



# CHRONIC ILLNESS AND PEOPLE WITH INTELLECTUAL DISABILITY

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Prevalence, prevention and management  
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## **About National Disability Services**

**National Disability Services** is the peak body for non-government disability services. Its purpose is to promote quality service provision and life opportunities for people with disability. NDS's Australia-wide membership includes more than 1300 non-government organisations, which support people with all forms of disability. NDS provides information and networking opportunities to its members and policy advice to state, territory and federal governments.

# CONTENTS

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<b>Introduction</b>	<b>4</b>
Chronic illness and responses to its management	5
<b>Context</b>	<b>6</b>
Physical health and wellbeing of people with ID	7
Mental illness—‘dual diagnosis’	10
Diabetes	12
Asthma	13
Cardiovascular Disease	14
Osteoporosis and arthritis	15
Summary	17
<b>Medically-guided approaches</b>	<b>17</b>
<b>Peer-led or peer-involved approaches</b>	<b>19</b>
<b>Behavioural and health promotion approaches</b>	<b>23</b>
<b>Conclusions</b>	<b>25</b>
<b>Recommendations</b>	<b>26</b>
<b>References</b>	<b>33</b>

# INTRODUCTION

This document reports on the prevalence, prevention and management of chronic conditions in people with intellectual disability in Australia. It begins by noting the burden of chronic conditions experienced by people with intellectual disability, and estimates of the prevalence of intellectual disability (ID), before turning to a review of the literature on chronic conditions - and the prevention or management of them - in this population.

People with intellectual disability (ID) experience more chronic illness than the general population (Haveman et al., 2010; Hermans & Evenhuis, 2014; Peterson, Gordon, & Hurvitz, 2013; Valk et al., 1997; White, Chant, Edwards, Townsend, & Waghorn, 2005). This applies to physical conditions (diabetes, cardiovascular disease, asthma, and conditions affecting the bones and joints—osteoporosis, arthritis) and to mental illnesses (White et al., 2005).

Intellectual disability affects between one and two per cent of the Australian population, with about one per cent having significant support needs (Australian Institute of Health and Welfare, 2008). Maulik, Mascarenhas, Mathers, Dua and Saxena (2008) found that low and middle income countries had higher rates of people with ID than did high income countries; estimates are, however, affected by measurement instruments.

In Australia, Indigenous people and other people experiencing socio-economic disadvantage are overrepresented in prevalence data. Glasson, Sullivan, Hussain and Bittles (2005) reported that 7.4 per cent of Indigenous Australians in West Australia were registered for ID services, with 19 per cent of those people having moderate intellectual disability and 12.1 per cent profound or severe intellectual disability. A similar rate (8 per cent) for ID among Indigenous Australians was reported by the Australian Bureau of Statistics (ABS) (2011), again with men more likely than women to have an intellectual disability, and three times as many Indigenous children being born with cerebral palsy than non-Indigenous children (Productivity Commission, 2011).<sup>1</sup> Socio-economic disadvantage is likely to be a contributing factor to the prevalence of ID among Indigenous Australians. Glasson et al. noted that:

⋮ *The disadvantaged social circumstances of many Indigenous communities mean that Aboriginal people have a significantly lower overall socio-economic profile than non-Indigenous Australians (Australian Bureau of Statistics, Australian Institute of Health and Welfare 2003). Poor socio-economic status has been particularly associated with an increased risk of mild to moderate ID in low income countries (Najman et al. 1991; Croen et al. 2001; Durkin 2002), and the*

## DEFINING INTELLECTUAL DISABILITY

Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society.

The use of the term intellectual disability in the context of the WHO initiative "Better health, better lives" includes children with autism who have intellectual impairments. It also encompasses children who have been placed in institutions because of perceived disabilities or family rejection and who consequently acquire developmental delays and psychological problems." (WHO)

<sup>1</sup> The Productivity Commission noted that, "Some Indigenous Australians find the concept of disability hard to understand or irrelevant," including for cultural reasons (2011, p. 532). This may contribute to under-reporting, which is compounded by much lower response rates to surveys (ibid.).

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... patterns of ID observed in the present study are in keeping with these reports. The degraded physical environments in which many Indigenous Australians live confer a further increased risk of general infections (some of which can lead to ID, e.g. meningitis), respiratory diseases and parasitic diseases. (p. 631)

Such disadvantage is thus not restricted to low income countries. Emerson's analysis (2012) of educational records for 5.18 million English children (aged 7–15) found that the prevalence of:

... all major forms of intellectual and developmental disability is greater among children in families of lower socio-economic position. Area disadvantage is also independently associated with increased prevalence of less severe intellectual disability. (p. 223)

## CHRONIC ILLNESS AND RESPONSES TO ITS MANAGEMENT

The present review scanned the academic and grey literature to ascertain prevalence data, as well as key directions in prevention and management.

The initial search was conducted through Google Scholar with subsequent searches of the archives of those journals that returned relevant results, and of reference lists of articles. In the field of intellectual disability, journals included the *Journal of Intellectual and Developmental Disability*, *American Journal of Mental Retardation*, *Research in Developmental Disabilities*, *Journal of Applied Research in Intellectual Disabilities* and *Journal of Intellectual and Developmental Disabilities*. A second search target was health promotion, where search results were returned for *Health Promotion International*, and *Health Education Behaviour*. In medical research, journals returning relevant results included the *British Medical Journal*, *Food Nutrition Research*, *Preventive Medicine* and *Obesity Reviews*. Behavioural and sociological journals returning relevant papers included *Sociology of Health & Illness*, *British Journal of Social Psychology*, *Personality and Social Psychology Bulletin*, *Organizational Behaviour and Human Decision Processes*, and *Social Science & Medicine*.

Search terms used were 'intellectual disability,' 'learning difficulty,' 'learning disability,' 'intellectual impairment' or 'mental retardation' (etc.), and 'chronic illness,' or '[specific conditions of interest],' and 'management' or 'prevention,' and 'health promotion.' The search was limited to material published in English, but no date parameters were set. Most items returned dated from after 1990, with the majority being published in the past 15 years. Four journal types were targeted: those focused on intellectual disability, health promotion, medical, and behavioural or sociological research.

A total of 298 articles was found. All abstracts were read. Articles were reviewed in full if they reported on:

- The prevalence of intellectual disability in particular populations, the prevalence of particular intellectual disabilities, and/or comorbidities of interest in people with ID
- Illness prevention or management in people with ID
- Health promotion approaches – including health promotion for people with ID

Reviewed articles that met one or more of the above criteria were used in the review (111 in total).

Prevalence of ID data informed the Introduction to this report; prevalence of comorbidities is reported in subsequent sections.

Two approaches to the prevention or management of chronic conditions in people with intellectual disability are apparent in the literature: those characterised by significant GP or other clinician involvement in assessment and management of conditions; and those characterised by peer involvement in mentoring and

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supporting people with ID to adopt healthy practices or to manage existing conditions. A third stream in the review is an inquiry into motivation: research on ‘planned behaviour,’ ‘goal intentions’ and ‘implementation intentions,’ and health promotion. This part of the review sought evidence of effective models for motivating and maintaining better lifestyle choices.

There are also projects and schemes operating that have been harder to track, since on-the-ground projects are often not reported on (other than to immediate stakeholders and funding bodies), lack ethical approval and so are not written up for formal publication, and are beset by daily pressures which make public reporting unlikely. Some, however, do leave traces. Examples include the ‘Be Healthy Toolkit,’ developed by Di Pullen and Matthew Spicer at Anglicare,<sup>2</sup> and the UK Health Trainers model, in which people with ID work as health trainers for their peers. The latter model appears particularly promising as its peer-to-peer method is well-supported by the literature.

This report is divided into the following sections:

- Prevalence studies
- Medically-guided approaches
- Peer-involved approaches
- Behavioural and health promotion approaches

The report turns first to the evidence about the prevalence of chronic illnesses in people with ID.

## CONTEXT

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Of specific causes of intellectual disability, Down syndrome is the most common in Australia. Other specific causes of intellectual disability include autism spectrum disorders, cerebral palsy, and Fragile X syndrome. Down Syndrome Australia estimates that one in every 1,100 babies is born with Down syndrome<sup>3</sup>. Down syndrome is a genetic condition, and genetic conditions as a group are the main cause of intellectual disability in Australia and elsewhere (Australian Institute of Health and Welfare, 2008), accounting for approximately 20 per cent of incidence. Detailed data on the prevalence of specific causes of ID in Australia is difficult to find. The Australian Bureau of Statistics’ Survey of Disability, Ageing and Carers asks participants to identify the main condition affecting their learning or understanding. Responses identify ‘intellectual and developmental disorder’ and ‘autism and related disorders,’ for

### SNAPSHOT OF CAUSES OF ID IN AUSTRALIA

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<b>Down syndrome</b>	12–15% of all Australians with ID (Bittles & Glasson, 2004)
<b>Autism spectrum disorder (causing severe or profound limitation)</b>	0.5% of Australians, with 71% experiencing severe or profound limitation (Australian Bureau of Statistics, 2014a)
<b>Cerebral palsy (with ID)</b>	0.07–0.2% of Australians (Australian Cerebral Palsy Register, 2013)
<b>Fragile X (with ID)</b>	<7,000 Australians (Brown, 2010)

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<sup>2</sup> This project has not been reported in detail in publicly available form.

<sup>3</sup> This rate is lower than reported internationally and may reflect high termination rates in Australia. ([http://www.downsyndrome.org.au/down\\_syndrome\\_population\\_statistics.html](http://www.downsyndrome.org.au/down_syndrome_population_statistics.html))

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example, but not specific diagnoses.

Mortality and life expectancy data for people with ID indicates an historically poorer life expectancy, but for at least some cohorts, life expectancy is increasing and in some places is close to that of the general population (see Glasson, Sullivan, Hussain, Petterson, Montgomery, & Bittles, 2002; Patja, Mölsä, & Iivanainen, 2001).

## PHYSICAL HEALTH AND WELLBEING OF PEOPLE WITH ID

### OVERVIEW

- People with ID are more likely than their non-disabled peers to have multiple co-morbidities, including mental illnesses.
- They have a lower life expectancy than non-disabled people, and life expectancy increases as severity of ID decreases.
- The most common causes of death mirror those in the general population, being cardiovascular disease, respiratory diseases and cancers.
- Quality of life for people with ID is impacted by physical health and by levels of self-determination.
- Prevalence rates for many conditions remain unclear. This is because people with ID are only sometimes identified in large-scale prevalence studies, the condition may present differently in people with ID, and some clinicians may lack the knowledge needed for accurate diagnosis.

### EVIDENCE

People with intellectual disability (ID) experience a variety of health inequalities compared with the general population, including higher mortality rates. In their UK population-based study, Tyrer, Smith and McGrother (2007) measured the extent of 'excess mortality' in people with ID compared with the general population. Comparing the all-cause and disease mortality ratios for all adults with ID and for all adults without ID in two UK counties, Tyrer et al. (2007) found that mortality for people with ID was three times higher than the general population. Younger people, people with Down syndrome and women with ID fared more poorly than others.

In Australia, Bittles and colleagues (Bittles et al., 2002) calculated survival probability rates of people with ID using a database maintained by the Disability Services Commission of Western Australia (8724 individuals, 7562 living). They found that the greater the severity of ID, the shorter the median life expectancy. People with mild ID had a median life expectancy of 74 years; for those with moderate ID the expectancy was 67.6 years, and for people with severe ID, life expectancy was only 58.6 years. This compares with the median life expectancy of the general population in Australia (for the same year) of 79.94 years (ABS, 2003). That life expectancy for people with ID is related to severity of disability has also been found elsewhere. A 35-year Finnish study of almost 70,000 people with ID (Patja, Iivanainen, Vesala,

### DEFINING QUALITY OF LIFE

The World Health Organisation defines Quality of Life as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment." (World Health Organization, 1997, p. 1).

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Oksanen, & Ruoppila, 2000) found that the life expectancy of people with ID was similar to that of the general population, but that the more severe the disability, the poorer the life expectancy. The proportion of life lost in people with profound disability was 20 per cent.

The major causes of death in the Finnish cohort, reported by Patja, Mölsä and Iivanainen (2001), were cardiovascular and respiratory diseases, and neoplasms (cancer), as was also the case for the general population. Rates of cardiac disease were, however, lower in the cohort of people with ID. Patja et al. (2001) speculate that this may be the result of a 'healthy survivor effect'; that is, physiologically frail people with ID have a higher risk of death before the age of 30, resulting in a healthier cohort of people after that age.

