



HealthyStart

A national strategy for children of
parents with learning difficulties

Estimated prevalence and living circumstances of parents with intellectual disability in Australia from selected national surveys

Technical report 1
July 2014



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Estimated prevalence and living circumstances of parents with intellectual disability in Australia from selected national surveys: Technical report 1



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Acknowledgements

Members of the reference group for this study on the prevalence of parents with intellectual disability are acknowledged for their helpful advice and comments regarding available data sources in Australia. In particular, Ros Madden and Xingyan Wen are gratefully acknowledged for sharing their insights on disability data in Australia, as is Eric Emerson for reviewing and commenting on a draft version of this technical report.

The results or views expressed are those of the authors, and not necessarily those of the members of the reference group or that of the data custodians or the data-collecting agencies and institutions.

Suggested citation

Man, N., Llewellyn, G., & Wade, C. (July 2014). *Estimated Prevalence and Living Circumstances of Parents with Intellectual Disability in Australia from Selected National Surveys: Technical Report 1*. Lidcombe, NSW: University of Sydney.

Amendments

Please note that there is the potential for minor revisions of data in this report. Please check the online version at <www.healthystart.net.au> for any amendments.

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Executive summary

This technical report details the processes undertaken to estimate the prevalence of parents with intellectual disability in the Australian population, their characteristics and living circumstance based on analysis of data available from Australian national surveys conducted by the Australian Bureau of Statistics (ABS).

Method

The *Survey of Disability, Ageing and Carers* (SDAC 2009) was used to determine prevalence and socio-demographic characteristics for parents with intellectual disability in comparison to parents with other disabilities and non-disabled parents.

The *General Social Survey* (GSS 2010) was used to examine the living circumstances of parents with intellectual disability on selected social indicators – employment, material resources, social and emotional wellbeing and health – compared to parents with other disabilities and non-disabled parents.

Findings

Analysis of SDAC 2009 data identified an estimated 0.41% of Australian parents had intellectual disability. This equates to an estimated 17,000 parents with intellectual disability residing in private dwellings in Australia.

- People with intellectual disability were about four times less likely to be parents compared with non-disabled people.
- People with intellectual disability were about three times less likely to be parents compared with people with other disabilities.
- Parents with intellectual disability were more likely than non-disabled parents to reside outside capital cities and to have only one child.
- There were no significant differences between parents with intellectual disability and non-disabled parents in relation to sex or age distribution, lone parenthood or the number of resident children.
- There were no significant differences between parents with intellectual disability and parents with other disabilities on any of the demographic variables examined.

Analysis of GSS 2010 data revealed that, compared with non-disabled parents and also compared with parents with other disabilities, parents with intellectual disability were significantly more likely to:

- be in a jobless household
- be in households in the lowest three deciles of equivalised weekly income
- be on government pensions as the main source of personal income
- have ever been without a permanent place to live

- have ever stayed in a shelter, squatted in an abandoned building and/or slept rough
- have less frequent contact with family and friends
- have negative or mixed feelings about life
- have poorer self-assessed health.

Parents with intellectual disability were also more likely to be unemployed or not in the labour force compared to non-disabled parents.

Summary

Compared to other Australian parents (non-disabled parents and parents with other disabilities), parents with intellectual disability are significantly disadvantaged in employment, income, housing, social relationships and health and wellbeing.

These findings will contribute to evidence-informed policy and service planning in family and parenting support.

Main report

Background

Parents with intellectual disability are frequently considered an at-risk group of parents. There is little available population data about this group of parents, which is needed for evidence-informed policy and service planning. Most studies rely on non-representative samples, such as service recipient or clinical populations.

The study described in this technical report was conducted under the Federal Government Department of Social Services funded *Healthy Start. A national strategy for parents with learning difficulties* (www.healthystart.net.au). One aim of *Healthy Start* is to conduct research that contributes to the development of a knowledge base about parents with intellectual disability and their children.

This technical report addresses the first of two studies conducted in 2012–14.

Study 1: To estimate the prevalence of parents with intellectual disability¹ in the Australian population, and to describe the characteristics and the living circumstances of these parents and their children.

Study 2: To examine the circumstances of parents with intellectual disability in social security and service administrative data, in order to describe the characteristics of these parents and their children.

This technical report presents the processes used to identify sources for estimating and describing prevalence, characteristics and living circumstances, as well as the analysis and findings as required by Study 1. The findings from Study 2 will appear in two subsequent technical reports.

Method

Four steps were undertaken to identify relevant national surveys for the purposes of Study 1.

Step 1 Scoping and sourcing of survey data for the estimation of prevalence of parents with intellectual disability

- In December 2011 and August 2012, a reference group from the Faculty of Health Sciences, University of Sydney, the Parenting Research Centre and the Australian Institute of Health and Welfare (AIHW) met to discuss potentially relevant national surveys.
- Scoping and sourcing of potential survey data sources was then carried out by investigating websites of the Australian Bureau of Statistics (ABS), AIHW, and relevant universities and research institutes (e.g., Melbourne Institute of Applied Economic and Social Research at the University of Melbourne). Available survey documentation generally included user guides with

¹ Parents with intellectual disability are herein defined, following a social systems approach, as those who have at least one of the three following characteristics: (1) a diagnosis of intellectual disability or mental retardation; (2) a history of special education (such as attendance at a special school or participation in a special education class in a regular school); (3) a service provider has identified that the parent has cognitive limitations resulting in learning difficulties which may limit the parent's ability to benefit from traditional methods of instruction. In Australian statistical sources, *difficulty learning or understanding things* is the functional description aligned with intellectual disability and cognitive limitations. In this technical report identification of the target group is described in relation to the particularities of each data source.

sampling method, questionnaires, data item lists and a statistical summary of results from the surveys. Where necessary, discussion with a relevant contact person at each organisation was undertaken to clarify the relevance of the survey for the purposes of Study 1.

