

# Persons with Disabilities, Caregivers, and Employment: The Case for a National Disability Support Program

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## Disability in Canada: Extent and Economic Impact

The statistics are startling. According to the *2012 Canadian Survey on Disability*, 1 in 7 working age Canadians live with a disability. This is equal to 3.8 million people, or approximately 21% of the available labour force,<sup>1</sup> and this number is expected to rise as people live longer, retire later, and experience higher incidence of chronic illness.<sup>2</sup> This reality is even more concerning when you consider that studies consistently find only about half of eligible people with disabilities are able to find work, as compared to roughly 80 per cent of those living without disabilities.<sup>3</sup>

For Canadians living with disabilities who are in the workforce, disability can dramatically impact their productivity. According to the 2011 Labour Force Survey, full-time workers were absent for an average of 9.3 days that year—7.7 days due to illness or disability,<sup>4</sup> a portion of which was specifically linked to having a chronic disability.<sup>5</sup> The Conference Board of Canada estimated that absenteeism cost the Canadian economy \$16.6 billion.<sup>6</sup>

While the full cost of Canadians with disabilities being un- or under-employed has been insufficiently studied, the Conference Board of Canada projected that improving workplace accommodations could enable 550,000 Canadians with physical disabilities to work more. This would lift the income of this population by more than \$13.5 billion and increase GDP by \$16.8 billion by 2030.<sup>7</sup> So lack of workforce participation amongst Canadians with disabilities has a very tangible impact on our economic performance overall.

Disability also affects the workforce participation and productivity of caregivers. 35% of the active Canadian workforce (more than 6 million people) have informal caregiving responsibilities.<sup>8</sup> The majority care for adults with long-term health conditions or disabilities, and many do so because they do not have access to affordable professional caregivers.<sup>9</sup> Informal caregiving takes a toll on Canadians' health and productivity: 28-55% of Canadians report experiencing stress and other health impacts while caregiving and 4 in 10 employed caregivers require time off to manage caring responsibilities. 15% cut work hours, 10% turn down promotion or job opportunities, and 40% enter less demanding jobs.<sup>10</sup> Of the 9.3 days, on average, that Canadians were absent from work in 2011, 1.6 were due to personal and family

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<sup>1</sup> Statistics Canada, 2011b

<sup>2</sup> World Health Organization, 2011

<sup>3</sup> Turcotte, 2014

<sup>4</sup> Statistics Canada, 2011a

<sup>5</sup> Zhang, McLeod & Koehoorn, 2016

<sup>6</sup> Conference Board of Canada, 2013

<sup>7</sup> Conference Board of Canada, 2018

<sup>8</sup> Employer Panel for Caregivers, 2015

<sup>9</sup> Turcotte, 2013

<sup>10</sup> Sinha, 2012

responsibilities, which included providing care to a loved one living with disability.<sup>11</sup> Canadians taking time off or exiting the workforce to manage caregiving responsibilities cost our economy an estimated \$1.3 billion in 2012.<sup>12</sup>

Unfortunately, data on the productivity costs of disability in Canada is limited and outdated. For instance, we know very little about the total cost of Canadians never entering the workforce due to disability. This presumably has a large ripple effect in the economy as fewer people contribute to the tax base and more individuals rely on social assistance and support from family members. As will be discussed in greater detail, mandated, expanded, and ongoing data collection to better understand the big-picture effects would be highly beneficial.

## **What is Causing the Employment Gap?**

Despite government efforts, employment amongst Canadians with disabilities remains significantly below that of the general population. Canadians with disabilities do want to be employed, but federal survey results demonstrate they “are more likely to be discouraged from looking for work” and may be able to attain a job but then have trouble retaining it.<sup>13</sup> The reasons for this are mainly attributable to three factors.

The first factor is employer fears that individuals with disabilities will be less productive, less reliable, and costlier than their non-disabled peers. However, research has thoroughly debunked these negative stereotypes. A 2007 literature review found that, when assessed, individuals with disabilities performed just as well or better than their non-disabled peers; that most accommodations could be implemented at no or low cost; and, that individuals with life-long disabilities had equal or lower rates of both absenteeism and turnover.<sup>14</sup> The Canadian government has tried to counteract employer misperceptions through initiatives including tax incentives for hiring individuals with disabilities, government funding for workplace adaptations, and training programs to make Canadians with disabilities more competitive. But employment outcomes have not significantly improved.