It is known that people with Down syndrome are more likely to have congenital cardiac defects (around 48 per cent of people with Down syndrome) (Bittles & Glasson, 2004). They also experience higher rates of gastrointestinal, immunological, respiratory, sensory, and orthopaedic problems and adult-onset epilepsy (affecting up to half of all people with Down syndrome over the age of 50) (ibid.) than the general population. They also experience age-related disorders earlier. In Cooper et al.'s (2015) analysis of the primary health care data of 1,424,378 adults in Scottish medical practices, people with ID were more likely than non-disabled people to have comorbidities. The more-commonly occurring conditions were epilepsy, constipation and visual impairment. People with ID were also more than twice as likely to have hearing loss, eczema, dyspepsia, thyroid disorders and Parkinson's disease. And there is greater prevalence of mental illness among people with ID (e.g., see Cooper et al., 2015; Deb, Thomas, & Bright, 2001a; White et al., 2005).

In their West Australian study (Sullivan, Hussain, Threlfall, & Bittles, 2004) examined cancer rates among people with ID, and found that overall rates were similar to those for the general population. But there were some cancers for which people with ID were at increased risk. For men with ID, these were leukaemia, brain and stomach cancers, and for women, leukaemia, corpus uteri and colorectal cancers. Men with ID had a lower risk of prostate cancer.

The management of chronic or other health conditions has been shown to impact upon quality of life (QoL), with health being one of the domains commonly measured in QoL scales. Hensel, Rose, Kroese, and Banks-Smith (2002) interviewed 31 people with ID and 31 matched controls about their QoL. The scales used were forms of the Comprehensive Quality of Life Scale (ComQoL)—one for the general adult population and the other for people with ID. The scales have measures of objective QoL and of the importance of or satisfaction with seven domains: material wellbeing, health, productivity, intimacy, safety, place in community and emotional wellbeing. Both groups reported generally high levels of satisfaction with aspects of life, though their reports did not correlate with their 'objective circumstances.' People with ID in the study ranked most items—other than health and community involvement—as more important than did the control group participants. But they also reported being much less satisfied with their health than did the non-disabled participants.

## QUALITY OF LIFE AND PEOPLE WITH ID

“Currently, the QOL concept is being used as a:

- sensitizing notion that gives us a sense of reference and guidance from the individual's perspective, focusing on the person and the individual's environment;
- unifying theme that is providing a framework for conceptualizing, measuring, and applying the QOL construct; and
- social construct that is being used as an over-riding principle to enhance an individual's well-being and to collaborate for programmatic, community, and societal change” (Schalock, 2004, p. 205).



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QoL, then, may be regarded as arising from the interaction between intrinsic and extrinsic factors. That is, individual's health and conditions interact with social, material and community experiences. This reflects Shakespeare's argument (2014a, 2014b) that the 'social model of disability' (M. Oliver, 1983, 1990) is a necessary but insufficient framework for explaining the experience of disability: people with ID or other disability also experience pain, and physical or learning and comprehension limitations caused by their disability.

The power to shape or influence one's circumstances, or 'self-determination' (SD), has also been linked with QoL. Nota, Ferrari, Soresi and Wehmeyer (2007) focused on the role of SD in quality of life for people with ID. In examining the interaction between individual characteristics, living situations and SD in a group of 141 people with ID in Italy, they found that greater severity of ID was associated with poorer SD and poorer QoL. These factors were linked with living in institutions. Men with ID also had poorer SD (Lachapelle et al., 2005, found strong support for SD's key role in QoL). Opportunities to participate in activities they valued (an aspect of self-determination) affected the sense of quality of life for adolescents with cerebral palsy in Shikako-Thomas and colleagues' (2009) study. This social inclusion dimension, along with self-determination, is among the eight domains in the QoL scale developed by Schalock and colleagues (2002) and since used extensively. In Schalock et al.'s work, physical wellbeing was one of several domains argued as underlying the assessment of QoL-related personal outcomes for people with ID. There is widespread agreement on these as the most useful domains in QoL measures (Bigby, Knox, Beadle Brown, & Bould, 2014; Claes, Hove, Loon, Vandeveld, & Schalock, 2010; Morisse, Vandemaele, Claes, Claes, & Vandeveld, 2013; Schalock, 2004; R. L. Schalock et al., 2002; Walsh et al., 2010):

- Physical wellbeing
- Personal development
- Self-determination (SD)
- Interpersonal relations
- Social inclusion (or civic participation)
- Rights
- Emotional wellbeing
- Material wellbeing

Attention has been drawn to the potential difficulties of gaining accurate data on QoL either from people with ID themselves, or from proxies (for example, see McVilly & Rawlinson, 1998), such as family members or staff. Bigby and colleagues (2014) avoided this risk by gathering data using participant observation over a 9 to 12 month period in seven Australian group homes (with 21 residents in all). Using Schalock et al.'s (2002) QoL measure and qualitative analysis, they found that "person-centered action and the practice of active support, whereby staff provide sufficient facilitative assistance to enable people to engage successfully in meaningful activities and social relationships" (p. 363) contributed to better QoL for residents.

## **SUMMARY**

In summary, the life expectancy of people with ID has been increasing. Those with the least limitation live almost as long as their non-disabled peers. However, people with ID are less satisfied than the general population with their health, may lack opportunities for self-determination and experience higher rates of the following:

- Mental illness (relates to all people with ID)
- Some cardiovascular diseases (especially people with Down syndrome)

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- Gastroenterological conditions (including constipation)
  - Respiratory conditions
  - Orthopaedic problems
  - Some cancers

This report focuses on five conditions—mental illness, cardiovascular disease, diabetes, asthma and osteoporosis and arthritis, where adjusting lifestyle factors has been shown to confer health benefit.

## MENTAL ILLNESS—‘DUAL DIAGNOSIS’

### OVERVIEW

For people with ID, mental illness:

- is a significant chronic condition
- is under-diagnosed in this population
- may manifest differently than in the general population

Further, treatment with psychotropic drugs often has negative side effects. Avoiding their use where possible is likely to lead to better health and wellbeing for people with ID. Staff (as well as clinicians) need to:

- learn the ways that mental illnesses may manifest in participants
- understand how to both prevent and respond to symptoms

Gaining knowledge of the individual circumstances, emotional and mental state of people with intellectual disability is thus a key part of providing effective support. Support workers and other members of a person’s team are also essential in assisting in diagnosis.

### EVIDENCE

Mental illness affects half of all Australians aged under 65 who have a severe or profound core activity limitation, but less than 10 per cent of those without disability (Australian Institute of Health and Welfare, 2016a). For people aged under 65 with mental health conditions, those with severe or profound core activity limitation were more likely than those without disability to acquire a mental health condition before the age of 25 (39 per cent versus 28 per cent) (Australian Institute of Health and Welfare, 2016a). Further, adults aged 18 to 64 with severe or profound core activity limitation were 20 times as likely as those without disability to have a very high level of psychological distress (22 per cent versus 1 per cent) (Australian Institute of Health and Welfare, 2016a). These prevalence data do not, however, distinguish between people with ID and people with physical disability.

White and colleagues (2005) used data from the national ‘Disability and Carers Survey, 1998’ to determine the prevalence of serious mental illness in Australians with intellectual disability. They report that “1.3% had a psychotic disorder, 8% had a depressive disorder and 14% had an anxiety disorder that had been present for at least 6 months and was of such severity that it too was disabling” (p. 395). Mental illnesses were a frequent comorbidity for people with ID in Cooper et al.’s (2015) very large Scottish study of the primary health data of 1,424,378 people. There, people with ID were less likely than their non-disabled neighbours to have no recorded mental illness, and “twice as likely to have one, two and three or more mental health conditions” (p. 3). Schizophrenia and bipolar disorder, anxiety and depression were much more prevalent in people with ID. Schizophrenia and phobic disorders were also found to be more prevalent in people with ID

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by Deb, Thomas and Bright (2001a). Sixty per cent of the sample had at least one behaviour disorder, and the overall prevalence of functional psychiatric illness in their Welsh sample (n = 101) was 16 per cent (similar to that in the general population). However, they found that the rates of schizophrenic illness (4.4 per cent of their sample) and phobic disorders were significantly higher. Around two per cent of people with ID in their sample had generalised anxiety disorder and the same percentage had depressive disorders. These authors cite studies showing that between 10 and 39 per cent of people with ID experience mental illness. Age and physical disability increased the likelihood of having a psychiatric illness.

Depression affected a larger proportion of people with ID in Cooper et al.'s Scottish study: 15.8 per cent (2015). Depression and other mood disorders are believed to be underreported, largely because describing mood is difficult for some people with ID (Evans, Cotton, Einfeld, & Florio, 1999, provide a useful review of the relevant literature). Evans et al. (1999) found that accurate diagnosis is highly reliant on caregivers (including support staff), that presentation is different in people with ID from people in the general population, and that the standard diagnostic criteria may need to be modified. Similarly, communication difficulties affected 10 per cent of Deb et al.'s (2001a) sample. They note that:

••• *The difficulty of diagnosing psychiatric illness, particularly psychosis in adults who do not have proper communicative abilities, is well known. In some studies, psychiatric illnesses were diagnosed by studying case registers, and in others, this was done by using screening questionnaires. Direct psychiatric interview has very seldom been used to diagnose cases. (p. 496)*

Deb and colleagues (2001b) also reported on risk factors for behaviour disorders for this population in Wales. There were 64 adults (60.4 per cent) with ID in their study with one or more behaviour disorders, including aggression, self-harm, screaming and destructiveness. There was evidence of an association between this rate and the rate of use of psychotropic medications (particularly for aggression). Being female, having epilepsy, attending day centre activities and severity of ID were associated with severe behaviour problems.

The role of psychotropic medications reported by Deb et al. (2001b) is supported by Sheehan et al. (2015), who explored the rates of prescription of psychotropic medications to people with ID (n = 33,016 adults) in the United Kingdom. Sheehan et al. (2015) found that many more people with ID were given psychotropic medication than had a diagnosed mental illness. Often, this was in response to 'challenging behaviour'—it was, in effect, chemical restraint. Yet psychotropic drugs have been linked with side effects, some of which are irreversible (e.g., dyskinesia; Hess, Matson, Neal, Mahan, Fodstad, & Bamburg, 2010). The use of psychotropics has also been linked (Janicas, 2014) with increased risk of obesity, diabetes and heart disease, and, according to Hess et al. (2010), people taking atypical antipsychotics, AEDs and mood stabilisers, and anxiolytics are at greater risk of endocrine/genitourinary and eye/ear/nose/throat problems. This requires clinicians (and support staff) to monitor side effects, and to be particularly "*careful with respect to add-on pharmacotherapies because psychotropic drugs from multiple drug classes (interclass) place the client at greater risk for untoward side effects*" (Hess, Matson, Neal, Mahan, Fodstad, Bamburg, et al., 2010, p. 94). At the same time, staff (i.e. disability support workers) have reported having insufficient knowledge of psychotropic drugs to keep clients safe (Donley, Chan, & Webber, 2012). Despite the drugs being used as a chemical restraint, staff felt ill-equipped to talk with doctors about medications and thus to communicate better with clients and to find out more about alternatives. Donley et al. (2012) argue that proactive strategies to prevent 'behaviours of concern' were more valued by workers, but that workers received little relevant training in this area (a finding that supported earlier work by Quigley, Murray, Mckenzie, & Elliot, 2001).

The prevalence data discussed here may not reflect the true prevalence of mental illness in people with ID. Mental illness often remains undiagnosed (implying that these figures under-report the extent of mental

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illness in people with intellectual disability), because of difficulties with diagnosis (relating to presentation) and in clinical assessment procedures (including communicative difficulties). Further, prevalence reports vary because of “*dissimilarities in the sample population of each study,*” “*the difference in research methodologies*” and “*the inclusion or exclusion of challenging behaviour or behaviour problems*” (Raghavan, 2004, p. 5).

## DIABETES

### OVERVIEW

- People with ID are at greater risk of developing both Type 1 and Type 2 diabetes.
- Psychotropic medications taken by people with ID contribute to this risk.
- Self-management mechanisms for people with ID are not meeting their needs.
- Carers often have too little knowledge to support self-management.

### EVIDENCE

Psychotropic medications, commonly prescribed to people with ID, can increase the risk of diabetes (Buse et al., 2003; Wirshing, Spellberg, Erhart, Marder, & Wirshing, 1998). It is the case that there may be “*an intrinsic relationship between abnormal glucose metabolism and bipolar I affective and schizoaffective disorders*” (Regenold, Thapar, Marano, Gavirneni, & Kondapavuluru, 2002, p. 19). This, combined with “*genetic, personal and socio-economic factors*” experienced by people with ID (McVilly et al., 2014, p. 897), means that they are at greater risk of Type 2 diabetes. It is also the case that being overweight or obese is a risk factor for Type 2 diabetes (Cameron et al., 2003; Resnick, Valsania, Halter, & Lin, 2000), and that adults with ID are more likely to be obese than other adults (Australian Institute of Health and Welfare, 2016a; Hsieh, Rimmer, & Heller, 2014; Yamaki, 2005).