- A short list of potential surveys for the purpose of Study 1 was generated, comprising: *Survey of Disability, Ageing and Carers* (SDAC) in 2009; *General Social Survey* (GSS) in 2010; *National Health Survey* (NHS) in 2007–08; and *Survey of Mental Health and Wellbeing* (SMHW) in 2007 (see table in Appendix 1 for overview of characteristics of each survey).
- The study focus was on the prevalence of parents with intellectual disability and the characteristics and living circumstances of these parents and their children. However, the potential of surveys was considered in relation to data about non-disabled parents (parents without disabilities) and parents with other disabilities for comparison purposes.

Step 2 Selection of survey(s) for the estimation of prevalence of parents with intellectual disability

Using the following criteria, the *Survey of Disability, Ageing and Carers* (SDAC) was identified as the best possible national survey source to estimate the prevalence of parents with intellectual disability in Australia.

Criteria

- Suitable questionnaire and data items that allow the identification of parents with intellectual disability. SDAC is recognised as the survey of choice for estimating the prevalence of disability and of intellectual disability in the Australian population (Australian Bureau of Statistics, 2010; Wen, 1997) because it has extensive information on disability of survey participants including their causal conditions. SDAC also provides socio-demographic information, including parenthood status of participants, in the private dwelling component of the survey.
- High response rates to yield unbiased estimates. ABS surveys generally yield high response rates (well over 80%) due to rigorous recruitment process.
- When investigating relatively rare or infrequent events, as large as possible sample sizes are important for obtaining a reliable estimate of prevalence. As parents with intellectual disability are thought to be a relatively small sub-group in the general population, the survey of choice is that which offers an easily identifiable sample of people with intellectual disability in Australia as well as identifying parenthood.
- Recent data is considered most useful for estimating prevalence. The latest year of SDAC was 2012, however this data was not available for analysis at the time of publication of this report (expected to be released mid-2014). Therefore SDAC 2009 was the survey of choice at the time of analysis.

Step 3 Examination of SDAC for estimating prevalence of parents with intellectual disability in Australia

Description of SDAC 2009

SDAC is a national survey that collects detailed information on:

- people with disability
- people 60 years of age and over

- carers who provide care for people with disability and/or people 60 years of age and over (Australian Bureau of Statistics, 2011b).

SDAC 2009 was conducted from April 2009 to December 2009. It was designed to sample Australian residents who resided in private dwellings, special dwellings (e.g., hotels, short-stay caravan parks) and cared accommodation (e.g., hospitals, nursing homes). A shortened version of the questionnaire was administered for participants in special dwelling and cared accommodation. Australian residents who were homeless (e.g., living on the streets) or living in other institutions (e.g., prison, barracks) were excluded from the sample. Analysis for this study only utilised data from the private dwelling component of the survey, as those living in special dwelling and aged care accommodation were not asked questions that could determine whether they had children.

In the private dwelling component, there were approximately 62,000 persons in the sample. Computer-assisted interviews (CAI) were administered to respondents by a trained ABS interviewer. The data was first collected by interviewing an adult in the private dwelling household who was designated as a responsible adult (ARA) who provided household-level information (e.g., home ownership), socio-demographic information on all household members, as well as answers to screening questions that identified household members with a disability or a long-term health condition or who were carers. All people in the household with a disability or a long-term health condition, people aged 60 years and over and carers were then personally interviewed with a detailed questionnaire about their condition(s) and how disability, old age or caring affected their lives. Where the person identified for detailed interviewing had difficulties understanding or responding to interview questions, the interview was conducted with a spokesperson in the household (interview by proxy) who had the best knowledge of the person.

Selection criteria for identifying parents with intellectual disability in SDAC 2009

Age criterion

For the purposes of the prevalence study on parents with intellectual disability, only persons living in a private dwelling and aged between 15 and 64 years were relevant for inclusion.

- Lower limit of age criterion: parenthood is only identified for participants aged 15 years and over in ABS surveys (Australian Bureau of Statistics, 2005a).
- Upper limit of age criterion: to exclude dementia and other age-related neuro-degenerative conditions as a cause of difficulty learning or understanding things. This criterion was also to allow comparability with other surveys where the causes of “difficulty learning or understanding things” were not given. The criterion should not unduly affect the estimated number of parents with dependent children in the population as the majority of these parents would be under 65 years of age.

Intellectual disability criterion

The latest AIHW publication on people with intellectual disability using SDAC data was examined, to gain an understanding of the questionnaire and data items that can be used to identify people with intellectual disability (Australian Institute of Health and Welfare, 2008). The AIHW (2008) publication utilises SDAC 2003, however the data items identifying disability and disabling conditions are similar to SDAC 2009. Correspondence and discussion with the author of that publication assisted in clarifying the methods used. To identify persons with intellectual disability in Australian surveys conducted by the ABS it is necessary to use the item “difficulty learning or understanding things”. There is no other item that specifies intellectual disability. Several issues associated with this item as a proxy for intellectual disability are discussed below.