The second factor is the inaccessibility of workplaces. Not only do the majority of Canadian workplaces lack universal design to make them physically accessible, few workplaces have inclusive practises and policies, such as modifying duties or allowing flexible hours or telework.<sup>15</sup> To resolve these problems, Canadian governments have introduced new building codes and funding for updating and adapting old buildings, while organizations like the Rick Hansen Foundation have introduced accessible building certification programs. The federal government is also integrating flexible work arrangements into the *Canada Labour Code*.<sup>16</sup>

These initiatives are a step in the right direction, but outcomes in the USA cast doubt on the ability of strictly employment-focused policies and programming to improve labour market participation. After the *Americans with Disabilities Act* was introduced, along with multiple

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<sup>11</sup> Battams, 2017

<sup>12</sup> Chenier, Hoganson & Thorpe (Conference Board of Canada), 2012

<sup>13</sup> Ibid.

<sup>14</sup> Lengnick-Hall, Gaunt & Brooks, 2007

<sup>15</sup> Conference Board of Canada, 2018

<sup>16</sup> Fantini, 2018

training programs and employer hiring incentives, employment amongst Americans with disabilities remained stagnant. This prompted a 2014 study by the U.S. Senate Committee on Health, Education, Labor & Pensions which found one of the key factors stalling workforce participation was lack of access to daily disability supports.<sup>17</sup> This finding was echoed in a study of working age youth with physical disabilities in Toronto. Participants reported that lack of accessible transportation and supports to develop self-care and communication skills, paired with fear of losing existing disability supports if income exceeded program eligibility limits, played a major role in whether or not they looked for jobs.<sup>18</sup>

These studies identify the third (and most overlooked) factor: access to essential disability supports. In meetings and focus groups with caregivers, Canadians with varying degrees and types of disability, and disability experts, representatives of the Every Canadian Counts Coalition repeatedly heard essential disability supports were the key to being able to attend training and acquire and retain a job.

### **The Importance of Essential Disability Supports**

The Council of Canadians with Disabilities has always emphasized the importance of access to disability supports to employment for both those with disabilities as well as their caregivers. Without supports such as attendant assistance to get ready for work, accessible and reliable transportation to get to work, and personal mobility and communication aids to navigate at work, Canadians with disabilities struggle to access job opportunities and maintain their employment commitments. Without access to specialists chronic disabilities can become worse and function can decline, reducing labour performance. And when home care, day programs, and residential supports are not available for individuals with severe disabilities who cannot work, it forces family members to reduce or leave work in order to provide care for them.

While government policies and programs to support training and employment have been established, and many leading corporations have introduced measures to diversify their workforces, all of these efforts are undermined because Canadians do not have access to needed disability supports. This needless and wasteful situation is gaining new urgency as Canada's pool of working age individuals shrinks. If we maintain our present approach, the cost to Canadians and to the economy will only grow.

### **Disability Support in Canada: The Service Gap**

Disability support systems across Canada are difficult to navigate and underfunded. These issues partially stem from the Canada Social Transfer, which does not enforce any minimum standard of service provision across the country and has been capped at a 3% annual increase until 2024. This increase does not account for inflation or population growth, so the actual amount transferred to provinces and territories shrinks each year as needs grow.<sup>19</sup>

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<sup>17</sup> U.S. Senate Committee on Health, Education, Labor & Pensions, 2014

<sup>18</sup> Lindsay et al., 2015

<sup>19</sup> Mussell, 2015

As a result, the supply of supports and services has not kept up with demand and tens of thousands of Canadians with disabilities are currently on waiting lists for critical supports like supportive and/or accessible housing, specialist care, day programs, and assistive devices.<sup>20</sup> In the interim, both those with disabilities and their caregivers have reduced ability to work as well as to take advantage of training and education programs. There is also great financial, physical, mental, and emotional strain placed on individuals and families. This sends many into crises including family breakup, bankruptcy, hospitalization, imprisonment, homelessness, abandonment of children, and even murder-suicides. These crises are incredibly costly to Canadian taxpayers, the wellbeing of our population, and our overall productivity as a country.

To complicate matters, those who do get access to essential disability services risk losing them during life stage transitions (such as youth to adulthood) when most governments force people to move from one ministry to another and reapply for services, even if needs have not changed. When needs do change, such as when adults with developmental disabilities want or need to leave their family home for a supported living environment, individuals and families must often cope for years before receiving the new supports.

