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IMPROVING OUR UNDERSTANDING OF UNMET NEEDS AMONG ADULTS WITH A DEVELOPMENTAL DISABILITY

Jonathan Lai, Stephanie Dunn and Jennifer Zwicker

SUMMARY

Nearly two-thirds of adults with a developmental disability in Canada are not in the workforce, according to findings from the 2012 Canadian Survey on Disability. Labour force participation among this group is only half that of people without a disability, and even lower for persons with autism spectrum disorder (ASD). Three in four respondents not working at the time of the survey reported that their disability had created barriers to employment. Common barriers included adverse employer attitudes, ill-suited work environments, inadequate job modifications, and unmet educational and daily living needs. With disability cited as the main barrier to employment, there is an urgent need for policies to be put in place to increase sustained and meaningful participation in the workforce for individuals with developmental disability. Many barriers to employment could be removed through policies targeted at the workplace (like job training programs, policies that promote accessibility and equal opportunity, employer training, and improved workplace practices) and broader policies promoting social inclusion and educational attainment.

WHY IS THIS AN IMPORTANT ISSUE?

Labour force participation is lowest for persons with developmental disabilities (DD) compared to any other disability in Canada, even though many are ready, willing and able to work. Those who are employed often work for less than minimum wage and receive minimal protection from labour legislation. Beyond these basic facts, little is known about employment outcomes for persons with DD in the Canadian context. Using national population survey data, the study supporting this communiqué explored the unmet employment, education and daily living needs of persons with two types of developmental disability: autism spectrum disorder (ASD) and cerebral palsy (CP; Zwicker, Zaresani and Emery, 2017).¹ Disability was cited as a key barrier to employment for those not in the labour force, highlighting an urgent need for policies that promote accessibility and equal opportunity, as well as improved workplace practices and employment services and supports. Beyond improving our understanding of the workplace, education and social support challenges faced by Canadians with DD – a group that has been largely absent from policy dialogue – the study’s findings highlight key factors for the design of policies that deliver efficient and equitable services.

BACKGROUND INFORMATION

This study analyzed self-reported data from the 2012 Canadian Survey on Disability (n=45,500 Canadians with a disability). Classification of disability was guided by the World Health Organization’s International Classification of Functioning framework that was administered to individuals who reported having a difficulty due to a long-term condition or health problem and experienced a limitation in daily activity.

The study focused on adults between the ages of 15 and 64 years with DD in Canada, comprising 16.5 per cent of all working-aged adults with a disability. All persons with DD reported at least one other type of disability (e.g., memory, learning, mental, physical or sensory disability). The prevalence of DD was doubled in younger adults under 25 compared to older age groups, and in men compared to women.

WHAT DOES THE RESEARCH TELL US?

Lowest rate of labour force participation among persons with DD

Labour force participation² for persons with DD is more than 50 per cent lower than for persons without a disability and the lowest among all other disabilities. Almost two-thirds of working-aged adults with DD were not in the labour force (and not actively seeking work) in 2012. One in four individuals with DD reported being employed in some capacity and seven per cent were unemployed but actively seeking work. These rates vary for different diagnoses; for example, persons with ASD reported even lower labour force participation and employment rates (21.5 per cent and 14.3 per cent, respectively).

¹ ASD and CP are two of the most common chronic developmental conditions that result in disability in Canadian children.

² Labour force participation includes both employed and unemployed individuals actively seeking work. Persons not participating in the labour force include those not working and not actively seeking work or retired.

Government transfers are a major source of income for most individuals with DD

Among those employed, the number of weekly hours worked was significantly lower for individuals with DD compared to other disabilities. The median annual employment incomes for people with CP and ASD were \$1,800 and \$2,900, respectively, and \$2,300 for all individuals with DD. Median total incomes for all groups were higher – around \$10,000 – with government transfers the major source of income for most adults with DD (69.1 per cent), CP (59.3 per cent) and ASD (63.0 per cent), noticeably higher than for those without disabilities (18.7 per cent).

