

# Every Canadian Counts

## MOVING FORWARD

Building the Framework for an Inclusive Future for  
People with Disabilities and their Families in Canada

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**NATIONAL DISABILITY STRATEGY FORMULATION REPORT**

**PREPARED BY THE EVERY CANADIAN COUNTS COALITION**

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## PREFACE

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The Every Canadian Counts Coalition<sup>1</sup> has been an activist organization on behalf of persons with disabilities since its inception in the fall of 2014. It was formed in the knowledge and belief that the support system in Canada for people with disabilities was not only failing but, in many jurisdictions, was getting worse.

The cause of this failing is simple: underfunding. The entire sector needs an injection of significant new funding.

This paper addresses that issue proposing a radically new and different funding model in the form of a national public disability insurance program. It also presents ideas about how to engage Canadians in the discussion about its design and comprehensiveness.

Over the course of our recent engagement not only with Canadians generally, but also among our supporter community, with people with disabilities, family members and other carers who support people with disabilities as well as with experts in the field, it became apparent that the approaches of the last 30 years, based on measures such as tax concessions to encourage additional private expenditure have had minimal effect. Following de-institutionalization, we jumped off a cliff and tried to make the parachute on the way down. We have crash-landed and nothing captures this more than one reality – perpetual waiting lists for services, in every province. Canadian governments at all levels have spent on the order of \$25 billion on the disability welfare system, not including the billions of dollars spent on related services. Despite this, there remains an unmet need for services – and it is growing, even with the support of innumerable family and other caregivers providing unpaid services and support.

The lack of a national perspective and proper coordination, planning and resource allocation, coupled with the growing demand at growth rates of (5-10% per year?), means the situation in the coming years will be substantially worse if the current system of supports does not change.

The Every Canadian Counts Coalition believes fundamental – indeed, transformational - change is required.

What would this transformational change look like? First, it would be a move away from the short term, ad hoc resource allocation and decision-making to a system where need, rather than chance<sup>2</sup> or bureaucratic dictum would determine the kind and quality of personal supports. Under this new system, the world of opportunity and possibilities for people with disabilities and their caregivers could open up, for the benefit of all Canadians.

A new system to replace the welfare/free market model of the last decades would see the creation **of a comprehensive public insurance program** that would deliver individualized care and supports to people with chronic and severe disabilities throughout their lifetime. This foundation, coupled with other measures such as income support and housing, would allow people with a disability to live in dignity.

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<sup>1</sup> The coalition is comprised of supporters (individuals), parent activists and endorsing agencies and organizations. See: [www.everycanadiancounts.com](http://www.everycanadiancounts.com)

<sup>2</sup> In the words of the Ontario Ombudsman, availability of services ‘is a crap shoot’.

The disability community in Canada and the broader Canadian community, as a whole, have not yet embraced the possibility that such a transformation is even possible. That is why Every Canadian Counts' central recommendation is that the Canadian Government, in consultation with provinces and territories, engage in a public education and information sharing campaign to inform the disability community and the wider Canadian public of the merits of a transformational approach to the delivery of essential supports to people with disabilities that a public insurance model affords.

The objectives of the campaign are to:

- Educate and inform the Canadian public and policy makers about the public insurance option and how it addresses the crisis in disability support services in Canada;
- Build and strengthen the constituency, alliances and representative organizations that would make building a national consensus about the viability and feasibility of the public insurance option possible; and
- Provide the basis and confirming support for and completion of a feasibility study on a national insurance program

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## **EXECUTIVE SUMMARY**

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### **DRAWBACKS OF THE CURRENT SYSTEM**

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Canada has a robust social security system that entitles all citizens to health services and income support based on individual needs and circumstances. While Canadians with a disability are entitled to these universal services, there is no equivalent entitlement to disability care and support services.

The current Canadian system of formal support is failing people with disability, their families, and caregivers. There are high levels of unmet need for disability services that have a heavy impact on people with disability, their families, and informal carers. Families are usually more than willing to care for family members with a disability when able to do so; however, without support and assistance, families can burn out, resulting in much higher ultimate costs to them, governments and society.

While some provinces have increased funding for disability services in recent years, none have committed to meeting all the essential needs of people with disability. Governments fund a range of services, but people with disability and their families have no certainty and no guaranteed access to a system of core support. The reliance on informal carers has enabled the effective rationing of resources to those in or on the verge of poverty and crisis.

A major drawback of the current disability services system is that the client is not at its centre. While more individualized packages of care are evolving and welcome, there is little opportunity for needs-based, life-course planning for individuals, which involves their families, helps them meet their aspirations and simultaneously prepares them for key transitions.

The current system is under considerable stress. Marginal change or add-on services only lock in models that continue to fail to meet the needs of people with disability, their families, and caregivers. Traditional program responses do little to ease the pressure of rising costs of services for governments and value for money in improved outcomes for clients and taxpayers.

A more robust nationally focused, the evidence-based governance structure is needed to help guide effective and integrated planning and service delivery and to evaluate outcomes. Currently, and unfortunately, there is very limited and uneven data collection and monitoring capacity to get us there.

### **EMERGING PRESSURES**

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Looking ahead, Canada's aging population together with smaller family size will increasingly stretch the existing system, especially given the strong correlation between age and disability. Over the next decades, there will be a steady increase in the number of people with a severe or profound disability. Over the next 70 years, the projected growth rate in the population with a severe and profound disability is between two and three times the population growth rate as a whole.

While the number of people with disability continues to grow, the availability of informal care is contracting. Fewer people take on informal caring roles because of a range of factors including increasing workforce participation by women and decreasing core family size. The impact of these trends on the disability services system is highly significant. Because non-paid care provides for more support than paid care, a 10 % reduction in providing informal care translates into a 40 % increase in the need for funded services. Already we are seeing that aging caregivers find it difficult to continue to care and many now need assistance themselves.

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## **A TRANSFORMATIONAL SHIFT**

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Every Canadian Counts has concluded that a transformational shift in policy and service delivery is essential. It is time to rethink and restructure the basis of disability policy in Canada. A multi-stream needs-based approach anchored in a national disability public insurance support program is a very real solution that already succeeds elsewhere.

The proposed new policy framework examines how government and private investment can work together to assist people with disability to manage their own lives and maximize their independence and contribution to the community.

The welfare model of disability services needs to be replaced with a multi-streamed policy, including:

- a new and comprehensive national disability public insurance program to deliver care and support for people with severe and profound disability using an individualized and lifetime approach, including reform of province/territory-based programs to include all traumatically injured people;
- a strong income support system that facilitates people with disability who cannot support themselves through work to live in dignity, including income support and housing;
- measures to better integrate health, carer and other support systems; and
- a range of measures to enable increased private contributions.