For the purposes of the current study, the following steps were undertaken to identify participants in SDAC 2009 with intellectual disability (Figure 1):

1. People with “difficulty learning or understanding things”. There is a preamble at the start of the disability screening module of the questionnaire: “I now have some questions about health conditions that have lasted, or are likely to last, for 6 months or more”, followed by a series of questions on impairments and long-term health conditions of household members. A positive response by the ARA to the question: “Do you (or anyone in the household) have difficulty learning or understanding things?” led to the identification of one or more household members with “difficulty learning or understanding things”. “Learning/understanding difficulties” may also be reported as a long-term effect of head injury, stroke or other kind of brain damage by ARA and/or during detailed interviewing of people reported to have a long-term health condition but not identified with a disability by ARA, and those who responded positively were also included.
2. All participants identified in Step 1 were reviewed to exclude people with the following conditions (with corresponding ABS codes) as the main cause of “difficulty learning or understanding things”:
 - a. ADHD (code 595)
 - b. dementia (511)
 - c. Parkinson’s disease (604)
 - d. Alzheimer’s disease (605).

The list of all disabling conditions and corresponding ICD-10 coding is available in an ABS information paper (Australian Bureau of Statistics, 2011c).

3. People with the following main conditions (with ABS codes) causing other impairments (e.g., speech difficulty) were included:
 - a. intellectual and developmental disorders n.e.c. (not elsewhere classified; 530)
 - b. mental retardation / intellectual disability (531).

People with “autism and related disorders (including Rett syndrome and Asperger’s syndrome)” (532) were not included in this step, as intellectual disability is not a criterion for autism-related disorders. If a person with autism or related disorder did have an intellectual disability, he/she would be captured and included in the identified sample at steps 1 and 2.

Parenting criteria

- Parenting status of included participants was identified by the ARA who provided information about the relationship between household members (Australian Bureau of Statistics, 2005b). There is a data item identifying parents of children under 15 years usually resident with them within the same household. Primary guardian of a usually resident child under 15 years who was not necessarily parent(s) of the child may also be identified as a parent (Australian Bureau of Statistics, 2005b). There is no data item on parents whose children were not usually resident with them. Therefore the target group identified in SDAC 2009 for estimation of prevalence of parents with intellectual disability excluded parents with intellectual disability whose children did not live with them.

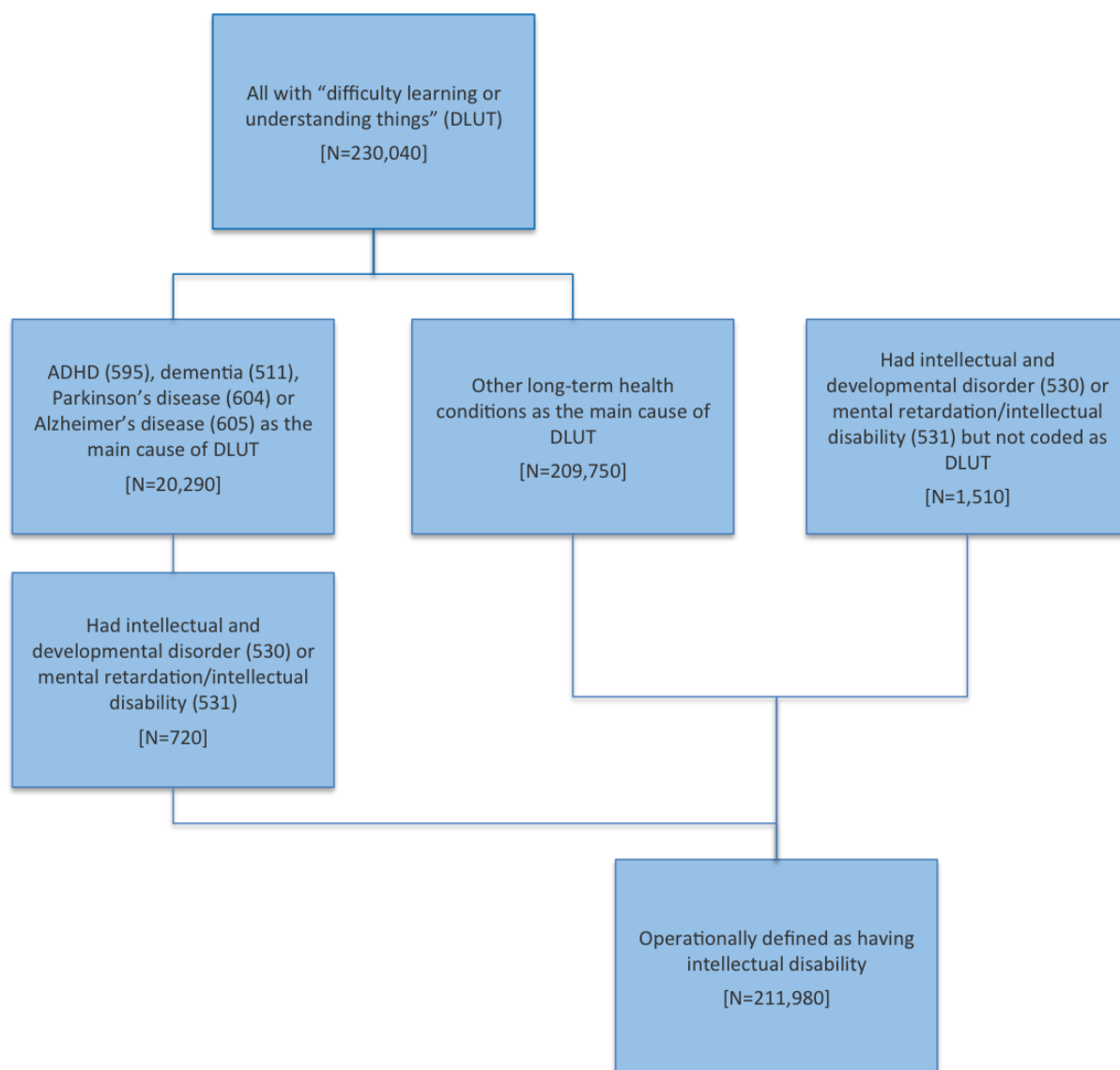


Figure 1: Operational definition of intellectual disability among people aged 15–64 years in private dwellings in Australia (weighted estimate of number in the population (N) is rounded to the nearest 10)

Step 4 Examination of survey data sources for describing characteristics of parents with intellectual disability in Australia

SDAC collected information on basic socio-demographic characteristics for all survey participants, and the details of support needs and living circumstances for participants who were aged 60 years and over, who had a disability, or who were carers.