Disability cited as the main barrier to employment

Of those surveyed, almost three-quarters of persons with DD and not in the labour force reported that their condition was a barrier to employment. Among those working or actively seeking work, at least 20 per cent reported being refused an interview, job or promotion due to their disability, with barriers to employment perceived to be higher among individuals with CP. One in five individuals with DD indicated they would work in the coming year if their condition improved, if the workplace changed or if further training was available.

Many report disadvantage at work due to required job modifications being unmet

The leading workplace needs for persons with DD were: workplace modifications (40.3 per cent), modified hours (28.9 per cent), modified duties (26.1 per cent), and human support (17.9 per cent). More than two-thirds of those requiring job modifications reported that not all their needs were met. Individuals with less visible disabilities often reported that their employer was not aware of their disability.

Support for activities of daily living is a necessity and mostly provided by families

Almost all participants indicated that they needed help in some aspect of daily life outside of the workplace. The level of unmet need in daily function was high for all persons with DD, with two-thirds reporting help was not received for at least one need. Family was most commonly identified as the primary provider of supports, while paid and unpaid organizations only contributed to support for 20 per cent of daily needs.

Educational attainment is noticeably different between individuals with ASD and CP

The majority of individuals with DD reported that their condition influenced their course selection, course load and time to complete education. Beyond academic load, peer exclusion and bullying were also cited as barriers to continued education. Educational attainment differed noticeably depending on the DD. Two-thirds of individuals with ASD did not graduate from high school, with fewer than five per cent completing post-secondary studies. In contrast, persons with CP have the highest rate of high school graduation (40.2 per cent) compared to other groups and higher rates of post-secondary completion (33.5 per cent) than persons with other DD. This may in part reflect access to educational supports, which were required by more than half of all persons with DD. One in three adults with ASD reported at least one unmet need in this domain, compared to most individuals with CP receiving needed supports.

WHAT ARE THE POLICY IMPLICATIONS?

The low rate of labour force participation among working-age adults with DD is indicative of labour market constraints requiring public policy responses in order to promote this group's entry and retention in the labour market. The federal government is currently developing accessibility legislation with the objective to "eliminate systematic barriers and deliver equality of opportunity". This is an opportunity to provide leadership for interjurisdictional and intergovernmental collaboration in developing policies to improve accessibility and inclusion for persons with DD (Government of Canada, 2016). Efforts to improve labour force participation will have to consider the diverse needs within this group. In contrast to other disabilities, persons with DD experience a disability in their early stages of development, meaning challenges are present throughout life: in inclusive education, gaining work experience and developing necessary skills to enter the labour market (Prince, 2016).

Policies that promote educational attainment, vocational training/education, work incentives and socialization are likely to be among the most effective in bolstering entry and retention for individuals with DD in the labour force (Dudley, Nicholas and Zwicker, 2015). There is a clear need for further support in terms of both employer education and job modifications in the workplace since half of those in the labour force require at least one modification (such as modified hours, duties or human support). More broadly, on-the-job training, vocational rehabilitation, including training and job modifications, job placement assistance and maintenance play a central role in employment success. Improved access to these supports and training presents an opportunity to boost sustainable labour force participation for those with ASD and CP.

Low labour force participation will not be resolved focusing solely on the workplace. Those with DD face considerable challenges before they even seek work, underpinned by unmet needs within the education system (like limited access to educational supports and aides), barriers to social inclusion and broader gaps in support with daily activities (most of which is provided by the family). Given that education lays a groundwork for adult employment and independence and is one of the most significant factors in achieving competitive employment, our findings support recent policy recommendations emphasizing the role for expanded post-secondary education and, particularly for those with ASD, point to a need for more inclusive education opportunities at all levels (Prince, 2016).

Policies that improve access to meaningful and sustainable job opportunities are particularly important for younger adults with DD, who list work and independent economic life as two of the most important domains related to their health and well-being. This highlights the importance of transition planning for youth, which can help linking support systems, improving employment outcomes and optimizing community participation (Huang et al., 2013).

Failure to address the existing disincentive to work has broader societal implications, with participation in the labour force providing benefits beyond income. Inclusion through employment enhances quality of life, cognitive functioning and the overall wellbeing of persons with DD by offering an opportunity for economic self-sufficiency, financial security, independent living, greater participation in the community and increased self-esteem.

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