



Curtin University

SCHOOL OF OCCUPATIONAL THERAPY AND SOCIAL WORK

# THE WA STUDY OF HEALTH AND INTELLECTUAL DISABILITY

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## Executive Summary

### Key findings:

- Participants reported high rates of chronic and long-term conditions.
- Medication use was high, as was the use of multiple medications.
- Health services usage, including mental health and hospital-based services, was also high.
- Many participants lived a sedentary lifestyle.
- Substance use was low in the study group when compared to the general population.
- There was generally insufficient health screening/prevention for participants.

### Recommendations:

- People with ID in WA would benefit from an ID-specific targeted health check, such as the Comprehensive Health Assessment Program (Lennox, *et al.*, 2011).
- Medical professionals, care staff and families need to be made aware of the importance of screening tests and preventive health measures for people with ID.
- Greater efforts need to be made to design and disseminate accessible public health promotion materials and programs for people with ID in WA, particularly those living independently.
- Investigations into levels of unmet health service need for people with ID are recommended to provide guidance for health service planning, particularly in regional areas.



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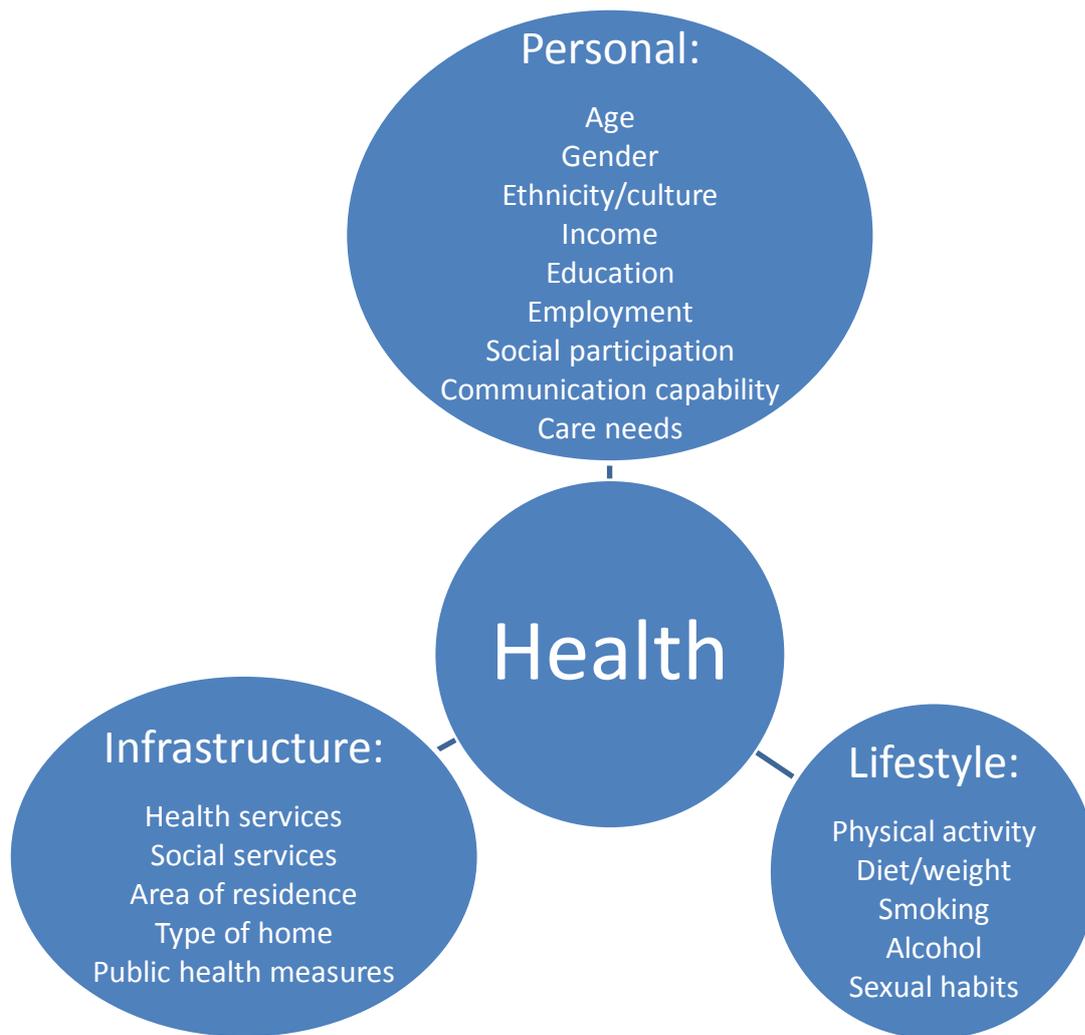
# The WA Study of Health and Intellectual Disability

## *Introduction*

There is little comprehensive information on the health status of people with intellectual disability (ID) nationally or in Western Australia (WA) (Australian Institute of Health and Welfare, 2010, 2012; Beange, *et al.*, 1995; Department of Health, 2011; Lennox, *et al.*, 2006), although this group represents a large number of vulnerable citizens for whom international research indicates significant health disparities (Emerson & Hatton, 2008; Krahn, *et al.*, 2006; Ouellette-Kuntz, 2005; Patrick, *et al.*, 2006). Health disparities are defined as differences in key health indicators between groups (Ouellette-Kuntz, 2005).

People with ID are generally at risk in two or more categories of the social determinants of health, and frequently require assistance to reduce the risk of poor health (Melville, *et al.*, 2006; Peterson, *et al.*, 2008; Zakrajsek, *et al.*, 2013). The identification and enhancement of social determinants of health is a vital step in improving the health of people with ID. Among the important factors are poverty, increasing age, poor education, social isolation, and lack of employment (Nicholson & Cooper, 2012; Ouellette-Kuntz, 2005; The Commission on Social Determinants of Health, 2008) (Figure 1).

Among other health determinants are various behavioural and lifestyle factors, such as physical activity, diet, smoking, alcohol consumption, and sexual health (Eastgate, 2008; Fleming, *et al.*, 2008; Grant, *et al.*, 2004; Heller, *et al.*, 2011; McGuire, *et al.*, 2007; Temple & Walkley, 2007; Tracy & Hosken, 1997) (Figure 1). Some health disparities may be a direct result of conditions associated with ID, e.g., epilepsy that occurs in almost all individuals with Angelman syndrome, thyroid disorders commonly occurring in people with Down syndrome. In addition, the ability to access appropriate medical assistance, including preventative health measures, has the potential to affect overall health (Figure 1).



**Figure 1 Factors affecting health**

Reduced access to health services and reduced quality of available services are common health inequalities experienced by people with ID (Allerton & Emerson, 2012; Cooper, *et al.*, 2011; Ramon, 2013), particularly in a rural or remote setting (Wark, *et al.*, 2013) (Figure 1). It has been known for two decades that there is insufficient disability-specific training within the health sciences across Australia (Iacono, *et al.*, 2003; Jess, *et al.*, 2008; Lennox & Diggins, 1999a, 1999b; Lennox & Kerr, 1997; Wark, *et al.*, 2013).

Preventive measures, such as screening tests and vaccinations, are not always administered according to guidelines (Cooper, *et al.*, 2011; Jensen, *et al.*, 2013; Sullivan, *et al.*, 2003), although there is some indication these measures are effective in improving

health for people with ID (Lennox, *et al.*, 2011; Robertson, *et al.*, 2011). In addition, although people with ID are at higher risk of developing mental illness, primary and secondary mental illness prevention early in life is often lacking (Allen, *et al.*, 2013).