How prevalent diabetes is in this population is the subject of some debate. While a US study (Reichard & Stolsle, 2011), using health budget data, found that the prevalence of diabetes among people with ID was 19.4%, compared with 3.8% in other adults, McVilly and colleagues’ more recent systematic review (2014) of published research found that the mean prevalence of diabetes in people with ID was 8.7%—higher than the 5.4% reported for the general population (<http://www.aihw.gov.au/how-common-is-diabetes/>). There is also evidence (McVilly et al., 2014) for greater prevalence of diabetes in people with autism and those with Down syndrome than in the population in general. Overall, however, the systematic review found scarce—and sometimes conflicting—prevalence data for this population. As a result, McVilly et al. (2014) suggest that the higher rates in specific groups warrant better recording and that population studies need to identify sub-groups (i.e. people with ID).

Perhaps more importantly, McVilly et al. (2014) note that the management of diabetes presents more challenges for people with ID since the monitoring and interpretation tasks, as well as achieving ideal levels of physical activity, may require the support of others. Documented evidence of effective, evidence-based practice approaches to management—including to self-management—is, they note, very scarce. Further, people with ID have been found to want more information about the condition (MacRae et al., 2015). Echoing McVilly et al. (2014), McCrae and colleagues (2015) found that existing management approaches were not meeting this group’s needs. Carers, too, reported a lack of knowledge and thus did not “routinely encourage diabetes self-management skills” (p. 352). The authors concluded that people with ID and diabetes “should be encouraged to participate in future research,” and, with McVilly et al. (2014), argue that ways to adapt mainstream diabetes management programs for people with ID should be sought, as should effective and appropriate self-management programs.

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# ASTHMA

## OVERVIEW

- Asthma is more prevalent among people with ID.
- Smoking and overweight or obesity both contribute to worse outcomes for people with asthma.
- Some medications decrease muscle coordination, affecting breathing.
- There is conflicting evidence regarding the prevalence of smoking among people with ID.

## EVIDENCE

The prevalence of asthma in people with ID is generally reported to be higher than in the non-disabled population. The AIHW reported a rate of 15 per cent in 2008 and a slightly higher rate in 2016. In the UK, Gale, Naqvi and Russ (2009) also reported a rate (12 per cent) higher than that for the general population (5.77 per cent). Examination of the clinic records for 2,253 patients with ID in an Australian health clinic, however, found a lower prevalence (6 per cent) than is experienced by non-disabled Australians (10 per cent) (Davis et al., 2014). Davis and colleagues (2014) suggest that some tracheal abnormalities in people with ID may result in misdiagnosis and partially explain the higher prevalence rates. Nonetheless, some syndromes “associated with ID may involve neuromuscular weakness, with loss of control of the larynx and pharynx, and ineffective cough, leading to aspiration. This in turn causes lung inflammation, airway obstruction and worsening restrictive lung disease” (Davis et al., 2014, p. 278). Here, too, prescribed medications can contribute, causing “sedation and decreased muscle coordination, which may affect muscles of the mouth, throat and oesophagus” (p. 279).

Being overweight or obese is implicated in the development of asthma, as well as in poorer outcomes for those with asthma or respiratory illnesses. Gale, Naqvi and Russ’s study (2009) of the health data of 1097 adults with ID in Bristol (UK) found a much higher prevalence of asthma than in the general population. Further, there was a link between being overweight or obese and developing asthma, and between smoking and developing asthma (Gale et al., 2009). A high proportion of those people with ID and asthma in their study smoked.

## SMOKING

Smoking is linked with asthma, COPD and cardiovascular disease, and this combination of factors is associated with worse disease outcomes. There is mixed evidence about smoking rates among people with ID. Tracy and Hosken found a 36 per cent smoking rate in a geographically defined sample of Australians with mild cognitive impairment (1997), far higher than the 26 per cent background rate at that time. On the other hand, smoking rates were low (11 per cent were current or former smokers) in Wallace and Schluter’s (2008) retrospective audit of the medical charts of 155 people with ID attending a specialised clinic for older people (aged 40 years or older) with ID in Brisbane, and Cooper et al. (2015) reported lower rates of smoking for people with ID in their Scottish study (as did the large Finnish study by Patja et al., 2000). Cooper et al. (2015) also found a corresponding lower prevalence of cardiovascular and chronic obstructive pulmonary diseases (COPD). Similarly, COPD accounted for only 11 per cent of deaths from respiratory conditions in Patja, Mölsä and Iivanainen’s study (2001); pneumonia was the most common cause of respiratory-related deaths (83 per cent).

AIHW data (2016a) showed that people with severe or profound disability were more likely to smoke, and to start smoking early, but their data does not distinguish between intellectual and physical disabilities. It is difficult, given these contrasting findings, to determine what proportion of people with ID are smokers.

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## CARDIOVASCULAR DISEASE

### OVERVIEW

- Cardiovascular disease prevalence among people with ID appears to be lower than for the non-disabled population.
- People with ID experience several risk factors, including genetic or congenital factors, chronic inflammation, medication side-effects, socioeconomic disadvantage, poorer access to healthcare, social isolation and insufficient exercise, contributing to poorer overall health and QoL.
- Mitigation of these risks relies on managing (and reducing, where possible) the use of psychotropic medications, increasing physical activity and supporting better nutrition.
- The active and informed involvement of formal and informal supporters is important in management.

### EVIDENCE

Longevity for people with ID has been increasing (Janicki, Dalton, Henderson, & Davidson, 1999). In common with the rest of the population, cardiovascular and respiratory diseases and cancers remain the most prevalent causes of death (Haveman et al., 2010; Patja et al., 2001), but while cardiovascular disease was the major cause of death among people with ID in Patja et al.'s Finnish study (2001), it was less common than in the age- and sex-matched general population.

For some sub-populations, however, the risk of cardiovascular disease is greater. Peterson, Gordon and Hurvitz (2013) focus on people with cerebral palsy (CP) among whom coronary heart disease is more prevalent than in the general population. This appears to be related to sedentary behaviour, premature muscle loss (sarcopenia) and obesity. They argue for "*the value of lifelong physical activity participation for both function and cardiometabolic health preservation*" (p. 171).<sup>4</sup> The higher rates of being overweight and obese in people with ID overall adds to their risk of cardiovascular disease. Further, "[a]lmost half (46%) of people aged 15–64 with severe or profound disability reported doing no physical exercise compared with 31% of people without disability" (Australian Institute of Health and Welfare, 2016a, p. 4). Lack of exercise was also found in Wallace and Schluter's (2008) chart review of 155 'supported' adults with ID. Poor exercise or activity rates and being overweight or obese were much more prevalent than in non-disabled people of the same age. Five percent of Wallace and Schluter's sample (of 155 people with ID) had cardiovascular disease. Indeed, the cardiovascular risk profile for people with ID in their review was more favourable than that of non-disabled people overall, for whom self-reported prevalence (in 2011–12) was twenty-two per cent (Australian Institute of Health and Welfare, 2016b). Wallace and Schluter (2008) found low prevalence despite the sample experiencing more risks for cardiovascular disease, including being overweight and obese, lack of physical activity, socioeconomic and social disadvantage, and chronic inflammation from a number of sources.

The role of other overall health and wellbeing risk factors informed Troller and Salomon's (2015) 'Early Intervention Framework.' Building on a comprehensive review of the literature and consultation with ID and cardiometabolic experts, they reported that people with ID "*have an elevated risk of cardiometabolic disturbances due in part to high rates of psychotropic use<sup>4</sup> and psychotropic polypharmacy<sup>5</sup> that begin at an early age.*" (Troller & Salomon, 2015, p. 1). Further, people with ID have:

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<sup>4</sup> Cardiometabolic health refers to risk of diabetes and heart disease and is ascertained by measures of weight, blood glucose and cholesterol.



- “high rates of chronic inflammation”;
- “low birth weight associated with premature development of atherosclerosis”;
- “genetic syndromes that compromise arterial and/or renal vasculature structure and function leading to increased risk of hypertension, glucose or lipid dysregulation”;
- “increased likelihood of sedentary lifestyle”;
- “low socioeconomic status”; and
- “unequal access to healthcare including preventative healthcare measures” (2015, p. 1)

The Framework “advocates a holistic and multidisciplinary approach to care including positive and preventative cardiometabolic monitoring and interventions for people with an ID” (Trollor & Salomon, 2015, p. 1).

## OSTEOPOROSIS AND ARTHRITIS

### OVERVIEW

- People with ID experience more osteoporosis and arthritis than the general population.
- Sedentary lifestyles, anti-epileptics and some other conditions contribute to this higher prevalence.
- Increased physical activity and early screening have been proposed to reduce the impact of osteoporosis and arthritis.

### EVIDENCE

Osteoporosis and arthritis are more common in people with cerebral palsy, people with diabetes (Vestergaard, Rejnmark, & Mosekilde, 2005) and people with ID overall (Australian Institute of Health and Welfare, 2016a; Srikanth, Cassidy, Joiner, & Teeluckdharry, 2011; Wagemans, Fiolet, Van Der Linden, & Menheere, 1998; Zylstra, Porter, Shapiro, & Prater, 2008). Several reasons have been proposed for this. Srikanth et al. (2011) reported that people with ID can be subject to a number of risk factors: immobility, a history of falls and fractures and, most significantly, the use of anti-epileptic medications. Falls and fractures are also independently associated with the use of anti-epileptics (Wagemans & Cluitmans, 2006). Srikanth et al. (2011) advocate early screening for osteoporosis and treatment to reduce morbidity. While ageing is a factor in the development of both arthritis and osteoporosis, Wagemans et al. (1998) found that among a group of bedridden people with ID, bone mineral density was poor, despite diets adequate in calcium and vitamin D. Lack of mobility or relative immobility is an important factor (Zylstra et al., 2008). A repeated co-morbidity is being obese, overweight and inactive.

### OVERVIEW: OVERWEIGHT AND OBESITY

- Being overweight and obese is prevalent among people with ID.
- Risk of being overweight or obese increases as severity of ID decreases.
- People living in more restrictive settings are less likely to be overweight or obese.
- Women with ID are more likely to be overweight or obese.

It has been established that adults with ID are at least as likely—and may be more likely—to be obese than other adults (Australian Institute of Health and Welfare, 2016a; Hsieh et al., 2014; Melville, Hamilton, Hankey, Miller, & Boyle, 2007; Rimmer & Yamaki, 2006; Yamaki, 2005). Being overweight and obese is linked with greater risk of mortality from cardiovascular disease, asthma, and diabetes, and the associated inactivity has additional negative outcomes in the form of arthritis and osteoporosis. Overweight and obesity appear throughout the reporting of morbidities for people with ID (and see Ells et al., 2006; Wallace & Schluter,

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2008). Emerson (2005) measured body mass index and levels of exercise in 1,542 adults with ID. Many were underweight and inactive. Women, however, were more likely to be obese. People with severe or profound activity limitation are somewhat more likely (70 per cent versus 60 per cent) to be overweight and almost twice as likely to be obese as people without disability (AIHW, 2016).

Place of residence (and thus level of disability) plays a role in this. Rimmer and Yamaki's (2006) study of obesity among people with ID in the United States found that people with milder impairments and those living in less controlled environments (i.e., with family, in group houses, or independently) were more likely to be obese. This may account for the lower likelihood of obesity in people with ID reported in Moran, Drane, McDermott, Dasari, Scurry and Platt's retrospective observational study (2005). Among the 680 patients with ID and an age-matched sample of 1806 non-disabled patients from two US family practices, those with more severe ID had a much lower prevalence of obesity. Moran et al. (2005) do not distinguish between places of residence, which are a likely factor in diet and weight control. This link between greater severity of disability and reduced prevalence of overweight or obesity has been consistently reported, as Melville et al.'s literature review found (2007): people with mild to moderate ID are more likely to be obese than those with severe or profound ID. Melville et al.'s review (2007) confirmed the link between more restrictive environments and lower likelihood of overweight or obesity. It also supported the finding that gender and age are determinants of obesity: women with ID are more likely to be obese than are men with ID and people with ID become overweight or obese earlier than their non-disabled peers.

## **OVERVIEW: LACK OF PHYSICAL ACTIVITY**

- People with ID in general do too little physical activity.
- Barriers to exercise include poor planning, financial costs, poor access to transport and lack of support.

## **EVIDENCE**

Increased physical activity was identified as "*the single most effective way of improving the health of people with intellectual disabilities*" by Robertson et al. (2000, p. 469). Similarly, Wallace and Schluter (2008) posit that ensuring better nutrition and increasing physical activity are the central requirements if the health and wellbeing of people with ID is to improve.