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## **OTHER IMPROVEMENTS TO SERVICES AND SUPPORT**

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In addition to a national disability public insurance program, the recommendations in this report are designed to help improve other aspects of services and support for people with disability, their families and carers, including:

- better employment opportunities and housing for people with disability, building on recent CMHC discussions and national accessibility legislation;
- meeting the health needs of people with disability by integrating health and disability outcomes measures and improving accessibility to health services, devices, and home care; and
- investing in a centre of excellence for inclusivity research to build the evidence base with more coordinated and reliable data collection, and, ultimately, service provision.

## **THE NATIONAL DISABILITY PUBLIC INSURANCE MODEL**

- A national disability public insurance program would provide a lifetime approach to care and support for people with disability, replacing current arrangements for funding specialist disability services.
- A social public insurance model is proposed in the tradition of Canadian universal health care. It would assess the risk of disability in the general population, calculate the costs of meeting the essential lifetime needs arising out of these disabilities and estimate the premium or contribution required from taxpayers to meet these needs.
- Instead of funding capped programs and services for people with disability to find and access, the scheme would fund on the basis of each individual's needs, which would, in turn, drive the development of necessary care and support services.
- The costs of national disability public insurance could be funded from general revenue or through a Medicare-like levy.
- Implementation should be staged over 7 to 10 years to enable new service infrastructure and workforce to develop and to balance the constraints of the medium-term fiscal outlook against intergenerational trends.

## **WHO WOULD BE ELIGIBLE?**

- People with a severe or profound disability acquired before 65 years of age, those who always or sometimes need help with a core activity or task, would be eligible for life.
- Carers would also be recognized and supported in their roles and opportunities to combine caring and work would be encouraged.
- People covered by province/territory-based accident compensation schemes would continue to be covered under them; the interaction of these schemes should be further investigated.
- The public insurance program would cover the existing eligible population under age 65 years at the time of implementation as well as people who become eligible in the future.

## **WHAT SERVICES AND BENEFITS WOULD PEOPLE RECEIVE?**

- Coordinated services based on need would provide care and support including respite, aids, equipment, transport, home modifications and a range of community and day programs.
- Other support funded outside the scheme such as income support, housing, and employment services would be integrated to provide support and opportunities for people with disability as part of a holistic approach.



- There would be an emphasis on early intervention and access to education and training to maximise long-term independence and potential.

### **HOW WOULD THE SCHEME BE GOVERNED?**

- A national disability public insurance program could operate under a new national disability commission, possibly a statutory authority or public agency, with a formal and independent governance model comprising a prudential board of directors to oversee the operation of the scheme and an advisory council of stakeholders to provide policy advice on the appropriateness and quality of the benefits.
- Public insurance principles would underpin the new arrangements. In particular, surplus premiums would be invested to maximize long-term returns, while active claims management, through comprehensive data analysis, research and provider monitoring, would lead to significant improvements in efficiency and effectiveness.

### **WHAT ARE THE BENEFITS?**

- People with disability and their families would have certainty and clarity about their options from the point of determination of a disability.
- Eligible people would be entitled to services determined on an individualized plan and needs basis, giving them access to an appropriate whole-of-life suite of services and support.
- Families would have more choices about the combination of work and informal care for family members at various life stages, as in other families.
- The proposed program addresses the current unmet and under-met need for care and support and the unsustainable reliance on carers.
- For the first time, there would be clear incentives in the service system to invest in timely interventions that promote independence and produce long-term benefits.
- The introduction of national disability public insurance would provide a sound platform of lifetime support to enable a range of innovative private contributions from individuals and families.

### **DOES IT WORK?**

- National programs exist in several countries, with Australia currently implementing a national public insurance program to great effect and in line with expectations. The Australian program is working well and enjoys widespread public support.

## PRINCIPAL RECOMMENDATIONS

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### *Recommendation 1*

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Every Canadian Counts recommends that the Canadian Government, in consultation with provinces and territories, launch a nation-wide awareness process to familiarize and garner community response to the creation of a national disability public insurance program. In parallel with this process, the federal government should undertake and fund preliminary research into the feasibility of such a program.

The awareness process would:

- engage stakeholders and caregivers from across the disability spectrum through a series of local events facilitated by distance conferencing technologies to reach smaller communities,
- document and establish the major concerns of Canadian about the program and advance a research agenda to address the issues, and
- with this, engage in a further round of consultations to address those concerns publicly with the aim of assessing support for the national disability public insurance idea.

The feasibility study should also consider:

- how provincial and territorial accident insurance should interact with the proposed national program and move to providing nationally-consistent, no-fault insurance for traumatically injured people, and
- the potential to enhance additional private provision for people with disability by making public insurance the centrepiece of a new multi-streamed disability policy framework.

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### *Recommendation 2*

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Every Canadian Counts recommends that the feasibility study into a national disability public insurance program include further examination of the potential for additional measures to enhance additional private provision for people with disability, including:

- Removing taxes on essential goods and services required by people with disability, their families, and caregivers;
- Introducing a disability support tax rebate to recognize the work-related costs of people with disability, their families, and caregivers; and

- Developing private housing and services models that could complement a national disability public insurance program.

This would also require consultation and coordination with other government initiatives, notably the Poverty Reduction Strategy and the Accessibility initiatives emerging from the passage of the Accessibility Act.

## SECTION I: DISABILITY IN CANADA

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### THE EXPERIENCE OF DISABILITY IN CANADA

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#### PEOPLE WITH DISABILITY

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In 2012, almost 14 % of the Canadian population aged 15 years or older—3.8 million individuals, one in nine persons<sup>3</sup>—reported having a disability that limited their daily activities, while 28 % of Canadians provide care to family members or friends with long-term health conditions, disability needs or aging needs. Of the 3.8 million Canadians aged 15 years or older who reported a disability, 32 % were classified as having a mild disability, 20 % a moderate disability, 23 % or 840,000 a severe disability and 26 % or 980,000 a very severe disability. The prevalence of severity did not differ significantly between men and women<sup>4</sup> with 1.82 million Canadians having a severe or very severe disability<sup>5</sup>.

#### *DATA GAPS AND INCONSISTENCIES PROBLEMATIC*

As a reflection of the inconsistent nature of data collection, the 2006 PALS\* report indicated that, in 2006, there were 4.4 million Canadians with an 'activity limiting' disability, a rate of 14.3 %. This is an increase from the 2001 disability rate of 12.4% when 3.6 million Canadians reported limitations in their everyday activities due to a physical or psychological condition or to a health condition.