There is little evidence that people with ID are targeted or engaged in preventive population health strategies and programs in WA, particularly given the lack of initiatives designed to account for cognitive limitations (Lennox, *et al.*, 2010). Developing and implementing suitable strategies will provide significant cost-savings to the Department of Health WA: well-directed primary health care is a cost-effective way to reduce tertiary care (Humphreys & Wakerman, 2008).

The WA Study of Health and Intellectual Disability (WASHID) investigated a number of health-related factors in a sample of adults with ID. A comprehensive picture of the current health of adults with ID in WA is essential to direct the design and implementation of appropriate health promotion and intervention programs to improve health outcomes for this population. This research project aimed to identify health disparities in the population of adults with ID in the state, and to provide a baseline of health status in adults with ID for future research. Such information can be used to compare with data collected from the National Disability Insurance Scheme and My Way trial sites in WA. These trials commenced in July 2014.



## ***Materials and Methods***

### ***Participants***

The study was promoted widely across the state of WA. Recruitment was purposive using an opt-in process. People interested in participating contacted the research team directly by mail, phone, or email.

Primary recruitment source: all adults (18 years old and over) with ID on the WA Disability Services Commission database were sent a study invitation from the Commission office in October 2012.

Secondary recruitment sources: a variety of service providers and non-government organisations sent the study invitation to their clients, staff, and family carers. In addition, promotion of the study was done via radio.

### ***Expert reference group***

This study was guided by an expert reference group with representatives from a number of stakeholder groups including the state government disability, health and mental health authorities, and state family, non-government and advocacy organisations.

These organisations were well positioned to advocate on behalf of other stakeholder groups, such as people with ID, family members, and advocates, and to refer other key stakeholders to the research. In addition, national and international (USA, UK, and Republic of Ireland) experts on health disparities and health promotion in people with ID provided advice on development of the study protocol.

### ***Survey Instrument and Measurement***

Health indicators can be defined as quantifiable characteristics of a population which researchers use as supporting evidence for describing the health of a population. After reviewing a number of ID-specific health surveys (Department of Health, 2011; Krahn, *et al.*, 2010; McCarron, *et al.*, 2011; Perry, *et al.*, 2010; Rimmer & Hsieh, 2011; Walsh, *et al.*, 2008), a list of potential health indicators was assembled and reviewed by the expert reference group. Items were divided into the domains of health status, health determinants, and health systems (Table 1).

**Table 1 Items within the WASHID health indicator set**

Health status	Health determinants	Health systems
General health	Physical activity	Preventive screening
Mental health	Body mass index (BMI)	Protective measures
Chronic and long-term conditions	Diet	Health literacy
Oral health	Weight management	Health service usage
Physical function and mobility	Smoking	Health care quality
Sensory function	Alcohol consumption	
Number of medications	Oral hygiene	
	Types of medications	

Various sources were examined to identify appropriate scales and questions to match items on the indicator set (e.g., Emerson & Hatton, 2007; Lennox, *et al.*, 2007). Surveys designed for the general population (Australian Bureau of Statistics, 2010; Craig, *et al.*, 2003) were also consulted to allow for comparisons. The expert reference group reviewed the questions for content, clarity, and significance to the study and to the target population. Questions were further revised and refined after feedback from the group.

The WASHID survey instrument was divided into four sections, three of which corresponded to domains of the health indicator set:

- Socio-demographics – included age, gender, education, living arrangement, employment, support need, economic status, social activity.
- Health status – included chronic disease, pain, oral health, mental health, vision and hearing, epilepsy.
- Health behaviours – included smoking, alcohol, diet, physical activity, medication.
- Health systems – included use of various health services, knowledge of health messages, use of health screening services.

Seven pilot tests of the survey were conducted by members of the study team which resulted in changes to the wording of some items to improve clarity, and amendments to the response categories to allow greater precision.

### Data collection

All volunteers were given the opportunity to complete the survey through a structured interview, with a support person if appropriate. The person/s who answered most of the survey questions is referred to as the informant/s throughout this report while the term 'participant/s' is used for the adult/s with ID. Participants unable to complete an interview were represented by a substitute informant, generally a family member or support worker. The members of the expert reference group wished to allow as many people with ID as possible to contribute to the study. Substitute informants were used only if necessary.

Face-to-face interviews were chosen as being the most likely to reduce missing data, and to promote standardisation of the data collected. Rural and remote area residents had the option to complete the interview at a regional centre, where possible, or by telephone.

Structured interviews were administered by specially trained interviewers. The interviewers were senior students from the Faculty of Health Sciences, and other individuals with experience in relating to people with ID. Each interviewer completed a training programme addressing: the aims and purpose of the study; the focus of the four sections of the questionnaire; some relevant issues around consent, confidentiality, participant well-being, and data handling and security; standardisation of the interview; administration of the interview; and the handling of adverse events.

Interviews took place between January and July 2013. The time required for each interview varied from thirty minutes to over one and a half hours. Most of the interviews were conducted in the home of the participant or a family member, however some were conducted by telephone due to distance and time constraints. There were no reported adverse events from the interviews.

### Ethical issues

Approval for this study (HR87/2012) was provided by the Human Research Ethics Committee of Curtin University. Prior to the interview all participants were given a plain English information sheet and requested to sign a consent form. Individuals with ID who were not able to sign for themselves had proxy consent provided by the appropriate person. Support persons and substitute informants were also required to provide consent for their own participation in the interview.

### Data analysis

All data were entered into an SPSS dataset and checked for accuracy before analysis. Standard descriptive statistics were used to summarise the survey responses: frequencies, percentages, and 95% confidence intervals for categorical variables; means and standard deviations for variables measured on a continuous scale. Percentages were based on all valid responses, i.e., excluding missing data, where relevant.

The WASHID data were compared to state and national population data from various sources; the Australian Institute of Health and Welfare, the WA Department of Health, and the Australian Bureau of Statistics. As people with ID have been reported to show age-related conditions earlier than the general population, the decision was made to divide the study cohort into younger (18-44) and older (45 and over) age groups and to use a similar division for the general population data.

An accessible summary of the results was sent to each participant (Appendix I) and this report will be available online.

## Results

### Study population

The purposive nature of study recruitment resulted in an interest in the study from 413 people with ID, family members or service providers of whom 328 completed the study. The ages of participants ranged from 18 – 82 years, with ten people over the age of 65.

The respondents comprised substitute informant only (55%), participant only (24%), and joint informants (21 %). In a majority of cases the survey was administered as a face-to-face interview.

**Table 2 Socio-demographic profile of the WASHID cohort (n=328) compared with various other populations**

Participant characteristic	WASHID % (number)	95% Confidence Interval (%)	WA Disability Services Commission %	Western Australia – general population (15 years and over) %
<b>Age group</b>				
18-24 years	24 (79)	20 – 30	25	16 <sup>a</sup>
25-34 years	28 (91)	24 – 34	24	17 <sup>a</sup>
35-44 years	15 (50)	12 – 20	19	17 <sup>a</sup>
45-54 years	18 (59)	14 – 23	17	16 <sup>a</sup>
55 and older	12 (39)	9 – 16	15	33 <sup>a</sup>
<b>Gender</b>				
Male	59 (192)	54 – 65	58	49 <sup>a</sup>
Female	41 (132)	35 – 46	42	51 <sup>a</sup>
<b>Region</b>				
Perth metropolitan	74 (242)	70 – 79	76	78 (all ages) <sup>b</sup>
Regional and remote	26 (83)	21 – 30	24	22 (all ages) <sup>b</sup>
<b>Indigenous</b>				
Australian-born	4 (13)	2 – 6	7 (all ages) <sup>c</sup>	3 <sup>a</sup>
	91 (298)	88 – 94		63 (all ages) <sup>d</sup>

<sup>a</sup>(Australian Bureau of Statistics, 2013) <sup>b</sup>(Davis & Joyce, 2011) <sup>c</sup>(Glasson, *et al.*, 2005)

<sup>d</sup>(Australian Bureau of Statistics, 2011)

Participants corresponded closely on age group, gender, and metropolitan/non-metropolitan residence with the cohort of adults with ID registered in the WA Disability Services Commission dataset (Table 2). The close match to the WA Disability Services

Commission dataset suggests that this study group could be considered to reflect the socio-demographic characteristics of the target population.