People with ID are less likely than the general population to do sufficient physical activity (L. L. Anderson et al., 2013; Australian Institute of Health and Welfare, 2016a; Emerson, 2005; Haveman et al., 2010; Robertson et al., 2000). There are several reasons for this. Mahy et al. (2010) reported that decisions to do physical activity were often initiated by support workers rather than the person themselves. This Melbourne-based study focused on people with Down syndrome and found that where support workers were not themselves active, such initiation was less likely. The other barriers to and enablers of physical activity for people in this study were much the same as those for the general population: the presence of a social component, fun and rewards were enablers, while time constraints and financial costs were barriers. There were also specific barriers for people with Down syndrome, "*including their difficulty in planning and organising physical activity, their difficulty in understanding its benefits (such as improved health and fitness) and their difficulty in understanding the health risks associated with physical inactivity (such as obesity and cardiac disease)*" (Mahy et al., 2010, p. 802). Financial costs, difficulty accessing transport, and a lack of awareness of options for physical activity were barriers identified in Bodde and Seo's (2009) systematic review of literature about physical activity and people with ID. The attitudes of support workers or carers and the absence of pro-activity policies in programs were also significant factors influencing whether people with ID engaged in adequate exercise.



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Perhaps a more fundamental barrier is that support workers, policy-makers and professionals can lack awareness of the importance of exercise (Janicas, 2014; Wallace & Schluter, 2008). As Janicas (2014) writes, people with ID “*have the right to the best possible care, which includes exercise in [their] daily routine. This will make [the person] feel healthy and happy.*” Thus, professionals should include “*exercise into [their] clients daily routine to facilitate success including positive reinforcement, a structured daily physical regime with the input of the client will benefit their health and wellness,*” and policymakers should consider exercise to be a “*standard in implementing the necessities of life*” (2014, p. 125).

## SUMMARY

Several factors combine to affect the physical health and wellbeing of people with ID. As Anderson et al. (2013) note, they are more likely to have poorer access to good medical care, health providers may be unprepared to meet their needs, they often experience greater socio-economic hardship and they have rarely been adequately included in public health campaigns. They are also likely to be less physically active than necessary, and more likely to be taking medications whose side-effects increase the risk—or severity—of chronic illness. McVilly et al. (2014) point out that chronic illness prevalence data for people with ID is scarce, and they are too infrequently included in research that directly affects them. Janicas’s (2014) argument for greater awareness of exercise at the policy- and professional-level is thus applicable to the prevention and management of chronic illnesses overall. While some prevalence studies exist, people with ID are somewhat infrequently the subject, and are infrequently considered to be a distinct category in epidemiological statistics for chronic illnesses.

The next section of this report turns to the interventions, reported in the literature, aimed at increasing the physical health and wellbeing of people with ID.

## MEDICALLY-GUIDED APPROACHES

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### OVERVIEW

- Medically-guided approaches have shown some success in chronic illness management and prevention.
- Communication and behaviour difficulties can be barriers to access and provision of appropriate medical care.
- Most medically-guided approaches provide GPs and other clinicians with strategies and tools for assessing the health of people with ID.

### EVIDENCE

Medical and other health professionals are essential in the maintenance of the health and wellbeing of people with ID. Yet several studies have found that there is a dearth of ID-specific medical research, and that medical practitioners often lack ID-specific knowledge or training (e.g., Janicki et al., 1999) that would enable them to communicate effectively with people with ID or their support people (see, e.g., P. C. Oliver et al., 2002). Lennox and Kerr (1997) included communication difficulties, behaviours that deter caregivers from accessing health services, and physician attitudes in a list of barriers to sufficient access to appropriate care for people with ID. Oliver and colleagues (2002) call for a “*fundamental change in attitudes to health service research in ID*” (p. 340). At present, evidence-based programs for responding to health promotion, illness prevention and illness management for people with ID are somewhat scarce, though there are some notable exceptions.

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There is a further difficulty: some programs and policies do not reflect best practice. The UK's National Learning Difficulty Professional Senate (2015) argued that a lack of resources has meant that evidence-based practices have been implemented patchily. As well as this, a lack of "*appropriately funded and skilled specialist learning disability health services [can result in] failure by social care services*" (National LD Professional Senate, 2015, p. 4). Thus, people with ID are faced with inappropriate, expensive, delayed or difficult-to-access services and their healthcare needs may remain unmet. The report noted some important elements in developing and delivering healthcare to people with ID. Perhaps the most relevant was that health services need to be supported to respond appropriately to people with ID who can be fearful of medical procedures and personnel. This includes the development of 'easy read' information and training for health and social providers. Secondly, medical and other health practitioners need to understand the changing needs of people with ID as they age and as their condition progresses.

Some medical-driven self-management and preventive health programs have been trialled. A systematic review of weight-loss interventions conducted by Hamilton et al. (2007), found that while there were few reported interventions for people with ID, those that took context and the involvement of carers into account were recommended. Hamilton et al. (2007) remarked on the need for accessible (that is, accessible to people with ID) clinical weight management services.

In Romeo et al.'s (2009) 'health check' intervention, a nurse (with experience working with people with ID) reviewed individual GP records before comprehensively assessing the person's health and wellbeing using a semi-structured health assessment instrument, a physical examination and blood tests. Results were then shared with the person's GP. The nurse could also follow algorithms to determine if and when to refer a patient to other specialists and services. This intervention was found to be both inexpensive and to result in health improvements.

Lennox and colleagues developed and trialled health assessment tools for use by GPs attending people with ID (2010) and a 5-year diary (described in Lennox et al., 2004) to enhance communication between people with ID and health professionals. In this Australian work, a health review tool (called CHAP) was used to document health history prior to consultation with the GP, who was then prompted to complete a guided health assessment. The diary (called Ask) for the person with ID, included an 'about me' section, tips on preparing to visit the doctor, a 'for the doctor,' section including tips on how to work effectively with people with ID and syndrome-specific checklists, and a medical record section. People with ID were invited to complete the diary and bring it to consultations. After 12 months using CHAP, GPs' clinical records revealed that they had undertaken more preventive health and health promotion activities with the patients. The diary, on the other hand, was associated with only modest improvements in epilepsy review and constipation investigation, but was strongly supported by people with ID and their support providers. It was seen as empowering people through better communication and better-informed advocacy.

The active engagement of practitioners in health planning and service development has been advocated (Kerr (2004). They propose that clinicians (in this instance, psychiatrists) engage at the practice level and address the poor levels of health promotion uptake and the impacts of behaviours on health. Similarly, Trollor and Salomon (2015) stress the need for clinicians to "*anticipate and address barriers to care such as communication difficulties and fear of blood tests; account for socioeconomic and genetic factors altering baseline cardiometabolic risk; and carefully rationalize psychotropic prescription*" (p. 1). Specifically, clinicians are advised to adapt their practice via: "*advanced planning, communication adjustments, the process of obtaining consent, engagement with support networks and setting aside extra time for appointments*" (p. 3), . These considerations have also been proposed by Foley and Trollor (2015) for working with people with autism spectrum disorders. Focusing on cardiometabolic health, they (Trollor & Salomon, 2015) led a team that

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developed an ID-specific algorithm (the Early Intervention Framework) to support preventative cardiometabolic health. The Framework includes a suite of cardiometabolic resources for people with ID and their formal and informal carers. The resources (available via the UNSW website) are:

- Standard Cardiometabolic Targets;
- Going To The Doctor;
- Consent;
- Psychotropic Medication;
- Blood Pressure;
- Having A Blood Test;
- Diabetes;
- Healthy Lifestyle;
- Overcoming Social And Economic Disadvantage;
- Managing Challenging Behaviour; and
- Planning For Adaptations To Clinical Practice.

Despite the programs described above, people with ID are only rarely given specific attention in chronic illness prevalence and prevention studies. Existing health promotion and chronic illness self-management training and programs are only infrequently developed with people with ID in mind; adaptation of existing programs is more common. Further, clinicians can lack awareness and skills, potentially contributing to the fear with which some people with ID regard medical attention and procedures (National LD Professional Senate, 2015; Trollor & Salomon, 2015). The programs discussed above all argue for person-centred approaches, as well as for increased health professional knowledge of appropriate healthcare provision for people with ID. Existing reactive approaches miss opportunities for better prevention (Janicki et al., 1999; National LD Professional Senate, 2015) and for the reduction in the chronic illness burden for people with ID.

## PEER-LED OR PEER-INVOLVED APPROACHES

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### OVERVIEW

- Peer-led and peer-involved approaches are consistent with person-centred support and active support and support autonomy.
- There is some evidence that such approaches increase the amount of self-management people with ID undertake.
- Peer-involved approaches have been shown to increase participants' sense of autonomy or self-determination (a domain of QoL).
- Peer-involved approaches require the active and knowledgeable engagement of support workers. This is not always present.
- Support workers have expressed concern that supporting self-management can veer into 'policing,' a role with which they are uncomfortable.

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## EVIDENCE

Autonomy is a goal for many people with ID. Peer-led or peer-involved processes support such autonomy, which can extend to taking an active role in illness prevention and in self-management of chronic conditions, including diabetes and asthma. McVilly et al. (2014) noted that self-management is an area where people with ID have received less attention than the rates at which they experience such conditions might warrant.

'Expert Patient' programmes (EPP) are "*grounded in principles of empowerment and inclusion*" (Wilson and Goodman, 2011, p. 311) and are run by and for people with chronic illness. Wilson and Goodman (2011) evaluated the adaptation of EPP for people with ID. At eight, weekly sessions, people set goals "*they are confident about achieving*" (p. 311). In Wilson and Goodman's (2011) work, EPP was modified by extending the length of the program (from its usual six weeks), delivering ID-specific training to the course's lay tutors (all of whom had a chronic illness but not ID) and developing a manual and DVD (using actors with ID) to support tutors in delivering EPP to people with ID. Participants' social engagement was enhanced by the program and behaviour change was reported. The authors argue that such education strategies can increase self-management skills and reduce inequalities for people with ID through information, training and support. More recently, Taggart and colleagues' (2015) have developed a self-management education program for people with ID and Type 2 diabetes. This is yet to be evaluated.

A similar autonomy-building approach was used by Lynnes, Nichols and Temple (2009) in a strength and aerobic exercise program for adults with intellectual disability. The participants were four competitors in the Special Olympics. While initial training was gained in a face-to-face sessions with coaches (in familiar settings), participants then had only minimal support at home for practice. Individualised support was also provided by telephone and the participants followed individualised plans. All followed the program at home and three of those involved increased their exercise frequency threefold.

Peer-to-peer programs also show some benefits. One potentially effective program is the Community Learning Disabilities Health Teams (UK. See, for example, Bristol Community Health's Community Learning Disabilities Team). These Teams include both medical and allied health professionals, and—in some situations—people with learning disabilities (ID) who are trained to provide peer-to-peer health information and support. Community Disability Learning Teams have been operating in the UK since the 1980s (see Slevin, Truesdale-Kennedy, McConkey, Barr, & Taggart, 2008, for a review of literature related to the program), with case management being a key role.

The drive for independence and autonomy, fostered by initiatives in which people with ID take leadership and mentoring roles, was an important element in the development of successful self-management strategies for people with ID in Whitehead et al.'s (2016) investigation of how autonomy operates for people with ID who have diabetes. Their interview study showed that participants and support workers negotiated autonomy in the management of diabetes and that this negotiation was repeated when changes occurred, always with the goal of increasing autonomy for the person with ID and diabetes. Whitehead et al. (2016) restate the need for people with ID to be supported to develop decision making skills, and for opportunities to be provided for supporting this skill.

Diabetes self-management relies on knowledge and understanding of the condition. In an earlier study involving Whitehead and colleagues (Hale, Trip, Whitehead, & Conder, 2011), 14 adults with ID and diabetes were interviewed (Type 1, or Type 2) (along with their nominated key informants). All were self-managing to some extent, and all had some understanding of how diet, blood glucose and exercise could affect the condition. While knowledge levels varied, all benefited from the support of other people, including support to exercise. The findings also reinforced the need for peer-led education and accessible resources. Another

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study by some of these researchers (Trip, Conder, Hale, & Whitehead, 2015) examined how key workers supported the diabetes self-management of people with ID. One concern expressed by the workers was that in supporting of the self-management of diabetes, they could become 'lifestyle police.' They were sometimes unsure as to "*where their responsibility lay in regard to the management of the person's diabetes and the potential impact on the therapeutic relationship if they needed to be directive about this*" (p. 3). This points to a challenge in delivering support more broadly: how to balance duty of care with enabling independence and autonomy. Separately, the key workers "experienced frustration in their role regarding monitoring dietary intake, expectations, information access for themselves, the individual and the wider network of support," and identified the need for more training. Some felt they lacked sufficient knowledge to progress the self-management goals of the people they support. Trip et al. (2015) argue that this need for greater knowledge should be addressed by provider organisations, and that training needs to include both support workers and the person with ID and diabetes. They also recommend approaches that focus on possibilities rather than limits or deficits.

