
NEWSLETTER

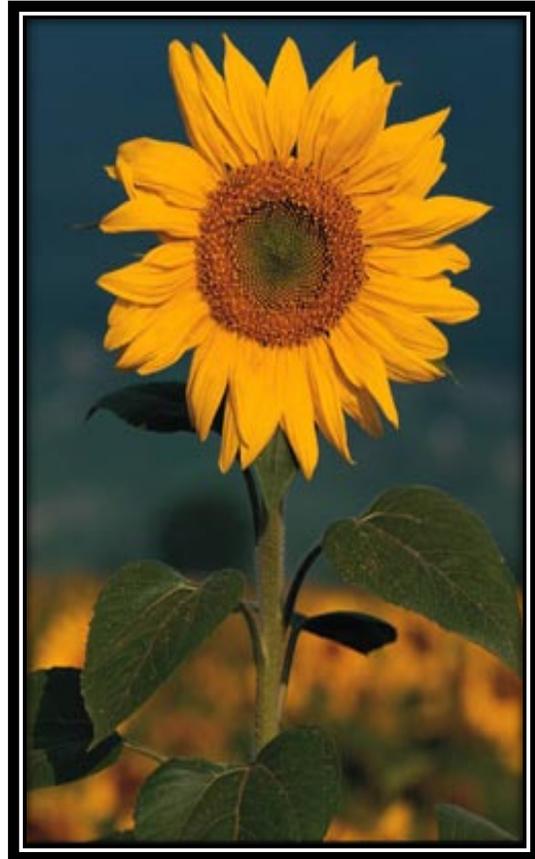
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Every Canadian Counts Coalition

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Editorial

When it comes to Disability Supports in Canada – We are all Americans

The disability support system in Canada has all the features of the public, uninsured American health care system. It is costly, inefficient, unfair, inflexible, and does not meet the needs of hundreds of thousands, if not millions, of people in need of support services. Even for those who get services it is a system of ‘what you can get’ not ‘what do you need’. And who gets even those services? In the words of the Ontario Ombudsman ‘it is a crap shoot’. The situation is, unfortunately, the same across Canada.

Canada is proud of its Medicare system, a system that provides essential health services to all Canadians on an entitlement basis, with no means test. Yet no such system exists for people permanently impacted by an affliction or disability that could be ameliorated if they had timely and appropriate supports.

How did this come to happen? It has a long history but permanent disabilities, especially developmental disabilities, have always been treated separately from health initially in large part perhaps because there was no ‘cure’. People with disabilities were seen as in need of permanent care and as a consequence became part of the welfare system. The architecture around their supports was separate and distinct from health – and they were never part of the creation of Medicare – they were never part of the debate as they were generally hidden away from society and not thought of or considered.

The medical delivery system in Canada in the 1950’s was like the disability support system is today in both the US and in the contemporary Canadian service delivery system for persons with disabilities. Canadians 5 decades ago found it unacceptable - and thus emerged Medicare.

But that raises the question, ‘Why are we still here’? Why can a sick person ‘get help no questions asked’, and a person with a disability cannot? Why has this continued to be the accepted norm? The reasons are both structural and historical.

The advocacy system in Canada does not speak with one voice. It perpetuates itself through fragmented competition: fragmented in agendas (for example, employment, education, housing, accessibility, inclusion) and in advocacy where multitudinous organizations compete for limited resources. It is a system that puts out fires (crisis management at great cost) and allocates resources according to who is noisiest and/or influential. Advocates lack a singular focus while missing the essential problem – that is, the need for personalized services and supports which are adequately funded so that all the various objectives and agendas can be efficiently and effectively addressed. In short, the problem is an inadequate poorly targeted funding model.

At the same time, there is also a danger in this ‘American’ model of social service delivery. It is the danger of partial victories. As firestorms are put out (autism in Ontario¹) or as accessibility is prioritized federally (very visible and very expensive) those without a voice and those needing other kinds of supports become increasingly invisible to the Canadian public. In the words of one prominent surgeon in Brampton when told of the situation of supports for people with disabilities, he expressed shock. “I thought they were looked after!” was the response. No Doctor, that is not the case.

It need not be this way. We can do better. We must. Families are less able to cope. They are smaller, more scattered, and increasingly involved in looking after elderly parents. Persons with disabilities are outliving their caregivers often with no where to go. The system must change. We pay now or pay later.

In the last decade Australia has introduced a Medicare for persons with disabilities in the form of a publicly funded national disability insurance program called the NDIS. An entitlement-based program it enjoys widespread support in Australia and has transformed the lives of hundreds of thousands of Australians with a disability.

The Every Canadian Counts Coalition believes such a program is the way of the future for Canada. In the words of Sharon Soltzberg-Grey, a founder of Canadian Medicare, “..this is some of the unfinished business of Medicare”.

The Disability Investment Group, a 2009 Report that helped lead to the founding of the NDIS in Australia stated:

“...barriers are less to do with particular impairments and more to do with the lack of guaranteed access to customized plans of timely support and development”.

Needs based and timely funding – a Medicare for persons with disabilities – is what is needed.