**Table 3 Socio-demographic characteristics of WASHID participants (n=328)**

Characteristic	WASHID % (number)
<b>Type of residence</b>	
Own home	23 (74)
Family home	52 (165)
Group home, hostel, nursing home	25 (79)
<b>Communication</b>	
Little difficulty	21 (65)
Some difficulty	80 (142)
<b>Need for assistance with everyday activities</b>	
Intermittent	54 (174)
Intensive	28 (91)
Pervasive	18 (57)
<b>Social contact with family, friends</b>	
7 or more per week	15 (39)
4-6 per week	54 (137)
3 or fewer per week	30 (77)
<b>Education</b>	
Did not complete high school	26 (74)
Completed high school	55 (158)
Certificate I/II	16 (46)
Certificate III/IV or higher	3 (10)
<b>Paid work</b>	
Alternatives To Employment (ATE)	41 (134)
<b>Volunteer work</b>	
Disability Support Pension	49 (60)
Funding from DSC	19 (61)
<b>Financial hardship</b>	
No hardship	94 (307)
Some hardship	72 (222)
Considerable hardship	57 (186)
<b>Socio-Economic Index For Australia, WA (decile rank)</b>	
	Median 7

Half of all participants lived in a family home, with a quarter each living in their own home or some form of congregate living (Table 3). This is in contrast to the situation reported from Europe, where 54 per cent lived in congregate settings, 34 per cent in a family home, and 12 per cent independently (Haveman, *et al.*, 2011).

More than three quarters of the study group experienced some communication difficulty, but less than one quarter needed extensive assistance with activities of daily living. Two thirds of the participants had regular contact with family and friends (Table 3), similarly to a European report (62%) (Haveman, *et al.*, 2011).

Three quarters of the study group were educated to at least the end of high school, in contrast to a population-based Victorian study of people with ID (Department of Health, 2011) which reported less than 15 per cent achieving completion of secondary school or higher. Slightly less than half of participants were in paid employment. Most participants received the Disability Support Pension, similarly to the Victorian study (95%) (Department of Health, 2011), and two thirds received some funding for support services from DSC. Slightly more than half of participants reported no financial hardship, and half were included in the seventh-tenth deciles on the Socio-Economic Index For Australia (SEIFA) WA, based on their postcode of residence (Table 3).

Few of the study group had ever married (17%) or had children (8%). Most participants (97%) had a Commonwealth Health Care Card, entitling them to greatly reduced medical costs, and two thirds (63%) had private health insurance, many more than the Victorian population with ID (33%) (Department of Health, 2011).

Specific diagnoses associated with ID, reported for ten per cent or more of participants, were autism spectrum disorders (21%), Down syndrome (14%), and cerebral palsy (11%). Other conditions, occurring at lower frequencies, included Fragile-X, Angelman, Prader-Willi, Rett and Williams syndromes, and spina bifida. Compared to the Victorian study (Department of Health, 2011), WASHID reported more people without a known diagnosis to explain their disability (46% and 76% respectively).

### Health status

Overall three-quarters of the informants reported 'good' or 'very good' health among participants, with a higher proportion in the younger age group (Table 4). Two-thirds of all informants said that the health of participants was much the same as the previous year.

Good/very good health was more commonly reported for participants from both age groups than the general population, and hearing problems occurred at higher rates than the general population or other groups with ID. Vision difficulties were less often reported in study participants than in both the general population and other studies of people with ID, while dental problems occurred at similar rates to the general population (Table 3).

**Table 4 Health status of WASHID participants (n=328) compared to general population data**

Health descriptor	WASHID % (number)	95% Confidence Interval (%)	Australia/WA – General population aged 15 and over %
Self-reported health (good/very good)	77 (251)	72 - 81	56 <sup>a</sup>
18-44 years	82 (178)*	77 - 87	67 <sup>b</sup>
45 years and older	65 (64)	55 - 75	54 (45-64 years) <sup>b</sup>
Health affects daily living	41 (132)	36 - 46	
Vision problems	19 (58)	24 - 34	52 (all ages) <sup>a</sup>
Hearing problems	26 (81)	20 - 29	13 (all ages) <sup>a</sup>
Current dental problems	35 (109)	30 - 40	>25 <sup>a</sup>

\*  $p < 0.005$  compared with older age group

<sup>a</sup>(Australian Institute of Health and Welfare, 2012) <sup>b</sup>(Davis & Joyce, 2011)

Almost one-third of the people who reported good/very good health also said that health problems sometimes affected the daily activities of participants. This apparent anomaly could indicate that informants think of participant health as ‘as good as expected’ or ‘better than expected’, even in the presence of activity limitations, by comparing participants against a reference group of some kind (Burgard & Chen, 2014). Informants in other studies have been reported to base responses on their general physical ability, the presence or absence of specific health conditions, or whether their lifestyle is ‘healthy’ or ‘unhealthy’ (Krause & Jay, 1994; Sargent-Cox, *et al.*, 2014). The authors suggested that the comparison group for self-assessments of health status may be influenced by the participant’s age, with young adults considering health behaviours when deciding on their healthiness, while older people tend to use the presence or absence of health problems as the basis of their self-rated health (Krause & Jay, 1994).

Overall, substitute or joint informants in WASHID assigned a better health rating for the participant on whose behalf they were responding than did self-informants. This may happen if support people see poor health in the participant as an adverse reflection on their own caring ability or skill, or if they have lower expectations for the people they care for and respond accordingly. Another option is that people with higher cognitive function and thus able to respond for themselves are less healthy, or that their comparison group is people without intellectual disability rather than people with disability.

#### Chronic or long-term conditions

Participants were reported to have a mean of 2.6 chronic or long-term health conditions (median 2.0 long-term or chronic conditions; range 0-10), and 11 per cent reported no such conditions. This was similar to the situation reported in the UK, the USA, the EU, and Ireland (Emerson, *et al.*, 2011; Haveman, *et al.*, 2011; McCarron, *et al.*, 2011; Rimmer & Hsieh, 2011). Predictably, our study showed that participants who had a greater number of long term health conditions tended to have poorer reported health than participants with fewer health conditions. Epilepsy, constipation, eczema, and allergies were all reported by more than one-quarter of participants across both age groups.

With younger participants (18-44 years), some conditions were reported considerably more often than in the general population. These include epilepsy, anxiety, obsessive/compulsive disorder, heart conditions, lung problems (not including asthma), osteoporosis and stroke. High blood pressure, high cholesterol and cancers were less often reported when compared to the general population (Table 5).