Peer-to-peer mentoring was a key element in the Bazzano and colleagues' (2009) 'Healthy Lifestyle Change Program.' The intervention aimed to increase the "*knowledge, skills, and self-efficacy regarding health, nutrition, and fitness*" (p. S201) of participants with ID. It featured peer-to-peer mentoring (11 adults with ID), interactive health education, supervised physical activity, behavioural modification, one-on-one health management education and advocacy, clinical support and a supportive social network (p. S203). The peer mentors were given training to support their leadership, teaching and mentoring roles and were responsible for leading physical activity sessions, keeping participants engaged, modelling healthy behaviours and effective interactions with health professionals and preparing healthy snacks. They were also part of facilitating reviews and evaluations and presented results at meetings and conferences. Participants completed a seven-month, twice-weekly education and exercise program. Two-thirds of participants with ID (n = 44 completing the 7-month intervention) lost or maintained weight, increased physical activity, and the duration of exercise also increased. There were also benefits in nutrition and healthcare access. Bazzano et al. (2009) suggest that key factors in these successes were that decision making was thoroughly collaborative, and that peer mentors had a strong sense of ownership of the project. Peer mentors were also effective in supporting participants' lifestyle changes. Support workers played a sometimes counter-productive role. In some instances, "*participants did not have control over food choices, as some clients reported that support staff accompanied them to fast food restaurants (even following the class) and prepared calorie-dense foods*" (p. S207) for residents.

Support staff are an essential part of successful interventions to increase physical health and wellbeing of people with ID. Mahy et al. (2010), for instance, argued that support people need to be educated about the importance of physical activity. Increasing their own activity levels made support workers more effective in supporting such change in residents. Thus, several projects have included both residents and staff. A recent Swedish project aiming to improve the diet and physical activity of people with ID living in the community, addressed the diet and physical activity needs of both residents and staff (the details and results of this intervention are reported in Bergström, Hagströmer, Hagberg, & Elinder, 2013; Bergström & Wihlman, 2011; Elinder, Bergström, Hagberg, Wihlman, & Hagströmer, 2010). The intervention consists of health education sessions for people with ID living in community residences, the appointment of a staff member in each residence as a health ambassador (who attends network meetings with ambassadors from other houses), and a staff study circle in each residence. The intervention takes between 12 and 15 months to complete. Evaluation of the intervention showed that physical activity increased and waist circumference measures reduced (slightly), though no change was found for body mass index (BMI), dietary quality or life satisfaction. In a follow-up exploration of managers' perceptions of the intervention, Wahlström, Bergström and Marttila

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(2014) found that external resources (including levels of support in the welfare system for people with ID) and group home-specific resources affected residents' health. Strengthening those external resources enabled residents' own internal resources to be increased. The presence of all such resources increased residents' "*sense of security and ultimately their health*" (p. 122). Group home specific resources included routines that were reliable but flexible, cooperative relationships with other staff and with external services, and observant and knowledgeable staff who were able to motivate residents and who were respectful. Among residents, access to a social life both within and outside the residence was an important factor, as was the opportunity for self-determination.

Workers' capacity to adequately support people with other chronic conditions—specifically people who are prescribed psychotropic medications—was investigated by Donley et al. (2012). They found that, here, too, workers' knowledge is a factor in efforts to reduce the use of psychotropic medication. This is important, since these drugs have serious and long term side effects. While workers and their supervisors may have a reasonable level of knowledge, the disability support workers in Donley et al.'s (2012) study wanted to know more than they did in order to reduce their use of psychotropics, to use them safely when needed, and to be able to have informed conversations with GPs or other health professionals. When Lennox and colleagues (van Dooren, Taylor-Gomez, Lennox, Dean, & Boyle, in press, 2015) interviewed support workers about the assessment tools for GPs discussed earlier (Lennox et al., 2010), they found that the workers' role in the projects' interactions between people with ID and their GPs both increased their own knowledge and capacity for advocacy. This role was, however, demanding. Concern with knowledge and capacity of support workers to support self-management of chronic illness echoes the findings that medical professionals may lack the knowledge and training to provide appropriate health care to people with ID, reported earlier. Van Doreen et al. (2015) argue that organisations, too, need to enable support workers by allocating "*sufficient time, resources and training to the task*" (p. 1). Where the load is too great, turnover can result in loss and discontinuity of the health history for people with ID.

The foregoing suggests that effective prevention and management approaches need to combine the following elements:

1. Accessible resources
2. Actively engaged and knowledgeable support workers/caregivers
3. Clinicians trained and resourced to provide appropriate health promotion, prevention and management
4. Peer-to-peer mentoring, engagement and support



# BEHAVIOURAL AND HEALTH PROMOTION APPROACHES

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## OVERVIEW

- Approaches that use goal-setting—for example, those using Implementation Intention strategies—have shown efficacy.
- Engagement in health-promoting behaviours is boosted by support from others, perceptions of the behaviour as fun or interesting, and the behaviour being routine and familiar. Medical and physiological problems can reduce engagement.
- There is recent evidence that self-identity (as a physically competent) is important for the adoption or maintenance of behaviours that support physical health and wellbeing.

## EVIDENCE

Motivation to increase beneficial behaviours is a challenge for most people, whether experiencing disability or not. Some behavioural approaches have demonstrated efficacy.

The Theory of Planned Behaviour (Ajzen, 1991) (a development from the Theory of Reasoned Action) proposes that behaviour is influenced by what the person believes about the behaviour (attitude toward behaviour), what they think their peers believe about it (subjective norms), and the effects of any barriers they perceive to adoption of the behaviour (perceived behavioural control). It was used by Mahy et al. (2010) to understand the results of their study of facilitators of and barriers to physical activity in people with Down syndrome. Analysis of participants' interviews revealed three facilitators:

- support from others;
- physical activity as fun or interesting; and
- routine and familiarity (p. 795).

Barriers were:

- lack of support;
- no desire to take part in physical activity; and
- medical and physiological factors (p. 795).

According to the Theory of Planned Behaviour:

⋮ *people are more likely to intend to engage in physical activity if they have a positive attitude, if they perceive social support to participate (subjective norm), [and] if they believe they will be successful and are motivated to engage in the activity (perceived behavioural control). (p. 802)*

The people with Down syndrome in Mahy et al.'s study had negative views of formal exercise but enjoyed social activities that included a physical activity component. Further, activities that the participants had mastered were more appealing (the perceived behavioural control component).

Mahy et al. (2010) also applied Social-Cognitive Theory to explain attitudes to physical activity among their study participants. Here, people are understood to gain new knowledge—and adopt new practices—by observing others in social contexts. This supports the evidence cited earlier that when support workers and people with ID participated together, the activity was more likely to be sustained. Modelling of intended behaviours influences others to adopt that behaviour. Finally, Mahy et al. (2010) interpreted their data using the Model of Human Occupation, in which the capacity to perform an action is a factor in its uptake. This is relevant since some people with ID have difficulty learning and applying information. For instance, the people

with Down syndrome in Mahy' et al.'s study "did not identify that a support person was required to initiate physical activity" (2010, p. 803), despite most being unable to use public transport independently.

Implementation Intention (Gollwitzer, 1999) has also been used to examine (and drive) the adoption of healthy diets (among non-disabled adults) (e.g., Luszczynska, Abraham, & Sobczyk, 2007) and increase physical activity. Adriaanse et al. (2011) conducted a systematic review of the literature on diet and implementation intention, and found that implementation intention was indeed effective in increasing consumption of beneficial foods (though not for decreasing unhealthy food intake). Implementation Intention links goals with actions. In Implementation Intention, the person sets out a goal, as well as a time, place and action towards meeting the goal. Thus, a goal of 'increase physical activity' may be linked with an action to 'run more' and a trigger: 'If it is six o'clock, and it is not raining, I will run,' or, 'If I am in the kitchen, and I am waiting for the kettle to boil, I will do six stretches.' (See below for an example chart.)

GOAL	ACTION	TRIGGER
<b>INCREASE PHYSICAL ACTIVITY</b>	Run more	If it is six o'clock (and it is not raining) I will run
	Stretch more	If I am in the kitchen, waiting for the kettle to boil, I will do six stretches

In the first example, six o'clock becomes a cue for the intention; in the second, being in the kitchen waiting for the kettle to boil cues the action. Implementation Intention is perhaps particularly relevant in models of support that use goal-setting.

Finally, there is new evidence that self-perception plays a major role in people's adoption of health-promoting behaviours. Professor Helen Berry presented a paper at the 2016 International Conference on Social Identity,<sup>5</sup> reporting on the correlation between an individual's sense of themselves as physically competent, and actions that were conducive to physical health and wellbeing. That is, those people with a sense of themselves as physically competent were more likely to be physically active and eat a beneficial diet. This work has not yet been published. Earlier work with adolescents (C. B. Anderson, Mâsse, Zhang, Coleman, & Chang, 2009) compared the results of an 'Athletic Identity Questionnaire' with levels of moderate-to-vigorous physical activity and organised sport team participation. Those adolescents who rated themselves highly on athletic appearance, competence, the importance of physical activity and sports, and on receiving encouragement for activity from parents, teachers, and friends, were also more likely to be physically active and engage in team sports. They write that the results:

... imply that the combination of multiple positive self-views and perceptions of encouragement, even if some individual component contributions are small, will have a positive impact on activity, and that this occurs regardless of a child/adolescent's weight, minority status, or gender. (p. 223)

This research suggests that how people with ID perceive themselves is an important factor in their exercise and diet behaviours. Peers, support workers, case managers, administrators, clinicians and other members of a person with ID's team, along with staff and users of sporting and other facilities and members of the wider community, have a clear role in supporting the person to see themselves as physically competent. This

<sup>5</sup> Held in Brisbane. Journal publication pending. In conversation with Professor Berry, she agreed that the model was applicable to people with ID and other people in marginalised groups.



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responsibility might begin with the person's immediate circle, but extending that scope is important if the physical health and wellbeing of people with ID is to be improved.

## CONCLUSIONS

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Around three percent of Australians have an intellectual disability. The most common single cause is Down syndrome, with other specific causes including autism spectrum disorders, cerebral palsy and Fragile X syndrome. There are also numerous less well-defined causes of intellectual disability. Socio-economic disadvantage is associated with higher rates of disability, as well as with poorer access to appropriate supports, beneficial lifestyle opportunities and appropriate health care.

Regardless of socioeconomic status, people with intellectual disability (ID) have been found to be less satisfied with their health and experience more chronic illness than the general population. This applies to physical conditions (diabetes, cardiovascular disease, asthma and respiratory illnesses and conditions affecting the bones and joints—osteoporosis, arthritis) and to mental illnesses and results in lower life-expectancy. While life expectancy overall for people with ID has been increasing, it is still much lower for people with more severe disability. As is the case for the general population, cardiovascular disease, respiratory disease and cancers are the most prevalent causes of death. Exact prevalence data for these and other conditions among people with ID remain unclear. This is partly because epidemiological studies haven't identified this sub-population and partly because diagnosis is not always accurate.

Mental illness and conditions linked with poor nutrition and a lack of physical activity are most prominent among people with ID. Further, there are links between mental illness, which has high prevalence among people with ID, the medications they are often prescribed, and several other morbidities such that diabetes, asthma and other respiratory conditions, osteoporosis, and lack of exercise (among other things) are all worse when psychotropic and/or antiepileptic medications are being taken. Most prominent in the data is the recurring presence of being overweight, obese and inactive. All are more common among people with ID and all are associated with poorer health outcomes.

As Anderson et al. (2013) summarised, people with ID are more likely to have poorer access to good medical care, health providers may be unprepared to meet their needs, they often experience greater socio-economic hardship and they have rarely been adequately included in public health campaigns. They are also likely to be less physically active than necessary, and more likely to be taking medications whose side-effects increase the risk or severity of chronic illness. Janicas's (2014) call for greater awareness of exercise at the policy- and professional-level is important for the prevention and management of chronic illnesses overall.

Responses to the poorer health and wellbeing of people with ID may be medically- or peer-guided. Both approaches have shown efficacy. Medical approaches have been demonstrated to increase clinicians' capacity to assess the health of people with ID and support chronic illness management and prevention. Approaches that train the person with ID in particular self-management or exercise programs have been effective. Where peers or peers and support workers are involved in supporting self-management, success appears more likely. In these models, autonomy and self-determination are bolstered, with benefits for quality of life. This approach also fits with the behavioural evidence that engagement in health-promoting behaviours is boosted by support from others, perceptions of the behaviour as fun or interesting, and the behaviour being routine and familiar.