\*Statistics Canada: Participation and Activity Limiting Survey 2006: Activity Report

As for disability rates in children for Canada, older estimates suggest that 7.7 % of children and youth had disabilities – similar to the 7.2 % determined by the 1991 Health and Activity Limitations Survey. Approximately 565,000 children and youth between birth and 19 years of age had disabilities in 2000<sup>6</sup>. This was considered an underestimate. In Australia, with its much more robust statistical base, it is 8.3 %.

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<sup>3</sup> There is no consensus on this number. The Rick Hansen Foundation, for example, has suggested it is closer to 4.4 million, one in seven Canadians. See: "Disability in Canada and around the world".

<sup>4</sup> Statistics Canada, Canadian Survey on Disability (CSD), 2012 (89-654-X)

<sup>5</sup> A global severity score was developed for the CSD. The score was calculated by taking into account the number of disability types, the level of difficulty, and the frequency of the activity limitation. To make the severity score easier to use, four severity classes were established: mild, moderate, severe, and very severe.

<sup>6</sup> Canadian Institute of Child Health (CICH), based on the 1996-97 National Population Health Survey (NPHS)

Projections in the growth of the disabled population are partial and imprecise, a reflection of the poor status of national data collection on disabilities in Canada. One suggestion is that this one in nine ratio will grow to one in five in the next generation<sup>7</sup>.

Generally, the prevalence of severe and profound disability increases with age, of particular significance for an aging population. Projections of the number of adults with intellectual and developmental disabilities 45 to 84 years of age over a 10-year period suggests moderate to small increases ranging between 4.1 and 20.5 % in that age group<sup>8</sup>. Data also suggests that increases over recent decades in the prevalence of some long-term health conditions, particularly related to disability, may result in further increases in the size of this population.

Over the next 70 years, the rate of growth in the population of people living with severe and very severe disabilities is expected to be between two and three times the rate of growth of the population as a whole.

Since the 1980s, policy trends have emphasized deinstitutionalisation of health and welfare services. Since 1981, there has been a movement to have people aged less than 65 years with severe or very severe limitations living in the community.

Between 2001 and 2006, the number of Canadians, excluding persons living in institutions and on First Nations reserves, who reported having a disability increased by roughly 750,000 people, with disability rates increased for nearly all age groups. Unfortunately, “support for people with disabilities has shifted out of institutions and hospitals without appropriate or sufficient resources for health and social services in the community. As a result, the burden has increased for families, informal carers and other sectors of our health and social system”<sup>9</sup>. The number living in cared accommodation has clearly fallen over the decades but the rate of this decrease is not known, due to lack of data.

These numbers seem staggering and any disability insurance program such as suggested here is not meant to be all things to all people with disabilities no matter how severe. For the severe and very severely disabled, however, such a program is urgently needed, not only for the people concerned but for their families, caregivers and for society as a whole. This is evident when we look at the numbers and see the impact, the inequities and the toll it takes on people and families as the following headlines indicate:

***Murder-suicide of B.C. mom and autistic son shows need for more support: family:***

Angie Robinson killed her autistic son and took her own life in April 2014 (CBC News Posted: Oct 26, 2015)

***'Exhausted' parents leave autistic son at government office:*** Amanda Telford says family can't keep 19-year-old safe anymore (CBC News Posted: May 01, 2013)

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<sup>7</sup> Martin Prosperity Institute, Releasing Constraints: Projecting the Economic Impacts of Improved Accessibility in Ontario, June 2010 (Rick Hansen op.cit.)

<sup>8</sup> Ouellette-Kuntz, Helene, “Population Aging and Intellectual and Developmental Disabilities: Projections for Canada” Journal of Policy and Practice in Intellectual Disabilities, December 2106

<sup>9</sup> Canadian research network for care in the community, “Diversity: Disability Issues in Home and Community Care” n.d.

These stories are not 'one-offs'. They occur again and again and take many forms: teens in long-term residences, people with disabilities in prison, losing a wheelchair because the family is moving to a different province. Every Canadian Counts recounts such stories every week. It could report them every day.

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## CAREGIVERS

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In 2012, about 8.1 million individuals or 28% of Canadians aged 15 years and older provided care to a family member or friend with a long-term health condition, disability or aging needs in the past year<sup>10</sup>. Three-quarters of this group were employed at the same time, accounting for 35% of all employed Canadians. More significantly, 13 million Canadians or nearly half (46%) of the total population have provided care at some point in their lives<sup>11</sup>. The number of who will require caregiving, in large part due to an aging population, is forecast to double over the next 30 years. As people age, the likelihood of having a chronic and debilitating disability only grows. But the challenges do not end there. Families and households are getting smaller, meaning fewer people in family settings to provide care.

In terms of hours per week involved in care, the highest number of hours per week was providing assistance for developmental disabilities. Over 50% spent 10 or more hours a week. For some, the time devoted to care can be the equivalent of a full-time job with 1 in 10 caregivers providing care for more than 30 hours per week.

Caregivers incur direct and indirect costs due to lost time in paid employment, out-of-pocket expenses and career development. Caregiving responsibilities resulted in financial hardship for 28% of those caring for a child and 20% of those caring for a spouse. These numbers will only grow as fewer young working people have jobs with benefits that would prevent such losses. In addition, 15% of employed caregivers reported cutting down on regular hours of work, while 14% lost employment benefits. Up to 10% of employed caregivers have turned down a job or did not pursue a new job or promotion because of their caregiving responsibilities. For disabled persons who have community-based support services, there is little ability to relocate as services for people with disabilities, especially developmentally disabled, are not transferable geographically.

Direct and indirect costs are not limited to caregivers and families. Employers also see increased absenteeism, higher turnover and additional benefit costs in the form of health care and disability leave. There are reduced returns on investment in employees, a result of distracted employees and spill-over effects.

There are also costs to the economy as a whole. Every year, Canada loses the equivalent of 558,000 full-time employees from the workforce due to the demands of care. In Australia, with an economy somewhat smaller than Canada's, employers lose an estimated \$5.5 billion annually in lost productivity due to caregiving-related absenteeism. In Canada, it is likely close to \$6 billion a year.

Caregiving is also a source of stress that has a profound impact on the well-being of caregivers and their families. Some 28% of people who provided care in the past year reported that they found it "somewhat or very" stressful. Within this group, 1 in 5 caregivers (19 %) said that their "physical and emotional health suffered" in the last 12 months as a result of their caregiving responsibilities.

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<sup>10</sup> Statistics Canada, "Study: Caregivers in Canada", 2012

<sup>11</sup> "A Snapshot of Family Care in Canada" The Vanier Institute

About half (49%) of adult caregivers with children under 18 indicated that their caregiving responsibilities caused them to “reduce the amount of time spent with [their] children.” For caregivers of persons with severe and chronic disabilities; all of these challenges are magnified, often manifold, but the full picture cannot be told – we simply do not have the data.