**Table 5 Frequency of ever having chronic and long term health conditions in WASHID participants compared to general population – adults 18-44 years of age (N=220)**

Condition	Yes (%) <sup>a</sup>	WASHID 95% Confidence Interval	Unknown (%) <sup>b</sup>	Australia/WA – General population aged 15-44 years (%)
Epilepsy	41	35 - 48	3	3-5 <sup>c</sup>
Constipation	32	26 - 38	1	
Eczema, skin rash	27	21 - 33	0	
Allergies	26	20 - 32	3	
Asthma	19	14 - 24.	1	19 <sup>d</sup>
Anxiety disorders	14	9 - 19	5	8 <sup>d</sup>
Sleep disorder	14	10 - 19	2	
Attention deficit	14	9 - 18	6	
Heart condition	12	7 - 16	1	1 <sup>d</sup>
Depression	11	6 - 15	7	8 <sup>d</sup>
Obsessive/compulsive	10	6 - 14	7	2 (16-85 years) <sup>e</sup>
Other lung problem	9	5 - 12	1	1 <sup>d</sup>
Thyroid disorder	9	5 - 12	5	
High blood pressure	8	5 - 12	3	13 <sup>d</sup>
Arthritis	6	3 - 9	3	6 <sup>d</sup>
Schizophrenia	5	2 - 8	6	4 <sup>f</sup>
High cholesterol	5	2 - 8	9	16 <sup>d</sup>
Osteoporosis	5	2 - 8	4	1 <sup>d</sup>
Stomach ulcer	3	1 - 6	4	
Diabetes	3	1 - 6	2	2 <sup>d</sup>
Eating disorder	3	1 - 5	6	
Bi-polar disorder	2	0 - 4	6	2 (16-85years) <sup>e</sup>
Stroke	2	0 - 4	1	0 <sup>d</sup>
Cancer (inc. skin)	2	0 - 4	1	5 <sup>d</sup>
Alzheimer's disease	1	0 - 2	6	Est 0.1 (0-64) <sup>g</sup>

<sup>a</sup> percentage of cases where the response is known (yes/no) <sup>b</sup> percentage of all cases (N=220). <sup>c</sup>(World Health Organization, 2006) <sup>d</sup>(Davis & Joyce, 2011) <sup>e</sup>(Australian Bureau of Statistics, 2008) <sup>f</sup>(Saha, *et al.*, 2005) <sup>g</sup>(Australian Institute of Health and Welfare, 2012)

**Table 6 Frequency of ever having chronic and long term health conditions in WASHID participants compared to general population – adults aged 45 years or more (N=98)**

Condition	WASHID			Australia/WA – General population aged 45 -64 (%)
	Yes (%) <sup>a</sup>	95% Confidence Interval	'Don't know' (%) <sup>b</sup>	
Epilepsy	38	28 - 48	5	3-5 <sup>c</sup>
Allergies	37	27 - 46	5	
Constipation	34	24 - 43	3	
Eczema, skin rash	32	22 - 41	0	
Arthritis	29	20 - 39	9	30 <sup>c</sup>
High blood pressure	27	18 - 36	4	34 <sup>c</sup>
High cholesterol	26	17 - 35	9	35 <sup>c</sup>
Asthma	18	10 - 25	1	13 <sup>c</sup>
Diabetes	15	8 - 22	0	9 <sup>c</sup>
Depression	14	6 - 21	10	9 <sup>c</sup>
Sleep disorder	12	6 - 19	0	
Heart condition	12	5 - 18	5	6 <sup>c</sup>
Other lung problem	12	5 - 18	4	4 <sup>c</sup>
Thyroid disorder	11	4 - 17	4	
Cancer (inc. skin)	10	4 - 16	1	23 <sup>c</sup>
Osteoporosis	10	4 - 17	11	6 <sup>c</sup>
Stomach ulcer	8	3 - 14	4	
Anxiety disorders	7	2 - 12	8	7 <sup>c</sup>
Alzheimer's disease	6	2- 12	6	Est 0.1 (0-64) <sup>d</sup>
Attention deficit	6	1 - 10	7	
Stroke	5	1 - 10	4	2 <sup>c</sup>
Obsessive/compulsive	2	0 - 5	8	2 (16-85) <sup>f</sup>
Eating disorder	2	0 - 5	7	
Schizophrenia	2	0 - 5	8	4 <sup>g</sup>
Bi-polar disorder	1	0 - 3	7	2 (16-85) <sup>e</sup>

<sup>a</sup> percentage of cases where the response is known (yes/no) <sup>b</sup> percentage of all cases (N=98) <sup>c</sup>(Davis & Joyce, 2011) <sup>d</sup>(Australian Institute of Health and Welfare, 2012) <sup>e</sup> (Australian Bureau of Statistics, 2008) <sup>f</sup>(Australian Bureau of Statistics, 2008) <sup>g</sup>(Saha, *et al.*, 2005)

Older participants in the study were more likely to have epilepsy, depression and/or lung problems (not including asthma) than the general population in that age group. High cholesterol and cancer were reported less often in the older participants than in the general population (Table 6). The reports of many conditions, notably arthritis, high blood pressure, high cholesterol and diabetes, were much higher in older than younger participants, as is commonly found among the general population.

There are some health conditions, such as cancer, arthritis, high cholesterol and asthma, reported to occur less frequently in people with ID than in the wider population (Morin, *et al.*, 2012; Rimmer & Hsieh, 2011). However a WA study using linked health services data found the overall incidence of cancer was very similar to the general population (Sullivan, *et al.*, 2004), in contrast to the current study in which cancers were rarely reported. Screening for various cancers, especially bowel and cervical, is often reported to be less widespread in people with ID than the general population (Cobigo, *et al.*, 2013; Hanna, *et al.*, 2011) and this may account for the low rates of cancer reported in this study (Tables 5 & 6). The reported rate for arthritis in this study cohort was much closer to that of the general population (Davis & Joyce, 2011) than to the rate (7.6% in the older group) in the European study reported by Haveman *et al.* (2011). This may indicate fewer people with undiagnosed arthritis in the study cohort, or there may be other factors affecting the prevalence of arthritis in different countries/cultures (Burgard & Chen, 2014).

In many cases, people with ID are at greater risk than the general population for certain long-term or chronic conditions including osteoporosis, diabetes, some mental health disorders, and epilepsy (Haveman, *et al.*, 2011; McCarron, *et al.*, 2011; Morgan, *et al.*, 2008; Rimmer & Hsieh, 2011; Tyler, *et al.*, 2000). The use of antiepileptic medication greatly increases the risk of osteoporosis (Srikanth, *et al.*, 2011) and a substantial number of participants in this study used such medication (Table 7). However, osteoporosis was reported much less frequently than expected in the older participants (Table 6) when compared with a similarly-aged group of people with intellectual disabilities attending sheltered workshops (21%) (Tyler, *et al.*, 2000), indicating that osteoporosis could be under-diagnosed within the WASHID cohort.

Of the mental health conditions included in the study, bi-polar disorder occurred at a similar frequency to the general population, similarly to a previous study in WA (Morgan, *et al.*, 2008). Participants under 45 years were more likely to have an anxiety disorder or

obsessive/compulsive disorder than their peers in the general population (Davis & Joyce, 2011) (Tables 5 & 6).

The proportion of participants for whom the occurrence of long-term or chronic conditions was reported as 'Don't know' varied from 0-11 per cent. In some cases, particularly mental health disorders, the proportion of 'Don't know' exceeded the 'Yes' responses (Tables 5 & 6).

