



Describing heterogeneity of unmet needs among adults with a developmental disability: An examination of the 2012 Canadian Survey on Disability



Jennifer Zwicker^{a,c,*}, Arezou Zaresani^b, J.C. Herb Emery^{a,1}

^a University of Calgary, School of Public Policy, Canada

^b University of Calgary Department of Economics, Canada

^c University of Calgary, Faculty of Kinesiology, Canada

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ABSTRACT

Background: As a signatory to the UN Convention on the Rights of Persons with Disabilities, Canada has committed to protect the rights and dignity of persons with developmental disabilities (DD), which means that labour markets, education, and training opportunities should be inclusive and accessible.

Purpose: Describe the unmet employment, education and daily needs of adults with DD, with a sub analysis of persons with autism spectrum disorder (ASD) and cerebral palsy (CP) in Canada, to inform efficient and equitable policy development.

Methods and procedures: Secondary analysis of 2012 Canadian Survey on Disability was used to study a sample including working age (15–64 years old) individuals with self-reported DD, CP and ASD. Persons with DD reported on their met and unmet needs in term of activities of daily living, education and employment.

Outcomes and results: Labour force participation is the lowest for those with DD compared to any other disability. Individuals with CP and ASD report a high level of unmet needs that differ in terms of educational, vocational and daily living supports.

Conclusions and implications: Improving labour force participation to be inclusive and accessible requires policy that considers the range of unmet needs that exist for persons with DD.

1. Introduction

Addressing the needs of Canadians with developmental disabilities (DD) has been absent from policy dialogue. This is despite the fact that Canadians with physical and mental disabilities face some of the highest levels of unemployment (Till, Leonard, Yeung, & Nicholls, 2015). Barriers to participating in the labor force, present in the workplace, education sector and social services and supports, unfortunately remain the experience of Canadians with DD (Bizier et al., 2015; Ministers Responsible for Social Services, 1998; Till et al., 2015). This is despite agreement by federal and provincial/territorial social services ministers in 1998 that, “Equal access to education, training and support programs will increase potential for employment and a better economic future” (Ministers Responsible for Social Services, 1998). Until these barriers are addressed, the promise of equality of opportunity in the labor market is not fulfilled.

* Corresponding author at: University of Calgary, School of Public Policy, 5th floor 906, 8th Ave. SW, Calgary, AB, Canada.

E-mail address: zwicker1@ucalgary.ca (J. Zwicker).

¹ Present address: Department of Economics, University of New Brunswick, PO Box 4400, 13 Bailey Drive, Fredericton, NB E3B 5A3, Canada.

At the national level, federal legislation has contributed to the equality of rights of Canadians with disabilities. The Canadian Charter of Rights and Freedoms protects against discrimination because of mental and physical disability, the Canadian Human Rights Act prohibits employers, service providers from discriminating based on disability, and the Employment Equity Act requires employers remove employment barriers faced by people with disabilities. Canada, as a signatory to the UN Convention on the Rights of Persons with Disabilities, has committed to protect the rights and dignity of persons with disabilities. This means labour markets, education, and training opportunities should be inclusive and accessible. To fulfill these duties, in part, the federal government is developing accessibility legislation with the objective to “eliminate systematic barriers and deliver equality of opportunity” (Government of Canada, 2016). This is an opportunity to provide leadership for interjurisdictional and intergovernmental collaboration in developing policies improving accessibility and inclusion for persons with DD. A better understanding of the experiences of those with DD pertaining to education, employment and barriers accessing services can help in designing policies to address gaps and plan for greater inclusion of future generations (World Health Organization, 2011a, 2011b; United Nations General Assembly, 2006).

The first step in policies for efficient and equitable services for those with DD is a better understanding of needs and challenges. DD are heterogeneous group of disabilities with onset in the developmental period characterized by impairments of personal, social, academic or occupational functioning (American Association on Intellectual and Developmental Disabilities, 2010; American Psychiatric Association, 2016; Sullivan et al., 2011). Persons with DD can experience specific limitations of learning or control of executive functions to global impairments of social skills or intelligence and as a result, service and support needs can vary. Persons with DD have poorer health, lower education achievement, fewer economic opportunities and higher rates of poverty than people without disabilities. The lack of services available to individuals with DD and the obstacles faced in their everyday lives, have been identified as key barriers (World Health Organization, 2011a, 2011b). There is very little data (administrative or population) in Canada describing how adequately services and supports are meeting the diverse needs of this population (Haveman et al., 2010; Ouellette-Kuntz et al., 2005; World Health Organization, 2011a, 2011b), despite a prevalence of DD in Canada estimated at approximately 1–3% (Ouellette-Kuntz et al., 2005; Sullivan et al., 2011).

Critical to this better understanding of the needs, is an appreciation of the heterogeneity within the population. Using population data, we expand on Statistics Canada’s recent brief report on needs of adult Canadians with DD (Bizier et al., 2015). In this study we focus on two particular DD; those with autism spectrum disorder (ASD) and cerebral palsy (CP). ASD and CP are two DD that are among the most common chronic conditions resulting in disability in children (Human Resources and Skills Development Canada, 2006). ASD is marked by impaired social interaction, repetitive behaviors, restricted interests and impaired communication (American Psychiatric Association, 2013). CP is marked by disorders in the development of movement and posture, inducing lifelong mobility limitations (American Psychiatric Association, 2013). We hypothesize that there may be some diverse service and support needs for consideration when designing policy and services for persons with DD and explore this with subgroup analysis of persons identifying as having ASD and/or CP. These subgroups are not exclusive, as some persons with DD may identify as having both CP and ASD (Zwaigenbaum, 2014). In this study we use population data to describe disability-specific experiences and self-reported barriers pertaining to education, employment and available supports and services to identify common challenges and unique needs. Ultimately, this information can inform planning and evaluation of services, programs and policies for adults with disabilities, to help enable their full participation in society.

2. Methods

2.1. Data and variables

2.1.1. Description of secondary data

The 2012 Canadian Survey on Disability (CSD) is a national cross-sectional population based survey of Canadian adults whose everyday activities are limited because of a long-term condition or health-related problems. Based on a social model of disabilities and guided by the World Health Organization’s International Classification of Functioning (ICF), Disability and Health framework of disability, the CSD collected information from respondents who reported difficulty or impairment due to a long-term condition or health problem and experience a limitation in their daily activities.

This secondary analysis used data from the 2012 CSD, with a sampling frame drawn from the Census and 2011 National Health Survey response database, which included a filter question about disability. The total sample size for the CSD was approximately 45,500 individuals and with a 75% overall response rate, provides reliable data on persons with disabilities for each province and territory of Canada (Statistics Canada, 2015). The CSD used Computer Assisted Telephone Interview (CATI) to survey residents of private dwellings,² aged 15 years and older as of May 10 2011, who reported an activity limitation on the 2011 National Household Survey. However, because of the time lag between the Census/NHS and CSD collection, all the information collected in the CSD represents the population’s characteristics as measured in the fall of 2012. The development process and technical properties of the 2012 CSD are described elsewhere (Statistics Canada, 2015).

² The CSD includes only those who live in private dwellings and excludes those living on a First Nations Indian reserve or in nursing houses or other collective dwellings. Data, particularly for the older age groups, should be interpreted accordingly.

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