ID (e.g. special school, special unit in a mainstream school, day activity programme or sheltered workshop). ^c Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.”

Living situations

The NDIA (2020) report on intellectual disability noted that a higher proportion of Scheme participants with a primary intellectual disability live in supported independent living (17%) compared to all participants of the Scheme (7%). The report notes that “As a result, total average committed supports are higher for participants with an intellectual disability. Notably, the utilisation of core supports for participants with a primary intellectual disability receiving supported independent living supports is much higher (89%) compared to those that do not have such supports in their plan (67%)” (p. 23).

Three studies were found in the peer-reviewed literature reporting on living situations for people with intellectual disability. These studies reported on very different aspects of housing using different data sources making any comparative comments difficult. The study by Gray and colleagues (2014) used data from the NSW and Victorian Australian Child to Adult Development Study demonstrating that people with mild and moderate levels of intellectual disability were more likely to be living at home than those with severe or profound intellectual disability who were more likely to be living in care. A study by Aitken and colleagues published in 2019 reported on data from the Household, Income and Labour Dynamics Australia (HILDA) Survey showing that of the 109 respondents with intellectual disability, the majority (34%) were living in housing owned outright but that this housing was in poor condition. A study by Nielsson and colleagues (2018), reviewed the medical records of people accessing mental health clinics in homeless hostels in central Sydney and showed that 5% of residents had an intellectual disability with 62% of this group having been homeless for a year or more.

Table 10 Living circumstances of people with intellectual disability

Source	Datasets	Sample	Measure	Findings
Gray et al. (2014)	Australian Child to Adult Development Study in NSW and Victoria	354 people with ID aged 20.5-37.6y when followed up at Wave 5 in 2008-2009 (Wave 1: 1991-1992)	Diagnosis, with severity based on the results of existing cognitive assessments and DSM-IV ranges	<p>Living circumstances at Wave 5:</p> <ul style="list-style-type: none"> • Mild impairment (IQ=50-69) <ul style="list-style-type: none"> - Home ^a (76.6%, n=85; Wave 1: 94.7%) - Care ^b (9.9%, n=11; Wave 1: 5.3%) - Independent (13.5%, n=15; Wave 1: 0%) • Moderate impairment (IQ=36-49) <ul style="list-style-type: none"> - Home ^a (69.9%, n=109; Wave 1: 90.3%) - Care ^b (19.2%, n=30; Wave 1: 9.7%) - Independent (10.9%, n=17; Wave 1: 0%) • Severe impairment (IQ=20-35) <ul style="list-style-type: none"> - Home ^a (26.7%, n=20; Wave 1: 63.9%) - Care ^b (73.3%, n=55; Wave 1: 36.1%) • Profound impairment (IQ<20)

				<ul style="list-style-type: none"> – Home ^a (2.5%, n=1; Wave 1: 47.1%) – Care ^b (87.5%, n=7; Wave 1: 52.9%).
Nielssen et al. (2018)	Medical records of a consecutive sample of people presenting to mental health clinics at the three large homeless hostels in inner city Sydney between 21 July 2008 and 31 December 2016	2,388 patients, 119 (5.0%) of whom had ID	Psychiatric diagnosis (no further information provided)	<p>Of the 119 people with ID, 74 (62.2%) had been homeless for more than a year. The pathways to homelessness of the 45 people with ID who had been homeless for less than a year were:</p> <ul style="list-style-type: none"> • Loss of other accommodation (40.0%, n=18) • Loss of public housing (26.7%, n=12) • Release from prison (24.4%, n=11) • Discharge from psychiatric hospital (8.9%, n=4). <p>In comparison, 1,314 (57.9%) of people without ID had been homeless for more than a year. The pathways to homelessness of the 955 people without ID who had been homeless for less than a year were:</p> <ul style="list-style-type: none"> • Loss of other accommodation (46.5%, n=444) • Loss of public housing (20.4%, n=195) • Release from prison (20.8%, n=199) • Discharge from psychiatric hospital (12.3%, n=117).
Aiken et al. (2019)	Household, Income and Labour Dynamics Australia (HILDA) Survey (11 th wave)	17,612 individuals aged 25-64y; 109 with intellectual impairment	Reported functional impairment relating to difficulty learning or understanding things affecting everyday activities having lasted, or expected to	<p>Compared to people without disability, those with intellectual impairment were more likely to be:</p> <ul style="list-style-type: none"> • Living in homes that were owned outright (33.9% vs 24.0%) • Public renters (18.4% vs 1.5%) • Living in unaffordable housing (19.1% vs 7.6%) • Living in homes that are derelict, very poor, poor, or average quality (41.8% vs 30.5%). <p>They were less likely to be:</p>