It is also congruent with the recent evidence that self-identity (as physically competent) is important for the adoption or maintenance of behaviours that support physical health and wellbeing. Where one is part of a

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group of like-people, all of whom are engaging in health-promoting activities or behaviours and who can support one another, identity as competent is likely to be shored up.

A final, but very significant, proviso is that those working with people with ID have a central role in the prevention and management of chronic illnesses. Support workers and informal carers have a role in modelling healthy behaviours and in supporting people with ID to access appropriate medical care. They need to know their clients, as well as having some understanding of the health conditions that their clients experience. The literature makes clear that support workers may have too little knowledge to adequately support people with ID to self-manage illnesses, they may be unprepared (or lack time or encouragement) to facilitate adequate physical activity by the people they support, and they may lack the skills needed to reduce the use of psychotropic medications that can compromise other health-promoting activities. Support workers need, in turn, the support of organisations to make time and provide tools for adequate exercise and appropriate nutrition.

## RECOMMENDATIONS

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Two actions are recommended as a result of this research:

1. A research-focused intervention using the resources developed<sup>6</sup> in a peer-mentor/train-the-trainer model.
2. Piloting of a specialised Community Disability Nurse position.

### 1. AN INTERVENTION RESEARCH PROJECT

**Aim:** To increase the adoption of behaviours that maintain or increase the physical health and wellbeing of people with ID living in supported accommodation. A staff wellness program would be included as part of the intervention.

#### **Desired outcomes (see Appendix for details of outcomes measures):**

- increased physical activity (by people with ID and DSWs),
- improved diet,
- reduced smoking and alcohol use,
- increased participation in social and recreational activities (as desired),
- increased self-determination and Quality of Life, and
- increased use of ‘motivational interviewing’<sup>7</sup> by DSWs to support participants to respond to their own physical health and wellbeing needs.

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<sup>6</sup> Principles identified in the report informed the development of two linked resources—one for people with ID and the other for DSWs. Making lifestyle choices for physical health and wellbeing, and Encouraging lifestyle choices for physical health and wellbeing are intended to be used collaboratively by people with ID and DSWs to inform and support lifestyle choices to maintain and increase physical health and wellbeing.

<sup>7</sup> “Motivational interviewing is a counselling method that involves enhancing a [person’s] motivation to change by means of four guiding principles, represented by the acronym RULE: Resist the righting reflex; Understand the [person’s] own motivations; Listen with empathy; and Empower the [person]” (Hall, Gibbie & Lubman, 2012, p. 660).

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**Design:** The research-based intervention involves the facilitator teams training the staff and residents of each house. To do this they will introduce and evaluate the Making lifestyle choices for physical health and wellbeing and Encouraging lifestyle choices for physical health and wellbeing resources. These resources will be complemented by an at-home toolkit comprising activity cards, recipe cards and planning templates for individuals.

**Participants:**

- People with ID living in eight different shared houses (each managed by a different disability service organisation) and the DSW staff associated with the house.
- Facilitator teams comprising one peer-facilitator and one support worker (between one and three teams depending on the locations of participating houses).
- Research team—researcher (overseeing design, intervention, analysis, evaluation and reporting), all members of the facilitator teams, and a facilitator coach from Speak Out Association.<sup>8</sup> All members of the research team would contribute to research design, analysis and evaluation, and reporting.

**Outcome measures:**

Outcome measures will be determined by the nature of the research project. Ideally, resourcing would be made available to fund a research model including a wait-list control group.<sup>9</sup> Indicative measures could include baseline (pre-intervention) and post-intervention data based on:

- observation,
- use of the NDS Social Impact Measurement Tool, and
- focus groups from training sessions and ongoing consultation with participants.

See the Appendix for further details of outcomes measures.

## **2. CREATE A SPECIALISED COMMUNITY DISABILITY NURSE ROLE**

**Aim:** To support people with ID to be informed about and manage their health, and to facilitate two-way informed engagement with mainstream health services

**Design:** Devise and create a specialist community disability nursing role to operate in community settings across Tasmania. The role would be similar to a mental health nurse practitioner but with an alternative focus

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<sup>8</sup> Speak Out Association is a membership advocacy organisation for people with ID. They provide expert services in coaching for peer-facilitators.

<sup>9</sup> This model would see two groups of shared supported accommodation residents and workers undergo the health risk assessment at the outset and end of the project. The intervention would commence immediately in one group, and after a period (six months) in the other, 'wait-list' control group. At the end of the six months, the resources, with the addition of any materials or practices developed by participants in the intervention group, would be provided to the control group.

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on ID.<sup>10</sup> This role would complement and support the principles of the DHHS Disability Services Medication Management Framework. The nurse would provide holistic service including case management, consumer education, referrals to and education of GPs and specialists, liaison with residential disability service providers, and advocating for mainstream provision of appropriate services.

The role would have specialised skills and knowledge in the following areas:

- Well-developed skills to communicate with people who employ a breadth of communication strategies.
- In-depth understanding of the conditions experienced by people with ID.
- In-depth understanding of the medications used to treat conditions that are prevalent among people with ID.
- In-depth understanding of mental health co-morbidities.

A 5-year trial of the specialist community disability nursing role, commencing before January, 2018, should be established in consultation with people with ID. An initial pilot should be funded by PHN or DHHS in Tasmania. The position's long-term funding could devolve to individual NDIS packages.

**Outcomes:** The perceived benefits of the role would be better health outcomes for people with ID across a range of measures, and cost savings in terms of hospitalisations and visits to medical practitioners by people with ID.

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<sup>10</sup> “A nurse practitioner is a registered nurse educated and authorised to function autonomously and collaboratively in an advanced and extended clinical role. The nurse practitioner role includes assessment and management of clients using nursing knowledge and skills and may include but is not limited to the direct referral of patients to other health care professionals, prescribing medications and ordering diagnostic investigations. The nurse practitioner role is grounded in the nursing profession's values, knowledge, theories and practice and provides innovative and flexible health care delivery that complements other health care providers...” (Australian Nursing and Midwifery Council (2006). Nurse practitioner competency standards (1st edition). Canberra: ANMC).

## Appendix: Measures, deliverables and milestones

### Recommendation 1

**Table 1. Outcome measures**

<b>Instrument/measure</b>	<b>Evidence of ...</b>
Health literacy assessment (PHT tool)	Health literacy
Chronic disease risk assessment (PHT tool)	Chronic disease risk
Short, qualitative interview	Views of self and of diet and exercise
Self-report smoking and alcohol consumption	Smoking and alcohol use
Frequency of access to GPs or other health professionals	Reduced anxiety around health procedures
Frequency of use of gymnasias, and/or of involvement in team sports and other recreational activities	Participation and/or engagement in physical activity
Household chore rosters	Participation and/or engagement in physical activity
Self-report of physical activity	Participation and/or engagement in physical activity
Household entertainment and recreation expenditure docket/accounts	Participation and/or engagement in physical activity
Household grocery and food expenditure docket/accounts	Diet (whole of household and, where possible, individual)
Observation of 'motivational interviewing' and active support language and principles in use	Appropriate communication
(evidence of) Appointments/consultation with exercise physiologists, accredited practising dietitians, or other relevant practitioners	Engagement of specialists in changing lifestyle factors
Schallock et al.'s (2004) Quality of Life measure/Social Impact Measurement Tool (NDS)	Quality of Life, including self-determination

**Table 2: Timing of measures**

<b>Time</b>	<b>Month 1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>
Intervention group	All measures completed by all participants	Consultation: identify strengths and weaknesses – what is and is not working, and to report case studies or alterations	Consultation	Consultation	Consultation	Consultation	All measures completed by all participants
	Commence collection of accounts and rosters	Continual collection of appointment, account and roster data	Continual collection of appointment, account and roster data	Continual collection of appointment, account and roster data	Continual collection of appointment, account and roster data	Continual collection of appointment, account and roster data	Final collection of appointment, account and roster data

**Table 3: Deliverables and milestones**

<b>Phase 1— Background research</b>	<b>Stage</b>	<b>Activity</b>	<b>By</b>
		Consult with: <ul style="list-style-type: none"> <li>• specialists identified by Primary Health Tasmania (PHT) to identify content for the learning resources</li> <li>• people with disability through a forum facilitated by SpeakOut Advocacy to seek feedback on the format and content of the learning resources</li> <li>• representatives of the DSP workforce to seek feedback on the format and content of the learning resources</li> </ul>	Completed
		Develop a learning resource for use by people with disability written in Easy English	Completed
		Develop a learning resource for use by DSPs written in Plain English	Completed
		Undertake research to inform the development of the intervention program to be implemented in phase 2. Produce a summary report of documented programs with a similar goal.	Completed
<b>Phase 2— Intervention</b>		Seek and gain ethical approval for the project from the Tasmanian Social Sciences Human Research Ethics Committee (SS HREC). <sup>11</sup> Stages 5 and following would include the involvement of researcher/ research team.	3 months prior to recruitment
		Seek agreement from eight disability service providers to invite the residents and workers from at least one of the houses they service to participate in the project	After ethical approval has been gained
		Formally recruit participants, including gaining consent (researcher, working with SpeakOut Advocacy and relevant bodies)	(up to 1 month)
		Consult with: <ul style="list-style-type: none"> <li>• people with disability participating in the project as well as any family, friends or carers they wish to invite, to refine the proposed method through forums facilitated by SpeakOut Advocacy</li> <li>• representatives of the disability service workforce participating in the project to refine the proposed method</li> </ul>	1 month before launch of intervention
		Develop a facilitator guide with overview of model and resource list (researcher in consultation with SpeakOut Advocacy and other relevant stakeholders/ experts)	By launch of intervention
		Develop 'at-home toolkit' resources for diet and physical activity, based on resources and research report (researcher in consultation with SpeakOut Advocacy and other relevant stakeholders/ experts)	By launch of intervention

<sup>11</sup> See <http://www.utas.edu.au/research-admin/research-integrity-and-ethics-unit-rieu/human-ethics/human-research-ethics-review-process/social-sciences-hrec>

	Source and coach, in collaboration with SpeakOut Advocacy, at least one person with disability, and their DSP(s) to conduct peer-facilitated sessions at stage 14	By launch of intervention
	Enable opportunity for PHT to engage with the DSPs and residents in each house to conduct a health literacy assessment and a chronic disease risk assessment (mediated by SpeakOut Advocacy and researcher)	Start of intervention (Month 1)
	Conduct eight training sessions with DSPs using the learning resource from phase 1  This approach may be modified as a result of research conducted during phase 1 and consultation during stage 8	2 sessions (Month 1), 1 session (monthly for 6 months)
	Conduct two training sessions at each residence with the people who live there and their support work team, adopting a peer facilitation methodology (in collaboration with SpeakOut Advocacy) and using resources developed in phase 1 and stages 9 and 10  This approach may be modified as a result of research conducted during phase 1 and consultation during stage 8	Month 2
	Develop up to 30 minutes of video material for use in future training to be shot during implementation of intervention  This approach may be modified as a result of research conducted during phase 1 and consultation during stage 8	
	Repeat all measures for all participants and implement intervention in wait control houses	Month 7
<b>Phase 3— Analysis and reporting</b>	Analysis of data (researchers + PHT), and reporting to participants	Months 8-10
	Reporting results in academic, peer-reviewed publications/conferences and industry forums	Post month 10