People can also lose essential disability services should they need to relocate. Disability supports are currently managed independently by each of the provinces and territories, so if you move from Nova Scotia to Saskatchewan you must reapply for services. As mentioned, there is often a wait, so most must find a way to bridge the gap either through paying out of pocket for private providers or seeking aid from charitable organizations. Even a move between cities can mean losing access to services, because there is no mandate or incentive to have the needed range of service providers available in every city. This massively hampers the mobility of Canadians and their ability to move to where their skills or labour is most needed.

Hurdles in accessing disability services and supports are further amplified in rural, remote, and Indigenous communities which already lack basic infrastructure and amenities. These communities also have a much harder time attracting outside workers to fulfill labour needs, so maximizing participation of the workforce they have available locally, including residents with disabilities and caregivers, is very important.

A final issue is that access to disability supports could be lost if program recipients are employed and earn too much income. Linking eligibility for disability supports to income level is common practice worldwide, but it demotivates people from entering the workforce. Even if earning a living wage, after accounting for the extra costs of disability supports, many would be forced below the poverty line. This is why the World Health Organization has stated support for policies that “separate the income support element from the element to compensate for the extra costs incurred by people with disabilities”.<sup>21</sup> In short: income support is not services support and should be treated separately. We must ensure Canadians with disabilities, regardless of work status and without risk of income loss, have access to publicly-funded supports and services that are needed to manage disability and participate in our economy.

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<sup>20</sup> ARCH, 2007; Ontario Ombudsman, 2016; The Family Support Institute of BC, 2016; Community Homes Action Group, 2017; Giesbrecht et al., 2017; Mullin, 2018

<sup>21</sup> World Health Organization, 2011

## A Path Forward

Canada needs to address barriers to employment in a more holistic way if we truly wish to see increased workforce participation. The Every Canadian Counts Coalition (ECCC) has been active on behalf of persons with disabilities and caregivers since its inception in the Fall of 2014 and was formed in the knowledge that disability support systems in Canada were not only failing but getting worse.

Viable options to fix these systems are limited. Essential disability support expenses cannot be shifted to or borne by employers, as the majority are needed in private homes or public community spaces. Further, as these supports are not utilized specifically for the purposes of education or work, they cannot be covered under existing public programs for disability accommodations in schools and workplaces. Nor can we rely on the private sector to fill the gap. Current private disability insurance programs are either time-limited with funding caps or prohibitively expensive for most individuals. And without insurance or government funding, few Canadians can afford to pay market prices for disability services, especially those with complex needs that require multiple services and care coordinators. As it stands, there is little incentive for private providers to expand or offer services beyond those funded or subsidized through block grants from the provinces and territories.

So, to overcome the issues of underfunding, fragmentation, service gaps, and portability, ECCC proposes a new approach: a public disability insurance program that is national in scope and to which all Canadians are entitled.

This is not as radical as it may sound. Canada has already embraced a national insurance model for our public healthcare system and is actively considering a similar model for delivering prescription medicine. While our healthcare system faces challenges, it is significantly more equitable and data-driven than our disability support systems currently are. Our healthcare system, regulated under the *Canada Health Act*, is administered by the Provinces/Territories but funded jointly with the federal government and has clear minimum standards of care provision. This means Canadians know which health services they can expect to have funded regardless of where they are in Canada. Furthermore, if they need to relocate, these entitlements move with them without any lapse or waiting period. This system is supported by ongoing data collection by the Canadian Institute for Health Information, which allows policy makers to better identify and predict areas of need as they direct funding.

In an economic sense, permanent disability is a classic ‘insurable’ event because:

- it affects a relatively small, but easily definable proportion of the population;
- when it occurs, the costs to the individual or family affected are exorbitantly high;
- permanent disability can hit any person or family, at any time, and although the overall proportions of the population that will be affected are known with some accuracy; no single individual case is foreseeable;
- pooling risk and costs among the total population is, therefore, the rational economic solution; and,

- small contributions from a large number of persons can yield very large benefits to the individuals affected and to the society as a whole, at a relatively low cost to any one individual.

Traditionally, the costs of disability services have taken a short- to medium-term outlook. Governments plan for expenditures over a 12-month to, at most, five-year time frame. Funds available for disability change depending on the economy, tax revenues, and the requirements of other portfolios. Consequently, disability services have had to perennially justify their existence and there are always short- to medium-term pressures to cap or cut costs.

Public insurance models are very different. Under a public insurance model, expenditure is factored in over the life of an individual. Program sustainability is based on calculating the total future costs of all those insured. This approach creates an incentive to make strategic investments that maximize opportunities and reduce long-term costs. For example, reducing long-term cost by increasing individuals' independence and participation in the community and the workforce.