The survey of choice to examine living circumstances of the general population and in which intellectual disability and parenthood can be identified is the *General Social Survey* (GSS), the most recent version of which was collected in 2010. Living circumstances as defined here include employment, material resources, social and emotional wellbeing and health following the approach taken by Llewellyn, Emerson & Honey (2013).

Two other national surveys carried out by the ABS were considered for the purpose of examining living circumstances of parents with intellectual disability and their children: the *National Health Survey* (NHS) 2007–08; and the *Survey of Mental Health and Wellbeing* (SMHW) 2007–08. However, neither was selected for the following reasons. The NHS is primarily about health of Australians with

a focus on National Health Priority Areas. NHS 2007–08 information did not contribute information on health status, living circumstances and general wellbeing of parents with intellectual disability over and above that collected by GSS 2010. The SMHW has a small sample size and a relatively low response rate and was therefore considered not suitable for this study.

Description of GSS 2010

GSS is:

“a multi-dimensional social survey ... (that) is designed to enable analysis of the interrelationships in social circumstances and outcomes, including the exploration of multiple advantage and disadvantage. (It) provides information on people’s health, family relationships, social and community involvement, education, employment, income and financial stress, assets and liabilities, housing and mobility, crime and safety, transport, attendance at culture and leisure venues, and sports attendance and participation” (Australian Bureau of Statistics, 2011a, p. 4).

“Only people who were usual residents of private dwellings in Australia were covered by the General social survey (GSS). People who usually reside in non-private dwellings (*or similarly to the special dwellings component of SDAC*) such as hotels, motels, hostels, hospitals and short-stay caravan parks were not included in the survey” (Australian Bureau of Statistics, 2011a, p. 17).

The latest GSS collected information from August to November 2010 from 15,028 private dwellings throughout non-remote areas of Australia (Australian Bureau of Statistics, 2011a). Much of the detail obtained from the GSS was provided by one person aged 18 years or over, randomly selected from each participating household. The random selection of this person was made once basic demographic and relationship information had been obtained from ARA in the household. Some financial and housing items collected in the GSS required the selected person to answer on behalf of other members of the household. In some cases, a spokesperson for the household was nominated to provide household information. Interviewing by proxy occurred where the participant had difficulties understanding and/or answering the questionnaire (e.g., because of old age, illness or intellectual disability) (Australian Bureau of Statistics, 2011a).

Selection criteria for identifying parents with intellectual disability in GSS 2010

Age criterion

For the purposes of the prevalence study on parents with intellectual disability, only persons living in private dwellings and aged between 18 and 64 years were included for GSS 2010.

- Lower limit for age criterion was predetermined, as GSS only interviewed people who were aged 18 years and over.
- Upper limit for age criterion was applied, to exclude dementia and other age-related neuro-degenerative conditions as a cause of difficulty learning or understanding things.

Intellectual disability criterion

For the purposes of the current study, people with intellectual disability were identified in GSS if during the interview the person identified having “difficulty learning or understanding things” as a condition he/she “may have, that have lasted, or are likely to last, for 6 months or more” (Australian Bureau of Statistics, 2011a). In GSS only the person being interviewed could be identified as having difficulty learning or understanding things compared to SDAC where one or more members of the household can be so identified.

Parenting criteria

A parent was defined as 'a parent of usually resident children under 15 years of age'. This identification is based on information about the relationship between household members provided by ARA.

The following steps were carried out to identify parents:

1. The data item on relationships in the household was used to identify a selected person who was 1) husband, wife or partner or 2) lone parent, as only a person with these relationships in the household could be identified as a parent with resident children in ABS surveys.
2. The data item on family composition was used to identify potential parents as a subset of those identified in step 1. The categories of this data item are:
 - a. couple family with dependent children only
 - b. couple family with dependent children and other persons
 - c. one-parent family with dependent children only
 - d. one-parent family with dependent children and other persons
 - e. couple only
 - f. other one-family households
 - g. multiple-family households with dependent children
 - h. multiple-family households with no dependent children
 - i. lone-person household
 - j. group household.

Categories a, b, c, d and g were used to narrow the identification of a husband, wife, partner or a lone parent who were in a household with dependent children.

3. The data item on the number of dependent children under 15 years in the household was used to identify a husband, wife, partner or a lone parent who were in a household with dependent children who were under 15 years of age.

Primary guardian of a usually resident child under 15 years but who is not necessarily a biological parent of the child may be identified as a parent (Australian Bureau of Statistics, 2005b). It should also be noted that the identification of parents in complex households, in particular multiple-family households with dependent children, was not definitive, as it could not be ascertained whether the members of a couple, or a lone parent, were the parents of dependent children. This is because the dependent children could belong in the same family as the selected person, or in another family.

Analyses

Estimates are design-weighted so that:

- population numbers can be estimated
- over-sampling (e.g., for disadvantaged geographic areas in GSS) can be appropriately accounted for

- non-response can be appropriately adjusted for.

All estimates based on survey samples are subject to sampling error. The 95% confidence intervals (CI) are provided as an indicator of the extent of error in corresponding estimates.