# REFERENCES

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- Adriaanse, M. A., Vinkers, C. D. W., De Ridder, D. T. D., Hox, J. J., & De Wit, J. B. F. (2011). Do implementation intentions help to eat a healthy diet? A systematic review and meta-analysis of the empirical evidence. *Appetite*, 56(1), 183-193. doi:<http://dx.doi.org/10.1016/j.appet.2010.10.012>
- Ajzen, I. (1991). The theory of planned behavior. *Organizational, Behavior and Human Decision Processes*, 50, 179-211.
- Anderson, C. B., Mâsse, L. C., Zhang, H., Coleman, K. J., & Chang, S. (2009). Research article: Contribution of athletic identity to child and adolescent physical activity. *American Journal of Preventive Medicine*, 37, 220-226. doi:10.1016/j.amepre.2009.05.017
- Anderson, L. L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. (2013). The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 51(5), 385-398. doi:10.1352/1934-9556-51.5.385
- Australian Bureau of Statistics. (2011). 4704.0 - The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples, Oct 2010. Retrieved from abs.gov.au website: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/lookup/4704.0Chapter510Oct+2010>
- Australian Bureau of Statistics. (2014a). 4428.0 - Autism in Australia, 2012. Retrieved from abs.gov.au website: <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features72012?opendocument&tabname=Summary&prodno=4428.0&issue=2012&num=&view=>
- Australian Bureau of Statistics. (2014b). 4433.0.55.003 - Intellectual disability, Australia, 2012. Retrieved from abs.gov.au website: <http://www.abs.gov.au/ausstats%5Cabs@.nsf/0/437CAC7624D4150CCA257D0400129092?Opendocument>
- Australian Bureau of Statistics. (2015). 4364.0.55.001 - National Health Survey: First Results, 2014-15. Retrieved from Australian Bureau of Statistics website: <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4364.0.55.001~2014-15~Main%20Features~Smoking~24>
- Australian Cerebral Palsy Register. (2013). Report of the Australian Cerebral Palsy Register, Birth Years 1993-2006.
- Australian Institute of Health and Welfare. (2008) Disability in Australia: Intellectual disability. Vol. Bulletin 67. Canberra, ACT: AIHW.
- Australian Institute of Health and Welfare. (2016a). Health status and risk factors of Australians with disability 2007–08 and 2011–12 Retrieved from Australian Institute of Health and Welfare website: [www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129554509](http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129554509)
- Australian Institute of Health and Welfare. (2016b). How many Australians have cardiovascular disease? Risk factors, diseases & death. Retrieved from Australian Institute of Health and Welfare website: <http://www.aihw.gov.au/cardiovascular-disease/prevalence/>
- Bazzano, A. T., Zeldin, A. S., Diab, I. R. S., Garro, N. M., Allevato, N. A., & Lehrer, D. (2009). The Healthy Lifestyle Change Program: A pilot of a community-based health promotion intervention for adults with developmental disabilities. *American Journal of Preventive Medicine*, 37(6, Supplement 1), S201-S208. doi:<http://dx.doi.org/10.1016/j.amepre.2009.08.005>

- 
- Bergström, H., Hagströmer, M., Hagberg, J., & Elinder, L. S. (2013). A multi-component universal intervention to improve diet and physical activity among adults with intellectual disabilities in community residences: A cluster randomised controlled trial. *Research in Developmental Disabilities, 34*(11), 3847-3857. doi:<http://dx.doi.org/10.1016/j.ridd.2013.07.019>
- Bergström, H., & Wihlman, U. (2011). The role of staff in health promotion in community residences for people with intellectual disabilities: Variation in views among managers and caregivers. *Journal of Intellectual Disabilities, 15*(3), 167-176. doi:[10.1177/1744629511424833](https://doi.org/10.1177/1744629511424833)
- Bigby, C., Knox, M., Beadle Brown, J., & Bould, E. (2014). Identifying good group homes: Qualitative indicators using a Quality of Life framework. *Intellectual and Developmental Disabilities, 52*(5), 348-366. doi:[10.1352/1934-9556-52.5.348](https://doi.org/10.1352/1934-9556-52.5.348)
- Bittles, A. H., & Glasson, E. J. (2004). Clinical, social, and ethical implications of changing life expectancy in Down syndrome. *Developmental Medicine & Child Neurology, 46*(4), 282-286. doi:[10.1111/j.1469-8749.2004.tb00483.x](https://doi.org/10.1111/j.1469-8749.2004.tb00483.x)
- Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., & Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 57*(7), M470-M472. doi:[10.1093/gerona/57.7.M470](https://doi.org/10.1093/gerona/57.7.M470)
- Bodde, A. E., & Seo, D.-C. (2009). A review of social and environmental barriers to physical activity for adults with intellectual disabilities. *Disability and Health Journal, 2*(2), 57-66. doi:<http://dx.doi.org/10.1016/j.dhjo.2008.11.004>
- Brown, L. (2010). The Prevalence of Fragile X Associated Disorders in Australia. Retrieved from Canberra, ACT:
- Buse, J. B., Cavazzoni, P., Hornbuckle, K., Hutchins, D., Breier, A., & Jovanovic, L. (2003). A retrospective cohort study of diabetes mellitus and antipsychotic treatment in the United States. *Journal of Clinical Epidemiology, 56*(2), 164-170.
- Cameron, A. J., Zimmet, P. Z., Dunstan, D. W., Dalton, M., Shaw, J. E., Welborn, T. A., . . . Jolley, D. (2003). Overweight and obesity in Australia: the 1999–2000 Australian Diabetes, Obesity and Lifestyle Study (AusDiab). *The Medical Journal of Australia, 178*(9), 427-432.
- Claes, C., Hove, G., Loon, J., Vandeveld, S., & Schalock, R. (2010). Quality of Life measurement in the field of intellectual disabilities: Eight principles for assessing Quality of Life-related personal outcomes. *Social Indicators Research, 98*(1), 61.
- Cooper, S.-A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: Population-based cross-sectional analysis. *BMC Family Practice, 16*(1), 1.
- Davis, S. R., Durvasula, S., Merhi, D., Young, P. M., Traini, D., & Bosnic-Anticevich, S. Z. (2014). Respiratory medication use in an Australian developmental disability clinic population: messages for health care professionals. *Australian Journal of Primary Health, 20*(3), 278-284.
- Deb, S., Thomas, M., & Bright, C. (2001a). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research, 45*(6), 495-505. doi:[10.1046/j.1365-2788.2001.00374.x](https://doi.org/10.1046/j.1365-2788.2001.00374.x)

- 
- Deb, S., Thomas, M., & Bright, C. (2001b). Mental disorder in adults with intellectual disability. 2: The rate of behaviour disorders among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6), 506-514. doi:10.1046/j.1365-2788.2001.00373.x
- Donley, M., Chan, J., & Webber, L. (2012). Disability support workers' knowledge and education needs about psychotropic medication. *British Journal of Learning Disabilities*, 40(4), 286-291. doi:10.1111/j.1468-3156.2011.00707.x
- Elinder, L. S., Bergström, H., Hagberg, J., Wihlman, U., & Hagströmer, M. (2010). Promoting a healthy diet and physical activity in adults with intellectual disabilities living in community residences: Design and evaluation of a cluster-randomized intervention. *BMC Public Health*, 10(1), 1-7. doi:10.1186/1471-2458-10-761
- Ells, L. J., Lang, R., Shield, J. P. H., Wilkinson, J. R., Lidstone, J. S. M., Coulton, S., & Summerbell, C. D. (2006). Obesity and disability – a short review. *Obesity Reviews*, 7(4), 341-345. doi:10.1111/j.1467-789X.2006.00233.x
- Emerson, E. (2005). Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *J Intellect Disabil Res*, 49. doi:10.1111/j.1365-2788.2004.00617.x
- Emerson, E. (2012). Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. *Journal of Epidemiology and Community Health*, 66(3), 218-224. doi:10.1136/jech.2010.111773
- Evans, K. M., Cotton, M. M., Einfeld, S. L., & Florio, T. (1999). Assessment of depression in adults with severe or profound intellectual disability. *Journal of Intellectual and Developmental Disability*, 24(2), 147-160. doi:10.1080/13668259900033941
- Foley, K.-R., & Trollor, J. (2015). Management of mental ill health in people with autism spectrum disorder. *Australian Family Physician*, 44(11).
- Gale, L., Naqvi, H., & Russ, L. (2009). Asthma, smoking and BMI in adults with intellectual disabilities: A community-based survey. *Journal of Intellectual Disability Research*, 53(9), 787-796. doi:10.1111/j.1365-2788.2009.01192.x
- Glasson, E. J., Sullivan, S. G., Hussain, R., & Bittles, A. H. (2005). An assessment of intellectual disability among Aboriginal Australians. *Journal of Intellectual Disability Research*, 49(8), 626-634. doi:10.1111/j.1365-2788.2005.00722.x
- Gollwitzer, P. M. (1999). Implementation intentions: Strong effects of simple plans. *American Psychologist*, 54(7), 493-503.
- Hale, L. A., Trip, H. T., Whitehead, L., & Conder, J. (2011). Self-management abilities of diabetes in people with an intellectual disability living in New Zealand. *Journal of Policy and Practice in Intellectual Disabilities*, 8(4), 223-230. doi:10.1111/j.1741-1130.2011.00314.x
- Hamilton, S., Hankey, C. R., Miller, S., Boyle, S., & Melville, C. A. (2007). A review of weight loss interventions for adults with intellectual disabilities. *Obesity Reviews*, 8(4), 339-345. doi:10.1111/j.1467-789X.2006.00307.x
- Haveman, M., Heller, T., Lee, L., Maaskant, M., Shoostari, S., & Strydom, A. (2010). Major health risks in aging persons with intellectual disabilities: An overview of recent studies. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 59-69. doi:10.1111/j.1741-1130.2010.00248.x

- 
- Hensel, E., Rose, J., Kroese, B. S., & Banks-Smith, J. (2002). Subjective judgements of quality of life: A comparison study between people with intellectual disability and those without disability. *Journal of Intellectual Disability Research*, 46(2), 95-107. doi:10.1046/j.1365-2788.2002.00343.x
- Hermans, H., & Evenhuis, H. M. (2014). Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 35(4), 776-783. doi:http://dx.doi.org/10.1016/j.ridd.2014.01.022
- Hess, J., Matson, J., Neal, D., Mahan, S., Fodstad, J., Bamburg, J., & Holloway, J. (2010). A comparison of psychotropic drug side effect profiles in adults diagnosed with intellectual disabilities and autism spectrum disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 3(2), 85-96. doi:10.1080/19315861003690588
- Hess, J., Matson, J., Neal, D., Mahan, S., Fodstad, J., & Bamburg, J. H., Jodie. (2010). A comparison of psychotropic drug side effect profiles in adults diagnosed with intellectual disabilities and autism spectrum disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 3(2), 85-96. doi:10.1080/19315861003690588
- Hsieh, K., Rimmer, J. H., & Heller, T. (2014). Obesity and associated factors in adults with intellectual disability. *Journal of Intellectual Disability Research*, 58(9), 851-863. doi:10.1111/jir.12100
- Janicas, K. (2014). COMMENTARY: Exercise as a treatment in intellectual and developmental disability. *Journal on Developmental Disabilities*, 20(1), 122-127.
- Janicki, M. P., Dalton, A. J., Henderson, M. C., & Davidson, P. W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation*, 21(5-6), 284-294. doi:10.1080/096382899297710
- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., . . . Walsh, P. N. (2005). The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research*, 49(10), 740-744. doi:10.1111/j.1365-2788.2005.00743.x
- Lennox, N., Bain, C., Rey-Conde, T., Taylor, M., Boyle, F. M., Purdie, D. M., & 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(4), 303-311. doi:10.1111/j.1468-3148.2009.00533.x
- Lennox, N., & Kerr, M. P. (1997). Primary health care and people with an intellectual disability: the evidence base. *Journal of Intellectual Disability Research*, 41(5), 365-372. doi:10.1111/j.1365-2788.1997.tb00723.x
- Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Boyle, F. M., & Purdie, D. M. (2004). Ask for it: development of a health advocacy intervention for adults with intellectual disability and their general practitioners. *Health Promotion International*, 19(2), 167-175. doi:10.1093/heapro/dah204
- Luszczynska, A., Abraham, C., & Sobczyk, A. (2007). Planning to lose weight: Randomized controlled trial of an implementation intention prompt to enhance weight reduction among overweight and obese women. *Health Psychology*, 26(4), 507-512. doi:10.1037/0278-6133.26.4.507
- Lynnes, M. D., Nichols, D., & Temple, V. A. (2009). Fostering independence in health-promoting exercise. *Journal of Intellectual Disabilities*, 13(2), 143-159. doi:10.1177/1744629509340815

- 
- MacRae, S., Brown, M., Karatzias, T., Taggart, L., Truesdale-Kennedy, M., Walley, R., . . . Davies, M. (2015). Diabetes in people with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities, 47*, 352-374. doi:10.1016/j.ridd.2015.10.003
- Mahy, J., Shields, N., Taylor, N. F., & Dodd, K. J. (2010). Identifying facilitators and barriers to physical activity for adults with Down syndrome. *Journal of Intellectual Disability Research, 54*(9), 795-805. doi:10.1111/j.1365-2788.2010.01308.x
- Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities, 32*(2), 419-436. doi:10.1016/j.ridd.2010.12.018
- McVilly, K. R., McGillivray, J., Curtis, A., Lehmann, J., Morrish, L., & Speight, J. (2014). Diabetes in people with an intellectual disability: a systematic review of prevalence, incidence and impact. *Diabetic Medicine, 31*(8), 897-904. doi:10.1111/dme.12494
- McVilly, K. R., & Rawlinson, R. B. (1998). Quality of life issues in the development and evaluation of services for people with intellectual disability. *Journal of Intellectual and Developmental Disability, 23*(3), 199-218. doi:10.1080/13668259800033701
- Melville, C. A., Hamilton, S., Hankey, C. R., Miller, S., & Boyle, S. (2007). The prevalence and determinants of obesity in adults with intellectual disabilities. *Obesity Reviews, 8*(3), 223-230. doi:10.1111/j.1467-789X.2006.00296.x
- Moran, R., Drane, W., McDermott, S., Dasari, S., Scurry, J. B., & Platt, T. (2005). Obesity among people with and without mental retardation across adulthood. *Obesity Research, 13*. doi:10.1038/oby.2005.46
- Morisse, F., Vandemaele, E., Claes, C., Claes, L., & Vandeveldel, S. (2013). Quality of life in persons with intellectual disabilities and mental health problems: An explorative study. *The Scientific World Journal, 2013*(491918).
- National LD Professional Senate. (2015). Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers. A Briefing Paper on Service Specifications and Best Practice for Professionals, NHS Commissioners, CQC and Providers of Community Learning Disabilities Health Team Retrieved from [https://www.bps.org.uk/system/files/user-files/DCP%20The%20Faculty%20for%20People%20with%20Intellectual%20Disabilities/public/national\\_ld\\_professional\\_senate\\_guidelines\\_for\\_cldt\\_specialist\\_health\\_services\\_specifications\\_and\\_practice\\_exec\\_summary\\_3\\_mar\\_2015.docx](https://www.bps.org.uk/system/files/user-files/DCP%20The%20Faculty%20for%20People%20with%20Intellectual%20Disabilities/public/national_ld_professional_senate_guidelines_for_cldt_specialist_health_services_specifications_and_practice_exec_summary_3_mar_2015.docx).
- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research, 51*(11), 850-865. doi:10.1111/j.1365-2788.2006.00939.x
- Oliver, M. (1983). *Social Work with Disabled People*. Basingstoke: Macmillan.
- Oliver, M. (1990). The individual and social models of disability Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with established locomotor disabilities in hospitals.