Another beneficial aspect of public insurance programs is that outcomes are continually compared to forecasts and divergences are investigated carefully to control long-term costs, enhance sustainability, and ensure needs of participants are being met.

A national disability insurance program could be regulated and funded in a similar fashion to our public healthcare program, with national legislation setting minimum standards and greater amounts of conditional funding from the federal government. This model would be in line with the national approach taken in other OECD nations such as Australia, Germany, and Denmark.

Key factors to enabling Canadians with disabilities and their caregivers to live and work in dignity with improved individual outcomes include:

- Individualized supports for chronic disabilities that impact core daily functions;
- Early intervention when disability is acquired/diagnosed and when essential support needs change; and,
- Sustained support over the course of life.

ECCC acknowledges that such a large shift will require buy-in from a number of parties: the federal government, provincial, territorial, and Aboriginal governments, disability service providers and advocacy groups, private insurance companies, and Canadian taxpayers.

This buy-in will require a few key components:

- a comprehensive and intelligently designed delivery system with a clear scope (definition of what constitutes an essential disability support and guidelines for eligibility);
- refined data collection on the prevalence of disability by location, type, and severity, the supply of disability supports in comparison to the demand, and the level of workforce and social participation amongst Canadians with disabilities *and* unpaid caregivers; and,
- cost modelling for various renditions of a national insurance program, identification of potential funding methods, and projections that capture the cost of doing nothing.

In anticipation, ECCC has been engaging key parties in discussion about the concept of national disability insurance program. The development of an effective “made in Canada” model will require input and contributions from all of them, in addition to negotiation and agreement upon the core tenets of the model. This proposal has prompted a variety of responses: a lot of excitement about the potential to fulfill unmet need, some anxiety amongst service providers that have adapted to an environment of scarcity and extreme competition for resources, and a healthy dose of skepticism.

In truth, this proposal is ambitious, but a major rethink is necessary as our piecemeal approach to improving funding models, delivery systems, individual outcomes, and workforce participation is not working. But, based on developments in Australia, we know this type of system *is possible* and could offer massive returns to our society in terms of productivity and inclusion.

## The Australian Experience

Australia’s National Disability Insurance Scheme (NDIS) was created in response to mass public pressure to improve support for Australians with disabilities and their caregivers. Many were underserved, leading to high rates of costly hospitalization, incarceration, and poverty (45% of Australians with disabilities were near or below the poverty line<sup>22</sup>), amongst other hardships.

A feasibility study of a universal disability support insurance program was carried out in 2011 by the Australian Productivity Commission. Their two-volume report outlined the costs and benefits of various program models. The Commission concluded that, due to Australia’s great wealth, the opportunity for long-term savings and gains from increased workforce participation and decreased pressure on health and welfare systems, national insurance was the most economically wise and morally correct policy to pursue.<sup>23</sup> Government representatives across all parties agreed and the NDIS pilot phase began in 2013, aiming for full implementation in 2019.

### About the NDIS

The NDIS provides individualized funding packages to Australians under age 65 who have a permanent impairment that substantially reduces physical, intellectual, cognitive, neurological, psychological, sensory, and/or social functioning as well as infants and toddlers exhibiting developmental delays. It is a “no-fault”, market-based insurance model that enables participants to pay fair market rates to drive and sustain service supply.

The NDIS prioritizes early intervention and exists *in addition to*:

- disability services provided to those ineligible for the NDIS (such as those with short-term or episodic disabilities) through state and territorial governments;
- a Disability Support Pension for those totally unable to work (ages 16 – 65+);
- employment support and workplace modification programs; and,
- a Carer Allowance for all caregivers (not income-tested) and Carer Payments for caregivers unable to work due to their caring responsibilities.

<sup>22</sup> Price Waterhouse Coopers, 2011

<sup>23</sup> Australian Productivity Commission, 2011

The full roll-out of the NDIS has been slightly delayed due to federal-state negotiations, the need to train government case workers and community service providers in the new standards of provision and delivery, and the need to certify about 70,000 additional support workers. The NDIS will now serve more individuals than initially estimated (475,000 Australians rather than 410,000) due to expansion of eligibility guidelines following consultation with national advocacy groups. It will also cost about \$8.9 billion more than projected (to total \$22 billion at maturity) due to increases in social work wages in 2012 and the larger recipient group.<sup>24</sup> Fortunately, these cost differences were factored in early, as in 2012 the Australian Government Actuary adjusted estimates to reflect deviations in program design from the Productivity Commission's recommendations as well as to account for inflation, wage, and population growth.