			last, 6 months or more	<ul style="list-style-type: none"> • Living in homes with mortgages (20.3% vs 42.7%). No difference between people with intellectual impairment and those without disability for: <ul style="list-style-type: none"> • Private renting (26.1% vs 29.5%).
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Note. DSM= Diagnostic and Statistical Manual of Mental Disorders, ID=intellectual disability, NSW=New South Wales. ^a At home with family (or foster parents), ^b In care (group home or large residential).

Custody

Professor Leanne Dowse and colleagues (2014) at UNSW Sydney (2014) note that estimates of the prevalence of intellectual disability among prisoner populations vary significantly depending on how intellectual disability is defined. They cite a 2011 study estimating that 77% of NSW juvenile detainees scored below the average range of intelligence functioning. Significantly, 20% of young Indigenous persons in custody had an intellectual disability and 39% were reported to be in the borderline intellectual disability range. Table 11 includes a study by Haysom and colleagues (2014) which reported on the population of young people in NSW juvenile custody in 2009 indicating that 46% were identified as having borderline or extremely low IQ.

Table 11 People with intellectual disability in custody

Source	Datasets	Sample	Measure	Findings
Haysom et al. (2014)	Data collected as part of the NSW Young People in Custody Health Survey	295 young people, representing 65% of the NSW Juvenile Custodial Population from August to October 2009	Wechsler Adult Intelligence Scale – Fourth Edition (WAIS-IV) Australian and New Zealand Language Adaptation for young people aged 17 years and over	<p>Results from the cognitive assessments (Full Scale IQ) were:</p> <ul style="list-style-type: none"> • 13.6% (n=40) had extremely low IQ (<70) • 32.2% (n=95) had borderline IQ (70-79) • 31.5% (n=93) had low average IQ (80-89) • 21.4% (n=63) had average IQ (90-109) • 1.3% (n=4) had high average/superior IQ (≥110). <p>Compared with non-Aboriginal young people (n=147), Aboriginal young people (n=148) had significantly lower Full Scale IQ scores (e.g., 20.3% vs 6.8% for Full Scale IQ<70). After adjusting for disparities in social disadvantage, however, Aboriginal origin was no longer a significant risk factor for ID (Full Scale IQ<70).</p>

Parents with intellectual disability

An under, but increasingly reported cohort includes people with intellectual disability with children. Table 12 includes a study by Man and colleagues (2017) which estimated a prevalence of parenthood at 8.0% of people with intellectual disability.

Table 12 Parents with intellectual disability

Source	Datasets	Sample	Measure	Findings
Man et al. (2017)	ABS's Survey of Disability, Ageing and Carers, 2009	61,900 survey participants in 24,800 private dwelling households sampled from April to December 2009 (number with ID unreported)	Self- or proxy-reported difficulty learning and understanding things	An estimated 17,000 (95% CI: 11,500, 22,400) people with ID aged 15-64y in private dwellings were parents. The prevalence of parenthood was 8.0% (95% CI: 5.9% 10.8%) of people with ID. Of all parents in Australia aged 15-64y and living in private dwellings, an estimated 0.41% (95% CI: 0.30%, 0.57%) had ID. Compared with people with ID, the likelihood of parenthood was greater for: <ul style="list-style-type: none">• People with other disabilities (OR=3.1; 95% CI: 2.2, 4.4)• People without disability (OR=5.0: 95% CI: 3.6, 6.9).

Note. ABS=Australian Bureau of Statistics, CI=confidence interval, ID=intellectual disability.

Access to technology

Table 13 reports data from the ABS SDAC (2019a, 2020b) indicating that, over a three month period, almost 65% of people with intellectual disability aged 15+ years had used the internet, 51% had used SMS, 41% had used social media, and 20% had used email.