Analyses of variables associated with socio-demographic characteristics and living circumstances involved comparing parents with intellectual disability with non-disabled parents and parents with other disabilities. To assess the extent of differences between parents with intellectual disability and other parents, odds ratios and their 95% CI are estimated for each comparison. Further explanation and interpretation of odds ratios and their 95% CI are given in the section on living circumstances below.

Results

1. Prevalence of parents with intellectual disability

The prevalence estimates of parents with intellectual disability and of intellectual disability among parents in the Australian population drawn from SDAC 2009 are provided in Table 1. The prevalence estimates of parenthood among people with other disabilities and among non-disabled people are provided for comparison.

In summary:

- An estimated 14,289,000 persons in private dwellings were aged 15–64 years, of whom 4,089,000 were parents (defined as persons with children aged under 15 years and usually living with them).
- An estimated 0.41% of these parents had intellectual disability, which equates to an estimated 17,000 (95% CI = 11,500–22,400) parents with intellectual disability residing in private dwellings in Australia.
- People with intellectual disability were significantly less likely to be parents compared with people with other disabilities (OR = 3.11; 95% CI = 2.18–4.42) and with non-disabled people (OR = 4.97; 95% CI = 3.58–6.89).

Table 1: Estimated prevalence of parents with intellectual disability among people who are 15–64 years in private dwellings in Australia from SDAC 2009

All parents 15–64 years with resident children under 15 years, number (95% CI)	% prevalence (95% CI) Intellectual disability among parents	% prevalence (95% CI) [OR (95% CI)]		
		Parenthood among people with intellectual disability	Parenthood among people with other disabilities	Parenthood among non-disabled people
4,089,000 (4,011,000– 4,167,000)	0.41 (0.30–0.57)	8.0 (5.9–10.8) [Ref]	21.2 (20.0–22.5) [3.11 (2.18–4.42)]	30.1 (29.5–30.7) [4.97 (3.58–6.89)]

Table 2 (following page) presents demographic characteristics of parents with intellectual disability compared with other parents in the Australian population drawn from SDAC 2009. The main results from this table are summarised below.

There were significant differences between parents with intellectual disability and non-disabled parents (but not parents with other disabilities) whereby parents with intellectual disability were more likely to:

- reside outside capital cities (OR = 2.27; 95% CI = 1.20–4.29)
- have only one child (OR = 2.49; 95% CI = 1.22–5.09).

There were no significant differences between parents with intellectual disability and parents with other disabilities and non-disabled parents in relation to sex or age distribution, lone parenthood and the number of resident children.

Table 2: Socio-demographic characteristics of parents with intellectual disability, compared with non-disabled parents and parents with other disabilities from SDAC 2009

Characteristic	Estimated % (95% CI) within each parent group			p-value [OR (95% CI)]	
	Parents with intellectual disability	Parents with other disabilities	Non-disabled parents	vs. parents with other disabilities	vs. non-disabled parents
SOCIO-DEMOGRAPHIC CHARACTERISTICS					
Gender				0.40	0.51
Female	48.0 (34.9–61.4)	54.4 (51.6–57.2)	53.4 (52.9–53.8)	[0.81 (0.50–1.33)]	[0.85 (0.51–1.40)]
Male	52.0 (38.6–65.1)	45.6 (42.8–48.4)	46.6 (46.2–47.1)	[Ref]	[Ref]
Age				0.52	0.06
Under 40 years	42.1 (29.0–56.5)	47.0 (43.8–50.2)	56.2 (55.3–57.1)	[0.82 (0.45–1.50)]	[0.57 (0.31–1.02)]
40 years and over	57.9 (43.5–71.0)	53.0 (49.8–56.2)	43.8 (42.9–44.7)	[Ref]	[Ref]
Geographical region				0.50	0.15
Major cities	53.1 (34.9–70.5)	61.1 (57.4–64.8)	69.7 (68.4–71.0)	[Ref]	[Ref]
Inner regional Australia	27.3 (13.4–47.7)	27.2 (23.4–31.2)	20.4 (18.7–22.2)	[1.16 (0.44–3.01)]	[1.75 (0.69–4.46)]
Other areas	19.6 (8.5–39.0)	11.7 (9.4–14.6)	9.9 (8.8–11.1)	[1.93 (0.64–5.78)]	[2.60 (0.92–7.40)]
Whether in a capital city				0.13	0.01
In a capital city	45.3 (30.1–61.4)	58.3 (54.7–61.8)	65.3 (64.4–66.1)	[Ref]	[Ref]
Not in a capital city	54.7 (38.6–69.9)	41.7 (38.2–45.3)	34.7 (33.9–35.6)	[1.69 (0.86–3.33)]	[2.27 (1.20–4.29)]
Number of children under 15 years				0.06	0.01
1 child	66.0 (48.6–79.9)	48.8 (45.3–52.3)	43.8 (42.6–44.9)	[2.03 (0.95–4.34)]	[2.49 (1.22–5.09)]
> 1 child	34.0 (20.1–51.4)	51.2 (47.7–54.7)	56.2 (55.1–57.4)	[Ref]	[Ref]
Family composition				0.88	0.08
In a single-parent family	18.8 (9.7–33.3)	19.7 (17.0–22.8)	10.1 (9.4–10.8)	[0.94 (0.43–2.06)]	[2.06 (0.92–4.63)]
In a couple family	81.2 (66.7–90.3)	80.3 (77.2–83.0)	89.9 (89.2–90.6)	[Ref]	[Ref]

2. Living circumstances of parents with intellectual disability compared to non-disabled parents

A description of the estimates for indicators of living circumstances, social wellbeing and health for parents with intellectual disability, for parents with other disabilities and for non-disabled parents in the Australian population drawn from GSS 2010 are provided in Tables 3 and 4. Only indicators that showed significant differences ($p < 0.05$, see Text box 1 for explanations of statistical interpretation) between parents with intellectual disability and non-disabled parents are provided.