### Use of medications

There was a high rate of medication use among participants (average 2.6 medications; range 0-21), two-thirds of whom took one or more medications (Table 7). Nineteen per cent of participants were currently using five or more medications. One-quarter of participants took one or more medications from the psychoactive class, and a similar number used anticonvulsants (Table 7) similarly to a North American study (Lunsky, *et al.*, 2002). These types of medications were also commonly used by participants in a Norwegian study (Holden & Gitlesen, 2004). Compared with 7.8 per cent of the general population currently receiving treatment for mental health issues (Davis & Joyce, 2011), participants were much more likely to be taking psychoactive medications (24.7%).

Among the general population four of the ten most common prescriptions are for cholesterol or blood pressure control (Australian Institute of Health and Welfare, 2007), and similar medications were used by almost 15 percent of participants (Table 7).

The 'Other medications' class (Table 7) included a wide variety of medications such as Nexium for gastro-oesophageal reflux, oral contraceptives for a variety of uses, antibiotics for infections, and Motilium for nausea and vomiting.

**Table 7 Frequency of current medication use in WASHID participants (n=328) by general class of medication**

Class of medication	Individuals %	Range (min-max)
No medications	31	N/A
Psychoactive medications (not anticonvulsants)	25	1-5
Epilepsy, convulsions	24	1-5
Cardiovascular, blood pressure, cholesterol	15	1-5
Pain relief	15	1-5
Bowel conditions	14	1-5
Eczema, skin conditions	11	1-5
Thyroid disorders	10	1-3
Sleep problems	6	1-2
Diabetes	5	1-3
Arthritis, joint inflammation	5	1-2
Asthma	3	1-2
Other medications	30	1-5

*Lifestyle factors*

Participants rarely engaged in ten minutes or more of vigorous physical activity at a time over a week, but over one-third reportedly participated in ten minutes or more of moderate activity four or more days a week. Almost half of the participants spent on average more than seven hours per day sitting down. Fifty-eight per cent of participants were overweight or obese, however the proportion was slightly lower than that found in the general population (Table 8).

**Table 8 Health behaviours of WASHID participants (n=328)**

Health behaviour	WASHID % (number)	95% CI	Australia/WA – General population 15 years and over %
Physical activity (at least ten minutes per session)			
Heavy activity: mean 1.2 days per week, standard deviation 1.9			
No days per week of heavy activity	61 (197)	56-66	
Moderate activity: mean 2.8 days per week, standard deviation 2.6			
No days per week of moderate activity	26 (84)	21-31	
Sitting: mean 6.7 hours per day, standard deviation 3.7			
>11 hours/day sitting	14 (42)	10-17	
7-11 hours/day sitting	32 (99)	27-37	
3-6 hours/day sitting	44 (136)	38-49	
2 or fewer hours/day sitting	7 (23)	4-10	
Wheelchair (always)	11 (36)	8-14	
Body Mass Index (BMI)			
Underweight (BMI < 18.5)	6 (15)	3-8	} 39 <sup>a</sup>
Healthy weight (BMI 18.5 - 25)	35 (95)	29-41	
Overweight/obese (BMI > 25)	56 (152)	50-62	
Fruit & vegetables (7 or more/day)	15 (48)	11-19	6 (>12 years) <sup>b</sup>
Fast food (<1/week)	50 (160)	44-55	64 <sup>a</sup>
Water (5 or more glasses/day)	52 (155)	46-58	
Soft drink (3 or more/day)	5 (15)	2-7	
Smoking (current)	6 (19)	4-9	15 <sup>a</sup>
Passive smoking	18 (54)	14-22	>5% <sup>b</sup>
Alcohol (more than twice/week)	4 (11)	2-6	47 <sup>b</sup>

<sup>a</sup>(Davis & Joyce, 2011) <sup>b</sup>(Australian Institute of Health and Welfare, 2012)

More participants reached the recommended daily intake of fruit and vegetables than the general population, and half drank five or more cups of water per day. Participants were more likely than the general population to have one or more serves of take-away food each week, and to be exposed to passive smoking. Soft drink consumption was low, as were rates of smoking and drinking alcohol (Table 8). In general, participants with intermittent care needs smoked and drank alcohol more than those with intensive or

pervasive care needs, however even these people did not reach the rates of consumption found in the wider population.

### Knowledge of public health factors

Most informants (65-72%) indicated that participants had some knowledge of various healthy lifestyle messages, although the extent of this knowledge was not determined. Families and the media were reported to be the major sources of that knowledge, however work, school, friends, service providers and medical professionals were also sources of health information. Responses to public health messages varied: 63 per cent of participants used one or more method of sun protection; 42 per cent changed their eating habits; 7 per cent wanted to, attempted to, or succeeded in stopping smoking; 32 per cent exercised more; and 18 per cent drank less alcohol.

### Use of health services

Most participants visited a General practitioner within the previous year, and this number was little different to the general population. Use of hospital-based services, mental health services and specialist practitioners, was higher among WASHID participants than the general population (Table 9). The range of other health services used included occupational therapist, physiotherapist, podiatrist, dietician, speech therapist, and chiropractor. Specialists included ophthalmologist, orthopaedic surgeon, and 'ear specialist'.

**Table 9 Use of medical services by WASHID participants (n=328) in the year previous to interview**

	Frequency (number)	%	95% CI	Australia/WA – General population 15 years and over %
General practitioner	90 (295)		87-93	88 <sup>a</sup>
Hospital, in-patient	20 (65)		16-24	
Hospital, out-patient	36 (119)		31-42	
Hospital, emergency department	24 (77)		19-28	
Any hospital service	47 (155)		42-53	27 <sup>a</sup>
Regular specialist	43 (141)		38-48	~25 <sup>a</sup>
Mental Health professional	22 (72)		18-26	7 <sup>a</sup>
Other health services	60 (198)		55-66	

<sup>a</sup>(Davis & Joyce, 2011)

### Experiences of the GP visit

Overall, interactions with the GP and the surgery staff were positive. Surgery staff were described as respectful, and the GP was respectful, knowledgeable, and engaged well with the participant. Participants most often were accompanied to appointments by a companion, and generally this was the same person. More than two-thirds had no trouble getting an appointment when wanted, and a third did not have to wait too long in the surgery before seeing the GP (Table 10).

**Table 10 Experiences of WASHID participants (n=328) when visiting a general practitioner.**

	Frequency % (number)
Respectful treatment from staff	96 (289)
GP listens to adult with ID	94 (245)
GP knows about the individual's condition	91 (283)
GP talks directly to adult with ID	91 (282)
GP explains matters clearly	89 (257)
Companion to appointments	88 (290)
Generally the same companion	76 (249)
Written take-home medical record	29 (94)
No difficulty getting appointment	69 (218)
No waiting at surgery	36 (109)

### Health screening and testing

Two-thirds of participants were reported to have an annual physical examination, similarly to people with ID in a study from Europe (Walsh, *et al.*, 2008). Around half had regular cholesterol tests and annual flu vaccinations. Three-quarters of the few females over the age of 50 had a mammogram within the previous five years, a rate similar to the general population between 50 and 70 years old, and half of the small number of men over 50 years old had prostate cancer screening in the previous five years. However, Pap smears were much rarer for female participants when compared with the general population (Table 11). Given the high risk of osteoporosis in people with ID there were very few bone density scans reported.

