1 Health issues for people with intellectual disabilities: the evidence base

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Introduction

People with intellectual disability experience significantly more health problems than the general population. Furthermore, there is considerable evidence that people with intellectual disability do not receive the same level of health care as other members of society. For example, health screening medical checks are given less often to people with intellectual disability than to the non-disabled population (Evenhuis et al. 2001), yet it has been shown consistently that health checks lead to detection of unmet health needs and lead to targeted actions to address health needs (Lennox et al. 2006; Robertson et al. 2007) (see Chapter 18). Jurisdictions across the world are signatories to the UN Convention on the Rights of Persons with Disabilities (2006), which states: 'parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'.

The UN Convention (2006) further states that parties shall 'provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including . . . population-based public health programmes'. Another core point the UN made was that service providers should offer 'health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons'. Access to health promotion and illness prevention services would be included within this remit.

While the gap is narrowing in some countries, on average people with intellectual disability have more significant health problems and die younger than their non-disabled peers, particularly those in the severe to profound range (Ouellette-Kuntz et al. 2005; Krahn et al. 2006). People with moderate to severe intellectual disabilities are three times as likely to die early than the non-disabled population (Turner 2011). This is due in part to the underlying cause of their disability and in part to predisposing and interrelated factors such as poverty, illiteracy and other social determinants. Improved health is likely to lead to improved quality of life for both the individuals with intellectual disability and their families. In this chapter, we review the evidence base for the major health problems of this population and provide readers with a synopsis of the up-to-date evidence of the health status of people with intellectual disability. We identify individual health targets and implications for health promotion, and examine the importance of the role of empirical evidence and how this needs to be clearly translated into practice.

Definitions

Intellectual disability

Intellectual disability is 'a disability characterised by significant limitations in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18 years' (AAIDD 2012). One criterion for determining the presence of intellectual disability is a standardized measure of intellectual functioning or IQ test. Significant impairment measured through this rating is said to be two standard deviations below average, which translates to an IQ that is below 70. There are also standardized measures for adaptive behaviour that include conceptual, social and practical skills.

The term intellectual disability is synonymous with previous terms such as mental retardation and mental handicap, and with terms used in other jurisdictions such as learning disability. People with intellectual disability have a broad range of abilities and these abilities will significantly influence the way they interact with the community, the types of choices they have in their lives, and the degree to which others support them.

According to the World Health Organization intellectual disability can be categorized as follows:

- Mild (IQ of 50–70) – the ability to communicate effectively and live relatively independently with minimal support within the community.
- Moderate (IQ of 35–49) – individuals who, with lifelong support, will have significant relationships, can communicate, handle money, travel on public transport, make choices for themselves, and understand daily schedules.
- Severe or Profound (IQ <34) – individuals who are almost totally dependent on those around them and will require lifelong help with personal care tasks, communication, and accessing and participating in community facilities, services and activities.

There is a wide range of aetiologies for intellectual disability, including chromosomal, single gene deficits, a range of environmental factors that include intra-uterine infections (for example, maternal rubella), peri-natal trauma, nutritional deficits (for example, iodine deficiency), maternal alcohol abuse, and childhood neglect and deprivation. In approximately half of cases no cause has yet been identified. The variation in social, political, economic and environmental factors influence the prevalence of particular causes of intellectual disability in each country, as they do the health and nutritional status of the non-disabled population.

Developmental disability

Developmental disabilities are those that relate to 'differences in neurologically based functions that have their onset before birth or during childhood, and are associated with significant long-term difficulties' (Graves 2003). As such, developmental disability is an umbrella term that includes intellectual disability but also includes other disabilities that are acknowledged during early childhood. Some developmental disabilities are derived largely from physical impairments, such as cerebral palsy and epilepsy. Some individuals may have a condition that includes a physical and intellectual disability, such as Down syndrome or foetal alcohol syndrome. Other developmental disabilities, such as cerebral palsy or autism spectrum disorders (autism or pervasive developmental disorder [PDD]) are often associated with intellectual disability, further adding to the complexity of their physical and mental health needs.

Health problems of people with intellectual disability

People with intellectual disability have a range of health vulnerabilities when considered as a population; however, specific aetiologies of intellectual disability carry with them more defined

risk profiles. Most of the large prevalence studies of health problems in this population are based on indirect assessments of the knowledge of staff of their clients' health status. The real prevalence tends to be underestimated because of the reduced ability of the individual with intellectual disability to present with symptoms, the difficulty for staff to recognize symptoms and signs, and limitations in the skills and available time of physicians to make their assessments (Haveman 2004). The prevalence of these problems has been found to be much higher in studies where direct assessment measures were undertaken by skilled clinicians.