Relative to non-disabled parents, parents with intellectual disability were significantly less likely to perform well with regard to *employment* (two indicators), *material resources* (four indicators), *social and emotional wellbeing* (two indicators) and *health* (one indicator). Findings on indicators with significant differences between parents with intellectual disability and non-disabled parents are illustrated in Figure 2.

Analysis of GSS 2010 data revealed that compared with parents with other disabilities and also compared with non-disabled parents, parents with intellectual disability were significantly more likely to:

- be in a jobless household
- be in households in the lowest three deciles of equivalised weekly income
- be on government pensions as the main source of personal income
- have ever been without a permanent place to live
- have ever stayed in a shelter, squatted in an abandoned building and/or slept rough
- have less frequent contact with family and friends
- have negative or mixed feelings about life
- have poorer self-assessed health.

Parents with intellectual disability were also more likely to be unemployed or not in the labour force, compared to non-disabled parents.

Table 3: Employment and material resources of parents with intellectual disability, compared with non-disabled parents and parents with other disabilities from GSS 2010

Characteristic	Estimated % (95% CI) within each parent group			p-value [OR (95% CI)]	
	Parents with intellectual disability	Parents with other disabilities	Non-disabled parents	vs. parents with other disabilities	vs. non-disabled parents
EMPLOYMENT					
Employment rate				0.09	0.01
Unemployed or not in labour force	49.5 (25.5–73.7)	27.6 (23.3–32.4)	19.7 (17.0–22.7)	[2.57 (0.87–7.62)]	[4.00 (1.40–11.48)]
Employed (full-time or part-time)	50.5 (26.3–74.5)	72.4 (67.6–76.7)	80.3 (77.3–83.0)	[Ref]	[Ref]
Jobless household				0.007	< 0.001
No one was employed in household	40.8 (19.9–65.6)	13.0 (10.2–16.4)	5.1 (4.0–6.4)	[4.62 (1.55–13.75)]	[12.89 (4.28–38.82)]
At least one person was employed	59.2 (34.4–80.1)	87.0 (83.6–89.8)	94.9 (93.6–96.0)	[Ref]	[Ref]
MATERIAL RESOURCES					
Main source of personal income				0.02	0.002
From government payments	52.1 (25.9–78.2)	23.8 (19.6–28.1)	16.5 (13.8–19.3)	[3.47 (1.18–10.21)]	[5.49 (1.91–15.74)]
Not from government payments	47.9 (21.8–74.1)	76.2 (71.9–80.4)	83.5 (80.7–86.2)	[Ref]	[Ref]
Equivalised weekly household income^a				0.001	< 0.001
Lowest three deciles	71.1 (49.0–86.2)	28.5 (23.2–34.5)	20.8 (18.0–24.0)	[6.15 (2.24–16.85)]	[9.33 (3.50–24.86)]
4th decile and above	28.9 (13.8–51.0)	71.5 (65.5–76.8)	79.2 (76.0–82.0)	[Ref]	[Ref]
Ever been without a permanent place to live				0.03	< 0.001
Had ever been without a permanent place to live ^b	50.5 (27.0–73.7)	24.2 (19.3–29.8)	10.6 (8.7–12.8)	[3.19 (1.11–9.18)]	[8.63 (3.17–23.53)]

Had never been without a permanent place to live	49.5 (26.3–73.0)	75.8 (70.2–80.7)	89.4 (87.2–91.3)	[Ref]	[Ref]
<i>Ever stayed in a shelter, squatted in an abandoned building and/or slept rough</i>				0.009	< 0.001
Had ever stayed in a shelter and/or slept rough ^c	28.4 (14.1–48.9)	9.5 (6.4–13.9)	3.0 (2.2–4.1)	[3.77 (1.41–10.07)]	[12.60 (5.34–29.73)]
Had never stayed in a shelter and/or slept rough	71.6 (51.1–85.9)	90.5 (86.1–93.6)	97.0 (95.9–97.8)	[Ref]	[Ref]

Notes:

^a 12.1% of household income was not reported (i.e. missing data).

^b This included stayed in a shelter (i.e., a night shelter, a shelter for the homeless and/or a refuge, e.g., women's shelter), squatted in an abandoned building and/or slept rough (including sleeping in cars, tents etc.), staying with relatives, at a friend's house, in a caravan, in a boarding house/hostel.

^c This is a subset of those who had ever been without a permanent place to live. The subset only included those who ever stayed in a shelter (i.e., a night shelter, a shelter for the homeless and/or a refuge, e.g., women's shelter), squatted in an abandoned building and/or slept rough (including sleeping in cars, tents etc.).