**Table 11** Frequencies of regular diagnostic or screening tests and preventive measures accessed by WASHID participants (n=328)

Test	Frequency (number)	%	95% CI	General population 15 years and over %
General physical examination (annual)	66 (193)		60-71	64 (19-90 years) <sup>a</sup>
Mammogram (females 50-69 years; last five years)	64 (14)		44-84	55 (50-69 years) <sup>b</sup>
Flu vaccine (annual)	48 (156)		42-53	53 <sup>b</sup>
Cholesterol test (last five years)	51 (129)		45-57	
Prostate examination or PSA test (males 50 years old and over; last five years)	50 (12)		30-70	
Glucose tolerance (last five years)	34 (87)		28-40	
Bowel cancer test (50 years old and over; last 5 years)	44 (24)		31-58	50 (50-65 years) <sup>c</sup>
Breast examination (females 20 years old and over; last 5 years)	34 (33)		25-44	
Pap smear (females 20 years old and over; last 5 years)	21 (20)		13-29	57 (20-69 years) <sup>c</sup>
Bone density scan (last five years)	11 (28)		7-15	

<sup>a</sup>(Walsh, *et al.*, 2008) <sup>b</sup>(Davis & Joyce, 2011) <sup>c</sup>(Australian Institute of Health and Welfare, 2012)

## ***Conclusion***

The WA Study of Health and Intellectual Disability aimed to describe a number of indicators of health for a vulnerable group within society. The lack of population-based studies globally indicates the difficulty in obtaining this information. Assistance from the WA Disability Services Commission and the extensive network of agencies which sent out invitations to join the study meant thorough coverage of this often hard-to-reach population.

Across the range of health indicators there were numerous areas in which adults with ID performed poorly when compared to the general population. These included morbidities such as hearing difficulties, dental problems, epilepsy, mental health issues and heart conditions; use of hospital-based services, mental health services and other specialist services; and poor uptake of Pap smears. In other areas, such as self-rated health, vision impairment, cancer, and raised cholesterol, the study group reported fewer problems than the general population. Adults with ID also reported lower rates of smoking and alcohol consumption, and higher rates of fruit and vegetable consumption.

How much the disparities in health conditions identified in the WA Study of Health and ID are due to over-diagnosis or under-diagnosis is hard to determine in a study such as this which relied solely on informant report. A recent review of health measurements identified a number of limitations including variable rates of prevalence for many diseases and disorders, inaccuracies in self-reported health, and problems with differing interpretations of some measures by different groups (Burgard & Chen, 2014).

Informants in this study may have had faulty recall or even no knowledge of some health problems and diagnoses, as indicated by the variable, but often high, numbers of 'Don't know' responses to different items of the survey. In addition, some disorders commonly reported in both this study and the European Union (Haveman, *et al.*, 2011), such as constipation and allergies, were often diagnosed by carers rather than by a medical professional which could cast some doubt on the accuracy of the diagnosis. Generally poor rates of health screening tests can also affect the reported prevalence of some disorders (Cobigo, *et al.*, 2013; Wood & Douglas, 2007). There is evidence that the consistent use of an ID-specific health check has the potential to improve diagnostic accuracy and lead to better health outcomes for people with ID (Felce, *et al.*, 2008; Lennox, *et al.*, 2010).

### Key findings:

- Participants reported high rates of chronic and long-term conditions.
- Medication use was high, as was the use of multiple medications.
- Health services usage, including mental health and hospital-based services, was also high.
- Many participants lived a sedentary lifestyle.
- Substance use was low in the study group when compared to the general population.
- There was generally insufficient health screening/prevention for participants.

### Anomalies:

- Although most participants reported good or very good health, a substantial number also experienced health-induced activity limitations.
- Substitute informants rated participant health higher than self-informants.

### Recommendations:

- People with ID in WA would benefit from an ID-specific targeted health check, such as the Comprehensive Health Assessment Program (Lennox, *et al.*, 2011).
- Medical professionals, care staff and families need to be made aware of the importance of screening tests and preventive measures for people with ID.
- Greater efforts need to be made to design and disseminate accessible public health promotion materials and programs for people with ID in WA, particularly those living independently.
- Investigations into levels of unmet health service need for people with ID are recommended to provide guidance for health service planning, particularly in regional areas.

## References

- Allen, D., Langthorne, P., Tonge, B., Emerson, E., McGill, P., Fletcher, R., Dosen, A. and Kennedy, C. (2013). Towards the prevention of behavioural and psychiatric disorders in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, n/a-n/a.
- Allerton, L. and Emerson, E. (2012). British adults with chronic health conditions or impairments face significant barriers to accessing health services. *Public Health*, 1-8. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/22959282>. doi:10.1016/j.puhe.2012.08.003.
- Australian Bureau of Statistics. (2008). *National Survey of Mental Health and Wellbeing: summary of results (2007)*. ABS, Canberra.
- Australian Bureau of Statistics. (2010). *4363.0.55.002 - NHS 2007–08 Questionnaire and prompt cards*. ABS, Canberra.
- Australian Bureau of Statistics. (2011). *National Regional Profile (ASGS): National Regional Profile: Population/People*. ABS, Canberra.
- Australian Bureau of Statistics. (2013). *3101.0 - Australian Demographic Statistics (Mar 2013)*. ABS, Canberra.
- Australian Institute of Health and Welfare. (2007). *Statistics on drug use in Australia 2006* (Cat. no. PHE 80). AIHW, Canberra.
- Australian Institute of Health and Welfare. (2010). *Health of Australians with disability: health status and risk factors. Bulletin no. 83. (AUS 132)*. AIHW, Canberra.
- Australian Institute of Health and Welfare. (2012). *Australia's Health 2012*. AIHW, Canberra.
- Beange, H., McElduff, A. and Baker, W. (1995). Medical disorders of adults with mental retardation: a population study. *American Journal on Mental Retardation* 99, 595-604.
- Burgard, S. A. and Chen, P. V. (2014). Challenges of health measurement in studies of health disparities. *Social Science & Medicine* 106, 143-150.
- Cobigo, V., Ouellette-Kuntz, H., Balogh, R., Leung, F., Lin, E. and Lunsy, Y. (2013). Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. *Journal of Intellectual Disability Research* 57, 478-88.
- Cooper, S. A., McConnachie, A., Allan, L. M., Melville, C., Smiley, E. and Morrison, J. (2011). Neighbourhood deprivation, health inequalities and service access by adults with intellectual disabilities: a cross-sectional study. *Journal of Intellectual Disability Research* 55, 313-323.
- Craig, C. L., Marshall, A. L., Sjostrom, M., Bauman, A. E., Booth, M. L., Ainsworth, B. E., Pratt, M., Ekelund, U. L. F., Yngve, A., Sallis, J. F. and Oja, P. (2003). International Physical Activity Questionnaire: 12-Country reliability and validity. *Medicine & Science in Sports & Exercise* 35, 1381-1395.
- Davis, P. and Joyce, S. (2011). *Health and Wellbeing of Adults in Western Australia 2010, Overview and Trends*. Department of Health, Western Australia.