## THE NEED FOR CHANGE

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The disability support system in Canada is characterized by multiple players trying to do the best with what they have. The focus is on performance and accountability in their respective spheres of action or responsibility. The collective systemic problems are known but seldom discussed or addressed because it is either beyond the scope of any given organization or, where addressed, is singular in focus: employment, housing, accessibility, income. This is aggravated by extreme fragmentation of service delivery operations and by disability-specific activism where no comprehensive national representation exists.

Service provisions for persons with disabilities in Canada are typically:

- **Inadequate** - many people with a disability lack the most basic essential devices, services and help with daily functions, and live in conditions that should not be acceptable in Canada today, best summarized by the phrase ‘waiting lists’;
- **A Lottery** - some individuals with permanent disability receive high-quality services while others get nothing at all;
- **Unequal** - the level of support varies dramatically from area to area, and province to province, often depending on who you are: how articulate the family or individual seeking services are or how well-off they are. We do not accept this level of inequity in health care or education – why should we accept it in disability support?
- **Inconsistent** - people with identical conditions often obtain very different levels and kinds of supports. It is not about what is needed; it is about what is available;
- **Unpredictable** - neither carers nor individuals can be sure if support will continue to be available year-to-year and cannot plan their lives nor involvement in the labour force accordingly;
- **Inefficient** - an uncoordinated patchwork of systems, agencies and organizations results in overlapping layers of management and higher costs; and
- **Inflexible** - both over time and distance. Changing needs over time may not be addressed while relocation will often mean the loss of services, especially between provinces but even within them.

These problems are well known and exist in all jurisdictions across Canada.

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## - GROWING STRESSES

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There are growing pressures on the support system for people with disabilities. One is the increasing number of people with disabilities. This is not only due to an increase in population overall but also to a greater recognition of disability conditions, such as brain injury. Another source of pressure is the reduced number of informal caregivers as a result of an aging population and reduced family sizes. Under the current fragmented system, the liabilities to families and governments will only grow.

The demand for specialist disability services will also increase in the years ahead. While statistics are lacking, evidence from Australia<sup>12</sup> suggests that 80% of supports for persons with disabilities come from families and caregivers and 20% from government and that every 1% drop in support from families represents a 5% increase for government. This dramatic drop-off in supports is happening annually in all provinces. Governments are not keeping up. Improved efficiency and effectiveness is needed to manage the costs of disability from an intergenerational perspective.

What to do? What would such an improved system look like? Fortunately, there are examples and experiences to draw from both from within and outside Canada. National programs such as those found in Australia, New Zealand, and Germany are among them; injury compensation programs and accident insurance programs are others.

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## LEVEL OF UNMET NEED

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There is no comprehensive picture of the level of unmet needs for services for persons with disabilities. Such data as exists needs to be compiled on a province-by-province basis while national data exists only in some targeted areas. For example, it is estimated that if the 2.2 million Canadians who received home care, including health-related services, in 2012, 15% (331,000) did not receive all the help needed. They are referred to as persons with 'partially met' home care needs. In addition, home care recipients with a physical disability were more likely to have partially met needs (18%) than those without a disability (10%). This analysis does not take into account the demand for accommodation and respite services or community access services. As the Canadian Council on Social Development noted in 2001, "there are few survey databases that can provide information on supports and services for persons with disabilities"<sup>13</sup>. In the same report, an indication of unmet need was provided with respect to assistive devices:

- Among children with disabilities, aged 5 to 14, over two-thirds (68%) require some type of aid or device. This represents 104,840 school-aged children.
- Among working-age adults with disabilities, aged 15 to 64 years, just over half (53% or 1,043,140 persons) have such a requirement.

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<sup>12</sup> Australia provides great insight into the socio-economic dimensions of the disability system in Canada and the benefits of something like a national disability insurance program. The structure of supports delivery in Australia was the same as Canada before the creation of the NDIS and the incidence and range of disabilities very similar. An exhaustive economic analysis was undertaken by the Australians and can be found in "Disability Care and Support: Inquiry Report" Productivity Commission: Government of Australia 2011 <http://www.pc.gov.au/inquiries/completed/disability-support/report>

<sup>13</sup> CCSD "Information Sheet, No. 1", 2001



- Among seniors with disabilities, aged 65 and older, two-thirds (66%) require some type of assistive aid or device, representing 965,310 individuals.
- Among adults with disabilities, aged 15+, the rate of the requirement for aids and devices increases from 37% for those with mild disabilities to 89% among those with very severe disabilities. A similar pattern is found among children with disabilities, aged 5 to 14. The likelihood of requiring an aid or device increases from 51% for those with mild disabilities to 89% among those with very severe disabilities.

In 2001 one-third of adults with a disability who required some type of aid or device had unmet needs, representing 657,000 Canadians. The situation was even worse for children with a disability who needed some kind of device, with almost half (46%) having unmet needs.

There is no reason to believe the situation has changed since 2001 to any significant degree. Indeed, it is very likely worse given the growing demand and stagnant funding in many jurisdictions. In addition, not considered in this is the quality of the assistive device provided. Every Canadian Counts' own research has shown that a major problem is affordability, leading many to buy the older, less expensive technologies simply because they are cheaper.

The lack of data reflects the reality that we do not have a systemic national approach to disability support services. There is no analysis of likely future demand for various services. We do not know the proportion of care needed over time, even if current service levels remain the same.

Without sufficient formal care and support, people with disability will continue to rely heavily on their families. The current system will continue to even more tightly ration resources specifically to those in or on the verge of crisis. Ongoing crisis management will be the norm. This will lead to increasing burn-out of carers and families with higher ultimate costs for governments. Many caregivers are too exhausted to work in paid employment or will themselves become disabled.

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### **DISABILITY IS FOR A LIFETIME**

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Chronic disabilities are for life and, just as persons with disabilities develop and change over time, so too do their support and intervention needs. Static point-in-time or rationing approaches fail to address this essential reality. Nowhere is this more evident than in the mindset that parents and caregivers have when approaching the system or when requesting services. It is 'I wonder what I can get?' with a hope for the best. It is not 'what do I need not only for now but in the future? Even when the needs are defined and self-evident, as with prostheses, affordability is an issue for many and affordability of the latest technologies is even more problematic.

#### *BASIC NEEDS ARE NOT BEING MET*

A popular Canadian TV Show the Rick Mercer Report went to Westpark Healthcare Rehabilitation Centre\* met with a client without a leg who had been on crutches for 9 years. Only through crowdfunding could the client eventually afford one. When Every Canadian Counts followed up with the clinic they commented: "That is half the story, what they did not tell you was that this was 50-year-old technology, and this is what most people get because they cannot afford the latest".