Every Canadian Counts Post-Election

For persons with disabilities this federal election looks like past ones – some recognition of the acute need, but with intentions to address only some of the issues.

The Liberals committed to a doubling of the Child Disability Benefit, and to the improvement of access to disability benefits and counseling services for Veterans. The priority however relates to the commitments to improved mental health services: for workers (under health and safety), veterans, those in the LGBTQ2 community (health crisis hot line), First Nations and people more generally notably through the setting of clear national standards.

The NDP committed to expanding the coverage of the Federal Accessibility Act to cover federal agencies; an expanded employment programs to make sure that quality employment opportunities are available to all,

¹ Where a plan to give everyone something gave way to a few getting what they need with accompanying waiting lists thus reverting to what was before.

and will develop and implement a national Autism strategy that will coordinate support for research, ensure access to needs-based services, promote employment, and help expand housing options.

The Green Party committed to a universal Guaranteed Livable Income (GLI) program.

The Conservatives committed to a Fairness for Persons with Disabilities Act, allowing 35,000 more Canadians to qualify and apply for the Disability Tax Credit.

Together what all this shows is that for the Liberals, the expansion and improvement of the mental health system would/will be the focus of attention over the next years, the Accessibility Act having been the focus in the recent past.

Addressing Disabilities in Canada: Where are we now?

There is no comparison to where we are now to where we were 5 years ago. First, the federal government is engaged in disability issues on a scale not seen in over 35 years. The passage of the Accessibility Act is proof of that. Similarly, and importantly, disability organizations and groups are working together as never before, thanks in large part to the efforts of Minister Qualtrough and her creation of FALA – Federal Accessibility Legislative Alliance. This cooperation has continued and is being strengthened.

In terms of the election and the respective platforms, the combination of tax credits (Liberals, Conservatives) and focus on housing/ employment (NDP) and income (Green) are common and easily recognized concerns and themes for persons with disabilities and their advocates. As such, it is in many ways a bit of the same old, same old, with improvements at the margins but many, many needs and problems still not being met or addressed. For the Every Canadian Counts Coalition the need for essential supports for everyone who needs them is still not a focus of attention, and more importantly, the continued funding shortages that plague the system are similarly not being addressed. But it is far from bad news and there are certainly reasons for hope.

Together Pharmacare and the focus on mental health issue meant there were two 'big ticket' health items in this election year. The chances of a third big ticket item (disability insurance) being added were slight given that it was too much to swallow in one election cycle. Also, the costs associated with the implementation of the Accessibility Act are by no means small and that is where the benefits for persons with disabilities rest for now. – and it is significant.

For Every Canadian Counts: What Next?

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FOR THE VOICE OF THE DISABILITY COMMUNITY THAT SUPPORTS EVERY
CANADIAN COUNTS ISSUES CONCERNING LACK OF PERSONAL SUPPORTS

*The policy processes of the political parties and the budgetary processes of
the federal government are the required targets for political activism – it is
not the election process.*

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of Kim Campbell, “Election time is not the time to discuss policy”. Developing question for politicians during the Campaign will not translate into government policy. That process occurs elsewhere. Policy development and implementation occur as a result of the budgetary cycle of the Ministry of Finance and the policy development processes of the respective political parties. Formulating questions during elections may serve to embarrass (not helpful) but will not force government action.

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Secondly, the sector lacks a unifying, simple message. The agenda is highly fragmented - employment, income, housing, accessibility, inclusion, human rights.

*A simple singular message, backed by the wide constituency that are persons
with disabilities and their supporters is vital to success. A call for a national
disability insurance program sends such a singular message.*

Thirdly, as a result of this fragmentation any emergent policy is at best offering only a partial solution to the litany of issues. Fragmented agendas result in fragmented or partial solutions.

*Enormous time efforts and energy is spent fighting for what in the end are
partial solutions to the real needs. This time effort and energy are needed for
care support and self-sustaining livelihoods. It is time to take a new road.*

A fourth problem, again a result of fragmentation, results in the loudest and best organized sub-constituency getting the attention and money, paying no attention to the needs of others with different disabilities. The result is ‘flavour of the month’ disability. In the 1950's and 60's it was Downs; 1970's deinstitutionalization (assuming needs could be met 'in the community', which they were not) 1980's Spinal Cord Injury (Rick Hansen in the lead); 1990's - 2000's - autism and mental health. Then there is ‘spot’ attention, like MS which

gain short term profile usually a result of ‘breakthrough’ medical research findings. However, as noted earlier, a new mood of cooperation exists giving hope that ALL disabilities can be addressed simultaneously. And it is this that must be strengthened.

The disability sector has been characterized by fragmented competition, much to the benefit of government agencies that can rob Peter to pay Paul. This must end.

Currently, employment and housing are the issues are front and centre - and at least are more cross cutting. But what of those who cannot work? And what good is it sitting in your basement apartment when you have no - otherwise needed - supports?

Severe disabilities can render people unemployable. Room must be made for them to live in dignity and to the fullest of their capability.

Finally, all of what has been presented here has not directly addressed the elephant in the room -i.e. the lack of funding so needs can be met on ALL fronts simultaneously.