- 
- Oliver, P. C., Piachaud, J., Done, J., Regan, A., Cooray, S., & Tyrer, P. (2002). Difficulties in conducting a randomized controlled trial of health service interventions in intellectual disability: implications for evidence-based practice. *Journal of Intellectual Disability Research*, 46(4), 340-345. doi:10.1046/j.1365-2788.2002.00408.x
- Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life expectancy of people with intellectual disability: A 35-year follow-up study. *Journal of Intellectual Disability Research*, 44(5), 591-599. doi:10.1046/j.1365-2788.2000.00280.x
- Patja, K., Mölsä, P., & Iivanainen, M. (2001). Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *Journal of Intellectual Disability Research*, 45(1), 30-40. doi:10.1111/j.1365-2788.2001.00290.x
- Peterson, M. D., Gordon, P. M., & Hurvitz, E. A. (2013). Chronic disease risk among adults with cerebral palsy: The role of premature sarcopenia, obesity and sedentary behaviour. *Obesity Reviews*, 14(2), 171-182. doi:10.1111/j.1467-789X.2012.01052.x
- Productivity Commission. (2011). *Disability Care and Support*. Productivity Commission Inquiry Report Volume 2. Retrieved from Canberra, ACT: <http://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume2.pdf>
- Quigley, A., Murray, G. C., McKenzie, K., & Elliot, G. (2001). Staff Knowledge about Symptoms of Mental Health Problems in People with Learning Disabilities. *Journal of Intellectual Disabilities*, 5(3), 235-244. doi:10.1177/146900470100500303
- Raghavan, R. (2004). Learning Disability and Mental Health: Reflections and future trends. *Journal of Learning Disabilities*, 8(1), 5-11. doi:10.1177/1469004704042085
- Regenold, W. T., Thapar, R. K., Marano, C., Gavirneni, S., & Kondapavuluru, P. V. (2002). Increased prevalence of type 2 diabetes mellitus among psychiatric inpatients with bipolar I affective and schizoaffective disorders independent of psychotropic drug use. *Journal of Affective Disorders*, 70(1), 19-26. doi:10.1016/S0165-0327(01)00456-6
- Reichard, A., & Stolsle, H. (2011). Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. *Intellectual and Developmental Disabilities*, 49(3), 141-154. doi:http://dx.doi.org/10.1352/1934-9556-49.2.141
- Resnick, H. E., Valsania, P., Halter, J. B., & Lin, X. (2000). Relation of weight gain and weight loss on subsequent diabetes risk in overweight adults. *Journal of Epidemiology and Community Health*, 54(8), 596-602. doi:10.1136/jech.54.8.596
- Rimmer, J. H., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews*, 12(1), 22-27. doi:10.1002/mrdd.20091
- Robertson, J., Emerson, E., Gregory, N., Hatto, C., Turner, S., Kessissoglou, S., & Hallam, A. (2000). Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Res Dev Disabil*, 21. doi:10.1016/s0891-4222(00)00053-6
- Romeo, R., M., K., Morrison, J., Melville, C., Allan, L., Finlayson, J., & Cooper, S. (2009). Cost estimation of a health-check intervention for adults with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, 53(5), 426-439. doi:10.1111/j.1365-2788.2009.01159.x



- 
- Schalock, R., Brown, I., Brown, R., Cummins, R. A., Felce, D., Keith, K. D., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40(6), 457-470. doi:10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2
- Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, 48(3), 203-216. doi:10.1111/j.1365-2788.2003.00558.x
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., . . . Parmenter, T. (2002). Conceptualization, measurement, and application of Quality of Life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40(6), 457-470. doi:doi:10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2
- Shakespeare, T. (2014a). *Disability Rights and Wrongs Revisited*. Oxford: Routledge.
- (2014b, 20 November 2014). *Models of Disability: Implications for Disability Policy & Programs* [Retrieved from <https://dl.dropboxusercontent.com/u/37331175/141120%20Tom%20Shakespeare%20Lecture%20MSEI.mp3>]
- Sheehan, R., Hassiotis, A., Walters, K., Osborn, D., Strydom, A., & Horsfall, L. (2015). Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *BMJ (Clinical Research Ed.)*, 351, h4326-h4326. doi:10.1136/bmj.h4326
- Shikako-Thomas, K., Lach, L., Majnemer, A., Nimigon, J., Cameron, K., & Shevell, M. (2009). Quality of life from the perspective of adolescents with cerebral palsy: "I just think I'm a normal kid, I just happen to have a disability". *Quality of Life Research*, 18(7), 825-832. doi:10.1007/s11136-009-9501-3
- Slevin, E., Truesdale-Kennedy, M., McConkey, R., Barr, O., & Taggart, L. (2008). Community learning disability teams: Developments, composition and good practice: A review of the literature. *Journal of Intellectual Disabilities*, 12(1), 59-79. doi:10.1177/1744629507083583
- Srikanth, R., Cassidy, G., Joiner, C., & 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(1), 53-62. doi:10.1111/j.1365-2788.2010.01346.x
- Sullivan, S. G., Hussain, R., Threlfall, T., & Bittles, A. H. (2004). The incidence of cancer in people with intellectual disabilities. *Cancer Causes & Control*, 15(10), 1021-1025. doi:10.1007/s10552-004-1256-0
- Taggart, L., Coates, V., Bunting, B., Davies, M., Carey, M., Northway, R., . . . Karatzias, T. (2015). A study protocol for a pilot randomised trial of a structured education programme for the self-management of Type 2 diabetes for adults with intellectual disabilities. *Trials*. doi:10.1186/s13063-015-0644-y
- Tracy, J., & Hosken, R. (1997). The importance of smoking education and preventative health strategies for people with intellectual disability. *Journal of Intellectual Disability Research*, 41(5), 416-421. doi:10.1111/j.1365-2788.1997.tb00729.x
- Trip, H., Conder, J., Hale, L., & Whitehead, L. (2015). The role of key workers in supporting people with intellectual disability in the self-management of their diabetes: a qualitative New Zealand study. *Health & Social Care in the Community*, n/a-n/a. doi:10.1111/hsc.12262

- 
- Trollor, J., & Salomon, C. (2015). Positive Cardiometabolic Health for People with an Intellectual Disability. An Early Intervention Framework. Retrieved from
- Tyrer, F., Smith, L. K., & McGrother, C. W. (2007). Mortality in adults with moderate to profound intellectual disability: a population-based study. *Journal of Intellectual Disability Research*, 51(7), 520-527. doi:10.1111/j.1365-2788.2006.00918.x
- Valk, H. M. J. v. S. L.-d., van den Akker, M., Maaskant, M. A., Haveman, M. J., Urlings, H. F. J., Kessels, A. G. H., & Crebolder, H. F. J. M. (1997). Prevalence and incidence of health problems in people with intellectual disability. *Journal of Intellectual Disability Research*, 41(1), 42-51.
- van Dooren, K., Taylor-Gomez, M., Lennox, N. G., Dean, J., & Boyle, F. M. (in press, 2015). Consider the support worker in the role of health assessments (letter to the Editor). *Journal of Applied Research in Intellectual Disabilities*. doi: 10.1111/jar.12211
- Vestergaard, P., Rejnmark, L., & Mosekilde, L. (2005). Relative fracture risk in patients with diabetes mellitus, and the impact of insulin and oral antidiabetic medication on relative fracture risk. *Diabetologia*, 48(7), 1292-1299. doi:10.1007/s00125-005-1786-3
- Wagemans, A. M. A., & Cluitmans, J. J. M. (2006). Falls and fractures: A major health risk for adults with intellectual disabilities in residential settings. *Journal of Policy and Practice in Intellectual Disabilities*, 3(2), 136-138. doi:10.1111/j.1741-1130.2006.00066.x
- Wagemans, A. M. A., Fiolet, J. F. B. M., Van Der Linden, E. S., & Menheere, P. P. C. A. (1998). Osteoporosis and intellectual disability: Is there any relation? *Journal of Intellectual Disability Research*, 42(5), 370-374. doi:10.1046/j.1365-2788.1998.00152.x
- Wahlström, L., Bergström, H., & Marttila, A. (2014). Promoting health of people with intellectual disabilities: Views of professionals working in group homes. *Journal of Intellectual Disabilities*. doi:10.1177/1744629514525133
- Wallace, R. A., & Schluter, P. (2008). Audit of cardiovascular disease risk factors among supported adults with intellectual disability attending an ageing clinic. *Journal of Intellectual and Developmental Disability*, 33(1), 48-58. doi:10.1080/13668250701858463
- Walsh, P. N., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R. L., & Moseley, C. (2010). Supported accommodation for people with intellectual disabilities and Quality of Life: An overview. *Journal of Policy and Practice in Intellectual Disabilities*, 7(2), 137-142. doi:10.1111/j.1741-1130.2010.00256.x
- White, P., Chant, D., Edwards, N., Townsend, C., & Waghorn, G. (2005). Prevalence of intellectual disability and comorbid mental illness in an Australian community sample. *Australian & New Zealand Journal of Psychiatry*, 39(5), 395-400 396p.
- Whitehead, L. C., Trip, H. T., Hale, L. A., & Conder, J. (2016). Negotiated autonomy in diabetes self-management: the experiences of adults with intellectual disability and their support workers. *Journal of Intellectual Disability Research*, 60(4), 389-397. doi:10.1111/jir.12257
- Wilson, P. M., & Goodman, C. (2011). Evaluation of a modified chronic disease self-management programme for people with intellectual disabilities. *Journal of Nursing and Healthcare of Chronic Illness*, 3(3), 310-318. doi:10.1111/j.1752-9824.2011.01105.x



---

Wirshing, D. A., Spellberg, B. J., Erhart, S. M., Marder, S. R., & Wirshing, W. C. (1998). Novel antipsychotics and new onset diabetes. *Biological Psychiatry*, 44(8), 778-783. doi:10.1016/S0006-3223(98)00100-0

World Health Organization. (1997). *Measuring Quality of Life: The World Health Organization Quality of Life instruments (the WHOQOL-100 and the WHOQOL-BREF)*. Retrieved from Geneva: [http://www.who.int/mental\\_health/media/68.pdf](http://www.who.int/mental_health/media/68.pdf)

World Health Organization (WHO). Definition: Intellectual disability. Retrieved from World Health Organization. Regional Office for Europe website: <http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability>

Yamaki, K. (2005). Body weight status among adults with intellectual disability in the community. *Mental Retardation*, 43(1), 1-10. doi: [http://dx.doi.org/10.1352/0047-6765\(2005\)43<1:BWSAAW>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(2005)43<1:BWSAAW>2.0.CO;2)

Zylstra, R. G., Porter, L. L., Shapiro, J. L., & Prater, C. D. (2008). Prevalence of Osteoporosis in Community-Dwelling Individuals with Intellectual and/or Developmental Disabilities. *Journal of the American Medical Directors Association*, 9(2), 109-113. doi:<http://dx.doi.org/10.1016/j.jamda.2007.09.008>