- Rick Mercer Report, CBC January 17, 2017

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## **THE WORLD IS WATCHING**

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The Canadian system of formal support is currently failing many people with disability, their families, and caregivers. If it remains business as usual, it will only get worse. Pressure is growing from an aging population and the growth of the single person and small family households.

On December 1, 2016, in Ottawa, Hon. Carla Qualtrough, Minister of Sport and Persons with Disabilities, and Hon. Stéphane Dion, Minister of Foreign Affairs, announced that Canada would ratify the Optional Protocol in 2017. The parties to the convention:

“recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing, and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realisation of this right without discrimination on the basis of disability.

If Canada is to meet its obligations under this Convention, things need to change significantly. The efforts to be undertaken must be on the scale of the Medicare reforms or the introduction of the Canada Pension Plan. Nothing less will get us there.

The Every Canadian Counts Coalition believes a national lifetime care and support program in the form of an entitlement-based public insurance program would address the inefficiencies, inequalities, and arbitrariness of the current system. Through such a program people with disabilities would be able to reach their full potential, better able to live independently and contribute to community and family life.

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## **IS CANADA READY?**

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While persons with disabilities, their families and caregivers are acutely aware of the inadequacies of the current system of disability supports in Canada, the general public is not. 'I thought they were looked after' is generally the out-of-sight and out-of-mind response. The inadequacies and inefficiencies of the system – and how much it is costing Canadians – are not commonly known. Communicating the need for change is a major challenge.

Canada has many hundreds of organizations, associations, agencies, companies, family and activist groups involved in disability issues. They cover the range of disability conditions and services, from health care to housing to employment to income to inclusion to accessibility and education. Recent years have been challenging, especially for the more national and activist organizations, as funding has been reduced or restricted. It has for many been about survival. The ability to work together for the mutual benefit of the person with disabilities has been limited. There have been noble efforts such as the Council of Canadians with Disabilities "In Unison" initiative of 2000. Since then, however, the system has reverted to its fragmented roots. The capacity to address the system comprehensively and nationally is almost non-existent.

Such a culture is not conducive to building a national disability public insurance program. Awareness and education about the inadequacies of the current system are necessary, not just for

the disabled community but with Canadians more broadly. Such awareness building is essential. Widespread public support is a prerequisite to any program adoption of this scale.

While there are many challenges associated with such a significant transformation of disability support services, Canada has many strengths to help meet those challenges. Canadians share a general appreciation that governments can be a force for the betterment of society, as evidenced by the continued support for Medicare, an acceptance of activist government and a strong commitment to fairness and inclusion as central to Canadian values. A quality and effective public service is also an important advantage<sup>14</sup>.

However, if these values and sensibilities are to be harnessed, a major effort at building consensus and commitment will need to be undertaken. Successful adoption needs to be based on comprehensive public engagement with leadership that is seen to be professional and non-partisan, not aligned with any special interest. It must also be a process that is inclusive and transparent, and efficient and effective in its implementation, to induce confidence that our government 'is getting it right'.

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<sup>14</sup> Institute for Governance, The International Civil Service Effectiveness (InCiSE) Index, UK, 2017

## **SECTION II: A NEW APPROACH**

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### **THE PUBLIC INSURANCE MODEL: THE CHALLENGE OF THE ICRPD**

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Every Canadian Counts believes that a national public insurance approach to funding disability support services in Canada has the potential to be the most efficient and effective means for Canada to meet its obligations as a signatory to the International Convention on the Rights of Persons with Disabilities – the ICRPD.

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### **THE COMPREHENSIVE VIEW**

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Canadian governments spend upwards of \$25 billion dollars per year in total on the disability welfare system, of which about \$7 billion is on payments to community care and support providers. In addition, nearly \$3 billion is paid to family and other informal caregivers. The bulk of the remainder is paid in the form of income supports for about 900,000 Canadians.

Eligibility, assessment, and access to disability services vary across provinces, territories, and regions, as well as across different individual services. Capacity constraints have left long waiting lists and substantial variable costs for families and caregivers. The rationing of services and the management of demands is proving wasteful of resources and diverts attention away from the service needs of people with disabilities and their families. From the individual and family's viewpoint, the service delivery environment is uncertain, fragmented, disconnected and inequitable. In the words of the Ontario Ombudsman: "it is a crap shoot".

Every Canadian Counts recommends a new public insurance approach and a comprehensive system to support people with disabilities that is individualized and available throughout their lifetime. Such an approach will differ from a welfare safety net approach in the way it meets the needs of claimants throughout their lifetime, determines prices and generates revenues for the program, takes advantage of bulk purchasing and economies of scale and in its management, governance, and oversight.

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### **NATIONAL PROGRAM: THE NEED AND THE PUBLIC INSURANCE OPTION**

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To date, federal government policy and programming development is characterized by sophisticated analysis and understanding, coupled with sporadic and highly partial interventions. In terms of research and analysis, the federal government over the last four decades has drafted over 25 different reports outlining the challenges faced by people with disabilities that have recommended many different courses of action. One in particular, the "Obstacles Report"<sup>15</sup> of 1981,

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<sup>15</sup> Smith, David (Chair) "Obstacles: Report of the Special Committee on the Disabled and Handicapped" 1981

was a high-water mark in attempts to address the nation-wide lack of supports for persons with disabilities. With 130 recommendations, it represented a comprehensive approach to addressing disability issues. What needed to be done has been long understood. What has been missing, however, has been the resources and incentive to act.

Following the issuing of the Obstacles Report, budgetary and ideological changes over the next three and a half decades reduced and reoriented federal government efforts. Initiatives for persons with disabilities were limited to institutional capacity building in the form of support for some national organizations and taxation measures, such as the Registered Disability Savings Plan. While useful, none of these efforts addressed the systemic challenges of the sector.

This reduced presence of the federal government over that period meant that national actions and approaches to dealing with the inadequacies of the disability support system in Canada atrophied. The federal government became an invisible player.

In 2015, the federal government created a Minister Responsible for Persons with Disabilities, a recommendation of the Obstacles Report, thus revitalizing federal government involvement in disability issues. Since that time, public engagement associated with the drafting of a proposed Accessibility Act has stimulated discussion, looking to continue with Canada's ratification of the Optional Protocol to the International Convention on the Rights of Persons with Disabilities. With this, the opportunity to address the serious and systemic issues of disability supports in Canada has never been more opportune. Now is the time to examine a national, comprehensive and entitlement-based disability system rooted in a public insurance option.

Why a national approach? It is increasingly clear that the Provinces cannot manage the needs on their own. Indeed the Drummond Report recognized this and suggested that Ontario look to the federal government for support, especially for those who could not work due to severe to very severe disabilities (Recommendation 8.6).