- Department of Health. (2011). *Victorian population health survey of people with an intellectual disability 2009*. State Government of Victoria, Melbourne.
- Eastgate, G. (2008). Sexual health for people with intellectual disability. *Salud Publica Mex* 50 Suppl 2, s255-9.
- Emerson, E. and Hatton, C. (2007). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication. *Journal of Intellectual Disability Research* 51, 866-874.
- Emerson, E. and Hatton, C. (2008). Socioeconomic disadvantage, social participation and networks and the self-rated health of English men and women with mild and moderate intellectual disabilities: cross sectional survey. *European Journal of Public Health* 18, 31-37.
- Emerson, E., Madden, R., Graham, H., Llewellyn, G., Hatton, C. and Robertson, J. (2011). The health of disabled people and the social determinants of health. *Public Health* 125, 145-147.
- Felce, D., Baxter, H., Lowe, K., Dunstan, F., Houston, H., Jones, G., Felce, J. and Kerr, M. (2008). The impact of repeated health checks for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 21, 585-596.
- Fleming, R. K., Stokes, E. A., Curtin, C., Bandini, L. G., Gleason, J., Scampini, R., Maslin, M. C. and Hamad, C. (2008). Behavioral health in developmental disabilities: a comprehensive program of nutrition, exercise, and weight reduction. *Int J Behav Consult Ther* 4, 287-296.
- Glasson, E. J., Sullivan, S. G., Hussain, R. and Bittles, A. H. (2005). An assessment of intellectual disability among Aboriginal Australians. *Journal of Intellectual Disability Research* 49, 626-634.
- Grant, E., Carlson, G. and Cullen-Erickson, M. (2004). Oral health for people with intellectual disability and high support needs: positive outcomes. *Special Care in Dentistry* 24, 70-79.
- Hanna, L. M., Taggart, L. and Cousins, W. (2011). Cancer prevention and health promotion for people with intellectual disabilities: an exploratory study of staff knowledge. *Journal of Intellectual Disability Research* 55, 281-291.
- Haveman, M., Perry, J., Salvador-Carulla, L., Walsh, P. N., Kerr, M., Van Schrojenstein Lantman-de Valk, H., Van Hove, G., Berger, D. M., Azema, B., Buono, S., Cara, A. C., Germanavicius, A., Linehan, C., Maatta, T., Tossebro, J. and Weber, G. (2011). Ageing and health status in adults with intellectual disabilities: results of the European POMONA II study. *Journal of Intellectual & Developmental Disability* 36, 49-60.
- Heller, T., McCubbin, J. A., Drum, C. and Peterson, J. (2011). Physical activity and nutrition health promotion interventions: What is working for people with intellectual disabilities? *Intellectual and Developmental Disabilities* 49, 26-36.
- Holden, B. and Gitlesen, J. P. (2004). Psychotropic medication in adults with mental retardation: prevalence, and prescription practices. *Research in Developmental Disabilities* 25, 509-21.

- Humphreys, J. and Wakerman, J. (2008). *Primary health care in rural and remote Australia : achieving equity of access and outcomes through national reform: A discussion paper*. National Health and Hospitals Reform Commission,
- Iacono, T., Davis, R., Humphreys, J. and Chandler, N. (2003). GP and support people's concerns and priorities for meeting the health care needs of individuals with developmental disabilities: a metropolitan and non-metropolitan comparison. *Journal of Intellectual & Developmental Disability* 28, 353-368.
- Jensen, K. M., Taylor, L. C. and Davis, M. M. (2013). Primary care for adults with Down syndrome: adherence to preventive healthcare recommendations. *Journal of Intellectual Disability Research* 57, 409-421.
- Jess, G., Torr, J., Cooper, S.-A., Lennox, N., Edwards, N., Galea, J. and O'Brien, G. (2008). Specialist versus generic models of psychiatry training and service provision for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 21, 183-193.
- Krahn, G., Fox, M. H., Campbell, V. A., Ramon, I. and Jesien, G. (2010). Developing a health surveillance system for people with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities* 7, 155-166.
- Krahn, G. L., Hammond, L. and Turner, A. (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews* 12, 70-82.
- Krause, N. M. and Jay, G. M. (1994). What Do Global Self-Rated Health Items Measure? *Medical Care* 32, 930-942.
- Lennox, N. and Diggins, J. (1999a). Medical education and intellectual disability: a survey of Australian medical schools. *Journal of Intellectual & Developmental Disability* 24, 333-340.
- Lennox, N. and Diggins, J. (1999b). Knowledge, skills and attitudes: Medical schools' coverage of an ideal curriculum on intellectual disability. *Journal of Intellectual and Developmental Disability* 24, 341-347.
- Lennox, N., Rey-Conde, T. and Cooling, N. (2006). Comprehensive health assessments during de-institutionalization: an observational study. *Journal of Intellectual Disability Research* 50, 719-724.
- Lennox, N., Bain, C., Rey-Conde, T., Purdie, D., Bush, R. and Pandeya, N. (2007). Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *International Journal of Epidemiology* 36, 139-146.
- Lennox, N., Bain, C., Rey-Conde, T., Taylor, M., Boyle, F. M., Purdie, D. M. and Ware, R. S. (2010). Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings. *Journal of Applied Research in Intellectual Disabilities* 23, 303-311.
- Lennox, N., Ware, R., Bain, C., Taylor Gomez, M. and Cooper, S. A. (2011). Effects of health screening for adults with intellectual disability: a pooled analysis. *The British Journal of General Practice* 61, 193-6.

- Lennox, N. G. and Kerr, M. P. (1997). Primary health care and people with an intellectual disability: the evidence base. *Journal of Intellectual Disability Research* 41, 365-72.
- Lunsky, Y., Emery, C. F. and Benson, B. A. (2002). Staff and self-reports of health behaviours, somatic complaints, and medications among adults with mild intellectual disability. *Journal of Intellectual and Developmental Disability* 27, 125-135.
- McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran, S. and McCallion, P. (2011). *Growing older with an intellectual disability in Ireland 2011: first results from the intellectual disability supplement of the Irish Longitudinal Study on Ageing*. Trinity College Dublin, Dublin.
- McGuire, B. E., Daly, P. and Smyth, F. (2007). Lifestyle and health behaviours of adults with an intellectual disability. *Journal of Intellectual Disability Research* 51, 497-510.
- Melville, C. A., Cooper, S.-A., Morrison, J., Finlayson, J., Allan, L., Robinson, N., Burns, E. and Martin, G. (2006). The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services. *Journal of Intellectual Disability Research* 50, 11-17.
- Morgan, V. A., Leonard, H., Bourke, J. and Jablensky, A. (2008). Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. *The British Journal of Psychiatry* 193, 364-372.
- Morin, D., Méryneau-Côté, J., Ouellette-Kuntz, H., Tassé, M. J. and Kerr, M. (2012). A comparison of the prevalence of chronic disease among people with and without intellectual disability. *American Journal on Intellectual and Developmental Disabilities* 117, 455-463.
- Nicholson, L. and Cooper, S. A. (2012). Social exclusion and people with intellectual disabilities: a rural-urban comparison. *Journal of Intellectual Disability Research* E-pub, 1-14.
- Ouellette-Kuntz, H. (2005). Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 18, 113-121.
- Patrick, D. L., Lee, R. S., Nucci, M., Grembowski, D., Jolles, C. Z. and Milgrom, P. (2006). Reducing oral health disparities: a focus on social and cultural determinants. *BMC Oral Health* 6 Suppl 1, S4.
- Perry, J., Linehan, C., Kerr, M., Salvador-Carulla, L., Zeilinger, E., Weber, G., Walsh, P., van Schroyen Lantman-de-Valk, H., Haveman, M., Azema, B., Buono, S., Cara, A. C., Germanavicius, A., Van Hove, G., Maatta, T., Berger, D. M. and Tossebro, J. (2010). The P15 - a multinational assessment battery for collecting data on health indicators relevant to adults with intellectual disabilities. *Journal of Intellectual Disability Research* 54, 981-991.
- Peterson, J. J., Janz, K. F. and Lowe, J. B. (2008). Physical activity among adults with intellectual disabilities living in community settings. *Preventive Medicine* 47, 101-6.

