Research in Developmental Disabilities 34 (2013) 4034–4042

Contents lists available at ScienceDirect

Research in Developmental Disabilities

Health and wellbeing of Victorian adults with intellectual disability compared to the general Victorian population

Syed Imran Haider [a,*], Zahid Ansari [b], Loretta Vaughan [a], Helen Matters [c], Eric Emerson [d]

[a] Health Intelligence Unit, Victorian Government Department of Health, 50 Lonsdale Street, Melbourne, Victoria 3000, Australia
[b] School of Public Health and Preventive Medicine, Monash University, Melbourne, Victoria, Australia
[c] Service Design and Implementation Group, Victorian Government, Department of Human Services, 50 Lonsdale Street, Melbourne, Victoria 3000, Australia
[d] Centre for Disability Research & Policy, University of Sydney, Australia

ARTICLE INFO

Article history:
Received 27 June 2013
Received in revised form 13 August 2013
Accepted 14 August 2013
Available online 13 September 2013

Keywords:
Intellectual disability
Developmental disability
Health surveys
Population health
Health monitoring

ABSTRACT

Multiple measures of health and wellbeing of people with intellectual disability (ID) and the general Victorian population were compared using representative population level data. The sample consisted of adults with ID ($N = 897$) and the general Victorian population ($N = 34{,}168$) living in the state of Victoria in Australia. Proxy respondents were interviewed on behalf of people with ID, while respondents from the general Victorian population were interviewed directly. The data were weighted to reflect the age/sex/geographic distribution of the population. Results revealed that adults with ID reported higher prevalence of poor social determinants of health, behavioural risk factors, depression, diabetes, poor or fair health. A higher proportion of people with ID reported blood pressure and blood glucose checks, while a lower proportion reported cervical and breast cancer screening, compared with the general Victorian population. The survey identified areas where targeted approaches may be undertaken to improve the health outcomes of people with ID and provide an important understanding of the health and wellbeing of these Victorians.

1. Introduction

Numerous research studies have documented high rates of mortality and morbidity among both children and adults with intellectual disability (ID) (Cooper, Melville, & Morrison, 2004; Emerson & Hatton, 2013; Haveman et al., 2010; Krahn & Fox, 2013; Krahn, Hammond, & Turner, 2006; Oeseburg, Dijkstra, Groothoff, Reijneveld, & Jansen, 2011; O'Hara, McCarthy, & Bouras, 2010; Ouellette-Kuntz, 2005; US Department of Health & Human Services, 2002b; Van Schrojenstein Lantman-de Valk, 2005). While the results of such studies are relatively consistent over time and jurisdictions, this evidence base may be criticised on two important counts (Emerson & Hatton, 2013; Krahn & Fox, 2013). First, the majority of studies are based on small scale convenience samples. Second, relatively few studies have collected comparable data from appropriate non-ID samples.

Current knowledge suggests that the causes of the inequality in health status between people with and without ID are varied and complex, including: specific secondary health conditions associated with syndromic causes of ID (e.g., congenital heart defects in infants with Down syndrome); poor health literacy; increased risk of exposure of people with ID to key social

---

* Corresponding author. Tel.: +61 3 90960000; fax: +61 3 90969176.
E-mail addresses: imran@imranhaider.com, imran.haider@health.vic.gov.au (S.I. Haider).

0891-4222/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ridd.2013.08.017

determinants of poorer health (e.g., childhood poverty); and barriers to accessing health promotion, primary, secondary and tertiary health care (Emerson & Hatton, 2013; Krahn & Fox, 2013).

It is clear that many of these causes are avoidable and unjust. As such they represent health inequities or inequalities (Whitehead, 1992). For example, a recent confidential inquiry that examined all deaths of people with ID in five selected areas of England over a two year period concluded that 42 per cent were premature in that the provision of appropriate health care would have been likely to have delayed the person's death by at least 12 months (Heslop et al., 2013). As a result of this accumulation of knowledge, United Nations agencies and several national governments are prioritising actions to reduce the health inequalities experienced by people with ID (Department of Health, 2009; US Department of Health & Human Services, 2002a; World Health Organization and the World Bank, 2011).