In spite of these setbacks, the NDIS is making remarkable headway. In 2017, 84% of participants reported being satisfied or very satisfied with the NDIS and, on average, participants and carers were receiving more types and hours of support and reported improved choice, improved wellbeing, and increased social participation. The Australian government also remains committed to ongoing and transparent reviews of the Scheme, the laws governing it, and the agency overseeing it. Projections for individual package costs appear to be on point, with average spending to date falling slightly below what was estimated. During the transition period the NDIS will also be responsible for creating 1 in every 5 new jobs in Australia and, at maturity, the NDIS is projected to add 1.3% to Australia's annual GDP.<sup>25</sup>

Even the most vocal critics of the NDIS see its fundamental value and potential. Some demand further expansion to include more people with psychosocial disabilities, while also calling on state governments to meet NDIS funding commitments without diverting resources away from non-NDIS disability services.<sup>26</sup> There has also been debate about where additional needed funding can be generated.<sup>27</sup> But even economically conservative critics only go so far as to warn about preventing “scope creep” and major players, like the Australian Medical Association, remain fiercely committed to working through each implementation hurdle.<sup>28</sup>

As a whole, Australians are willing to do what it takes to make the NDIS work. In a recent survey 70% agreed that “providing full funding for the NDIS to provide the support Australians living with a disability need should be a top priority for government”.<sup>29</sup>

## **Opportunities for Canada & Next Steps**

There are many similarities between Canada and Australia in terms of governance—both countries manage public services through a series of funding agreements between the federal and state governments. Both have also ended up in very similar positions in regard to the wellbeing and productivity of our citizens with disabilities and their caregivers. But after investing in public consultation, data collection and modelling, Australia is now delivering a disability

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<sup>24</sup> Australian Government Productivity Commission, 2017

<sup>25</sup> Australian Government Productivity Commission, 2017

<sup>26</sup> Pro Bono News, 2018

<sup>27</sup> Dickinson, 2018

<sup>28</sup> Australian Medical Association, 2018

<sup>29</sup> The Guardian, 2018



support system informed by disability experts and analysis that is expected to grow their economy rather than drain it. Meanwhile Canadian provinces and territories continue to offer programs largely designed in response to crisis, negative media attention, and budget constraints.

Australia's program, which is being implemented in real time with assessment at every stage by multiple government and non-government agencies, offers an invaluable learning opportunity for Canada. It is increasingly clear that a national disability system is not just the right thing to do, it is good economics, with the potential to:

- Lower long-term costs through early intervention and sustained, appropriate supports that prevent crises and improve individual functioning and outcomes;
- Facilitate productivity gains by enabling Canadians with disabilities and family caregivers to enter or re-enter the workforce;
- Rationalize Canada's existing patchwork of disability service and support systems, making them easier to navigate;
- Present opportunities for more cost-effective bulk procurement, economies of scale, and private investment into disability supports and services; and,
- Serve as a pure form of stimulus spending by creating new jobs and boosting purchasing power amongst Canadians with disabilities and their caregivers.

In addition to economic benefits, a national disability support program would reassure all Canadians that, whether they or a loved one are born with or acquire a disability through illness or injury, they will have access to an appropriate whole-of-life suite of supports. Further, that this would not be contingent on where they live or infringe on their ability to earn a decent income.

Few specific design features of a national disability insurance model are addressed in this paper, as we do not know what it will ultimately look like. As noted, modelling and design of such a program will require consultation with Canadians with disabilities, caregivers, disability organizations and experts, various levels of government, and economists, among others.

The critical next step will be gathering more data on the number of people living with disability in Canada, the prevalence of specific disabilities and the severity, the availability of various supports, utilization of supports, and the percentage of individuals that have unmet or underserved needs. We also need to understand how much government-funded supports cost, the amount non-profits and charitable organizations are spending to bridge existing gaps, and the amount being spent on crisis interventions (such as individuals residing in hospitals full-time) and diversion programs for the underserved (residence in homeless shelters, incarceration, placement of youth in long-term care facilities, etc.).

Without the whole picture, our policy-making and system design will continue to be ineffective for Canadians with disabilities and their families and overly costly to all Canadian taxpayers. It will also continue to stunt the growth of our labour force and fail to address our coming labour needs as baby boomers age out of the workforce and the prevalence of chronic disability increases. The time to enable our people and our economy is now.

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