People with intellectual disability are one of the most marginalized groups in our society, as they have extremely limited access to education, employment, and financial resources. They are subject to the very powerful social determinants of health, poverty, and social class. Epidemiological studies of the health of people with intellectual disability have looked at both their health in general as well as specific health problems (Van Schrojenstein Lantman-de Valk and Walsh 2008). These have shown that this group is particularly vulnerable to a range of chronic health problems that include:

- sensory problems (including vision, hearing and dental)
- poor nutrition
- constipation
- thyroid problems
- gastro-oesophageal reflux disease (GERD) and *Helicobacter pylori*
- obesity
- osteoporosis
- epilepsy
- cardiovascular disease
- Type 1 and Type 2 diabetes
- some types of cancers (particularly stomach and gall-bladder)
- mental health problems
- addictions
- ageing problems.

Furthermore, there is general agreement that people with intellectual disability do not use and engage fully in:

- health education/information
- health promotion programmes, such as those for healthy eating, weight reduction, physical activity, and exercise classes
- health screening programmes, including health checks, *Helicobacter pylori* screening, sexual health (for example, contraception), women's health (for example, breast and cervical cancer screening), men's health (for example, testicular cancer screening), and dementia screening.

The Health Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disability (IASSID) met in 1999 under the auspices of the WHO to develop a consensus on health targets and recommendations for people with intellectual disability (see Web Resources).

Key determinants of health inequalities

According to Emerson (2011), there are five key determinants of health inequalities affecting people with intellectual disabilities:

1. Greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness.
2. Increased risk of health problems associated with specific genetic, biological, and environmental causes of intellectual disabilities.

3. Communication difficulties and reduced health literacy.
4. Personal health risks and behaviours such as poor diet and lack of exercise.
5. Deficiencies relating to access to healthcare provision.

Specific health issues in people with intellectual disability

Sensory problems (including vision, hearing, and oral health)

Research shows clearly that problems with vision are strongly associated with intellectual disability, and that the prevalence of these problems increases with age (Janicki and Dalton 1998). The condition is under-recognized; it has been shown that the assessment and management of poor vision in this population requires specialized skills (Evenhuis et al. 2001). Having deficiencies in vision when other faculties are already compromised has implications for mobility, learning, and behaviour. Monitoring sight and providing timely intervention is an important aspect of health care in this population (Evenhuis et al. 2009). Intervention not only involves improving the person's visual capabilities but also ensuring that health professionals are aware of the issues, so that the effect of the visual deficit is minimized by appropriate adjustments to the physical and interpersonal environment (see Chapter 3).

Hearing impairments in adults with intellectual disability who are aged 50 years and over range from 8 per cent to as many as 28 per cent in those with Down syndrome (van Schrojenstein Lantman-de Valk et al. 1994). There is a wide range of causes, some of which are similar to those in the non-disabled population while others are associated with the underlying aetiology (for example, Down syndrome, congenital rubella). The diagnosis is dependent on the awareness of people with intellectual disability to recognize their hearing impairments, as well as the awareness of those who support them: given the high prevalence there is need for regular hearing checks. As with visual impairments, advice on adjustment to the environment can make a major difference to people with hearing impairments (Meuwese-Jongejeugd et al. 2006) (see Chapter 3).

A higher proportion of people with intellectual disability have tooth extractions and filled teeth compared with the general population (Cumella et al. 2000). Access to regular dental review from an early age and throughout adult life is fundamental to good dental health. Proper dental hygiene in people with intellectual disability is as an important preventative health measure as it is in the wider population (see Chapter 3).

Nutrition

Many people with intellectual disability have less nutritional diets compared with the non-disabled population, and those with more severe and profound disability have higher rates of under-nutrition (Gravestock 2000) (see Chapter 4). The reason for this may be swallowing difficulties or concurrent problems with their gastrointestinal tract. Chronic malnutrition makes an individual vulnerable to infection; it can also compromise skeletal integrity and the resultant muscle weakness will often limit mobility. This is one of the major causes of morbidity and premature death in this population. Services need to monitor the diets and weights of this population and take appropriate action when problems are identified.

Obesity

The underlying problems of poor nutritional diet and inadequate activity and exercise that cause obesity in the non-disabled population, also impact on people with intellectual disability, who have higher rates of obesity (see Chapter 5). Obesity leads to many health problems and also brings with it an increased risk of cardiovascular disease and diabetes. People with intellectual

disability have, to a large extent, not received the preventative health messages and programmes that have been directed to the rest of the community, and are thus less informed to make appropriate food choices. Their relative poverty makes cheaper and accessible sources of calories particularly attractive. People living independently make food choices for themselves, while those in supported settings are often reliant on support staff to make those choices for them. There is evidence that people in supported environments have healthier diets. The challenge for services supporting more independent options is to ensure that the message on diet and exercise gets through to this population.