Only a national program can address major inefficiencies and inequities in the system such as cross-province mobility, lack of standards, and consistent data collection, diagnosis and intervention.

Adopting a national disability system is not just the right thing to do; it is good economics, with the potential to:

- Rationalize the existing patchwork of duplicating and overlapping systems that can result in substantial resource savings;
- Facilitate major potential productivity gains from allowing family members currently caring for the disabled to re-enter the labour force and from greater labour force participation by the disabled themselves;
- Lower total long-term costs to the economy through a more unified program of early and appropriate supports to the disabled;
- Present system-wide opportunities for bulk procurement and economies of scale, delivering services more cost-effectively; and
- Serve as a pure form of stimulus spending as a result of economic multipliers from spending on disability support in many ways.

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## WHY PUBLIC INSURANCE?

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The Every Canadian Counts Coalition and its Every Canadian Counts Project partners believe that a public insurance approach offers the most practical and sustainable option for dramatically reforming the system of care and support for people with disability in Canada. Adopting this approach would signal a Canada-wide commitment to meeting the essential needs of people with disability.

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

- it affects a definable proportion of the population;
- when it occurs, the costs to the individual or family affected are exorbitantly high;
- 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 who are insured. This approach creates an incentive to make strategic investments that maximize lifetime opportunities and reduce long-term costs. For example, the best way to reduce long-term costs is to increase an individual's independence and lift his or her participation in the community and the workforce.

Another beneficial aspect of public insurance programs is that they continually compare the experience with forecasts. Divergences are investigated carefully as part of a public insurance prudential governance cycle to control long-term costs, enhance program sustainability and ensure that it best meets the needs of people with disability. In the case of Australian program, one recent example of learning and adapting are the changes to its approach to early intervention, particularly for children with autism and developmental delay, which has now become the accepted wisdom around the world.

This lifetime approach to care and support for people with disability would replace the current arrangements for funding specialist disability services.

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## **THERE ARE 'GREY' AREAS**

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With respect to existing disability programs, people who are covered by provincial or territorial accident and workplace compensation programs, for example, could continue to be covered. However, the interaction of these programs would need to be further investigated. Additionally, there would be implications for private insurers and how their compensation programs would be structured. Clearly, interactions in these areas would need to be investigated but, here too, Australia's experience would be informative. Important to the integrity of the public insurance system is the recognition that this is not a program designed to fill the gaps in existing programming.

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## **FEATURES OF A PUBLIC INSURANCE PROGRAM**

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### **HOW WOULD THE PROGRAM WORK?**

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A public insurance program would:

- assess the risk of disability in the general population, calculate the costs of meeting the essential lifetime needs arising out of these disabilities and estimate the premium or contribution required from taxpayers to meet these needs;
- fund on the basis of each individual's needs, which, in turn, would drive the development of necessary care and support services, instead of funding capped programs and services for people with disability to find and access;
- be funded from general revenue or through a Medicare-like levy; and
- be phased in over 8 to 10 years to enable new service infrastructure and workforce to develop, and to balance the constraints of the medium-term fiscal outlook against intergenerational trends. Lessons learned from Australia could help smooth this process.

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## **INCENTIVES TO INVEST**

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The proposed national public insurance model would create a compelling incentive to invest in individual capacity. For the first time, a national program would establish a direct relationship between improved capacity and moderating future costs. It would boost effective demand for services, stimulating creativity and would enable access to higher quality services and technologies.

Timely interventions and treatments, appropriate aids and equipment and training and development that improve functioning become sensible investments rather than welfare handouts. The program would lead to more positive results for a person's wellbeing as well as being fiscally responsible.

A national disability public insurance program could also be structured to create incentives for families to invest or co-invest in services and support and thereby further contribute to lower long-term costs to government.

A national program would also empower all service providers to be efficiently coordinated, achieve economies of scale and collective procurement, realizing very substantial cost and operational efficiencies.

Finally, the efficiencies gained through reduced duplication and improved effectiveness would free up capital and resources that could be put into innovation and creative programming and even 'spaces'. The creativity and innovations coming from an accessible technologies development fund could be deployed and mainstreamed through the insurance system, to Canada's economic benefit.

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## **THE PROPOSED PUBLIC INSURANCE MODEL**

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In proposing a national public funded disability insurance model, many specific design features are not addressed in this paper. We do not know what it will ultimately look like as this is something that will involve consultation with persons with disabilities, caregivers and disability organizations, provincial governments and others. In the specific design of the program, its costs, benefits, targeted interventions, and even governance are all important factors in success. Fortunately, this is a real-world solution, not just a policy model. Fortunately too, we can look to others on what might work.

Every Canadian Counts has chosen to draw substantially on the Australian experience. Canada will, in the end, choose its own path and design, but the many similarities between Canada and Australia in terms of governance - a federation where the responsibilities for disability services were once almost the exclusive domain of the states - together with Australia's advanced thinking and programming with respect to disability needs and services means there is much to draw on.

There will be different views about the elements of any proposed model for Canada and, therefore, these should be considered in more detail in a proposed next phase - a feasibility study to examine the wide range of issues and variables to be considered in the design of a national disability public insurance program. There are a number of considerations in any costing model, including underlying population estimates and projections, the observed aggregate severity distributions and the assumed dollar cost distributions. There is also the sensitivity of the population estimates to the assumptions around eligibility and exit rates from the program with the consequence that the actual population could differ significantly from any estimates. All this would flow through to the costs of the program.

The proposed public insurance approach would provide clients with an individualized and lifetime approach to care and support. The program would treat people equitably on the basis of need, not on the basis of the cause of the disability, where they live, what services happen to be available, or media and political pressure.



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## PROGRAM COVERAGE

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The program would cover people with a severe or very severe disability with onset before 65 years of age. It would cover care and support and related services on a needs basis for this population, for life.

Disabilities related to pain, flexibility, and mobility are the most frequent. About 12 % of Canadians aged 15 years or older, just over 3 million, reported having at least one of these disabilities, and many people reported more than one of them. For example, 66 % of those who reported mobility disabilities also reported the other two, and 35 % of Canadians with disabilities reported having all three.

Mental health-related, dexterity and hearing disabilities were the next most commonly reported, followed by seeing, learning, and memory disabilities. Less than 1 % of Canadians aged 15 years or older reported a developmental disability.

The 2015 prevalence of this population, most of whom have more than one disability, is about 1.8 million in total with condition groupings as follows<sup>16</sup>:

• Physical conditions	1,793,400*
• Sensory conditions	1,527,000**
• Congenital anomalies and intellectual disability	58,800
• Mental health conditions	382,000
• Cognitive conditions	550,000***
*	Includes pain, flexibility, mobility, dexterity conditions
**	Includes hearing, seeing conditions*
***	Includes learning and memory conditions

Further work is needed to consider the extent to which all of these conditions, particularly some of the physical conditions where the care required is very illness-related, are appropriately funded through a disability public insurance system rather than through the health system. Health-related exclusions could reduce the scope and cost of the program significantly.