It is about the funding. Period.

There have been movements afoot to ***creating national strategies*** – for autism, for brain injury, and more comprehensively for disabilities as a whole. Strategies are fine, but how do they (or better all) get funded?

For the Every Canadian Counts Coalition, the funding issue is the primary and central focus as outlined in our Policy Paper “*Moving Forward: Building the Framework for an Inclusive Future for People with Disabilities and their Families in Canada*”. It outlines the case for a universal entitlement -based insurance model - publicly funded – which ECCC believes would address the funding elephant. ECCC also believes that advocating for such a system can be the single and unifying message the sector needs and which is capable of addressing all the sub-agendas simultaneously. It is in the spirit of Medicare for All and why the insurance program enjoys such strong support of the general public in Australia where it now exists.

Strategic and Action Considerations

First, it is time to convene a National Conference on Disability Insurance attended by all disability-related stakeholders and put an end to the culture of competitive fragmentation.

Second, in recognition of the need for better information and data and related cost analysis, a request for research to better define need and response is in order. It could be linked to the annual budgetary process in the form of a request for research funds.

Other Items

Every Canadian Counts Joins ‘Creating an Accessible Canada Alliance’

The Creating and Accessible Canada Alliance was formed during the creation and passage of the Accessibility Act of 2019. It was instrumental in seeing to the successful passage of the act and was notable in working with the Senate amendment process.

With the passage of the Act the group has opted to continue its operations forming a Working/Project group *Accessibility in Action* to assist with implementation of the Act.

The creation of this group is highly welcomed by the Every Canadian Counts Coalition as it represents the bringing together of the sector in a way that allows them to speak with one voice.

Every Canadian Counts will work with the Alliance to gain its support for the national disability insurance public policy alternative.

For details on the Accessibility Alliance go to <https://www.include-me.ca/>

Every Canadian Counts joins the Ontario Disability Coalition

The Ontario Disability Coalition (ODC) is a grassroots coalition that was established in 2017 to be the voice of parents, caregivers, health service professionals and persons with disabilities.

Its stated goals are “...to advocate for health care services that a person needs to find their way towards achieving as normal a life as possible, ...(and) to ensure that all publicly funded services have minimal wait times (and) are fully accessible and flexible to meet the needs of all disabled individuals”.

The ODC and Every Canadian Counts share many of the same goals and as a consequence ODC has welcomed our participation. ECC particularly welcomes its representation of the parents and caregivers.

For more information on the ODC go to <https://odcoalition.com/author/odcoalition/>

Every Canadian Counts seeks PONDA Endorsement

PONDA, established in 2011, is a network of physicians and psychologists in Ontario, whose goal is to advocate for children and youth with special health needs. The children and youth have chronic physical, developmental, behavioural and/or emotional challenges and require higher levels of health related services than typically developing children and youth.

PONDA seeks to optimize services and maximize the function and participation of children with special needs in accordance with the International Classification of Functioning, Disability, and Health framework for Children and Youth (ICF-CY)

Their Mission is to optimize the well-being of individuals with neurodevelopmental needs in Ontario by promoting evidence informed policy in the systems of care.

PONDA has approached Every Canadian Counts out of interest in the insurance policy option. We hope the engagement leads to formal endorsement but that is our challenge ahead.

Every Canadian Counts attends IIDL Conference, Ottawa and Washington D.C

Every Canadian Counts has been an engaged member of the IIDL since 2016 where it has established links with advocates/administrators and policy makers across the member organizations. . Through it ECC was able to recruit our BC Rep Natalie Clos and renewed contact with colleagues internationally. These include Cecile Sullivan Elder, Executive Officer, Family Advocacy, NSW, Australia; Ola Balke, Senior advisor at The Swedish Agency for Participation; Aisling Blackmore of the NDIS , Brian Coffey of the Office of Disability Issues New Zealand among others. Look toward a national conference.

Every Canadian Counts works with The Asset to Upgrade its Operations

Every Canadian Counts is pleased to welcome The Asset Group to help upgrade and develop our IT capability.

The Asset was formed to provide technology services to small and medium businesses by providing targeted systems and products that are tied together under one roof together with integrated training and customer support. It focuses on implementing a customized suite of services and systems that will meet needs while suggesting ideas as to prepare for inevitable growth.

In partnership with Google it provides networked cloud solutions, project management solutions, communication tools, and other products that will all talk to each other.

We are looking forward to working with Jon Moore, lead consultant as we improve our communication and networking capability.

Every Canadian Counts has new Regional Reps for British Columbia and PEI

Natalie Clos, HR Manager at Its My Life Kamloops Society has joined us as Champion in British Columbia. As Champion Natalie joins Jen Coughlin of Prince Edward Island and Bruce Harber of Toronto. Jen ran as the NDP Candidate in Cornwall-Meadowbank while Bruce is the former CEO at the York regional Hospital. We welcome them on board and look forward to their continued engagement.

Every Canadian Counts continues its outreach

Every Canadian Counts has recently engaged in positive discussions with **Independent Living Canada**, and **Citizen Advocacy** about the disability insurance public policy option both having expressed interest and support for the idea.