Diabetes

People with intellectual disabilities are estimated to be three to four times more likely to have diabetes than the non-disabled population (see Chapter 6). Anwar et al. (2004) found that Type 1 diabetes was more prevalent in individuals with Down syndrome than those with other genetic causes of intellectual disability. Young people and adults with intellectual disabilities are more likely to develop Type 2 diabetes as a result of leading a more sedentary lifestyle, undertaking low levels of exercise and consuming high-fat diets, all of which can contribute towards obesity. Like the non-disabled population, people with intellectual disabilities are living longer, thereby making them more susceptible to developing Type 2 diabetes. There is a dearth of studies that have examined the extent to which their diabetes is managed or whether the quality indicators for diabetes care are met (Taggart et al. 2012).

Epilepsy

The prevalence of epilepsy in people with intellectual disability in the literature ranges from 14 to 44 per cent. This variation is associated with the degree of disability, the population, underlying aetiology, research methodology, and accommodation setting (Bowley and Kerr 2000) (see Chapter 7). Management not only includes the use and monitoring of appropriate medication but also the provision of a safe living environment, adjustments in lifestyle, setting appropriate safety standards, skills in the monitoring and reporting of seizures, and established protocols for responding to seizures.

Cardiovascular disease

Coronary heart disease (CHD) is the second largest cause of premature death for people with intellectual disabilities. They are more likely than the general population to have high blood pressure, be overweight or obese, and be inactive, all of which are risk factors for CHD (de Winter et al. 2012) (see Chapter 8).

Respiratory disease

A 25-year follow up of 2369 people with intellectual disability reported that those under 40 years were more than twice as likely to die as a result of a respiratory disease (87 per cent as a result of pneumonia) than the general population (Patja et al. 2000). Higher rates of aspiration pneumonia and inhalation of foreign bodies were also observed in this population. The risk of respiratory disease was found to increase with the degree of disability, gastro-oesophageal disease, dysmorphias in the oral cavity and a range of immunological deficits.

Cancer

Globally, it is estimated that over 12 million people are diagnosed with cancer every year. The global cancer burden doubled in the final 30 years of the twentieth century, and it is estimated that this will double again by 2020 and nearly triple by 2030. Overall, the incidence of cancer

among people with intellectual disabilities has been reported to be lower than that of the general population (see Chapter 9). Research has shown that nearly half of all cancers in people with intellectual disabilities are gastrointestinal and oesophageal cancers; this may result from a higher incidence of *Helicobacter pylori* infection. The next main group of cancers is the urogenital cancers (for example, breast and cervical cancers for women, and testicular and prostate cancers for men) (Patja et al. 2001).

Sexual health

People with intellectual disabilities commonly experience opposition to sexual activity and face difficulties in expressing their sexuality in a safe and healthy way. Those supporting them face complex challenges (see Chapter 10). Lack of acceptance of the sexuality of people with intellectual disabilities has implications for their access to sexuality related health promotion, screening, and health care (Van Schrojenstein Lantman-de Valk et al. 2002). The key areas in sexual health promotion for this population include: relationship formation; sexual abuse and relationship violence; appropriate sexual behaviour; contraception, sterilization and menstrual management; pregnancy and parenting; and screening in sexual and reproductive health.

Mental health

The prevalence of mental health problems in people with intellectual disability varies depending on the diagnostic criteria and the research methodology. The overwhelming volume of research shows a much higher prevalence of mental health disorders compared with the non-disabled population (see Chapter 11). Cooper et al. (2007) found double the rate of all mental health problems using the DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with People with Adults with Learning Disabilities/Mental Retardation; Royal College of Psychiatrists 2001). This study indicated a prevalence of psychotic illness of 4.6 per cent compared with 0.4 per cent in the general population. Cooper and colleagues also showed that 6.6 per cent of people with intellectual disability suffered from affective disorders, and 3.6 per cent from anxiety disorders. Social and environmental factors can contribute to the development of mental health disorders in this population. Communication difficulties, social isolation, lack of employment opportunities, loss and grief when carers move on, and limitations in their choice of with whom and where they live are all significant stressors that need to be considered in the prevention and management of mental health problems.

Addictions

In the non-disabled population, cessation of smoking is one of the most significant preventative health programmes impacting on respiratory disease, cardiovascular health, cancer, and diabetes. Emerson (2005) reported that smoking was more prevalent in people with intellectual disability living in the community than those living in supported accommodation. This situation will evolve as public health policies in reference to smoke free environments are being implemented in different countries. A study of 1097 people with intellectual disability found that 17.3 per cent smoked tobacco and that asthma rates in those who smoked was double that of those who did not (Gale et al. 2009) (see Chapter 12).