Questions have been raised about whether this program would cover seniors – people over 65. The age cut-off for entry into the program could be considered in this context. On balance, Every Canadian Counts takes the view that people who acquire disability over the age of 65 years are currently better treated in the aged care and health systems, though some reforms may be needed to improve services for people with non-health related disabilities. The disability public insurance system and the health systems would need to coordinate and improve seamless delivery of supports over time.

Since the design of supports would be based on functional need rather than diagnosis, it will be important to ascertain the distribution of persons with disabilities in terms of the severity or level of support need whether it is constant support need, frequent, regular or lower. Every Canadian Counts is not aware of data that addresses the disability support system in this manner as the diagnostic approach drives current data collection processes. As noted earlier of the 3.8 million Canadians with a disability, 32 % were classified as having a mild disability; 20 %, a moderate

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<sup>16</sup> Statistics Canada, Canadian Survey on Disability, 2012

disability; 23 % or 840,000 a severe disability; and 26 % or 980,000 a very severe disability. While this is indicative of the support levels that might be needed, it is indicative only. A needs-based assessment based on functionality would better serve program and personal support needs.

### **New National Disability Public Insurance Program**

#### **Coverage**

- People with severe and profound disability, acquired before the age of 65 years, would be eligible for life.
- The program would cover the existing eligible population at start-up as well as new incidences.
- An entry assessment tool would be developed based on functional requirement rather than the cause of impairment or medical diagnosis, replacing the multitude of existing assessment instruments.
- Coordinated services would provide care and support including respite, accommodation support, aids, equipment, transport and a range of community and day programs.
- Income support, housing, and employment services would remain separately funded from the program but should be integrated to provide support and opportunities for people with disability as part of a holistic approach.

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### **MANAGEMENT, GOVERNANCE, AND RISKS**

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Within Canada's federal structure, disability support services have been a responsibility of the provinces, with the federal government taking an incidental role through very specific and targeted interventions and efforts, such as taxation and income support. As with Medicare, there is nothing to prevent the federal government from taking a more active role. Every Canadian Counts considers that to be effective, the federal government should take a leading role in the establishment of national standards of performance and service based on a more solid footing of national data collection. This would include the creation of a new national institute of disability health information (or an expansion of CIHI responsibilities), the creation of a centre for inclusivity research and the funding of needs for essential supports people with disabilities. These initiatives could work to ensure that efficient and effective programming and monitoring systems are in place and that administration remains attuned to innovations and improvements in the system.

To be sustainable, a public insurance program must be well governed and managed. Every Canadian Counts proposes that a new statutory authority or agency be established to govern the program. The program would also require disciplined monitoring and evaluation across a number of dimensions of each client's life plan such as health outcomes, work outcomes, and service use.

The proposed public insurance model faces several key risks:

- The program could become financially non-viable. Canada limits the current disability system by rationing expenditure through fixed budgets and some indexation. These limits have resulted in the current levels of unmet need. In the proposed program, a strong prudentially-focussed and commercially-oriented board of directors would deal with this risk by managing upward pressures on costs and maintaining an eye for efficiency balanced with effectiveness.
- Stakeholder support for the new program may decline because of dissatisfaction with the quality of services and poor outcomes for clients. A 'demand-push' by beneficiaries and their carers and advocates for more benefits would put upward pressure on costs and would need to be managed by clear engagement with stakeholders (beneficiaries and carers) and their representatives. An advisory council including representatives of beneficiaries, caregivers, service providers, and governments is proposed to provide advice on quality and appropriateness of services and manage expectations.

Drawing on the experience of accident compensation programs, these two opposing pressures can be harnessed through good governance and management to achieve a balance between available benefits and affordable levies.

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### **WHAT ARE THE COSTS?**

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The costs of a public insurance program will depend on ultimate decisions about the parameters and operation of the program, such as coverage, level of service provided and funding arrangements (pay-as-you-go, partial or full funding), and will need to be calculated in the context of a detailed feasibility study.

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### **MEASURING PERFORMANCE: MERGING HEALTH AND DISABILITY OUTCOMES**

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It has become evident to Every Canadian Counts that increasingly the health and disability service provider communities (medical and professional support staff) are assessing results of their interventions and supports in terms of the increased ability of the individual to function and perform at a higher level than their current condition allows. This functional approach to health and disability support outcomes has the potential to bring system-wide improvements in reporting, monitoring and intake evaluation in a way that is more integrated. It also reduces the stigma of welfare, as it is more openly seen as an investment in good health and disability outcomes. A strong performance reporting system is important to ensure program integrity, efficiency, and effectiveness and will be instrumental in maintaining public support.

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## PROGRAM DELIVERY

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The public insurance model proposed is a funding model. Under it, service delivery models of many types can be supported by operating principles based on individual choice and preference and on lived experience. These would be the drivers of the quality and design of service. Person-directed needs-based funding rooted in individual requirements, however, does not necessarily mean individualized funding. Funds could flow in many ways, through families, through agencies or even managed personally. The choice could be offered.

### NATIONAL DISABILITY PUBLIC INSURANCE PROGRAM -

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#### SUMMARY

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The benefits include:

- all people with a disability would be entitled to an appropriate whole-of-life suite of services and supports available across the country;
- people with a disability and their families would have certainty and clarity about options from the point of determination of a disability;
- case management would be available to facilitate independence, maximize potential and work with individuals and families to plan transitions over their lifetime;
- early intervention would be a top priority;
- training, development, and access to work would build self-esteem and reduce long-term costs;
- families would be able to make choices about the combination of work and informal care for family members at various life stages, as in other families;
- an integrated system of funding, purchasing and delivering disability services would be available to Canadians for the first time;
- the proposed program addresses the current unmet and under-met need for care and support, and the unsustainable reliance on caregivers;
- the program would strengthen and make more effective other support interventions and programs; and
- the introduction of such a program would enable a range of innovative private investment opportunities to emerge.