Table 4: Social wellbeing and health of parents with intellectual disability, compared with non-disabled parents and parents with other disabilities from GSS 2010

Characteristic	Estimated % (95% CI) within each parent group			p-value [OR (95% CI)]	
	Parents with intellectual disability	Parents with other disabilities	Non-disabled parents	vs. parents with other disabilities	vs. non-disabled parents
SOCIAL AND EMOTIONAL WELLBEING					
Contact with family/friends				0.003	0.02
Less than weekly contact	14.9 (4.6–38.9)	2.0 (1.2–3.2)	2.5 (1.3–4.7)	[13.47 (3.07–9.16)]	[10.49 (1.99–55.44)]
At least weekly contact but less than daily	56.5 (32.5–77.8)	46.2 (38.7–53.9)	48.2 (43.9–52.4)	[2.21 (0.74–6.63)]	[2.02 (0.71–5.78)]
Had daily contact	28.6 (13.9–49.9)	51.8 (44.5–58.9)	49.4 (45.0–53.8)	[Ref]	[Ref]
Feeling about life				0.004	< 0.001
Terrible / Unhappy / Mostly dissatisfied / Mixed	64.6 (41.5–82.4)	29.8 (25.3–34.8)	15.7 (12.9–19.1)	[4.29 (1.62–11.36)]	[9.76 (3.65–26.09)]
Mostly satisfied / Pleased / Delighted	35.4 (17.6–58.5)	70.2 (65.2–74.7)	84.3 (80.9–87.1)	[Ref]	[Ref]
HEALTH					
Self-assessed health				0.03	< 0.001
Poor / Fair	44.7 (23.9–67.6)	21.7 (16.6–27.8)	3.9 (2.6–5.7)	[2.92 (1.12–.65)]	[20.14 (7.52–53.90)]
Excellent / Very good / Good	55.3 (32.4–76.1)	78.3 (72.2–83.4)	96.1 (94.3–97.4)	[Ref]	[Ref]

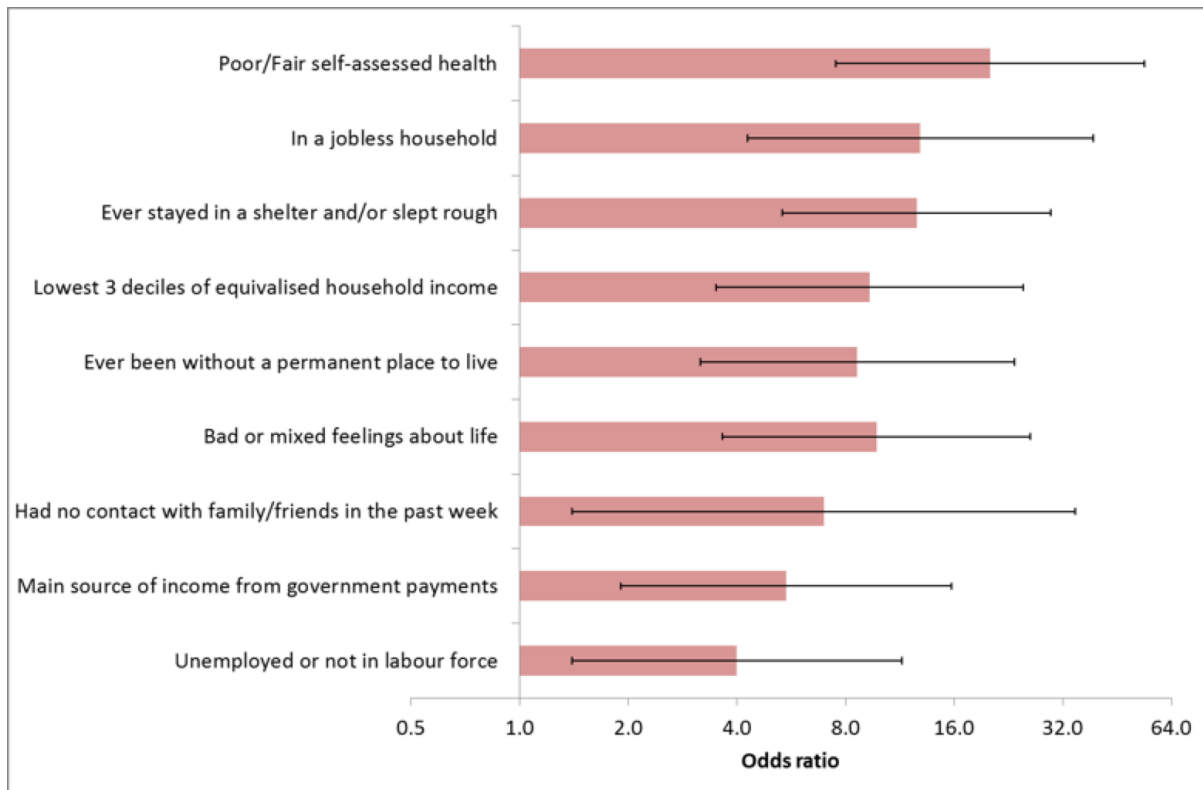


Figure 2: Experience of social disadvantage among parents with intellectual disability compared with non-disabled parents (note: odds ratio is presented on the logarithmic scale on the horizontal axis)

Text box 1: Odds ratio (OR), 95% confidence intervals (95% CI) and *p*-values

The bars in Figure 2 showing the estimated odds ratio (OR) provides a measure of the extent of social disadvantage experienced by parents with intellectual disability compared with non-disabled parents. An OR of one indicates that there is no difference between parents with intellectual disability and non-disabled parents. An OR of *more than one* indicates that parents with intellectual disability are *more* disadvantaged than non-disabled parents. An OR of four, for example, indicates that the odds (chances) of experiencing disadvantage are four times greater for parents with intellectual disability when compared to non-disabled parents. An OR of *less than one* indicates that parents with intellectual disability are *less* disadvantaged than non-disabled parents. An OR of 0.5, for example, indicates that the odds (chances) of experiencing disadvantage are two times less likely for parents with intellectual disability when compared to other parents. An interpretation of being *n* times more or less likely means that OR is a multiplicative estimate that may be more appropriately represented on a logarithmic scale as given in Figure 2.