A key barrier to progress in this area is the invisibility of people with ID in national health surveillance systems (Centers for Disease Control and Prevention (CDC) & National Center on Birth Defects and Developmental Disabilities (NCBDDD) Health Surveillance Work Group, 2009; Glover & Emerson, 2011; Krahn & Fox, 2013; Krahn, Fox, Campbell, Ramon, & Jesien, 2010; Linehan, Walsh, Van Schrojenstein Lantman-deValk, Kerr, & Dawson, 2009). As a result, while research has identified the likely existence of health inequalities, information on the extent, patterning and change over time of inequalities in specific localities is rarely available. For example, in Australia, there is as yet no coherent, evidence-based strategy for monitoring the health and wellbeing of people with ID so as to permit comparisons between this population and their peers without disability, or between the states. Without such evidence and strategy, attempts to design interventions, health promotion activities and thus promote the healthy ageing of Australians with ID are likely to falter.

The aims of the present paper are to describe and present results from the Victorian Population Health Survey of People with an Intellectual Disability 2009 (VPHS-ID 2009), the first population level survey in Victoria, Australia and to compare the health and wellbeing of people with ID to the general Victorian population.

2. Methods

2.1. Design and data source

This study was based on data from two state-wide population health surveys; the 'Victorian Population Health Survey of people with an Intellectual Disability 2009' (VPHS-ID 2009) and the 'Victorian Population Health Survey 2008' (VPHS 2008). The surveys were designed to provide information on the health and wellbeing of the population to inform policy and planning. The Victorian Department of Health conducts the Victorian Population Health Survey (VPHS) each year to measure the health and wellbeing of people living in the state of Victoria, Australia (2011 population 5.5 million). A public health model of the social determinants of health, provided the theoretical framework for the VPHS and informed the development of the questionnaire (Ansari, Carson, Ackland, Vaughan, & Serraglio, 2003). Essentially the model predicts that the underlying social determinants of health, which include socioeconomic determinants, psychosocial risk factors and community and societal characteristics (social determinants), impact on the health of the individuals (health outcomes) both directly and indirectly via the healthcare system and disease-inducing behaviours (Ansari et al., 2003).

2.2. Sampling frame

A full description of details about design, recruitment and representativeness of the sample, as well as diagnostic methods, has been published elsewhere (Department of Health, 2008, 2011). An administrative database of people with ID who had previously sought assistance from the Victorian Department of Human Services was used as the sampling frame for the VPHS-ID 2009. The database contained information on approximately 21,210 people aged 18 years and over who were listed on the administrative database and resided in Victoria and had ID as either a primary or secondary condition (0.5% of the resident adult population of Victoria). 7106 recruitment packages were mailed to a randomly selected sample of people aged 18 years and over with ID. 897 people with ID, and their proxy respondents agreed to participate, giving a response rate of 14% of people with whom contact was made. The overall participation rate defined as completed interviews divided by people who agreed to participate in the survey was 90.7%. This study population was representative of the total Victorian population with ID who had previously sought assistance from the Victorian Department of Human Services.

The VPHS 2008 was conducted by computer-assisted telephone interview (CATI) in a randomly selected representative sample of males and females aged 18 years and over, who resided in private dwellings in Victoria. People who were homeless, itinerant, in hospitals or other institutions, were excluded from the survey. The sampling frame was an electronic listing of Victorian telephone exchange prefixes and localities and random digit dialling was used to generate a sample of telephone numbers that formed the household sample. Only one person per household, aged 18 years or older, was randomly selected for interview, based on having the most recent birthday.

2.3. Data collection

The telephone interviews were conducted with 897 proxy respondents on behalf of people with ID for VPHS-ID 2009. For VPHS 2008 the total sample achieved was 34,168 completed interviews with selected respondents. The interview questions were posted in advance to proxy respondents to assist them in preparing for their telephone interviews. In the VPHS 2008,