## HOW REALISTIC IS A NATIONAL DISABILITY PUBLIC INSURANCE PROGRAM?

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The Every Canadian Counts Coalition has drawn much of its inspiration from the experience of Australia, which has been rolling out its National Disability Insurance Scheme, a public insurance model, this past year. The preparation for its rollout, which began in 2008, has been exhaustive, with comprehensive cost analysis, widespread public engagement and strict performance oversight, resulting in an implementation that has been accurate in its assessments and able to maintain citizen support throughout the country. In the words of the Productivity Commission Position Paper of the Government of Australia which reviewed the rollout,

“Based on trial and transition data, NDIS costs are broadly on track with the NDIA’s long-term modelling. While there are some emerging cost pressures (such as higher numbers of children entering the scheme), the NDIA (National Disability Insurance Agency) has put in place initiatives to address them. The benefits of the NDIS are also becoming apparent. Early evidence suggests that many (but not all) NDIS participants are receiving more disability supports than previously, and they have more choice and control”.<sup>17</sup>

The Australian example not only provides insight into both whether it is workable and effective (in which case the answer is ‘yes’) but also highlights the challenges of implementing such a major and socially transformative initiative. Canada can only benefit from the Australian experience in that regard. Vitally important to Australian success has been the support of the Australian citizenry, a support that has been sustained through ten years of research, pilot efforts and now implementation. Without that, the program would have succumbed to all the normal political maneuverings and fractiousness that has historically plagued the sector. Important too was that the program was not a partisan effort but one which gained all-Party agreement in the Australian House of Commons.

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### INVESTING LONG-TERM

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Providing people with essential supports throughout their lifetime, the purpose and intent of such a public insurance program would represent an investment in people that would help them maximize their potential and provide opportunity. Instead of caring for survival, the focus would shift to improving personal capability and capacity so they can better manage their own lives and engage as full citizens in their communities.

This is not to suggest that a public insurance program in and of itself would be sufficient. Clearly, other measures would be needed, such as income support and housing. There also need to be measures to leverage private funds harnessed by the stimulus effect of this new funding. But, by providing essential supports through a public insurance type program, accessibility to housing, income and new and innovative program supports is made that much easier. It is the cornerstone to building an efficient and effective national system of disability supports.

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<sup>17</sup> Productivity Commission, National Disability Insurance Scheme (NDIS) Costs, Position Paper, Overview and Recommendations, June 2017.

## **SECTION III: NEXT STEPS**

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### **FOSTERING NATIONAL DISCUSSION**

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#### **PUTTING PUBLIC INSURANCE ON THE AGENDA: ENGAGING NATIONALLY**

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Driven by the need of Canada to honour its commitments under the International Declaration on the Rights of Persons with Disabilities and in the spirit of enabling full inclusion of persons with a disability in Canadian society, Every Canadian Counts has put together a coalition of partners in support of a project, the Every Canadian Counts Project, to foster discussion and engage all Canadians in the merits of and need for a national disability public insurance service delivery model to provide essential supports for persons with a chronic disability. Project objectives include:

- familiarizing the Canadian population with the need for a holistic approach based on a better understanding of the failings and costliness of the current system of supports,
- mobilizing the disability community behind the idea, including people with a disability, caregivers and service agencies and organizations and private and other related interests,
- Gaining insight on the features of the program and performance expectation,
- Defining the research issues that emerge from public discussion, and
- Ensuring the broad participation of various sectors in the process, including rural communities, Indigenous peoples, and immigrant and ethnic groups.

#### **ACHIEVING THE NECESSARY CONSENSUS**

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##### ***AMONG CANADIANS***

Building a national disability public insurance program that enjoys the support of all Canadians will require unifying a fragmented group of stakeholders, bringing individuals from family groups, service agencies and consumer advocacy groups together to form a coalition with one voice. It must also engage the wider Canadian community as it is the average citizen who will pay for it and make inclusion happen. From the very start it will be important to put differences in priorities aside to advocate together for the features of a program that all can support. By way of example, this kind of consensus was achieved in Australia and took the form of program 'non-negotiables', a set of program features that all agreed needed to be incorporated into an effective disability insurance program. The 10 'non-negotiable' aspects of the Australian national program:

1. Designed to fill the disability supports gap in Australia's social safety net.
2. Aims to remove barriers to the full social, economic, and cultural participation of individuals living with disabilities and their families.
3. Reframes disability support as an economically responsible investment rather than charity.
4. Focuses on early intervention and sustained support to produce better long-term outcomes.

5. Relieves families of unpaid care work and of being primarily responsible for providing disability supports to loved ones.
  6. Offers person-centred funding.
  7. Covers cost of regular care, support, therapy, equipment, residential needs, and training (personal care, life skills, employability).
  8. Provides choice to individuals and families in regards to how funding for supports is managed (indirect vs. direct funding).
  9. Offers equitable levels of support to individuals with a similar type/severity of disability.
  10. Available to all Australians who are born with or acquire a long-term disability.
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An objective of the Every Canadian Counts Project is to try to build a similar consensus related to project objectives and operational features. Every Canadian Counts sees these 'non-negotiables' as guiding principles.

As the program proceeds, it is important that all Canadians can embrace the principle that a disability can happen to anyone; it is not the reserve of those only with current lived experience. All Canadians are affected by disabilities: families, employers, governments, communities. It is a truly pan-Canadian issue and addressing it is not only a matter of right but of the right thing to do for everyone.

### ***AMONG GOVERNMENTS***

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Governments must start talking to each other in order to build a sense of shared responsibilities when it comes to providing support services for persons with disability. They could revive the *In Unison: A Canadian Approach to Disability Issues* initiative of 1998, a process, which worked on "a policy framework to guide future government action in the area of disabilities", was a result of "First Ministers, federal, provincial and territorial governments ... working together ... to develop a common vision aimed at promoting greater equality and inclusion of persons with disabilities in all aspects of Canadian society"<sup>18</sup>. A similar initiative is needed today, including civil society sectors, persons with disabilities and their caregivers in the process. The focus of discussion should address an enhanced role for the federal government given Canada's commitments under the ICRPD while addressing the public insurance option as a way of dealing with issues of under-resourcing, inequity, inconsistent programming and performance expectations, lack of mobility and person-centred, needs-based provision of services.

Finally, there is a need for a feasibility and cost study. Such a study was crucial to garnering public support in Australia for a national disability insurance program. These studies<sup>19</sup> were important because:

- They provided the strong factual basis for why a new approach was needed; the inefficiencies were addressed and highlighted and the needed consensus for change fostered;

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<sup>18</sup> NEWS RELEASE – Federal-Provincial-Territorial Ministers responsible for Social Services continue their work to support children and persons with disabilities May 14, 1999

<sup>19</sup> Inquiry Report, Disability Care and Support, Productivity Commission, Government of Australia, August 2011

- The economics of the program were addressed and it showed that this approach was not a cost to the economy as much as an investment and a savings regimen;
- They ended any 'we cannot afford this' concerns and established an 'it is the right thing to do' discussion; and
- The program was seen as benefiting all of the Australian society – at a cost people were more than prepared to pay.



## **ACKNOWLEDGEMENTS**

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