Table 13 People with intellectual disability with access to technology

Source	Datasets	Sample	Measure	Findings
ABS (2019a, 2020b)	Survey of Disability, Ageing and Carers, 2018	65,805 people (54,142 from households and 11,663 from cared accommodation)	Self- or proxy-reported difficulty learning or understanding things ^a	<p>With respect to the last 3 months, of the estimated 432,500 people with ID in Australia aged 15+ and living in households (percentages for people with disability and primary carers, respectively, given in parentheses):</p> <ul style="list-style-type: none"> • 64.9% had used the internet (71.5%, 85.5%) • 50.9% had SMS contact with family or friends not living in same household (61.9%, 76.3%) • 40.7% had social networking/chat room contact with family or friends not living in same household (42.3%, 53.8%) • 20.1% had email contact with family or friends not living in the same household (39.8%, 49.0%). <p>Reasons given for people with ID not using the internet in the past 3 months were (percentages for people with disability and primary carers, respectively, given in parentheses):</p> <ul style="list-style-type: none"> • Have no need/no interest, 8.4% (2.2%, 8.5%) • No access to a computer or mobile technology, 19% (6.2%, 15.2%) • Cost, 29.8% (14.6%, 37.6%) • Privacy or security concerns, N/A (18.1%, N/A) • Lack of confidence/knowledge in accessing the internet, 10.7% (5%, 15.6%) • Can rely on friends/family to use the internet for them, 17% (7.4%, 23.1%)

				<ul style="list-style-type: none"> • Lack of assistive technology, np% (20.9%, 47.7%) • No time, 0% (23.9%, N/A) • Internet services not available/of too poor quality for use in local area, 48.2% (20.2%, 39.4%) • Other reason, 12.6% (8.6%, N/A)
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Note. N/A=not available for publication. ^a Intellectual disability defined as “difficulty learning or understanding things” where disability refers to “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.

Gaps and Recommendations

The compilation of data for this report, highlighted the difficulties in accessing reliable and comparable information about people with intellectual disability in Australia. As noted previously, there is a need for agreement on definitions of intellectual disability to inform consistent data collection at Commonwealth and state and territory levels to enable comparison and accurate reporting to inform the provision of relevant supports and services including advocacy.

Gaps

We were unable to find any publicly available data to report on the breakdown of prevalence by specific conditions (e.g., Down syndrome, Fragile X syndrome). Similarly, data indicating multiple diagnoses is lacking. Government data related to those with intellectual disability in aged care, and those receiving education and skills training, those with Guardianship and financial management is similarly lacking. A breakdown of the numbers and types of accommodation for people with intellectual disability is not available.

Recommendation

The proposed National Disability Data Set should go some way to filling these gaps but only if data are recorded and reported in ways that are meaningful to researchers, advocacy groups, policy makers, and others who seek to use it including using consistent definitions to assist with identifying those who have lifelong intellectual disability.

Appendix A: Search terms and result numbers

(N= 1,928)

MH "Intellectual Disability+" OR TI ("intellectual* disab*" OR "learning disab*") OR AB ("intellectual* disab*" OR "learning disab*")

AND

MH "Australia+" OR TI (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart) OR AB (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart)

Limits: 2010-, English language

MEDLINE results: 525

MH "Intellectual Disability+" OR TI ("intellectual* disab*" OR "learning disab*") OR AB ("intellectual* disab*" OR "learning disab*")

AND

MH "Australia+" OR TI (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart) OR AB (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart)

Limits: 2010-, English language

CINAHL results: 611

DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease" OR TI ("intellectual* disab*" OR "learning disab*") OR AB ("intellectual* disab*" OR "learning disab*")

AND

TI (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart) OR AB (Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart)

Limits: 2010-, English language, peer reviewed

PsycInfo results: 345

(TI=("intellectual* disab*" OR "learning disab*") OR AB=("intellectual* disab*" OR "learning disab*")) AND (TI=(Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart) OR AB=(Australia* OR "Northern Territory" OR Queensland* OR "New South Wales" OR Victoria* OR Tasmania* OR Perth OR Darwin OR Adelaide OR Brisbane OR Sydney OR Canberra OR Melbourne OR Hobart))

Limits: 2010-, English language, articles

Web of Science Core Collection results: 447

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