- Ramon, I. A. (2013). *Differences in health-care access and utilization between people with intellectual disabilities and people without intellectual disabilities*. Unpublished Ph.D., Walden University, Ann Arbor.
- Rimmer, J. and Hsieh, K. (2011) *Longitudinal health and intellectual disability study (LHIDS) on obesity and health risk behaviors*. Lifespan Health and Function of Adults with Intellectual and Developmental Disabilities: Translating Research into Practice: Bethesda, Maryland. pp 4-17.
- Robertson, J., Roberts, H., Emerson, E., Turner, S. and Greig, R. (2011). The impact of health checks for people with intellectual disabilities: a systematic review of evidence. *Journal of Intellectual Disability Research* 55, 1009-1019.
- Saha, S., Chant, D., Welham, J. and McGrath, J. (2005). A systematic review of the prevalence of schizophrenia. *PLoS Med* 2, 413-433.
- Sargent-Cox, K., Cherbuin, N., Morris, L., Butterworth, P. and Anstey, K. J. (2014). The effect of health behavior change on self-rated health across the adult life course: a longitudinal cohort study. *Preventive Medicine* 58, 75-80.
- Srikanth, R., Cassidy, G., Joiner, C. and Teeluckdharry, S. (2011). Osteoporosis in people with intellectual disabilities: a review and a brief study of risk factors for osteoporosis in a community sample of people with intellectual disabilities. *Journal of Intellectual Disability Research* 55, 53-62.
- Sullivan, S. G., Glasson, E. J., Hussain, R., Petterson, B. A., Slack-Smith, L. M., Montgomery, P. D. and Bittles, A. H. (2003). Breast cancer and the uptake of mammography screening services by women with intellectual disabilities. *Preventive Medicine* 37, 507-512.
- Sullivan, S. G., Hussain, R., Threlfall, T. and Bittles, A. H. (2004). The incidence of cancer in people with intellectual disabilities. *Cancer Causes and Control* 15, 1021-1025.
- Temple, V. A. and Walkley, J. W. (2007). Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability. *Journal of Intellectual & Developmental Disability* 32, 28-38.
- The Commission on Social Determinants of Health. (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health*. World Health Organization, Geneva.
- Tracy, J. and Hosken, R. (1997). The importance of smoking education and preventative health strategies for people with intellectual disability. *Journal of Intellectual Disability Research* 41, 416-421.
- Tyler, C. V., Jr., Snyder, C. W. and Zyzanski, S. (2000). Screening for osteoporosis in community-dwelling adults with mental retardation. *Mental Retardation* 38, 316-321.
- Walsh, P. N., Hall, L. and Ryan, D. (2008). *Health indicators for people with intellectual disability: using an indicator set*. European Commission, Dublin, Ireland.
- Wark, S., Hussain, R. and Edwards, H. (2013). Rural and remote area service provision for people aging with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities* 10, 62-70.

- Wood, R. and Douglas, M. (2007). Cervical screening for women with learning disability: current practice and attitudes within primary care in Edinburgh. *British Journal of Learning Disabilities* 35, 84-92.
- World Health Organization. (2006). *Neurological disorders: public health challenges*. World Health Organization, Geneva.
- Zakrajsek, A. G., Hammel, J. and Scazzero, J. A. (2013). Supporting people with intellectual and developmental disabilities to participate in their communities through support staff pilot intervention. *Journal of Applied Research in Intellectual Disabilities*, n/a-n/a.

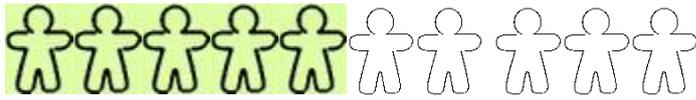
## What we found out

 9 out of 10 people say they feel healthy.

Typically, people had 2 health problems in the last year



 3 out of 10 people had epilepsy at some time in their lives.



**5 out of 10 people**

**have healthy teeth**



**2 out of 10 people**

**take more than 4 different medicines**

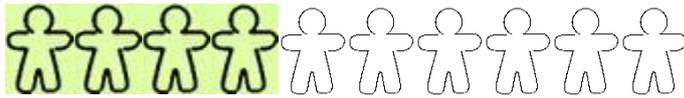


**3 out of 10 people do**

**not take any medicine**



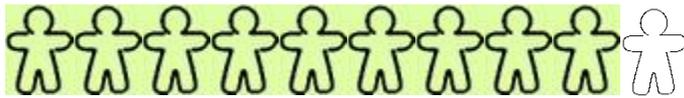
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**4 out of 10 people had**

**been to a mental health professional in the last year**

**Anxiety and depression were the most common reasons**



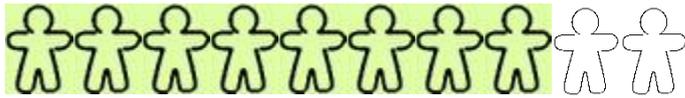
**9 out of 10 people**

**have a regular doctor**



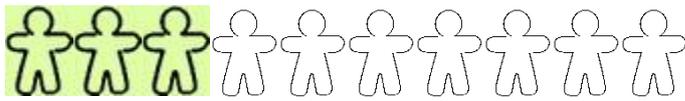
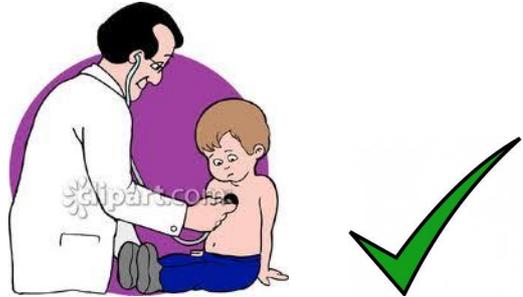
**4 out of 10 people go**

**to a regular specialist**



**8 out of 10 people**

**think their doctor treats them well**



**3 out of 10 people do**

**not always understand the doctor**



**3 out of 10 people are**

**a healthy weight**



**3 out of 10 people**

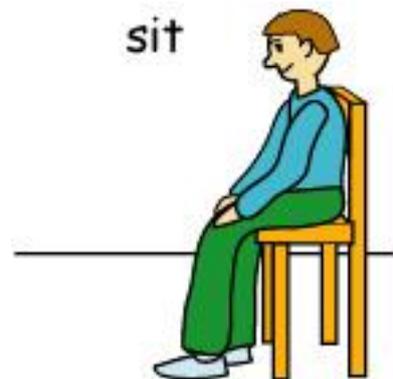
**walk most days**

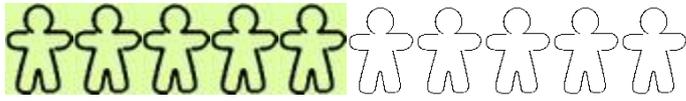


**4 out of 10 people**

**spend less than 5 hours a day sitting**

sit





**5 out of 10 people**

**rarely have takeaway food**



**2 out of 10 people eat**

**enough fruit and vegetables**



**8 out of 10 people**

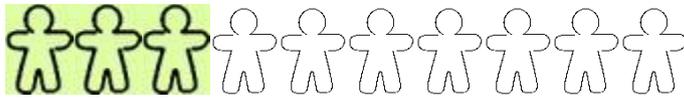
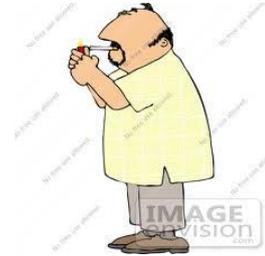
**drink less than 1 soft drink a day**





**Fewer than 1 out of 10**

**people smoke**



**3 out of 10 people**

**drink alcohol**



**Many people know about what makes you healthy. They often find out about this from their family, TV or magazines.**

**Thank you for helping us with our research by talking about your health**

## For further information

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