In a review of 67 substance users with intellectual disability in Northern Ireland, Taggart et al. (2007) showed that alcohol was the main substance misused; in 20 per cent of cases this was in combination with illicit drugs and/or prescribed medication. There was an increased risk of substance abuse among males who were young with borderline/mild intellectual disability, living independently, and who had mental health problems. Problematic behaviours related to the addiction were also seen as an issue of concern (Taggart et al. 2006). Research has suggested a need for earlier identification to limit long-established patterns of use and associated behaviours (see Chapter 12).

Ageing

The authors of a critical review of the international literature from 1999 to 2009 that focused on age-related health risks, age-related oral health and lifestyle health risks in older people with intellectual disabilities, reported that cardiovascular disease is as prevalent and as common a cause of death among older people with intellectual disabilities as in the general population (Haveman et al. 2011). There are, however, variations in prevalence, which are culturally dependent: lifestyle health risks included poor nutrition, a lack of exercise, and poor mobility leading to higher obesity levels (Hilgenkamp et al. 2012) (see Chapter 13). As in the non-disabled population, healthier lifestyles, improved nutrition and increased exercise, as well as regular health checks to improve surveillance of health risks, are reported as key to improving the health status of older adults with intellectual disabilities (Evenhuis et al. 2012).

Medication

The efficacy and side-effects of medications used in this population are less reliant on patient reports and more reliant on the observations of others. People with intellectual disability are some of the highest consumers of psychotropic and anti-epileptic medications with high rates of potentially serious side-effects and the potential for significant interactions (McGillicuddy 2006; de Kuijper et al. 2010). If we are to prevent or minimize iatrogenic disease from medications, people with intellectual disabilities and their carers need to be active participants in both the reporting of outcomes and the observation of side-effects. As some side-effects, such as weight gain associated with certain medications, can be anticipated, active health promotion strategies around diet and exercise need to be put in place from the outset.

Systemic issues

Regular health checks, including physical examinations that include a record of blood pressure, weight, review of dentition, breast or testicular examination, and assessment of vision and hearing, should be part of a person's health management programme (see Chapter 18). Research has shown that when this is done regularly, health problems are identified earlier (Lennox et al. 2006). While this is becoming a requirement of support services in some jurisdictions, people with intellectual disability who live independently or with their families also need to be aware of the need for regular health checks that focus on their health vulnerabilities.

People with intellectual disabilities and the need for health promotion

Major progress in improving the health of the wider community has come about through public health measures targeting social disparities and through specific health education, health promotion programmes and health screening initiatives (see Chapter 2). This has proven to be a cost-effective way of tackling the major health problems in the community, especially when targeting chronic diseases.

People with intellectual disability have the same right to access these interventions as the non-disabled population (UN 2006). While people with intellectual disability are subject to the same range of major health problems as the general population, research has shown that they have particular vulnerabilities. The health promotional activities commonly used in the non-disabled population may need to be adapted for people with intellectual disability and their carers. Where greater health vulnerabilities have been identified health education, health promotion programmes, and health screening initiatives need to be better targeted.

Summary

The social determinants of health are extremely important for this population and lessons learnt from approaches used in other marginalized groups should be considered. Research and evaluation is critical to ensure that interventions achieve the expected outcomes in the most cost-effective manner (see Chapter 20). The challenge in establishing equitable health promotion programmes for people with intellectual disability is an issue in many countries. The need to measure health outcomes and to build new or extend existing partnerships with key stakeholders to improve access to health promotion activities is now widely recognized. Developing and promoting a good evidence base for health promotion activities in this population would help support services achieve better outcomes. Not only do priorities need to be established, it is also important to target interventions appropriately: times of transition, such as leaving school, the start of living independently, moving from the family home, or retirement, provide opportunities for targeted interventions. Better health is a key foundation for better lives in people with intellectual disability.

Useful resources

- *Health Inequalities and People with Learning Disabilities in the UK: 2012* (Emerson et al. 2012) summarizes the latest evidence about the extent, nature, and determinants of health inequalities experienced by people with learning disabilities in the UK. Available at: http://www.improvinghealthandlives.org.uk/publications/1165/Health_Inequalities_&_People_with_Learning_Disabilities_in_the_UK:_2012

Web resources

- Health Guidelines for Adults with an Intellectual Disability, IASSID: www.iassid.org/pdf/healthguidelines-2002.pdf
- The Improving Health and Lives Learning Disabilities Observatory are here to keep a watch on the health of people with learning disabilities and the health care they receive: www.improvinghealthandlives.org.uk/
- The following site offers fact sheets on common health problems for people with intellectual disabilities: www.nswcid.org.au/health/se-health-pages/standard-fact-sheets.html

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