The error bars (|—| lines) show the 95% confidence intervals (95% CI) for each OR estimate. They indicate that in 95% of instances, the true extent of disadvantage is expected to lie within the interval provided. If the 95% CI does not cross 1 then the difference between parents with intellectual disability and non-disabled parents is considered *statistically significant*. This level of statistical significance corresponds to a *p*-value of less than 0.05, which is the conventional threshold for statistical significance. The OR estimates that are statistically significant are highlighted in bold in the tables.

References

- Australian Bureau of Statistics. (2005a). Overview of family, household and income unit standards – definitions of common concepts. In *Family, Household and Income Unit Variables, 2005* [online]. Canberra: ABS cat. no. 1286.0. Australian Bureau of Statistics. Retrieved from www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/BA8F3E7DC2E073E1CA25703C0082B0D8?opendocument.
- Australian Bureau of Statistics. (2005b). Relationship in household – collection methods. In *Family, Household and Income Unit Variables, 2005* [online]. Canberra: ABS cat. no. 1286.0. Australian Bureau of Statistics. Retrieved from www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/125BEE6B875DCCE2CA25703C0082B0DF?opendocument.
- Australian Bureau of Statistics. (2010). *Information Paper: ABS Sources of Disability Information, Australia 2003–2008*. Canberra: ABS cat. no. 4431.0.55.002. Australian Bureau of Statistics. Retrieved from [www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/69F4AB340D15511ACA25778900119EC6/\\$File/attqvre7.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/69F4AB340D15511ACA25778900119EC6/$File/attqvre7.pdf).
- Australian Bureau of Statistics. (2011a). *General Social Survey: User Guide, Australia, 2010*. Canberra: ABS cat. no. 4159.0.55.002. Australian Bureau of Statistics. Retrieved from [www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/0E2339CDEB9EB039CA25795E0014E2BF/\\$File/4159055002_2010.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/0E2339CDEB9EB039CA25795E0014E2BF/$File/4159055002_2010.pdf).
- Australian Bureau of Statistics. (2011b). *Information paper: Disability, Ageing and Carers, Australia: User Guide, 2009*. Canberra: ABS cat. no. 4431.0.55.001. Australian Bureau of Statistics. Retrieved from [www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/E01AA04B925A1E0DCA2578B100186453/\\$File/4431055001_2009.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/E01AA04B925A1E0DCA2578B100186453/$File/4431055001_2009.pdf).
- Australian Bureau of Statistics. (2011c). *Information paper: Disability, Ageing and Carers, Basic CURF, Australia, 2009*. Canberra: ABS cat. no. 4430.0.00.001. Australian Bureau of Statistics. Retrieved from [www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/29913C6CB1F38EC5CA25788100166CDE/\\$File/4430000001_2009.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/29913C6CB1F38EC5CA25788100166CDE/$File/4430000001_2009.pdf).
- Australian Institute of Health and Welfare. (2008). *Disability in Australia: Intellectual Disability* (Bulletin no. 67). Canberra. Retrieved from www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442452891.
- Llewellyn, G., Emerson, E., & Honey, A. (2013). *Left Behind: Monitoring the Social Inclusion of Young Australians with Self-Reported Long Term Health Conditions, Impairments or Disabilities 2001–2011* (Policy bulletin no. 1). Retrieved from http://sydney.edu.au/health-sciences/cdrp/pdfs/left_behind-2013-policy-bulletin-1.pdf.
- Wen, X. (1997). *The Definition and Prevalence of Intellectual Disability in Australia*. Canberra: Australian Institute of Health and Welfare.

Appendix 1.

Table 5: Table of surveys identifying parents with intellectual disability in private dwellings in Australia

	SDAC 2009^a	GSS^{2010 a}	NHS 2007/08^a	SMHW 2007^a
Special/vulnerable groups that are identified, sampled or over-sampled	Sampled special dwelling (e.g., motels) and cared accommodations (e.g., nursing homes), but family relationships not asked for these population groups	Identified people who had been homeless or were at risk of being so; over-sampling of disadvantaged areas	Over-sampling of disadvantaged areas	Identified people who had ever been homeless / in prison
Age range in which parents are identified	15–85+ ^b	18–85+ ^b	15–85+ ^b	16–85
Response rate^c	90%	87.6%	91%	60%
Number of participants 15–64 years^d	41,300	11,800	13,600	6,900
Disability-related limitation and participation^e	***	** ^f	** ^f	** ^f
Employment and income^e	**	**	*	*
Dwelling ownership^e	*	**	X	X
Assets and financial stress^e	X	**	X	*
Social network^e	(*) ^g	**	X	**
Emotional wellbeing and mental health^e	(*) ^g	*	*	***
Physical health^e	(*) ^g	(*)	***	**
Lifestyle factors related to health^e	X	X	***	**

Notes:

^a SDAC = *Survey of Disability, Ageing and Carers*; GSS = *General Social Survey*; NHS = *National Health Survey*; SMHW = *Survey of Mental Health and Wellbeing*.

^b Technically no upper age limit, but those in the oldest age categories were grouped together (e.g., those 85 years and older in the 85+ age group) because of small cell counts.

^c This was the percentage of participants or dwellings that fully or adequately responded.

^d Rounded to the nearest hundred. Only those survey participants who were asked questions that could identify whether they were parents with intellectual disability were included.

^e X = no data; (*) = little or incomplete data on the topic; * = adequate data on the topic; ** = good data on the topic; *** = best data on the topic among all available surveys. This did not take into account the adequacy of the data in identifying parents with intellectual disability, the sample size and/or other data limitations.

^f Only with respect to the core activities of daily living (self-care, communication and mobility), employment and education.

^g Only if the person had a disability or long-term health condition, was a carer and/or was aged 60 years or over.



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